

## DOCTORAL THESIS

**The voices of young people with autism spectrum disorders in transition to post-secondary destinations, following the introduction of the new Special Educational Needs and Disability Code of Practice in England**

Gaona, Carolina

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The voices of young people with Autism Spectrum Disorders in transition to post-secondary destinations, following the introduction of the new Special Educational Needs and Disability Code of Practice in England

by

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A thesis submitted in partial fulfilment of the requirements for the degree of  
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## **Abstract**

*This mixed methods study explored the voices of 29 young people with Autism Spectrum Disorders (ASD) in the 15 to 19 age range concerning their views and experiences of transition to post-secondary destinations, in the context of the English Special Educational Needs and Disability (SEND) reform. Individual semi-structured interviews were conducted with the young people, followed by the collection and analysis of their respective Education Health and Care (EHC) plans, the new statutory documents for individuals with SEND. The requirement to include the voices of young people and their families in these documents suggests a complementary way of accessing their views, providing invaluable information about young people's aspirations, needs, and the outcomes sought for them at this crucial time in their lives. The International Classification of Functioning, Disability and Health: Children and Youth Version (ICF-CY) served as a tool to perform content analysis, supporting the categorisation of the content of both interviews and EHC plans in a systematic, standardised way, to explore the domains of functioning that made up the fabric of young people's experiences, needs and outcomes. Additionally, these outcomes were assessed using the Goal Functionality Scale (GFS III) to explore their overall quality with a focus on participation, considering the aspirations, views and needs of this group.*

*This thesis unearthed first-hand aspirations of autonomy, experiences of anxiety and ambivalent feelings about the future for young people with ASD, and the importance of contextual factors, predominantly the support of immediate family members and relevant school staff for participation in day-to-day activities. These themes could be of significant value to steer the conversation around transition to post-secondary life for this particular group. A series of discrepancies emerged concerning the content of young people's EHC plans regarding the actual involvement of young people in the development of these documents and the methods used to capture their views in the context of communication and interaction difficulties. The use of the ICF-CY taxonomy to analyse plans unearthed a predominant focus on activities and participation dimensions of functioning, followed by body functions and environmental factors, highlighting the relevance of involvement in life situations to describe their views and aspirations. Discrepancies in the organisation of content related to needs were found and overlaps in functioning content were identified in the categorisation of needs across education, health and social care, suggesting limitations to the proposed separation of needs in these terms and confusion about their implementation in the new SEND system. Finally, the analysis of outcomes*

*sought for young people showed these were of overall poor quality and predominantly focused on academic dimensions at a time of life-skills aspirations for transition.*

*The findings from this study have implications for policy, schools, front-line practitioners and service-providers highlighting the need for further guidance for practitioners to enact the principles of the new SEND policy; to further collaboration with young people in realising their voices and aspirations in the development of their plans and in the provision put in place for an effective transition; describing their needs in a biopsychosocial way incorporating aspects of the environment to remove barriers to participation; and in the development of outcomes and provision that are responsive to the wishes and aspirations of young people in their transition to post-secondary destinations.*

**Key words:** voices; young people; autism spectrum disorders (ASD); special educational needs and disability (SEND); transition; post-secondary; Code of Practice.

*'It is our choices, Harry, that show what we  
truly are, far more than our abilities'*

*Albus Dumbledore*

Harry Potter and the Chamber of Secrets

By J.K. Rowling



## Table of contents

<b>Abstract.....</b>	<b>3</b>
<b>Table of contents.....</b>	<b>7</b>
<b>List of Figures.....</b>	<b>15</b>
<b>List of Tables .....</b>	<b>19</b>
<b>List of abbreviations used in this thesis.....</b>	<b>21</b>
<b>List of publications stemming from this thesis.....</b>	<b>23</b>
<b>Acknowledgments.....</b>	<b>25</b>
<b>Ethics Declaration .....</b>	<b>27</b>
<b>1. Introduction .....</b>	<b>29</b>
1.1 Statement of the research problem .....	29
1.2 Aims of this study .....	32
1.3 Worldview .....	33
1.4 Terminology.....	35
1.4.1 <i>Autism Spectrum Disorders</i> .....	35
1.4.2 <i>Voice</i> .....	36
1.5 Organisation of this thesis .....	37
1.6 Summary .....	40
<b>2. Literature Review .....</b>	<b>43</b>
2.1 Introduction.....	43
2.2 The voices of children and young people.....	43
2.2.1 <i>Voice in the education context</i> .....	47
2.2.2 <i>Current research on the views of young people and the new English</i> <i>SEND framework</i> .....	50



2.3 Autism Spectrum Disorders .....	57
2.3.1 A lifelong neurodevelopmental condition.....	57
2.3.2 Prevalence of ASD.....	59
2.3.3 Functioning and disability in ASD.....	64
2.3.4 Education provision and ASD.....	66
2.3.5 ASD and adolescence.....	69
2.3.6 Post-16 education and employment of individuals with ASD .....	71
2.4 Classification of children's and young people's needs.....	74
2.4.1 The classification of SEND in the education context.....	76
2.5 The International Classification of Functioning, Disability and Health for Children and Youth .....	79
2.5.1 The ICF Model.....	80
2.5.2 Structure of the ICF.....	83
2.6 The education and SEND policy contexts in England .....	86
2.6.1 The current education context in England: inclusion and marketisation .	86
2.6.2 A historical overview of the SEND legislative framework.....	88
2.6.3 The new Special Educational Needs and Disability Code of Practice.....	90
2.6.4 The introduction of Education Health and Care plans.....	92
2.7 Research aims and questions .....	99
2.7.1 Research aims .....	99
2.7.2 Research questions.....	100
2.8 Summary .....	105
<b>3. Research Methodology.....</b>	<b>107</b>
3.1 Introduction .....	107
3.2 Research design .....	107
3.3 Participants .....	109
3.3.1 Sampling strategy.....	111

3.3.2 Sample size .....	112
3.3.3 Criteria for selection of participants .....	112
3.4 Materials .....	113
3.4.1 Education, Health and Care Plans .....	113
3.4.2 Social Communication Questionnaire .....	116
3.4.3 Goal Functionality Scale.....	120
3.5 Ethical considerations .....	121
3.6 Procedures .....	123
3.6.1 Recruitment .....	123
3.6.2 Pilot study.....	127
3.6.3 Interviews .....	127
3.6.4 Collection of EHC plans .....	130
3.7 Data Analyses .....	130
3.7.1 Strand 1: The voices of young people with ASD in transition to post-16 education and employment .....	131
3.7.2 Strand 2: The functioning-related views and needs of young people with ASD, and the outcomes sought for them according to their EHC plans.....	142
3.8 Integration of findings .....	145
3.9 Summary .....	146
<b>4. Results: Capturing the voices of young people with ASD in transition to post-secondary destinations .....</b>	<b>147</b>
4.1 Introduction.....	147
4.2 Findings .....	148
4.2.1 Phenomenological thematic analysis .....	148
4.2.2 Deductive content analysis.....	159
4.3 Summary .....	176

<b>5. Results: The functioning-related views, aspirations, needs and outcomes of young people with ASD in EHC plans.....</b>	<b>179</b>
5.1 Introduction .....	179
5.2 Findings.....	180
5.2.1 <i>Structure and organisation of EHC plans</i> .....	181
5.2.2 <i>Capturing the voices of young people with ASD in EHC plans</i> .....	182
5.2.3 <i>Matching the content of EHC plans to the ICF-CY</i> .....	183
5.2.4 <i>Functioning dimensions identified as the views, interests and aspirations of young people with ASD</i> .....	188
5.2.5 <i>Functioning dimensions identified as education, health and social care needs of young people with ASD</i> .....	193
5.2.6 <i>Functioning dimensions identified as outcomes sought for young people with ASD</i> .....	203
5.2.7 <i>Extent of the match between outcomes and aspirations</i> .....	206
5.3 Summary .....	209
<b>6. Results: Matching the views of young people with ASD from semi-structured interviews and Section A of EHC plans. ....</b>	<b>211</b>
6.1 Introduction .....	211
6.2 Findings.....	212
6.2.1 <i>Body functions</i> .....	228
6.2.2 <i>Activities and Participation</i> .....	231
6.2.3 <i>Environmental factors</i> .....	234
6.2.4 <i>Body structures</i> .....	236
6.3 Summary .....	237
<b>7. Results: Quality evaluation of outcomes sought for young people with ASD in transition to post-secondary destinations .....</b>	<b>239</b>

7.1 Introduction.....	239
7.2 Findings .....	240
7.2.1 Overall quality of outcomes identified for young people with ASD in EHC plans.....	241
7.2.2 Does the quality of outcomes vary by local authority? .....	245
7.2.3 Does the quality of outcomes vary according to the type of school? ....	248
7.2.4 Does the overall quality of outcomes vary according to the year group they are developed for?.....	250
7.3 Summary .....	252
<b>8. Discussion .....</b>	<b>255</b>
8.1 Introduction.....	255
8.2 The voices of young people with ASD in transition to post-secondary destinations .....	256
8.2.1 Limitations .....	261
8.2.2 Summary .....	262
8.3 The functioning-related views, aspirations, needs and outcomes of young people with ASD in EHC plans.....	263
8.3.1 Capturing the voices of young people with ASD in EHC plans .....	264
8.3.2 Functioning descriptions of the views, wishes and aspirations of young people with ASD.....	266
8.3.3 Functioning dimensions identified as education, health and social care needs.....	268
8.3.4 Outcomes sought for young people with ASD.....	273
8.3.5 The use of the ICF-CY as a theoretical and analytical framework .....	277
8.3.6 Limitations .....	278
8.3.7 Implications for practitioners and professionals working in SEND .....	279
8.3.8 Summary .....	281

8.4 Matching the views of young people with ASD from semi-structured interviews and EHC plans .....	282
8.4.1 <i>Implications for professionals and practitioners in SEND</i> .....	286
8.4.2 <i>Summary</i> .....	287
8.5 Quality evaluation of outcomes sought for young people with ASD in transition to post-secondary destinations. ....	288
8.5.1 <i>Limitations</i> .....	292
8.5.2 <i>Summary</i> .....	293
8.6 Summary of discussion .....	294
<b>9. Summary of findings and conclusions .....</b>	<b>299</b>
9.1 Introduction .....	299
9.2 Overview of findings related to the views of young people with ASD in transition to post-secondary destinations.....	299
9.2.1 <i>The views of young people with ASD</i> .....	300
9.2.2 <i>Capturing the voices of young people with ASD</i> .....	301
9.3 Overview of findings related to the nature of the content and functioning dimensions identified in the EHC plans of young people with ASD .....	303
9.4 Overview of findings related to the outcomes sought for young people with ASD at time of transition .....	305
9.5 Methodological considerations and limitations .....	307
9.5.1 <i>Participants</i> .....	308
9.5.2 <i>Documents</i> .....	309
9.5.3 <i>Methodology</i> .....	310
9.6 Suggestions for future research .....	312
9.7 Implications for policy and practice .....	313
9.8 Closing remarks .....	315
<b>APPENDICES .....</b>	<b>317</b>

Appendix A. Interview schedule .....	319
Appendix B. Examples of Talking Mats to support interviews.....	321
Appendix C. Extracts from interviews with initial coding .....	325
Appendix D. Extracts from Education Health and Care plans from participants, with coding using the ICF-CY .....	327
Appendix E. List of all International Classification of Functioning – Children and Youth version (ICF-CY) codes identified in 28 interviews and 23 Education Health and Care (EHC) Plans.....	329
Appendix F. Extracts of outcomes from EHC plans coded with the Goal Functionality Scale III (GFS III) .....	353
Appendix G. Social Communication Questionnaire .....	355
Appendix H. Introductory letter to organisations .....	359
Appendix I. Information sheet and consent forms .....	363
<i>I.1 Information sheet and consent form for headteachers.....</i>	<i>363</i>
<i>I.2 Information sheet and consent form for parents.....</i>	<i>369</i>
<i>I.3 Information sheet and consent form for young people .....</i>	<i>373</i>
<i>I.4 Information sheet and consent form for participants – adapted version....</i>	<i>377</i>
<b>References .....</b>	<b>383</b>



## List of Figures

<i>Figure 2.1</i>	Ladder of participation (adapted from Hart, 1992).....	46
<i>Figure 2.2</i>	The ICF Model (WHO, 2001).....	81
<i>Figure 2.3</i>	The ICF alphanumeric coding system.....	85
<i>Figure 3.1</i>	Extract from SCQ Lifetime Form.....	117
<i>Figure 3.2</i>	Extract from SCQ Current Form.....	118
<i>Figure 3.3</i>	Flowchart of school identification and engagement for participant recruitment.....	124
<i>Figure 3.4</i>	Timeline of research project.....	125
<i>Figure 3.5</i>	Examples of symbols included in the Talking Mats framework.....	135
<i>Figure 3.6</i>	Example of a finalised Talking Mat.....	136
<i>Figure 4.1</i>	Occurrence and frequency of ICF-CY codes identified in interviews, by functioning component.....	161
<i>Figure 4.2</i>	Occurrence of ICF-CY codes found across interview themes, by functioning component.....	162
<i>Figure 5.1</i>	Occurrence of ICF-CY codes found across EHC plan sections, by functioning component.....	187
<i>Figure 5.2</i>	Frequency of ICF-CY codes found across EHC plan sections, by functioning component.....	187
<i>Figure 5.3</i>	Occurrence of ICF-CY codes identified in Section A, by component chapter.....	190
<i>Figure 5.4</i>	Frequency of ICF-CY codes identified in Section A, by component chapter.....	191
<i>Figure 5.5</i>	Occurrence and frequency of ICF-CY codes identified in Section C, by component chapter.....	196



<i>Figure 5.6</i>	Occurrence and frequency of ICF-CY codes identified in Section C, by component chapter.....	200
<i>Figure 5.7</i>	Occurrence and frequency of ICF-CY codes identified in Section D, by component chapter.....	203
<i>Figure 5.8</i>	Occurrence and frequency of ICF-CY codes identified in Section E, by component chapter.....	205
<i>Figure 5.9</i>	Occurrence and frequency of ICF-CY Codes identified in Sections A and E, by functioning component.....	207
<i>Figure 5.10</i>	Occurrence of overlapping Section A and E ICF-CY codes, by component chapter.....	208
<i>Figure 6.1</i>	Occurrence of ICF-CY codes in Section A and interviews, by functioning component.....	215
<i>Figure 6.2</i>	Frequency of ICF-CY codes in Section A and interviews, by functioning component.....	216
<i>Figure 6.3</i>	Overview of Section A and Interview ICF-CY code distribution and overlap.....	217
<i>Figure 6.4</i>	Occurrence and frequency of Body Functions codes in Section A and interviews, organised by ICF-CY component chapter.....	229
<i>Figure 6.5</i>	Frequency of overlapping Body Functions codes identified in Section A and interviews.....	230
<i>Figure 6.6</i>	Occurrence and frequency of Activities and Participation codes identified in Section A and interviews, by component chapter.....	231
<i>Figure 6.7</i>	Frequency of overlapping Activities and Participation codes identified in Section A and interviews.....	232

<i>Figure 6.8</i>	Occurrence and frequency of Environmental Factors codes identified in Section A and interviews, by component chapter.....	235
<i>Figure 6.9</i>	Frequency of overlapping Environmental Factors codes identified in Section A and interviews.....	236
<i>Figure B.1</i>	Talking Mat from participant YP 17.....	321
<i>Figure B.2</i>	Talking Mat from participant YP 21.....	321
<i>Figure B.3</i>	Talking Mat from participant YP 23.....	322
<i>Figure B.4</i>	Talking Mat from participant YP 1.....	322
<i>Figure B.5</i>	Talking Mat from participant YP 25.....	323
<i>Figure B.6</i>	Talking Mat from participant YP 4.....	323



## List of Tables

Table 2.1	<i>Content of Education Health and Care plans, adapted from the SEND Code of Practice (DfE &amp; DoH, p.164-165) .....</i>	94
Table 3.1	<i>General sample characteristics.....</i>	109
Table 3.2	<i>Participants' characteristics.....</i>	114
Table 3.3	<i>Overview of participants' recruited, number of interviews and EHC plans, analytical approach and results chapter .....</i>	133
Table 4.1	<i>Occurrence and frequency of ICF-CY codes identified in interviews, by functioning domain.....</i>	160
Table 4.2	<i>ICF-CY codes found in interviews, by theme and functioning component.....</i>	162
Table 4.3	<i>Identified ICF-CY codes with descriptions, organised by functioning component and interview theme.....</i>	163
Table 5.1	<i>Occurrence and frequency of identified ICF-CY codes, by section and functioning domain.....</i>	185
Table 5.2	<i>Extracts of coded EHC plans, by ICF-CY component....</i>	186
Table 5.3	<i>Occurrence and frequency of ICF-CY codes identified in Section A, by functioning component.....</i>	188
Table 5.4	<i>Occurrence and frequency of ICF-CY codes identified in Sections B, C, and D, by functioning component.....</i>	194
Table 5.5	<i>Occurrence, frequency and percentages of identified ICF-CY codes in Section B, by functioning component...</i>	195
Table 5.6	<i>Occurrence, frequency and percentages of identified ICF-CY codes in Section C, by functioning component...</i>	199

Table 5.7	<i>Occurrence, frequency and percentages of identified ICF-CY codes in Section D, by functioning component.....</i>	202
Table 5.8	<i>Occurrence, frequency and percentages of identified ICF-CY codes in Section E, by functioning component..</i>	204
Table 5.9	<i>Occurrence of identified ICF-CY codes in Sections A and E, and overlapping codes.....</i>	206
Table 6.1	<i>Extracts of coded interview transcripts and Section A of EHC plans, by component of ICF-CY .....</i>	213
Table 6.2	<i>Occurrence and frequency of ICF-CY codes identified across interviews and Section A of EHC plans.....</i>	214
Table 6.3	<i>Occurrence of ICF-CY codes identified in Section A and interviews, and proportion of overlapping codes.....</i>	217
Table 6.4	<i>List of ICF-CY codes with descriptions and frequencies, as identified in Section A of EHC plans and interviews of n = 22 participants.....</i>	218
Table 7.1	<i>Cross-tabulation of GFS III scores .....</i>	242
Table 7.2	<i>Frequency of ratings for outcomes analysed using the GFS III.....</i>	244
Table 7.3	<i>Mean quality scores across outcomes per GFS III indicator.....</i>	245
Table E	<i>List of all ICF-CY codes identified in 28 interviews and 23 EHC plans.....</i>	329

## **List of abbreviations used in this thesis**

ADI-R = Autism Diagnostic Interview - Revised

APA = American Psychiatric Association

AS = Autism spectrum

ASC = Autism spectrum condition

ASD = Autism spectrum disorder

*b* codes = Body functions codes

BERA = British Educational Research Association

BPS = British Psychological Society

CRPD = Convention on the Rights of Persons with Disabilities

*d* codes = Activities and participation codes

DfE = Department for Education

DfEE = Department for Education and Employment

DfES = Department for Education and Skills

DoH = Department of Health

DSM-5 = Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> Revision

DSM-IV-TR= Diagnostic and Statistical Manual of Mental Disorders, 4<sup>th</sup> Revision

*e* codes = Environmental factors codes

EHC plan = Education Health and Care plan

GFS III= Goal Functionality Scale III

ICD-10 = International Classification of Diseases, 10<sup>th</sup> Revision

ICD-11 = International Classification of Diseases, 11<sup>th</sup> Revision

ICF = International Classification of Functioning, Disability and Health

ICF-CY = International Classification of Functioning, Disability and Health: Children and Youth version

ICIDH = International Classification of Impairments, Disabilities and Handicaps

IDACI = Income Deprivation Affecting Children Index

IEP = Individual education plan

ILP = Individual learning plan

LA = Local authority

M = Mean

MATs = Multi-academy trusts

Mdn = Median

N/A = Not available

NAS = National Autistic Society

ONS = Office for National Statistics

PECS = Picture Exchange Communication System

PDD = Pervasive developmental disorder

PDD-NOS = Pervasive developmental disorder – not otherwise specified

s codes = Body structures codes

SCQ = Social Communication Questionnaire

SD = Standard deviation

SENCo = Special Educational Needs Co-ordinator

SEND = Special educational needs and disability

SMART = Specific, measurable, achievable, realistic, time-bound

UN = United Nations

UNCRC = United Nations Convention on the Rights of the Child

UNESCO = United Nations Educational, Scientific and Cultural Organisation

WHO = World Health Organisation

WHO-FIC = Family of International Classifications of the World Health Organisation

YP = Young person/people

### List of publications stemming from this thesis

This thesis was supported by the University of Roehampton Vice-Chancellor's Studentship. Portions arising from this thesis appear in the following publications:

1. Gaona, C., Palikara, O., & Castro, S. (2018) 'I'm ready for a new chapter': The voices of young people with Autism Spectrum Disorders in transition to post-16 education and employment. *British Educational Research Journal*. DOI:10.1002/berj.3497
2. Gaona, C., Castro, S., & Palikara, O. (2019) The views and aspirations of young people with Autism Spectrum Disorders and their provision in the new Education Health and Care plans in England. *Disability and Rehabilitation*. DOI:10.1080/09638288.2019.1593520
3. Gaona, C., Eirinaki, V., Palikara, O., Castro, S. (in preparation) An evaluation of the quality of outcomes sought for young people with ASD in their Education Health and Care plans. *Journal of Autism and Developmental Disorders*
4. Gaona, C., Castro, S., & Palikara, O. (in preparation) A holistic look into the needs of young people with ASD in their Education Health and Care plans: are categories of needs responsive to a person-centred approach?





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## **Ethics Declaration**

The research for this project was submitted for ethics consideration under the reference EDU 16/112 in the School of Education, and was approved under the procedures of the University of Roehampton's Ethics Committee on October 21 2016.

I hereby declare that this thesis represents my own work; the material included in this volume has not been submitted wholly or in part for any academic award or qualification other than that for which it is now submitted. It has correct use of sources, references and quotes, and contains all relevant literature which has been used in the reference list.

Carolina Maria Gaona

June 2019

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## **1. Introduction**

### **1.1 Statement of the research problem**

In recent decades there has been a significant increase in research on Autism Spectrum Disorders (ASD). However, the focus of investigation at international level has predominantly pointed in the direction of basic science, with an emphasis on the unravelling of neural, cognitive systems, genetics and other risk factors, and the understanding of the condition from its causes, correlates and consequences (Pellicano, Dinsmore, & Charman, 2014a). The biological focus of research on the condition emerged with the hope that the understanding of these dimensions might ultimately translate into benefits that will enhance the lives of the autism community – that is autistic people themselves, their families and their support networks (Insel & Daniels, 2011; Pellicano et al., 2014a). A review of the available literature reveals underexplored areas of research in ASD, particularly when it comes to exploring the views of young people with ASD, and their transition to post-16 education and to adulthood (Hendricks & Wehman, 2009; Pellicano et al., 2014a).

This mixed methods study aimed at addressing this paucity in research; firstly, it aimed to give voice to young people with ASD by gathering their views and experiences of transition to post-secondary destinations through semi-structured interviews. Secondly, it aimed to explore how the views of these young people, together with their needs, and the outcomes sought for them were depicted in the newly introduced Education Health and Care (EHC) plans in the context of the new Special Educational Needs and Disability (SEND) policy reform in England.

The passage from secondary school to post-16 education and employment constitutes one of the hallmarks of adolescence, a critical developmental period of identity exploration and reconfiguration of relationships with family and peers (Hauser-Cram, Krauss, & Kersh, 2009). The exit from secondary school opens the door to a time of newly found independence for adolescents (Wei, Wagner, Hudson, Yu &

Shattuck, 2015). For those with developmental disabilities, such as ASD, this period becomes more complex as individuals leave the 'comfort' of the education system and face an increase in their need for social support and understanding, and are at risk of developing comorbid disorders, such as depression and anxiety among others (American Psychiatric Association [APA], 2013; Carrington & Graham, 2001; Humphrey & Lewis, 2008). For families, this is also a period of additional stress as parents face the dilemma of their dual role in promoting autonomy and independence for their child, and protecting them from harm (Thorin, Yovanoff & Irvin, 1996).

The changes in provision for SEND introduced by the new Special Educational Needs and Disability Code of Practice, following the enactment of the Children and Families Act 2014 in England, have given a new and significant place to the views of young people with special needs and their families. This responds to international trends and efforts stemming from the United Nations Convention on the Rights of the Child (UNCRC) (UN, 1989) and the Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2006) that call for a more person-centred and holistic approach to special needs and disabilities, empowering people with disabilities to become change agents of their own lives (Hendricks & Wehman, 2009; UN, 2006). Furthermore, the autistic community has underlined the need to include voices of autistic people themselves in research – as they can give a more accurate account on their experiences, their views, needs and opportunities, give an in-depth account on their everyday lives, the challenges they face, the services they have access to (Bölte, 2017; Pellicano et al., 2014a; Pellicano et al., 2018). They have a unique knowledge of their own needs and circumstances that cannot be acquired by exploring the views of other stakeholders. Moving towards a progressively more inclusive society requires the participation and involvement of persons with disabilities across different settings, and within this frame of thought it is that voices of young people with ASD have a crucial role in research (Howard, Katsos, & Gibson, 2019; Rix, Sheehy, Fletcher-Campbell, Crisp, & Harper, 2013).

The need for giving voice and agency to young people with SEND to direct the path of their lives has been widely recognised in the literature, and increasingly in policy at international level (Heasley, 2017; Hendricks & Wehman, 2009; Lundy, 2007; Robinson, 2014; UN, 2006). Policy changes in provision for SEND in England represent a step forward in this direction, with the enactment of the Children and Families Act, 2014, the introduction of the new SEND Code of Practice and the newly developed EHC plans. These plans are statutory documents for children and young people with SEND who are in need of additional and different support than the generally provided at schools (DfE & DoH, 2015). The views, goals and aspirations of the child or young person, and their families, constitute the starting point of an EHC plan. Participation of the individual in decision-making is a key underpinning principle of the new SEND provision, and places the voice of children, young people and their families in a central position. It is within legal duties of local authorities (LAs) to have regards to these views, feelings and wishes in the development of tailor-made provision that would ultimately contribute to an effective preparation for adulthood. Arrangements of specialist provision for them not only must be aligned with what the child, young person, and their families need, but also with what they themselves want to achieve. For this reason, the second strand of this study explored how these young people's views and functioning are reflected in their EHC plans. It could be argued, therefore, that analysing the content of EHC plans is a complementary way of accessing the views of young people with ASD, as the process of developing these documents must involve them. These documents contain relevant information from, and about young people, their needs, aspirations, and the outcomes they expect to achieve at the time of transition to post-secondary life.

The ecological nature of the newly developed EHC plans is aptly aligned with the International Classification of Functionality, Disability and Health for Children and Youth (ICF-CY, hereon), by the World Health Organisation (WHO; 2007), based on a biopsychosocial model of disability. It is a classification system for functioning



aspects, rather than diagnosis, designed to record characteristics of the developing child and the influence of their surrounding environment. It is not destined to replace diagnostic classifications – instead, it is intended to be used as a complement to them, as diagnostic information alone is of limited value when it comes to providing descriptions of functional impact of such diagnosis (WHO, 2007). This classification provides a unified and standard framework to code a wide range of information about health states, rather than disease, recording issues related to functions and structures of the body, activities and participation, and relevant environmental factors in a neutral and universal language (Lollar & Simeonsson, 2005). In this framework, disability is understood as a multidimensional phenomenon that results from the interaction between people and their physical and social environment. Since its publication in 2007, there has been mounting interest in its application in fields such as nursing, rehabilitation, psychology, medicine (Augustine, Lygnegård, Granlund, & Adolfsson, 2018; Nguyen & Gorter, 2014; Worrall et al., 2011), early childhood assessment and intervention (i.e. Pan, Hwang, Simeonsson, Lu, & Liao, 2015), and education (Florian et al., 2006; Hollenweger, 2013) to name a few. The multidimensional approach to functioning and disability of the ICF-CY is aptly aligned with the principles of the new SEND policy in England (Castro & Palikara, 2016). It provides a fitting framework to understand the views of individuals with a history of ASD from a functioning perspective, taking into account characteristics of themselves and of their surrounding environment; it allows to explore their views, needs and outcomes in a universal and cross-disciplinary language endorsed by the WHO (2007).

## **1.2 Aims of this study**

In light of the paucity in research concerning the views of young people, their transition to post-secondary destinations and adulthood, effective interventions and service provision (Hendricks & Wehman, 2009; Howlin, 2013; Pellicano et al., 2014a;

Roux et al., 2013), and the emergence of a biopsychosocial model of functioning and disability for SEND provision (Adolfsson, 2011; Castro & Palikara, 2019) this mixed methods study aimed to explore the views and experiences of young people with ASD in transition to post-secondary destinations, in the context of the changes introduced by the new SEND legislation in England. This chapter introduces the general research aims, while Chapter 2 provides specific research questions stemming from each aim following up from the literature review. The aims of this study were:

- a. To give voice to young people with ASD by exploring their views and experiences of transition to post-secondary destinations.
- b. To explore the functioning dimensions identified as the views, needs, and outcomes of young people with ASD as portrayed in their newly developed EHC plans.
- c. To explore the extent of the match between the views of young people with ASD obtained through interviews and those depicted in their respective EHC plans.
- d. To evaluate the quality of outcomes sought for young people with ASD in their EHC plans with regards to their focus on functioning and participation at the time of transition to post-secondary destinations.

### **1.3 Worldview**

The present study adopted a mixed methods research design. One of the main features of mixed methods designs is that they allow combining both quantitative and qualitative approaches to methods and data, combining the strengths of both in an attempt to address the research question through the collection of complementary data on the same topic (Cohen, Manion, & Morrison, 2018).

Cohen and colleagues (2018) assert that methodological approaches are seen to reside in paradigms: systems of belief or worldviews that guide what is to be investigated, the questions that should be asked and the ways in which the phenomena under study should be approached (Cohen et al., 2018; Kuhn, 1996). This study was conceived in line with the values of the transformative paradigm. This paradigm emerged 'as a way to bring visibility of communities who have been pushed to societal margins throughout history and to bring their voices into the world of research in order to enhance social justice' (Mertens, Bledsoe, Sullivan, & Wilson, 2010, p.196). The relevance of this paradigm for this thesis is reflected in the main aim of the study, concerned with giving voice to young people with ASD in transition to post-secondary destinations under the new SEND policy context in England. The transformative paradigm seemed the most suitable to guide ethically sound methodological decision-making to conduct research whose processes and outcomes would contribute to further the social justice agenda (Mertens et al., 2010).

Creswell and Plano Clark (2010) embrace the suggestion that mixed methods research allows for more than one worldview to be incorporated throughout a study, which the researcher should acknowledge. In addition to the transformative paradigm, this study was also informed and designed in line with elements of the pragmatic paradigm. The pragmatic worldview highlights the relevance of the research question, and focuses on the use of a multiplicity of methods for data collection to inform the problems under study; in this respect, the pragmatic paradigm is pluralistic in nature and oriented towards 'what works' and practice (Creswell & Plano Clark, 2010). These worldviews, therefore, complement each other in guiding the development of a research design that is sensitive to the nuances of the research questions in addressing issues of social justice - for example, by exploring the underrepresented voices of young people with ASD –, while at the same time acknowledging the role of 'what works' approaches that would reflect on practice, such as the identification of issues in the implementation of the new SEND policy context in England through the

analyses of EHC plans of young people with ASD. The elements of pragmatic and transformative worldviews enrich the research design by enabling the researcher to adopt a pluralistic stance in order to gather different types of data through complementary methods to best address the research transformative and pragmatic aims of this study.

Combining the change-oriented focus of the transformative paradigm with the real world, practice-oriented focus of the pragmatic paradigm (Creswell & Plano Clark, 2010) was deemed suitable for the purposes of looking at how to advance the understanding of the lived experiences of young people with ASD in transition to post-secondary destinations as an underrepresented group in the research community, while reflecting on policy implementation that echoes practice in the new SEND framework through the collection and analysis of EHC plans of young people.

## **1.4 Terminology**

### ***1.4.1 Autism Spectrum Disorders***

The way in which the scientific, medical, and broader communities understand what autism spectrum disorder (ASD) is has changed greatly throughout the last century, and so has the terminology used to describe it (Kenny et al., 2015). The debate concerning how to address or refer to this and other conditions extends contentiously across the contexts of special educational needs, learning difficulties, disabilities, and rights, with ongoing discussions around the intricate relationships among the language we use, constructions of ability and disability, and the ways we respond to diversity (Hardy & Woodcock, 2015; Harpur, 2012; Ho, 2004; Norwich, 2009; Terzi, 2005).

In relation to ASD, it is imperative to acknowledge the number of terms that are currently in use to describe it and the use of terminology across this study. Some of these terms refer to previous ways of classifying the condition, such as autism, and

Asperger's. Other terms refer to its spectral dimension, such as autism spectrum (AS), autism spectrum condition (ASC), or autism spectrum disorder (ASD). These terms are, in turn, further reflected in the use of person-first language, i.e. 'person with ASD' or 'person on the autism spectrum'; or in the use of disability-first language, i.e. 'autistic person'. A recent study conducted by Kenny and colleagues (2015) explored the perspectives of the UK autism community -namely people with ASD, their families, and support professionals and networks- about the terms used to describe autism. This study has shown lack of consensus on a single preferred term, and great variability across different groups with regards to their preferences to describe the condition. Nevertheless, the authors found that terms such as 'autism' and 'on the autism spectrum' were the most highly endorsed terms across community groups, followed by 'autism spectrum disorder' (Kenny et al., 2015). This thesis adopted the term 'autism spectrum disorder' (ASD) representing a compromise between the most updated definitions of the condition in the scientific field, and community preferences on terminology.

#### **1.4.2 Voice**

The use of the term *voice* in this thesis is located in the framework of the UNCRC (UN, 1989), considered a foundational gold standard for participation of children and young people in matters that affect them (Cele & Van der Burgt, 2015). Article 12 of this convention calls for State Parties to assure the right of a child to express their views freely in all matters affecting them, and the right of having their views being given due weight (UN, 1989). In this respect, the concept of voice is understood to have a dimension that goes beyond the expression of views and is inextricably linked to the spheres of choice and participation (Lundy, 2007; Heasley, 2017).

In the UK context, Article 12 has been adopted and embraced; practices of eliciting the voices of children have been incorporated in a range of policy initiatives and practice, with an emphasis on the education setting (Robinson, 2014; Walker & Logan, 2008). Many have highlighted there is still significant work to do to elicit underrepresented voices such as those of children with special educational needs and disabilities (SEND), and the risks of over-formalising the process of listening to the voice of the child (Felce, 2002; Lewis & Porter, 2004; Lundy, 2007). In the context of the new English policy for SEND, the concepts of voice, choice and participation are represented as vital principles that should lead the way towards participatory, person-centred practices for and with children and young people with SEND and their families (Department for Education [DfE] & Department of Health [DoH], 2015). However, it could be argued that while voice and choice occur within the boundaries of this system, ruled by strict procedures, deadlines and budgets, there is a risk for these processes to be confined to the limits imposed by that system. This is arguably one of the challenges faced by the new SEND Code of Practice. However, it is not the scope of this section to address these issues; the concept of voice in education, its uses and challenges are addressed in more detail in Chapter 2 of this thesis.

## **1.5 Organisation of this thesis**

This first chapter presents an overview of the research context in which this study is located, the aims of the study, the worldviews in which it is inscribed, and the key terminology adopted.

Chapter 2 of this thesis presents the literature review to contextualise this study in further detail and the research aims and questions stemming from this review. The chapter offers an introduction to the concept of *voice* in the context of children's rights and its implications for and applications in the education context; this is followed by current research in the English context concerning the voices of children and young

people in the scope of the new SEND policy, and evidence stemming from studies looking at different spheres and stakeholders' perspectives on the SEND reform in England. The chapter then proceeds to define key conceptualisations relevant to the study; an overview of the characteristics of ASD with regards to manifestations, educational provision available, and its complexities during the adolescent period and transition to post-secondary settings are presented. After that, issues around the classification of disability and children in education are discussed, followed by the introduction of the International Classification of Functioning, Disability and Health for Children and Youth as a theoretical and analytical framework aptly aligned to the new policy of SEND in England. Thus, this section is followed by a detailed account of the English educational landscape and the newly introduced policy for SEND, the principles underpinning this significant reform, and the implications of this policy for children and young people with regards to their participation in decision-making in matters affecting them. In light of these conceptualisations and the extant literature in the field, the research aims, and their respective research questions are presented.

This is followed by Chapter 3, in which the methodology of this study is discussed in greater detail. It provides a description of the purpose to explore the views and experiences of transition of young people with ASD in the context of the SEND reform in England. It describes the design of the study, together with the ethical issues that emerged from conducting research with vulnerable young people. The chapter also describes the sampling strategy and procedures for recruitment and data collection. This is followed by an overview of the two strands that aim to answer the study's research questions. One of the strands focuses on capturing the voices of young people with ASD in transition to post-secondary destinations, while the second one focuses on the functioning-related dimensions linked to the descriptions of young people with ASD in their respective Education Health and Care (EHC) plans. The analytical approach of both strands is described, together with a section on the integration of findings.

The results are presented in Chapters 4, 5, 6, and 7. More specifically, Chapter 4 presents the results concerning the first aim by exploring the voices of a group of young people with ASD in transition to post-secondary destinations in the context of the English SEND reform, as informed by individual semi-structured interviews. The views of young people are examined through phenomenological thematic analysis with regards to their feelings and aspirations for the future and life after compulsory education. They offer insights on the importance of support systems such as family, friends and school staff. These insights are also examined through deductive content analysis using the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) to identify the functioning dimensions that make up the fabric of the themes identified in the interviews.

Chapter 5 addresses the second aim by exploring the functioning-related views, needs and outcomes of the same group of young people with ASD, as portrayed in their respective EHC plans. Five sections of the young people's EHC plans were analysed through deductive content analysis using the ICF-CY as a system of predefined codes, namely the section concerning the views, wishes and aspirations of the young people (Section A), the special educational needs (Section B), health needs (Section C), and social care needs (Section D), followed by the . Each section presents its own constellation of ICF-CY functioning codes, although similar patterns of codes emerge throughout them.

Following from the ICF-CY coding of interviews and EHC plans, Chapter 6 focuses on the extent of the match between the views of young people with ASD as obtained through semi-structured interviews (Chapter 4) and the views included in their respective EHC plans (Chapter 5). Using the ICF-CY as a universal language, this chapter identifies the overlapping and different functioning dimensions that are relevant to, and meaningful for, young people with ASD at time of transition to post-secondary destinations.



Chapter 7 builds on previous findings with regards to the outcomes sought for young people with ASD at the time of their transition to post-secondary destinations. This chapter presents results from the evaluation of the quality of outcomes sought for young people with ASD as indicated in their EHC plans using the Goal Functionality Scale (GFS III) (McWilliam, 2009) as an instrument to measure a range of quality dimensions identified in the outcomes.

Chapter 8 discusses the findings stemming from Chapters 4 to 7 in light of the new SEND policy, and internationally recommended holistic and participatory approaches to SEND. More specifically, it discusses the views of young people with ASD at the time of transition to post-secondary destinations from semi-structured interviews and EHC plans; the functioning dimensions identified as their views and needs, and the outcomes sought for them resulting from the analyses of these using the ICF-CY; and the evaluation of the quality of outcomes sought for young people with ASD at a time of transition.

Lastly, Chapter 9 presents a concluding summary of findings in relation to relevant literature. Methodological considerations and limitations are discussed, and contributions stemming from this study to the ASD and SEND literature are put forward. The chapter also includes suggestions for future research, and implications for policy, practitioners and professionals working with children and young people with ASD and SEND.

## **1.6 Summary**

This thesis addresses the paucity in research in relation to the views and experiences of young people with ASD in transition to post-secondary destinations under the SEND reform in England. The study provides novel data concerning the voices of young people with ASD gathered through semi-structured interviews, following an in-depth phenomenological analysis. This analysis is complemented by

the collection and subsequent analyses of the EHC plans of this group of young people, to obtain a broad picture concerning their views, aspirations, and needs as described in the new statutory documents, and the outcomes sought for them at a time of transition. The systematic approach to analysis of the EHC plans through the use of the ICF-CY as a theoretical and analytical framework provides a detailed, yet holistic picture of the dimensions of functioning of young people with ASD that make up the fabric of their aspirations, needs, and goals. This study contributes new knowledge in the scope of the requirements for LAs to have regards to the views of young people and their families as a guiding principle of person-centred approaches to SEND, advocated by the new law in England.



## **2. Literature Review**

### **2.1 Introduction**

The purpose of this chapter is to contextualise the study in light of the extant literature in the field. It begins by reviewing the literature concerning the concept of *voice* in the context of children's rights and its implications for and applications in the education context and highlighting evidence on latest research in the field of voice and the new SEND policy context in England. The review continues to explore key concepts relevant for the present work, such as the definition of ASD and prevalence, and functioning implications; it is followed by a consideration of educational provision available in the UK, and extant research around the complexities emerging during the adolescent period, and for transition to post-secondary settings. After that, issues around the classification of disability and children in education are discussed, followed by the introduction of the International Classification of Functioning, Disability and Health for Children and Youth as a theoretical and analytical framework aptly aligned with the new policy of SEND in England. This policy is contextualised in light of international and national debates for provision for children with SEND, the principles underpinning this significant reform, and the implications of this policy for children and young people with regards to their participation in decision-making in matters affecting them.

### **2.2 The voices of children and young people**

The concept of 'voice' has been widely recognised in research, policy and practice as a synonym of the right of children and young people to express their views freely about matters affecting them (Robinson, 2014). Since the ratification of the UNCRC (UN, 1989), there has been widespread recognition on the need to include these views of children and young people in all matters that affect their own lives (UN,

1989). Article 12 of this convention is considered the foundational standard of the right of children and young people to express their opinions and to be heard. By this article, States Parties 'shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child' (art 12, 1). This article also requires that

'for this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child (art 12, 2)' (UN, 1989).

Children and young people represent 34% of the world's population (UN Population Fund, 2018); the recognition of this particular group as a valuable stakeholder has been well documented since the UNCRC, however their participation remains underrepresented or even absent from spheres of collective decision-making (Giroux, 2003; Hinton, Tisdall, Gallagher, & Elsley, 2008). In light of this, a wide array of initiatives has emerged worldwide to honour the commitment, and legally binding obligation, to make room to these views (Lundy, 2007; Porter, 2014).

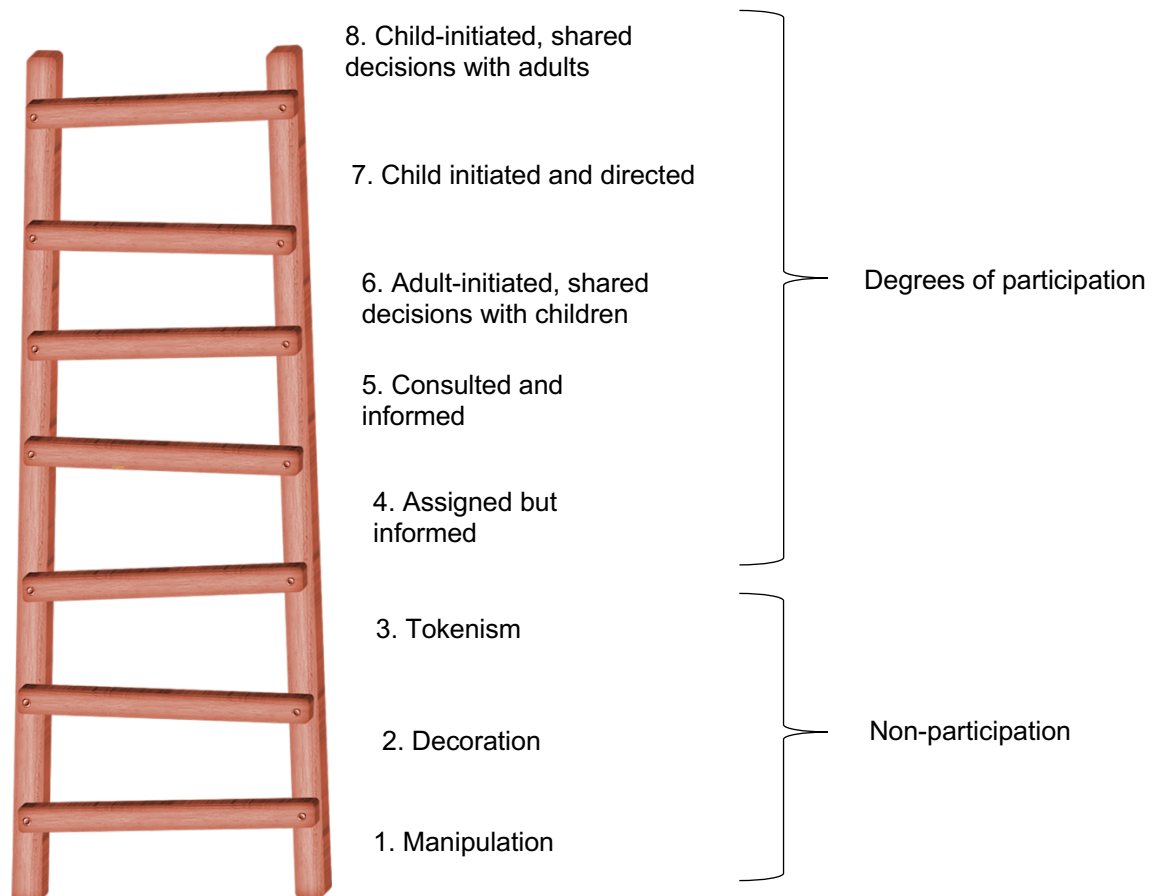
In the UK context, the UK government, together with initiatives led by non-governmental institutions and organisations have called for children and young people to participate in voicing aspects of their school life and welfare (Morgan, 2011). References to the need for the child's participation and involvement in matters affecting their lives can be found in key policy documents such as the Education Act 2002, which explicitly calls for consulting students with regards to matters that affect them (i.e. Section 176). In addition, the Children Act 2004 introduced the Office of the Children's Commissioner, whose role is to promote awareness of the rights and views of children and young people, and speak up for them in the sphere of policymaking, so that their say is represented and taken into account when making decisions that

will affect them (Children's Commissioner for England, 2017). In 2008, the Department for Children, Schools and Families (DCSF) published a guidance document titled 'Working together: listening to the voices of children and young people' to assist schools in the promotion of best practice in children and young people's participation, by listening to their voices. Moreover, the role of pupil voice and that of the Children's Commissioner has become more prominent since the introduction of the Children and Families Act 2014 and the new SEND Code of Practice (DfE & DoH, 2015), which highlights as an underpinning principle that children and young people have the 'right to receive and impart information, to express an opinion and to have that opinion taken into account in any matters affecting them from the early years. Their views should be given due weight according to their age, maturity and capability' (DfE & DoH, 2015, section 1.6). Thus, the new SEND policy explicitly refers to its intention of further securing the voices of children, young people and their families in the context of SEND.

In the education context, the terms 'student voice' and 'pupil voice' are used to refer to a wide range of work occurring in schools involving both children and young people to have a say in aspects of their school lives which affect them, and to have the power to bring about changes that will contribute to improving their school experience (Fletcher, 2014; Robinson & Taylor, 2013). However, the concept of voice is associated with wider participation of children and young people in a broad range of matters affecting them, and not solely circumscribed to the sphere of education. Hart (1992) describes participation as a fundamental right of citizenship, and defines it as 'the process of sharing decisions which affect one's life and the life of the community in which one lives' (p.6). In his essay 'Children's participation: from tokenism to citizenship', he introduced a model of participation in which he used a ladder as a metaphor to illustrate multiple levels (each represented by one step) of children participation in projects. The participation ladder is divided into two categories representing non-participation and degrees of participation of children in projects and

matters affecting them. The first three steps of this eight-step ladder are considered forms of non-participation (tokenism, manipulation and decoration); the ladder includes another five steps that illustrate consecutive, higher degrees of participation. Thus, the last step on the ladder refers to the child initiating projects, and sharing the decision-making with adults (Hart, 1992); Figure 1.1 depicts Hart's ladder of participation.

One of the challenges that arise from the pressure of policy initiatives with regards to the voice of children and young people is that of over-formalising the process of listening; this in turn could lead into transforming the exercise into an ubiquitous imperative rather than reflecting a sincere rights-based agenda (Lewis & Porter, 2004). Listening to the voice of children is a matter of rights, and as such it entails responsibilities that are often not recognised (Rudduck & McIntyre, 2007). Indeed, eliciting their views should not be an end on itself, as it entails the responsibility of being listened to.



*Figure 2.1*

Lundy (2007) highlights that this is one of the main challenges arising from listening to the views of children; the author argues that transforming rhetoric into practice can be particularly arduous when these views question or oppose to the status quo and prevailing ideas, when they are controversial or represent a cost. Lewis and Porter (2004) argue that there is still plenty to do to move from hearing individual children's views to helping them present a "collective choir" including those with special educational needs and disabilities (SEND) (p.196). A range of assumptions seem to underpin the challenges of this endeavour, such as the undermining of the child's voice on the assumption that they lack capacity to form a view, that their difficulties and inherent challenges to elicit them outweigh those views, or that their voice as a collective is just one and homogeneous (Lundy, 2007; Robinson & Taylor, 2007; Whitehurst, 2007).

### ***2.2.1 Voice in the education context***

The adhesion of the UK to the UNCRC (1989) means that there are a series of mechanisms in place by the United Nations Committee on the Rights of the Child, which aim to regulate and monitor the implementation of the UNCRC. In its last report on the implementation of the UNCRC in the UK, the United Nations Committee on the Rights of the Child (2016) suggested to the UK to further develop

structures for the active and meaningful participation of children and give due weight to their views in designing laws, policies, programmes and services at the local and national level', paying particular attention to the involvement of younger children and children in vulnerable situations, such as those with disabilities (United Nations Committee on the Rights of the Child, 2016, p.6-7).

In the education context, practices that aim to incorporate the child's voice are reflected, for example, in the creation of school councils, where children are elected



by their peers to form a group that represents them and their views in school processes that concern making suggestions or problem solving (Children's Commissioner for England, 2017). In the field of SEND, the concepts of voice and participation are at the core of the changes introduced by the new SEND Code of Practice (DfE & DoH, 2015). According to the new SEND policy, LAs must have regards to the views of children, young people and their families in decision-making processes related to the planning and delivery of services to cater for their needs, increase their participation and wellbeing. In this respect, the purpose of voice in the new SEND policy context could be understood as concerned with processes of individualisation of provision (Clarke, 2010), and engagement (Goepel, 2009), whereby the views of the child and their families could lead to the development of provision that matches their aspirations, needs and goals, resulting in greater participation and satisfaction (Harris, 2009).

As outlined in the first chapter of this thesis, the scope of the concept of voice is understood to go beyond expressing views and having these views given due weight (Lundy, 2007). In the UK and internationally, the notion of choice emerged as a fundamental idea and organising principle for public service reform, moving from the 'one-size-fits-all' approach to service provision to one that suggests the power of individuals to make decisions in choosing providers and services, replicating or mimicking market processes in the sphere of public service (Clarke, Newman, & Westmarland, 2007). In this respect, choice takes on the meaning of representing what service users or consumers want, an opportunity to drive up the quality of services, as well as promoting personalisation of services and provision (Clarke et al., 2007).

These principles could be seen reflected in the context of the latest SEND policy reform. One of the principles set in the new SEND Code of Practice is that of 'greater choice and control for parents and young people over their support' (DfE & DoH, 2015, p.24). The instrumentation of choice in this context could be seen in the

development of a local offer, which delineates the provision available in a particular area across health, education and social care for children and young people who have SEND, including those who do not have an EHC plan. The purpose of the local offer is twofold: on the one hand, it aims to provide comprehensive yet accessible information about available services in a particular locality and how to access them; on the other hand it aims 'to make provision more responsive to local needs and aspirations' by involving service providers, children with SEND and their families in the development and review of the local offer (DfE & DoH, 2015, p.60). This approach constitutes an opportunity to co-produce, design and shape local services in light of the needs of a specific local area, placing service users at the centre (Lamb, 2013; Palikara, Castro, Gaona, & Eirinaki, 2018a). Therefore, in the context of the new SEND policy context, choice could be understood as a higher level of voice by which young people and their families instrument their voice, exercising control over the support they receive. However, the existence of *real* choice commands the existence of more than one available option to choose from (Beadle-Brown, Roberts, & Mills, 2009).

The present study aimed to address the paucity in research particularly concerning the voices of young people with ASD with regards to their transition to post-secondary destinations under the newly adopted framework for SEND in England. In this respect, this study explored not only the views and experiences of transition to post-secondary life of this particular group through their own voices, but also the ways in which those views were represented in their respective EHC plans, and materialised in outcomes sought for them, in light of their wishes, aspirations, and needs. The next section (Section 2.2.2) provides an overview of the current state of the field concerning the views of children and young people, and the new English SEND policy context, thus locating this study in the broader field of SEND reform.

## **2.2.2 Current research on the views of young people and the new English**

### ***SEND framework***

As previously stated, the enactment of the Children and Families Act 2014 in England represented the most significant change in SEND policy in thirty years, bringing about a series of implications for professional practice and service provision for vulnerable children and young people (Castro & Palikara, 2016). These changes have sparked debate concerning the extent and nature of the reform. Norwich and Eaton (2015) suggest that the changes to the SEND system result from tightening and extending already existing principles and practices, rather than presenting a radically new system, as intended by the 2011 Green Paper 'Support and Aspiration: A new approach to special educational needs' (DfE, 2011).

In addition, although the new legislation brought about a shift in assessment and intervention processes for children and young people with SEND, it has been argued that there is still a theoretical gap between the changes introduced at policy level and their implementation in practice. Castro and Palikara (2016) highlight the lack of congruence observed between the principles enshrined in the new Code of Practice, and 'the lack of an evidence-based framework to actually implement them' (p.2). In this respect, they recognise the shift towards a biopsychosocial, multidimensional model of SEND that calls for the articulation of education, health and social care services; however, they highlight that service provision is still aligned with a medical model of SEND; the Equality Act 2010 is still referred to as the policy's frame of reference for professionals working in SEND, where disability is understood in terms of diagnosis and impairment (Castro & Palikara, 2016). Paradoxically, although not explicitly mentioned, the multidimensional approach to SEND adopted by the new law and guidance is theoretically aligned with bioecological and biopsychosocial models of development and disability, which also constitute the basis for the development of the International Classification of Functioning, Disability and

Health – Children and Youth Version (ICF-CY) by the WHO (2007) (Castro & Palikara, 2016).

#### *2.2.2.1 Professionals' views concerning the changes in SEND legislation*

A survey conducted by Pearson, Mitchell, and Rapti (2015) in 2012 investigated 326 special educational needs coordinators' (SENCOs) views on the then likely implications of the changes that the new legislation would posit to their roles in schools working with children and young people with SEND. The study found that the majority of SENCOs agreed with the principle of multiagency collaboration that the new legislation suggested for the development of the new EHC plans; nevertheless, SENCOs also casted doubt on the practicalities of carrying out this proposed collaboration. Moreover, SENCOs anticipated that their role would be subject to increased bureaucratic processes, represented by an expected increase in paperwork which in turn could expand their professional role by incorporating teaching responsibilities with more administrative and managerial activities in the school context. Concerning the EHC plans, SENCOs expressed concerns with regards to the skills and knowledge that their development would require, wondering whether these would exceed their current capacity (Pearson, Mitchell, & Rapti, 2015).

Another small-scale study explored the views of 74 SENCOs six months after the entry into force of the new SEND policy in England. In line with Pearson and colleagues' findings on prospective changes (2015), SENCOs highlighted the bureaucratic and statutory nature of the responsibilities they faced following the introduction of the SEND reform, including the writing of the schools' SEND policy (Curran, Mortimore, & Riddell, 2017). Similarly, Boesley and Crane (2018) conducted a study using individual semi-structured interviews with 16 SENCOs working in primary and secondary schools, which focused on their perspectives of the implementation of EHC plans and SEN aspects of the reform, namely person-centred

planning, multi-agency collaboration. Their findings are also in line with those of Curran, Mortimore, and Riddell (2017) and Pearson and colleagues (2015), in that SENCOs were concerned with the financial aspects of the implementation of the reform in light of budgetary cuts, its impact on staffing and availability of provision. The findings also point towards a rushed implementation of EHC plans before they were fully defined, with little and ongoing guidance about the processes; concerning multiagency collaboration, SENCOs reported support towards increased collaboration among services, but stressed that in the scope of a promised 'radical reform', the education sector bears most of the responsibility and finds it difficult to systematically incorporate health and care sectors to the EHC planning process, particularly for children and young people with social, emotional and mental health needs (Boesley & Crane, 2018).

In a similar vein, Palikara and colleagues (2018a) conducted an online survey was administered to 374 professionals working in SEND (SENCOs, educational psychologists, speech and language therapists, headteachers, teachers, and other professionals) to explore their views about the changes introduced by the Children and Families Act 2014 and the new SEND Code of Practice. Findings from this study revealed that professionals agreed in theory with most of the newly introduced changes and principles such as the extension of SEND provision to cover the 0-25 age range, the introduction of more holistic statutory documents (EHC plans) to replace previous statements of SEND, multiagency collaboration between education, health and social care services in the EHC assessment and planning process. However, professionals referred to challenges in translating these changes and principles into practice, referring particularly to constrained budgets, general lack of information coming from the government and LAs as to how to address implementation, and facing difficulties in increasing multiagency collaboration; in this respect, professionals highlighted that the new SEND framework in practice is still predominantly focused on education, where most of the information concerning health

and social care needs included in the EHC plans are only included as long as addressing these would contribute to training or educating the child (DfE & DoH, 2015). Thus, the inclusion of these other agencies in the context of EHC plan development is limited to their educational/training value (Norwich & Eaton, 2015).

In sum, the studies presented in this section highlighted some of the challenges faced by practitioners working in the field of SEND in translating the new policy into practice. These findings suggest an overall agreement with the principles and ideology that underpins the new policy; nevertheless, it also strengthens the need for the development of training opportunities for front-line practitioners to inform their practice so that the principles of the new SEND Code of Practice could be honoured. The difficulties in implementation were also signalled in terms of budget and funding constraints, lack of uniformity across local authorities with regards to the development of EHC plans and multi-agency collaboration.

#### *2.2.2.2 Eliciting the views of children and young people in the new SEND framework*

Another study by Palikara and colleagues (2018b) analysed the content of Section A of 184 EHC plans belonging to children and young people with SEND, which includes the views, wishes and aspirations of children and their families, and young people, in order to explore how those views were captured and recorded, and what functioning dimensions they reflect, using the ICF-CY (WHO, 2007) as a system for analysing the content of the plans. From their analyses of 184 EHC plans collected across nine London LAs, the authors found great regional variability in the processes of capturing the voices of children with SEND, and methods used to do so. Furthermore, significant differences were found between different types of placement, namely special and mainstream schools, in the way the child's views were captured and reported in EHC plans, highlighting that EHC plans from mainstream schools provided more detail about the child and their functioning. Finally, they highlighted the

alignment of the ICF-CY framework with the new SEND policy, and emphasised the advantage of using this classification system to explore the nature of the content included in the EHC plans, and as a universal language to enhance the quality of these documents.

In the scope of placing the views of children and young people at the core of the EHC planning process, Fayette and Bond (2018) conducted a small-scale study in which they explored the processes followed by two schools in North West England to elicit and capture the voices of young people with ASD in planning their transition to adulthood. To do this, they conducted semi-structured interviews with nine teaching staff (including teachers, teaching assistants, assistant headteachers, key stage leaders) working in two special schools in north-west England, and observed a transition meeting of one pupil with ASD. Findings from this study highlight that a person-centred school ethos is required in the process of capturing and including the views of young people with ASD in transition planning. Furthermore, the authors emphasised the commitment from school staff to develop practices that enable eliciting the views of young people regardless of their level of communication and making informed decisions throughout the pupil's journey in school (Fayette & Bond, 2018). In this sense, the use of different communication tools such as Picture Exchange Communication System (PECS), Talking Mats, switches and behavioural observations were identified as crucial support elements incorporated in the process of capturing the views of young people with ASD. It was suggested, however, that the success in eliciting and recording the views of young people was dependent on staff's awareness and knowledge of each young person's communication medium, and that of ASD.

In line with the changes stemming from the SEND reform concerning the views of young people and transition to post-secondary settings, Shepherd (2015) investigated the views of six young people with ASD leaving special secondary school to attend mainstream college in the scope of the changes in SEND policy, and

reported a series of methodological implications arising from conducting research interviews with individuals with ASD by presenting a case study of one participant. Consistent with findings presented by Fayette and Bond (2018), the author emphasised the need to explore a range of tools and methods to enhance communication, and provided evidence of the use of collages, card sort exercises, and 'walking interviews' (Clark & Emmel, 2010) to support data collection in a way that is meaningful for, and relevant to the young person's communication medium.

#### *2.2.2.3 Participation and high-quality outcomes in EHC plans*

The new SEND policy's focus on participation as a desired outcome resulting from provision reflects international trends that incorporate aspects of the natural environment of the child and the child's involvement in everyday life situations as the focus of interventions to promote participation, instead of directing efforts towards context-removed interventions implemented on a one-to-one basis with the child (Adolfsson, 2013; Castro et al., 2019; Simeonsson, 2006; Whiteneck, 2006). So in other words, to aim at promoting and enhancing participation means to focus on increasing opportunities for attending and being involved in everyday life situations (Imms et al., 2016). In the context of service provision for SEND, improving outcomes at participation level requires adopting an approach to intervention at the level of daily life situations, which suggests the need for multi-agency collaboration and articulation of services to integrate provision in education, health, and social care that would in turn result in increased participation of children and young people with SEND (Castro & Palikara, 2016). To achieve this, the new SEND Code of Practice provides a range of criteria that outcomes designed for children and young people with SEND should meet as a measure of quality assurance for provision, identified with the acronym 'SMART'.



In order to assess the overall quality of outcomes sought for children with SEND in their EHC plans, Castro, Grande, and Palikara (2019) analysed 2813 outcomes contained in 236 EHC plans of children and young people with SEND in the Greater London area using the Goal Functionality Scale (GFS III) (McWilliam, 2009). This instrument was developed for assessing and developing functional goals with a focus on participation in everyday life routines for the field of special education and early childhood intervention. The proposed criteria for assessing goals suggested that a) goals should specify a daily routine in which the child would participate; b) they should accurately describe what the child is expected to do; c) the behaviour or skill should be relevant for the child's participation; d) an acquisition criterion should be stated; e) the acquisition criterion should be relevant for the child's overall participation; f) a generalisation criterion should be stated; g) a timeframe for acquisition of the behaviour or skill should be stated as well. Castro and colleagues (2019) have argued that the criteria proposed by McWilliam (2009) was aptly connected to the SMART criteria set by the SEND Code of Practice, suggesting that the first two criteria (a and b) contribute to the specificity of the outcome; criteria c) and e) contribute to the relevance of the outcome; criteria d) and f) relate to the measurability dimension of the outcome, criterion e) contributes to identifying attainment of the outcome; and criterion g) is linked to the timeframe set for the outcomes (Castro et al., 2019).

In light of the match between the SMART criteria of the Code of Practice and the criteria of the GFS, the authors looked at the quality of 2813 outcomes contained in 236 EHC plans of children and young people with SEND in the Greater London area. Although the GFS III has been used in other studies to analyse the quality of outcomes developed for children with special educational needs and disabilities, where high levels of inter-rater agreement were obtained (i.e. Boavida et al., 2010; Castro et al., 2019; Rakap, 2015), this was the first time this instrument was used in the context of EHC plans. Their findings highlighted that overall the quality of the

outcomes written for these children was low; they also found differences in quality of outcomes, and that these differences seemed dependent on the LA that developed the EHC plan, the type of school the child attended, the timeframe to achieve the outcomes (that is, specified as a long-term or a short-term outcome), and to a lesser extent, it was dependent on the type of need of the children (Castro et al., 2019).

The studies presented in this section (Section 2.2.) have highlighted the timely findings and the continued need for research concerning the introduction of the new SEND policy in England. While these current studies present commonalities in terms of the challenges and opportunities arising from the SEND reform for service delivery, little has been explored with regards to the views of children and young people by eliciting their own perspectives, the transition to post-secondary destinations in individuals with ASD in light of the English policy context for SEND. Thus, the present study aimed to address this paucity in research by exploring the views and experiences of young people with ASD in transition to post-secondary destinations through individual semi-structured interviews with youth with ASD in the 15 to 19 age group, and through the analysis of their recently developed EHC plans. The sections that follow in this chapter provide an in-depth account on key issues relevant for this work; they provide conceptual clarity, historical and current perspectives on the fields of ASD, the classification of children and young people's needs, the role of classification systems in the field of SEND and details of the current policy landscape in SEND in which this study is located.

## **2.3 Autism Spectrum Disorders**

### ***2.3.1 A lifelong neurodevelopmental condition***

ASD is a complex, lifelong neurodevelopmental condition that affects how an individual communicates with, and relates to, other people and the world around them,

causing clinically significant impairments in different areas of functioning (APA, 2013; The National Autistic Society [NAS], 2017). Neurodevelopmental disorders are conditions that have an onset in the developmental period. This means that ASD typically manifests early in development, and is characterised by developmental deficits that translate into impairments across areas of functioning such as personal, social, academic, or occupational life (APA, 2013; Miles, 2011). The features of ASD translate into difficulties in social and emotional reciprocity; in non-verbal communicative behaviours that accompany social interaction, and in developing, maintaining and understanding relationships. In addition, they include the presence of stereotyped or repetitive motor movements, use of objects or speech; an insistence on sameness, inflexible adherence to routines, or ritualised patterns of behaviour; and restricted interests unusual in their intensity or focus (APA, 2013).

ASD has also been widely associated with impairment in imagination (Ten Eycke & Muller, 2015). In their conceptualisation of the ASD triad of symptoms, Wing, Gould, and Gillberg (2011) consider that impairments in social imagination, which is the ability to 'think about and predict the consequences of one's own actions for oneself and for other people' (p. 769), are a key part of the ASD definition. Together with difficulties in social communication and interaction, they are associated with restricted and stereotyped patterns of activity. They argue that the difficulties in social imagination in ASD are probably among the most disabling consequences of the condition as this translates into an inability to imagine or predict thoughts and feelings of other people, and what goes on in their minds (Carrington et al., 2015; Wing, Gould, & Gillberg, 2011).

There is agreement in the field that people with ASD share some common areas of strength and difficulty; as a spectrum condition, the broad manifestations of ASD result in large disparities in functional characteristics from one individual to another, and variable levels of performance across domains (Castro & Pinto, 2013; de Schipper et al., 2015; Humphrey & Hebron, 2015). These difficulties may vary

depending on the severity of ASD symptoms, the presence of other conditions, chronological age and developmental level (APA, 2013). ASD also occurs in the spectrum of intellectual ability and may be associated with comorbid disorders such as anxiety, depression, challenging behaviour and other emotional difficulties (Christensen et al., 2016; Ho, Stephenson, & Carter, 2018; Salazar et al., 2015). In light of the breadth of manifestations of ASD, the presence of a diagnostic label alone seems insufficient to explain the functional implications of the diagnosis (WHO, 2007). Furthermore, while many systems of care (i.e. health, social welfare, education) may rely in the presence of a diagnostic label to establish eligibility for services, it is important to highlight that the information that the diagnostic category conveys on its own is of limited reach when it comes to recognising the specificity of the services and provision that an individual may need, and how to address and cater for these (Castro, Pinto, & Maia, 2011; Lollar & Simeonsson, 2005; Norwich, 2014). The following sections provide information regarding prevalence rates of ASD (section 2.3.2), and address the limitations of diagnostic categories in ASD by introducing a complementary perspective to diagnosis which focuses on aspects of functioning in ASD (section 2.3.3).

### **2.3.2 Prevalence of ASD**

Recent studies suggest that in the UK, an estimate of 1% of the population has an ASD (Baird et al., 2006; Brugha et al., 2011; Pellicano, Dinsmore, & Charman, 2014b), and similar estimates were recorded in other parts of the world (Elsabbagh et al., 2012). It should be acknowledged that the past decades have seen an increase in awareness, understanding and recognition of ASD, resulting from the significant growth in research evidence, and an increase in the number of individuals identified as having ASD (Sipes, Matson, Horovitz, & Shoemaker, 2011). However, this increase is subject to controversial debate. Broadening diagnostic criteria, increased

awareness on ASD, new identification and assessment instruments and diagnostic practices, younger age of diagnosis are among the reasons that reportedly may account for the increasing rates (Baxter et al., 2015; Hansen, Schendel, & Parner, 2015; Lai, Lombardo, & Baron-Cohen, 2014; Mattila et al., 2011; Matson and Kozlowski, 2011; Nassar et al., 2009). Nevertheless, the discussion remains as to whether the increase in prevalence is real or whether the factors described above have influenced these rates, together with health professionals becoming increasingly familiar with diagnostic categories, and accessibility to better services being insured by the presence of a specific diagnostic category (Elsabbagh et al., 2012).

In terms of the broadening of diagnostic criteria, a look back at Kanner's (1943) first description reflects a narrower and qualitatively more severe form of the autism phenotype, associated with severely impaired cognitive skills and language delay (Achkova & Manolova, 2014). This definition has progressively become wider, by referring to less severe manifestations to include forms of ASD that occur without an intellectual disability – such as 'high functioning' autism-, or by providing separate diagnostic categories, such as PDD-Not otherwise specified (PDD-NOS), within a broader class of autism conditions. The presentation of the diagnostic category of ASD in the DSM-5 is the result of the trajectory of progressive dimensionalisation of the autism definition and phenotype (APA, 2013; Elsabbagh et al., 2012). This dimensionalisation, however, brings along a series of research, clinical and service provision challenges and implications. Among these significant changes was the introduction of ASD as an overarching category, the transformation of the triad of symptoms to a dyad – where social communication and social interaction are presented together, and restrictive, repetitive and stereotyped patterns of behaviours become the second half of the dyad - and the specification of levels of severity (Smith, Reichow, & Volkmar, 2015; Volkmar, Reichow, & McPartland, 2012). The controversial changes for the scientific community were those of the elimination of sub-threshold categories (like present in DSM-IV-TR), and the reduced level of detail

in the diagnostic criteria, decreasing its sensitivity and flexibility (Smith et al., 2015). This has raised concerns with regards to possible exclusions of previously diagnosed individuals under Pervasive Developmental Disorder (PDD) criteria –DSM-IV-TR's nomenclature – under the new criteria set by DSM-5.

Since the DSM-5 draft version and final publication in 2013, systematic reviews have evaluated the new criteria by comparing it to DSM-IV-TR to establish percentages of maintenance of the autism spectrum diagnosis under the DSM-5 (Kulage, Smaldone, & Cohn, 2014; Sturmey & Dalfern, 2014). Although these studies vary in terms of sample size, methodology, diagnostic tools for ASD identification and used versions of the DSM-5, a review of the literature revealed that there is a significant proportion of sub-diagnosis by the DSM-5 criteria (Smith et al., 2015). This means that a significant number of individuals who have been previously diagnosed under the DSM-IV-TR's PDD might not meet the diagnostic criteria set in the DSM-5 (Smith et al., 2015). In their review, Smith and colleagues (2015) have found that the decrease in identification of ASD in the new DSM-5 affects mostly those individuals who fall under DSM-IV-TR diagnosis of PDD-NOS, Asperger's syndrome and individuals with an IQ greater than 70, often referred to as 'high functioning'. Indeed, it is in the case of high functioning individuals that the new criteria might have the most significant consequences, as the increased specificity and decreased sensitivity of DSM-5 will make it more difficult for this group to be diagnosed at an early age and receive the quality support they need (Smith et al., 2015).

Achieving greater levels of independence, community participation and inclusion have been associated with early diagnosis and milder symptoms at time of diagnosis (Orinstein et al., 2014). Therefore, individuals identified as high functioning are the ones who might face a greater loss with the new DSM-5 criteria. Although the new criteria contribute to ensure consistency in diagnosis by introducing an overarching diagnostic label, it is argued that 'this should not come at cost of individuals with milder – but still clinically significant – deficits losing services' (Smith

et al., 2015, p. 2550). Many individuals who present ASD symptoms at a sub-threshold level will still face significant difficulties and may not receive the support and access services that were granted to them under the PDD-NOS label (Harstad, Fogler, Weas, Mauras, & Barbaresi, 2015; Kulage et al., 2014). In the context of provision, changes in diagnostic categories as described above can represent great challenges for individuals seeking services and those providing them when eligibility and access to these is tied to the presence of a diagnostic label. Nevertheless, it is not the diagnostic category itself that will inform which services or interventions are required for the individual, but the functioning implications of such diagnosis (Lollar & Simeonsson, 2005). It has been widely acknowledged that two people may share the same diagnosis, and yet present considerably different functioning profiles, shaped by their own biological, psychological and social factors (Castro & Palikara, 2016; Norwich, 2016).

A common finding among studies in prevalence of ASD is that the diagnosis is given more frequently to male than females, that girls are less likely to be diagnosed than boys, and if they receive the diagnosis, it occurs later than in boys (Wing, 1981; Brugha et al., 2011; Rutherford et al., 2016; Constantino & Charman, 2012; Giarelli et al., 2010; Lai et al., 2014). A recent systematic review and meta-analysis conducted by Loomes, Hull, and Mandy (2017) found that the male-to-female ratio is lower than previously thought, close to 3:1. Different perspectives have emerged in relation to this to try to explain how gender is related to ASD. One proposed reason points to the existence of a female autism phenotype, a female-specific manifestation of ASD strengths and difficulties (Bargiela, Steward, & Mandy, 2016). Though this field of research is at an early stage, several studies have identified that girls and women are more likely than males to present internalising problems such as anxiety or depression than to present externalising behaviours (Dean, Harwood, & Kasari, 2017; Mandy et al., 2012; Mandy & Lai, 2016), present less repetitive and stereotyped behaviour (Lai et al., 2014; Lai, Lombardo, Auyeung, Chakrabarti, & Baron-Cohen,

2015), and display higher motivation and capacity to form friendships than males (Sedgewick, Hill, Yates, Pickering, & Pellicano, 2015). Furthermore, these gender differences in ASD may have implications to understanding causation of ASD from genetic to environmental perspectives, bringing about the question of female-protective factors or increased male-risk factors in the aetiology of ASD (Lai et al., 2014).

Another theory put forward to explain gender differences in ASD characteristics is that of the extreme male brain theory, and the empathising-systemising theory (Baron-Cohen, 2002; 2010). Concerning the empathising-systemising theory, Baron-Cohen suggests that in addition to having an impaired Theory of Mind (that is, the underlying cognitive ability to attribute, understand, and anticipate other people's thoughts, feelings and behaviour) (Baron-Cohen, Leslie, & Frith, 1985), individuals with ASD present a different profile to their typically developing counterparts with regards to two psychological domains, namely empathy, which is below average, and systemising (above average) (2010). The ability to systemise is that of analysing and constructing systems based on the understanding of rules that govern a system, so as to anticipate and predict its behaviour (Baron-Cohen, 2006). In this theory, below average empathising ability could explain the social-communicational difficulties in the ASD profile, whereas the average or above average systemising ability could explain the repetitive and stereotyped features that characterise the ASD profile (Baron-Cohen, 2010). This theory has been extended and complemented by the extreme male brain theory of ASD (Baron-Cohen, 2002), which highlights gender differences in the empathising and systemising processes: females tend to perform better in empathising than males, whereas males perform better in systemising. Thus, the extreme male brain theory suggests that individuals with ASD are more likely to present above average systemising abilities and underperform in empathising, representing an extreme version of the male brain (Baron-Cohen, 2010).



### **2.3.3 Functioning and disability in ASD**

Although theories of causation of ASD are still being investigated, it has been recognised that as a neurodevelopmental disorder there is a significant, complex interplay of biological and environmental factors (Lai et al., 2014). A series of cognitive accounts have been developed in the past thirty years to explain the behavioural symptoms of ASD, with the premise that the study of cognition could assist grouping the diverse behavioural manifestations of ASD, and aid the understanding of the neurobiological processes that underpin them, to ultimately improve targeted interventions to address these behaviours (Jones et al., 2018; Lai et al., 2014).

Albeit the significance of these advances in cognition understanding, in recent years research in ASD has also emphasised that regardless of cognitive levels, individuals with this condition often have poor outcomes in relation to school, employment, engagement in post-secondary education and activities, they struggle to start and maintain relationships, and present lower levels of physical and mental health, and low overall quality of life (de Schipper et al., 2015; Howlin & Moss, 2012; Howlin, Moss, Savage, & Rutter, 2013; Lai et al., 2014; Levy & Perry, 2011; Pan, 2014; Shattuck et al., 2012a). In addition to these implications, research has also identified areas of differences in outcomes among individuals with ASD. These differences in outcomes seem to respond to a combination of factors such as the presence of a comorbid condition (such as depression, anxiety, attention deficit and hyperactivity disorder, epilepsy, to name a few), language ability and general intelligence of the individual, together with factors of the environment (Brunsdon & Happé, 2014; de Schipper et al, 2016). Furthermore, the presence of certain areas of strength, and gendered manifestations of the ASD profile have been stressed (Halladay et al., 2015 Happé & Frith, 2009).

These emerging differences in ASD presentation are not explicitly covered in diagnostic classifications such as the DSM-5 (APA, 2013), but recognised in an

abbreviated manner in one of the diagnostic criteria. The first three criteria for ASD in the DSM-5 refer to core features of the condition and onset period, namely deficits in social communication and interaction across multiple contexts (criterion A), the presence of restricted, repetitive patterns of behaviour, interests, or activities (criterion B), and presence of the symptomatology in the early developmental period (criterion C) (APA, 2013). The fourth criterion (criterion D) highlights the causation of 'clinically significant impairment in social, occupational, or other important areas of current functioning' (APA, 2013, p.50). In other words, while diagnostic systems provide 'useful categorical descriptions of illness and disorder' (De Vries & Bölte, 2016, p.894), meeting the criteria for a condition provides little information about the functioning implications of that diagnosis for an individual in everyday life situations (Castro & Pinto, 2012; de Schipper et al., 2016; Lollar & Simeonsson, 2005).

This recognition requires adopting a complementary perspective to that of diagnostic categories that would allow the definition and quantification of functional abilities and disabilities in individuals diagnosed with ASD (De Vries & Bölte, 2016). In this respect, the International Classification of Functioning for Children and Youth (ICF-CY) by the World Health Organisation (WHO; 2007) represents a good complement to diagnostic classifications, such as the WHO's International Classification of Diseases (ICD-11), now in its eleventh revision (WHO, 2018). The ICF recognises functioning and disability as separate from diagnostic categories or pathology, adopting a biopsychosocial perspective. This perspective does not undermine or deny the presence of a diagnosis, but defines the level of functioning of an individual as the result of the interplay of functions and structures of the body (physiological functions and anatomical parts), activities (execution of tasks), participation (involvement in life situations) and environmental factors (i.e. characteristics of the physical, attitudinal and social environment) (WHO, 2007). Understanding this perspective means that, for example, in the school context two individuals with the same diagnosis could have completely different functioning

profiles, given the individuality of the interplay of these domains of functioning for each person (Lollar & Simeonsson, 2005). Adopting this biopsychosocial perspective of functioning and disability is relevant and timely for the education context, particularly in the context of the English SEND reform, as it has the potential to offer much more detailed information for the development of strategies, interventions and provision for children and young people with SEND than using diagnostic categories on their own (Castro & Palikara, 2018).

### ***2.3.4 Education provision and ASD***

The individuality of ASD manifestations and needs represents a challenge in terms of service provision for this particular group (Bond & Hebron, 2016). According to the NAS there are around 700,000 people in the UK who may have an ASD, with around 70% of children and young people with ASD being educated in mainstream settings (DfE, 2018; NAS, 2018). This means that it is very likely for schools to have pupils with ASD in their student rolls, and most teachers will have students with ASD in their classrooms at some point (Ravet, 2011). In England, 14.6% of pupils in schools are identified as having special educational needs and disabilities (SEND), and students with ASD represent 10.3% of that population (DfE & ONS, 2018). A small percentage of pupils (2.9%) require specialist provision to be made for them under the newly introduced EHC plans (DfE & ONS, 2018). These are statutory documents which describe the child, their needs and aspirations, and the provision and outcomes sought for them (DfE & DoH, 2015). Issues related to their introduction and development under the new English legislative framework are discussed in section 2.4 of this chapter. More than a fourth (28.2%) of those pupils who require provision in line with an EHC plan are identified as having an ASD as their primary area of need, consolidating ASD as the largest group in need for specialist

educational provision (DfE & ONS, 2018). Furthermore, they represent 28.5% of the population of special schools.

The education of children and young people with SEND in mainstream settings and the development of inclusive schools have been a policy priority in the UK since the Warnock Report (DES, 1978), and internationally since the Salamanca Declaration (United Nations Educational, Scientific and Cultural Organisation [UNESCO], 1994). In the context of ASD, the breadth of manifestations calls for a continuum of provision to cater for the variety and complexity of needs that may not necessarily be met in a single type of placement (Jones et al., 2008; Norwich, 2008). The move towards an inclusive education system in which students with SEND learn among peers without SEND has generated a debate concerning the future of special schools, and in terms of the benefits and drawbacks that emerge from educating children and young people with ASD in different settings (Florian, 2008; Lindsay, Proulx, Thomson, & Scott, 2013; Norwich, 2008; Runswick-Cole, 2011).

On the one hand, studies have shown that children with ASD who were exposed to typically developing children in mainstream settings showed an improvement in social behaviour (Eldar, Talmor, & Wolf-Zukerman, 2010; Osborne & Reed, 2011; Rowley et al., 2012). Children and young people with ASD manifest a desire to build friendships, and particularly during the adolescent period peer relationships are considered the most significant factor associated with quality of life (DaWalt, Usher, Greenberg, & Mailick, 2017; Falkmer, Oehlers, Granlund, & Falkmer, 2015; Helseth & Misvaer, 2010); however, they also refer to feelings of loneliness more frequently than typically developing children, and report that loneliness is one of the aspects of their mainstream placement they find most stressful (Bauminger & Kasari, 2000; Humphrey & Lewis, 2008; Humphrey & Symes, 2010a; Osborne & Reed, 2011; Rowley et al., 2012). In addition, the experience of poor quality friendships and loneliness in adolescents with an ASD can increase the risk of mental health problems such as depression and anxiety, and can also result in increased

likelihood of getting bullied by others (Bauminger & Kasari, 2000; Hebron & Humphrey, 2014; O'Hagan & Hebron, 2017). The struggle of individuals with ASD in decoding the complexities of nonverbal communication, namely tone of voice, facial expressions, body language, and issues with literal interpretation and idiosyncratic use of language may hinder their understanding of social rules and motives of their peers may make them 'an easy target for derision and mockery' (Rowley et al., 2012, p.1127). In this respect, the academic ability of a student with ASD to perform in a mainstream setting should not be confused with their ability to cope with other aspects of mainstream school (Humphrey & Symes, 2010a).

Waddington and Reed (2017)'s comparison of the effects of mainstream and special school on National Curriculum outcomes of children with ASD in the South East of England suggest that those placed in mainstream settings have no greater academic success than those in specialist provision. Nevertheless, research on specialist settings for children with ASD suggests that exposing children with ASD to other types of needs may improve emotional and behavioural aspects of functioning, but hinder social behaviour (Osborne & Reed, 2011). Among the beneficial aspects of special settings is that of the specialist knowledge and expertise of members of staff, and the smaller student-teacher ratio, which allows for further personalisation and tailoring of education plans for pupils (Eldar et al., 2010; Reed, Osborne, & Waddington, 2012; Rowley et al., 2012). The current state of knowledge regarding the efficacy and desirability of inclusive education in mainstream schools for children with ASD remains scarce, as a variety of results arising from research conducted in both mainstream and specialised placements suggest that there is not a single type of provision, placement or strategy in a position to cover and meet the needs of *all* individuals with ASD (Lewis & Norwich, 2005; Machalicek et al., 2008; Parsons, Lewis, & Ellins, 2009, Sung et al., 2018; Wehman et al., 2014a). The variety of manifestations of the spectrum reveals the complex debate around the most

appropriate and effective ways of supporting the learning of these pupils (Parsons et al., 2011).

### **2.3.5 ASD and adolescence**

The term adolescence derives from the Latin word *adolescere*, which means to grow into maturity or to grow up (Lerner & Steinberg, 2009). It is a developmental period characterised by anatomical, physiological and psychosocial changes. From the psychosocial perspective, it could be described as a period of identity exploration, in which the individual faces the challenging task of developing a more complex – and changing – understanding of the self. It is also a period of relationship reconfiguration, particularly with parents and siblings, where stronger connections to others take place, and peers play a significant role (Hauser-Cram et al., 2009). There is a renewed meaning for friendships, which change from being oriented to activities, to being relationships with strong emotional ties. These relationships contribute in advances in socio-cognitive levels, such as reciprocity and intimacy, conflict resolution, loyalty and trust (Hartup, 1993). Social acceptance and physical appearance are areas that contribute strongly to the overall sense of self (Harter, 1986).

During the adolescent period, independence and autonomy gain a central place, where the individual seeks opportunities to act with regards to their own preferences and wishes, product of a better and deeper understanding of the self (Harter, 2012). This is also accompanied by a greater sense of responsibility and increased self-reliance. This new sense of and need for independence reconfigures the relationship with parents; the transition from childhood to adulthood is characterised by a constant push and pull of protectiveness, authority and supervision of parents, while balancing these with the needs for autonomy of the adolescent, moving towards the building of a less hierarchical and more egalitarian relationship with parents (Hauser-Cram et al., 2009). Another feature of the change in the

relationship with parents is a decrease in the priority of physical care of the child, to be replaced by an increasing interest in vocational preparation.

The changes that occur during this time can be challenging to all adolescents. These changes may have a more salient impact on young people with developmental disabilities than on their typically developing peers. Glidden and Zetlin (1992, cited in Hauser-Cram et al., 2009) suggest that part of this challenge could be attributed to 'the need for and resistance to awareness of their differences, especially if they perceive such differences as likely to impact directly on their daily lives' (p. 597). Given the developmental nature of ASD, manifestations of this condition vary greatly through the course of development, and from one individual to another. Those changes are such that by adolescence and early adulthood it is estimated that the symptoms that had led to the initial diagnosis would have changed (Schall & McDonough, 2010). Nevertheless, in spite of these changes the literature indicates that most individuals with ASD will continue to display behavioural characteristics of ASD through adolescence and early adulthood that validate the diagnosis (Schall & McDonough, 2010). Furthermore, the developmental trajectory of individuals with an ASD 'is neither uniform nor linearly ascending' (Schall & McDonough, 2010, p.82; Anderson et al., 2016). The entrance to the adolescent period shows an increased social interest, with some improvements in communication. Seltzer, Shattuck, Abbeduto, and Greenberg (2004) also note that as individuals with ASD age they adjust to change and decrease the presence of stereotyped behaviour, and show some level of improvement in adaptive functioning over time, particularly in daily living skills; however, impairments in social interaction and social communication persist into adulthood (Magiati, Tay, & Howlin, 2014; Seltzer et al., 2004; Schall & McDonough, 2010).

### **2.3.6 Post-16 education and employment of individuals with ASD**

Enrolling in post-secondary education and finding employment constitute two normative social role transitions for young people exiting secondary education (Chen, Leader, Sung, & Leahy, 2014). As increasingly more individuals with ASD leave the comfort of the education system and the services linked to it, there is a need for more qualitative research that aims at producing insider accounts on real-life experiences through the voices of autistic people themselves (Hendricks & Wehman, 2009; Pellicano et al., 2014a). Therefore, it is of utmost relevance to stress the significance of exploring issues related to post-16 education and employment through the voices of young people with ASD themselves.

The end of secondary education constitutes a turning point in the life of all adolescents and their families, as it represents an event that alters the direction of the life-course relative to previously established trajectories (Taylor & Seltzer, 2010). The period after leaving secondary school could be seen as a time of exploration and newly found independence for young people, in which the pursuit of education and employment is embedded (Wei et al., 2015). Indeed, participation in employment and increased financial independence are generally seen as central performances of socially accepted adult roles, and constitute key elements of an individual's post-school quality of life (Anderson et al., 2014; Halpern, 1993). However, for young people with ASD and their families, this period is lived as a challenging one, as many individuals leave the 'comfort' of the education system with feelings of unpreparedness for adult life at work, post-secondary education or community living, and with less experiences of autonomy and independence expected of youth transitioning to adulthood (Pellicano et al., 2014; Schall & McDonough, 2010; Taylor & Seltzer, 2011; Wehman et al., 2014a). These challenges call for the development and improvement of services available to them (Fayette & Bond, 2018). Among these challenges are also the transfer from an environment that offers high levels of support



to one where support is lower, and facing a labour market that increasingly values higher qualifications with a particular emphasis in literacy and numeracy skills (Pellicano et al., 2014a; Robinson, Moore, & Hooley, 2018). Moreover, young people and their families need to learn to navigate various systems in the move from children's to adults' services, and develop new relationships of support and advocacy with a new range of professionals (Nag, 2014; Pellicano et al., 2014b; Rehm, Fuentes-Afflick, Fisher, & Chesla, 2012; Robinson et al., 2018).

Across the ability spectrum, individuals with ASD present lower rates of participation in vocational or technical education, employment, and postsecondary education than their peers with learning disabilities, speech and language impairments, or intellectual disabilities (Shattuck et al., 2012; Wehman et al., 2014b). Research suggests that higher income and higher functional ability are associated with higher adjusted odds of participation and engagement in postsecondary education and employment, while lower cognitive and language functioning have been associated with lower rates of employment (Shattuck et al., 2012a; Howlin, Mawhood, & Rutter, 2000; Graetz, 2010). Socioeconomic status and access to services have been considered in the literature as contributors to postsecondary outcomes, suggesting that lower rates of participation have been found in individuals coming from low income backgrounds (Shattuck et al., 2012b); this has also been found in individuals with more severe impairments and comorbid conditions, associating impairments in functional skills with worse postsecondary outcomes and high risk for disengagement in adulthood (Howlin & Moss, 2012; Seltzer et al., 2004; Shattuck et al., 2012a; Taylor & Seltzer, 2011).

Findings report that as a group, individuals with ASD exhibit an overall low participation in competitive employment, with unemployment rates that range from 50% to as high as 86% in spite of many years of participation in intensive special education services (Taylor & Seltzer, 2011; Shattuck et al., 2012b; Wehman et al., 2014b). Furthermore, those who are employed tend to work in temporary, low wage,

low skills positions which are often below their level of education, and have difficulties in maintaining stable employment (Hendricks, 2010; Hurlbutt & Chalmers, 2004; Shattuck et al. 2012a). A study conducted on postsecondary expectations of secondary students with ASD found an interdependence and sequencing of transition domains, suggesting that individuals with ASD attribute success in one adult role domain to the realisation of another one – in other words, participation in meaningful employment is contingent on, or fostered by, participation in education (Sneed, Hamagami, McArdle, Cohen, & Chen, 2007; Anderson et al., 2016).

There is a paucity of literature describing ASD in late adolescence and adulthood (Shall & McDonough, 2010). There is little research about how social and psychological factors of ASD impact individuals during their transition out of school (Wehman et al., 2014). Shattuck et al. (2012a) reported that young people with ASD have the highest risk of being completely disengaged from any kind of postsecondary education or employment compared to individuals with a history of speech and language impairment, intellectual disability and learning disabilities. The authors added that this risk is particularly high for the first two years after exiting secondary school. They also suggested that these findings might point to a potential gap in transition planning and the removal of barriers to participation that may be specific to this population (Shattuck et al., 2012a). Further investigation of the transition experience of emerging adults with ASD is a necessary step toward improved social policy and programme development catered to this group of individuals, as generally services for adults with ASD have been found to be costly, scarce and/or inadequate (Anderson et al., 2016 – p.9; Magiati et al., 2014). Magiati and colleagues (2014) pointed out that although investigation of individual characteristics is a great contribution to increase our understanding of ASD, there is a stronger need for research that takes into consideration environmental and social factors from multiple perspectives. Indeed, as Gerhardt and Lainer (2011) suggested that ‘the potential of individuals with ASD to become employed and engaged adults seems limited more

by the failure of the systems charged with supporting them than by the challenges directly associated with their diagnosis' (p.38). This constitutes a strong rationale for adopting the biopsychosocial model of the ICF-CY to explore the views of young people with a history of ASD, as it allows to shift the focus from characteristics associated with symptomatology of ASD, therefore located 'within' the individual, to one of functioning that conveys the interactive nature of the relationship between an individual and their environment, in a cross-disciplinary language endorsed by the WHO (2007).

This section raised a number of issues with regards to the needs of young people with ASD at the time of transition, and around the development of provision that would allow them to engage with and participate in post-secondary destinations in order to make an effective transition to adult life. Given the heterogeneity of the ASD profile and the challenges that they face in their transition to post-school destinations, policy and provision to address and support the needs of young people with ASD at this time in their lives becomes crucial. The following section addresses the history and significant role of classification systems in the identification of children and young people's needs in the health and education contexts, and the purposes they served, followed by the current SEND policy landscape and its implications for transitioning youth.

## **2.4 Classification of children's and young people's needs**

The conceptualisations of ability and disability have evolved significantly over time, and the evolution of these concepts is deemed to respond to the shifts in society's perceptions of life and death, health and illness (Hollenweger, 2008; Simeonsson, 2006; Whiteneck, 2006). Classification systems emerged as tools for knowledge representation to ensure a common conceptualisation of a particular sphere of life of significant importance to individuals and society (Hollenweger, 2008).

The processes by which these are created result from the standardisation of discursive practices in professional groups to ensure a shared conceptual repertoire and a common application of specific terminology (Hollenweger, 2013). In order to understand principles and issues related to the classification of children with SEND in education contexts, it is important to briefly explore the development of classification systems, in particular with regards to children's needs. The shifts in the ways we conceptualise and classify SEND ultimately translate into a series of practices to cater for children and young people's needs that respond to these particular conceptualisations.

The earliest international classification system in the domain of health and disability dates back to 1893, and was developed by the Chief of Statistics for the City of Paris, Jacques Bertillon. He developed a list of diseases, causes of death and incapacity for work, a precursor for the internationally adopted 1900's International List of Causes of Death (also known as the Bertillon Classification), which set the basis for the one of the WHO's current classification systems: the International Classification of Diseases (ICD) (Moriyama, Loy, & Robb-Smith, 2011). As shown by the title, the scope of Bertillon's classification was circumscribed to 'distinguishing between general diseases and those localised to a particular organ or anatomical site' and identifying which ones were more likely to cause death (WHO, 2010, p.164). Currently in its eleventh revision, today's ICD is broader, as it does not only include disease categories, but also categories of disorders or syndromes, and developmental disorders of learning skills, describing their aetiology and phenomenology (WHO, 2010).

By 1980, with the ICD in its ninth revision, the WHO published another classification system to accompany the ICD, focusing on the consequences of diseases rather than on their causes or manifestations: the International Classification of Impairments, Disabilities and Handicaps (ICIDH). The emergence of this classification denoted society's shift in conceptualisations of health and disability,

emerging from a growing understanding of treatment and prevention of illness and death, improved hygiene conditions, and longer life expectancy; by then the attention had swiftly shifted from identifying causation of death towards issues related to social participation of persons with problems in functioning (Hollenweger, 2008). This classification system was a precursor to the International Classification of Functioning, Disability and Health (ICF), first published in 2001 by the WHO, and followed by a children and youth version (ICF-CY), introduced in 2007. The ICF is a universal and multidimensional conceptual framework based on a biopsychosocial model of health, human functioning and disability (Adolfsson, 2013) that allows the recording of a wide range of information about health states, rather than disease, in terms of functions and structures of the body, activities and participation, and relevant environmental factors, in a neutral and universal language, endorsed by the WHO (Lollar & Simeonsson, 2005). Within this framework, disability is not understood as a result of infirmity or disease, but as the result of the dynamic interaction between the individual and the context in which they develop (Castro & Palikara, 2016). A number of authors suggest that the functioning model of the ICF-CY constitutes a good match for education contexts, in particular as a framework for children and young people with SEND (Castro & Palikara, 2016; Florian et al., 2006; Hollenweger, 2018; Maxwell, Granlund, & Augustine, 2012; Norwich, 2014). Further discussion about this classification system, its relevance for the English SEND policy context and its use in this study are detailed in section 2.5 of this chapter.

#### ***2.4.1 The classification of SEND in the education context***

The use of categories in education, in particular with reference to SEND, has changed over time in response to evolving conceptualisations of what is and what causes disability, the consequences in functioning stemming from this, and to policy

advances that reflect these changes in society's perceptions and attitudes to SEND and to notions of the rights of individuals (Wedell, 2008).

In the context of special education provision, a central place has been given to the use of categories to classify children's learning difficulties (Florian, 2008; Norwich, 2014b). The significance that categories have traditionally held in this field lied on understanding the nature of disability and the implications stemming from it for the purposes of intervention, with the premise that identification of disability would lead to develop provision for children who were deemed exceptional (Norwich, 2014b; Wedell, 2008). Under a medical model of disability, where disability is understood as a result of a deficit or deviance in the individual which needed to be cured or fixed (Shakespeare, 2013), diagnosis of impairment was central to identifying its implications for the education setting. Medical classifications and diagnostic categories adopted a teaching purpose by allowing the identification of disorders or impairments in the assessment of children who struggled to learn (Norwich, 2014; Wedell, 2008).

The rise of the disability rights movement placed the issue of categorising people at the centre of discussion, leading to the recognition that categorisation could lead to stigma and stereotyping (Wedell, 2008). In the UK context, the emergence of the Warnock Report (1978) was suggested as the end of disability categories in education, introducing a new, overarching concept, that of special educational needs (SEN), which would allow for a more individualised approach to the needs of children (Norwich, 2014). In this respect, the introduction of this category would allow to determine, for example, the type of placement a child should attend, and the provision they would require in this particular setting; it would also allow shaping the design of the curriculum and the adaptations needed in terms of teaching strategies and approaches to content (Florian, 2008). In spite of the introduction of the concept of SEND, diagnostic categories and labels coexisted with the identification of a child

having SEND – this was evident under previous statements of SEND, which allowed the specification of a primary area of need usually defined in diagnostic terms.

However, it has been acknowledged that diagnostic categories on their own do not provide functioning information when it comes to identifying how a child would perform in different areas of life, such as in school (Castro & Palikara, 2016; Norwich, 2014b). Intervention and curriculum planning for teaching on the basis of a diagnostic profile of strengths and difficulties would not account for the individuality of the child and their interaction with an environment that could act as a support or hindrance to their learning (Lewis & Norwich, 2005). Identifying educational needs or requirements for children with disabilities and difficulties involves balancing common and different needs. In this vein, two individuals could share the same diagnostic category and have some common areas of need as well as different areas of need; similarly, two children with different diagnoses could have common areas of need (Castro & Palikara, 2016; Norwich, 2016). The ICF-CY represents a move from using medical categories related to disorders or disease to focus on functioning in a range of social contexts (WHO, 2001). It embodies an integration between the social and medical models into a multi-level, multi-disciplinary and interactive model (Lollar & Simeonsson, 2005; Tate & Perdices, 2008).

Since its publication in 2001, and the introduction of a version for children and young people (WHO, 2007), a growing body of research across the globe has investigated the potential and applications of this framework in a broad range of fields, including education, health, rehabilitation, among others (Florian et al., 2006; Castro & Palikara, 2018). In light of the changes in the SEND framework in England as a result of the Children and Families Act 2014, the ICF-CY (2007) has been suggested as an apt framework to support the implementation of this new policy (Castro & Palikara, 2016; Norwich, 2016). The following section introduces the classification system, describing its purpose and relevance, its structural organisation and the procedures for the use of the functioning codes.

## **2.5 The International Classification of Functioning, Disability and Health for Children and Youth**

The International Classification of Functionality, Disability and Health (ICF) is a classification system that aims to provide 'a unified and standardised language and framework for the description of health and health-related states' (WHO, 2001, p. 3). This classification system belongs to the Family of International Classifications of the World Health Organisation (WHO-FIC), and was published and approved to use in 2001; in 2007, a companion classification for children and youth was introduced (ICF-CY). The ICF-CY is a universal and multidimensional conceptual framework based on a biopsychosocial model of health, human functioning and disability (Adolfsson, 2011) that allows the recording of a wide range of information about health states, rather than disease, in terms of functions and structures of the body, activities and participation, and relevant environmental factors, in a neutral and universal language, endorsed by the WHO (Lollar & Simeonsson, 2005).

In this respect, the ICF and/or ICF-CY can serve as complements to the International Classification of Diseases, Eleventh Revision (ICD-11; WHO, 2018), which is a taxonomy framework to classify morbidity data, with a particular focus on medical diagnoses of diseases and other health problems. With regards to the ICD, it is important to stress that the presence of a diagnosis is not sufficient to predict functioning. Indeed, diagnostic information alone is of limited value when it comes to providing descriptions of functional impact of such diagnosis (WHO, 2007). Thus, the ICF/ICF-CY serves as a complement to the ICD, as it allows the description of a person from a holistic and contextual perspective, with regards to their body system, functional activity, participation, and environment in which they live (Castro et al., 2011; Lollar and Simeonsson, 2005; Tate & Perdices, 2008).

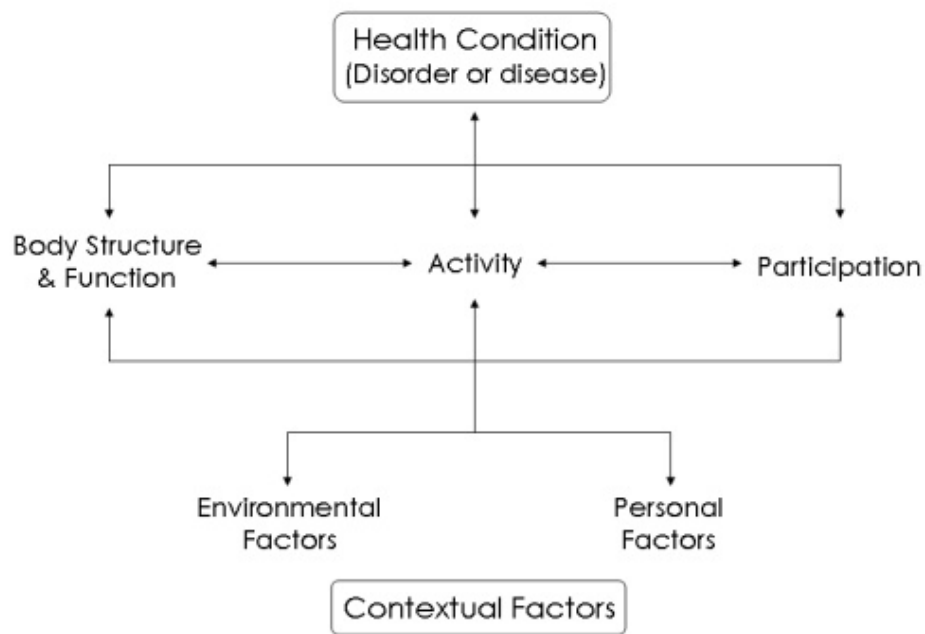


Within this model, disability is considered to have a universal nature, integrated as a natural experience of living, rather than associated to illness. It is understood as a multidimensional phenomenon that results from the interaction between people and their physical and social environment. In this respect, the ICF can assist in the identification of the principal 'problem' of disability, whether it is in the environment in the form of a barrier, the absence of a facilitator, and the limited capacity of the individual themselves, or a combination of factors (WHO, 2007).

One of the underlying principles of the ICF is its universality, as it can be applied to describe functioning of all people, irrespective of their health condition, and in all contexts – physical, social and cultural. It acknowledges that anyone can experience some disability, shifting the focus from a health condition to functioning, in an interactive health model (Adolfsson, 2011). Another relevant principle to this classification is its neutrality in language. Indeed, the language proposed by the ICF framework does not prompt negative connotations, remaining value and cause neutral (Lollar & Simeonsson, 2005). This allows recording aspects of human functioning and disability, where functioning covers the positive and neutral aspects of the interaction between a person's health condition in terms of body functions and structures, activities and participation, and their respective contextual factors, both environmental and personal. On the other hand, disability refers to impairments, activity limitations and participation restrictions (Lollar & Simeonsson, 2005).

### **2.5.1 The ICF Model**

The ICF is based on a framework of six dimensions of human functioning that interact with and influence each other: health condition, body factors –namely functions and structures of the body-, activities; participation, and contextual factors, i.e. environmental and personal factors (Figure 2.1)



*Figure 2.2 ICF-CY Model (WHO, 2007)*

The dimension of body factors refers to the physiological functions as well as the anatomical parts of the body – body functions and body structures, respectively. Impairments in this dimension refer to problems in the body system in terms of deviation or loss. The Activity dimension is defined as the execution of a task or action by an individual; therefore, activity limitations refer to difficulties an individual may face in executing activities. Participation is described as involvement in a life situation; thus, participation restrictions are understood as difficulties or problems an individual may experience in involvement in life situations. Environmental factors refer to the physical, social and attitudinal environment in which people live and conduct their lives. These can be described either as barriers to or facilitators of the person's functioning. Personal functions, lastly, refer to the particular background of an individual's life and living that are not part of a health condition or health state. Due to the 'large social and cultural variance associated with them' (WHO, 2001, p. 8), personal factors are not classified yet with the ICF. Obtaining information related to functioning in these dimensions offers valuable descriptions of a person's strengths

and weaknesses within their context; it also contributes to guiding assessment, intervention and evaluation of outcomes, to ultimately improve wellbeing, reduce functioning limitations, and increase participation (Adolfsson, 2011; Bruyere, Van Looy, & Peterson, 2005; Martinuzzi et al., 2010).

The concept of participation has been subject to contentious debate with regards to its definition and scope, its measurement, and its role as an intervention goal for children with SEND (Granlund, 2013). This term is one widely used in a range of settings, leading to different definitions and operationalisations across contexts. In the previous discussion regarding the voice of the child (section 2.2), for example, participation is conceptualised under a framework of the exercise of the right to have a say in matters that affect them, and is thus related to the concept of citizenship and democratic practices (Hart, 1992). This is also visible in the SEND Code of Practice (DfE & DoH, 2015), where participation constitutes one of the underpinning principles of the policy. In here, the principle of participation in decision-making reflects a duty for LAs and schools to provide support and information for children and young people with SEND to be involved in making decisions about support to be put in place for them. In this context, participation 'should lead to a better fit between families' needs and the services provided' (DfE & DoH, 2015). It also constitutes a desired outcome from removing barriers to learning (section 1.26 of the Code of Practice), and a result from effective SEND service provision (section 8.1 of the Code of Practice) (DfE & DoH, 2015). In this regard, participation is understood to have a sociologic dimension (Granlund et al, 2012), that relates to the implications of laws and regulations with regards to the 'availability, accessibility and affordability of resources and opportunities' to participate in society (p.86).

In the context of disability and health, definitions of participation have been suggested to reflect the individual's *attendance* in daily life situations, and to have a component of *involvement* in these situations (Maxwell, Alves, & Granlund, 2012). The nuance of this differentiation suggests that participation is not a single construct

but a multidimensional one, and this has been reflected in the structure and operationalisation of the ICF framework (2001). One of the main objectives of the ICF-CY is to increase children's participation in everyday life. The component of Activities and Participation of the ICF-CY does not provide a clear separation of activities, understood as the execution of a task, and participation, defined as involvement in a life situation. Instead it provides four different approaches that can be adopted when using the classification (ICF-CY) in this component, for example, dividing chapters of the component into activity-focused chapters, and participation-focused ones; or partially overlapping chapters of the component. These different approaches generated controversial debate in the field, with some authors arguing that performing a task constitutes a singular dimension of being involved in a life situation; and that tools to measure participation integrally in its entire scope of attending/doing (i.e. performing a task) and being involved/engaged (i.e. involvement in a life situation) are required (Granlund, 2013; Maxwell, Augustine, & Granlund, 2012). The development of such tools would allow developing interventions for children with the purpose of increasing their participation in everyday life situations (Adolfsson, 2013; Adolfsson, Granlund, & Pless, 2011; Granlund, 2013). For the purpose of this thesis, the component of activities and participation of the ICF-CY's taxonomy has been used as a whole, where each chapter is considered to have both dimensions of task performance and involvement in a life situation (WHO, 2007).

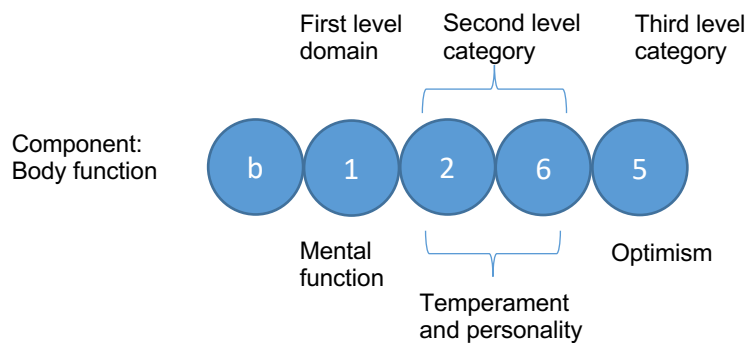
### **2.5.2 Structure of the ICF**

The ICF is structured in a hierarchical, stem-branch-leaf arrangement, as depicted in Figure 2.1. Firstly, it is divided in two parts: 1) Functioning and Disability; 2) Contextual factors. These two parts are divided into components. Functioning and disability contains three components: Body Functions, Body Structures, and Activities and Participation. The Contextual Factors part is also divided into two components:

Environmental factors and Personal Factors. Another subdivision happens at the component level. Components are divided into domains or chapters, which constitute the first level of classification in the ICF system.

The Body Component has eight domains for each body structures and body functions. Each domain of body structure corresponds to one of function. I.e. structures of the nervous system correspond with mental functions; eye, ear and related structures correspond with sensory and pain functions, and so on. The Activities and Participation component has nine domains that cover the full range of areas of life, starting with learning and applying knowledge to community, social and civic life. The environmental factors component is comprised of five domains that include physical, social and attitudinal factors. Lastly, as stated before, the Personal factors component has no further subdivision given the large social and cultural variance associated with them (WHO, 2007).

Each domain is subdivided into categories that represent the second, third, and fourth level of classification, constituting the most detailed level of ICF taxonomy. It should be noted, however, that not all domains have a fourth-level category classification – there is variability among domains in the degree of detail they allow to classify (Tate & Perdices, 2008). Nevertheless, the ICF extends to 1,424 categories. In addition to this, the ICF assigns a code for each of the four components it classifies: ‘b’ for body functions, ‘s’ for body structures, ‘d’ for Activities and Participation, and ‘e’ for environmental factors. As we move towards the first to fourth level of classification domains, a series of digits are added next to the respective component letter. The first digit after the letter represents the first domain or level of classification; the next two numbers refer to the second level category; lastly, two additional digits are applied for the subdivision at the third and fourth level, respectively (Tate and Perdices, 2008). The code b1265 represented in Figure 2.2 serves as an example for the interpretation of the alphanumeric system used in the ICF classification. Take, for instance, code b1265 - Optimism:



*Figure 2.3* Example of an alphanumeric code in the ICF-CY

In the example shown in Figure 2.2, the classification reaches the third level, as the domain of temperament and personality reaches up to the third level of classification. In addition to the category codes described above, the ICF also uses numeric descriptors called qualifiers, which appear following a point after a code. The ICF manual emphasises that the qualifiers are the ones that give meaning to a code; these qualifiers provide specific information concerning functioning status with regards to a code, reflecting the magnitude, location and nature of a problem (WHO, 2001). A code may have more than one qualifier. The first qualifier is generic in nature and refers to the extent of the problem or degree of severity. The second and third qualifiers can be used in body structures to refer to the nature of the impairment, and the location of the impairment respectively. For activities and Participation, two qualifiers are used to refer to performance – what a person actually does in the current or usual environment, including performance with the use of assistive devices or personal help – and capacity, which is the individual's true ability not enhanced by an assistive device or personal assistance (WHO, 2001). Both qualifiers use the generic listing. Similarly, environmental factors use the same set of generic qualifiers to describe the extent of the barriers. A plus (+) sign preceding the qualifier is used to identify a facilitator (WHO, 2001).

## **2.6 The education and SEND policy contexts in England**

### ***2.6.1 The current education context in England: inclusion and marketisation***

In order to understand the path that led to the changes introduced in the SEND system with the Children and Families Act 2014, it is important to provide an overview of the broader, current education context in England in which this new legislation is inscribed. In brief, this broader context is that of the development of inclusive education policy in England, on one hand, and the marketisation of the education system on the other. The Lamb Inquiry (2009), a key milestone in the development of the new SEND legislation is at the core of these two domains of educational policy, highlighting not only the momentum of these dimensions at this point in the history of English education policy, but also their inextricable link in the development of a fairer education system.

Although the ideology of inclusion in the education context is not new, as it dates to the beginning of the 20<sup>th</sup> century (O'Brien, 2002), the current form of what we call inclusion is the result of a journey that began during the 1960s when extensive debate over segregation in education started with the civil rights movement (Hodkinson, 2010). It is not in the scope of this section to address these historical developments in detail, as they are addressed in Section 2.6.2 of this chapter. However, they are brought to attention in this section given their relevance in setting the scene for what later the Coalition Government promised to be a radical change in the SEND system (Runswick-Cole, 2011). The arrival of a New Labour government in 1997 brought new impetus to educational policy reform, bringing inclusion to the centre of the scene. Among the changes introduced through their initiatives and policies, the Government introduced the Green Paper 'Excellence for all Children: Meeting Special Educational Needs' (DfEE, 1997), and a revised curriculum (DfEE, 1999) formulated on the basis of 'three inclusionary principles: setting suitable learning challenges, responding to pupils' diverse learning needs, and overcoming

potential barriers to learning and assessment for individuals and groups of pupils' (Hodkinson, 2010, p. 62).

While the New Labour had located inclusion at the core of its rights-based agenda, further advanced by other legislation and initiatives such as the Special Educational Needs and Disability Act 2001, and the introduction of a Code of Practice for Special Educational Needs (DfES, 2001), it was soon evident that the strong adherence to the principles of inclusion faced some practical constraints, with the continued existence of a 'twin-track' system for SEND and segregation practices within the education system (Barton, 2003). In addition to this, during this government a new wave of marketisation had entered the scene of public services. Following from the re-definition of parents as customers who need to be informed to make rational decisions in choosing, for example, a school for their children, this new, complementary wave brought about the concept of personalisation of services (Hartley, 2010; Varney, 2006) to the arena of education. In this sphere, the New Labour Government introduced a report '*2020 Vision: Report of the Teaching and Learning in 2020*' (DfES, 2007) in which it emphasised the belief on the personalisation of teaching and learning as a key to transform the English education service. Once more, several discrepancies and contradictions were highlighted in relation to inclusion and personalisation, for example with regards to the lack of plans to reduce class sizes as a path towards greater personalisation of learning (Hartley, 2010; Hodkinson, 2010).

In the context of growing number of policies of inclusion and marketisation of the education system through personalisation, the Lamb Inquiry (2009) was established to 'investigate a range of ways in which parental confidence in the SEN system of assessment and provision might be improved' (Lamb, 2009, p.2), following from the identification of significant failures to provide statutory information to parents, resulting in their loss of confidence in the SEN system and the professionals working in it. The findings of this inquiry constituted an inflection point in the role of parental



voice and quality assurance, by incorporating a right of appeal for parents in case of disagreement with local authorities, and placing a duty on Ofsted to include in their reports their evaluation on the quality of education provided for children with SEND.

Shortly after the inquiry on parental confidence and the SEND system, a Coalition Government emerged in 2010, promising to ‘respond to the frustrations of children, young people and families to the landmark policy [...] of inclusion’ by the Labour government (Hodkinson, 2012, p. 4). The introduction of the Green Paper ‘Support and aspiration: a new approach to special educational needs and disability’ (DfE, 2011) was the steppingstone for the development of what was promised to be a ‘radically new’ SEND system, as expressed in the Conservative manifesto, with an emphasis on bringing to an end the ‘bias towards inclusive education’ (Norwich, 2014; Runswick-Cole, 2011). The following section offers a comprehensive overview of the changes in legislation that reflect on changes in conceptualisations of ability and disability, rights and provision undergone by the English context.

### ***2.6.2 A historical overview of the SEND legislative framework***

The education of children and young people with SEND has gone through substantial changes throughout the past decades. During the 1960s, the emphasis of the civil rights movement opened the debate concerning policies and practices of educational segregation. Until the Education Act 1972, the concept of ‘ineducable’ was commonplace for individuals with disabilities, and its abolition by the new law led the path to the development of a new education system in which children and young people with SEND had the right to be educated regardless of the severity of their disabilities. This new direction in SEND called for the introduction of principles of universal education, and a committee of inquiry was set up in 1974 with the purpose of establishing such principles, aiming to articulate ‘a concept of education that could make sense in the context of any child, anywhere in the continuum of ability and disability’ (Warnock & Norwich, 2010, p.16). The reported conclusions and

recommendations from this committee, known as the Warnock Report (1978), constituted a milestone in the development of policies regarding education and provision for individuals with SEND, setting the basis for the Education Act 1981.

The new law introduced for the first time a definition of SEND and special education provision, understood as one that is 'additional to, or otherwise different from, the educational provision made generally for children of his age' (Education Act 1981, p.2). The system of assessment and the issuing of statements of SEND for children with learning difficulties were introduced; these documents conferred the right to special provision to be made in order to help these children achieve their educational goals, and imposed on LAs a legal duty to provide it (Warnock, 2005). The new law replaced disability specific categories with the more general term SEN in order to focus on the individual needs of a particular child, with regards to the curriculum and its relevance for teaching (Norwich, 2014b). According to Warnock, the statements of SEND had a protective nature to ensure that the right to education of those children was respected, regardless of their disability (2005).

In addition, under the Education Act 1981 parents had the right to provide additional information about the child, to be included in the special needs' assessment. Their participation in this process so far remained optional and secondary, as it was place for the LA to inform the parents about the special needs assessment to be carried out on the grounds of suspecting the child's need for specialist provision. In this respect, although the views of parents were recognised as valuable there was no statutory requirement for them to be included in the assessment process; thus, their involvement remained discretionary.

The introduction of the Education Act 1988 and that of the National Curriculum opened a new era for the education system, characterised by competitiveness and an increasing pressure to raise academic standards. It has been argued that the performativity agenda set in schools concerning measurable outcomes and climbing higher in the rankings in league tables compromised the commitment to inclusion

(McGlynn & London, 2013). Lastly, in 2001, with the enactment of the Special Educational Needs and Disability Act, disability discrimination provision was introduced to the field of education, emphasising the right of children with SEND to be educated in mainstream schools. This legislative change brought about a new duty on schools not to treat students with disabilities less favourably than others, in line with the Disability Discrimination Act 2001, which called for reasonable adjustments to be made to ensure that students with SEND were not disadvantaged (Norwich & Eaton, 2015). This section highlighted some of the most significant changes the education system had faced in the past decades. However, it is worth noting that up until this point the system of assessment and statements of SEN had not been subject to substantial change since their first introduction by the Education Act in 1981.

### ***2.6.3 The new Special Educational Needs and Disability Code of Practice***

Following a practically unchanged landscape in the field of SEND for many years, in 2011 the Coalition government published the SEND Green Paper 'Support and Aspiration', which aimed to bring a radical reform to the statutory assessment of SEND (Norwich, 2014). One of the key elements of this reform was the introduction of EHC assessment and plans, to gradually replace statements for a single, yet holistic, procedure to identify and cater for children with SEN. The focus on improving life outcomes for children and young people required an increased level of integration of education, social care and health services, and placing the children, their families, and young people at the heart of the process to foster the development of a more user-led system (Lamb, 2013; Norwich, 2014).

In keeping with this movement, participation of children, their parents, and young people in decision-making constitute one of the key underpinning principles of the new law and the statutory guidance that stems from it, the SEND Code of Practice

(DfE & DoH, 2015). Furthermore, this legislation extended provision for SEND to cover from birth to 25 years of age, meaning that services and provision go beyond compulsory education. This extension places transition to adulthood planning in a compelling position, stressed by the new SEND Code of Practice, which states that preparation for adult life must be an element of discussion and conversation with children and their families from the earliest years, and should start when students are in Year 9, namely 13-14 years of age (DfE & DoH, 2015). The Act also introduced the new EHC plans to replace previous statements of special educational needs. The development of EHC plans calls for multiagency collaboration in the assessment and implementation process, to learn and discuss the best ways to meet the needs of the child or young person, and to make joint decisions about resourcing, resulting in a more holistic, participatory and person-centred approach to SEND.

This approach emphasises the principles of agency and choice, collaboration, empowerment and equality that support the involvement and participation of the individual and those around them in planning and decision-making in matters affecting their lives (Corrigan, 2014). In the context of the new SEND Code of Practice, the principle of participation of the individual in decision-making establishes a legal duty upon LAs for them to regard the views, wishes and feelings of the child or young person, and of the child's parents. In addition, it highlights the duty to inform and provide children, their families and young people with the necessary support and information to enable their participation decision-making, and to help them achieve the best possible outcomes, preparing them effectively for adulthood (DfE & DoH, 2015). This principle and the extension of provision to 25 years of age give young people (16 and older), for the first time, the opportunity and the right to engage directly with LAs and other agencies to discuss and make joint decisions about support and provision, in light of their own wishes and goals. This collaborative approach would enable the development of multidimensional provision that would help remove

barriers to participation and enhance quality of life of children and young people with SEND (DfE & DoH, 2015).

#### ***2.6.4 The introduction of Education Health and Care plans***

As part of the SEND reform stemming from the Children and Families Act 2014, Education Health and Care (EHC) plans were introduced to replace previous statements of SEND. An EHC plan is a single document produced by a LA, resulting from an EHC needs assessment conducted in collaboration and consultation with the child, their parents, or young person, relevant school staff and a wide range of professionals. When, in spite of the education provider having taken action to identify, assess and meet the special educational needs of the child or young person, they have not made expected progress, the EHC needs assessment resolves to make special provision in accordance to an EHC plan to meet the needs of the child (DfE & DoH, 2015). The EHC plan should contain information about the needs and strengths of the child, described in a multidisciplinary and holistic way, and must include the child and their family perspective. It should be noted, however, that not all children with SEN or disabilities would require an EHC plan. The new Code of Practice states that a child or young person has a SEN if they have a learning difficulty or disability which calls for special educational provision to be made for them due to a greater difficulty in learning than the majority of others of the same age, or to a disability which prevents or hinders them from using facilities of a kind generally provided to others of the same age in mainstream schools or post-16 institutions (DfE & DoH, 2015, p.15-16).

Following the principle of participation in decision-making, the SEND Code of Practice states that decisions concerning the content of an EHC plan should be the result of a collaborative process and discussion among parents, children, young people, relevant school staff, professionals and the LA, and it should be clear how the

child or young person has contributed to the plan, and how their views are portrayed in it (DfE & DoH, 2015). In addition, given the holistic nature of the plan, it should show how different services and agencies in education, care and health will co-ordinate to support the child or young person with SEND to achieve the outcomes sought for them.

The SEND Code of Practice delineates clearly the content of each section of the EHC plan, suggesting a standard particular order to be replicated across LAs. It allows a degree of flexibility with regards to the presentation of the content, i.e. using a tabular format to include different sections, as long as the sections are clearly and separately identified with the labels provided by the Code. This requires from plans to include a section in which the views of the child, their parents or the young person are portrayed (Section A), together with the respective sections dedicated to describing the needs of the child or young person in education (Section B), health (Section C) and social care (Section D), and the outcomes (Section E) sought for the child or young person. Sections F, G and H are dedicated to providing details of the provision required for education (Section F), health (Section G) and social care (Section H) in order to meet the diverse range of needs of children and young people with SEND; section I refers to the placement where the child or young person attend, namely the name and type of school. The new policy also introduced personal budgets to the new statutory documents; in this section (Section J) details about the arrangements of budget for education, health and social care, together with the needs and outcomes that will be met by the budget. Table 2.1 presents a summary of the content to be included in EHC plans, adapted from the Code of Practice (DfE & DoH, 2015, p.162-163).

Table 2.1 Content of Education, Health and Care plans, adapted from the SEND Code of Practice (DfE & DoH, 2015, p. 164-169)

Section	Content
Section A	The views, interests and aspirations of the child and his or her parents, or the young person.
Section B	The child or young person's special educational needs.
Section C	The child or young person's health needs which are related to their SEN.
Section D	The child or young person's social care needs which are related to their SEN or to a disability.
Section E	The outcomes sought for the child or the young person. This should include outcomes for adult life. The EHC plan should also identify the arrangements for the setting of shorter term targets by early years provider, school, college or other education or training provider.
Section F	The special educational provision required by the child or the young person.
Section G	Any health provision reasonably required by the learning difficulties or disabilities which result in the child or young person having SEN. Where an Individual Health Care plan is made for them, that plan should be included.
Section H1	Any social care provision which must be made for a child or young person under 18 resulting from section 2 of the Chronically Sick and Disabled Persons Act 1970.
Section H2	Any other social care provision reasonably required by the learning difficulties or disabilities which result in the child or young person

Section	Content
	having SEN. This will include any adult social care provision being provided to meet a young person's eligible needs (through a statutory care and support plan) under the Care Act 2014.
Section I	The name and type of the school, maintained nursery school, post-16 institution or other institution to be attended by the child or young person and the type of that institution (or, where the name of a school or other institution is not specified in the EHC plan, the type of school or other institution to be attended by the child or young person).
Section J	Where there is a Personal Budget, the details of how the Personal Budget will support particular outcomes, the provision it will be used for including any flexibility in its usage and the arrangements for any direct payments for education, health and social care. The special educational needs and outcomes that are to be met by any direct payment must be specified.
Section K	The advice and information gathered during the EHC needs assessment must be attached (in appendices). There should be a list of this advice and information.

#### *2.6.4.1 Views, aspirations, and needs of children with SEND*

The first five sections of EHC plans are considered the most relevant for the line of study adopted in this thesis, as these were the ones concerned with providing a broad description of the individual in terms of their views and aspirations, their needs, and outcomes sought for them. It is important to stress that the views of young people, their wishes and aspirations are at the centre of the development of the new EHC plans. This acknowledgment by the new law is in line with international trends and charters that recognise the right of children and young people to have their views



heard and be given due weight in matters affecting their lives, and the recognition of the rights of people with disabilities to be included and participating fully in society (Porter, 2014; UN, 1989; UN, 2006). In the EHC plan process, the views of young people are required to be recorded in the first section of the plan, Section A. The Code of Practice establishes that this section must provide the following information:

- Details about the child or young person's aspirations and goals for the future (but not details of outcomes to be achieved). When agreeing the aspirations, consideration should be given to the child or young person's aspirations for paid employment, independent living and community participation
- Details about play, health, schooling, independence, friendships, further education and future plans including employment (where practical)
- A summary on how to communicate with the child or young person and engage them in decision-making.
- The child or young person's history
- If written in the first person, the plan should make clear whether the child or young person is being quoted directly, or if the views of the parents or professionals are being represented.

(DfE & DoH, 2015, p.164)

Sections B, C, and D were dedicated to the special educational, health, and social care needs, respectively. It is worth noting that although these three domains look separate in terms of their content, details of sections C and D remain closely linked to education. In fact, the Code of Practice stresses that EHC plans should contain information on health and social care needs of a child or young person as long as these needs are related to their special educational needs, in the sense that addressing them has implications for education and training of the individual (DfE & DoH, 2015). In addition, the needs stated in section D that relate to social care are

defined by the content of section 2 of the Chronically Sick and Disabled Persons Act 1970. This section describes the provision of, and arrangement for, welfare services available from a LA in relation to practical assistance for the person in the home, in conducting works to adapt their home for greater safety, comfort and convenience, assistance and provision in recreational activities, travelling, communication arrangements and equipment, to name a few.

#### *2.6.4.2 Towards SMART outcomes for children and young people with SEND in the new EHC plans*

Section E of the new EHC plan is dedicated to the specification of outcomes in education and training, health and social care sought for children and young people in order to enable progress in their learning, and to prepare them progressively for adulthood (DfE & DoH, 2015). Outcomes are descriptors of what needs to be achieved by the end of a stage, and should consider what is important to and for the child or young person, in order to help them progress towards the next stage. In this sense, the Code of Practice specifies that these outcomes should be aspirational, as they should allow children and young people move towards the long-term aspirations defined in Section A of the plans, suggesting a link between these two sections in their development. This is of particular relevance by the time the young person reaches year 9 (13-14 years of age), as outcomes set at this stage of their schooling should reflect their preparation for adulthood. This section is concerned with key changes in an individual's life, like changing schools, transferring from children to adult services or transitioning from education and training to adulthood (DfE & DoH, 2015).

Under the new Code of Practice (DfE & DoH, 2015; p.160), an outcome is defined as:

*'the benefit or difference made to an individual as a result of an intervention. It should be personal and not expressed from a service perspective; it should be something that those involved have control and influence over, and while*

*it does not always have to be formal or accredited, it should be specific, measurable, achievable, realistic and time bound (SMART).'*

The adoption of this definition and how this translates into high quality outcomes is an issue that recent research in relation to the SEND reform has highlighted as challenging given the lack of guidance and clarity from the Code of Practice on how to instrument these criteria (Palikara et al., 2018a).

The literature of the SMART criteria offers a range of definitions for each letter of the acronym; it is commonly understood that SMART would refer to goals or outcomes being specific (i.e. Jung, 2007), measurable (Bovend'Eerd, Botel, & Wade, 2009; O'Neill & Conzemius, 2006); attainable, accountable or action-oriented (Piskurich, 2015; Rubin, 2002); relevant or realistic (Jung, 2007; Rubin, 2002); and time framed, or time-bound (O'Neill & Conzemius, 2006). Thus, the mark of being SMART represents that outcomes and goals devised using these criteria are considered to be of higher quality than those that do not follow these criteria. In the scope of the Code of Practice, outcomes are a significant part of the EHC plan process as they highlight what a child or young person is expected to achieve as a result of an intervention, which in turn would increase or enhance participation. The Code of Practice highlights that outcomes should not address information of the service or intervention, but rather focus on what the individual would be able to do as a result (DfE & DoH, 2015).

Developing high-quality outcomes requires a comprehensive understanding of the child or young person's functioning, and of the ways in which this can be linked to interventions that would lead to supporting the individual's learning and development (Bagnato, McLean, Macy, & Neisworth, 2011; Rakap, 2015). Furthermore, the development of high-quality goals also supports monitoring progress and effectiveness of interventions (Boavida et al., 2010). In the context of the new Code of Practice, EHC plans must be reviewed annually. At the stage of EHC plan annual

reviews, outcomes sought for a child as described and written in Section E of the EHC plans should be appraised considering whether they were achieved or not, allowing an examination of the provision put in place to operationalise those agreed outcomes. Another relevant aspect to consider with regards to the quality of outcomes is linked to its functionality. Rakap (2015) suggests that an outcome or goal is deemed functional if it increases the individual's autonomy and their ability to adapt to changes in their environment. In this respect, the functionality dimension of outcomes is well suited with the overall aim of the SEND provision as stipulated by the Children and Families Act 2014. As previously discussed, the overall purpose of the EHC plan is to instrument provision, in light of the views and needs of a child and their family, which would lead to greater levels of participation of the individual.

The descriptions of views, aspirations and needs in the first four sections are tied to the section on provision, which mobilises services and support to meet the needs and achieve the proposed outcomes stemming from the aspirations. However, the Code of Practice highlights that while efforts should be directed towards achieving outcomes, EHC plans cannot be maintained until the achievement of stated aspirations; for example, if getting a job is an aspiration of an individual, the LA is not obliged to maintain their plan until the aspiration is secured or achieved.

## **2.7 Research aims and questions**

### **2.7.1 Research aims**

While recent decades have seen a significant increase in research on ASD, the literature review presented in this chapter highlighted a number of underexplored areas of research, particularly those concerning the views of young people, their transition to post-secondary destinations, and the implementation of the new SEND policy for this particular group. This study aimed to address this paucity in research by exploring the views and experiences of young people with ASD transitioning to

post-secondary life, in the context of the new SEND legislation in England. Thus, this study aimed:

- a. To give voice to young people with ASD by exploring their views and experiences of transition to post-secondary destinations.
- b. To explore the functioning dimensions identified as the views, needs, and outcomes of young people with ASD as portrayed in their newly developed EHC plans.
- c. To explore the extent of the match between the views of young people with ASD obtained through interviews and those depicted in their respective EHC plans.
- d. To evaluate the quality of outcomes sought for young people with ASD in their EHC plans with regards to their focus on functioning and participation at the time of transition to post-secondary destinations.

### ***2.7.2 Research questions***

This thesis addressed a total of 11 research questions to respond to the research aims previously presented. For clarity purposes, these research questions are organised here under the subsequent chapters that responded to them. The questions are followed by a brief overview of the methodology used to address the questions. Chapter 3 of this volume addresses in greater detail the methodology used for each strand of study.

#### *2.7.2.1 Capturing the voices of young people with ASD in transition to post-secondary destinations (Chapter 4)*

This study responded mainly to the first aim, by exploring the views and experiences of young people with ASD in their transition to post-16 education and employment through semi-structured interviews, and by describing the dimensions of functioning conveyed in these young people's views obtained through the interviews. For this chapter, two research questions were identified:

- a. What are the views of young people with ASD about their transition to post-secondary destinations?
- b. What are the ICF-CY functioning dimensions identified in the views of young people with ASD as extracted from the interviews?

Appendix A provides a full account of the interview schedule built to guide the interview process. Furthermore, Appendix B presents some exemplars of the digital visual cards (Talking Mats) used throughout interviews to facilitate eliciting and recording the views of young people and enhance communication. In order to answer these research questions, first an inductive thematic analysis was performed, followed by deductive content analysis using the ICF-CY framework and codes to analyse the content of 28 individual semi-structured interviews. Appendix C contains examples of relevant quotes that emerged during interviews with participants in order to illustrate the initial coding and the emergence of themes. Findings stemming from this strand of study are presented in Chapter 4 of this thesis.

#### *2.7.2.2 The functioning-related views, aspirations, needs and outcomes of young people with ASD in EHC plans (Chapter 5)*

The purpose of this strand of study was to explore how the views and aspirations, needs and outcomes sought for young people with ASD were portrayed in their EHC

plans, using the ICF-CY (WHO, 2007) as a holistic taxonomy that would enable to have a common language across plans. Considering the statutory requirements stemming from the new Code of Practice with regards to the nature and the content of the EHC plans, the following research questions were identified:

- a. What are the methods used to capture the views of young people with ASD in their EHC plans?
- b. What are the ICF-CY functioning dimensions identified in the EHC plans as the young person's views, interests and aspirations?
- c. What are the functioning dimensions reported as special educational, health, and social care needs of young people with ASD?
- d. What are the functioning dimensions identified as the outcomes sought for young people with ASD?

The EHC plans of 23 young people with ASD were collected and subsequently analysed. The first strand of analysis consisted of a qualitative inductive approach to explore the overall structure and content of the EHC plans, followed by a deductive content analysis approach in which the ICF-CY served as a system to map and analyse the content of the plans in terms of functioning dimensions. Appendix D contains coded extracts of the EHC plans of the young people to illustrate the resulting ICF-CY coding of the plan content. An exhaustive list of ICF-CY codes identified across EHC plans sections and interviews can be found in Appendix I. The findings stemming from this strand of study are presented in Chapter 5 of this thesis.

#### *2.7.2.3 Matching the views of young people with ASD from semi-structured interviews and Section A of EHC plans (Chapter 6)*

This strand of study built on the analysis of findings stemming from Chapters 4 and 5. It explored the extent of the match between the views and experiences of

young people with ASD in transition to post-16 education and employment as reported through semi-structured interviews (Chapter 4), and those stemming from each young person's EHC plan (Chapter 5). The following research question was identified:

- a. To what extent do the ICF-CY functioning dimensions identified as the young people's views in Section A of EHC plans match those identified by the young people themselves in semi-structured interviews?

In order to describe the extent of the match between these two sources, the ICF-CY's framework and codes were used to analyse the content of Section A of EHC plans and individual semi-structured interviews. The codes identified in both plans and interview transcripts were computed and quantified, and the functioning dimensions identified in both plans and transcripts were compared to explore the extent to which the views of young people as identified in interviews matched those written in their respective EHC plans. The findings stemming from this analysis are presented in Chapter 6 of this thesis.

#### *2.7.2.4 Quality evaluation of outcomes sought for young people with ASD in transition to post-secondary destinations (Chapter 7)*

The main aim of this study was to provide further evidence about the content and overall quality of outcomes described for young people with ASD at a time of transition, in light of the SMART criteria proposed by the SEND Code of Practice (DfE & DoH, 2015). The purpose of this study was to explore whether there are differences in the quality of those outcomes according to the LA that produced the EHC plans, the type of setting the young people attended (mainstream or special), and the year group in which the young people were in (secondary – year 11; or post-secondary). The following research questions emerged:



- a. What is the overall quality of outcomes defined for young people with ASD in their EHC plans?
- b. Does the quality of the outcomes depend on the LA that produced them?
- c. Does the quality of the outcomes vary depending on the type of school that produced them?
- d. Does the quality of the outcomes vary depending on the year group they are written for?

For the purpose of this strand, 265 outcomes were extracted from Section E of 23 EHC plans and were assessed using the Goal Functionality Scale III (GFS III) (McWilliam, 2009). Each outcome was assessed using the seven quality indicators of the GFS III and was scored using a four-point scale. Descriptive statistics for each indicator were computed and calculate; non-parametric tests were ran to further analyse the data, as assumptions for parametric testing were not met. Appendix B contains examples of the outcomes extracted from EHC plans and their respective scoring using the GFS III. The findings stemming from this strand are presented in Chapter 7 of this thesis.

In sum, Chapter 4 of this thesis presents the results that address the first aim related to the views of young people; chapter 5 explores the content of EHC plans to answer the second research aim by using deductive content analysis and the ICF-CY framework to systematically translate the plans and transcripts into the universal language of the ICF-CY. Chapter 6 addresses the third aim by integrating and comparing results stemming from the chapters 4 (semi-structured interviews) and 5 (section A of EHC plans). Finally, Chapter 7 goes into further detail in the EHC plan analysis by exploring the quality of the outcomes sought for young people with ASD to address the fourth aim of this study, using the ICF-CY as a system of codes and the GFS III to evaluate the quality of outcomes.

## **2.8 Summary**

This literature review chapter has characterised the state of the field concerning voice, ASD and the newly introduced English SEND framework. The review of literature in these fields has recognised some strengths, challenges and opportunities that the changes introduced by the Children and Families Act 2014 present for the field of SEND, particularly with regards to the views of children and young people, and the development of EHC plans to cater for their needs. In spite of this growing body of literature in the field of ASD and in the scope of the new SEND policy, this chapter has highlighted areas in which research in the area is underexplored. Among these areas are those involving individuals with ASD themselves in research and transition to post-secondary destinations.

The introduction of a new SEND policy in England represented a renewed opportunity for young people with SEND to express their views concerning their wishes and aspirations for the future and engage in a joint decision-making process with LAs and providers about services that would meet their needs and support them in achieving their aspirations. Evidence presented in this chapter suggests that young people with ASD are at increased risk of being disengaged and excluded from participation in post-secondary education and employment, and their communities, particularly within the first two years after exiting secondary school. Participation in everyday life has been described in the literature as a crucial component of inclusion, and it constitutes a core element of the WHO's (2007) suggested approach to disability and health, advocated in the framework of the ICF-CY. Thus, the investigation of the views of young people with ASD about their transition to post-secondary destinations in the scope of the new SEND policy is timely and relevant for children and their families, practitioners and service providers working in SEND and for the English policy context. Recent studies in the field have looked at the implications for implementation of the new SEND policy for a range of stakeholders,

but limited research has been conducted involving young people themselves in these processes. In light of these gaps and underexplored areas of study, four research aims and 11 research questions were identified to conduct the present study.

### **3. Research Methodology**

#### **3.1 Introduction**

The current chapter discusses the methodology chosen to conduct the present study. The main objective of the study was to gain an in-depth understanding about the experiences and views of young people with ASD following their transition to post-16 education and employment. To do this, the study has been divided in two different but complementary strands, where semi-structured interviews were conducted, and statutory documents of SEND provision, namely EHC plans were collected. The rationale for diversifying methods in this study was to obtain richer data from complementary perspectives on the topic under investigation, and for this reason a sequential exploratory research design was deemed to be the most appropriate (Robson, 2011; Creswell & Plano Clark, 2010).

Throughout this chapter, discussions on the chosen research design and methodology take place to justify the study from a methodological perspective. The chapter first addresses the research aims and research questions arising from the review of the current state of the field, as described in Chapter 2. A discussion of the methods for data collection takes place, as well as procedures regarding the analytical approaches adopted for the collected data. Moreover, ethical considerations are discussed in light of issues arising from engaging vulnerable children in research.

#### **3.2 Research design**

The present study adopted a mixed methods design. This research design can be defined as a collection of steps and procedures for collecting, analysing and combining – ‘mixing’- both quantitative and qualitative approaches to methods and data in a single study or series of studies, providing the researcher with complementary data on the same topic (Cohen et al., 2018). This allows a better and

deeper understanding of the phenomena under study by bringing together the strength of both approaches (Creswell, 2012; Creswell & Plano Clark, 2010; Punch & Oancea, 2014). Within the mixed methods approaches, this study followed an exploratory sequential design (Creswell & Plano Clark, 2010). This design begun with an exploration of the phenomenon under study by collecting and analysing qualitative data, in this case obtained by conducting semi-structured interviews and collecting each participant's EHC plan. This phase was followed by a quantitative phase, in which the researcher built from the exploration of the qualitative phase by gathering quantitative data (Creswell & Plano Clark, 2010).

In the case of this study, both interview transcripts and the content of the EHC plans were analysed first inductively, and then using a deductive content analysis approach to quantify the gathered qualitative data by transforming it into the ICF-CY's system of pre-defined codes, following linking rules used in previous studies (Augustine et al., 2018; Castro, Pinto, & Simeonsson, 2014; Cieza, Fayed, Bickenbach, & Proding, 2016; Palikara et al, 2018b; WHO, 2001).

Cohen, Manion, and Morrison (2018) assert that every method in research acts as a filter through which the environment is selectively experienced and that reliance on solely one method 'may bias or distort the researcher's picture of the particular slice of reality being investigated' (p.141). Triangulation approaches to research methods offer the researcher the confidence that the generated data are the result of the complex nature of the phenomenon under study which requires a holistic perspective that cannot be captured by one specific method (Cohen et al., 2018). The aforementioned research questions called for the development of two strands of study that could be informed separately while at the same time still contributed to the development of a holistic picture of the views and experiences of young people with a history of ASD about their transition to post-secondary destinations, as well as their functioning. This was achieved through the complementary perspectives gathered by semi-structured interviews, and the collection and analysis of the young people's

respective EHC plans. Thus, this research design was regarded the most suitable for the proposed study.

### 3.3 Participants

A total of 29 young people with ASD (26 male; 3 female) in the 15-19 age range ( $M = 16.3$ ;  $SD = 1.14$ ) were recruited and agreed to take part in this study. They were interviewed at their schools/colleges, and their EHC plans were collected as per consent of both parents and participants themselves. They were attending 13 schools and colleges located across 13 LAs in the Greater London area. The majority of participants were attending their last year of secondary school (Year 11) ( $n=23$ ), and six participants were enrolled in post-secondary settings. Twenty-six out of 29 participants attended special schools, whereas only three participants attended mainstream settings. It has been widely accepted that ASD occurs more frequently in males than females; currently it is estimated that the ratio of female-male ASD occurrence is 1:3 to 1:5 (Lai et al., 2014). However, it should be noted that the proportion of males in the sample of this study was greater than current ratio estimations. Table 3.1 provides a summary of characteristics of the sample.

Table 3.1  
*General sample characteristics*

Participants' general information (n = 29)		
<i>Gender</i>	Male (%)	26 (89.7)
	Female (%)	3 (10.3%)
<i>Age</i>	Range	15-19
	Mean (SD)	16.3 (1.14)
<i>Year group</i>	Year 11 (%)	23 (79.3%)
	Post-16 (%)	6 (20.7%)

Table 3.1

*General sample characteristics*

Participants' general information (n = 29)		
<i>Setting</i>	Special (%)	26 (89.7%)
	Mainstream (%)	3 (10.3%)
<i>SCQ Score</i>	Range	8-31
	Mean (SD)	17.6 (5.89)

In order to provide more specific contextual information of participants and schools, the Income Deprivation Affecting Children Index (IDACI) was used as an indicator of the socioeconomic context of schools and colleges that the young people were attending. This index is a sub-set of the Income Deprivation domain, which measures the proportion of children living in income deprived families (Department for Communities and Local Government [DCLG] & Office for National Statistics [ONS], 2015). Thus, those LAs ranked in higher IDACI positions represent areas of greater income deprivation, whereas those in lower IDACI positions represent more affluent areas. Given that the study was conducted in schools located in the Greater London area, the indices reported here need to be considered with reference to this particular area. Four LAs were among higher ranking IDACI positions, three LAs were placed within the average for Greater London LAs, and six LAs had lower IDACI positions. So overall, following the IDACI rankings, it could be said that participants came from a wide range of socioeconomic contexts. For the purpose of preserving anonymity of both schools and participants, the specific statistic for each LA was not included. Given that most participants attended special schools, with some of them catering specifically for ASD, and the small number of special secondary schools per LA in the Greater London area, it was considered that providing the exact IDACI for each borough could lead to the identification of the schools.

The following subsections address the sampling strategy adopted in this study, provide details of criteria for selection of participants, individual characteristics of the sample that took part in the study, procedures followed to recruit participants and to conduct the study, and materials used.

### ***3.3.1 Sampling strategy***

The sample procedure for this study was purposeful. This means that individuals and sites of study were selected because they could purposively inform an understanding of the research problem and central phenomenon in the study (Creswell, 2013). Purposive sampling techniques allow the collection of great in-depth data from a number of carefully selected cases that 'will yield the most information about a particular phenomenon' (Teddlie & Yu, 2007, p. 83). In other words, through purposeful sampling a series of particular settings, events or persons are selected deliberately for the relevance of the information they can provide, and that otherwise could not be gotten from other choices (Maxwell, 1997).

Teddlie and Yu (2007) describe a series of categories of purposive sampling techniques, in which specific types of strategies are embedded. These strategies are employed depending on the aim of the researcher in relation to the purposive sample. A purposive sample strategy could be used, for example, to illustrate a special or unique case; a sequential purposive sampling strategy – that is, a gradual selection of units or cases based on their relevance to the research question – could be used when the sample evolves during the course of data collection (Teddlie & Yu, 2007). The most adequate strategy adopted by this study was a purposive technique to achieve representativeness or comparability. The main goals of this strategy are: a) to find instances that are typical or representative of a particular type of case on a dimension of interest; and b) to achieve comparability across different types of cases on a dimension of interest (Teddlie & Yu, 2007). In the case of the present study, the



main goal was to obtain an in-depth picture of the views and experiences of young people with ASD following their exit from secondary school and their transition to post-secondary destinations, to be able to identify aspects of their experiences that were common to participants across the sample, while at the same time explore their differences.

### **3.3.2 Sample size**

Teddlie and Yu (2007) suggest that sampling techniques could be seen as a continuum, placing purposive sampling techniques in one end, providing the gathering of in-depth data in small samples; and probability sampling techniques in the other end, allowing gathering broader data in larger samples. The number of participants was selected in light of the nature of the study, where there was a focus not only on gathering in-depth, but also on breadth of information across the two research strands (Teddlie & Yu, 2007). An in-depth understanding of the views and experiences of post-16 education of young people with ASD in the context of SEND reform called for a number of participants that was large enough to capture a wide range of experiences, but remained manageable to explore data in-depth in order to build a thorough picture of the current life situation of this particular group.

### **3.3.3 Criteria for selection of participants**

The sample was selected on the basis of the following criteria: (a) the young person had a diagnosis of an ASD according to the criteria established by the Diagnostic and Statistical Manual of Mental Disorders (4<sup>th</sup> Edition – Revised; 5<sup>th</sup> Revision) (APA, 2000, 2013) or by the International Classification of Diseases (10<sup>th</sup> Revision) (WHO, 2010); (b) The young person had or was eligible for a maintained Education, Health and Care (EHC) plan; (c) the EHC plan indicated the young person's ASD; (d) The young person was in the 15 to 19 age range, either at the end

of secondary school or already in post-16 education or training. Table 3.2 presents participants' characteristics in detail, including gender, age, type of setting and year group they were attending, SCQ score, whether they had a final version of their EHC plans, the sections of EHC plans which had content for analysis, the number of outcomes identified in Section E, and the LA where their schools/colleges were located.

### **3.4 Materials**

#### ***3.4.1 Education, Health and Care Plans***

The new statutory documents for SEND were a key component for the present study. As explored in Chapters 2 and 3 of this volume, the study focused on analysing the content of the first five sections of the EHC plans: Section A, covering the views, wishes and aspirations of young people and their families; Section B, which addressed the special educational needs of the young person; Section C, which covered their health needs; Section D, which contained information concerning social care needs of the young person; and lastly, Section E, which covered the outcomes sought for the young person. Analysing these first five sections of EHC plans was deemed the most appropriate approach to obtain valuable information concerning the views of young people with ASD at the time of their transition to post-secondary destinations, providing information not only about their wishes and aspirations, but also about their needs in education, health and social care terms, and the outcomes proposed for this transition. Thus, these five sections were aptly aligned with the main aim of this study.

According to the SEN Report from the Department for Education (DfE) and the Office for National Statistics (ONS), as of January 2018, 63.6% of previous statements

Table 3.2

*Participants' characteristics*

YP	Gender	Age (y, m)	Year group	Type of Setting	SCQ	Interview	EHC Plan	EHC plan sections					No. Outcomes	LA
								A	B	C	D	E		
YP 1	Male	16y, 5m	Year 11	Special	26	Yes	Yes	X	X	X	--	X	7	1
YP 2	Female	16y, 1m	Year 11	Special	31	Yes	Yes	X	X	--	X	X	8	1
YP 3	Male	16y, 0m	Year 11	Special	15	Yes	Yes	X	X	X	X	X	7	1
YP 4	Male	16y, 6m	Year 11	Special	14	Yes	Not finalised	--	--	--	--	--	--	1
YP 5	Male	15y, 11m	Year 11	Special	19	Yes	Yes	X	X	--	--	X	5	9
YP 6	Male	16y, 1m	Year 11	Special	23	Yes	Yes	X	X	--	--	X	11	1
YP 7	Male	16y, 0m	Year 11	Special	N/A	Yes	Yes	X	X	--	X	X	6	1
YP 8	Male	16y, 4m	Year 11	Special	27	Yes	Yes	X	X	X	X	X	8	1
YP 9	Male	16y, 4m	Year 11	Special	19	Yes	Yes	X	X	X	X	X	9	3
YP 10	Male	15y, 11m	Year 11	Special	20	Yes	Yes	X	X	--	--	X	10	3
YP 11	Female	15y, 7m	Year 11	Special	23	Yes	Yes	X	X	X	--	X	9	3
YP 12	Male	16y, 0m	Year 11	Special	13	Yes	Yes	X	X	--	--	X	10	2
YP 13	Male	16y, 5m	Year 11	Special	N/A	Yes	Not finalised	--	--	--	--	--	--	1
YP 14	Male	16y, 1m	Year 11	Special	13	Yes	Yes	X	X	--	--	X	10	2
YP 15	Male	16y, 1m	Year 11	Special	8	Yes	Yes	X	X	--	--	X	12	2

*Note.* YP = Young Person; y = years; m = months; SCQ = Social Communication Questionnaire score; Section A = Views, wishes and aspirations; Section B = Special educational needs; Section C = Health needs; Section D = Social care needs; Section E = Outcomes; N/A = Not available; X = content available; -- = No content; LA = Local authority

Table 3.2

*Participants' characteristics*

YP	Gender	Age (y, m)	Year group	Type of Setting	SCQ	Interview	EHC Plan	EHC plan sections					No. Outcomes	LA
								A	B	C	D	E		
YP 16	Male	18y, 0m	Post-16	Special	20	Yes	Yes	X	X	X	--	X	17	4
YP 17	Male	16y, 4m	Year 11	Special	16	Yes	Not finalised	--	--	--	--	--	--	
YP 18	Male	15y, 8m	Year 11	Special	N/A	Yes	Not finalised	--	--	--	--	--	--	
YP 19	Male	19y, 1m	Post-16	Mainstream	8	Yes	Yes	X	X	X	--	X	10	6
YP 20	Male	17y, 10m	Post-16	Mainstream	20	Yes	Yes	X	X	X	--	X	11	7
YP 21	Male	15y, 2m	Year 11	Special	11	Yes	Yes	X	X	--	--	X	17	2
YP 22	Male	15y, 8m	Year 11	Special	20	Yes	Not Finalised	--	--	--	--	--	--	10
YP 23	Male	17y, 4m	Year 11	Special	16	Yes	Yes	X	X	X	X	X	9	10
YP 24	Male	16y, 7m	Year 11	Special	21	Yes	Yes	X	X	X		X	15	10
YP 25	Male	19y, 3m	Post-16	Special	15	Yes	Yes	X	X	X	X	X	13	5
YP 26	Male	15y, 8m	Year 11	Special	N/A	Yes	Not finalised	--	--	--	--	--	--	13
YP 27	Male	16y, 11m	Year 11	Special	8	No	Yes	X	X	X	--	X	9	2
YP 28	Female	19y, 2m	Post-16	Mainstream	16	Yes	Yes	X	X	X	X	X	35	3
YP 29	Male	17y, 11m	Post-16	Special	18	Yes	Yes	X	X	X	X	X	17	8

*Note.* YP = Young Person; y = years; m = months; SCQ = Social Communication Questionnaire score; Section A = Views, wishes and aspirations; Section B = Special educational needs; Section C = Health needs; Section D = Social care needs; Section E = Outcomes; N/A = Not available; X = content available; -- = No content; LA = Local authority

of SEND had been converted to EHC plans (DfE & ONS, 2018). At the time of writing this volume, six out of 29 participants did not have a finalised version of their EHC plan in place. For consistency purposes and given the non-statutory nature of draft versions of the EHC plans, those participants who did not have an EHC plan signed off by their respective LA (N = 6) were excluded from the strands of study that analysed the content of these documents.

### **3.4.2 Social Communication Questionnaire**

Parents and primary caregivers of the young people who took part in this study were asked to complete this questionnaire, which was sent to them together with parental consent forms. The Social Communication Questionnaire (SCQ) is a brief screening tool consisting of 40 yes-or-no questions that tap symptomatology associated with ASD in the three core domains of ASD characteristics: reciprocal social interaction, communication, and restrictive, repetitive and stereotyped patterns of behaviour (Rutter, Bailey, & Lord, 2003). The questionnaire was designed to be completed by parents or primary caregivers of children aged four and older and takes about ten minutes to complete. It was not conceived as a diagnostic instrument itself, yet it was designed as a companion tool to the Autism Diagnostic Interview (ADI-R) (Rutter, Le Couteur, & Lord, 2003), a standardised structured interview used to diagnose ASD. The items of the SCQ were developed to match the items in the ADI-R that were found to have discriminative ASD diagnostic validity (Rutter, Bailey, & Lord, 2003). In this respect, the SCQ offers a briefer content coverage of the diagnostic interview through a dimensional measure, focusing on behaviours considered rare in individuals who do not have an ASD. Reliability analysis conducted on a sample of 214 children showed good internal consistency indices across age groups, children with and without language, and diagnostic classification, with alpha values ranging from .81 to .93 (Rutter, Bailey, et al., 2003).

The instrument offers two different questionnaire forms: The Lifetime form, and the Current form. The former considers the 40 items with reference to the individual's entire developmental history, whereas the latter is completed with regards to the individual's behaviour during the most recent three-month period. The Current form is considered more pertinent to understand everyday life experiences and to evaluate interventions and educational plans (Rutter, Bailey, et al., 2003). For this reason, participants' parents and caregivers were asked to complete the Current form of this questionnaire. Examples of items belonging to both Lifetime and Current forms are found in Figures 3.1 and 3.2, respectively; in addition, a blank SCQ Current form can be found in Appendix A.

<b>8.</b>	Has she/he ever had things that she/he seemed to have to do in a very particular way or order or rituals that she/he insisted that you go through?	yes	no
<b>9.</b>	Has her/his facial expression usually seemed appropriate to the particular situation, as far as you could tell?	yes	no
<b>10.</b>	Has she/he ever used your hand like a tool or as if it were part of hers/his own body (e.g., pointing with your finger or putting your hand on a doorknob to get you to open the door)?	yes	no
<b>11.</b>	Has she/he ever had any interests that preoccupy her/him and might seem odd to other people (e.g., traffic lights, drainpipes, or timetables)?	yes	no

*Figure 3.1* Extract from SCQ Lifetime Form.

1.	Is she/he now able to talk using short phrases or sentences? If <i>no</i> , skip to question 8.	yes	no
2.	Do you have a to and fro 'conversation' with her/him that involves taking turns or building on what you have said?	yes	no
3.	Does she/he ever use odd phrases or say the same thing over and over in almost exactly the same way (either phrases that she/he hears other people use or ones that she/he makes up)?	yes	no
4.	Does she/he ever use socially inappropriate questions or statements? For example, does she/he ever regularly ask personal questions or make personal comments at awkward times?	yes	no

Figure 3.2 *Extract from SCQ Current Form.*

To calculate the score of the instrument - in both Lifetime and Current forms - each questionnaire item is assigned a score of 0 or 1, and the total score is calculated by adding individual items' scores. This measure has a cut-off score of 15; meaning that a total score of 15 or above indicates a likelihood that an individual has an ASD, and that a more thorough clinical investigation is required to confirm or rule out an ASD diagnosis (Rutter, Bailey, et al., 2003). Nevertheless, the authors caution that scores below the cut-off point should not be taken as conclusive of no presence of ASD, as research conducted with the tool has shown the presence of false negatives; this translates into cases in which individuals who received a score below 15 were later identified as having an ASD when assessed in detail (Rutter, Bailey, et al., 2003).

As discussed in Chapter 2, the ways we define and refer to ASD have changed throughout time; these changes include those of diagnostic categories and criteria. What in previous diagnostic classifications was referred to as, i.e. a Pervasive Developmental Disorder, Asperger's Syndrome, or autism, today falls under the umbrella of ASD, following the latest definition and diagnostic criteria endorsed by the APA (2013). The purpose of administering the SCQ in this study was not to confirm the diagnosis of ASD in selected participants, but to obtain an overview of current

ASD characteristics of a group who may have been diagnosed under different diagnostic criteria at different times.

Section 3.3.3 specified the criteria for selection participants; one of the criteria was that the young people had a diagnosis of ASD based on DSM-IV-TR/ICD-10 criteria, and that they were eligible for or had an EHC plan in place to cater for their ASD. Given the stringent assessment process behind the issuing of an EHC plan, the fact that all EHC plans stated the presence of an ASD, it was not considered necessary to subject the young people to further assessment of ASD such as ADI-R to confirm their diagnoses. Instead, the SCQ current form was deemed appropriate to establish a homogenous baseline and overview of current ASD symptom severity to incorporate this information in planning and adapting the interview process before meeting the participants.

As observed in Table 3.2, it was not possible to obtain the SCQ score of four participants due to their parents not returning the completed questionnaire to their child's school or to the researcher; for that reason, their score was indicated as not available (N/A). Moreover, this table also shows that seven participants out of 29 scored below the cut-off score of 15 highlighted above. Nevertheless, these young people were still considered for participation in the study; as previously described, the SCQ was not used as a tool to confirm ASD diagnosis, but to obtain an overview of ASD symptom severity prior to the interviews in order to adapt the process to each participant's social communication profile. Given the stringent assessment process behind the issuing of statement of SEND and an EHC plan and the fact that all EHC plans (previous statements, final versions or drafts) stated the presence of an ASD, it was not deemed necessary to subject individuals to further assessments to confirm their diagnoses. Instead, parents were required to complete the SCQ current form to obtain an overview of ASD symptomatology at the time of participation in the study given the different times at which they were assessed for ASD.



### **3.4.3 Goal Functionality Scale**

The second strand of this study aimed at exploring the views, needs and outcomes sought for young people with ASD as depicted in their EHC plans. The analysis of Section E of the collected EHC plans, which covered the outcomes sought for young people with ASD, was analysed using the Goal Functionality Scale III (GFS III) (McWilliam, 2009) as a rating tool. Results from this analysis are presented in detail in Chapter 7 of this thesis. The GFS III is an instrument designed to evaluate the quality of goals/outcomes in individual education plans (IEPs), and has been used widely used in previous research exploring the quality of goals sought for children with a wide range of needs in education and intervention contexts (i.e. Boavida, Aguiar, McWilliam, & Pimentel, 2010; Rakap, 2015; Sanches-Ferreira, Lopes-dos-Santos, Alves, Santos, & Silveira-Maia, 2013). In the UK context, it was recently used to evaluate and provide evidence of the quality of outcomes designed for children with SEND in their EHC plans in light of the SEND reform (Castro, Grande, & Palikara, 2019). The instrument consists of seven items or dimensions, which explore whether the goal (a) emphasises participation/engagement in routines, (b) states specifically what the child will do, (c) addresses a necessary or useful skill, (d) quantification of the acquisition criterion, (e) indicates an acquisition criterion, (f) indicates a generalisation criterion, and (g) presents a timeframe criterion for acquisition. Each outcome or goal is given a score for each of the seven dimensions, on a scale from one to four, where 1 means 'not at all', 2 means 'somewhat', 3 means 'much', and 4 means 'very much' (Boavida et al., 2010). Two mean scores can be obtained using this scale: a mean score for each outcome, resulting from calculating the average score obtained by an individual outcome across the seven dimensions of the scale; and a mean score of each of the seven dimensions, which can be obtained by calculating an average score across a group of outcomes on an individual dimension.

Appendix B contains examples of the extracted outcomes, and their respective ratings in each of the dimensions of the GFS III. Thus, these two types of score inform on the overall quality of individual outcomes, while at the same time provide a closer look into the dimensions of quality of a group of outcomes, helping identify specific aspects of outcomes that are of higher quality and those that would require improvement.

### **3.5 Ethical considerations**

The project to conduct the study that led to this volume was submitted for ethics consideration under the reference EDU 16/112 in the School of Education and was approved under the procedures of the University of Roehampton's Ethics Committee on October 21, 2016. Issues related to the protection of participants' interest and wellbeing, informed consent, right to withdraw, confidentiality and anonymity were addressed, following the relevant ethical guidelines of the British Psychological Society (BPS) (2014) and the British Educational Research Association (BERA) (2018).

The nature of this study called for special attention to these issues. Conducting research with vulnerable groups, such as young people with ASD, constituted a challenge throughout the entire process. To gain consent from the participants (and their parents), it was of utmost importance to present the study, its aims and procedures in a clear and accessible way, in accordance with each participant's communication needs. Familiarisation of participants with the researcher prior to data collection was another relevant matter to take into account to enhance participant engagement. This translated into visiting schools where headteacher consent had been obtained, to meet potential participants during the recruitment process accompanied by a familiar member of staff.

In addition, it was critical to preserve and promote participants' wellbeing during data collection. An outline of the interview schedule was given to the participants in advance, so that they could familiarise with the topics and therefore know what to

expect, helping to minimise the anxiety that the unknown or unexpected could trigger. Preserving participants' identity and assuring that the collected data would be safely stored and treated as strictly confidential was relevant to safeguard their wellbeing throughout the research process. Prior to each encounter, the researcher had liaised with a relevant carer of each participant (i.e. a teacher, parent) so that they were available during the day of the interview to support the participant (by being in a proximal room or having a phone available to receive a call) in case of distress. The researcher had an available phone and noted contact details of participants' carers should they need to contact them. In addition, the researcher provided their supervisors with relevant contact information on the days of data collection so that they were informed of the location where the researcher would be interviewing participants.

Participants were assigned a number to protect their identity; these numbers applied to both their interviews and plans, so that the identifying number, i.e. YP (young person) 1, refers to the same individual in the analyses of interview transcripts and their respective EHC plan throughout this thesis. Moreover, in order to maintain confidentiality and anonymity of schools, LAs were also assigned a number. Given that most participants attended specialist settings, and the small number of special schools per LA, it was considered that the identification of the LA could lead to the identification of schools and participants. The interview transcripts, audio files from interviews and the collected EHC plans were stored in password-protected folders. Those EHC plans which were collected in hard-copy format, together with consent forms and questionnaires, were safely stored in a locked-cabinet located at the University of Roehampton.

### **3.6 Procedures**

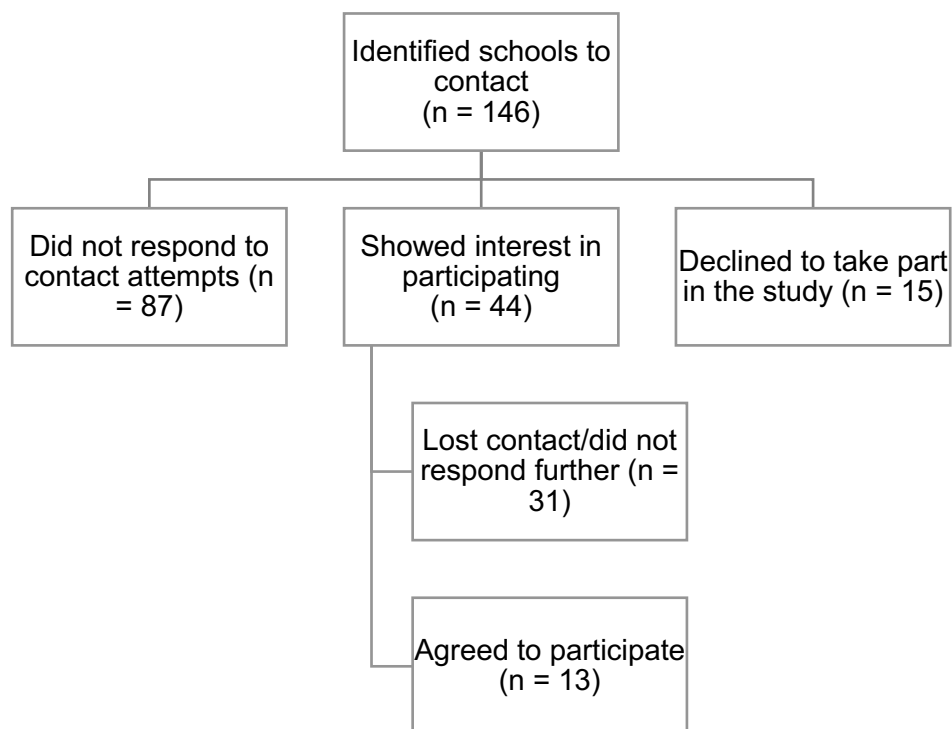
#### **3.6.1 Recruitment**

Participants for this project were recruited from schools, sixth forms and colleges of further education working with children and young people with SEND in the Greater London area. In order to recruit participants, a database with educational institutions' contact details was built based on the information available in the 'Local offer' section of each of London's boroughs. According to the Code of Practice all LAs 'must publish a Local Offer, setting out in one place information about provision they expect to be available across education, health and social care for children and young people who have SEN or are disabled, including those who do not have Education, Health and Care (EHC) plans' (DfE & DoH, 2015, p. 59).

The researcher searched the local offer of the 33 London LAs' websites and built a list of 146 schools (including secondary, sixth forms and colleges) who, as stated in their respective local offer's website, catered for children and young people with ASD. Figure 3.3 illustrates the number of schools contacted at the beginning of this study (n = 146), and the number of schools which ultimately collaborated in the study (n = 13). These educational providers differed in terms of their source of funding. Out of these 13 educational providers eight were state-funded, one was voluntary-aided, and four were academies belonging to multi-academy trusts (MATs).

The recruitment of participants and data collection for this study began upon project confirmation from the University of Roehampton's Research Degrees Board and ethical approval from the Research Ethics Committee (November 2016) and finished in April 2018. Figure 3.4 presents an overview of the timeline of the study from project confirmation to thesis submission. Letters describing the project were sent out to these institutions, addressed to Special Educational Needs Coordinators (SENCOs) and headteachers in schools, managers in workplaces and organisations,

explaining the aim of the study and asking them to provide consent for participation in the study.



*Figure 3.3* Flowchart of school identification and engagement for participant recruitment

On some occasions, a short meeting in person was agreed with the potential collaborating school, in order to introduce the study in further detail and discuss practicalities around what participation in the research project meant for schools, parents and participants. A copy of the introductory letter sent to schools has been included in Appendix C. Once schools and organisations had agreed to participate in the study, parental consent forms were provided to schools in order to be passed to the parents of the young people with ASD. In the consent forms parents were informed about the aims of the study, the right to withdraw their children from the study at any point and they were reassured about the anonymity and confidentiality of the information provided.

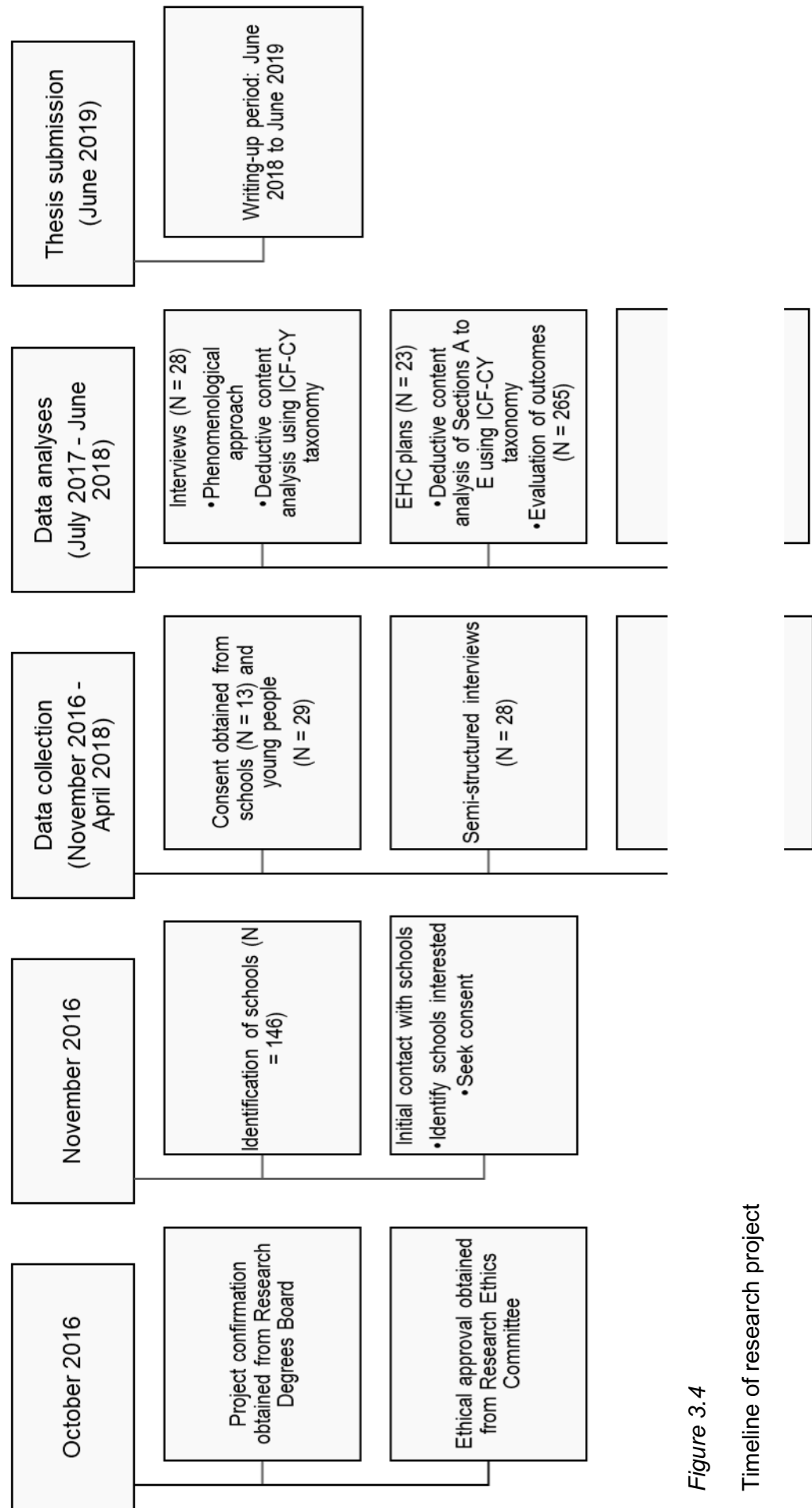


Figure 3.4

Timeline of research project

Additionally, they were informed in the consent letter that there was no compulsion or pressure to take part in the project, and that should a parent decline to participate or subsequently withdraw, their child would not be adversely affected. The consent letter also requested them to complete the SCQ and return it to their child's school if they were to agree to take part in the study, together with the signed consent form. In addition to obtaining parental consent, young people in the study were also required to give their consent to participate. They were provided with a consent form explaining the aims of the project in a simple language, what participation entailed, and addressed issues related to anonymity, confidentiality, their right to withdraw at any point, and that there was no compulsion or pressure to take part in the project, and that declining to participate would not affect them adversely.

To gain consent from the participants (and their parents), it was of utmost importance to present the study, its aims and procedures in a clear and accessible way, in accordance with each participant's communication needs. Once headteacher and parental consent were in place, the researcher met the participants at their schools to introduce herself and the study. During these encounters the researcher presented the aims of the study to the young people, and they discussed practical details about what taking part meant, the content of the interviews and the rationale for collecting their EHC plans. An adapted information sheet and consent form using picture symbols was also built for those participants whose communication needs required more visually supported means to access the information regarding aims and procedures of the project, what participation entails, issues related to confidentiality, anonymity and withdrawal, as well as obtaining their consent, as informed by previous research (Cameron & Murphy, 2002; Harrington, Foster, Rodger, & Ashburner, 2014; Preece & Jordan, 2010; Shepherd, 2015). An exemplar of each consent form (headteacher, parents, participants, and adapted consent form for participants) is available in Appendix D. In these meetings all participants gave verbal consent to take

part in the study and kept a copy of the information sheet. Participants met the researcher a second time to take part in semi-structured interviews and discussed once again the details of the study. This was to ensure there were ongoing opportunities for young people to ask questions and decide on their participation. All young people agreed to participate in the study and gave written consent.

### **3.6.2 Pilot study**

The study was piloted with four young people, two with ASD and two with other SEND in order to get a broad picture of the adaptations that might be needed to reach a wide range of communication abilities and difficulties that characterised participants with ASD. This was a way of recognising commonalities and differences in needs to ensure that the individual needs of each participant were met throughout the study (Norwich & Lewis, 2005). As a result from the pilot study, the wording of a small number of questions was modified to make the interview content more accessible. In addition, some prompts were added to the questions to remain as a support to open-ended questions that participants might find difficult to address. Lastly, the order of some questions was altered to reflect the flow of the conversation that emerged during these encounters. Special attention was dedicated to ensuring that interview questions were accessible, that the generated answers remained true to what was enquired and that they did not affect the wellbeing of the participant (BERA, 2018; BPS, 2014; Brinkmann & Kvale, 2015).

### **3.6.3 Interviews**

From the outset of this study, it was acknowledged that potential difficulties may arise from interviewing young people with ASD, as difficulties in social interaction and communication constitute a significant part of the ASD profile. This could translate into participants not making eye contact, not having much language, struggling with



social situations (such as the interview itself), feeling anxious or disconcerted by the presence of strangers (Harrington et al., 2014; Shepherd, 2015). It was anticipated that these manifestations could vary in presence and intensity from participant to participant. The diverse range of communication and interaction abilities and difficulties in ASD required considering not only needs that were common to all participants, but also to those that were individual and exceptional (Norwich & Lewis, 2005).

For this reason, an interview schedule was built to explore the topics to be covered as well as the wording. As previously mentioned, the schedule is included in this thesis in Appendix A. Additionally, the content of the questions was supported with visual cues in a tablet using a software called 'Talking Mats', as previous studies suggest the significance of visual stimuli to enhance and complement the interview process (Lewis, Newton, & Vials, 2008; Shepherd, 2015). This schedule comprised 20 to 25 open-ended questions, with additional prompts to facilitate the eliciting from those young people with more severe communication difficulties.

Participation in the study involved participants attending an interview and collecting their respective EHC plans. These encounters were audio recorded as per participant previous consent, to be later transcribed verbatim for analysis. A total of 28 young people took part in the interviews. Although the final number of recruited participants was 29, one participant could not take part in the interview due to their parent declining their involvement on the day the interview was taking place. Given this young person was below 18 years of age and the parent's written decline for this to be carried out, this participant was not included in the interview strand of study. Nevertheless, this young person had a finalised EHC plan, so they were included in the strand of study dedicated to the analysis of EHC plans. The interviews were administered on a one to one basis, in each participants' school, college, workplace or home, to ensure they were in a familiar environment, as the ASD profile indicated difficulties in coping with change and unfamiliarity. Interviews were conducted during

sociable hours, at a convenient time for participants, and agreed with them and their parents or headteacher, as appropriate for each case. Twenty-eight interviews were conducted, lasting between 10 and 42 minutes ( $M = 22.2$ ).

The interview started with an opening question related to how the young people felt about finishing, or having finished secondary school, followed by questions related to their current or prospective post-16 destination –i.e. college, work, apprenticeship, etc. – their views, likes, dislikes, feelings and concerns about it. These questions were followed by ones that explored their family relationships and their role after finishing secondary school. In this section, issues about support, concerns, autonomy and decision making were explored. The subsequent set of questions explored more deeply the topic of change from secondary school to their new post-16 destination, their feelings and aspirations for the future and their expectations from this new path. Lastly, a set of questions related to friendship explored the value of these relationships for this group, whether they have maintained old friends and/or made new ones in their new destinations. Activities and interests pursued during their free time were also enquired. For a full coverage of the interview schedule, please refer to the Appendix A.

An outline of the interview schedule was given to the participants in advance, so that they could familiarise with the topics and therefore know what to expect, helping to minimise the anxiety that the unknown or unexpected could trigger. Preserving their identity and assuring that the collected data would be safely stored and treated as strictly confidential are relevant to safeguard their wellbeing throughout the study. All participants' names were anonymised, assigning them a code for the interviews and their respective EHC plans.

### **3.6.4 Collection of EHC plans**

The collection of EHC plans was dependent on parental and young people's consent to get access to these. Given that the participants were recruited from schools, it was usually the school which was in charge of sending to the researcher a copy of the finalised version of the EHC plan. As discussed, the delays in LAs in transferring old statements of SEND into the new plans were considerable. At point of recruitment, all participants had an EHC plan, a statement of SEND in process of conversion to the new system, or a draft EHC plan – which at that stage they are not statutory, and therefore not legally-binding. At the beginning of the process of data collection it was difficult to anticipate the extent of the delay to be expected in order to gather the finalised EHC plans. At the time of writing this thesis, six participants out of 29 did not have a final version of these documents. For this reason, the findings stemming from the collection of EHC plans reflects the analyses conducted on 23 EHC plans rather than 29.

The documents were collected in hard copy and electronic formats. Those that were sent in hard copies were anonymised, assigned a number and securely stored in a locked cabinet located at the University of Roehampton. Those that were sent in electronic format were also anonymised and assigned number and stored as password protected files in a password protected folder.

### **3.7 Data Analyses**

A sample of 29 young people with ASD between 15 and 19 years of age was purposefully drawn from schools, sixth forms, colleges and organisations working with young people with special educational needs and disabilities in the Greater London area. As stated before, 28 young people took part in interviews – one participant could not take part due to their parent's decline to this particular aspect of the study on the day of the interview; in addition, six young people did not hold a finalised version of

their EHC plans, leaving the total number of collected documents at 23. For organisation purposes, Table 3.3 provides an overview of the total numbers of participants recruited, interviewed and documents collected, and how these data were analysed and reported in subsequent chapters of this thesis.

### ***3.7.1 Strand 1: The voices of young people with ASD in transition to post-16 education and employment***

The aim of this study was to give voice to young people with ASD by gathering their views and experiences of post-16 education and employment, following their transition from secondary school. For the purpose of this strand, 28 semi-structured interviews were conducted to collect the views of young people with ASD.

#### ***3.7.1.1 Phenomenological approach to interviewing young people with ASD in transition***

The nature of the main aim of this study called for adopting a phenomenological approach to research. According to Creswell (2013), phenomenological studies are concerned with describing ‘the meaning for several individuals of their lived experiences of a concept or phenomenon’ (p.57). The emphasis of this approach to research is placed on identifying the commonalities in the experiences of a group of individuals as they experience a phenomenon in order to achieve a description of the universal essence of the experience (Creswell, 2013). This approach views research participants ‘as the experts of their own personal and social worlds’ (Howard et al., 2019, p.1), and therefore they constitute the best informants to shed some light about the phenomenon under investigation. In the case of this study, young people with ASD were construed the best informants to build the common lived experience of transition to post-secondary life.

The adoption of this approach finds its place in this study in that the deep understanding of these shared common experiences are relevant to develop and improve policies and practices meaningful to the lives of those that have lived or are going through the phenomenon under study (Creswell, 2013; Robson, 2011). A condensed description of the essence of the experience – shared by all participants – derives from answering the questions of ‘what’ the individuals experienced, and ‘how’ they experienced the phenomenon (Creswell, 2013). By employing this approach, the study aims to go from a detailed exploration of the individual, specific, to find universals which bring novelty in knowledge and understanding in the field (MacLeod, Allan, Lewis, & Robertson, 2018; Smith, Flowers, & Larkin, 2009).

Given the purpose of this study, data was collected in the form of individual, semi-structured interviews. Interview is one of the richest instruments to collect qualitative data, and for this reason is widely used in qualitative research. As a collection tool, it allows to access people’s perceptions, definitions, and meanings of situations, and constructions of reality (Punch & Oancea, 2014). Brinkmann and Kvale (2015) describe interviews primarily as social encounters that attempt to understand the world from the perspective of the interviewee; they assert that such encounters are instances of knowledge production that result from the inter-action between the

Table 3.3

Overview of participants recruited, number of interviews and EHC plans collected, analytical approach and results chapter

Recruited participants	Of which	Data analysed	Notes	Analytical approach	Results Chapter
	N = 28 were interviewed (Strand 1)	N = 28 interview transcripts	N = 1 participant was not interviewed but had EHC plan	Phenomenological thematic analysis  Deductive content analysis using ICF-CY Framework	Chapter 4
N = 29		Sections A, B, C, D, and E of N = 23 EHC plans	N = 6 participants did not have a finalized EHC plan	Deductive content analysis using ICF-CY framework	Chapter 5
	N = 23 had EHC plans (Strand 2)	N = 22 Interview transcripts and N = 22 Section A of EHC plans	N = 22 participants with an EHC plan also took part in interviews  N = 1 EHC plan excluded due to no interview	Deductive content analysis using ICF-CY framework	Chapter 6
		N = 265 outcomes written in Section E of N = 23 EHC plans	N = 265 outcomes were extracted from 23 EHC plans	Quality assessment using Goal Functionality Scale III	Chapter 7

*Note.* Section A = views, wishes and aspirations; Section B = special educational needs; Section C = health needs; Section D = social care needs; Section E = outcomes

interviewer and the interviewee, stressing the interdependence nature of human interaction in the production of knowledge. For this reason, interviews were an essential part of this study, as they were used to elicit the views and experiences of young people with a history of ASD in post-16 education and employment, to ultimately co-construct knowledge on their views through their own voices. As research instruments, interviews can vary in their degree of structure and depth, depending on the research purpose they serve (Cohen et al., 2018; Creswell, 2013). In this case, semi-structured interviews seemed the most appropriate method to collect data. As the name indicates, a semi-structured interview offers the possibility of covering a series of topics related to the research question, in a pre-defined manner, providing beforehand an order and default wording to the questions to be asked, with the flexibility of adjusting these to the flow of the conversation, allowing the emergence of unplanned, additional, follow-up questions in accordance with what the interviewee says (Robson, 2011).

To guide the interview process, an interview schedule was built and piloted. Interviews were audio recorded as per previous consent of the participants, and were visually supported with a tablet, using a software called Talking Mats (Cameron & Murphy, 2002), as previous studies suggest the use of visual cues to enhance communication in cases where participants have low language ability and communication difficulties (Lewis et al., 2008; Shepherd, 2015). Talking Mats is a tool based on picture symbols that act as support to communication, allowing people with difficulties in this area to express their views. The software has been developed based on extensive research and designed by speech and language therapists working with people with a broad range of communication abilities across a wide range of ages and settings, such as health, social work, education and at home (Cameron & Murphy, 2002). The visual framework of Talking Mats consists of a virtual mat and cards that show line drawings of different topics and daily life situations that people with communication difficulties can use to indicate choices and communicate their needs

(Pettit, Tönsing, & Dada, 2017). Figure 3.5 provides examples of some of the picture symbols included in this framework. As an interactive resource, Talking Mats uses three sets of picture symbols: a) topics, which refer to the subject of conversation or exchange; b) options, which relate specifically to the topic of discussion; and c) a visual scale, which indicates general feelings about a specific topic an option (Murphy, Cameron, & Boa, 2013).



*Figure 3.5* Examples of symbols included in the Talking Mats framework

Figure 3.6 depicts a finalised Talking Mat on the topic of learning and thinking, where the three sets of symbols (visual scale, topic, and options) are clearly identified. The visual scale is flexible in the meaning it can adopt. For example, each of the symbols of the scale can refer to likes and dislikes (I like, I am unsure, I don't like), feelings (I am happy, unsure, not happy), and coping (I am managing, I am unsure, I am not managing). Each participant was introduced to the software before starting the interview, and was invited to do a mat on the topic of animals to familiarise with the software, as previous research has shown that the topic is simple to grasp and familiar enough for participants to relate to it (Murphy, Gray, & Cox, 2007). This



software allowed saving the layout of the mat after each encounter, thus producing a record of the picture symbols used by the participants during the interviews. The visual scale used with participants referred to their feelings about topics and options, thus the scale represented whether participants felt happy, unsure, or unhappy about the topic being discussed.

In addition, notes were taken during the interviews. These notes were relevant to record non-verbal cues and body language from the participants, as well as to stress the significance of phrases and quotes that arise from the posed questions (Brinkmann & Kvale, 2015).

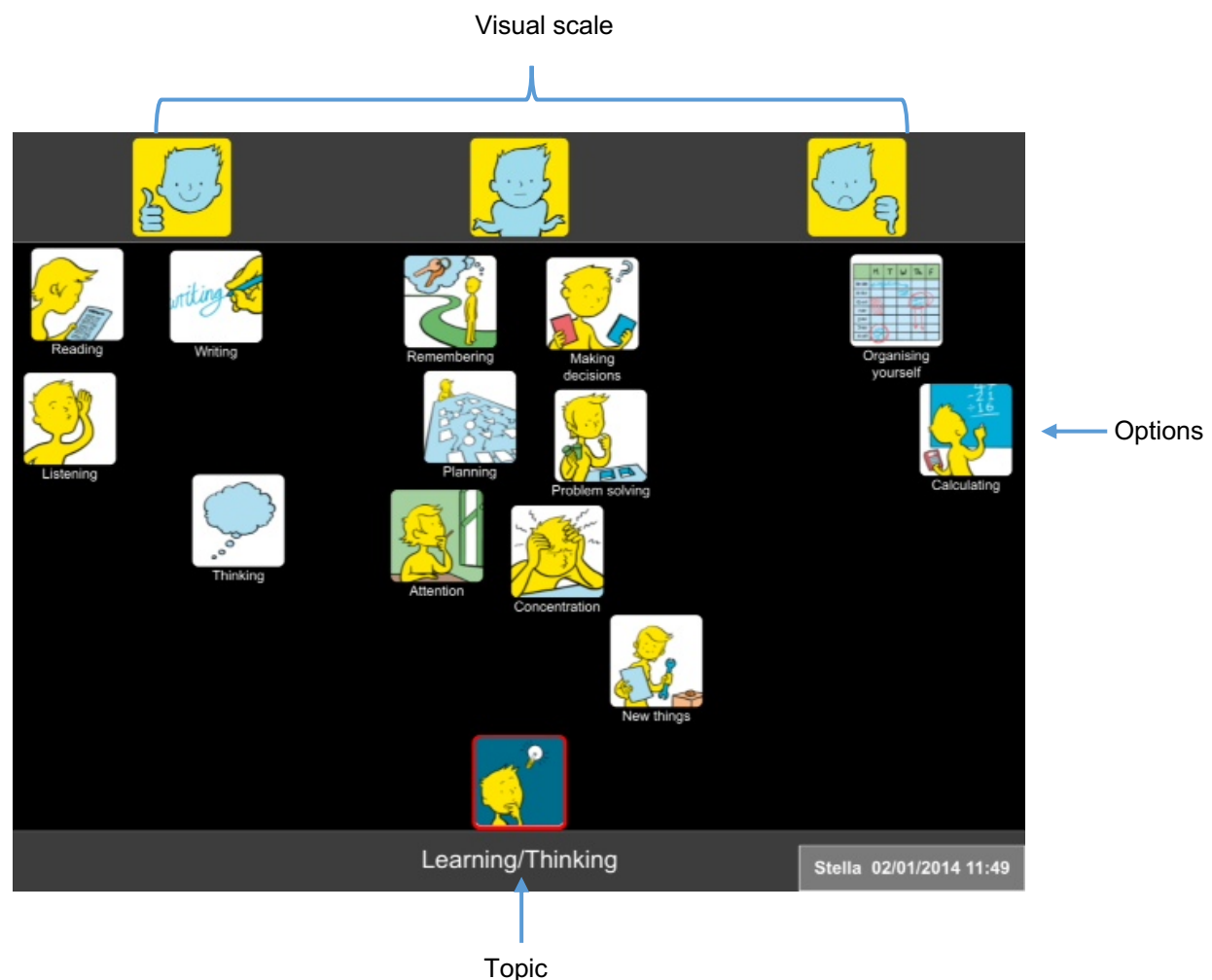


Figure 3.6 Example of a finalised Talking Mat <sup>TM</sup>

### *3.7.1.2 Analytical approach*

This study of mainly qualitative nature followed a sequential exploratory design, as it started from qualitative analyses, and then quantified the found categories (Creswell & Plano Clark, 2010). The generated qualitative data from interviews was approached in two complementary strands: a qualitative one using a phenomenological approach, and a second through deductive content analysis. Firstly, under the phenomenological approach transcripts followed an inductive, thematic approach to data in order to identify, analyse and report patterns or themes that emerged from interviews (Kvale, 2007). The second strand of interview analysis consisted on approaching data in a deductive way through content analysis, using the ICF-CY framework as a system of pre-defined codes to be matched to the interview transcripts, following the linking rules and procedures that have been used in previous studies (Castro, Ferreira, Dababnah, & Pinto, 2013; Cieza et al., 2016). These two strands are described in the following section.

#### *3.7.1.2.1 Phenomenological Thematic Analysis*

Thematic analysis is one of the most widely used approaches to qualitative data analysis, such as in-depth interviews (Creswell, 2007). There are other forms of analysing the content of the interviews, and variations on this process depend on the research questions. Under the phenomenological approach, the focus was placed on identifying themes that would help unearth the essence and the meaning of the lived experience (Creswell, 2013; Guest, MacQueen, & Namey, 2014) for a group of young people with ASD who were in transition to post-secondary settings through an inductive process of narrowing data into themes.

This process emphasised identifying and describing both implicit and explicit ideas within the data, that is, themes (Guest et al., 2014). Creswell (2012) suggests that a preliminary exploration of the data constituted a good first step towards its

analysis. In this case, this meant reading the transcripts of interviews several times in order to get a sense of the whole, writing notes on the margins like short phrases, ideas, concepts, and incorporating the notes taken during the interview, that would later help to think about the organisation of the data and its posterior coding.

After this initial immersion, a step further towards the analysis began by coding the data. This process consisted on initially highlighting significant statements, relevant quotes, phrases or sentences that provide an insight to the views and experiences of participants. By doing this, the researcher was able to then segment and label the text to form descriptions and broad themes within the data, assigning a word or phrase that described in an accurate way the meaning of a particular text segment. This procedure is often described as meaning condensation (Creswell, 2012). Following the initial coding the data, a list of all code words was created, in order to group similar codes together and look for those which were redundant, so as to reduce the codes to a more manageable number. By creating this list, the researcher was able to go back to the data and try out this preliminary organising scheme, to see whether new codes emerged. Creswell (2012) suggests also circling or highlighting those statements or quotes that best support the codes.

Once this list of codes was finalised, it was reduced to a few themes or descriptions that could account for the essence of the lived experience of young people. Themes can also be referred to as categories and are similar codes that are aggregated together so as to form a major idea. To do this, the created codes were then examined. In order to create the themes, special attention was given to those codes to which participants referred more frequently, those which were unique or not expected, those which had the most evidence to support them, or were the ones expected to be found when studying the phenomenon (Creswell, 2012). Identification of these themes could also help organise them in a layered or interconnected form, making room for minor themes to be included within a major theme, offering different perspectives or highlighting different aspects of the identified major theme (Creswell,

2012). Describing and developing themes from the data, therefore, consisted on building the in-depth understanding of the phenomenon under study in order to answer the research question. A narrative discussion was developed to present the findings of the thematic analysis in detail. This discussion included presenting the themes with the relevant quotes from interviews that supported the significance of the theme and its emergence through the interviews.

#### *3.7.1.2.2 Content analysis and the role of the second rater*

For the second strand of this study, data was analysed using deductive content analysis as a method, to later on quantify the data condensed in codes, using the framework and system of codes of the ICF-CY (2007). Content analysis can be defined as an objective and systematic method for analysing verbal, written or visual data, allowing the researcher to test theoretical issues that might improve the understanding of such data (Elo & Kyngäs, 2008). This method allows condensing text into a few content-related categories that share the same meaning, granting the production of knowledge through valid inferences from the data to the context where they derive from.

According to Elo and Kyngäs (2008), the aim of content analysis is to achieve a broad and condensed description of the phenomenon under study by building concepts or categories that best describe it. The development of such categories or concepts is usually linked to the building of a model or conceptual system. Among the benefits highlighted for this method is its sensitivity to content, and its flexibility in terms of research design. Furthermore, its usefulness to understand the meaning of communication and to identify critical processes have also been underlined as strengths. Lastly, the interrelation with meanings, intentions, consequences and context makes content analysis a valuable method to be used with either qualitative or quantitative data (Elo & Kyngäs, 2008).

This approach can be used in a deductive or inductive way, depending on the purpose of the investigation. Inductive content analysis is recommended when there is not enough prior knowledge about the studied phenomenon, or the available knowledge is fragmented. On the other hand, a deductive approach is based on previous knowledge, such as a theory or a conceptual model, on which the structure of the analysis is operationalised (Elo & Kyngäs, 2008). The movement of deductive content analysis from the general to the specific makes this approach appropriate for theory testing. The content analysis strategy adopted for this strand is deductive, as the ICF system serves as a theoretical framework whose functionality domains consequently serve as pre-defined categories to analyse the content of the interviews, the EHC plans and the assessment instruments, all described previously in this chapter.

Elo and Kyngäs (2008) describe three main phases for conducting content analysis, whether it is carried out in a deductive or inductive way, and these are: a) the preparation phase; b) the organising phase; and c) the reporting phase. The present strand has followed these phases to conduct the deductive content analysis. The preparation phase consists of selecting the unit of analysis, which can be a word or a theme. Graneheim and Lundman (2004) suggest that a unit of analysis needs to be 'large enough to be considered as a whole, and small enough to be possible to keep in mind as a context for the meaning unit' (p. 106) during the process of analysis. The unit of meaning is then defined, which can be words, sentences or paragraphs that are related to each other through their content and context (Graneheim & Lundman, 2004). In the strand of study concerning the identification of ICF-CY functioning dimensions in interviews and EHC plans, different types of units of analysis were defined to analyse these data of each participant.

The functionality domains of the ICF-CY have been defined as the units of meaning to conduct the analyses of the three studies. Therefore, units of meaning under the ICF-CY system consist of a constellation of words or statements that relate

to: a) a body structure or function; b) an activity or form of participation, or c) an aspect of the environment (Castro et al., 2012; WHO, 2007). The condensed units of meaning are later labelled with a code. In the context of this strand of study, this means allocating the found meaning units present in the data sets to the coding structure of the ICF-CY. Once the content of the interviews was analysed using the taxonomy of the ICF as a matrix of pre-defined categories, the ICF-CY codes found in the transcripts were quantified. Frequencies for each of the ICF-CY components – body structures and functions; activities and participation; environmental factors – were computed to identify the domains of this framework that were more frequently addressed during the interviews by the young people with ASD on their transition to post-16 education.

In addition, a comparison on the distribution of the ICF-CY domains between interviews and Section A (views, wishes and aspirations) of EHC plans was drawn to explore the extent of the match between the views of young people with ASD as reported in their statutory SEND documents and in interviews. The results of this exploration are presented in Chapter 6 of this volume.

Graneheim and Lundman (2004) state that consideration should be given to the degrees of interpretation that might emerge from approaching qualitative data in the form of text. In order to increase the rigour and exhaustiveness of analysis and interpretation, there is agreement in the research community that incorporating a second (or more) person to the data analysis process would contribute to enhancing a study's trustworthiness (Burla et al., 2008; Elo et al., 2014). For this purpose, a second rater undertook the task of coding 20% of the data extracted from both interviews and EHC plans, systematically linking it to the taxonomy of the ICF-CY. The second rater had a similar professional background to that of the researcher in the field of Psychology and had undertaken the same training on the ICF-CY system as the researcher. In addition to this, they also had knowledge and experience using the Goal Functionality Scale (GFS III) (McWilliam, 2009) as a tool to assess the overall

quality of the outcomes (Section E) written in the EHC plans of the participants. Given this similar experience and knowledge, this second rater was deemed suitable to undertake the task of double coding data following ICF-CY linking rules (Cieza et al., 2016) and the procedures of the GFS III (McWilliam, 2009).

### ***3.7.2 Strand 2: The functioning-related views and needs of young people with ASD, and the outcomes sought for them according to their EHC plans***

The second research aim of this study aimed at exploring the functioning dimensions identified as the views, needs and outcomes of young people with ASD in post-16 education in their EHC plans. To do this, the EHC plans of 23 out of the 29 recruited young people with ASD were gathered as per previous consent of the youngsters and their parents/carers. Eligibility for this strand of study was based on the criteria for participation established in Section 3.3.3 of this chapter.

From a holistic approach in line with international trends in provision for children and young people with special educational needs and disabilities (WHO, 2007), and placing the individual at the centre, the views, interests and aspirations of the young person are the starting point of an EHC plan. The content of these plans covers a broad range of areas of a person's life, needs and goals, with arrangements not only in educational terms, but also considering aspects of health and social care. These arrangements are based on what the person wants and need to achieve to improve their outcomes for life. This holistic approach to catering for special educational needs and disabilities is aptly aligned with the ICF framework (WHO, 2007). As previously discussed, in this framework disability is understood as 'the outcome of a complex relationship of an individual's health condition and personal factors, and of the external factors that represent the circumstances in which the individual lives' (WHO, 2007, p. 15). The focus of this classification system on functioning aspects, rather than diagnosis, within a health state or condition, and

considering body functions and structures, activities and participation, and aspects of the environment, makes this framework a rich tool to capture in detail the uniqueness of the life experience of each young person with ASD and their functioning (i.e. products and technology, supports and relationships, services, systems and policies, mobility and transport, self-care, interpersonal interactions and relationships, community, social and civic life) (WHO, 2007).

### *3.7.2.1 Analytical approach*

#### *3.7.2.1.1 Exploring the functioning-related views, needs, and outcomes sought for young people with ASD*

Twenty-three EHC plans were collected, belonging to 23 of the 29 participants that took part in the first strand. As previously expressed, six recruited participants were excluded from this strand of analysis, as they did not have a finalised or complete version of their EHC plans at the time of writing. Five sections of EHC plans were analysed through deductive content analysis, using once again the ICF system as pre-defined codes to be matched to the content of the EHC plans. The sections analysed using this framework were the ones covering the views, wishes and aspirations of the young person (Section A), their special educational needs (Section B), their health needs (Section C), their social care needs (Section D), and the outcomes sought for them (Section E). The deductive content analysis using the ICF-CY system has been covered in detail in the section describing the ICF-CY analysis of interviews, (Section 3.7.1.2.2 of this chapter). In order to increase reliability of the analytical procedure, 20% of the content of the interview transcripts as well as the EHC plans were coded by a second rater with knowledge of the ICF-CY system, and the codes were discussed until saturation was reached, as described in Section 3.7.1.2.2.



#### 3.7.2.1.2 *Quality evaluation of outcomes sought for young people with ASD*

In addition, in order to explore the overall quality of the outcomes sought for young people with ASD, these outcomes were rated using the GFS III (McWilliam, 2009). A total of 265 outcomes were identified in the 23 EHC plans belonging to the young people. The researcher extracted these outcomes and transferred them to a database for rating. The data inputted in the database was analysed using SPSS software (version 25). All outcomes were rated following the seven dimensions of the GFS III. The instrument allowed computing two types of scores to explore the quality of the outcomes described in the EHC plans. A mean score was calculated for each individual outcome, and another score was calculated for each quality indicator of the GFS III. An overall mean score was calculated for all 265 outcomes, and so were seven mean scores for each quality indicator across outcomes. Descriptive data on the GFS III was explored to identify the number of outcomes described in each EHC plan, and also per LA, type of setting and year group of young people with ASD.

A second coder independently rated 62 of them to ensure reliability of the coding process. The outcomes rated by the second coder were chosen using a computer software that randomly selected 62 numbers, from 1 to 265, each one representing one outcome. Weighted kappa ( $\kappa_w$ ) with linear weights (Cicchetti & Allison, 1971) was run to determine if there was agreement between the two raters on the quality of outcomes sought for young people with ASD in their EHC plans across all seven quality indicators from the GFS III. A cross-tabulation of the ratings followed this analysis to explore where the rating differences lied between the two coders. This analysis revealed that there was an excellent level of agreement between the two raters, as confirmed through weighted kappa coefficient,  $K_w = 0.925$ , 95% CI [.901, .949],  $p < .001$ . Weighted kappa was selected as a procedure for computing inter-rater agreement, as it is considered a good measure of agreement between two raters for ordinal scales (Fleiss, Levin, & Paik, 2003).

Normality testing was conducted to explore whether scores deviated from a normal distribution. Since the scores of the quality of EHC plan outcomes violated assumptions of normality, nonparametric tests were chosen to further analyse the data. Assumptions were met to perform non-parametric analysis of variance. Kruskal-Wallis tests and post-hoc assessment of independent samples were run to explore whether the quality of the 265 identified outcomes varied by local authority; in addition, Mann-Whitney *U* tests were performed to explore whether the quality of outcomes varied by the type of setting, and year group that the young people were attending.

### **3.8 Integration of findings**

Mixed methods designs are characterised by triangulation approaches, which are considered to be the core principle that justify and underpin mixed methods research (Torrance, 2012). A comprehensive account on the phenomenon under investigation is unlikely to be understood by the use of one single method. Indeed, by using more than just one method we are able to generate different perspectives which provide a richer and more informative picture of the phenomenon under study (Torrance, 2012). The present study aimed at building an understanding of the real-life experiences of young people with ASD on post-16 education by gathering their views from different perspectives. Creswell and Plano Clark (2007) assert that the integration of data, both quantitative and qualitative – in meaningful and complementary ways extends and clarifies each set of data. It is the combination of data sets that allows a more robust analysis (Youngs & Piggot-Irvine, 2012). The use of the ICF-CY system to code and analyse the content of interviews and EHC plans served as a valuable tool to systematically identify and code qualitative data emerging from interviews and EHC plans. These qualitative data were transformed into ICF-CY codes, allowing quantification of categories, following linking rules and procedures used in previous studies (Castro et al., 2013; Cieza et al., 2016). The use of these

codes granted an analysis of the views, needs and outcomes of young people with ASD at the time of transition to post-secondary destinations in two complementary strands; this allowed dimensions of functioning to emerge as conveyed by the young people themselves and their respective EHC plans.

### **3.9 Summary**

This chapter presented the overall methodology adopted for this study. The separation of this study into strands allowed the exploration of the views and experiences of transition of young people with ASD in the context of the SEND reform in England from complementary perspectives. The use of the phenomenological approach to conducting and analysing the interviews with young people with ASD highlights the expertise of these individuals in the exploration of their own personal and social worlds (Howard et al., 2019), and to build the essence of their lived experiences of transition to post-secondary destinations through their voices. On the other hand, the ICF-CY classification system is used in this research as a common language to reveal the functioning codes that emerged in the identified themes stemming from the phenomenological analysis. The purpose of doing so is to explore the pattern of functioning codes that made up the fabric of each theme, so that they could be expressed in a universal language of functioning useful for practice. The use of the ICF-CY in this way contribute to give specificity to each theme. This has implications for practice, as EHC plans often present vague/broad statements about aspirations. The specificity of the taxonomy and the holistic nature of the ICF-CY can be a significant framework to develop holistic yet detailed EHC plans.

## **4. Results: Capturing the voices of young people with ASD in transition to post-secondary destinations**

### **4.1 Introduction**

This strand aimed to explore the views and experiences of young people with ASD in their transition to post-16 education and employment through semi-structured interviews, and to describe the dimensions of functioning conveyed in these young people's views obtained through the interviews. The research questions that stemmed from this aim were the following:

- a) What are the views of young people with ASD about their transition to post-secondary destinations?
- b) What are the ICF-CY functioning dimensions identified in the views of young people with ASD as extracted from individual semi-structured interviews?

To address these questions, first an inductive thematic analysis was performed on the interview transcripts following a phenomenological approach, followed by deductive content analysis, using the ICF-CY framework and codes to analyse the content of 28 individual semi-structured interviews. Please refer to Appendices A to C for an overview of the interview content, examples of the use of Talking Mats during interviews, and initial interview coding. As previously stated, although the final number of young people recruited for this study was 29, 28 participants took part in the one-to-one interview. The parent of one participant, in spite of having given consent for their child to take part in the study, declined their child's involvement in the interview on the day the meeting with the young person was scheduled, but agreed for them to participate by providing the EHC plan of their child. The young person was eager to have the interview but given that at the time he was

below 18 years of age, the interview was not conducted. For this reason, the findings from interviews reported in this chapter belong to 28 young people with ASD.

## **4.2 Findings**

### **4.2.1 Phenomenological thematic analysis**

A total of five themes emerged from the inductive analysis. These were: *ambivalence of feelings about the future; independence; friendship and free time; bullying; and school and family support*. The following section presents a summary of each theme, with relevant quotes to support them. In order to protect participants' identities, each young person (YP) has been assigned a number. Twenty-two out of 28 young people were in their last year of secondary school (year 11 in England), and six young people were in post-16 education (one in college, and five in the sixth form of their schools). Of those in year 11, ten transferring to a local college upon exiting secondary school, while 12 were moving to the sixth form contained in their secondary schools. Regarding those in post-16, one participant was continuing his college education, and two were moving to a vocational college; one participant was transferring to a special residential setting; another young person was moving to higher education, while the remaining young person was moving on to an apprenticeship.

*Ambivalence of feelings about the future.* Participants were asked about their aspirations for and feelings about the future and the next post-16 stage in their lives. The common denominator of answers across interviews was a mixture of feelings that underpinned the experience of facing change. On the one hand, participants reported feeling excited about moving on, expressing wishes to become more independent and acknowledging that these changes are intimately related to growing up.

*'I feel a bit sad, I am feeling a bit heartbroken because I have known [name of] school since I was a child, but not anymore... because now I am a teenager and I'm ready for a new chapter' (YP 16, 18 years old)*

*'Um... well, I'm likely going to miss this school since I've been here for quite a long time now... like a year, two... but the university I'm going to move to is really nice' (YP 28, 19 years old)*

*'Umm, I feel a bit of mixed emotions, because I really enjoy school, and gaining confidence because I didn't feel confident at the beginning. I did travel training and I gained confidence and support from the school. So it's going to be hard leaving, but then everybody needs to move on, and I am actually looking forward to college' (YP 7, 15 years old)*

In this respect, participants were positive about the prospect of new opportunities to develop. Nevertheless, these feelings of excitement were also accompanied by those of uncertainty and sadness. They recognised that moving to post-16 settings also translated into leaving behind beloved people and places who had seen them grow up, to make room for new learning experiences and challenges.

*'A little bit upset, because I really like [name of school] and there's some friends who will be staying here and I'll be in college [...] Well, we all have to move on' (YP 9, 16 years old)*

*'When I finish here, I cannot come back. It's time to move on, because if I stay here, I'm gonna keep on doing the same things, so the good thing for me is to move on so I can get a job' (YP 10, 16 years old)*

On the other hand, 19 participants expressed feeling nervous or unsure about moving on to the next stage, revealing concerns about what they would be doing the following year. Although they knew where they would be going to, some of these young people did not know what kind of courses and tasks they would be undertaking in their new placement, and worried about the changes stemming from a new routine and timetable.

*'I am still anxious about it because it is a new place and I haven't been there before, at least not for a while, and I'm going to miss this school, as I said, because they helped me a lot building confidence' (YP 7, 15 years old)*

*'I feel ok about it, but I am not really sure about what to do afterwards. I might get a job, I'm not really sure [...] I mean I'm pretty sure I will get a job, or I will go to college, not sure but probably a job.' (YP 20, 17 years old)*

*'Yes, the start of college, and maybe the job... but I know that it will be the start of college, I know I will be a little bit nervous because I don't know what it is the timetable like there' (YP 1, 16 years old)*

*'I'm upset, because I'm going to miss everyone, and because we are all leaving, and I might turn out to have a bad future... I might not get to achieve anything in the future, I might not even get a job!' (YP 26, 15 years old).*

These concerns also extended to uncertainty about the people they will meet and interact with, and the availability of support in their new placements. These issues are further discussed under other themes in this chapter. In spite of the uncertainty that moving to another stage represented for the young people, the vast majority of participants identified concrete aspirations for the future that were manifest in a range of life domains. For some participants these aspirations related to passing exams and milestones of life at secondary school, for others these aspirations were linked to career or job prospects; for other participants it meant learning new things and acquiring new skills.

*'I want to do well in my subjects, and I want to pass with flying colours, I want to feel like, I want to feel like I'm a smart ass in some ways, you know? I want to feel like, hey you know this, you know that... I feel I can learn a lot of things, and I want to feel like I'm content with the things I've learned' (YP 24, 16 years old)*

*'Um... I'm hoping to look for a college or a job where I can be with animals, cause I loved animals since I was very young, like cats, and dogs, and horses and sheep, snakes, spiders, birds, fish... yeah, you name it, I like all to do with*

*animals. And I share a special relationship with them, especially the creepy ones like spiders and bugs'* (YP 29, 17 years old)

*'Like train to make food. And there is a chef thing at college. There college where they teach cooking is in [name of] College, where I went for 25 weeks since September, and I finished going on Fridays in May... I'd like to do that'* (YP 13, 16 years old)

*'Well, you know... like, one time I had like this, you know, fascination with animation and stuff and, wanted to make like, maybe short films or even some longer films, one day in the future...'* (YP 28, 19 years old)

*'I'd like to do new skills for writing, for history and geography. And photography, and all of it. Go to Comic Academy. I like to draw and, I would like to get a photographic job'* (YP 4, 16 years old)

*Independence.* This theme was one expected to emerge in the interviews with young people exiting secondary school and moving on to apprenticeships, employment and further education. However, independence has been shaped differently across participants. Broadly speaking, this label was used predominantly to refer to the topics of mobility and the use of transport, domestic life, and self-care, and was alluded to as an achievement, or as something participants wanted to improve in the near future. For example, for participant 12 being independent was related to acquiring more skills in order to have an autonomous domestic life, like learning to use appliances, and cooking a meal without assistance from others:

*'I think I am independent, I think I can go a bit further in my independence... um, like learning to make a meal on my own, for myself, with no help. And learning a few things like plumbing, electronics, just in case of emergencies'* (YP 12, 16 years old).

In the quote above, this participant (12) hinted the wish to live independently in the future, which was later confirmed in the course of the interview. He was the only



one who explicitly considered living outside the family home as an independence goal for his future. Another participant conveyed his wish to become more independent in terms of domestic life:

*'I think there is something I can improve. Maybe being more independent, like using the toaster and sorting out washing, but that's not in school. I don't do the washing very much because my mum does it' (YP 1, 16 years old)*

For more than half of the participants, being independent translated into being able to move around outside the house on their own, as well as using public transport without assistance or supervision. Fifteen participants mentioned that, although they wanted to move around independently, they did not go out on their own without a parent/carer.

*'At first it is kind of daunting, like, this new path, like trying to remember go this way, and then go this way, and then take this bus, and all that... but it grows on you and you can begin to remember it better.'* (YP 28, 19 years old)

*'I'm quite independent, like in school... but at home, not as much. I mean, I am not able to go out by myself; so, it's only the usual places, this block, next block and to the shop... I mean, that is definitely something that I would like to change. To be able to actually get to places by myself, to hang out there for a little bit [...] how to be free and go where I please. You know, as opposed to being stuck indoors all day, and I'll be able go around the block, and the block shop' (YP 21, 15 years old)*

YP1: *So, in the mornings we walk to school. My mum... we walk together and then, just, you know, just... leaving the street, she stops kind of in the middle, and there's a hill, and then I walk here.*

CG: *So, you walk halfway with your mum, and halfway on your own?*

YP1: *Yes, that's it.*

CG: *And would you like to walk the whole way on your own?*

YP1: *Yes, I would like to. But my mum loves walking as well.*

*'I also come home with the school minibus, 'cause I can't cross the roads. I will do travel training in sixth form [...] I mean, once I have learnt to cross the roads,*

*I'll be able to join and go to places - that's something I want to achieve.'* (YP 13, 16 years old)

The process of decision-making was also one linked to independence. All participants mentioned consulting their parents, teachers, and support staff to make decisions about their lives, suggesting that adults usually know best, they have more experience or have been through the same process before, therefore participating adults and family members in the process made them feel more comfortable and safe about their choices. However, four participants highlighted that they sometimes found themselves alone in making important decisions about their lives, mostly because of differences between the young person and their parents, and occasionally staff, in establishing priorities and giving due weight to the preferences of the young person.

*'I mean, I'm grateful for their support and company because it has really helped me through this, although maybe towards college, maybe [I'd like to] be a bit more independent about my decisions and actions.'* (YP 7, 15 years old)

*'Well, because in my opinion they [his family] just want me to do other stuff. They don't focus on the near future I would like to have. So, then it's basically myself'* (YP 15, 16 years old).

YP 26: *I don't like the students in there [new placement] ... some of them have gooey fingers, I mean their hands... I don't know if I want to talk about it.*

CG: *And why did you choose to go to [college name]?*

YP 26: *Because my support worker chose it.*

*Friendship and free time.* Concerning the role of friends in their lives, participants acknowledged that friends have a crucial place. All young people reported that most of their friendships were formed at school, and in some cases, these dated back to primary school; two participants revealed to have a few friends from outside school. They acknowledged feeling supported by their friends when dealing with

problems or concerns and recognised their relevance in sharing their free time and spending time together.

*'We are always there for each other, we have each other's backs. And I think that is a key part in life, friendships. So, we can fall back on each other and just have that relationship between one another, it's just very special.'* (YP 7, 15 years old).

*'Friendship is absolutely important, I need to communicate with other people'* (YP 16, 18 years old)

*'I can tell what I feel to a friend I trust. They've always got your back for you'* (YP 11, 16 years old)

*'Well, if I have a problem, or we have a problem, we work together to sort it out'* (YP 12, 16 years old)

All participants referred to having conversations with friends as their main activity, 'having a laugh' or telling jokes, as well as watching videos online and playing computer games. Only seven participants reported going to a friend's house for a meal or to spend time together as a free-time activity outside school. Nevertheless, the majority acknowledged spending a great deal of their free time indoors, on their own, watching television or videos online, or playing videogames.

*'I mostly go and play on my computer'* (YP 9, 16 years old)

*'I play X-Box. Unsurprisingly, I am not really outdoorsy. I would just sit in my room, talk to people on it, and play Fifa'* (YP 14, 16 years old).

*'I play games, I could play some other games than just Sonic, but that doesn't mean I am not a Sonic fan. I go out to a park or take a dog for a walk.'* (YP 26, 15 years old).

Furthermore, almost all participants recognised that finishing school and advancing to their next stage represented a saddening event, to a certain extent, in

terms of friendships. Participants reported the realisation that the move to a different setting translated into seeing friends less frequently and wondered about the future of those relationships at this time of change, where their life paths were taking different directions. Some young people feared losing touch with school friends altogether after their transfer to different post-16 settings and reported feeling anxious about the prospect of making new friends in the new setting. Concerning this, eight young people explained that they had spent most of their childhood in the same school and therefore moving on to a new placement represented a challenge.

*'Maybe starting again... making new friends in college. That could be quite difficult, never really made new friends for a while now'* (YP 12, 16 years old)

*'I suppose there is like keeping in touch with my friends from here. I'm not exactly a social person, I only have like two friends from my class, and of course that there is this thing about me trying to make new friends at the new school'* (YP 28, 19 years old)

Five participants reported having a number of friends but preferred being alone than to contact them to socialise or spend free time together. The rationale behind these attitudes, however, differed between them. Two of them defined themselves as loners being better off on their own, while a third participant described feeling anxious about contacting friends, as he feared rejection. Thus, the choice not to approach friends was based on the premise of avoiding this potential scenario.

*'Um... I have a lot of friends but I'm sort of like, I don't really contact anyone, I'm not great at it [...] I don't contact them, I am just scared to contact people'* (YP 19, 19 years old)

*'I am not a social kind of kid anyway... I mean, when I was in like primary school, or kindergarten, whenever it was, I used to stand in a corner of the yard and whenever a kid came around, I just pushed them.'* (YP 21, 15 years old)

*Bullying.* Participants referred to previous experiences of bullying as a source of concern at their current placements, with some young people acknowledging that these past experiences could happen in future placements. Four participants perceived that engaging with new people in an unfamiliar setting – i.e. college – could result in being bullied, and thus found the task of interacting and developing new friendships challenging.

*'Well, what I didn't like about it is that we had this one guy, big guy, and apparently what he'd do basically- I'm not changing the subject, but I'm telling you what happened- he is sort of a bully, and what he'd do is take your money'* (YP 19, 19 years old).

Additionally, another challenge attributed to the change of setting was that of the handling of bullying in post-16. Although the majority of participants reported being aware of how to deal with these situations at school – by usually involving an adult or a person in a position of authority -, six participants acknowledged not being sure of how to do so in their new setting.

*'I am a bit afraid of getting bullied, 'cause... I hope college is much different than school, but I am not sure they deal with bullying the same way they do at school [...] I'll just call a security guard'* (YP 8, 16 years old).

*'I think that everything is suitable for me and what I want to achieve for my future, so I think that at the moment everything is stable, but if there's a [bullying] problem I'd probably say to the people that I'm not too quite comfortable with this.'* (YP 7, 15 years old).

Four participants expressed concerns about attitudes of people, strangers in particular, towards them, with two of them reporting avoiding activities or social spaces that would expose them. For example, one participant acknowledged wanting to get fit but avoided going to the gym altogether because he felt people stared at him while exercising.

*'Well, when I go there [to college] I most certainly wouldn't want to be teased or picked on' (YP 10, 16 years old)*

*'When I get name-called I just don't want to speak to anyone' (YP 9, 16 years old).*

*'There could be some that could act like complete jerks. Some that don't care about autism and things like that. There could be some bullies, and there is so much to keep up with, it will stress me out' (YP 29, 17 years old).*

*School and family support.* All participants recognised the significant role their families play in their day-to-day lives. When it comes to solving problems, and making important life decisions, young people reported choosing their parents to assist them. All participants acknowledged that parents were experienced and that their knowledge was key to support them. Six participants mentioned trying to sort out their problems on their own first and asking for their help when difficulties persisted.

*'I'd go first to my parents, because they are more responsible and probably, they have more experience about the problems I have' (YP 12, 16 years old).*

Four participants recognised that at times they tried to mask problems or difficulties to avoid being 'a burden' to their parents. These participants acknowledged that part of growing up meant dealing with their difficulties on their own, instead of seeking support.

*I would like to turn to like my mum for support but sometimes it is not... well, sometimes I feel that if I do tell her my problems it will cause more stress for her, because she has a lot of stuff going on - she is usually pretty busy, with housework and taking care of us, and bills... you know, all that stuff. I sometimes feel that if I tell her that I have a problem then it will just put a weight more so than she already has. (YP 28, 19 years old)*

*'I don't want to put a burden on people, it's something I never liked doing. I mean, I see myself as being a burden from the past, and I don't want to make myself a burden again'. (YP 24, 16 years old)*

CG: *And have you told anyone that you are concerned about these things?*

YP 26: *No, I just keep it a secret from the staff.*

CG: *And why is that?*

YP 26: *So that they can think that I am doing fine.*

Regarding making decisions about their lives - i.e. going to college, applying for an apprenticeship - all participants reported that parents were key stakeholders, and that school staff were great contributors to help them in the process. However, one participant acknowledged he would have liked further involvement in his work experience application, stressing the feeling of being left out of his own application process.

*'I'm not sure on the process because the teachers do all the applications and things, and it's quite secretive [...] I don't really like secrecy though, I would have liked more transparency' (YP 14, 16 years old)*

Concerning the support put in place at school, all participants mentioned the relevance and helpfulness of school staff as contributors towards a positive school experience. Ten participants praised the disposition and willingness of professionals to help them 'get more questions right' (YP 8), and overcome difficulties arising in the school context.

*'Well, they help me understand, they help me communicate with others, how to be sociable, how to speak to others kindly, without ignoring them' (YP 16, 18 years old).*

*'Oh yeah, I am getting towards my exams and I always need help with questions that I don't understand, so I can always ask a teacher or a TA' (YP 1, 16 years old).*

*'If something happens, we just, tell them and they sort it out. And then I go to talk to a teacher' (YP 5, 15 years old).*

Three participants highlighted they sometimes did not feel they received the support they needed, at school or at home. One participant referred to this as the teacher not being able to spend more time supporting her due to the teacher's duty to support other students at the same time.

*'Only like the teacher in the class help other children [...] I think she helps everyone in the class' (YP 11, 16 years old)*

Another participant reported his desire to prove to his teacher that he can improve and pass a relevant exam, although this came accompanied by a realisation that it would be a challenge.

*'I want to pass the test and I want to do well, to prove the teacher that I can do it. Because he thinks I can't do it... well, he thinks it's going to be tough and I want to show him that I can do it. But I know that I probably can't do it, even if I want to – but I do want to do it' (YP 19, 19 years old).*

#### **4.2.2 Deductive content analysis**

The deductive content analysis performed on the interview transcripts aimed at exploring what were the ICF-CY functioning dimensions identified as the views of young people with ASD. Once the themes were identified and analysed inductively, the ICF-CY framework was used as a system of pre-defined codes to analyse the views and experiences of the participants with regards to their transition to post-secondary destination. Appendix E presents the list of all ICF-CY codes identified in interview transcripts. This section presents firstly an overview of the identified functioning codes across domains, followed by a description of the most salient functioning aspects coded per interview theme. For this purpose, the themes identified in the thematic analysis serve as headlines. Moreover, examples of relevant thematic quotes and their respective functioning codes are presented to illustrate



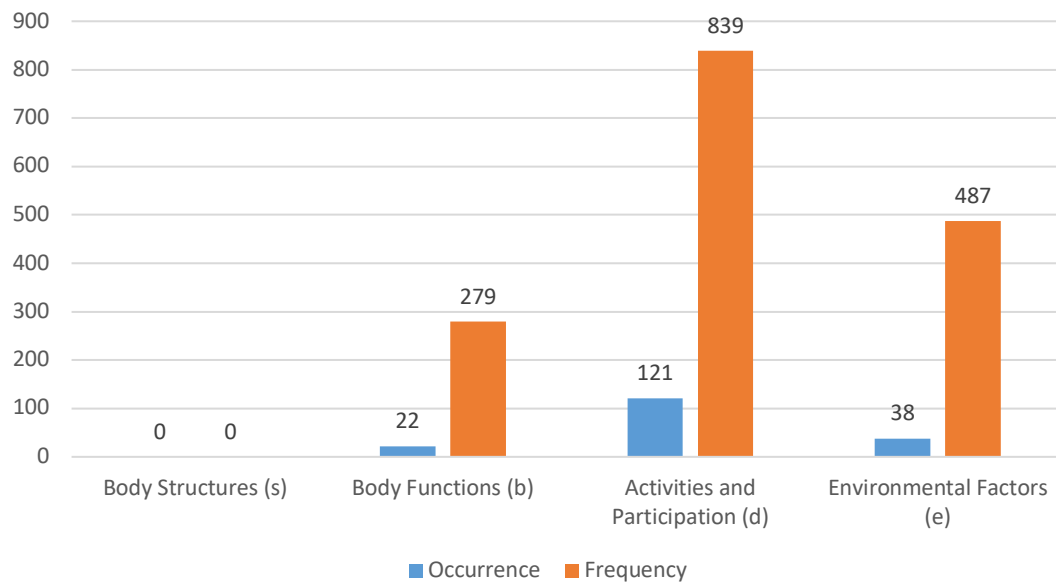
holistically the interplay of codes within each theme. For clarification purposes, the term *occurrence* is used throughout this strand to indicate the number of ICF-CY codes found across the interviews, and *frequency* is used to notate the rate of occurrence of said codes – that is, the number of times a code or group of codes appear in the interview transcripts.

*Overview of identified functioning codes.* A total of 181 ICF-CY codes were matched to the content of the interviews. As Table 4.1 and Figure 4.1 show, the majority of the identified codes belonged to the component of activities and participation (*d* codes), followed environmental factors (*e* codes), and lastly, body functions (*b* codes). The component of body structures refers to anatomical parts of the body; given the nature of the interviews, it was expected not to find evidence of these codes among participant's responses, as it was unlikely for them to describe themselves in these terms.

Table 4.1

*Occurrence and frequency of ICF-CY codes identified in interviews, by functioning domain*

Interviews (n = 28)				
	Occurrence	% occurrence	Frequency	% Frequency
<i>Body Structures (s)</i>	0	0	0	0
<i>Body Functions (b)</i>	22	12.2	279	17.4
<i>Activities and Participation (d)</i>	121	66.9	839	52.3
<i>Environmental Factors (e)</i>	38	21.0	487	30.3
Total	181	100	1605	100



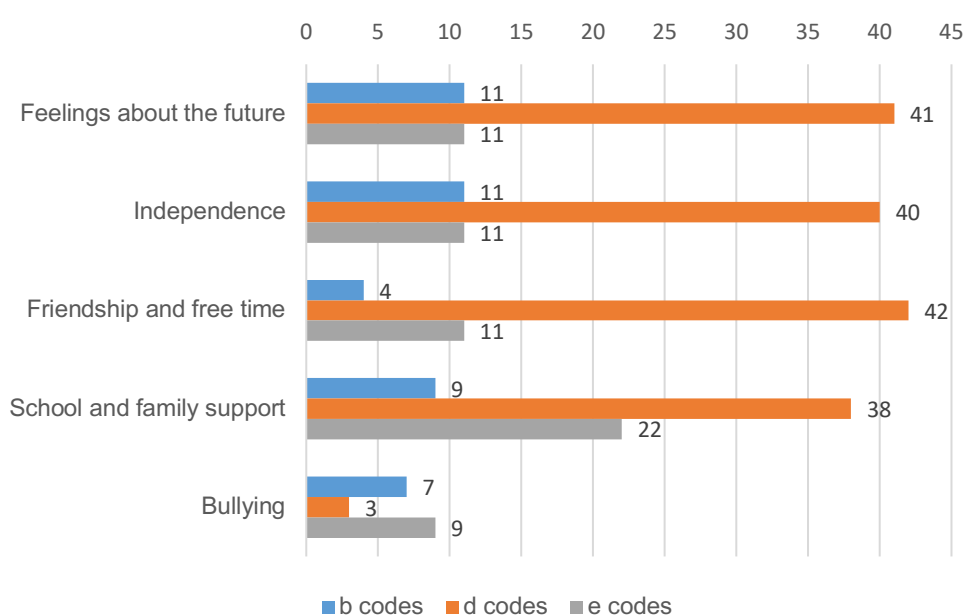
*Figure 4.1* Occurrence and frequency of ICF-CY codes identified in interviews, by functioning component

The proportion of identified ICF-CY codes within each theme as reflected in Table 4.2 seems to broadly mirror the overall code proportion presented in Table 4.1. The component of activities and participation (*d* codes) contains more than half of the ICF-CY codes in all themes, followed by environmental factors (*e* codes), and lastly body functions (*b* codes), with the exception of the theme of bullying, in which environmental factors takes the lead ahead of activities and participation; and the theme of independence, in which body functions overtakes that of environmental factors.

Table 4.2

*ICF-CY codes found in interviews, by theme and functioning component*

Theme	<i>b</i> codes	<i>d</i> codes	<i>e</i> codes	Total
Feelings about the future	11	41	11	63
Independence	11	40	11	62
Friendship and free time	4	42	11	57
School and family support	9	38	22	69
Bullying	7	3	9	19
Total	42	164	64	270



*Figure 4.2* Occurrence of ICF-CY codes found across interview themes, by functioning component

Given that the focus of the interviews was placed on the views and experiences of young people with ASD in transition to post-16 settings, it was expected to find some of the same codes across themes. It is in the different combination of the emerged functioning codes across and within themes that the functioning constellation of each theme is revealed. Table 4.3 presents all identified ICF-CY codes across interviews, highlighting their occurrence across and within themes in order to explore in more detail the particular ways in which codes relate to each other.

Table 4.3

*Identified ICF-CY codes with descriptions, organised by functioning component and interview theme.*

ICF-CY Code	Code description	Feelings about the future	Independence	Friendship	School and Family Support	Bullying
<i>Body Functions (b)</i>						
Dispositions and intra-personal						
b125	functions		x		x	
b1250	Adaptability	x				
b1252	Activity level	x				
Temperament and personality						
b126	functions		x		x	
b1260	Extraversion		x	x	x	x
b1262	Conscientiousness	x				
b1263	Psychic stability					x

ICF-CY Code	Code description	Feelings about the future	Independence	Friendship	School and Family Support	Bullying
b1264	Openness to experience	x				
b1265	Optimism	x				
b1266	Confidence	x	x		x	x
b130	Energy and drive functions		x			
b1300	Energy level					x
b1301	Motivation	x	x	x	x	
b134	Sleep functions					x
b140	Attention functions	x			x	
b152	Emotional functions	x	x	x	x	x
b160	Thought functions		x			
b1641	Organisation and planning	x	x			
b1642	Time management				x	
b1646	Problem-solving	x	x	x	x	
b530	Weight maintenance functions		x			x
21 <i>b codes</i>		11	11	4	9	7

*Activities and Participation (d)*

d1	Learning and applying knowledge	x			x	
d110	Watching			x	x	
d115	Listening			x		
d135	Rehearsing	x				
d137	Acquiring concepts	x			x	
d155	Acquiring skills	x	x			
d1551	Acquiring complex skills	x				

ICF-CY Code	Code description	Feelings about the future	Independence	Friendship	School and Family Support	Bullying
d160	Focusing attention				x	
d166	Reading		x			
d170	Writing	x			x	
d172	Calculating	x			x	
d175	Solving problems		x	x	x	
d177	Making decisions	x	x		x	
d220	Undertaking multiple tasks			x		
	Undertaking multiple tasks					
d2202	independently		x			
d230	Carrying out daily routine	x	x		x	
d2302	Completing the daily routine			x	x	
d2303	Managing one's own activity level			x	x	
d2304	Managing changes in daily routine		x			
d2305	Managing one's time				x	
	Handling stress and other					
d240	psychological demands	x	x	x	x	x
	Handling stress and other					
d2401	psychological demands	x				
d2402	Handling crisis	x				
d250	Managing one's behaviour	x				
d2502	Approaching persons or situations				x	
d3	Communication			x		
	Communicating with - receiving -					
d310	spoken messages			x	x	

ICF-CY Code	Code description	Feelings about the future	Independence	Friendship	School and Family Support	Bullying
d330	Speaking	x				
	Producing drawings and					
d3352	photographs	x				
d345	Writing messages	x				
d350	Conversation			x	x	x
d355	Discussion			x		
	Using communication devices and					
d360	techniques				x	
d430	Lifting and carrying objects	x	x			
d4503	Walking around obstacles		x		x	
d455	Moving around			x		
d460	Moving around in different locations		x		x	
	Moving around within buildings					
d4601	other than home		x			
	Moving around outside the home					
d4602	and other buildings		x			
	Walking and moving, other					
d469	specified and unspecified		x			
d470	Using transportation		x		x	
	Using private motorised					
d4701	transportation		x		x	
	Using public motorised					
d4702	transportation		x		x	
d5	Self-care		x			

ICF-CY Code	Code description	Feelings about the future	Independence	Friendship	School and Family Support	Bullying
d520	Caring for body parts		x			
d570	Looking after one's health				x	
d5701	Managing diet and fitness				x	
d5702	Maintaining one's health				x	
	Seeking advice or assistance from					
d57021	caregivers or professionals				x	
d571	Looking after one's safety		x			
d6	Domestic life		x		x	
d610	Acquiring a place to live		x			
d620	Acquisition of goods and services		x	x	x	
d6200	Shopping		x			
d630	Preparing meals	x	x			
d6301	Preparing complex meals		x			
d640	Doing housework	x	x			
d6402	Cleaning living area		x			
d6403	Using household appliances		x			
d6406	Helping to do housework		x		x	
d650	Caring for household objects		x			
	Taking care of plants, indoors and					
d6505	outdoors			x		
d6506	Taking care of animals		x			
d660	Assisting others			x		
d6606	Helping assisting others			x		
d710	Basic interpersonal interactions			x		



ICF-CY Code	Code description	Feelings about the future	Independence	Friendship	School and Family Support	Bullying
	Respect and warmth in					
d7100	relationships			x		
d7101	Appreciation in relationships			x		
d7102	Tolerance in relationships			x		
d720	Complex interpersonal interactions	x	x	x		
d7200	Forming relationships	x		x		
d7201	Terminating relationships	x		x		
	Regulating behaviours within					
d7202	interactions	x		x		x
d730	Relating with strangers	x	x			
d740	Formal relationships	x				
d750	Informal social relationships			x	x	
d7500	Informal relationships with friends			x		
	Informal relationships with					
d7502	acquaintances			x		
d7504	Informal relationships with peers			x		
d760	Family relationships				x	
d7600	Parent-child relationships				x	
d7601	Child-parent relationships				x	
d7602	Sibling relationship				x	
d770	Intimate relationships			x		
d820	School education	x				
	Moving into educational programme					
d8200	or across levels	x				

ICF-CY Code	Code description	Feelings about the future	Independence	Friendship	School and Family Support	Bullying
d8201	Maintaining educational programme				x	
	Progressing in educational					
d8202	programme	x				
	Terminating educational					
d8203	programme or school levels	x				
d825	Vocational training	x			x	
	Moving into vocational training					
d8250	programme or across levels	x				
	Maintaining vocational training					
d8251	programme	x				
	Progressing in vocational training					
d8252	programme	x		x		
d830	Higher education	x				
	Moving into higher education or					
d8300	across levels	x				
	Progressing in higher education					
d8302	programme	x				
d835	School life and related activities			x		
d840	Apprenticeship (work preparation)	x	x			
	Acquiring, keeping and terminating					
d845	a job	x	x			
d860	Basic economic transactions		x			
d880	Engagement in play			x		
d8800	Solitary play			x		

ICF-CY Code	Code description	Feelings about the future	Independence	Friendship	School and Family Support	Bullying
d8803	Shared cooperative play			x		
d910	Community life			x		
d9100	Informal associations			x	x	
d9103	Informal community life			x		
d920	Recreation and leisure		x	x		
d9200	Play			x		
d9201	Sports	x	x	x		
d9202	Arts and culture	x	x	x	x	
d9203	Crafts	x				
d9205	Socialising			x		
112 d codes		41	40	42	38	3

#### *Environmental Factors*

e1101	Drugs		x			
e1152	Products and technology used for play			x		
e1201	General products and technology for personal indoor and outdoor mobility and transportation		x			
e125	Products and technology for communication			x		
e130	Products and technology for education	x				

ICF-CY Code	Code description	Feelings about the future	Independence	Friendship	School and Family Support	Bullying
	General products and technology					
e1300	for education				x	
	Products and technology for					
e140	culture, recreation and sport		x	x		
	General products and technology					
e1400	for culture, recreation and sport			x		
	Design, construction and building					
	products and technology of					
e150	buildings for public use	x		x	x	
	Design, construction and building					
	products and technology of					
e155	buildings for private use		x		x	
e220	Flora and fauna			x		
e3	Support and relationships	x	x		x	
e310	Immediate family		x		x	x
e315	Extended family				x	
e320	Friends	x		x	x	
	Acquaintances, peers colleagues, neighbours and community					
e325	members			x	x	
e330	People in positions of authority		x		x	x
	Personal care providers and					
e340	personal assistants				x	
e350	Domesticated animals			x		

ICF-CY Code	Code description	Feelings about the future	Independence	Friendship	School and Family Support	Bullying
e355	Health professionals				x	
e360	Other professionals				x	x
e4	Attitudes	x				
	Individual attitudes of immediate					
e410	family members		x		x	x
e420	Individual attitudes of friends			x	x	x
	Individual attitudes of acquaintances, peer colleagues, neighbours and community					
e425	members		x	x	x	x
	Individual attitudes of people in					
e430	positions of authority					x
e445	Individual attitudes of strangers	x				x
	Individual attitudes of health					
e450	professionals				x	
	Individual attitudes of other					
e455	professionals	x			x	x
e460	Societal attitudes		x			
e5	Services, systems and policies				x	
e5400	Transportation services		x			
	Health services, systems and					
e580	policies				x	
	Education and training services,					
e585	systems and policies	x				

ICF-CY Code	Code description	Feelings about the future	Independence	Friendship	School and Family Support	Bullying
e5850	Education and training services	x				
e5851	Education and training systems				x	
e5852	Education and training policies	x			x	
	Special education and training					
e5853	services	x			x	
38 e codes		11	11	11	22	9

*Independence.* This was a significant theme across participants. In terms of the ICF-CY, here the narrative of the interviews translated predominantly into meaning units referring to the execution of tasks or actions (activities) and the involvement of the individual in a life situation (participation). In these terms, participants expressed their views on what being independent means with regards to problem-solving and decision-making (d172, d177, respectively), carrying out their routine and handling stress (d230, d240). Furthermore, they highlighted the place of mobility (family of d4 codes) as synonym of independence, as part of growing up, making room for insights about the use of public transport and going out of the house on their own. Codes belonging to the chapter of self-care and domestic life (d5 and d6 codes, respectively) reflected on individuals' insights about everyday activities of an independent life, such as shopping (d6200), preparing meals (d630) or doing housework (d240). Moreover, participants acknowledged the role of relationships and managing interactions (d720, d730) as part of becoming increasingly independent. Preparing for life at work and moving towards getting a job (d840, d845) were aspects addressed by the young people as significant in relation to independence. Individuals talked about their feelings (b152) of independence, their aspirations and motivation

(b1301), and made reference to themselves in terms of dispositions and personality characteristics (b125, b126). They also highlighted the importance of support in the process of becoming more independent, attitudes of other people around them (e3 and e4 codes, respectively).

*School and family support.* Participants gave a central place to family and school as support systems in their lives. Chapters three and four of the environmental factors' component – dedicated to support, relationships, and attitudes of other people – acquire great importance in this theme. As contextual factors, these codes appeared inextricably related to the activities and participation in which support is embedded – making decisions, for example (d177), mobility (d4) and domestic life (d6). Furthermore, codes from the body functions component, were also identified within support-related experiences, particularly those mental functions codes that refer to the individuals' dispositions and intra-personal functions (b125), and temperament and personality characteristics (b126). Moreover, within this theme participants acknowledged the role of education services in their lives (e5).

*Ambivalent feelings about change and the future.* Participants' views about their future were underpinned by ambivalent feelings. In this theme, the future was mostly depicted through dilemmatic dimensions, where leaving school was portrayed as an exciting event, accompanied by new challenges, skills, places and people, while at the same time it represented leaving behind routines, familiar places and people – teachers and friends – turning this into a saddening event. These feelings were linked to the code of emotional functions (b152), whereas aspirations for their future were captured by the code of motivation (b1301), both in the body functions component. The activities and participation component was the one that produced most codes for this theme, particularly chapter eight. This chapter is dedicated to functioning in major life areas, where codes on school education (d820), vocational training (d825), higher education (d830), apprenticeship (d840), and acquiring, keeping and terminating a

job (d845) constitute one third of the categories participants linked to this theme. Decision-making (d177), carrying out routine (d230), managing stress (d240) and regulating behaviour (d250) were addressed by participants when describing their future prospects, and the implications of the upcoming changes linked to moving on to the next stage. In this respect, consideration was also given to domestic life (d630, d640), interpersonal interactions, particularly with strangers (d730), and participation in leisure activities (d9201, d9202, d9203).

*Friendship and free time.* Participants' descriptions of the role of friendship in the transition period was dominated by activities and participation codes. Distinctly, participants' accounts on friendship transpired mostly in codes of interpersonal interactions and relationships (d7 codes), and recreation and leisure (d9 codes). This highlights the close association individuals placed between friendship and free time. Furthermore, they recognised the support of friends (e320) in their lives, as well as their attitudes (e420) as meaningful aspects of friendship. Despite the link between leisure and friendship, many participants acknowledged spending a great deal of their free time indoors, on their own, playing computer games or watching television (d8800, d110, e1152), and leaving socialising activities for the school environment. Some participants highlighted having many friends at school, but not contacting them or engaging in activities together beyond the boundaries of school, leaving many participants feeling lonely.

*Bullying.* The number of functioning codes identified within this theme is considerably smaller than those featuring previously described themes. However, this does not preclude exploring young people's views concerning bullying in depth. Participants emphasised the compelling position of attitudes of other people in this phenomenon, either as protective factors or barriers. Two thirds of the identified environmental factors codes specifically referred to the attitudes of immediate family (e410), friends (e420), acquaintances, peer colleagues, neighbours and community



members (e425), people in positions of authority (e430), strangers (e445), and professionals (e455). Moreover, they recognised the supportive role of family (e310), people in positions of authority (e330) and professionals (e360) in taking steps against this. Participants also referred to feelings (b152) and their emotional wellbeing, and other mental functions particularly related to temperament and personality traits, such as extraversion (b1260), psychic stability (b1263) and confidence (b1266). This was also reflected in the activities and participation component, as participants linked this theme with the management of stress (d240), regulation of behaviour in interaction with others (d7202), and aspects of communication, especially conversation (d350).

### **4.3 Summary**

This chapter addressed the views of a group of young people with ASD through semi-structured interviews analysed following a phenomenological approach to unearth the themes that made up the fabric of their lived experiences of transition and their future after secondary school. Findings from this strand of study suggest that at time of transition young people with ASD reported wishes to become increasingly more independent and autonomous in their day-to-day lives, particularly with regards to mobility, self-care, domestic life and other major life areas. They recognised the value of support they receive from their parents and school staff, however they expressed wishes to become more autonomous in their decision-making processes. In addition, they reported experiencing ambivalent feelings about the change of setting upon finishing their compulsory education journey, and with regards to the future. Participants highlighted feeling anxious about meeting new people and learning to navigate their new settings, and the systems of support available to them. They have emphasised the role of friendship in their lives, and wondered about the future of those bonds upon departure of the context in which these developed.

Concerning the analysis of interviews using the ICF-CY, the use of this framework allowed to explore the pattern of functioning codes emerging from each theme. The views of young people were predominantly translated into activities and participation codes, followed by body functions and environmental factors codes. The use of this classification system allowed a shift in the focus of young people's views, traditionally seen from 'within'-individual characteristics associated with ASD, to one that conveys the uniqueness of their functioning, portraying the interactive nature of the relationship between an individual and their environment (WHO, 2007).

The findings stemming from this strand of study are of significance in the context of the new SEND policy in England. Participation in decision-making and person-centred approaches to service provision are at the core of the changes introduced by the new legislation and in the new SEND Code of Practice, in a move to transform services through collaboration with their users, making these more responsive to their needs. The themes identified in this chapter provide evidence of what is relevant for young people with ASD, identified by themselves at this point in their lives. In this respect, these themes can serve as a starting point to steer the conversation about transition to post-secondary life and enhance front-line providers' understanding of what is important for the young person to achieve their aspirations for life after secondary and compulsory education. In recognising these important points, the design of provision could become more responsive to the needs and aspirations of the young person, contributing to mobilise resources for transitional arrangements that would cater specifically to the dimensions of these period that are most significant to them.



## **5. Results: The functioning-related views, aspirations, needs and outcomes of young people with ASD in EHC plans.**

### **5.1 Introduction**

As discussed in Chapter 2, the Children and Families Act 2014 marked an inflection point in the field of SEND in England. The extension of provision to cover the 0-25 age range, and the introduction of EHC plans to replace statements of SEND in England constitute key changes stemming from the new law, with the purpose of developing holistic, multidisciplinary provision for children and young people with SEND to prepare them effectively for adulthood. The purpose of this strand was to explore how the views, needs and outcomes sought for young people with ASD in transition to post-16 education and employment were portrayed in the newly developed EHC plans. Four research questions emerged to address this aim:

- a. What are the methods used to capture the views of young people with ASD in their EHC plans?
- b. What are the ICF-CY functioning dimensions identified in the EHC plans as the young people's views, wishes and aspirations?
- c. What are the ICF-CY functioning dimensions identified in EHC plans as the special educational, health, and social care needs of young people with ASD?
- d. What are the ICF-CY functioning dimensions identified as the outcomes sought for young people with ASD in their respective EHC plans?

The EHC plans developed for 23 young people with ASD, in the 15 to 19 age range, were collected and analysed. Given the delays faced by LAs in finalising the documents, six participants out of the 29 recruited did not hold a final version of their EHC plan at the time of writing, and therefore were not included in the analysis. The collected documents were analysed first in an inductive manner, followed by a

deductive content analysis approach using the International Classification of Functioning, Disability and Health – Children and Youth version (ICF-CY) by the WHO (2007), as a system of pre-defined codes. For an overview of the coding procedure followed to analyse the EHC plans using the ICF-CY system, please refer to Appendix D; a complete list of ICF-CY codes identified in EHC plans can be found in Appendix E. The results presented in this chapter correspond to the analyses of five sections of the EHC plans. The sections covered the views, wishes and aspirations of young people with ASD and their families (Section A), the special educational needs of the young people (Section B), their health needs (Section C), social care needs (Section D), and the outcomes written for the young people (Section E).

## **5.2 Findings**

An inductive approach was used to explore the overall structure and organisation of 23 EHC plans. Given the plans were co-produced by different schools and LAs, the inductive approach allowed the identification of shared characteristics and differences in the ways they presented the EHC plan content across sections, particularly with regards to the manner in which the voices of young people were presented and the methods used to elicit their views. This was followed by a deductive content analysis to explore the functioning dimensions identified as the young people's views, interests and aspirations (Section A), their special educational (Section B), health (Section C) and social care (Section D) needs and the outcomes (Section E) sought for them. For organisation purposes, the results section present first findings arising from the inductive content analysis, followed by deductive content analyses of each individual section.

### **5.2.1 Structure and organisation of EHC plans**

The collected EHC plans belonged to 23 young people with ASD between 15 and 19 years old ( $M = 16.5$ ), of which three were girls and 17 boys. The majority of participants ( $N = 17$ ) were attending year 11 of secondary school, four were in sixth form, and one was attending a further education college. All participants were enrolled with education providers located in Greater London LAs, however the plans were developed by ten Greater London and South East LAs. The EHC plans were organised as per the sections described in the SEND Code of Practice, where each section was clearly identified with a letter and a descriptive label indicating its content. However, it should be noted that not all of the EHC plans collected presented content in sections concerning health and social care (Sections C and D, respectively). As indicated on Table 3.2 (Chapter 3) the 23 EHC plans that have been analysed presented content in sections concerning the views of young people (Section A), their special educational needs (Section B) and outcomes (Section E).

However, 14 out of 23 plans included information in the section of health needs (Section C), and nine plans included information related to social care needs (Section D). So overall, there were only seven plans which presented information across all three sections dedicated to needs (Sections B, C, and D). According to the Code of Practice, information on health and social care needs should be included in these sections as long as they have been identified through the EHC needs assessment and they relate to the child or young person's SEND. These discrepancies in the presentation of content related to identified needs raises the question of the rationale for categorising needs in the scope of a renewed SEND system that aims at producing holistic characterisations of young people. These issues are addressed in detail in the discussion section (Chapter 8). Variation in the length of the documents was another salient characteristic, ranging between 12 and 26 pages long ( $M = 16.7$ ). This results into some plans containing more information about the young people than others,

although not necessarily *new* information as plans presented a great deal of repetition.

### **5.2.2 Capturing the voices of young people with ASD in EHC plans**

Following the Code of Practice, the first section of EHC plans is dedicated to the views, wishes and aspirations of the child or young person, and their parents, and as previously detailed, it should contain information on the child or young person's history and communication style, aspirations and goals for the future. It also should include details about play, schooling, independence, friendships and overall health; further education and future plans including employment. All collected plans included information in this section. The length of this section varied across plans, from two to nine pages long ( $M = 3.1$ ). The specificity of the content of this section also varied across plans, however a common denominator identified was the repetition of information throughout.

The Code of Practice allows for this section to be written in the first or third person, and requires for the plan to be explicit with regards to the use of the first person, instructing to specify whether the child or the young person is being quoted directly, or if the views of parents and professionals are being represented. In this respect, 10 out of 23 plans have used the third person exclusively, whereas 13 out of 23 plans presented a combination of the first and the third person. Concerning the methods to elicit the views of young people, four plans presented a one-page profile prepared by the young person on their own or with the support of a member of staff at school, in which they documented their views and provided details about how these views were elicited, such as by using a slide presentation to introduce themselves. These one-page profiles were followed by third person descriptions provided by parents; other plans alternated presenting the young person's and their parents' views on a specific topic within the section. For instance, they would introduce the topic of

aspirations for the future, where the young person would express their views on this, followed by parents' aspirations for the young person's future. However, occasionally plans included rather broad statements to refer to the contribution of young people in their EHC process, i.e. *'he was present at the annual review meeting and communicated his aspirations'* with no further indication of the processes underpinning these contributions. Moreover, seven out of 10 plans using the third person did not mention at all how the views of young people have been collected nor acknowledged how the young people have contributed to the EHC plan process.

In a similar vein, in eight out of 23 plans Section A acknowledges the contributions of other people to their completion but does not provide details of the nature or capacity of these. In all eight cases reported, this acknowledgment comes in the form of a general, vague statement, for example: *'this section has been completed with contributions from R, his mum and people who have worked with R and know him well'*. Parental views were included in all analysed plans and reported as collected through meetings, written reports in preparation for annual review meetings, or both. These findings raise several questions with regards to the effective participation of the young person in decision-making, the underlying processes of eliciting the views of young people and how these views are recorded and documented in their EHC plans.

### **5.2.3 Matching the content of EHC plans to the ICF-CY**

The ICF-CY was used as a system of predefined codes to be matched to the EHC plans, and translate them into the categories of the framework, namely body functions and body structures, activities and participation, and environmental factors, following linking rules and procedures used and established in previous studies (Augustine et al., 2017; Ballert et al., 2016; Castro et al., 2013; Cieza et al., 2016).



Table 5.1 summarises the occurrence and frequency of ICF-CY codes identified across the five analysed sections of the EHC plans, and provides totals for each section and ICF-CY component, respectively (for a complete coverage of all ICF-CY codes identified in EHC plans, with their respective definitions and frequencies across sections, please refer to Appendix D).

Overall, the component of activities and participation was the one that yielded the greatest proportion of ICF-CY codes in all sections of the EHC plans, followed by the component of Body functions, environmental factors, and lastly, the body structures component, as seen in Figure 5.1. This last domain refers to the anatomical parts of the body, such as organs, limbs, and their components. Only two ICF-CY codes for this component were identified in EHC plans, in section A and section C; it should be noted that the one identified in section A coincides with one identified in section C. A low number of codes from this domain was expected; this could be explained by the fact that the most common characteristics of individuals with ASD are not usually associated with descriptors at the level of body structures such as anatomical issues about their bones, muscles -for example- but rather at the level of psychological functions, which are captured by the component body functions, their communication and interaction characteristics, and activities in general, which are captured by the activities and participation component.

Figure 5.2 depicts the frequency of ICF-CY codes identified in each EHC plan section analysed; this figure highlights once more that the component of activities and participation is predominant across sections. This is followed by Table 5.2 which provides some examples of information extracted from EHC plans. These extracts are shown in the context of the ICF-CY coding process, where the meaning units are coded first in terms of the ICF-CY component they relate to, the component chapter, and lastly the assigned ICF-CY code together with its respective description.

Table 5.1

*Occurrence and frequency of identified ICF-CY codes, by EHC plan section and functioning domain*

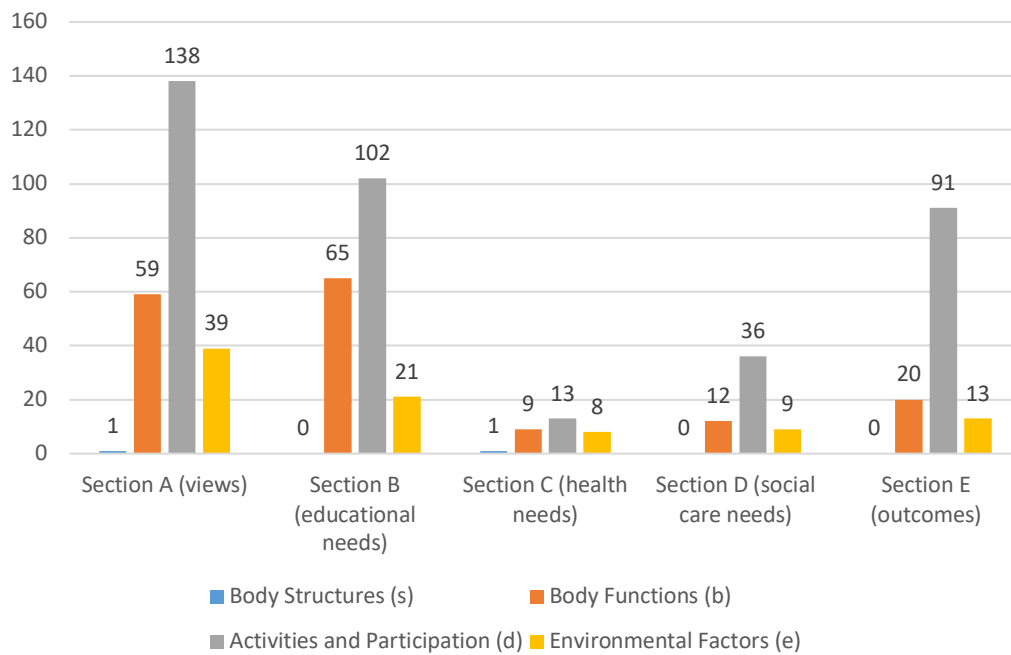
	Section A		Section B		Section C		Section D		Section E		Total	
	Occ.	Freq.	Occ.	Freq.	Occ.	Freq.	Occ.	Freq.	Occ.	Freq.	Occ.	Freq.
Body Structures (s)	1	2	0	0	1	1	0	0	0	0	1	3
Body Functions (b)	59	319	65	224	9	12	12	19	20	59	88	633
Activities and Participation (d)	138	519	102	339	13	19	36	80	91	301	183	1258
Environmental Factors (e)	39	181	21	97	8	21	9	16	13	21	50	336
Total	237	1021	188	660	31	53	57	115	124	381	322	2230

*Note.* Occ. = occurrence of code; Freq. = frequency of code. Section A = views, wishes and aspirations; Section B = special educational needs; Section C = health needs; Section D = social care needs; Section E = outcomes

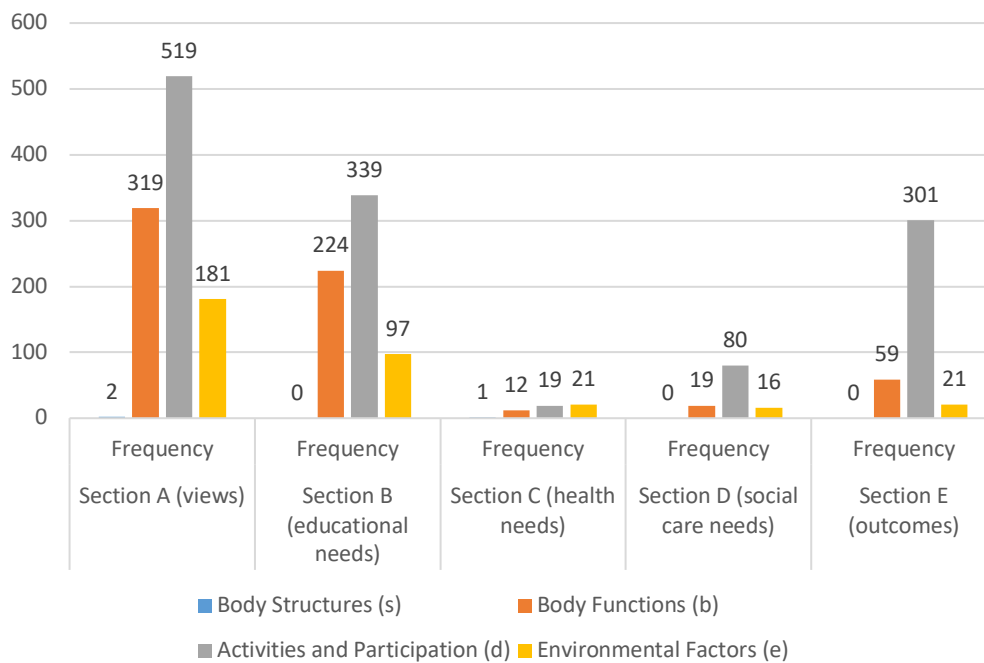
Table 5.2

*Extracts of coded EHC plans, by ICF-CY component*

EHC Plan extract	ICF-CY component	Component chapter	Assigned ICF-CY code	Code description
'He is an extremely polite and charming young man' (YP 6)	Body Functions	b1 – Mental functions	b126	Temperament and personality functions
'He follows the front board schedule which is used for the whole class. He likes the security of knowing what is happening, it gives him control of what will be happening during the day' (YP 14)	Activities and Participation	d2 – General tasks and demands	d230	Carrying out daily routine
He is not ready to travel independently, although he will now walk down the road after school where his mum will be waiting for him in the car. (YP 1)	Activities and Participation	d4 - Mobility	d4602	Moving around outside the home and other buildings
			d4701	Using private motorised transportation
'He will often look to his peers for support, especially when getting a bus, or walking somewhere, and the students are required to lead' (YP 15)	Environmental factors	e3 – Support and relationships	e325	Acquaintances, peers, colleagues, neighbours and community members
'It is important for [YP 8] that those around him understand the impact that his ASD and tics have on him, and respond to these appropriately' (YP 8)	Environmental factors	e4 - Attitudes	e425	Individual attitudes of acquaintances, peers, colleagues, neighbours and community members
'The school is working to develop his independence skills' (YP 15)	Not definable	****	****	****



*Figure 5.1* Occurrence of ICF-CY codes found across EHC plan sections, by functioning component.



*Figure 5.2* Frequency of ICF-CY codes across EHC plan sections, by functioning component.

#### 5.2.4 Functioning dimensions identified as the views, interests and aspirations of young people with ASD

The deductive content analysis performed across the section on the views of young people using the ICF-CY framework resulted in meaning units being linked to a total of 237 ICF-CY codes across the four components. The component of activities and participation was the one that yielded the largest number of codes in terms of occurrence and frequency, followed by body functions, environmental factors and body structures. It should be noted that a total of 80 meaning units could not be linked to any code of the ICF-CY framework. This is because the content they conveyed was too general or vague to be linked to the content of one or more codes from the ICF. For example, 'B needs to improve her independence skills', or 'F wants to achieve the goals set out for him'. The expression 'independence skills' could be related to mobility and the use of public transport, the use of money and basic economic transactions, domestic life or self-care.

Table 5.3

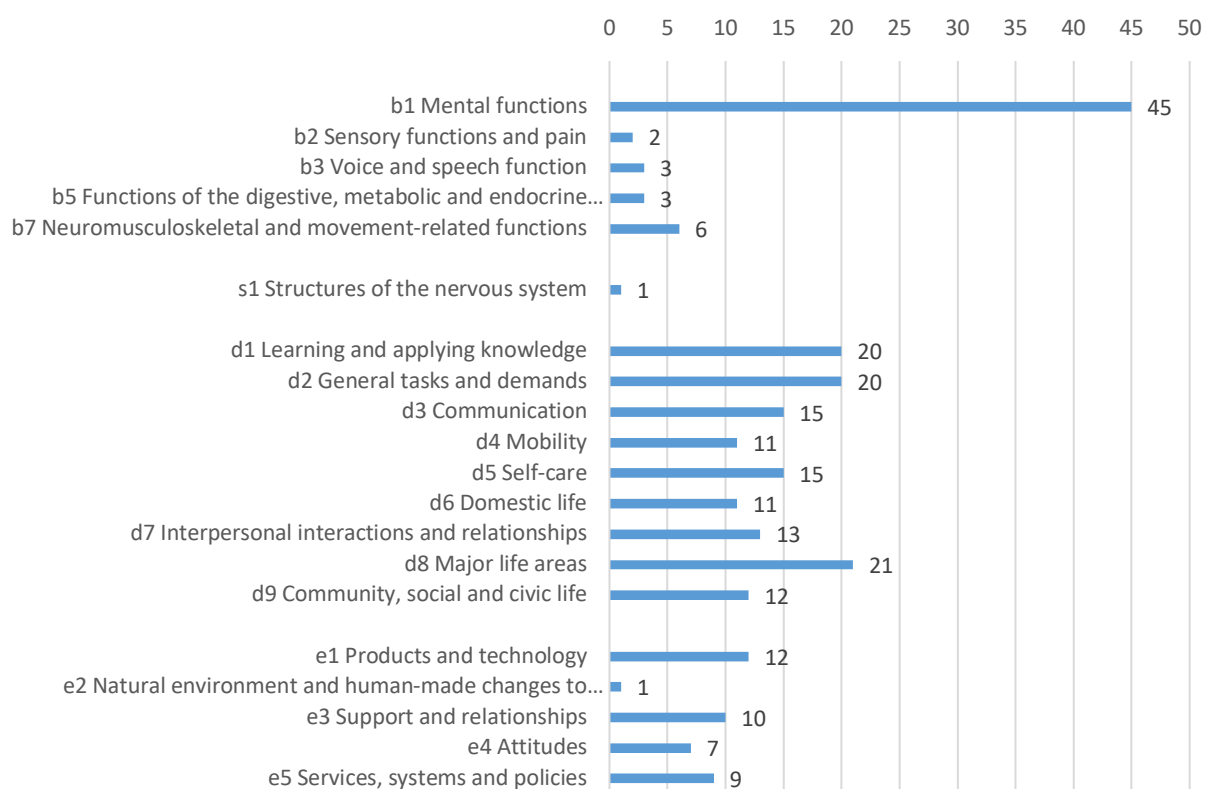
*Occurrence and frequency of identified ICF-CY codes in Section A, by functioning component.*

	Section A			
	Occ.	% occ.	f	% f
<i>Body Structures (s)</i>	1	0.4	2	0.2
<i>Body Functions (b)</i>	59	24.9	319	31.2
<i>Activities and Participation (d)</i>	138	58.2	519	50.8
<i>Environmental Factors (e)</i>	39	16.5	181	17.7
Total	237	100.0	1021	100.0

As seen in Table 5.3, 58.2% of the total number of ICF-CY codes mapped to Section A of the plans belonged to the component of activities and participation. This

means that the narrative of Section A predominantly translated into meaning units that referred to the execution of a task or an action by individuals (activities) and the involvement of the individuals in a life situation (participation), representing 138 codes out of 237 codes. Figures 5.3 and 5.4 present an overview of the occurrence and frequency of ICF-CY codes in this section of the plans. Within this component, the chapters of learning and applying knowledge (d1 codes) and major life areas (d8) were the ones that yielded the greatest number of ICF-CY codes, with codes in the latter chapter being the most frequently assigned to meaning units. This chapter is dedicated to education, work and employment, and economic life. In this respect, the codes most frequently used were those referring to school education (d820), particularly with regards to making progress in a school programme (d8202), and those referring to acquiring, keeping and terminating a job (d845), and remunerative employment (d850), suggesting that these spheres are of particular relevance to young people with ASD and their families. As for the chapter covering learning and applying knowledge, emphasis has been given to codes related to basic learning such as acquiring concepts (d137), learning to read (d140), to calculate (d150) and acquiring skills (d155).

In the chapter of general tasks and demands (d2) the codes that stand out refer to undertaking tasks (d210, d220), carrying out daily routine (d230) with emphasis in managing changes occurring in daily routine (d2304), and managing stress and other psychological demands (d240). These codes were often identified in the context of young people's need for a structured routine and anticipation in case of changes throughout their day, and their behavioural responses to these. Concerning the completion of tasks, plans referred to the management of tasks independently, as part of a group or with support in the context of school and activities within this context.



*Figure 5.3* Occurrence of ICF-CY codes identified in Section A, by component chapter.

Codes belonging to the chapters of communication (d3) and interpersonal interactions and relationships (d7) emerged in all EHC plans, particularly those related to receiving spoken messages (d310 and subsequent codes), speaking (d330), and conversation (d350), together with the codes referring to basic (d710), complex personal interactions (d720), and informal social relationships (d750). This is likely to be linked to the fact that section A describes the characteristics that are associated with the ASD profile in terms of social communication and interaction difficulties.

The chapter of community, social and civic life (d9) was highly frequent in section A of the plans, where codes concerned with recreation and leisure (d920) constituted the most frequent. In these terms, the plans referred to the young people's free time, emphasising their participation in sports (d9201), arts and culture (d9202), and socialising (d9205). Furthermore, in this section a series of codes emerged

relating to young people's independence and autonomy and were linked predominantly to those belonging to the chapters of mobility (d4), self-care (d5), and domestic life (d6).

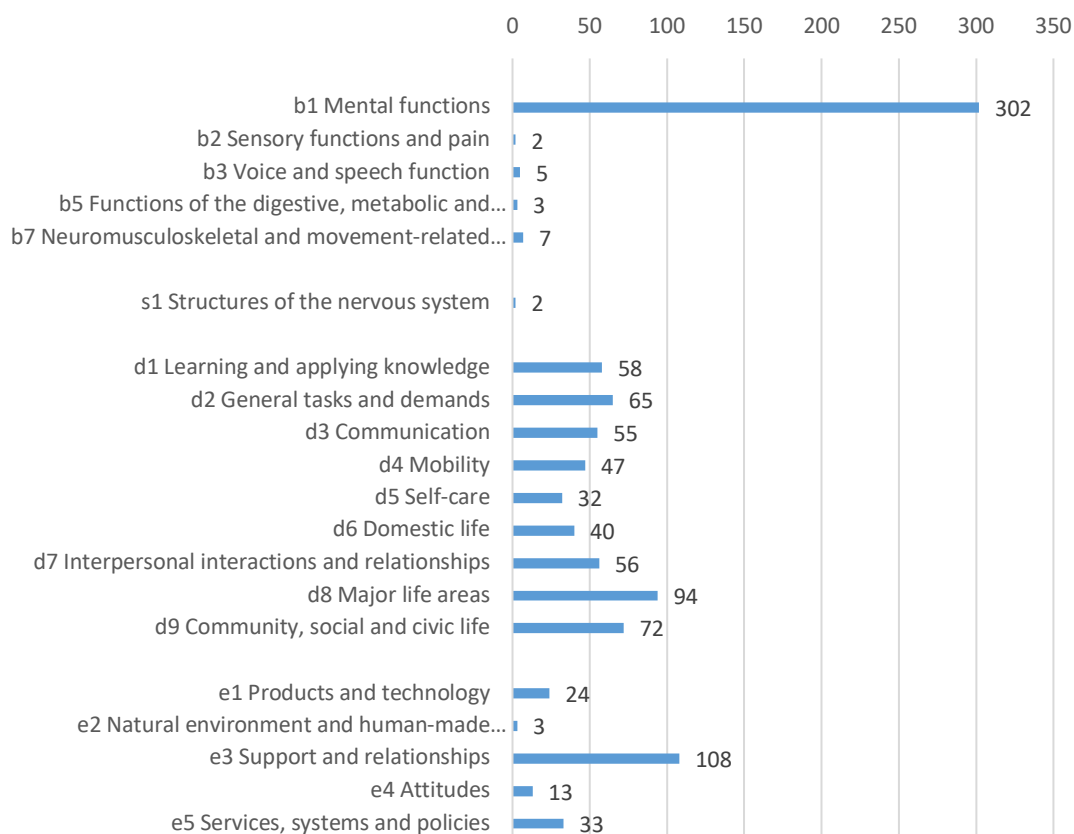


Figure 5.4 Frequency of ICF-CY codes identified in Section A, by component chapter

The emergence of these codes stresses the significance of independence for participants and their families at a time of transition. Concerning mobility, the codes most frequently identified were those covering mobility outside the house (d460, d4601, d4602), and moving around using transportation (d470, d4701, d4702). These codes were seen as targets or goals to achieve by the young people. Codes belonging to the chapter of self-care (d5) were also linked to aspects of independence that related to the young people being able to wash themselves (d510), caring for body parts (d520), as well as eating (d550), taking care of one's health (d570) and safety (d571) in an effective way to lead an autonomous life. In this same line, a series of



codes in the chapter of domestic life were linked to aspects of independent life to achieve or already achieved in the home, like preparing meals (d630), acquiring goods and services (d620), doing housework (d640) and assisting others (d660).

The component of body functions refers to the physiological functions of body systems, in which psychological functions are included. A total of 59 body functions codes were identified in section A of the EHC plans, conforming 24.9% of the extracted codes, as seen in Table 5.3. It should be noted that the vast majority of meaning units linked to ICF-CY codes belonged to the chapter of mental functions, with the code for motivation (b1301) being the single most frequently presented across plans. This code was mapped to content commonly describing likes and dislikes of the young people, as well as their wishes, aspirations and goals. Given the duty to make this content manifest in section A of plans, the high frequency of this code was expected throughout plans. Body functions codes describing dispositions and intra-personal functions (b125, b1250, b1251, b1253, b1255), and those describing temperament and personality functions (particularly b126, b1260, b1261, b1262, b1266) were also frequently found, appearing 111 out of 319 times. This finding is in line with the requirement of providing an overall picture of the individual in this section of the plan, as outlined by the Code of Practice. Lastly, emotional functions (b152) was another frequently found code in section A. This code describes specific mental functions related to the feeling and affective component of the processes of the mind (WHO, 2007). The emergence of this code resulted mostly from the expression of different feelings and emotions about topics like finishing secondary school, making decisions about the future, and managing change in their lives, particularly change related to routines and the unexpected, and the regulation of emotion.

The component of environmental factors (e codes) refers to the physical, social and attitudinal environment in which people live and conduct their lives and constitute either barriers to or facilitators of the person's functioning. An overall look

into this component shows that the chapter of support and relationships was the most predominant in terms of frequency of codes. Throughout section A, a strong emphasis has been put on the role of support networks and relationships in the lives of young people with ASD, highlighting the relevance of immediate family (e310) and friends (e320). Another interesting finding from this component was on the chapter that covers services, systems and policies (e5). The analysis of plans in this domain revealed the significance of services available for young people with ASD and their families, which highlighted the role of education and training services, systems and policies (e585), particularly those services related to specialist support (e5853). The occurrence of this code in more than half of the plans suggests that availability of services and the quality of these remain an important aspect of the life of young people with ASD and their families, particularly at a time of transition.

#### ***5.2.5 Functioning dimensions identified as education, health and social care needs of young people with ASD***

The Code of Practice requires that the identified special educational, health and social care needs of the child or young person are organised in three consecutive sections which address them separately, in terms of special education (Section B), health (Section C) and social care (Section D). As previously mentioned, an overview of these sections has shown that all 23 plans contained information in the section destined to describing special educational needs (Section B). However, the sections dedicated to describing health needs (Section C) and social care needs (Section D) were left blank in a number of EHC plans. At first glance, this finding could suggest that the conceptualisation of needs is not clearly defined in the Code of Practice, and highlights an imperative to problematize the prescriptive nature of categorising needs in the context of the SEND reform, the value they add to the holistic portrayal of children and young people, and the difficulties of implementing this categorisation, as

transpired from the analyses across the three sections of needs covered by the EHC plans. The next section addresses the content and the ICF-CY functioning dimensions of the three areas of need separately, namely special educational (Section B), health (Section C), and social care (Section D) needs, as this is how they were portrayed in the EHC plans. Table 5.4 provides an overview of the number of ICF-CY codes identified across EHC plans sections concerning the different types of needs of young people with ASD; the frequency of these codes is also presented, organised by functioning component.

Table 5.4

*Occurrence and frequency of ICF-CY codes identified in Sections B, C, and D, by functioning component*

	Section B		Section C		Section D	
	Occ.	Freq.	Occ.	Freq.	Occ.	Freq.
<i>Body Structures (s)</i>	0	0	1	1	0	0
<i>Body Functions (b)</i>	65	224	9	12	12	19
<i>Activities and Participation (d)</i>	102	339	13	19	36	80
<i>Environmental Factors (e)</i>	21	97	8	21	9	16
<b>Total</b>	<b>188</b>	<b>660</b>	<b>31</b>	<b>53</b>	<b>57</b>	<b>115</b>

*Note.* Section B = educational needs; Section C = health needs; Section D = social care needs; Occ. = occurrence; freq. = frequency

#### 5.2.5.1 Functioning dimensions identified as special educational needs.

A total of 188 ICF-CY codes were linked to meaning units in the section concerning the identified special educational needs of young people (Table 5.5); the component of activities and participation once again was the one that presented the highest number of codes both in occurrence and frequency, followed by the body

functions domain, and environmental factors. The breadth and variety of codes identified in this section across functioning components suggest that the description of needs cannot be addressed unidimensionally. The identified ICF-CY codes described a combination of abilities and disabilities in terms of body functions, execution of tasks and participation, and the barriers and facilitators from the environment that mediate them, providing an overview of the functioning of young people. Thus, the categorisation of needs as being only educational is somewhat unworkable. The label of ‘educational’ seems to be only applicable in as much as it refers to the school context, but not because the needs are exclusively related to the school context.

Table 5.5

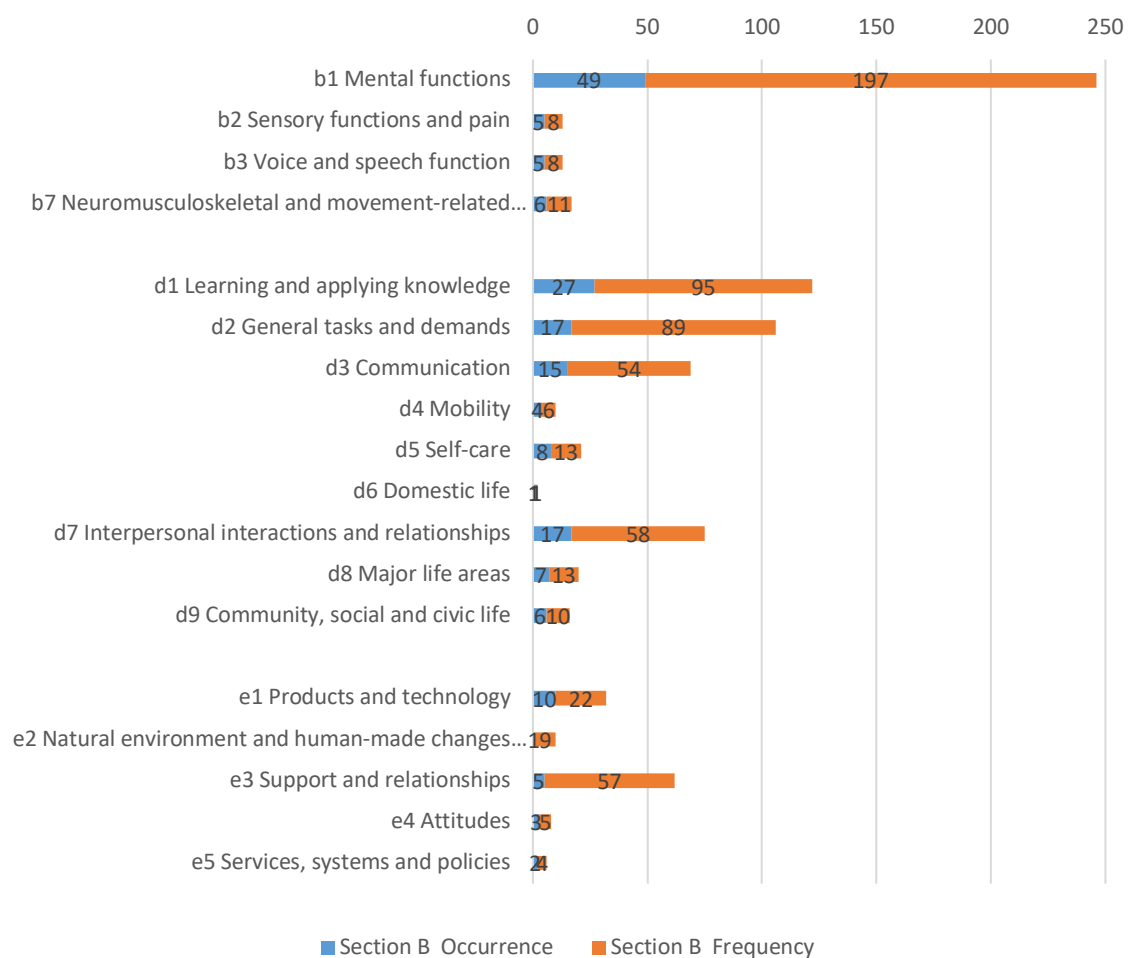
*Occurrence, frequency and percentages of identified ICF-CY codes in Section B.*

	Section B			
	Occ.	% occ.	Freq.	% Freq.
Body Structures (s)	0	0	0	0
Body Functions (b)	65	34.57	224	33.94
Activities and Participation (d)	102	54.26	339	51.36
Environmental Factors (e)	21	11.17	97	14.70
Total	188	100	660	100

*Note.* Section B = educational needs; Occ. = occurrence; freq. = frequency; % = percentage

As evidenced in figure 5.5, twenty-seven codes were linked to categories belonging to the chapter of learning and applying knowledge (d1), of which those related to focusing attention (d160), thinking (d163), learning to read and reading (d140, d166 respectively), learning to write and writing (d145, d170 respectively),

learning to calculate and calculating (d150, d172 respectively) stand out. The chapters of communication (d3) and interpersonal interaction and relationships (d7) have also yielded a significant number of codes in terms of occurrence and frequency, especially codes for communicating with – receiving – spoken messages (d310 and subsequent codes), and speaking (d330), basic and complex interpersonal interactions (d710, d720, and subsequent codes respectively).



*Figure 5.5* Occurrence and frequency of ICF-CY codes in Section B (special educational needs), by component chapter

These codes alluded predominantly to the difficulties in social communication and interaction that characterise the profile of individuals with ASD, and have direct

implications for life at school, as they highlight their relevance to navigate a socially mediated environment.

Another significant chapter within this section has been that of general tasks and demands (d2). The content of the plans has been linked to this chapter to refer to needs concerning the undertaking of a single and multiple tasks (d210, d220, respectively) in groups or independently as part of classroom activities. Furthermore, the management of change in daily routine (d2304), handling stress (d240) management of behaviour (d250) were highlighted across various plans as a need to be addressed, given the difficulty of young people with ASD to effectively adapt to unexpected changes in their environment, and to regulate their behaviour in accordance to the demands of the situation they are in. Similarly, the role of emotional functions (b152) in the body functions component was present in all EHC plans to stress young people's emotional response to different situations, usually referring to anxiety and to the regulation of emotion (b1521). The code for temperament and personality functions (b126, and subsequent codes) appeared across plans to refer to young people's personality characteristics, such as confidence (b1266), agreeableness (b1261), and openness to experience (b1264).

The chapter of support and relationships (e3) was the one most frequently found across section B of the analysed plans, highlighting the relevance of environmental factors in mediating engagement in activities and participation. It should be noted that in the majority of plans the reference to support lacked specificity in terms of who is the provider of support in the execution of tasks or in engaging in a life situation. An interesting finding is that thirteen health conditions were identified in this section – as such, they could not be coded under the ICF-CY framework.

The Code of Practice expresses that some health needs that relate to an individual's SEND might be better placed in the section of special educational needs, as they are significant for the individual's learning. The argument for these to be present within this section is based on the implications that such conditions may have

for the learning of young people. The fact that these diagnostic conditions were described in the section of education needs raises once more the question concerning the rationale for separating needs in EHC plans in three discrete categories. In practice, needs and strengths are presented following an interactive model of functioning; incorporating descriptions of medical conditions in this section while acknowledging the functional implications that may derive from the presence of a diagnosis suggest the need for a broader understanding of health and needs in EHC plans.

#### *5.2.5.2 Functioning dimensions identified as health needs (Section C).*

The analysis of this section led to identify a series of issues regarding the conceptualisation of health as operationalised by the Code of Practice with regards to EHC plans. According to the Code of Practice, health needs which relate to a child or young person's SEND must be included in section C of EHC plans, and adopt a somewhat prescriptive definition related to biological, physical aspects. At first glance, this seems at odds with the incorporation of health needs in the section dedicated to educational needs, for they may highlight functional implications of a diagnosis that have relevance for the education context. The Code goes on to specify that this does not mean that all health care needs should be included in the plans, and that those needs which are unrelated to the education or training of the child or young person are unlikely to be included. These two stances not only are contradictory, but also draw attention to the inconsistencies arising from the adoption of prescriptive definitions to separate needs into succinct categories in the scope of a biopsychosocial, interactive model of health and functioning as advocated by the new SEND framework. As previously mentioned, this section was empty in half of the collected EHC plans, and also contained little information related to health details as

understood by the Code of Practice. A summary of the identified functioning dimensions is shown in Table 5.6.

A total of 31 ICF-CY codes were linked to ten plans which presented content in Section C. It should be noted that in seven out of 10 plans, the label of ASD was presented as a health need, but no further details were provided in relation to this. Within the ICF-CY classification system, specific diagnoses are not coded – a diagnosis should be coded with a diagnostic classification, not a functional one such as the ICF. For this reason, the seven ASD labels identified in this section were computed as not codable due to them being health conditions. In this respect, the presence of a diagnostic label does not provide any specific information concerning the implications of that diagnosis to overall functioning and participation.

Table 5.6

*Occurrence, frequency and percentages of identified ICF-CY codes in Section C, by functioning component.*

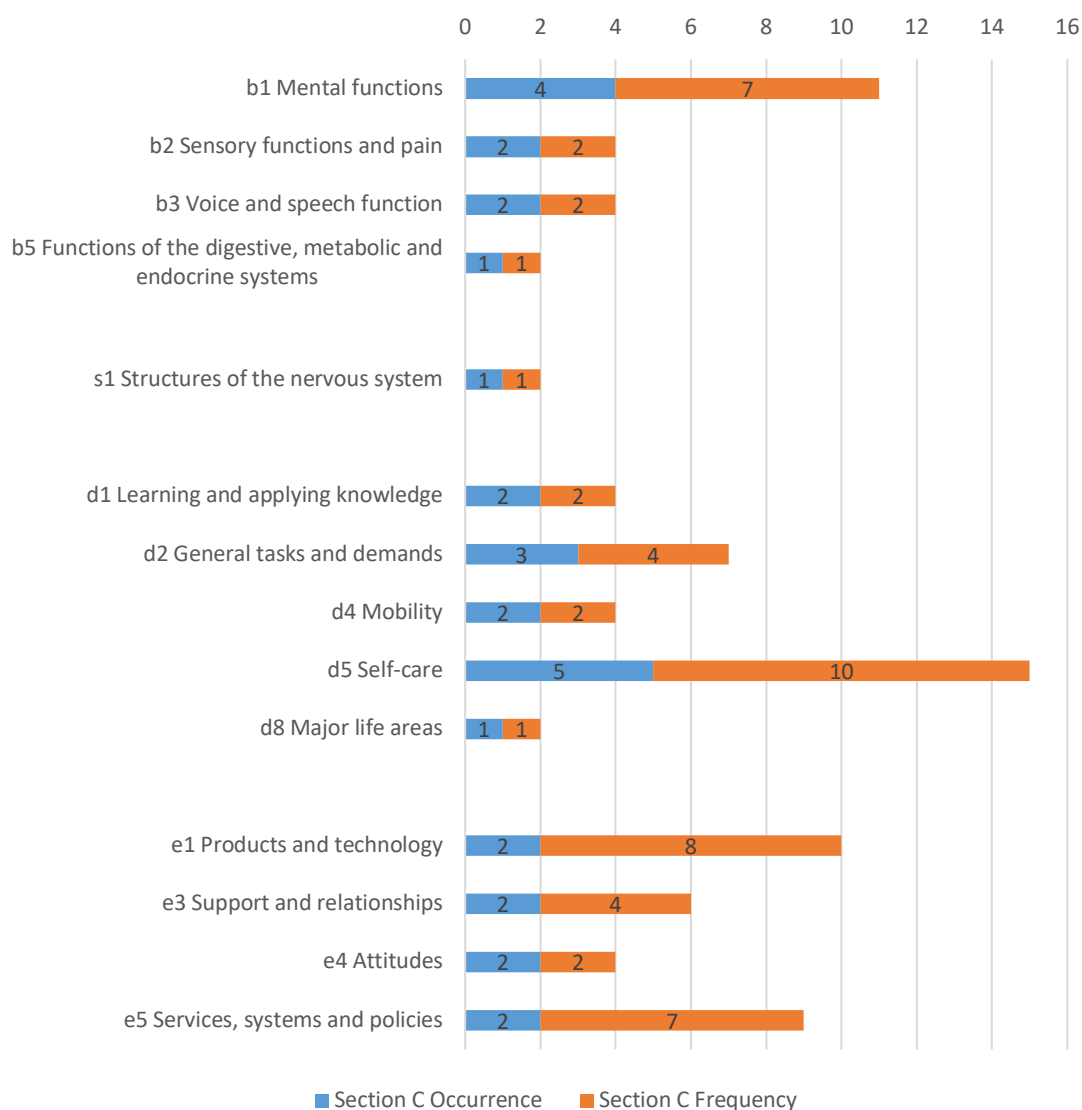
	Section C			
	Occ.	% Occ.	Freq.	% Freq.
Body Structures (s)	1	3.2	1	1.9
Body Functions (b)	9	29.0	12	22.6
Activities and Participation (d)	13	41.9	19	35.8
Environmental Factors (e)	8	25.8	21	39.6
	31	100	53	100

*Note.* Section C = health needs; Occ. = occurrence; freq. = frequency; % = percentage

Figure 5.6 illustrates that in the context of this section, five out of 13 activities and participation codes belonged to the chapter of self-care (d5), where the code for looking after one's health (d570) and subsequent codes related to managing diet and fitness (d5701), and maintaining one's health (d5702) were emphasised. These codes



were related to participants' difficulties in eating and drinking a variety of foods due to sensory needs, such as not liking the texture, smell, taste or even colour of some foods, thus presenting a restricted diet. The ICF-CY codes from the body functions component belonged to the chapters of mental functions (b1), sensory functions and pain (b2) and functions of the digestive, metabolic and endocrine systems (b5), in line with the conveyed sensory and dietary needs of participants.



*Figure 5.6* Occurrence and frequency of ICF-CY codes identified in Section C, by component chapter

The identified ICF-CY codes from the body functions component belonged to the chapters of mental functions (b1), sensory functions and pain (b2), voice and speech functions (b3), and functions of the digestive, metabolic and endocrine systems (b5), in line with the conveyed sensory and dietary needs of participants. Regarding the environmental factors component, the code most frequently elicited was that of drugs (e1101), as five plans referred to the use of medication to treat a range of needs. As an example, in two plans medication was described for the treatment of epilepsy and seizures, and in another one for digestive problems such as reflux. The roles of support from family (e310) and availability of health services (e5800) were also reported in this section.

#### *5.2.5.3 Functioning dimensions identified as social care needs.*

Only seven plans out of 23 included details in this section; thus, the information about ICF-CY codes identified in this section (Table 5.7) only reflect the analysis of seven plans. It should be noted that the content of this section is referenced to the provision of welfare services as required by Section 2 of the Chronically Sick and Disabled Persons Act 1970. Since the new legislation on SEND focuses on promoting participation of children and young people with SEND, it is noteworthy that only seven plans referred to it. A potential reason for this could be due to the 'boundaries' set by the Code of Practice in requiring that the listing of needs in the context of the Chronically Sick and Disabled Persons Act 1970 should be incorporated in EHC plans on the basis of their value for training or educating the child.

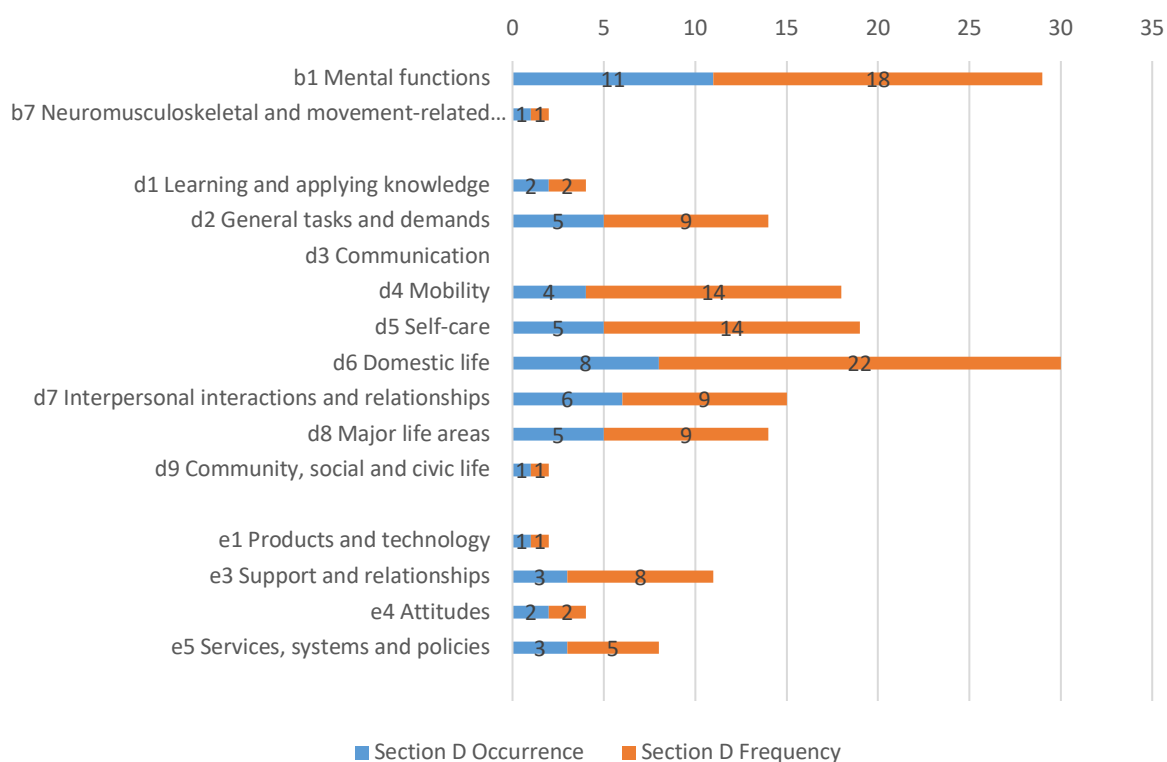
Table 5.7

*Occurrence and frequency of identified ICF-CY codes in Section D.*

	Section D			
	Occ.	% occ.	Freq.	% Freq.
Body Structures (s)	0	0.0	0	0
Body Functions (b)	12	21.1	19	16.5
Activities and Participation (d)	36	63.2	80	69.6
Environmental Factors (e)	9	15.8	16	13.9
Total	57	100.0	115	100

*Note.* Section D = Social care needs; Occ. = occurrence; freq. = frequency; % = percentage

Concerning the ICF-CY categories for this section, activities and participation codes were the most frequently identified, especially those belonging to the chapters of self-care (d5) and domestic life (d6). Washing oneself (d510), caring for body parts (d520) and dressing (d540) were the codes that reflected the young people's social care needs, together with acquisition of goods and services (d610), preparing meals (d630) and doing housework (d640). These plans highlighted the role of support (e3 codes) to address these needs, as they expressed young people's need for assistance or reminders in taking care of themselves, both physically and in relation to house care, in a progressively more independent manner. As for the body functions component, four out of five codes were linked to the chapter of mental functions, in particular to temperament and personality functions concerning extraversion and confidence (b1260 and b1266, respectively), emotional functions (b152) and perceptual functions (b156), as shown in Figure 5.7.



*Figure 5.7 Occurrence and frequency of ICF-CY codes identified in Section D, by component chapter*

### **5.2.6 Functioning dimensions identified as outcomes sought for young people with ASD**

Section E of EHC plans was dedicated to the outcomes sought for the young people with a focus on education and training, health and care that will enable them to make progress in their learning and to prepare well for adulthood. In the context of the Code of Practice, an outcome is defined as the difference or benefit made to an individual resulting from an intervention, and they should enable young people to move towards achieving their long-term aspirations in terms of independent living, community participation, higher education or employment, as specified in Section A of the plans (DfE & DoH, 2015). Therefore, it could be said that the content of this section is oriented to the views and aspirations of young people, as well as their needs.

In terms of ICF-CY functioning codes, a total of 124 codes emerged from the analysis of section E, dedicated to outcomes sought for the young people. As seen in Table 5.8, the component that stands out in this section is activities and participation with 73.4% of the codes, appearing in substantially higher proportion than the codes of the components of body functions and environmental factors.

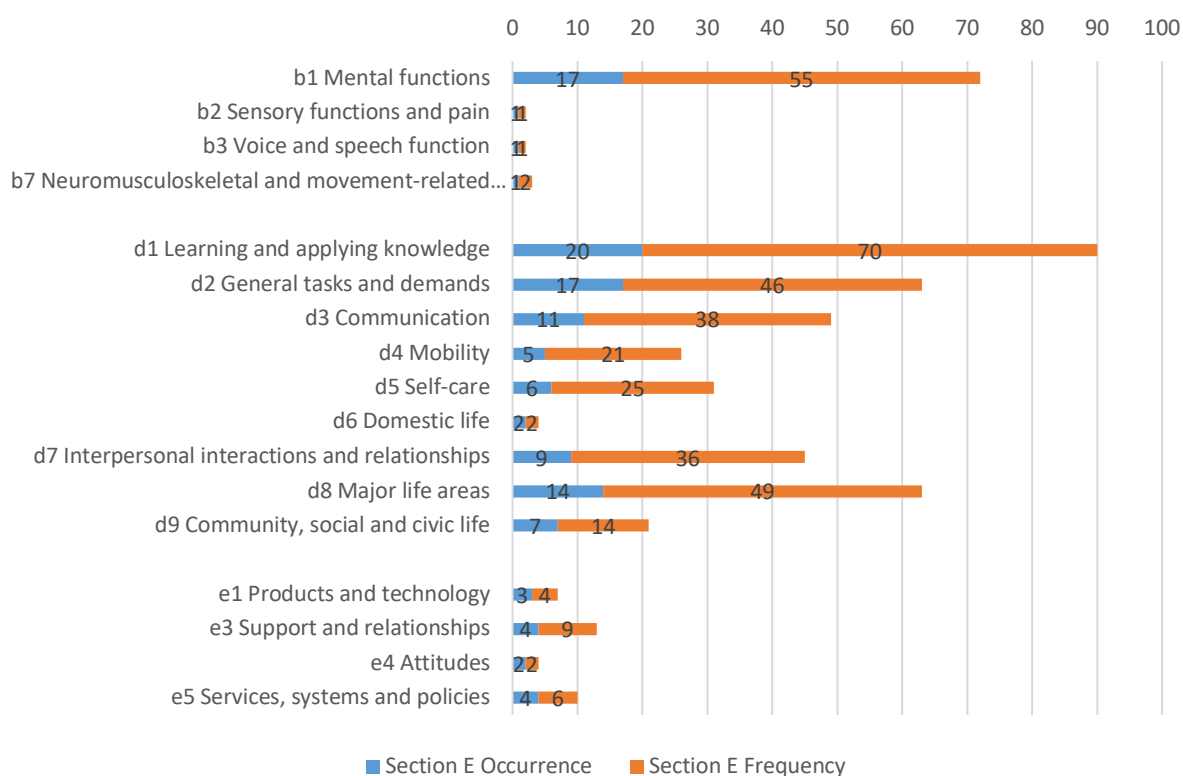
Table 5.8

*Occurrence and frequency of identified ICF-CY codes in Section E.*

	Section E			
	Occ.	% occ.	Freq.	% Freq.
Body Structures (s)	0	0	0	0
Body Functions (b)	20	16.1	59	15.5
Activities and Participation (d)	91	73.4	301	79.0
Environmental Factors (e)	13	10.5	21	5.5
Total	124	100.0	381	100.0

*Note.* Section E = Outcomes; Occ. = occurrence; freq. = frequency; % = percentage

As illustrated in Figure 5.8, over one fourth of the identified codes belong to the chapter of learning and applying knowledge (d1), in which the codes for reading (d166), writing (d170) and calculating (d172) result the most predominant within the component of activities and participation. The code that refers to managing one's behaviour (d250) was another significant code that emerged in the outcomes and has been related to the appropriateness and adjustment of behaviour to the demands of context, accepting novelty and change. With regards to communication (d3) and interaction and relationships (d7) codes, these once more appeared frequently in the section of outcomes, as they related directly to the main areas of difficulty experienced by individuals with ASD.



*Figure 5.8 Occurrence and frequency of ICF-CY codes identified in Section E, by component chapter*

In these chapters, the codes that emerged most frequently were those entailing speaking (d330) and conversation (d350 and subsequent codes), and both basic (d710) and complex interpersonal interactions (d720), as shown in figure 5.8. Emphasis has been placed in codes of major life areas (d8), particularly those concerning making progress in a school programme (d8202), employment (d859) and basic economic transactions (d860). Regarding the component of body functions, only a small number of codes were identified, and reported in very low frequencies across EHC plans, where six out of eight codes corresponded to the chapter of mental functions. As for the component of environmental factors, this component yielded seven codes, and three were linked to meaning units that were too broad to assign to a more specific code, and thus refer only to the main chapter to which they belong,

namely support, attitudes, and services, systems and policies (e3, e4 and e5, respectively).

### **5.2.7 Extent of the match between outcomes and aspirations**

In order to explore whether the outcomes set in the plans reflected the aspirations defined by young people and their families in Section A, the ICF-CY codes identified in both sections were quantified and their overlap was computed to see the extent of their match. Table 5.9 presents the occurrence of codes identified in section A, section E, and both, whilst Figure 5.9 provides details of the component chapters where the overlap of codes occurred. From the Table 5.9 it could be seen a total of 93 overlapping ICF-CY codes, meaning that these were found both in the section of aspirations (Section A) and outcomes (Section E). It is worth noting that this overlap of codes is particularly significant for the component of activities and participation, which concentrates the vast majority of identified codes in both sections.

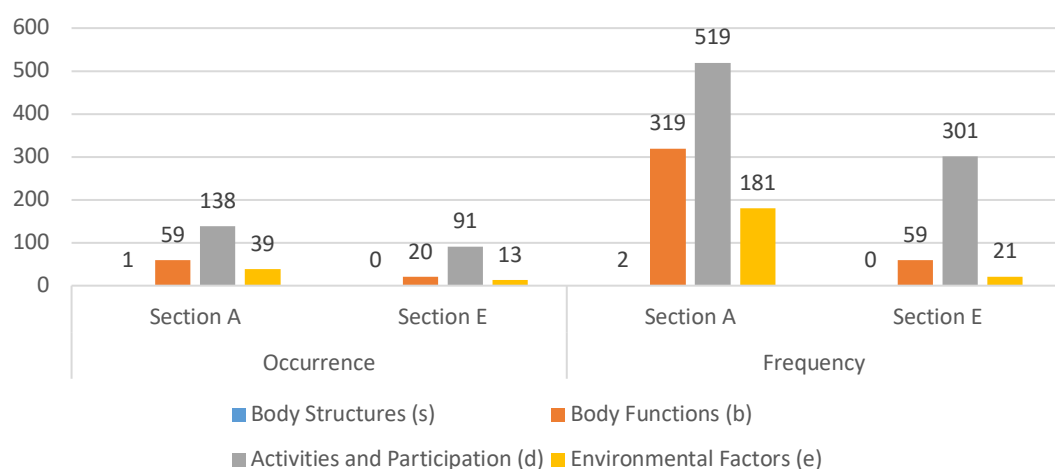
Table 5.9

*Occurrence of identified ICF-CY codes in Sections A and E and overlapping codes.*

	Occurrence			Overlap	
	Section A	Section E	Total combined	Occ.	%
<i>Body Structures (s)</i>	1	0	1	0	0
<i>Body Functions (b)</i>	59	20	64	15	23.4
<i>Activities and Participation (d)</i>	138	91	157	71	45.2
<i>Environmental Factors (e)</i>	39	13	43	9	20.9
<b>Total</b>	<b>237</b>	<b>124</b>	<b>265</b>	<b>93</b>	<b>35.1</b>

*Note.* Section A = views, wishes and aspirations; Section E = outcomes; Occ. = occurrence; % = percentage

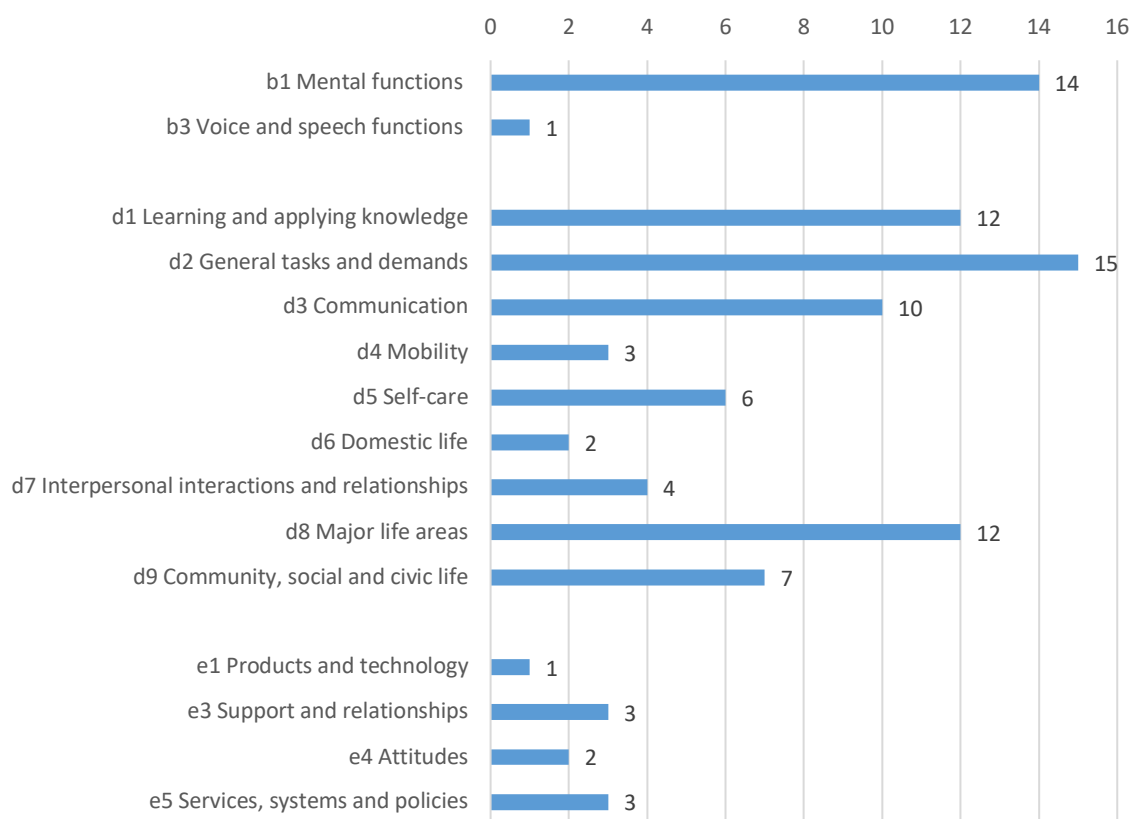
The chapter of learning and applying knowledge (d1) was the one that drew the greatest overlap within this component, and where the codes for reading (d166), writing (d170) and calculating (d172) stand out. In a similar manner, codes pertaining to the chapter of communication (d3) are among those overlapping across section A and E, suggesting the aspiration and goal to overcome communication difficulties that characterise individuals with ASD. The chapters of general tasks and demands (d2) and major life areas (d8) are among those whose codes most frequently appeared in both sections. Undertaking a single task (d210), carrying out daily routine (d230) and particularly the management of changes in routine (d2304), handling stress (d240) and managing one's behaviour (d250) were codes that appeared consistently in sections concerning views and aspirations, special educational needs, and outcomes. With regards to the major life areas chapter (d8), the outcomes section has predominantly matched section A's codes related to making progress in educational programmes (d8202), employment (d845-d859), and basic economic transactions (d860). These codes stress the expectation for young people to advance in their school education, finding some kind of employment (full or part time, voluntary, apprenticeship) and learning how to use money in everyday life.



*Figure 5.9* Occurrence and frequency of ICF-CY Codes identified in Sections A (views, wishes and aspirations) and E (outcomes), by functioning component



As for the components of body functions, a total of 15 codes were found to match the content of both section A and section E. As shown in Figure 5.10, the chapter of mental functions in this component was the one that yielded most overlapping ICF-CY codes. Aspirations and outcomes coded within this chapter were mapped to codes describing orientation to time (b1140), psychomotor control (b1470), perceptual functions (b156), and organisation and planning (b1641). In the environmental factors component, codes referring to support and relationships (e3) and attitudes (e4) were among those that matched both the content of section A and E, followed by the code of assistive products and technology for education (e1301).



*Figure 5.10* Occurrence of overlapping Section A and E ICF-CY codes, by component chapter

### 5.3 Summary

This chapter provided a comprehensive account on the nature and dimension of the content presented in a range of sections of 23 EHC plans belonging to a group of young people with ASD in transition to post-secondary destinations. The analysis of the sections of the EHC plans showed that the views (Section A), the education (Section B), health (Section C), and social care (Section D) needs, and outcomes (Section E) sought for young people with ASD go beyond the boundaries of diagnostic characteristics, and across services.

In ICF-CY terms, this translated mostly into a predominance of activities and participation codes identified to describe the views, needs and outcomes sought for young people, highlighting the participatory focus of these descriptions. Of particular significance throughout sections were codes related to learning and applying knowledge, decision-making, mobility, self-care, domestic life, and major life areas.

Indeed, while different sections of EHC plans are designed to address what appears to be succinct information concerned with a particular domain or provider (for example, related to special educational needs, or health needs), the overall picture of the mapping of EHC plans to the taxonomy of the ICF-CY coding system seemed to suggest that these descriptions could not be easily located in one domain – i.e. education – and appeared across sections of these documents, raising the question of the potential value of separating descriptions in these terms, as the functioning language of the ICF-CY has shown.

Another significant finding from this analysis was that of the role of environmental factors across sections. In Section A of EHC plans (concerning the views, wishes and aspirations of young people) a larger proportion of these codes was found when compared to the needs (Section B, C, and D) and outcomes (Section E) sections. This result highlights that the views of young people incorporated more frequently aspects of the environment as contributors to their day-to-day functioning; as such, it

would have been expected to find these environmental characterisations in sections concerning their needs and outcomes, as they were recognised as relevant and a significant part of the individual's functioning. The relatively small number of occurrences of environmental factors codes in these sections suggests that, under the headings of EHC plans, needs are still conceptualised and understood to be located within the individual, and so are the outcomes sought for young people. This seems to represent a contradiction to the principle of producing holistic portrayals of children and young people with SEND under the new Code of Practice, as the environment plays a significant role for participation, and for these documents to be truly holistic.

## **6. Results: Matching the views of young people with ASD from semi-structured interviews and Section A of EHC plans.**

### **6.1 Introduction**

The aim of the present chapter is to expand the analysis of the views of young people with ASD by exploring the extent to which the views obtained from semi-structured interviews, as described in Chapter 4, matched those appearing in Section A of the EHC plans of young people with ASD, as described in Chapter 5. One of the main aims of this thesis was to gain an in-depth understanding of the lived experiences of young people at time of transition in the context of the new SEND policy and Code of Practice. The research question that guided this line of enquiry was:

- a. To what extent do the ICF-CY functioning dimensions identified as the young person's views in Section A of the EHC plans match those identified by the young people themselves through semi-structured interviews?

The interview schedule (Appendix A) that guided the interviews conducted with young people was built using the content of Section A as a guide; this content was described in chapter 2 of this thesis and it can be found in Chapter 9 of the SEND Code of Practice (DfE & DoH, 2015). As both interviews and EHC plans were analysed deductively using the ICF-CY taxonomy, the codes found in both sources of data served as a common language to explore the extent to which these sections overlapped in the functioning dimensions that described the views, wishes and aspirations of young people with ASD. Given that not all participants had a finalised version of their EHC plan at the time of analysis, and that one participant (YP 27) did not take part in the interview, the results reported in this chapter correspond to the

analyses of 22 interviews and EHC plans. For consistency purposes, it was crucial to include in the analyses those participants who had been interviewed and had a finalised EHC plan in place.

## **6.2 Findings**

Deductive content analysis was performed to 22 interview transcripts and Section A of 22 EHC plans to explore the extent of the match between views of the young people as reported through semi-structured interviews, and in their respective EHC plans. As reported in Chapter 3, although a total of 29 participants were recruited for the study, and 23 EHC plans were collected; in addition, one participant did not take part in the interview. Given that there is no interview data available for this participant, their respective EHC plan was excluded from the analysis. This strand of study included those participants who were interviewed and had an EHC plan in place (N = 22).

The interview transcripts and EHC plans were analysed using the ICF-CY system as pre-defined codes to match their content and translate it into the categories of the ICF-CY (i.e. body functions, body structures, activities and participation, and environmental factors), following linking rules and procedures established in other studies . (Augustine et al., 2018; Ballert et al., 2016; Castro, Pinto & Maia, 2011; Cieza et al., 2016). Extracts of EHC plans with examples of ICF-CY coding of their content can be found in Appendix D. Table 6.1 presents extracts from the interview transcripts and the EHC plans together with their respective ICF-CY codes to exemplify the coding process of both sources of data. More examples of the coding process can be found in Appendices F and G. To protect participant's identity, each young person (YP) and EHC plan have been assigned a number.

Table 6.1.

*Extracts of coded interview transcripts and Section A of EHC plans, by component of the ICF-CY.*

ICF-CY* component	Interview	EHC Plan**
<i>Body Functions</i> <i>b1 – Mental functions</i>	[On using public transport, YP feels] 'confident' (YP 06, code b1266)	'He is an extremely polite and charming young man' (YP 06, code b126)
<i>Activities and Participation</i> <i>d2 – General tasks and demands</i>	'I know it will be the start of college, I will be a bit nervous because I don't know what the timetable is like there' (YP 01, code d230)	'He follows the front board schedule which is used for the whole class. He likes the security of knowing what is happening, it gives him control of what will be happening during the day' (YP 14, code d230)
<i>d4 - Mobility</i>	'So in the mornings, we walk to school. My mum... we walk together and then just [...] she stops kind of in the middle, there's a hill and then I walk from there' (YP 01, code d4602)	He is not ready to travel independently, although he will now walk down the road after school where his mum will be waiting for him in the car. (YP 01, code d4602, d4702)
<i>Environmental factors</i> <i>e3 – Support and relationships</i>	'...and when I get upset, my friend [name] cheers me up sometimes' (YP 10, code e320)	'He will often look to his peers for support, especially when getting a bus, or walking somewhere, and the students are required to lead' (YP 15, code e325)
<i>e4 - Attitudes</i>	'My travel trainer was not particularly interested in shortcuts or how I was going, he didn't like the idea of using shortcuts' (YP 16, code 455)	'It is important for [YP 8] that those around him understand the impact that his ASD and tics have on him, and respond to these appropriately' (YP 8, code e445)

ICF-CY* component	Interview	EHC Plan**
<i>Not definable</i>		'The school is working to develop his independence skills' (YP 15, ND)

From the Table 6.2, it can be observed that a total of 273 ICF-CY codes were linked to the content of both interview transcripts and Section A of EHC plans.

Table 6.2

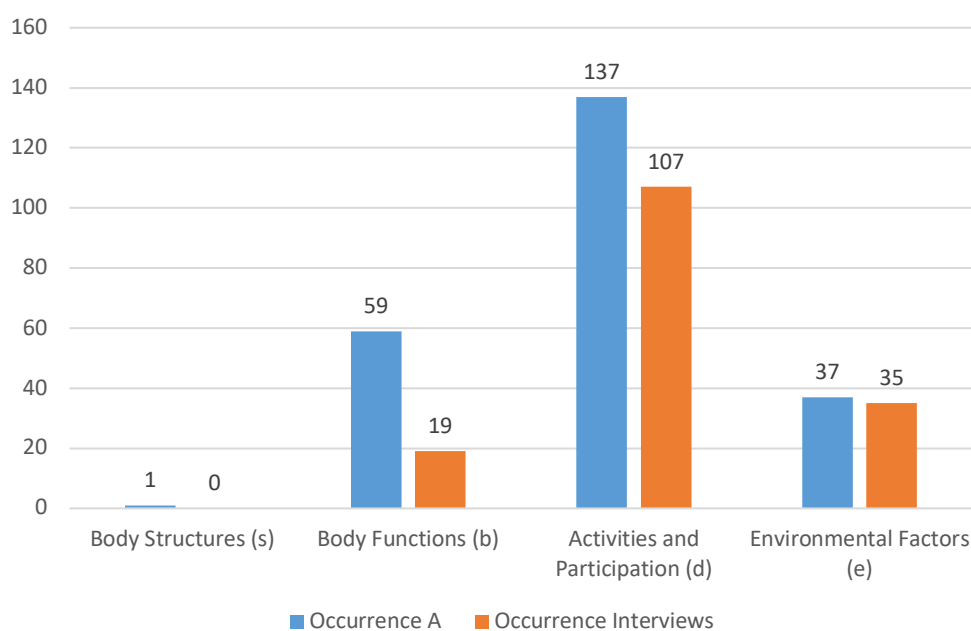
*Occurrence and frequency of ICF-CY codes identified across interviews and Section A of EHC plans*

	Occurrence			Frequency		
	Section A	Interviews	Total	Section A	Interviews	Total
Body Structures (s)	1	0	1	2	0	2
Body Functions (b)	59	19	61	302	226	528
Activities and Participation (d)	137	107	162	496	659	1155
Environmental Factors (e)	37	35	49	167	393	560
Total	234	161	273	967	1278	2245

*Note.* Section A = views, wishes and aspirations

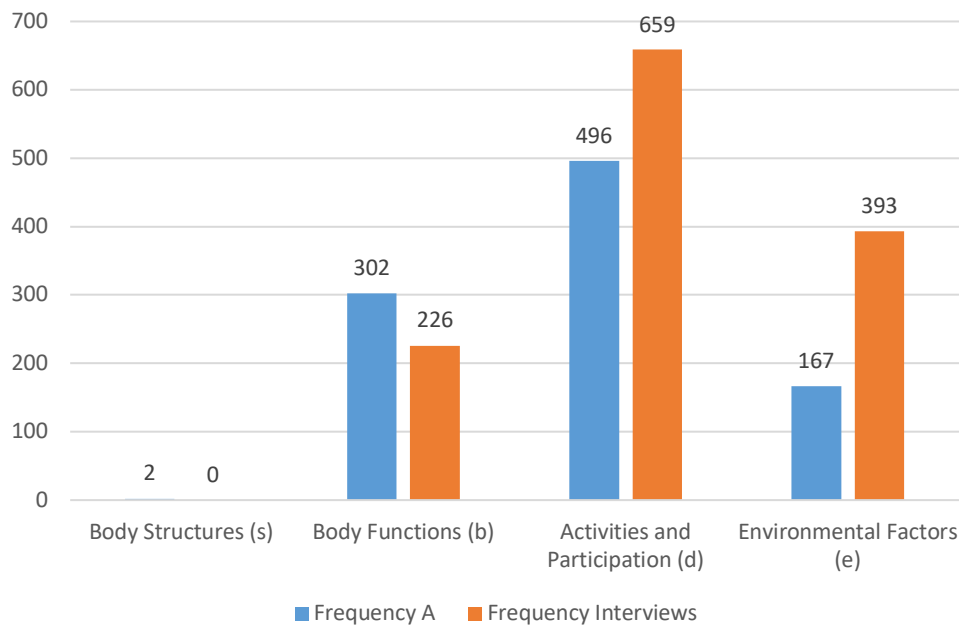
The ICF-CY's Activities and Participation component was the one that yielded the greatest proportion of identified codes (occurrence) in both interviews and EHC plans, followed by the domains of Body Functions, and Environmental Factors. Only

one ICF-CY code from the component of Body Structures was linked to the content of Section A. In terms of frequency, however, the component of Environmental Factors followed the Activities and Participation domain in interviews. As noted in Chapter 4, during the interviews participants emphasised the role of support and attitudes of others in their day to day lives. This emphasis is reflected in both occurrence and frequency of e codes when compared to those of Section A. Although in young people's transcripts there were slightly fewer e codes identified than in EHC plans (35 vs 37), the frequency of these codes more than doubles in interviews when compared to Section A. Figures 6.1 and 6.2 illustrate the distribution of ICF-CY codes per functioning component, as identified in Section A and EHC plans.



*Figure 6.1* Occurrence of ICF-CY codes in Section A (views, wishes and aspirations) and interviews, by functioning component





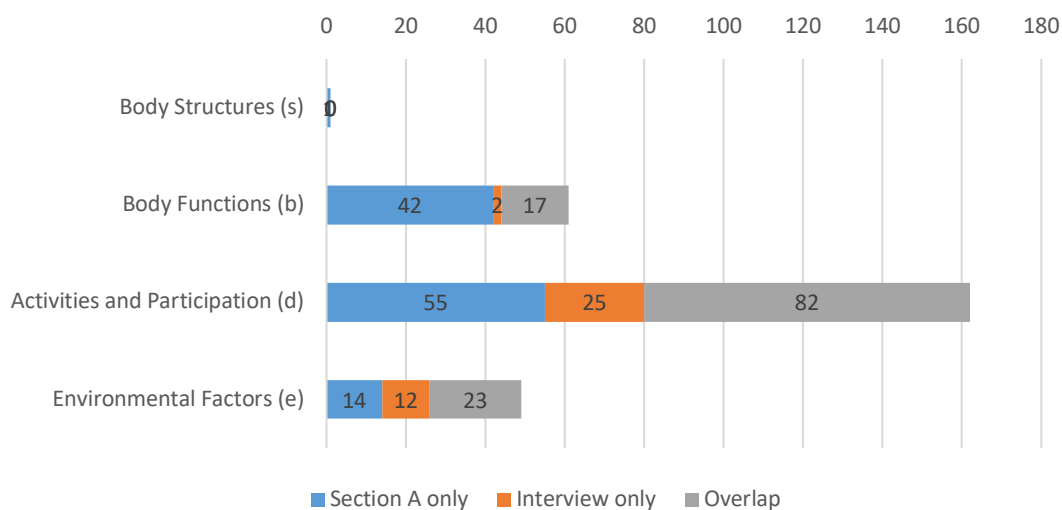
*Figure 6.2.* Frequency of ICF-CY codes in Section A (views, wishes and aspirations) and interviews, by functioning component

Table 6.3 presents an overview of the codes that were identified in interviews and EHC plans, and the occurrence of overlapping codes across both datasets, organised by ICF-CY domain. In order to establish the extent of the match between the views reported in the interviews and those conveyed in Section A of the EHC plans, the identified codes were then organised by ICF-CY component, and distributed in terms of where they occurred – interview only, EHC plan only, and those appearing in both. Overall, 122 out of 273 codes were identified as matching codes in EHC plans and interviews, which translates to an overall 44.7% overlap. Individual percentages were also calculated by ICF-CY component to obtain a more nuanced picture with regards to the proportion of matching codes found within the domains. This table (6.3) is followed by Figure 6.3, enhancing the visualisation of the overlap of ICF-CY codes across Section A and interviews.

Table 6.3

*Occurrence of ICF-CY codes identified in Section A and interviews, and proportion of overlapping codes.*

	Section A only	Interview only	Overlap	Overlap %
Body Structures (s)	1	0	0	0
Body Functions (b)	42	2	17	27.9
Activities and Participation (d)	55	25	82	50.6
Environmental Factors (e)	14	12	23	47.9
Total	112	39	122	



*Figure 6.3 Overview of Section A and Interview ICF-CY code distribution and overlap*

Table 6.4 presents a thorough depiction of the frequency of the total 273 codes that emerged from semi-structured interviews and EHC plans using the ICF-CY classification system. This table (6.4) expands on the data presented in Tables 6.2

and 6.3, allowing a comprehensive scrutiny of extracted codes, organised by ICF-CY component and by source of data – that is, interviews and EHC plans. It also provides the frequency of each ICF-CY code identified by source of data, and their total frequency. The presentation of data in these three tables provides a general-to-specific approach in the exploration and analysis of the data.

Table 6.4

*ICF-CY codes and frequencies, as identified in Section A of EHC plans and interviews*

Code	Code description	Section A	Interview	Total
<i>Body structures (s)</i>				
s110		2		2
1 code		2	0	2
<i>Body functions (b)</i>				
b114	Orientation functions	1		1
b1140	Orientation to time	1		1
b1141	Orientation to place	1		1
b11420	Orientation to self	1		1
b117	Intellectual functions	4		4
b122	Global psychosocial functions	1		1
b125	Dispositions and intra-personal functions	12	13	25
b1250	Adaptability	8		8
b1251	Responsivity	1		1
b1252	Activity level		1	1
b1253	Predictability	5		5
b1255	Approachability	4		4
b126	Temperament and personality functions	24	17	41
b1260	Extraversion	6	3	9

Code	Code description	Section A	Interview	Total
b1261	Agreeableness	15		15
b1262	Conscientiousness	8		8
b1263	Psychic stability	1	7	8
b1264	Openness to experience	2	1	3
b1265	Optimism	4	1	5
b1266	Confidence	8	7	15
b1267	Trustworthiness	1		1
b130	Energy and drive functions		2	2
b1300	Energy level	1	2	3
b1301	Motivation	86	72	158
b1302	Appetite	1	1	2
b1303	Craving	1		1
b134	Sleep functions	2	6	8
b140	Attention functions	2	6	8
b1400	Sustaining attention	1		1
b144	Memory functions	4		4
b1440	Short-term memory	1		1
b147	Psychomotor functions	4		4
b1470	Psychomotor control	1		1
b152	Emotional functions	33	70	103
b1521	Appropriateness of emotion	2		2
b156	Perceptual functions	1		1
b160	Thought functions	8	1	9
b1603	Control of thought	1		1
b164	High-level cognitive functions	3		3
b1641	Organisation and planning	3	5	8
b1642	Time management	1	1	2
b1643	Cognitive flexibility	5		5
b1644	Insight	4		4
b1646	Problem-solving	2	10	12
b167	Mental functions of language	5		5

Code	Code description	Section A	Interview	Total
b1670	Reception of spoken language	1		1
b1671	Reception of written language	4		4
b230	Hearing functions	1		1
b265	Touch function	1		1
b3	Voice and speech functions	2		2
b330	Fluency and rhythm of speech functions	2		2
b3302	Speed of speech	1		1
b5	Functions of the digestive, metabolic and endocrine systems	1		1
b510	Ingestion functions	1		1
b530	Weight maintenance functions	1		1
b7	Neuromusculoskeletal and movement-related functions	1		1
b710	Mobility of joint functions	1		1
b760	Control of voluntary movement functions	1		1
b765	Involuntary movement functions	1		1
b7652	Tics and mannerisms	1		1
b7653	Stereotypies and motor perseveration	2		2
<i>61 codes</i>		302	226	528

*Activities and Participation (d)*

d1	Learning and applying knowledge		4	4
d110	Watching	6	3	9
d115	Listening	6	5	11
d132	Acquiring information	3		3
d133	Acquiring language	1		1
d134	Acquiring additional language	1		1
d135	Rehearsing		3	3
d137	Acquiring concepts	2	2	4
d140	Learning to read	1		1
d150	Learning to calculate	1		1
d155	Acquiring skills	3	8	11

Code	Code description	Section A	Interview	Total
d1551	Acquiring complex skills	1	2	3
d160	Focusing attention	3		3
d161	Directing attention	2		2
d163	Thinking	2		2
d166	Reading	6	4	10
d170	Writing	4	6	10
d1701	Using grammatical and mechanical conventions in written compositions	1		1
d1702	Using general skills and strategies to complete compositions	1		1
d172	Calculating	4	16	20
d175	Solving problems		13	13
d177	Making decisions	6	48	54
d210	Undertaking a single task	4		4
d2100	Undertaking a simple task	1		1
d2102	Undertaking a simple task independently	2		2
d220	Undertaking multiple tasks	2	1	3
d2202	Undertaking multiple tasks independently	2	1	3
d2203	Undertaking multiple tasks in a group	1		1
d2204	Completing multiple tasks independently	1		1
d230	Carrying out daily routine	14	22	36
d2300	Following routines	1		1
d2301	Managing daily routine	1		1
d2302	Completing the daily routine		2	2
d2303	Managing one's own activity level		2	2
d2304	Managing changes in daily routine	10	4	14
d2305	Managing one's time	1	2	3
d240	Handling stress and other psychological demands	4	22	26
d2400	Handling responsibilities	1		1
d2401	Handling stress	1	4	5
d2402	Handling crisis	1	3	4
d250	Managing one's own behaviour	8	15	23
d2500	Accepting novelty	1		1

Code	Code description	Section A	Interview	Total
d2501	Responding to demands	1		1
d2502	Approaching persons or situations		2	2
d2504	Adapting activity level	1		1
d3	Communication	5	1	6
d310	Communicating with - receiving - spoken messages	6	6	12
d3102	Comprehending complex spoken messages	3		3
d3150	Communicating with - receiving - body gestures	2		2
d3151	Communicating with - receiving - general signs and symbols	1		1
d325	Communicating with - receiving - written messages	1		1
d330	Speaking	15	3	18
d3350	Producing body language	1		1
d345	Writing messages	2		2
d350	Conversation	7	12	19
d3500	Starting a conversation	3		3
d3501	Sustaining a conversation	1	1	2
d3509	Conversation, unspecified	1		1
d355	Discussion	1	4	5
d360	Using communicating devices and techniques	4	1	5
d4	Mobility	1	1	2
d430	Lifting and carrying objects		1	1
d4503	Walking around obstacles		2	2
d4554	Swimming	2		2
d460	Moving around in different locations	9	26	35
d4601	Moving around within buildings other than home	4	2	6
d4602	Moving around outside the home and other buildings	4	10	14
d470	Using transportation	14	18	32
d4701	Using private motorised transportation	1	10	11
d4702	Using public motorised transportation	4	14	18
d475	Driving	1	1	2
d4750	Driving human-powered transportation	2		2

Code	Code description	Section A	Interview	Total
d4751	Driving motorised vehicles	3		3
d5	Self-care	3	3	6
d510	Washing oneself	2		2
d520	Caring for body parts	1		1
d5201	Caring for teeth	2		2
d530	Toileting	1		1
d5404	Choosing appropriate clothing	1		1
d550	Eating	3	1	4
d5500	Indicating need for eating	1		1
d5501	Carrying out eating appropriately	2		2
d570	Looking after one's health	5	1	6
d5701	Managing diet	3	3	6
d5702	Maintaining one's health	1		1
d57020	Managing medications and following health advice	1		1
d57021	Seeking advice or assistance from caregivers or professionals	1	2	3
d571	Looking after one's safety	4	2	6
d6	Domestic life		1	1
d610	Acquiring a place to live	4	3	7
d620	Acquisition of goods and services	1	6	7
d6200	Shopping	6	4	10
d630	Preparing meals	10	12	22
d6300	Preparing simple meals	1		1
d6302	Helping prepare meals	1		1
d640	Doing housework	4	3	7
d6406	Helping to do housework		4	4
d650	Caring for household objects		1	1
d6503	Maintaining vehicles	1		1
d6505	Taking care of plants, indoors and outdoors	2	1	3
d6506	Taking care of animals	2	4	6
d660	Assisting others	8	4	12
d710	Basic interpersonal interactions and relationships	7	3	10



Code	Code description	Section A	Interview	Total
d7100	Respect and warmth in relationships		1	1
d7101	Appreciation in relationships		1	1
d7102	Tolerance in relationships		1	1
d7103	Criticism in relationships	1		1
d7106	Differentiation of familiar persons	4		4
d720	Complex interpersonal interactions	9	15	24
d7200	Forming relationships	6	3	9
d7201	Terminating relationships		1	1
d7202	Regulating behaviours within interactions		2	2
d730	Relating with strangers	5	1	6
d750	Informal social relationships	5	4	9
d7500	Informal relationships with friends	4	5	9
d7502	Informal relationships with acquaintances		1	1
d7504	Informal relationships with peers	2	1	3
d760	Family relationships	4	1	5
d7601	Child-parent relationships	1	3	4
d7602	Sibling relationships	3	7	10
d770	Intimate relationships	4	2	6
d8	Major life areas	1	1	2
d8150	Moving into preschool education programme or across levels	1		1
d820	School education	3	13	16
d8200	Moving into educational programme or across levels		1	1
d8201	Maintaining educational programme	1	4	5
d8202	Progressing in educational programme	21	15	36
d8203	Terminating educational programme or school levels	2	11	13
d825	Vocational training	7	16	23
d8250	Moving into vocational training programme or across levels		2	2
d8251	Maintaining vocational training programme		1	1
d8252	Progressing in vocational training programme		1	1
d830	Higher education	5	7	12

Code	Code description	Section A	Interview	Total
d8300	Moving into higher education or across levels	3	6	9
d8302	Progressing in higher education programme		1	1
d835	School life and related activities	1	6	7
d840	Apprenticeship (work preparation)	6	6	12
d845	Acquiring, keeping and terminating a job	18	24	42
d850	Remunerative employment	2		2
d8501	Part-time employment	1		1
d855	Non-remunerative employment	1		1
d859	Work and employment, other specified and unspecified	1		1
d860	Basic economic transactions	4	2	6
d870	Economic self-sufficiency	3	1	4
d8700	Personal economic resources		1	1
d880	Engagement in play	2	8	10
d8800	Solitary play	6	2	8
d8801	Onlooker play	1		1
d8803	Shared cooperative play		1	1
d9	Community, social and civic life	1		1
d910	Community life	5	1	6
d9100	Informal associations	6	5	11
d9103	Informal community life	1	1	2
d920	Recreation and leisure	8	11	19
d9200	Play	1	4	5
d9201	Sports	17	24	41
d9202	Arts and culture	19	34	53
d9203	Crafts	2	2	4
d9204	Hobbies	1		1
d9205	Socialising	8	32	40
d9209	Recreation and leisure, unspecified		1	1
d930	Religion and spirituality	1		1
<i>162 codes</i>		<i>496</i>	<i>659</i>	<i>1155</i>

Code	Code description	Section A	Interview	Total
<i>Environmental factors (e)</i>				
e110	Products or substances for personal consumption	2		2
e1100	Food	1		1
e1101	Drugs	1	1	2
e115	Products and technology for personal use in daily living	1		1
e1152	Products and technology used for play	3	4	7
e120	Products and technology for personal indoor and outdoor mobility and transportation	1		1
e125	Products and technology for communication	2	3	5
e130	Products and technology for education	2	2	4
e1300	General products and technology for education	2	5	7
e140	Products and technology for culture, recreation and sport	2	6	8
e150	Design, construction and building products and technology of buildings for public use	1	3	4
e155	Design, construction and building products and technology of buildings for private use		1	1
e220	Flora and fauna		1	1
e250	Sound	3		3
e3	Support and relationships	14	23	37
e310	Immediate family	39	92	131
e315	Extended family	3		3
e320	Friends	22	42	64
e325	Acquaintances, peers, colleagues, neighbours and community members	4	12	16
e330	People in positions of authority		50	50
e340	Personal care providers and personal assistants	7	2	9
e345	Strangers	1		1
e350	Domesticated animals	3	9	12
e355	Health professionals	4	2	6
e360	Other professionals	5	19	24
e4	Attitudes	1	2	3
e410	Individual attitudes of immediate family members	3	21	24

Code	Code description	Section A	Interview	Total
e420	Individual attitudes of friends	1	10	11
e425	Individual attitudes of acquaintances, peers, colleagues, neighbours and community members	3	18	21
e430	Individual attitudes of people in positions of authority	1	6	7
e445	Individual attitudes of strangers	2	6	8
e450	Individual attitudes of health professionals		4	4
e455	Individual attitudes of other professionals		5	5
e460	Societal attitudes		2	2
e5	Services, systems and policies		1	1
e535	Communication services, systems and policies	1		1
e5400	Transportation services		1	1
e5550	Associations and organisational services	2		2
e5700	Social security services	1		1
e575	General social support services, systems and policies	1		1
e5750	General social support services	1		1
e580	Health services, systems and policies	2	1	3
e5800	Health services	3		3
e585	Education and training services, systems and policies	4	5	9
e5850	Education and training services		5	5
e5851	Education and training systems		2	2
e5852	Education and training policies		1	1
e5853	Special education and training services	18	26	44
49 codes		167	393	560

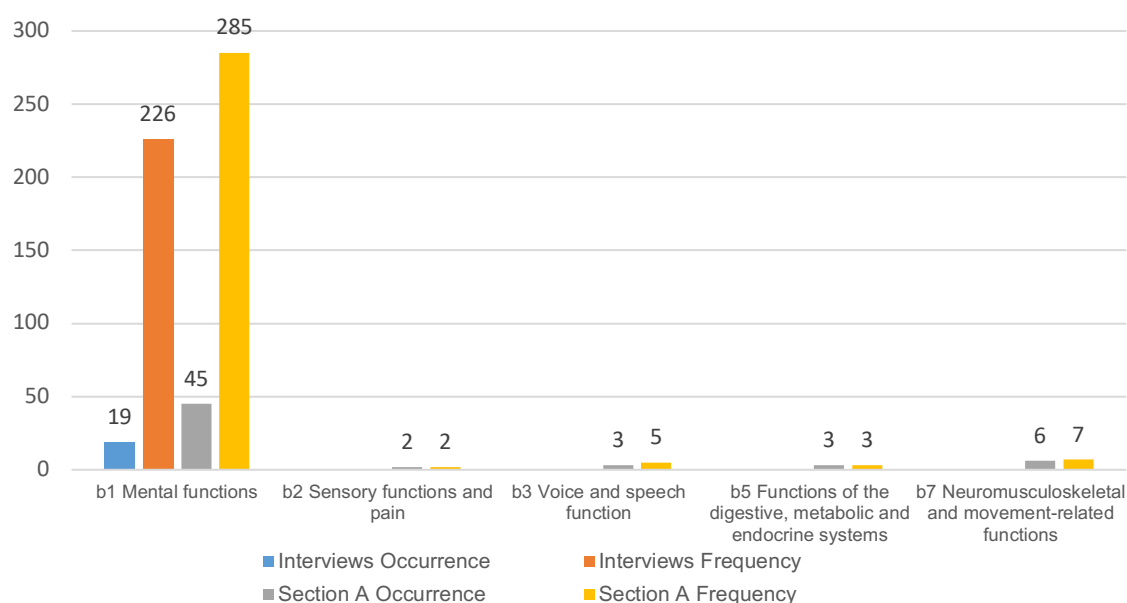
Given the vastness of identified codes and descriptions across EHC plans and interview transcripts, the following section reports on the findings stemming from the analysis conducted at ICF-CY component level. This means that the identified codes in interviews and EHC plans were grouped together under the headlines of the ICF-

CY framework, and analysed within each domain with regards to their occurrence and frequency in interviews and plans, and to the extent of the overlap of codes in each component.

### **6.2.1 Body functions**

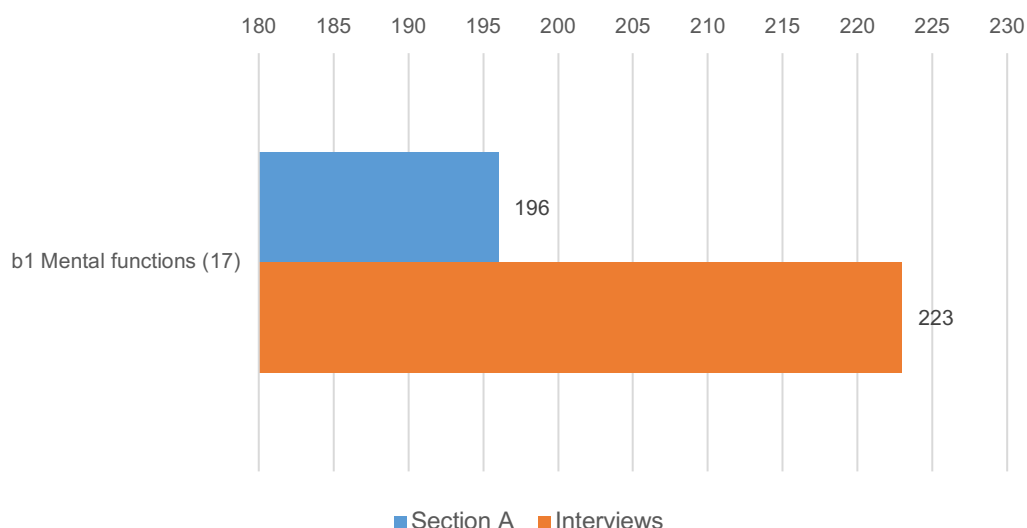
The component of body functions refers to the physiological functions of body systems, in which psychological functions are included. A total of 61 body functions codes were identified between interviews and EHC plans, conforming 22.4% of the extracted codes. The occurrence and frequency of these codes was higher in EHC plans than in interviews, as shown in Figure 6.4. The majority of codes identified in Section A corresponded to the chapter of mental functions (b1); as for the interviews, all identified codes in the component belonged also to the mental functions chapter.

Codes from this chapter were the most frequently found in both Section A and interviews. It is worth noting that of the codes describing mental functions across the 22 analysed EHC plans, those describing dispositions and intra-personal functions (b125, b1250, b1261, b1253, b1255), and those describing temperament and personality functions (b126, b1260 to b1267) were the most frequently found, occurring 100 times out of 302. This finding seems to be in line with the requirement of EHC plans to provide a general picture of the individual as outlined in the SEND Code of Practice (DfE & DoH, 2015). In this context, the observation of more *b* codes in EHC plans than in interviews was anticipated, as it was considered that young people would not refer to themselves and their views in Body Functions terms, but in Activities and Participation. This was also observed in the frequency of body functions codes found in interviews, below the frequency of codes found in EHC plans and all of them belonged to the chapter of mental functions. Concerning the match of codes between interviews and plans, a total of 17 *b* codes were found in both sources of data, all part of the chapter of mental functions, as previously described.



*Figure 6.4.* Occurrence and frequency of Body Functions codes in Section A and interviews, organised by ICF-CY component chapter.

From Figure 6.5 it can be noted that the frequency of mental functions was higher in interviews than in EHC plans. The most significant overlap of codes within this domain corresponded to motivation (b1301), commonly used to describe likes and dislikes of the young person, as well as wishes, aspirations or goals; dispositions and intra personal functions (b125 and subsequent codes); temperament and personality functions (b126 and subsequent codes); and emotional functions (b152), which are specific mental functions related to the feeling and affective component of the processes of the mind (WHO, 2007). The motivation (b1301) code emerged frequently during the interviews as participants described what they wanted to achieve in their new placement, what were their wishes for the future, the things they liked doing (or not) at school and during their free time, to name a few.

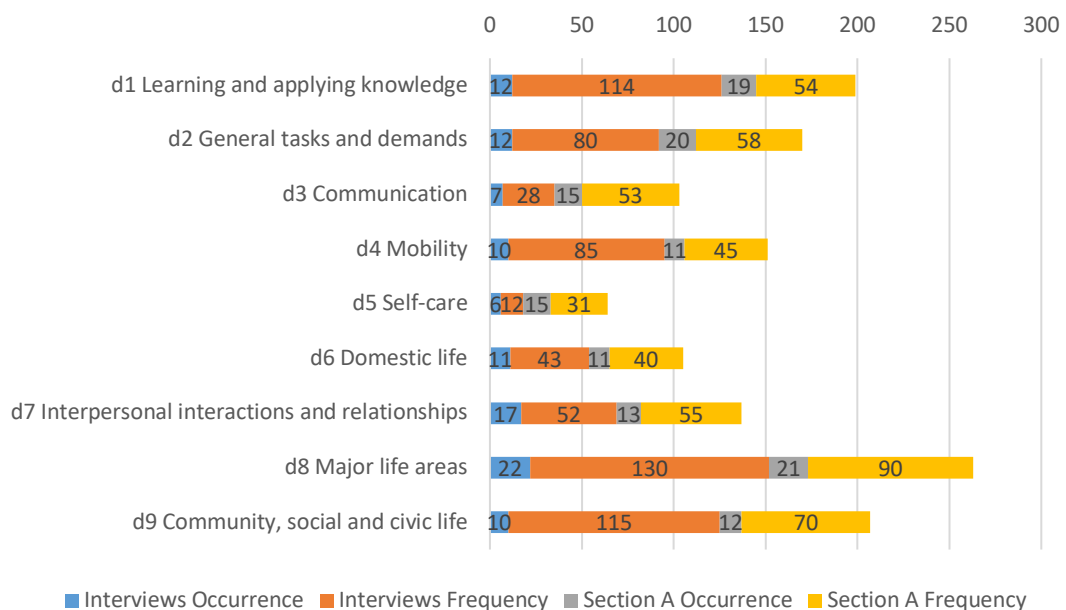


*Figure 6.5* Frequency of overlapping Body Functions codes identified in Section A and interviews

The emergence of emotional functions (b152) code resulted from the expression of young people's different feelings and emotions about topics like finishing secondary school, making decisions about their future, and independence. In this respect, the interviews revealed that at time of transition, young people with ASD experience somewhat contradictory feelings about their future. The reported ambivalence responded to experiences of anxiety with regards to their post-16 prospects, the characteristics, demands and support available in these settings, while at the same time feeling excited about future experiences and the potential for more autonomy and independence. This was also reflected in their descriptions in terms of personality and intra-personal functions, as described by codes b125 and b126. In particular, young people reported their wishes to become increasingly independent, especially regarding mobility, the use of public transport, self-care and domestic life. Content of these characteristics was also found across EHC plans and in similar proportion, as it was expected from the guidelines set by the SEND Code of Practice. These are explored in the section concerning the Activities and Participation component.

### 6.2.2 Activities and Participation

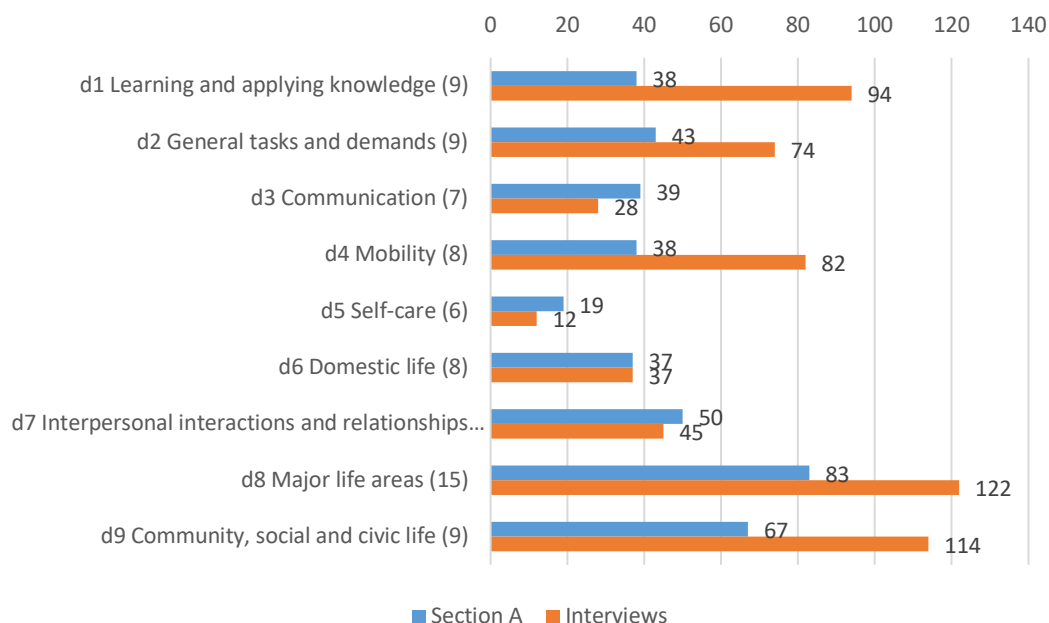
This component explores the execution of a task or action by an individual (activity), and the involvement of the individual in a life situation (participation). The identified codes belonging to this domain represent 59.6% of the total number of codes mapped to the interviews and EHC plans. This means that the narrative of the interviews and Section A of the documents predominantly translated into meaning units that referred to the young people's engagement in life situations and the execution of tasks, representing 162 codes of a total of 272. Given the significant representation of this component, this section provides an overview of the most relevant findings to highlight from each domain chapter. Figure 6.6 presents a visual summary of the occurrence and frequency of Activities and Participation codes found across Section A and EHC plans.



*Figure 6.6.* Occurrence and frequency of Activities and Participation codes identified in Section A and interviews, by component chapter.



From this figure (6.6) it can be observed that the chapter of major life areas (d8) is the one that yielded the largest number of codes, and the highest frequencies in both EHC plans and interviews. This chapter saw a 15-code overlap, as it can be observed from Figure 6.7. Amongst these overlapping codes, the most significant were those referring to school education (d820, d8202, and d8203), vocational training (d825), higher education (d830), apprenticeship (d840), and acquiring, keeping and terminating a job (d845). These codes were expected to emerge in both EHC plans and interviews, as they have an important role in the context of transition to post-16 education and employment for young people with ASD.



*Figure 6.7* Frequency of overlapping Activities and Participation codes identified in Section A and interviews

This chapter was followed by the chapter of learning and applying knowledge (d1), and community, social and civic life (d9). Following up from the findings in major life areas (d8), it should be noted that the most predominant code across the whole Activities and Participation component was that of making decisions (d177). This code

emerged a total of 54 times, out of which 48 emerged in interviews. As aforementioned, this particular code has an important place in the context of transition; participants were at the end of their compulsory education journey, some of them facing the future with uncertainty, others calling for school and family support in making their minds up about the next steps following the end of secondary school. The chapter of community, social and civic life (d9) yielded similar numbers of occurring codes for both interviews and EHC plans, although in frequency these codes resulted higher in interviews by almost two thirds. The most relevant codes in this chapter were those concerned with recreation and leisure (d920, and subsequent codes), which constitute the highest in frequency for both EHC plans and interviews. During interviews, participants referred extensively to their free time, emphasising their participation in sports (d9201), arts and culture (d9202), and socialising (d9205) as relevant aspects of their functioning and day-to-day engagement in life situations.

Regarding the chapter of general tasks and demands (d2), a significant overlap was found between EHC plans and interviews referring to carrying out daily routine (d230) and subsequent codes (d2304, d2305); handling stress and other psychological demands (d240, and subsequent codes); and lastly, managing one's own behaviour (d250, and subsequent codes) . In relation to the chapter covering communication (d3), the codes in this chapter were predominantly identified in EHC plans. This is probably linked to the expectations of EHC plans to provide description of characteristics that make up for the ASD profile in terms of communication and interaction difficulties. The chapter covering mobility (d4) was one that yielded codes with similar occurrence across EHC plans and interviews. However, as previously observed in Figure 6.6 the frequency of these codes almost doubles in interviews. The most significant overlaps from this chapter were codes which designated moving around outside the house (d460, d4601, d4602) and moving around using transportation (d470, d4701, d4702). These codes were associated across plans and interviews as synonyms of independence and autonomy, and in many cases, goals

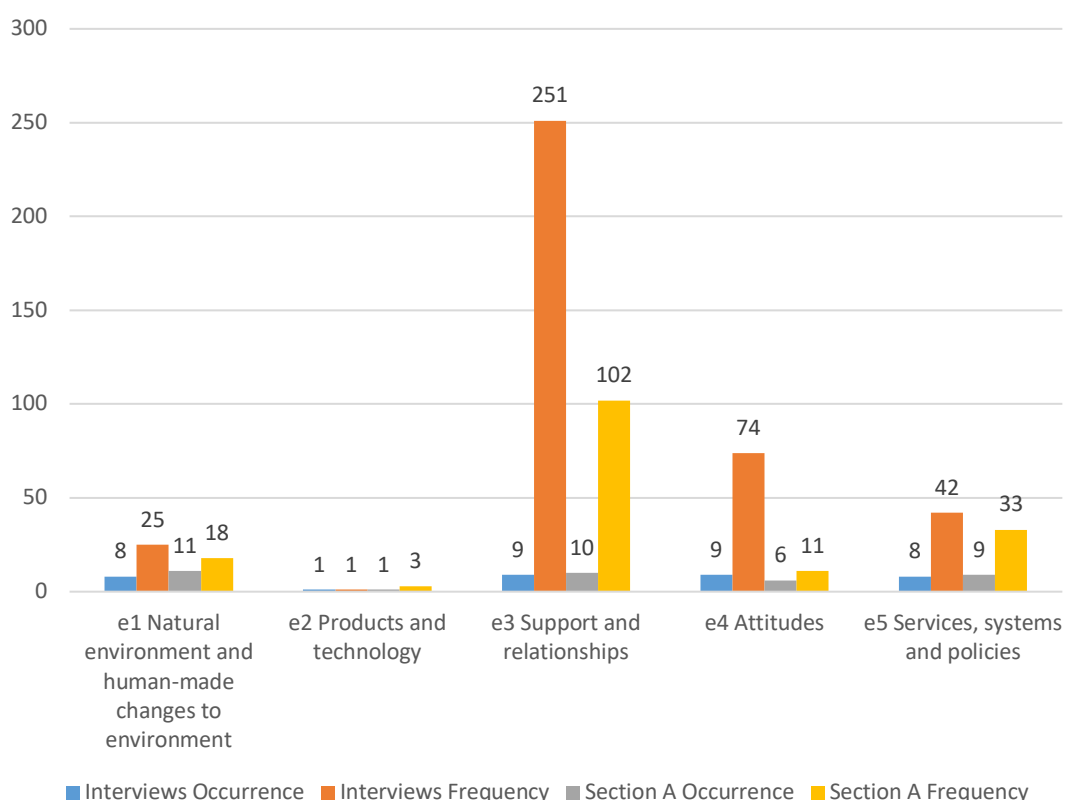
to achieve by participants, as described in Chapter 5 of this thesis. Concerning the chapter of interpersonal interactions and relationships (d7), a considerably higher frequency was found in EHC plans than in interviews. As in the case of the chapter of communication, this could also refer to the description of characteristics associated with the ASD profile in the documents. The codes that referred to complex interpersonal interactions (d720) and informal social relationships (d750) were the most significant overlaps of the chapter.

Lastly, codes belonging to the chapter of self-care (d5) were mainly indicated in EHC plans. The most relevant codes stemming from this chapter were those referring to washing oneself (d510) and caring for body parts (d520), as well as eating (d550), and taking care of one's health (d570) and safety (d571). A noteworthy overlap in the chapter of domestic life (d6) was that of code d630 and subsequent codes, which covered preparing meals; this code was followed by acquisition of goods and services (d620), doing housework (d640), and assisting others (d660).

### **6.2.3 Environmental factors**

The component of environmental factors of the ICF-CY refers to the physical, social and attitudinal environment in which people live and conduct their lives and could constitute either barriers to or facilitators of the person's functioning. The identification of ICF-CY codes from this component across interviews and EHC plans has produced some of the most relevant and interesting insights into the role that the environment plays in day-to-day lives of young people with ASD. Although the occurrences of codes across domain chapters was somewhat similar, at a glance at Figure 6.8 it is evident that the chapter of support and relationships (e3) was the predominant one in frequency terms in both interviews and EHC plans. Interestingly, a closer look into the frequency of identified codes in this domain suggests that in the interviews young people have placed a strong emphasis on their support networks

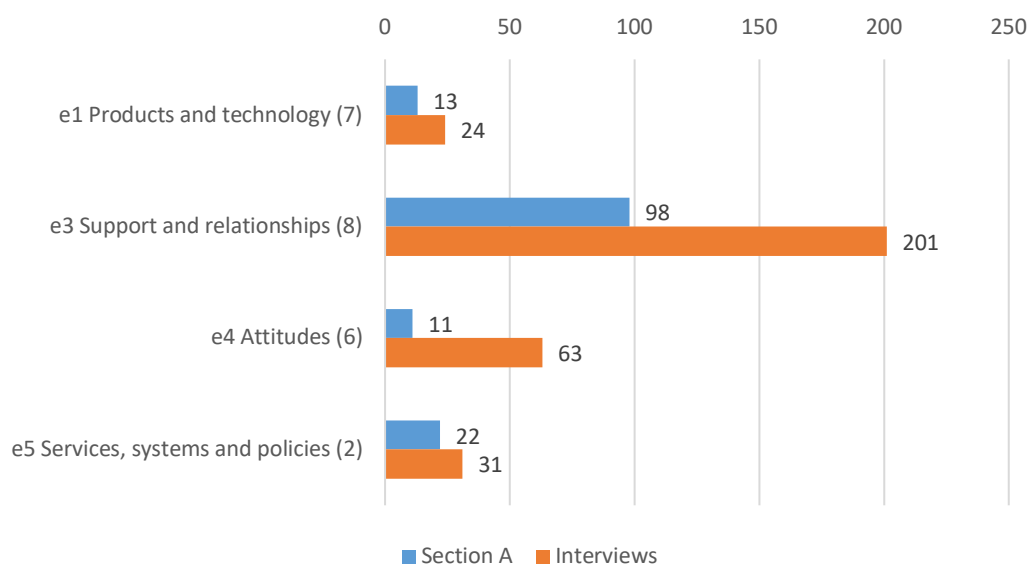
and relationships, highlighting the relevance of their immediate family (e310), friends (e320), people in position of authority –i.e. teachers, managers – and other professionals working with them (e360).



*Figure 6.8* Occurrence and frequency of Environmental Factors codes identified in Section A and interviews, by component chapter.

Another interesting finding from this domain was on the chapter that covers attitudes, described in the ICF-CY as the observable consequences of customs, practices, ideologies, values, norms, factual beliefs and religious beliefs (WHO, 2007). These attitudes refer to those around the person being described. The interviews revealed that when it comes to young people's views, the attitudes of other people play a significant role in their functioning, in particular those individual attitudes of immediate family members (e410), friends (e420), acquaintances, peers,

colleagues, neighbours and community members (e425), and those of other professionals (e460). This finding suggests that although EHC plans cover a wide range of environmental aspects of the young people's profile, they fall short in the recognition of the role of support, relationships and attitudes of other people as highlighted throughout the interviews, as seen in Figure 6.9.



*Figure 6.9* Frequency of overlapping Environmental Factors codes identified in Section A and interviews

#### **6.2.4 Body structures**

The domain of Body Structures refers to the anatomical parts of the body, such as organs, limbs and their components. Only one code was identified twice in one EHC plan, when referring briefly to the structure of the brain of one participant, under the chapter of structure of the nervous system. A low number of codes from this domain was expected from both interviews and EHC plans. Firstly, because given the nature of the questions to ask the participants, it was unlikely to find them describing themselves in these terms or making statements about their anatomy. Regarding the

EHC plans, the focus on this case was on extensive descriptions of the individual's ASD and characteristics related to their cognitive profile (Body Functions), communication characteristics and their activities in general (Activities and Participation).

### **6.3 Summary**

This chapter analysed the extent of the match between the views of young people with ASD as reported in semi-structured interviews and in Section A of their respective EHC plans using the ICF-CY as a theoretical and analytical framework to systematically translate the content of both sources into a universal, holistic language (WHO, 2007). This strand showed that the views of young people had a focus on engagement in routines and involvement in life situations, as shown in the large number of codes identified from the ICF-CY's activities and participation component. Nonetheless, despite these similarities, some differences were also identified concerning the scope of activities and participation functioning codes that emerged in EHC plans and interviews.

On the one hand, throughout interviews young people emphasised their wishes for gaining further autonomy and increasing their participation in everyday life situations, manifested in ICF-CY codes from the chapters of mobility, self-care, domestic life, and major life areas. On the other hand, EHC plans placed the emphasis on participation in other dimensions of functioning such as learning and applying knowledge, and general tasks and demands. These discrepancies in the scope of activities and participation domains seem to accentuate the fact that in the new SEND policy EHC plans are conceived as statutory documents with a predominantly educational focus and of relevance for the school context in particular, where dimensions of participation could appear to be circumscribed to the sphere learning

and applying knowledge. This is further emphasised in the Code of Practice when guiding the inclusion of specific content in the sections concerning health and social care needs: the information to be added in this section should be of relevance as long as addressing these needs through specific provision would contribute to the education or training of the individual. Thus, the differences in scope between interviews and EHC plans could be understood from the value the EHC plan process places on education and training.

## **7. Results: Quality evaluation of outcomes sought for young people with ASD in transition to post-secondary destinations**

### **7.1 Introduction**

In previous chapters, this thesis has referred to the views and experiences of transition to post-secondary destinations for a group of young people with ASD as described by the young people themselves, and in their EHC plans. These were contextualised with regards to the changes in SEND service provision and delivery introduced by the Children and Families Act 2014, and the new SEND Code of Practice. It has also provided a detailed analysis of the functioning dimensions that described the views, needs, and outcomes sought for young people with ASD. This chapter takes another look at the outcomes defined for this group of young people by analysing their overall quality with regards to their participatory focus as proposed by the new SEND Code of Practice. While previous chapters have addressed the content of the EHC plans using the systematic framework of the ICF-CY to analyse the data, this strand takes a different approach to the analysis of outcomes written for young people with ASD by using a participation-focused instrument to rate them: the GFS III (McWilliam, 2009) to explore the overall quality of these outcomes. The research questions that emerged were:

- a. What is the overall quality of outcomes defined for young people with ASD in their EHC plans?
- b. Does the quality of outcomes vary depending on the LA that produced them?
- c. Does the quality of outcomes vary depending on the type of placement that the young people attended?
- d. Does the quality of outcomes vary depending on the year group the young people were attending?



For this purpose, a total of 265 outcomes were identified written in the 23 finalised EHC plans of young people, produced by ten LAs. These outcomes were rated on the seven quality dimensions of the GFS III (Chapter 3, Section 3.7.2.1.2), on a scale from 1 to 4, where 1 represented the low quality (*not at all*) and 4 represented high quality (*very much*). Examples of outcomes coded with the GFS III can be found in Appendix F. A second coder rated 62 out of the 265 outcomes for reliability purposes, and weighted kappa was calculated to explore inter-rater agreement. The data did not meet assumptions for parametric testing, and for this reason non-parametric tests were used to further analyse the data to answer the research questions for this line of enquiry.

## 7.2 Findings

The number of outcomes sought for each young person varied from one plan to another, ranging from five to 35 ( $M = 11.5$ ,  $SD = 6.14$ ). Details of the number of outcomes per EHC plan and LA can be found in Chapter 3 of this thesis, as they are included on Table 3.2 where participants' characteristics were presented in detail.

Weighted kappa ( $\kappa_w$ ) with linear weights (Cicchetti & Allison, 1971) was run to determine if there was agreement between the two raters on the quality of outcomes sought for young people with ASD in their EHC plans across all seven quality indicators from the GFS. Each outcome was rated for each indicator on a scale from 1 to 4, where 1 meant *not at all*, thus suggesting poor quality for that indicator, and 4 meaning *very much*, indicating high quality. There was a statistically significant agreement between the two raters,  $\kappa_w = .925$ , 95% CI [.901, .949],  $p < .001$ . The strength of the agreement was classified as excellent (Fleiss, Levin, & Paik, 2003). In order to explore the level of agreement in more detail, agreement between raters was also calculated for each of the seven criteria of the GFS III. It was not possible to obtain kappa values for the quality indicator exploring the presence of a generalisation

criterion (criterion g), and for timeframe (criterion h) due to all ratings being the same for one or both raters. The most evident case for this was in the criterion for timeframe – as all outcomes require an annual review, both raters gave the same score to this indicator across outcomes. Concerning the remaining five criteria from the GFS, there was a statistically significant agreement between the two raters in all of them. The levels of agreement ranged from .765 to .861, considered very good (Fleiss et al., 2003). For criterion a,  $\kappa_w = .792$ , 95% CI [.653, .932],  $p < .001$ ; criterion b,  $\kappa_w = .781$ , 95% CI [.651, .912],  $p < .001$ ; criterion c,  $\kappa_w = .765$ , 95% CI [.647, .882],  $p < .001$ ; criterion d,  $\kappa_w = .861$ , 95% CI [.719, 1.003],  $p < .001$ , criterion e,  $\kappa_w = .849$ , 95% CI [.558, 1.139],  $p < .001$ .

Table 7.1 displays the distribution of scores between the two coders across each of the criteria of the GFS, illustrating high levels of agreement. If we consider categories of rating as high (*very much* and *much*) and low (*somewhat* and *not at all*), the agreement between coders is almost perfect. For the GFS criterion that explores the extent to which a desired behaviour is relevant for the child's participation (criterion c), the coders disagreed in the high-low categorisation of outcomes.

### **7.2.1 Overall quality of outcomes identified for young people with ASD in EHC plans**

The GFS III allowed computing two types of scores to explore the quality of the outcomes described in the EHC plans. A mean score was calculated for each individual outcome, and another score was calculated for each quality indicator of the GFS III. The mean scores for the quality of each of the 265 outcomes ranged from 1.43 to 3.00 ( $M = 1.89.0$ ,  $SD = .34$ ).

Table 7.1

*Cross tabulation of GFS scores*

	Coder 1	Coder 2				<i>Total</i>
		Not at all	Somewhat	Much	Very Much	
Indicates participation in a routine (criterion a)	Not at all	41	4	0	0	45
	Somewhat	3	7	0	0	10
	Much	0	0	6	1	7
	Very Much	0	0	0	0	0
	<i>Total</i>	44	11	6	1	62
Specifies desired behaviour (criterion b)	Not at all	23	6	0	0	29
	Somewhat	1	23	2	0	26
	Much	0	1	5	0	6
	Very Much	0	0	0	1	1
	<i>Total</i>	24	30	7	1	62
Relevance of behaviour for child's participation (criterion c)	Not at all	5	4	0	0	9
	Somewhat	0	21	7	0	28
	Much	0	2	13	0	15
	Very Much	0	0	1	9	10
	<i>Total</i>	5	27	21	9	62
Quantification of the acquisition criterion (criterion d)	Not at all	48	2	0	0	50
	Somewhat	0	11	1	0	12
	Much	0	0	0	0	0
	Very Much	0	0	0	0	0
	<i>Total</i>	48	13	1	0	62
Relevance of the acquisition criterion (criterion e)	Not at all	58	1	0	0	59
	Somewhat	0	3	0	0	3
	Much	0	0	0	0	0
	Very Much	0	0	0	0	0
	<i>Total</i>	58	4	0	0	62
Presence of a generalisation criterion (criterion f)	Not at all	62	0	0	0	62
	Somewhat	0	0	0	0	0
	Much	0	0	0	0	0
	Very Much	0	0	0	0	0
	<i>Total</i>	62	0	0	0	62
Presence of a timeframe criterion (criterion g)	Not at all	0	0	0	0	0
	Somewhat	0	0	0	0	0
	Much	0	0	0	0	0
	Very Much	0	0	0	62	62
	<i>Total</i>	0	0	0	0	62

Table 7.2 presents the frequency of ratings for the 265 analysed outcomes. From this table it can be observed that outcomes were predominantly rated as *not at all* and *somewhat*, which are the ratings that suggest low quality for the indicators, with the exception of ratings for the criteria addressing whether the outcome addresses a need useful for participation, and the one concerning timeframe. For the former criterion ratings were inclined towards high quality; as for the latter criterion, given that the EHC plans have a duty to be reviewed on an annual basis, all outcomes were considered to have a default timeframe of one year for achieving the proposed goal. For this reason, they were rated as *very much* for the timeframe criterion. Given that there was no variance in the timeframe scores, this indicator was not included in further analyses.

A close look to the mean scores (Table 7.3) obtained for each quality indicator, it could be seen that the overall the quality of the outcomes sought for young people with ASD in their EHC plans is quite poor across GFS III indicators, with the majority of mean scores below 2, which in the GFS is at the lower end of quality. This is the case for all of the indicators except for the criterion concerning the relevance of the skill for participation (criterion c), and the one regarding the presence of a timeframe (criterion g). This low quality can be particularly observed when considering whether outcomes included a generalisation criterion (criterion f), which was not the case for 261 out of 265 observed outcomes. A substantial number of outcomes did not include a meaningful acquisition criterion (criterion e; 251 out of 265), nor stated a clear acquisition criterion (criterion d; 216 out of 265). On the other hand, the GFS criterion that received more frequent ratings of *much* and *very much* was the one that explores whether outcomes address a skill that is useful for participation (criterion c). As previously stated, the criterion for timeframe (criterion g) was constant across all outcomes, rated at *very much* given the fact that all EHC plans are reviewed annually, so therefore outcomes are time-bound to a one-year period.

Table 7.2

Frequency of ratings for outcomes

Quality criteria: to what extent does the outcome	GFS ratings				Total
	Not at all	Somewhat	Much	Very much	
(a) Emphasise the child's participation in a routine (i.e. activity)?	184	47	28	6	265
(b) State specifically (i.e. in an observable and measurable manner) what the child will do?	97	111	46	11	265
(c) Address a skill that is either necessary or useful for participation?	49	73	81	62	265
(d) State an acquisition criterion?	216	37	9	3	265
(e) Have a meaningful acquisition criterion?	251	13	1	0	265
(f) Have a generalisation criterion?	261	3	1	0	265
(g) Have a criterion for timeframe?	0	0	0	265	265

Table 7.3

*Mean quality scores across outcomes per GFS III indicator*

<i>GFS Criteria</i>	<i>M</i>	<i>SD</i>	<i>Mdn</i>	<i>s<sup>2</sup></i>	Range	
					<i>Min.</i>	<i>Max.</i>
(a) Skill useful for participation	1.46	0.77	1.00	0.60	1	4
(b) Observable and measurable	1.89	0.83	2.00	0.70	1	4
(c) Useful or necessary for participation	2.59	1.04	3.00	1.08	1	4
(d) Acquisition criterion	1.24	0.57	1.00	0.32	1	4
(e) Meaningful acquisition	1.06	0.25	1.00	0.06	1	3
(f) Generalization criterion	1.02	0.16	1.00	0.03	1	3
(g) Timeframe	4.00	0.00	4.00	0.00	4	4

**7.2.2 Does the quality of outcomes vary by local authority?**

As previously stated, assumptions for parametric testing were not met, therefore data was analysed following non-parametric procedures. A Kruskal-Wallis test was conducted to examine whether there were differences between the ten LAs (LA 1 to 10) in the scores obtained for each GFS III indicator for 265 identified outcomes. Statistically significant differences were found in the distribution of GFS III scores between LAs concerning five out of seven indicators, presenting low to high effect sizes. Eta-squared estimates ( $\eta^2$ ) were used as effect size measure for the Kruskal-Wallis test, ranging from 0 to 1, and where multiplied by 100% allows to explore the percentage of variance in the dependent variable that could be explained by the independent variable (Tomczak & Tomczak, 2014). The results for each criterion were the following: for participation in a routine (criterion a),  $\chi^2(9) = 24.799$ ,  $p = .003$ ,  $\eta^2 = .06$ ; measurability of the outcome (criterion b),  $\chi^2(9) = 64.557$ ,  $p < .001$ ,  $\eta^2 = .22$ ; usefulness for participation (criterion c),  $\chi^2(9) = 32.068$ ,  $p < .001$ ,  $\eta^2 = .09$ ; acquisition criterion (criterion d),  $\chi^2(9) = 38.399$ ,  $p < .001$ ,  $\eta^2 = .12$ ; and lastly,

generalisation criterion (criterion f),  $\chi^2(9) = 210.382$ ,  $p < .001$ ,  $\eta^2 = .79$ . The criterion for meaningful acquisition (criterion e) did not produce statistically significant differences,  $\chi^2(9) = 9.928$ ,  $p = .356$ ,  $\eta^2 = .004$ ; As the scores for timeframe were identical across outcomes, they were not further analysed.

In order to identify where the differences lied, post-hoc pairwise comparisons were performed following Dunn's procedure with a Bonferroni correction for multiple comparisons (Dunn, 1964). Values are mean ranks unless otherwise stated, and adjusted  $p$ -values are presented. With regards to the first criterion of the GFS III, post-hoc analyses revealed statistically significant differences in the distribution of *participation in a routine* (criterion a), scores between LA 1 (111.3) and LA 3 (152.6) ( $p = .025$ ), LA 1 (111.3) and LA 8 (168.0) ( $p = .036$ ), and LA 8 (168.0) and LA 4 (99.3) ( $p = .042$ ). In relation to this criterion, LA 1's (Mdn = 1) 85.1% of outcomes were rated as *not at all*, whereas LA 3 had 55.6%, and LA 8 (Mdn = 2) had less than half (47.4%) of its outcomes rated at this level. LA 4 (Mdn = 1) had the largest proportion of outcomes across all LAs rated as *not at all* for this criterion, with 94.1% of outcomes. Concerning the GFS III indicator referring to the *measurability of the outcome* (criterion b), statistically significant differences were found in the distribution of scores between LA 1 (111.3) and LA 5 (212.3) ( $p = .043$ ). Differences between LA 2 (164.1) and four other LAs, namely LA 3 (105.2) ( $p < .001$ ), LA 4 (99.3) ( $p = .002$ ), LA 6 (69.8) ( $p = .005$ ), and LA 8 (99.7) ( $p = .030$ ). More than three quarters of the outcomes produced by LA 2 were rated as *somewhat* (48.3%) and *much* (27.6%), whereas LAs 3, 4, 6 and 8 had more than half of their outcomes rated as *not at all* for the indicator of observability and measurability of proposed outcomes, with percentages ranging from 50.8% to 80%.

For the criterion that refers to a *skill that is necessary or useful for participation* (criterion c), statistically significant differences were found in the distribution of scores between LA 4 (80.7) with regards to LA 1 (149.3) ( $p = .047$ ), LA 5 (184.5) ( $p = .006$ ), and LA 9 (220.2) ( $p = .009$ ). Eighty percent of the scores for this criterion in LA 9

were rated as *very much*, suggesting that this LA was significantly better at describing skills necessary for participation in the development of their outcomes when compared to LA 4, which had no outcomes rated at this level and whose majority of outcomes were rated as *somewhat* in this domain. Similarly, LA 5 had 92.3% of their outcomes rated as *much* (53.8%) and *very much* (38.5%) for this GFS III indicator, suggesting higher quality for their outcomes in this respect. Similar differences were found between LA 6 (80.7) and LA 5 (184.5) ( $p = .038$ ), and LA 9 (220.2) ( $p = .026$ ). LA 6 had 70% of their outcomes rated as *not at all* for identifying skills useful or necessary for participation, whereas LA 5 and 9 produced better quality outcomes in this respect, with above 90% of their ratings as *much* and *very much* for this criterion.

With regards to whether the outcome *states an acquisition criterion* (criterion d), statistically significant differences in the distribution of scores were found between LA 7 (203.7) and a number of LAs, namely LA 1 (127.3) ( $p = .002$ ), LA 3 (114.5) ( $p < .001$ ), LA 4 (130.8) ( $p = .028$ ), LA 6 (108.5) ( $p = .003$ ), LA 8 (121.8) ( $p = .004$ ), and lastly LA 10 (131.5) ( $p = .016$ ). The majority of the scores for the outcomes stemming from these LAs were rated as *not at all* for this criterion, with percentages ranging from 65.5% at this level, when compared to LA 7, which presented higher scores and almost half (44.6%) of the outcomes rated at *much* and *very much* for this quality criterion.

There were no statistically significant differences in the distribution of scores among LAs for the criterion concerning the presence of a *meaningful acquisition criterion* (criterion e) for outcomes. Lastly, statistically significant differences in the indicator regarding the *presence of a generalisation criterion* (criterion f) were found between LA 9 (237.0) and all other LAs (all ranks at 131.0) ( $p < .001$ ). All LAs except LA 9 had 100% of their outcomes rated as *not at all* for the indicator of a generalisation criterion, whereas LA 9 had only 20%; 60% of their outcomes were rated as *somewhat* and 20% as *much*, suggesting better quality in this particular domain compared to the rest of the LAs.



In sum, these findings highlight that the quality of the outcomes as portrayed in EHC plans was quite poor, and that despite their quality, there was significant variation of quality scores across GFS III indicators, the LAs that developed the outcomes, varying as well depending on the type of setting (special or mainstream) and year group (secondary or post-secondary) for which they were developed.

### ***7.2.3 Does the quality of outcomes vary according to the type of school?***

A series of Mann-Whitney *U* tests were run to explore whether there were differences in the quality of the outcome scores obtained between year groups – that is, those describing outcomes for year 11 and post-secondary – and between types of setting – special and mainstream. The criterion referring to whether outcomes included a timeframe (criterion g) was excluded from these analyses, as the score was identical for all 265 outcomes. Therefore, six out of seven criteria were included in the analyses. Some aspects of the quality of outcomes varied between mainstream and special settings, with small to medium effect sizes - represented as Pearson's *r*, with .1 meaning small, .3 medium, and .5 large - (Cohen, 1988) in those statistically significant differences, ranging from  $r = .19$  to  $.31$ .

Distributions of the GFS III scores for special and mainstream setting outcomes were similar for all analysed GFS III indicators except for the indicator of measurability of the outcome (criterion b), as assessed by visual inspection. A statistically significant difference was found in median GFS III scores between special ( $Mdn = 1$ ; mean rank = 123.22) and mainstream settings ( $Mdn = 2$ ; mean rank = 171.23) with regards to the indicators referring to *participation in a routine* (criterion a),  $U = 3632.5$ ,  $p < .001$ ,  $r = .31$ . In this respect, although the overall quality of outcomes for this GFS III criterion remained in the low-quality end of scoring, it would appear that mainstream settings performed significantly better in producing outcomes that refer to skills useful for participation of young people in routines than special

settings. Indeed, 76.8% of outcomes coming from special settings were rated at *not at all*, compared to mainstream settings, whose majority of outcomes (67.3%) were rated at *somewhat* (35.2%) and *much* (32.1%). With regards to the distribution of scores for the GFS III indicator of measurability of the outcome, which explores whether the outcome *specifies the skill or behaviour that the child should present* (criterion b), statistically significant differences were found between special (mean rank = 139.9) and mainstream settings (mean rank = 105.93),  $U = 4235$ ,  $p = .002$ ,  $r = .20$ . More than half (55.6%) of the outcomes from mainstream settings were rated as *not at all*, whereas a similar proportion of outcomes from special settings were rated as *somewhat* (44.5%) and *much* (19%), deeming outcomes of higher quality for this criterion.

There were no statistically significant differences in median scores between groups for the remaining four quality indicators. For the criterion referring to the *relevance of a behaviour for the child's participation* (criterion c), results show that outcomes described from both special ( $Mdn = 3$ ; mean rank = 129.1) and mainstream settings ( $Mdn = 3$ ; mean rank = 148.3) did not differ significantly for this indicator,  $U = 4869$ ,  $p = .088$ ,  $r = .10$ . More than half of the outcomes from special settings (51.5%) were rated as *much* (31.3%) and *very much* (20.4%) for this criterion; similarly, the majority of mainstream settings' outcomes were predominantly rated as *much* (27.8%) and *very much* (35.2%). Thus, outcomes are deemed to be of good or relatively good quality in relation to this indicator for both settings.

Regarding the criterion exploring the *presence and quantification of an acquisition criterion* (criterion d), no statistically significant difference between special ( $Mdn = 1$ ; mean rank = 134.61) and mainstream settings ( $Mdn = 1$ ; mean rank = 126.71) were found,  $U = 5358$ ,  $p = .317$ ,  $r = .06$ . More than three quarters of outcomes across settings (80.1% special, 87% mainstream) were rated as *not at all* concerning the presence of an acquisition criterion. A similar distribution of these ratings was found for the indicator of mentioning the *relevance of the acquisition criterion* (criterion

e), with no statistically different scores between special ( $Mdn = 1$ ; mean rank = 133.88) and mainstream ( $Mdn = 1$ ; mean rank = 133.46) settings,  $U = 5672$ ,  $p = .898$ ,  $r = .01$ . The vast majority of mainstream schools' (94.4%) and special schools' (94.8%) outcomes were rated as *not at all* for this criterion, suggesting very low quality in this respect. Concerning the *criterion for generalisation* (criterion f), special ( $Mdn = 1$ ; mean rank = 133.51) and mainstream schools' ( $Mdn = 1$ ; mean rank = 131.00) outcomes scored similarly low for this criterion, and thus no significant difference was found,  $U = 5589$ ,  $p = .309$ ,  $r = .06$ . Ninety-eight percent of special school outcomes were rated as *not at all* for this criterion, whereas 100% of mainstream school outcomes received the same rating.

#### **7.2.4 Does the overall quality of outcomes vary according to the year group they are developed for?**

Once more the criterion of *timeframe* (criterion g) was excluded from the analysis, as the scores for the outcomes in both secondary and post-secondary settings was identical for all 265 outcomes. Therefore, six out of seven criteria were included in the analyses. Distributions of the engagement scores for secondary and post-secondary outcomes were similar for all GFS III indicators except for the indicator of measurability of the outcome (criterion b), as assessed by visual inspection. A statistically significant difference was found in median GFS III scores between outcomes described for secondary ( $Mdn = 1$ ; mean rank = 119.85) and post-secondary ( $Mdn = 1$ ; mean rank = 153.67) groups with regards to the indicator referring to *participation in a routine* (criterion a),  $U = 6213.5$ ,  $p < .001$ ,  $r = .27$ . The overall quality of outcomes in relation to this indicator remained quite low and the distribution of scores remained similar, however 79% of outcomes stemming from secondary settings were rated as *not at all* for this criterion, whereas the same proportion of outcomes (79.6%) produced by post-secondary settings were rated between *not at all* (54.4%) and *somewhat* (25.2%).

Concerning the indicator of *measurability of the outcome* (criterion b), a statistically significant difference in the distribution of scores was found between year 11 (mean rank = 144.69) and post-secondary (mean rank = 114.62),  $U = 6449.5$ ,  $p = .001$ ,  $r = .20$ . More than half (52.4%) of outcomes stemming from post-secondary settings were rated as *not at all* for this criterion, compared to the 26.5% from secondary settings rated at this level. Conversely, 50% of outcomes from secondary settings were rated as *somewhat* compared to 29.1% from their post-secondary counterparts. A lower proportion of outcomes from post-secondary settings were rated at *much* (12.6%) in relation to the 20.4% of those from secondary settings rated at this same level.

No statistically significant differences were found in median scores between the secondary and post-secondary groups for outcomes assessed under the remaining criteria. For the criterion referring to the *relevance of a behaviour for the child's participation* (criterion c), secondary ( $Mdn = 3$ ; mean rank = 129.36) and post-secondary ( $Mdn = 3$ ; mean rank = 138.73) settings presented no significant difference in their median scores,  $U = 7753$ ,  $p = .315$ ,  $r = .06$ . More than half of the outcomes stemming from both settings were rated as *much* (31.5% in secondary, 29.1% in post-secondary settings) and *very much* (21% in secondary, 27.2% in post-secondary settings), suggesting somewhat high quality of outcomes in identifying relevant behaviours for participation of young people. As expressed before, no significant differences were found between outcomes from secondary and post-secondary settings for criteria referring to the quantification of an acquisition criterion (criterion d) secondary ( $Mdn = 1$ ; mean rank = 135.98); post-secondary ( $Mdn = 1$ ; mean rank = 128.32);  $U = 7861$ ,  $p = .240$ ,  $r = .07$ ; *relevance of the acquisition criterion* (criterion e), secondary ( $Mdn = 1$ ; mean rank = 133.33); post-secondary ( $Mdn = 1$ ; mean rank = 132.48);  $U = 8289$ ,  $p = .819$ ,  $r = .01$ ; and *presence of a generalisation criterion* (criterion f), secondary ( $Mdn = 1$ ; mean rank = 134.27), post-secondary ( $Mdn = 1$ ; mean rank = 131.00);  $U = 8137$ ,  $p = .109$ ,  $r = .10$ . An increasing proportion of ratings

as *not at all* were found across criterion e to criterion f, for outcomes from both secondary and post-secondary settings. The percentages ranged from 79% to 100% at *not at all* level, suggesting that outcomes were of very poor quality with regards to these GFS III criteria in both secondary and post-secondary settings.

### 7.3 Summary

In summary, this chapter analysed the quality of 265 outcomes written for 23 young people with ASD in transition to post-secondary destinations. These outcomes were analysed using the GFS III as a rating tool to explore their quality in the seven quality dimensions/indicators of the tool. The findings from this analysis highlight that the quality of the outcomes as portrayed in EHC plans was quite poor across plans particularly with regards to the inclusion of a generalisation criterion (criterion f), meaningful acquisition criterion (criterion e) and clear acquisition criterion (d), dimensions in which a substantial number of analysed outcomes scored low. In contrast, the criteria for addressing a skill useful for participation (criterion c) and the presence of a timeframe for acquisition (criterion g) received higher scores across outcomes, suggesting that the relevance for participation was a more easily identified trait to incorporate to the development of outcomes than other dimensions.

In addition, and in spite of their overall low quality, statistically significant differences in quality scores were found across GFS III indicators with regards to the LAs that developed the outcomes. This finding suggests variability not only among LAs but also across quality criteria with regards to the production of SMART outcomes for young people with ASD, highlighting inconsistencies in the writing of high-quality outcomes. Furthermore, statistically significant variability in the quality scores of outcomes was found with regards to the type of setting (special or mainstream) and year group (secondary or post-secondary) for which the outcomes were developed. With regards to the type of setting, results show that mainstream settings had a better

performance than special settings in writing outcomes for young people that refer to skills useful for their participation (criterion c). At the same time, special settings performed better than mainstream settings in the criterion that explores whether the outcome specifies the skill that the child should present (criterion b). Concerning the year group the young people attended, findings suggest better performance of secondary schools in writing outcomes that include a criterion for measurability of the outcome (criterion b) compared to post-secondary settings. As outcomes in the EHC plans mobilise provision for children and young people with SEND, it is crucial for LAs and stakeholders working with children with SEND – including the children themselves – to work on the development high quality outcomes, with a focus on enhancing participation in everyday life as advocated by the new SEND Code of Practice.



## **8. Discussion**

### **8.1 Introduction**

The end of secondary school constitutes a turning point in the life of all adolescents and their families, and for young people with ASD this period could be challenging (Hendricks & Wehman, 2009; Taylor & Seltzer, 2011). This study aimed to address the dearth in this research area and to provide novel data regarding the views and experiences of young people with ASD in their transition to post-16 destinations in the scope of the changes in SEND legislation introduced by the Children and Families Act 2014 in England. Underpinned by the principle of participation of young people in decision-making in matters affecting their lives, the development of EHC plans, and the extension of SEND provision until 25 years of age, the views of young people and transition to adulthood are at the centre of the stage.

The purpose of this chapter is to discuss the findings stemming from this study in light of the current literature in the field. As detailed in Chapters 1 and 2 of this thesis, the aim of the present study was to give voice to young people with ASD by exploring their views and experiences of transition to post-secondary destinations; to explore the functioning dimensions identified as the views, needs and outcomes of young people with ASD as portrayed in their EHC plans; to explore the extent of the match between the views of young people with ASD obtained through interviews and those depicted in their respective EHC plans; and lastly, to evaluate the quality of outcomes sought for young people with ASD in their EHC plans with regards to their focus on functioning and participation at the time of transition to post-secondary destinations.

Twenty-nine young people with ASD in the 15 to 19 age range took part in this study, which involved conducting 28 semi-structured interviews, and collecting 23



EHC plans. Interview transcripts were analysed inductively following a phenomenological thematic analysis to explore the views of young people at a time of transition, and also deductively using the ICF-CY as a system of pre-defined codes to perform content analysis to explore the functioning dimensions identified as their views (Chapter 4). The EHC plans were also analysed first inductively, and then deductively again using the ICF-CY system to explore the functioning dimensions identified as the views of young people, their needs, and the outcomes sought for them in the newly introduced statutory documents (Chapter 5). The identified codes in both interviews and Section A (concerning the views of young people) were then brought together for analysis to explore the extent of the match of the views of young people between interviews and as portrayed in their EHC plans (Chapter 6). Lastly, the outcomes sought for young people in their EHC plans were also analysed using the GFS III (McWilliam, 2009) to measure their overall quality across the seven dimensions of the instrument (Chapter 7). For organisation purposes, this chapter discusses the findings following the chapter order in which the results were reported.

## **8.2 The voices of young people with ASD in transition to post-secondary destinations**

This strand aimed to provide novel data regarding the views and experiences of young people with ASD in transition to post-secondary destinations in the scope of the changes in SEND legislation introduced by the Children and Families Act 2014 in England. Two research questions were identified for this strand:

- a. What are the views of young people with ASD about their transition to post-secondary destinations?
- b. What are the ICF-CY functioning dimensions identified in the views of young people with ASD as extracted from the interviews?

The findings from this strand (Chapter 4) have shown that at the time of transition to post-secondary settings, young people with ASD experienced ambivalent feelings about change and the future. The narratives from interviews portrayed their wishes to become more autonomous and independent in day to day life, and recognised the importance of support networks available to them, namely their families, relevant support staff, and friends. They manifested concerns about potential bullying experiences in their new setting and losing friendships developed in their current placements, bringing anxiety to their transition process. It has been suggested that engaging young people in discussions about the transition process and their future from early stages of their education journey could constitute an effective way of supporting transition (Carter, Trainor, Cakiroglu, Sweeden, & Owens, 2010; Robinson et al., 2018).

In line with findings in the literature, this strand revealed that enrolling in post-secondary education and training and becoming increasingly more independent constitute key transition goals and aspirations for young people with ASD at the end of their compulsory education journey (Chen et al., 2014; Wehman et al., 2014a). Independence was a major theme throughout the interviews, shaped by descriptions of different everyday life situations in which they felt, or wished to be more, independent. Participants reflected on being autonomous around the house, preparing meals and sorting out washing, for example, and offered varied accounts on the use of public transport and going out without adult supervision. Consistent with previous findings, young people interviewed reported that they did not feel they experience high levels of personal autonomy expected from youth exiting secondary education, and thus expressed their wish to develop skills that would foster leading a progressively more autonomous life (Schall & McDonough, 2010; Taylor & Seltzer, 2011; Wehman et al., 2014b).

This theme was linked to the role of immediate family members as crucial support. Although participants acknowledged the significance of family support, and appreciated it when seeking for help, on occasion seemed at odds with their wishes for autonomy. Indeed, most participants indicated relying on their parents for making difficult decisions, protection and companionship in the home, mirroring the 'push and pull' of parental roles that characterises the changes in familial relationships as young people embark in their transition to adulthood. In this respect, parents were portrayed in a dilemmatic position of letting go and reducing dependency to promote autonomy, while at the same time protecting their children from harm (Hauser-Cram et al., 2009).

Adolescence is not only a time for reconfiguration of familial relationships, but also for that of friendships, which move towards being relationships with strong emotional ties (Hauser-Cram et al., 2009). Young people acknowledged the relevance of friends in their lives, highlighting the supportive nature of these relationships, and described socialising, sharing interests and leisure time, problems and concerns with them. These descriptions are aligned with the characterisation of friendship proposed by Bukowski, Hoza, and Boivin (1994), reflected in the qualities of companionship, closeness, helpfulness and security. Nevertheless, the majority of participants reported spending a great deal of their out-of-school free time on their own, predominantly engaging in solitary activities, like watching television or playing videogames, and going out mostly with family members, consistent with other reported findings (Bauminger & Shulman, 2003; Kuo, Orsmond, Cohn, & Coster, 2013; Orsmond & Kuo, 2011). Furthermore, a high proportion of young people contemplated leaving secondary school as a synonym of leaving friends behind, wondering about the future of those relationships as they moved to different post-16 destinations. In this respect, a number of participants recognised making new friends a challenging endeavour for their next stage, having spent a good part of their schooling in the same setting. As it transpired from the interviews, young people

expressed a broad range of ambivalent feelings about the future, where most of the participants reported feeling excited about a new stage in their lives, while at the same time struggling to come to terms with the uncertainties that revolve around such change. During adolescence peer relationships are considered the most significant factor associated with quality of life; consequently, uncertainties on the future of this sphere is observed as a threat to their perceived quality of life (DaWalt et al., 2017; Helseth & Misvær, 2010).

In consonance with Humphrey and Lewis (2008), the experience of bullying emerged as another central theme in young people's views about transition to post-secondary settings. Participants' accounts of distressing experiences at school and outside revealed a dimension of anxiety underpinned to the change of setting. When describing these experiences, participants reported their coping strategies, where the majority would actively seek for support from parents, teachers, professionals or people in positions of authority, whereas a small number would simply put up with it, or try to ignore the situation, at best (Humphrey & Symes, 2010b). Actively seeking for help seemed related to knowing the setting – i.e. what are the rules and norms, and who to turn to in case these situations arise. Leaving school for the majority of the participants meant leaving familiar rules, places and people who they had learnt to trust. Thus, the change of setting translated into losing trustworthy links that served as a safe base; the unfamiliarity of the context and people in their new placement hindered the young people's opportunities to grasp the mechanisms of support available, and reduce the anxiety accompanying this uncertainty.

Regarding the analytical approach, the use of an inductive and a deductive approach complemented each other. The inductive thematic analysis allowed the emergence of themes following participants' views on their own transition, focusing on the in-depth exploration of first-hand accounts as young people themselves have a unique knowledge of their own views, circumstances, needs, and the ways to

address these (Carrington & Graham, 2001; Palikara, Lindsay, & Dockrell, 2009). Concerning the deductive content analysis, the ICF-CY served as a system aptly aligned to the requirements of the Code of Practice to record the views of children and young people in a biopsychosocial way, focusing on participation and placing the individual at the centre (Douglas, Pavey, Corcoran, & Clements, 2011). This is of particular relevance for the development of EHC plans, honouring the commitment to develop integrated provision that accounts not solely for the individual wishes, aspirations and characteristics of the young person, but for the multifaceted aspects of the physical, social, and cultural systems and environments in which they develop.

Indeed, throughout the interviews participants consistently referred to significant aspects of their environment across themes, represented with e codes in the ICF-CY framework, which account for the need of adopting a holistic system that includes contextual characteristics, often forgotten when designing personalised interventions (Castro et al., 2014). The specificity of the ICF-CY system and the uniqueness by which the codes are brought together to shape a theme allowed a detailed understanding of the functioning dimensions that make up the fabric of the views and experiences of young people with ASD. As a common language, the ICF-CY helps to communicate different factors and needs that influence the functioning of young people with ASD in diverse environments, and provides a framework to guide transdisciplinary processes and support multiagency collaboration (Adolfsson, 2011; Kraus de Camargo, 2011; Lollar & Simeonsson, 2005; WHO, 2007). The breadth and universality of the ICF-CY system also enables professionals to address functioning dimensions across life domains equally, and comparisons of data within and across individuals, schools, LAs, and countries, as prioritised by the Children and Families Act 2014.

### **8.2.1 Limitations**

In terms of limitations, the ICF-CY system recognises that personal factors (i.e. age, gender, ethnicity, etc.) contribute to the functioning profile of an individual; however, these cannot be coded under the current system and therefore were not included in the analysis. Identified ICF-CY codes were discussed between coders until saturation was reached to ensure trustworthiness of the coding process. Additionally, the sample was small and geographically focused on Greater London and included only participants who had an ASD and EHC plan. Participants were screened for ASD characteristics; however, diagnosis was not corroborated through standard diagnostic instruments. Further research is needed in relation to young people's voice, and in the field of transition to post-16 following legislative SEND changes in England and the introduction of EHC plans. It would be interesting to explore the extent to which the ICF-CY functioning domains identified in the views of young people with ASD match those of young people with other, and those without SEND.

Throughout this thesis, it has been emphasised that diagnostic labels do not predict nor explain participation and functioning (Adolfsson, 2011; Castro & Palikara, 2019; WHO, 2007). From this perspective, analysing the views and experiences of young people with other SEND and those without SEND might shed some light concerning the functioning dimensions that make up the fabric of their experiences. By using the systematic taxonomy of the ICF-CY it may be possible to identify commonalities in functioning related to transition to post-secondary destinations irrespective of the presence of a diagnostic label or a SEND category. This approach could inform or highlight universal experiences that transcend the borders of diagnosis. The specificity of the ICF-CY could, at the same time, provide nuanced details about these experiences. It may well be that young people with ASD want to become autonomous and independent in different ways than those with other SEND.

For example, independence for individuals with ASD could be related to using public transport on their own, whereas for other groups it may refer to handling money or helping around the house. Conversely, their wishes for autonomy may fall under the same functioning domains for all young people regardless the presence of a diagnostic label or SEND category. By using the ICF-CY as a common language and framework, this exercise might highlight commonalities and differences that would be useful for building services that are responsive to functionality beyond diagnosis, while allowing agencies to work jointly in the development of ecological provision that recognises the individuality of the functioning profile of each person.

### **8.2.2 Summary**

This study explored the views of young people with ASD in transition to post-16 education and employment, in the scope of the new SEND legislation and framework in England from a biopsychosocial perspective. The use of a phenomenological approach allowed exploring these views and conveying through their narratives the essence of their lived experiences of this group of young people at a crucial point in their lives. In addition, the use of the ICF-CY framework to analyse the views of young people allowed a shift in the focus of young people's views, traditionally seen from 'within'-individual characteristics associated with ASD, to one that conveys the uniqueness of their functioning, portraying the interactive nature of the relationship between an individual and their environment (WHO, 2007). This approach is particularly relevant in the EHC plan process, as the commitment to develop ecological provision requires a holistic framework that contributes to reducing the gap between general diagnostic characteristics associated with ASD and the requirement for interventions that match individual young people with distinct functioning and contextual profiles (Castro & Palikara, 2016; Norwich, 2016).

### **8.3 The functioning-related views, aspirations, needs and outcomes of young people with ASD in EHC plans**

This strand explored how the voices, needs of, and outcomes sought for, 23 young people with ASD in their transition to post-16 education and employment were portrayed in their newly developed EHC plans, following the implementation of English SEND reform. EHC plans were collected in the period between November 2016 and April 2018. The following research questions emerged:

- a. What are the methods used to capture the views of young people with ASD in their EHC plans?
- b. What are the ICF-CY functioning dimensions identified in the EHC plans as the young person's views, interests and aspirations?
- c. What are the functioning dimensions reported as special educational, health, and social care needs of young people with ASD?
- d. What are the functioning dimensions identified as the outcomes sought for young people with ASD?

The content of 23 EHC plans of young people with ASD enrolled in 10 secondary schools and three post-16 education providers in the Greater London area were analysed first through an inductive approach, and then deductively using the ICF-CY as a theoretical and analytical framework. The content related to outcomes sought for young people with ASD was further analysed using the GFS III to assess the overall quality of the outcomes as expressed in the EHC plans.

The findings of the strand highlight variability in the ways the views of young people are elicited and portrayed in their EHC plans. In addition, they provide a detailed description of functioning dimensions that are relevant to the lives of young people with ASD in transition age to post-secondary destinations and adulthood, and their families. The analysis concerning the views of young people showed further



independence and participation in everyday life situations as key aspirations for the transition to post-16 destinations, and stressed the relevance of aspects of the environment such as support and attitudes as barriers and facilitators to their participation. Furthermore, the analysis of the special educational, health and social care needs of young people with ASD using the ICF-CY system, and the breadth of identified codes across sections indicated the difficulties in separating the needs of individuals in these terms. Undertaking a holistic approach to portraying these needs requires first the acknowledgment that individuals present needs that go beyond the labels of diagnosis and services, and therefore classifying their needs in terms of services seems to fragment the opportunities to meet these in a collaborative, biopsychosocial manner. Concerning the outcomes sought for young people, these reflected aspects of participation related to increasing independence in light of transition to post-secondary destinations addressed in the section regarding aspirations; these were related mostly to learning and applying knowledge, self-care and domestic life, and major life areas. However, the deductive analysis of outcomes showed that environmental factors were not incorporated with the same emphasis as they have in the section concerning aspirations. As for analysis of these using GFS III suggests that in spite of an overlap with codes identified in Section A, the overall quality of outcomes is somewhat poor and requires refinement.

The following subsections discuss in further detail the findings in light of the policy change in the field of SEND and current research. Limitations and implications of this strand are addressed.

### ***8.3.1 Capturing the voices of young people with ASD in EHC plans***

The findings emerging from this strand suggest that not all EHC plans collected have included the actual voices of young people with ASD, and that their collaboration in the inclusion of their views, wishes and aspirations in more than half

of the cases was only assumed. Although the law makes clear the legally binding requirement to make room for the views of the young person, it was striking to observe that some young people did not appear as contributors towards the development of their own plan. Broad statements such as 'he was present at the annual review meeting' appeared to portray the young person's involvement in decision-making, as intended by the SEND Code of Practice; however, these portrayals do not provide enough evidence of being the participatory, person-centred approaches to SEND advocated by the Children and Families Act 2014. The obligation to elicit the views of young people with ASD, regardless of their abilities, should supersede the difficulties and challenges that may arise in doing so; keeping with the obligation to consult with them should encourage the development of strategies that target the areas of difficulty for this particular group (MacLeod et al., 2013; Shepherd, 2015). In spite of the advances in the recognition of young people's rights to have their views given due weight, findings stemming from this strand show that some young people with ASD may still face exclusion in consultation and decision-making (Fayette & Bond, 2017, 2018; Pellicano et al., 2014a).

As for the content of the EHC plans, discrepancies have been found in terms of the amount of information they provide and how this information is presented (Palikara, et al, 2018b). This could be seen as a result of the freedom with which LAs operate in the organisational aspects of EHC plans. There is no prescriptive template stemming from the Code of Practice dictating how to produce a plan, as the guidance provided is general in terms of sections and content. One of the key aspects of the SEND reform was the move towards a more user-led, decentralised system, services and provision: these are shaped by parents, children and young people, who are seen as co-producers in consultation with LAs and professionals (Lamb, 2013). The discrepancies found among plans raise the question about equality, consistency and comparability of service provision at local and regional level. Although professionals have welcomed the principle of multiagency collaboration and the shift towards a

more user-led system, recent studies concerning the experiences of professionals of the SEND reform have suggested that the implementation of these principles was somewhat challenging. They highlighted the need for specific guidelines for the development of plans that would tackle the disparity found across LAs, and more training opportunities for practitioners involved in the EHC assessment and planning process to implement the new SEND policy effectively and consistently across the country (Boesley & Crane, 2018; Palikara et al., 2018a). Future research should address the identification of best practices to elicit the views of children and young people with SEND in the scope of the EHC planning process, and aim to develop guidelines that would enhance the quality of plans and comparability of provision at national level.

### ***8.3.2 Functioning descriptions of the views, wishes and aspirations of young people with ASD***

The results of this strand illustrated in detail the areas of functioning that made up the fabric of the views, wishes and aspirations of young people with ASD at the end of compulsory education as portrayed in Section A of their EHC plans. The use of the ICF-CY as a taxonomy to translate the content of the EHC plans into functioning categories split into body functions and structures, activities and participation, and environmental factors was deemed appropriate to explore how holistic these documents were when describing the views of young people. A total of 225 ICF-CY codes were identified following from the deductive content analysis performed in EHC plans. This analysis revealed a predominance of Activities and Participation codes (58.2%), followed by codes from the component of Body Functions (24.4%), Environmental Factors (16.9%), and lastly Body Structures (0.5%).

The SEND Code of Practice specifies that Section A of the plans must include the history of the young person and a profile of his or her characteristics (DfE & DoH,

2015). In ICF-CY terms, this section focused greatly in the execution of tasks or actions (activities) and involvement of an individual in a life situation (participation). The overall predominance of activities and participation codes across all EHC sections, and particularly section A, suggests the crucial role participation plays in the lives of young people with ASD at time of transition. In this context, the most salient features related to young people's activities and participation referred to aspects of mobility (d4), self-care (d5) and domestic life (d6); these codes were linked across plans concerning young people's wishes to become increasingly independent and autonomous as they transition to their next phase in their lives. These findings are consistent with other findings in the literature that suggest young people with ASD have less experiences of independence and autonomy than those expected from youth transitioning to adulthood. Research has reported that adolescents with ASD leave secondary school feeling unsure or unprepared for adult life, post-secondary education, community living and life at work (Pellicano et al., 2014a; Schall & McDonough, 2010; Taylor & Seltzer, 2011; Wehman et al., 2014a). For individuals with ASD and their families, moving on to post-compulsory education translated into aspirations of autonomy related to the involvement of young people in day-to-day activities, like learning to prepare a meal on their own, sorting out washing, or using public transport without adult supervision.

The content linked to the component of environmental factors should be highlighted in this regard, as support and relationships (e3), and attitudes of other people (e4) were indicated as key components of the lives of youth with ASD in transition. A holistic approach towards service provision should not only consider the individual characteristics of the young person and their needs, but those of the context in which they are immersed. This finding shows the invaluable contribution of the ICF-CY framework to systematically identify all areas of functioning; highlighting that what young people and their families wish to achieve occurs in a context that has the potential to act as a barrier or as a facilitator to their participation (Castro & Palikara,

2016). Therefore, when addressing the views, wishes and aspirations of young people in their EHC plans, special attention should be given to environmental factors, often underrepresented in planning and provision as they will play a key role as mediators of the young person's participation (Castro et al., 2012).

Finally, a large number of body functions codes were found in this section as well, describing physiological functions of body systems, including psychosocial functions. Descriptions that referred to young people's intellectual functions, temperament and personality, their dispositions and intra-personal characteristics, attention, memory and psychomotor functions, together with descriptions of their emotional functioning, language and higher cognitive abilities were broadly found across EHC plans. This finding highlights that a great extent of the focus in Section A relates to diagnostic categories or to 'within child' characteristics. Portrayals of the individual in these terms are well suited in the context of the plan as they build an understanding of the individual; nevertheless, it might be pertinent as well to expand these characterisations to include aspects of functioning that are relevant for participation in day-to-day activities and that reflect on the implications of those characteristics for the education context (Palikara et al., 2018b).

### ***8.3.3 Functioning dimensions identified as education, health and social care needs.***

In the broader context of the SEND reform, the Code of Practice aimed to introduce a more holistic system of assessment and provision to support SEND by incorporating education, health and social care needs sections in the new statutory documents. This has strengthened the duty of other agencies involved with the child to take active part in the EHC assessment, planning process and in the delivery of provision. Although the principle of multiagency collaboration has been well received by stakeholders, the introduction of the sections of health and social care has been

quite controversial and faced criticism with regards to the actual implementation and collaboration of these sectors (Boesley & Crane, 2018; Lamb, 2013; Palikara et al., 2018a). In this respect, Norwich (2014, p.146) suggested that 'calling the new plans *education, health and care plans* is also misleading, as they are basically education plans where health and social care needs are included in so far as they relate to special educational needs. They are not, for example, about health provision unrelated to special educational needs'. This raises a series of issues regarding the differentiation of needs and their suitability in light of a new SEND system that aims to be holistic.

First, the use of the ICF-CY taxonomy to analyse the content of the three sections of plans dedicated to needs, namely special educational (Section B), health (Section C) and social care (Section D) needs, has drawn attention to the interactive nature of functioning domains appearing within and across sections, and highlighted the difficulty in separating needs in these terms. Indeed, in all three sections meaning units were linked to ICF-CY codes that refer to activities and participation, environmental factors and body functions, indicating that the needs of young people go beyond the description of individual characteristics, as they appeared associated with aspects of the environment, and their involvement in everyday life situations. Furthermore, the breadth of functioning codes across needs sections suggests that in practice the description of needs cut across the boundaries of services. The current structure of the plans divided in sections for education, health and social care creates artificial boundaries to the needs of individuals. As an example of this, the Code of Practice 'allows' some health and social care needs to be described in the SEN section (Section B) as they might be closely related to the SEN of an individual. This means that there is a degree of acknowledgment from the Code that the separation of needs in these three categories is not entirely possible as they are interrelated; this may lead to translating compartmentalised needs into sectorised provision, perhaps

reducing the opportunity that the legislation posits on building services that are truly holistic.

Concerning the section on special educational needs (Section B), the Code of Practice states that this section should include identified needs through the EHC assessment, and that these may include needs that relate to health and social care, as long as these educate or train the child or young person (DfE & DoH, 2015). Furthermore, it introduces broad areas of need, namely communication and interaction, cognition and learning, social, emotional and mental health difficulties, and sensory and/or physical needs. A total of 147 ICF-CY codes were identified within this section, with 12 plans organised the content of this section following these broad areas of need, highlighting both ability and disability functioning aspects of the young people, building a clear picture of what is going well or working for them, and what requires attention.

In the context of what the Code describes as health needs, this strand has identified some inconsistencies with the holistic framework that the new law proposes. The WHO defines health as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (WHO, 2014, p.1). In this context, any special need – whether labelled educational, health or social care related – will be a health need in as much as it relates to the holistic wellbeing and quality of life of an individual. However, in the context of the analysed EHC plans health needs were presented mostly in terms of medical diagnoses. Seven out of ten plans that included information in the health section referred to the individual having a diagnosis of ASD as a health need. This understanding draws attention to the lack of clarity of the Code of Practice in the overall conceptualisation of needs and how these should be portrayed in the plans.

Describing specific diagnoses as health needs could lead to confusion about what the actual needs of the individual are. Having an ASD does not constitute a need on its own; the functional implications of the diagnosis, however, may entail different

needs that may affect the individual's participation (Castro & Palikara, 2016). Assigning the label of health needs, as understood by the Code of Practice, to those that stem from a medical diagnosis is somewhat limiting, given that the implications of a diagnosis in the functioning profile of the individual exceeds the boundaries of the biological and manifests in the individual's participation and wellbeing. This does not mean that those diagnoses should be excluded from the documents, as they provide valuable information about the individual. Nevertheless, it should be noted that this understanding of needs related solely to biological, physiological, anatomical aspects of health and health conditions seems to be at odds with the holistic conceptualisation of health proposed by the WHO and the biopsychosocial model that underpins the new legislation.

There seems to be a conceptual gap in the new legislation as the structure of the plans as it is seems to compromise how holistic and person-centred they could be. The breadth of the identified codes across the three needs sections suggests that what makes a plan holistic is its ability to recognise and describe functioning and disability across life areas, and not necessarily categorising them in education, health and social care terms. It has been acknowledged that young people with ASD face a series of barriers to participation that might be specific to their group, and that these are linked to the difficulties in social communication and interaction they experience (APA, 2013; Shattuck et al., 2012). In the context of the EHC plans, calling these needs *educational* suggests considering these difficulties in light of the implications they have for the education context. This is contradictory to the position of the Code of Practice about extending provision beyond education, to building a holistic picture of the child that is also person-centred, and to the focus on participation, wellbeing and preparation for adulthood.

Moreover, one of the main goals of a person-centred approach to SEND is for provision to be built with 'a focus on the support required to achieve goals, rather than limiting the goals to what services can provide' (Beadle-Brown, 2006, p.5). In this



respect, the current organisation of the plans seem to fit the latter, placing the young person and their needs within the boundaries of a particular service. An example of this is in the organisation of Section D to cover social care needs. According to the Code of Practice, the needs of young people contained in this section should be aligned to the provision of welfare services as required by Section 2 of the Chronically Sick and Disabled Persons Act 1970 (DfE & DoH, 2015). Thus, the separation of needs in these three different categories could be somewhat challenging to develop ecological provision, and in turn it could lead to fragmented or even disconnected provision. Perhaps it would be more holistic and person-centred to present the individual's functioning and needs as a whole as part of a multidisciplinary, collaborative process, without the categorisation of needs. By doing this, addressing the involvement of different agencies could take place at the stage of describing the provision required to meet those needs; it may well be that the same need or difficulty could be met or catered for by different services or agencies through complementary interventions and practices.

This may represent a new set of challenges at implementation level. Professionals and practitioners consulted on the implications of the SEND reform for their work have emphasised their agreement with the principles of multiagency collaboration and person-centred planning introduced by the new Code of Practice (Boesley & Crane, 2018; Hellowell, 2017; Palikara et al., 2018a; Pearson et al., 2015). While there is wide recognition that children and young people may have needs with implications beyond the boundaries of the education sphere, they highlighted the constraints of front-line joint, collaborative work. Particularly, they stressed the predominance of the education sector in leading the development of EHC plans, and the difficulties of involving practitioners from other services in a meaningful way (Boesley & Crane, 2018; Hellowell, 2017; Palikara et al., 2018a; Pearson et al., 2015). In order for multiagency partnerships to be fruitful in their shared endeavour to solve social problems, there is a need for a shared sense of aims across services. A clear

understanding of professional-specific agendas, roles between and within services and individuals is key for bridging the existing gaps in service provision by combining the strengths of professional expertise (Milbourne, Macrae, & Maguire, 2003; Lindqvist, Nilholm, Almqvist, & Wetso, 2011; Palikara et al., 2018a).

#### **8.3.4 Outcomes sought for young people with ASD**

The analyses of Section E aimed to explore the overall functioning domains and categories identified as outcomes sought for young people with ASD in their EHC plans, following a deductive approach using the ICF-CY framework as a system of pre-defined codes (Castro et al., 2013; Cieza et al., 2016). Furthermore, they aimed to explore the extent to which the outcomes matched the views, wishes and aspirations of young people as identified in Section A of the EHC plans. Lastly, they aimed to investigate the overall quality of the outcomes, and to examine whether there was significant variation across quality indicators and LAs.

Eighty-four ICF-CY codes were linked to meaning units in Section E of the EHC plans. The component of activities and participation was the one that yielded the greatest proportion of functioning codes in terms of both occurrence and frequency. This finding emphasises once again the focus of EHC plans on the execution of tasks and involvement of individuals in a wide range of life situations. The chapter of learning and applying knowledge (d1) resulted the most salient one, suggesting significant consideration given to activities related to academic life. In this respect, significant codes identified in this chapter revealed a strong emphasis on the improvement of literacy and numeracy skills, in line with suggestions concerning the predominant role that education has in the newly developed plans (Norwich & Eaton, 2015; Robinson et al., 2018). Managing one's behaviour (d250) was another salient code found in this section, together with the chapters of communication (d3), and interaction and relationships (d7). The identification of these codes among outcomes

sought for young people suggests the need to target difficulties traditionally associated with ASD, thus were expected to emerge across plans.

Outcomes formulated in terms of body functions and environmental factors were found in smaller yet similar proportions. The small number of codes belonging to the component of environmental factors in this section suggests that while the outcomes sought for young people with ASD focused on the individual's skills, capacities and participation, they neglected including characteristics of the context in which the young person is embedded (Sanches-Ferreira et al., 2013). The development of individualised interventions and provision requires recognising the role contextual factors may have in the individual's participation, and so the environment could potentially find a place within outcomes as a promotor of change, aligned with bioecological models of development and health (Castro et al., 2014; Ziviani, Desha, Feeney, & Boyd, 2010).

Concerning the match between wishes and aspirations of young people and the outcomes sought for them, a noteworthy overlap of ICF-CY codes across sections has been identified in the domain of activities and participation. Indeed, out of the 131 activities and participation codes linked to meaning units in Section A, 56 were also linked to outcomes in Section E. The overlapping codes referred predominantly to functioning categories concerned with developing literacy and numeracy skills. This indicates that a considerable proportion of interventions to be put in place for young people point to functioning aspects concerned with learning. In addition, the outcomes echoed the individual's wishes to become increasingly more autonomous in transitioning to post-secondary destinations, expressed in codes referring to carrying out daily routines, managing one's behaviour and handling stress, making progress in educational programmes, or gaining employment. This finding illustrates a common thread between both sections, as the Code of Practice advocates for the development of outcomes that reflect the views, wishes, and aspirations of young people and their families.

Nonetheless, as described above, the analysed outcomes did not incorporate aspects of the environment, and this transpired in the match between views and outcomes as only four environmental factors codes were identified as occurring in both Section A and Section E of the plans. This is a notable finding given the emphasis placed on support and relationships, attitudes of other people, policies and services available to young people in the section concerning their views. As previously highlighted, an important proportion of overlapping codes between sections indicated that outcomes targeted the young person's ability to learn. Environmental factors play a great part in facilitating or hindering an individual's participation, so developing high quality interventions would require a careful assessment of the context, and considering those aspects of the environment that would contribute to increasing the young person's participation (Boavida et al., 2010; Castro & Palikara, 2016).

Lastly, the main conclusions stemming from the analysis of outcomes using the GFS III is that the overall quality of the outcomes sought for young people with ASD is objectively poor, and that there are significant differences in the quality of these outcomes across GFS III indicators and LAs. Although the Code of Practice stresses the need for outcomes to be expressed in SMART terms (specific, measurable, achievable, realistic, and time-bound) (DfE & DoH, 2015), a close look at the GFS III scores indicates that the development of outcomes requires quality refinement. Consistent with findings from previous research, a large number of outcomes sought for young people with ASD did not address functional skills that would enhance the young person's participation in everyday functioning (Boavida et al., 2010; Rakap, 2015; Sanches-Ferreira et al., 2013). The development of these skills is critical, as once they are learned they enable the individual to become more independent in their everyday lives (Rakap, 2015).

A common denominator across plans has been that of the breadth and vagueness of the outcomes sought for young people with ASD. A quote that illustrates this: 'I will be working towards achieving my targets' exemplifies the lack of specificity

of the skill to achieve in terms of participation, as shown by the GFS III indicators for participation in a routine or activity and usefulness of skill for participation. The low score for the indicator of generalisation criterion could be related to the breadth of the outcomes, as; the precision with which an outcome is written. With regards to measurability, high quality outcomes in these terms are those that allow professionals and practitioners working with the individual to assess and establish whether the individual has acquired the proposed skill. In this strand of study, it was found that outcomes sought for young people with ASD rarely include details pertaining indications of how to measure performance or assess the achievement of a skill, as they often lack another critical element which concerns the criteria for acquisition of a particular skill. These findings are consistent with evidence of prior research (Boavida et al., 2010; Sanches-Ferreira et al., 2013, Rakap, 2015). The precision with which an outcome is written has a crucial implication for practitioners and families, as it allows those interacting with the young person to know what are the skills that require development, the characteristics of the context in which to teach them, and how to prompt them in a wide range of contexts and situations (Lignugaris-Kraft, Marchand-Martella, & Martella, 2001; Rakap, 2015).

Findings of this strand with regards to the differences in outcome quality scores showed significant differences between LAs, in spite of the overall poor quality of outcomes. These findings provide further evidence of the disparities found among LAs in the development of EHC plans, and is consistent with recent findings from studies concerning the experiences of different professionals with regards to the implementation of the new legislation in England (Boesley & Crane, 2018; Hellawell, 2017; Palikara et al., 2018a; Pearson et al., 2015). The variability of approaches adopted by LAs, and the lack of specific guidelines to produce high quality EHC plans resulted a common denominator of practitioners' experiences across these studies.

### **8.3.5 The use of the ICF-CY as a theoretical and analytical framework**

The use of the ICF-CY system to analyse deductively the content of EHC plans offered the possibility of approaching each section of the collected EHC plans in a systematic manner. It also provided a universal language with which to reflect on how holistic they were in the portrayal the views of young people with ASD, their needs and the outcomes sought for them (Lollar & Simeonsson, 2005). The detailed nature and systematic organisation of the ICF-CY classification served as an apt tool for the identification of functioning characteristics of young people with ASD in a standardised, biopsychosocial way, in line with recommendations stemming from the new SEND Code of Practice (DfE & DoH, 2015).

The specificity of the ICF-CY system and the uniqueness by which the codes were brought together within and across sections of the plans permitted a detailed understanding of the functioning dimensions that make up the fabric of the experiences of young people with ASD. This allowed to account not solely for the individual wishes, aspirations and characteristics of the young person, but for the multifaceted aspects of the physical, social, and cultural systems and environments in which they develop (Castro & Palikara, 2016; Douglas et al., 2011). Thus, this approach has significant implications not only for exploring the quality of the content of these plans, but also for their development (Castro & Palikara, 2016). As a common language, the ICF-CY helps to communicate different factors and needs that influence the functioning of young people with ASD in diverse environments, and provides a framework to guide transdisciplinary processes, and support multiagency collaboration (Adolfsson, 2013; Kraus de Camargo, 2011).

In this respect, the adoption of a biopsychosocial, functioning taxonomy as the ICF-CY in the EHC plan development suggests that the categorisation of needs in education, health and social care in EHC plans would be unnecessary. By adopting this approach, professionals and practitioners would be able to describe these in

specific functioning dimensions with the ICF-CY's universal language, covering all life areas without overemphasising one over the other (Castro et al., 2013). Furthermore, the breadth and universality of the ICF-CY system and language would also enable professionals to compare functioning data within and across individuals, schools, LAs and countries, as prioritised by the Children and Families Act 2014.

### **8.3.6 Limitations**

There are a series of limitations that should be considered. Firstly, the number of collected EHC plans was lower than what the researcher initially anticipated to collect. The researcher put in place a broad range of measures to attract a larger number of participants; due to the difficulties in recruiting participants, and the delays faced by LAs in converting old statements of SEN into the new EHC plans, obtaining a larger sample was not possible. It should be noted that the identification and data collection phases of this strand of study took part during the transition period stipulated by the new law for LAs to convert old statements of SEN into the new EHC plans. This transition period started in September 2014 and ended in April 2018. The conversion process has faced delays; according to the Office for National Statistics (ONS), by January 2018 almost two thirds of the existing statements have been transferred to EHC plans (DfE & ONS, 2018). These delays might have affected the final number of plans collected for the purposes of this research. In fact, although 29 participants were recruited to take part in the whole study, six participants have been excluded from the EHC plan analysis strand as they held EHC plan drafts and annual reviews summaries, but the final version of their EHC plans were pending at the time of writing. However, given that the main aim of this research was concerned with the views of young people themselves at this particular point in their lives, the fact that they did not have a finalised EHC plan at this point was not seen as representing a constraint to gathering their views.

Participants' EHC plans confirmed the presence of ASD diagnosis, and the researcher did not corroborate the presence of ASD diagnosis through standard diagnostic instruments, such as ADI-R or Autism Diagnostic Observation Schedule (ADOS). Diagnosing ASD involves a multidisciplinary assessment procedure that calls for a detailed investigation of the developmental history of the individual, examination of current behaviours, cognitive and language assessments, and observation of functioning in a wide range of contexts (Le Couteur, Haden, Hammal, & McConachie, 2008). This thorough exploration is usually complemented with the use of standardised instruments such as ADI-R and ADOS, and combined with clinical judgement by professionals with expertise on ASD (Baird et al., 2006). Given the rigorous procedures and assessments conducted by the LA in order to decide issuing an EHC plan based on the profile of needs of the young people, and the difficulties in recruiting participants, it was considered that screening the participants for current ASD symptomatology with the SCQ would suffice to provide an overall picture of the communication profile of each individual at one point in time in order to inform interview adaptation processes.

### ***8.3.7 Implications for practitioners and professionals working in SEND***

This strand of study explored the way the voices of young people with ASD, their needs and the outcomes sought for them were portrayed in the newly developed EHC plans. This study stressed that following the introduction of the new SEND legislation, there is variation in the ways the voices of young people and their families are portrayed in their EHC plans. Furthermore, the use of the ICF-CY system as an analytical tool allowed the identification of specific areas of functioning that are relevant for young people with ASD at the end of their compulsory education journey, placing a significant emphasis on participation. By analysing the plans with this systematic framework, it was possible to translate the views and aspirations of young



people into detailed functioning dimensions that could in turn be helpful to develop specific, tailor-made provision to achieve outcomes sought for these young people. In addition, it highlighted some difficulties around organising the content of the plans by classifying needs in terms of education, health and social care sections. This suggests that the move towards a more holistic, interdisciplinary and person-centred approach to assessment and service provision for children and young people with SEND requires representing those needs in a language that is universally understood, which focuses on functioning rather than diagnoses or services. By using this system to support the implementation of the SEND framework the stratification of needs of young people to match services becomes irrelevant, as the holistic portrayal of the individual advocated in the new law is obtained by describing them in functioning dimensions that include body functions and structures, activities and participation, and environmental factors.

In this respect, the ICF-CY can play a key role in building high quality, holistic EHC plans. The ICF-CY provides a framework that encompasses all dimensions of human functioning, with a focus on health rather than disease, and an understanding of disability as a universal dimension of life (Castro et al., 2014; Lollar & Simeonsson, 2005). In this respect, the ICF-CY system can serve as a tool to record characteristics of children and young people's functioning in detail, including relevant aspects of the environment, using a neutral and universal language.

Further research is needed in relation to the development and analysis of EHC plans from a functioning perspective. In particular, research is needed about processes concerned with eliciting and documenting the views of young people with ASD and other SEND in their EHC plans, and concerning the aspirations and outcomes of individuals with a history of ASD as they move towards post-secondary destinations and adulthood. It would be interesting to explore the extent to which the ICF-CY functioning domains identified in the views, needs, and outcomes of young people with ASD match or relate to those of young people with other SEND, and how

these functioning dimensions change throughout the transition period. The use of the ICF-CY as a common language and system in this exercise might highlight commonalities and differences in experiences and needs that go beyond the borders of diagnostic characteristics and services, and would allow a detailed identification of changes in functioning dimensions following a longitudinal approach. This would allow agencies to work jointly, in collaboration with young people and their families, in the development of ecological provision that recognises the individuality of the functioning profile of each person. Lastly, it is imperative to highlight the need for training and guidance for members of staff at school, LA and agency level for those involved in the EHC assessment and process, to advance skills that would secure consistency and quality in the development of holistic EHC plans.

### **8.3.8 Summary**

The results of this strand of study have shown that in spite LAs embracing the principles of the new SEND Code of Practice, the content and organisation of the EHC plans of young people with ASD did not seem to honour those principles. This strand provided evidence that the views, needs and outcomes of children and young people go beyond diagnostic labels and across the boundaries of services. Findings stemming from this strand recognise the significance for young people with ASD to become increasingly more independent and to participate further in their communities as they move to post-secondary destinations. The development of person-centred provision calls for adopting practices that would help professionals and practitioners elicit and record the views of young people and their families in a holistic way, and incorporate them to the development of multidisciplinary services. The systematic adoption of the ICF-CY could help bridge this gap by providing a universal language and system to build a detailed picture of the child, identifying ecologically specific functioning dimensions across life areas that relevant to them. This strand also

emphasised that obtaining a holistic view of the young person does not equal to compartmentalising needs so that different services make arrangements to meet those needs. Implementing the principle of person-centred planning to the development of holistic provision requires practitioners to place the individual at the centre, recognise them as a whole, indivisible in terms of needs, and to incorporate aspects of the environment that may act as barriers or facilitators of individual participation.

#### **8.4 Matching the views of young people with ASD from semi-structured interviews and EHC plans**

This strand of study explored the extent of the match between the views of 22 young people with ASD in their transition to post-16 education and employment obtained through individual, semi-structured interviews, and through the analysis of their respective EHC plans. The following research question emerged:

- a. To what extent do the ICF-CY functioning dimensions identified as the young people's views in Section A of EHC plans match those identified by the young people themselves in semi-structured interviews?

The use of the ICF-CY system to analyse deductively the content of interviews and EHC plans offered the possibility of building a detailed picture of the views of young people with ASD, and functioning dimensions associated with their views in a holistic manner, as suggested by the new SEND Code of Practice (DfE & DoH, 2015). Furthermore, the common language provided by the ICF-CY classification system to analyse the views of young people with ASD from both sources of data allowed the exploration of the extent of their match, and the identification of gaps in the development of EHC plans, with an emphasis on Section A. The universality of the language of the ICF-CY is aligned with the collaborative nature of these newly

developed documents, thus constitutes an apt framework to support multi-agency working (Castro & Palikara, 2016; Palikara et al., 2018b).

A total of 273 ICF-CY codes were identified following from the deductive content analysis performed in interviews and EHC plans. This analysis revealed a predominance of Activities and Participation codes (59.6%) across EHC plans and interviews, followed by codes from the component of Body Functions (22.4%), Environmental Factors (17.6%), and lastly Body Structures (0.4%). In addition, a 44.9% of ICF-CY code overlap was identified when looking at the proportion of ICF-CY codes that emerged both in interviews and EHC plans. Although on one hand this finding suggests certain concordance in the functioning-related content of interviews and EHC plans, it also suggests disparities. It could be argued that the nature of the interviews and the nature of EHC plans could have emphasised different aspects of functioning, in spite of the interview having been built on the basis of the content of Section A as expressed in the Code of Practice.

Another important aspect to consider with regards to these discrepancies is the fact that, as described in Chapter 6, many EHC plans did not present evidence about the contributions of the young person in the development of Section A and the rest of the documents. It could be hypothesised that the discrepancies in the functioning codes could be due to the young people giving emphasis to aspects of their day-to-day life in the interviews, than those being represented in their EHC plans as their views.

The SEND Code of Practice establishes that Section A of the plans must include the history of the young person and a profile of his or her characteristics (DfE & DoH, 2015). In ICF-CY terms, this section focused greatly in the execution of tasks or actions (activities) and involvement of an individual in a life situation (participation). Thus, the overall predominance of activities and participation codes across EHC plans in these terms was expected. Similarly, these codes were found at large in interview transcripts, as questions were aligned to the content of section A of EHC plans. It is

noteworthy that the code for decision-making (d177) was the most frequently found code of all ICF-CY codes identified in interviews and Section A of the EHC plans. This particular code is one of enhanced significance in the period of transition to post-16 education and employment. Indeed, the Code of Practice presents participation of the child, their family, and the young person in decision-making as the first key underpinning principle of the new SEND framework; participants discussed this at length in interviews, as portrayed in Chapter 5.

Findings referring to mobility (d4), self-care (d5) and domestic life (d6) codes were linked across interviews to young people's wishes to become increasingly independent and autonomous as they transition to their next phase in their lives, while at the same time acknowledging the significant role of support and relationships (e3), and attitudes (e4) in their lives. These findings are consistent with literature suggesting less experiences of independence and autonomy in ASD than those expected of youth transitioning to adulthood, together with feeling unsure or unprepared for adult life, post-secondary education, community living and life at work (Pellicano et al., 2014a; Schall & McDonough, 2010; Shattuck et al., 2012a; Taylor & Seltzer, 2011; Wehman et al., 2014a).

A large number of Body Functions codes were found in this section as well, describing physiological functions of body systems, including psychosocial functions. Descriptions that referred to young people's intellectual functions, temperament and personality, their dispositions and intra-personal characteristics, attention, memory and psychomotor functions, together with descriptions of their emotional functioning, language and higher cognitive abilities were broadly found across EHC plans. The significant discrepancy in the representation of these codes in relation to the interviews suggests that although the intention of the EHC plan is to portray a holistic view of the individual, a great extent of the focus in Section A relates to diagnostic categories or to 'within child' characteristics. In contrast, young people tended to refer to themselves and their functioning mostly in Activities and Participation, and usually

in Environmental factors terms, rather than by making descriptive statements about their personalities, their intellectual functions, as identified mostly across EHC plans. Nevertheless, the code for emotional functions (b152) was addressed significantly by participants during the interviews, in particular to refer to how they felt about their future, and so was the code for motivation (b1301) in matters concerning young people's preferences, likes and dislikes.

The Environmental Factors domain was that produced the most interesting and significant findings stemming from interviews and EHC plans. The analysis using the ICF-CY revealed the presence of a similar range of codes from environmental factors domain; however, the striking finding is the substantial difference in frequencies found between interviews and EHC plans. The higher frequency of these codes in interviews suggests that, although plans did cover a wide range of environmental aspects of the youth, they did not capture the extent to which support and relationships, and attitudes of other people may impact the functioning of young people. This finding indicates a significant underrepresentation of relevant functioning characteristics when addressing the views and experiences of young people with ASD in their EHC plans, particularly when Section A is the starting point of a plan. In this regard, the holistic nature of the ICF-CY framework facilitated the identification of functioning characteristics across all life domains, including aspects of the environment that were relevant to the young people.

Previous studies exploring the content of individualised education plans (IEP) (i.e. Castro et al., 2014) and EHC plans (i.e. Palikara et al., 2018b) using the ICF-CY framework reported similar findings concerning the representation of environmental factors in these documents. In the scope of the development of holistic documents that capture a wide range of functioning dimensions, the systematic use of the ICF-CY domains allows professionals to address and represent functioning dimensions in equal proportions, without overemphasising one domain over another (WHO, 2007).

In this strand, in-depth accounts of the views, aspirations and experiences of finishing secondary school and moving into post-16 education and employment of 20 young people with ASD were obtained through two complementary strands. The content analysis using the ICF-CY framework as a predefined system to code data allowed capturing a wide range of characteristics and functioning aspects of young people with ASD in a universal language. Given the small sample used in this study, generalisation of findings is limited. In addition to this, the ICF-CY model acknowledges that personal factors (i.e. age, gender, ethnicity, etc.) contribute to the functioning profile of an individual, however these variables cannot be coded under the current framework, and therefore there are aspects of their functioning which have not been translated into the ICF-CY language for analysis.

#### ***8.4.1 Implications for professionals and practitioners in SEND***

As young people with ASD leave the secondary education context and begin their transition to adulthood, there is a recognised need for agency and self-determination (Hendricks, 2010); therefore, individual accounts on aspirations and needs are required to develop tailored provision to support them in this trajectory. The use of the ICF-CY framework helped in the identification of discrepancies in the young people's functioning between interviews and plans, evidencing that functioning aspects relevant to young people themselves were not portrayed in Section A of their plans. The move towards a more holistic, interdisciplinary and person-centred approach to assessment and service provision for children and young people with SEND – as proposed by the Children and Families Act 2014 – requires a language that is universally understood services and disciplines. In this respect, the ICF-CY can play a key role in assisting the development of EHC plans and multidisciplinary provision, allowing a detailed and individualised approach to portrayals of young people's functioning, while being holistic and covering a wide range of areas of

functioning, supporting inter-professional collaboration (Castro & Palikara, 2016; Palikara et al., 2018b). The statutory nature of the views of young people to be included in their EHC plans calls for greater awareness of the fact that “respecting children’s views is not just a model of good pedagogical practice or policy making, but a legally binding obligation” (Lundy, 2007, p.930). In this regard, the themes that emerged in semi-structured interviews could help guide the conversation of transition to life after secondary school in light of what it is meaningful for young people themselves at that particular time.

#### **8.4.2 Summary**

In sum, the present strand identified the dimensions of functioning that were captured both in semi-structured interviews and Section A of EHC plans. The findings from this strand show that although there is a match in some areas of functioning, particularly those related to activities and participation and environmental factors, they differ in the scope of the functioning dimension and component. One of the most salient findings was that young people stressed the relevance of aspects of the environment as facilitating factors in their functioning, such as the role of family, friends and relevant staff members at school, while recognising as well the significant impact of attitudes of other people towards them to their functioning. In this regard, the identification of this discrepancy was possible through the analysis of both interviews and EHC plans using the language of the ICF-CY. By adopting a biopsychosocial framework to explore the views of young people with ASD in their transition to post-secondary destinations, we make room for the emergence of an individual in context. The experience of functioning and disability under this framework results from complex interactions between biological, social and psychological factors, and not by the presence of a diagnosis. Thus, the use of the ICF-CY as a theoretical and analytical framework in SEND facilitates the recognition of a broad



range of functioning dimensions that go beyond those located 'within' the individual, which could assist the development of EHC plans, interventions and provision tailor-made to match the views and individuality of each person, accounting for all life areas.

### **8.5 Quality evaluation of outcomes sought for young people with ASD in transition to post-secondary destinations.**

The purpose of this strand of study was to provide evidence on the quality of the outcomes sought for young people with ASD as defined in their respective EHC plans, in light of their imminent transition to post-secondary life. Four research questions emerged with regards to the quality of outcomes:

- a. What is the overall quality of outcomes defined for young people with ASD in their EHC plans?
- b. Does the quality of the outcomes depend on the LA that produced them?
- c. Does the quality of the outcomes vary depending on the type of school that produced them?
- d. Does the quality of the outcomes vary depending on the year group they are written for?

A total of 265 outcomes were analysed using the seven quality indicators of the GFS III (McWilliam, 2009). Results have shown that these outcomes were strikingly low in quality, and that quality differs in relation to the LAs that produced the outcomes, the type of setting (special or mainstream), and the year group (secondary or post-secondary) that they belonged to. Given that the outcomes section of EHC plans provide guidance to the provision required to put in place to achieve the

proposed outcomes, the low quality of these raises concerns with regards to how they would translate into high quality provision for this particular group.

Concerning the quality of outcomes and the LAs that developed the EHC plans, it was observed that those LAs with a higher ranking on the IDACI produced outcomes of lower quality than those with a lower ranking, therefore more socioeconomically affluent. Conversely, LAs of more affluence produced higher quality outcomes for the EHC plans for young people with ASD. This finding is consistent with findings reported by Castro and colleagues (2019) in their analysis of over 2800 outcomes for children and young people with SEND, and warrants further investigation. A series of questions emerge in this respect concerning the reasons behind this phenomenon. It could be hypothesised that LAs in more affluent areas are in a better position to offer opportunities for training to those involved in the development of the EHC plans, which could contribute to enhancing the overall quality of the documents and the outcomes included in them; another potential reason behind this phenomenon could be linked to the level of involvement of parents in the EHC plan process and with regards to the needs of their children, by providing feedback and input during the EHC plan development and review process.

As it previously mentioned, the overall quality of outcomes was quite poor across LAs, type of school and year group. With regards to the type of school, the analyses performed showed statistically significant differences between types of school in two out of seven quality indicators from the GFS III. It was observed that mainstream schools performed slightly better than special schools in the first criterion of the GFS III, which observes whether the outcome *emphasises the child's participation in a routine* (criterion a). More than three quarters of outcomes developed by special schools were assigned the lowest rating for this criterion, whereas more than two thirds of those from mainstream settings were rated from *somewhat* to *much*. Generally, outcomes produced by mainstream schools were more focused on the overall participation of the young person than special schools.

This finding was quite surprising as special schools are traditionally associated with having a more detailed focus and expertise than mainstream schools, and from that stemmed the anticipation that these schools would perform better in this regard than mainstream settings. In spite of this expectation, a possible explanation for this finding could be that children and young people attending special schools would be working at a lower school level than those in mainstream settings, and therefore their outcomes might have had a stronger focus on improving academic skills, which may have an implication either in their use or necessity for participation (as explored by criterion c), but may not represent direct involvement of the young person in an activity or routine.

This finding could be linked to findings stemming from the analysis of outcomes using the ICF-CY system, as described in Chapter 5 of this thesis. In this analysis, the chapter of learning and applying knowledge (d1 codes) was the most salient among activities and participation codes, which suggested that an emphasis to activities related to academic life. Outcomes coded as belonging to this code family usually referred to the improvement of literacy and numeracy skills, rather than broader everyday life skills. This seems to reflect some of the criticism that arose with the introduction of the new EHC plans and the new SEND policy, which highlighted that in spite of promises of 'radical change' the system would still place a strong emphasis on education and training understood in academic terms (Boesley & Crane, 2018; Norwich & Eaton, 2015; Robinson et al., 2018).

Another significant difference in terms of type of setting arose with regards to the indicator that explored whether the outcome *specified the skill or behaviour the child should present* (criterion b). Special schools have a significantly higher frequency of high scores for this criterion than mainstream schools. One of the possible reasons that might help explain this phenomenon for this setting could be the presence of more nuanced approach and detailed processes for implementing strategies monitoring their progress in specialist settings when compared to

mainstream settings. This could also be linked to the overall profile of strengths and difficulties of students, and the pace of their learning, which may call for a closer look to the nuances of their progress (Scruggs, Mastropieri, Berkeley, & Graetz, 2010). This is consistent with findings from Boavida, Aguiar, McWilliam, and Pimentel (2010); in their study exploring the quality of goals in IEPs they found that higher scores for the criterion of measurability was positively associated with higher levels of severity of needs in children with SEND; it was suggested that as children with more severe disabilities might make progress in smaller steps, teachers would pay more attention to the measurability of their progress. This finding could also be explained within the SEND landscape of budget cuts, performativity and increased local accountability, whereby these forces could call for greater pressure in practices of monitoring pupil progress (Norwich, 2014, Pearson et al., 2015).

When looking at the year group to which the outcome corresponded, and how this could influence the distribution of the quality ratings of the outcomes, it was observed once again that in spite of the overall low quality of outcomes, statistically significant differences were found between secondary and post-secondary school ratings for the criteria of *participation in a routine* (criterion a), and *measurability of the outcome* (criterion b). With regards to the first criterion, post-secondary settings performed better in this respect than their secondary counterparts. This could be explained by the fact that post-secondary settings might place a stronger emphasis on engagement on everyday life activities and on the acquisition of day-to-day life skills rather than on acquiring or reinforcing academic skills. Thus, it was expected from post-secondary settings to develop outcomes for young people with ASD that highlight self-help, domestic life and wider independence in a range of life areas (Machalicek et al., 2008). With regards to the indicator of *measurability of the outcome* (criterion b), secondary schools performed statistically significantly better than post-secondary settings. Once again, this could be related to the heightened focus of

secondary schools to closely monitor pupil progress and the pressures for accountability of attainment and progression of children with SEND.

### **8.5.1 Limitations**

A number of limitations need to be considered with regards to this strand of study. First, although 265 outcomes developed for young people with ASD were included for analysis, these outcomes were extracted from only 23 EHC plans of young people between 15 and 19 years of age, in the Greater London area; thus, these findings do not allow building a geographically wide picture of the outcomes sought for young people with ASD and their overall quality. In this respect, future research should aim at evaluating the quality of outcomes emerging from a variety of regions across the country to confirm the overall low-quality trends identified in this strand of study for youth with ASD transitioning to post-secondary life. Although the overall low-quality of outcomes reported in this strand seem to concur with those of Castro and colleagues (2019) following the analysis of 2813 outcomes identified in 236 EHC plans of children and young people with SEND between 4 and 21 years of age. It would be interesting to explore in more detail the outcomes of young people with ASD across the country and confirm this trend, as discrepancies found in this regard among LAs suggest an uneven picture of high quality outcome production.

Another limitation refers to the effect sizes reported; these results should be looked at with caution, as the overall majority of effect size estimates were small to medium (Fritz, Morris, & Richler, 2012). Albeit this being a limitation, it suggests that the differences of quality found among outcomes may not respond necessarily to the type of setting (special or mainstream), or the education stages that they responded to (secondary or post-secondary), and might reflect that the overall landscape for the development of outcomes requires improvement to address their pooriness. Other factors could be contributing to this which were not accounted for in the analysis. The

writing process of EHC plans varies across LAs, on occasion schools taking the lead in their writing (i.e. SENCo), whereas other LAs employ individuals to put together the EHC plans based on the reports received from practitioners and professionals (Palikara et al., 2018b). These different practices among LAs could also account for the low quality of outcomes and should be further explored.

Lastly, a note should be in place with regards to the GFS III (McWilliam, 2009) as a tool for the task of evaluating the quality of outcomes of EHC plans. It must be acknowledged that although the elements of this tool might constitute a good match to evaluate outcomes, it was not designed to address and evaluate specifically EHC plans outcomes. In this respect, it would be beneficial that future research takes on the task to develop a tool that is in line with the requirements and criteria of high quality set in the SEND Code of Practice (DfE & DoH, 2015), so that the evaluation of outcomes would be a closer, truer reflection of the principles set in the new SEND framework in England (Castro et al., 2019).

### **8.5.2 Summary**

This chapter provided evidence of the overall quality of outcomes sought for young people with ASD at a time of transition to post-secondary destinations by analysing 265 outcomes defined in 23 EHC plans of young people. It has been emphasised in the new law that schools should be preparing children and young people with SEND for adulthood from the earliest years, and that involves engaging with them, their families and all stakeholders in conversations about the future, their aspirations and developing collaboratively the outcomes sought for them, in light of their ambitions, goals and their needs.

Findings from this strand indicate that overall, the quality of outcomes as defined in the newly introduced documents is considerably poor. This strand has also shown that the quality of outcomes varies significantly by LAs, year group the participants

were attending, and the type of setting in which participants were enrolled with regards to a number of quality indicators from the GFS III. In spite of the low quality of outcomes, variations were found for five dimensions of the GFS III across LAs, namely *participation in a routine criterion* (criterion a), *measurability of the outcome* (criterion b), *skill necessary or useful for participation* (criterion c), *states an acquisition criterion* (criterion d), and *presence of a generalisation criterion* (criterion f). Concerning the type of schools, mainstream schools performed better in producing outcomes with higher quality indicators for *participation in a routine* (criterion a), whereas special schools had a significantly higher frequency of high scores for the criterion that *specifies the skill or behaviour the child should present* (criterion b). Lastly, regarding the year group to which the outcomes responded, it was observed that post-secondary settings performed better in producing higher quality outcomes for the criterion of *participation in a routine* (criterion a), whereas secondary schools performed statistically significantly better than post-secondary settings for the criterion of *measurability of the outcome* (criterion b).

These findings call for further training of professionals and practitioners with the task of developing outcomes for young people at a time of transition in the scope of the EHC plan process. In this vein, Castro and colleagues (2019) suggest that training should be standardised across LAs, irrespective of the type of school, to ensure that outcomes and provision sought for children and young people with SEND are consistent with their individual needs and aspirations.

## **8.6 Summary of discussion**

This chapter presented the findings stemming from this thesis organised in sections that follow the order of research aims introduced in Chapter 1 and 2 of this thesis, and their relevant discussion with regards to the extant literature in the field. It also incorporated limitations to methodological approaches, sampling characteristics

and constraints in conducting this research. Concerning results, firstly, this chapter addressed the findings of the strand of study that explored the voices of young people with ASD in transition to post-secondary destinations in the scope of the changes introduced by the Children and Families Act 2014 and the new SEND Code of Practice. The phenomenological approach to methodology adopted for this strand, together with the themes that emerged as a result were highlighted as central to honouring the principle of involvement and participation of the young people in the development of provision to respond to their wishes, aspirations, and needs, that would ultimately mobilise provision to achieve the outcomes proposed for a meaningful and successful transition to post-secondary life. The relevance of systems of support emphasised by participants in semi-structured interviews accentuate the predominant role of environmental factors in paving the way for enhanced participation in their communities as well as in their education trajectories. Moreover, the analysis of interview transcripts using the ICF-CY framework has also enabled the characterisation of themes in rich detail, emphasising the nuanced and interconnected nature of functioning dimensions identified in these to deepen understanding of these views adopting a holistic perspective as advocated by the SEND Code of Practice.

The analyses of EHC plans through the lens of the ICF-CY taxonomy allowed unpacking dimensions of functioning that made up the fabric of the views, wishes, aspirations, needs and outcomes of young people with ASD at the point of transition to post-secondary life. In this respect, particularly important were findings concerned the predominance of activities and participation dimensions of functioning in the description of young people in these terms. In line with the extant literature in the field, a key aspiration for young people at this stage is increasing participation in the contexts in which they develop; the significance of these aspirations transpired in the functioning domains identified as the young people's views in their EHC plans. A similar emphasis was placed with regards to environmental factors to facilitate



participation; however, the significantly lower number of contextual factors identified in the sections concerning the needs and outcomes of young people seem to suggest that addressing these needs was a matter more related to the individuals themselves than to the environments in which they were embedded. This finding seems to be at odds with the proposal of the new SEND Code of Practice to provide holistic portrayals of young people with SEND so that LAs would be able to develop provision that is responsive to these. A holistic approach to SEND as advocated by the WHO (2007) requires the recognition that functioning and disability are part of the same continuum, and conditioned on the interaction of multiple domains of functioning – not merely body functions and structures, located within the individual – such as activities and participation, and the environmental context with which the individual interacts. Results stemming from this thesis indicate that there is still work to be done concerning ecological conceptualisations of SEND and holistic documentation of views, needs and outcomes that incorporate all these dimensions.

As for the outcomes extracted from the EHC plans and analysed with the GFS III, results from this strand of study suggest once again that outcomes written for young people with ASD at the point of transition to post-secondary life were of poor quality, and presented significant differences in the quality indicators among LAs that produced them, the type of school that the young people were attending, - that is, special or mainstream – and the year group for which they were designed – i.e. year 11 or post-16 education. These discrepancies not only highlight variability across outcomes, plans and LAs in general, but also pinpoint to specific quality domains that should be enhanced to develop high-quality, SMART outcomes that reflect the transitional aspirations and need of young people with ASD.

The new legislation and policy guidance on SEND was designed to build service provision that is responsive not only to the needs of a child or young person and their families, but also to their views and wishes, in an attempt to make services fit for purpose and restore parental confidence in the SEND system (Lamb, 2013). It

is stressed in the Code of Practice that schools must prepare children and young people with SEND for adulthood from the earliest years (DfE & DoH, 2015); for this purpose, engaging in conversations about the future with them, their families and other stakeholders constitutes a crucial starting point to effective preparation for adulthood. Children with SEND and their families have unique knowledge about their circumstances and their needs (Palikara et al., 2009); consultation with these groups should be ongoing to reflect the changes in their aspirations and needs. Collaborative work in the context of the SEND reform not only applies to engaging in conversations with children and families, but also with other agencies and stakeholders. Holistic provision is one that reflects the interconnected dimensions of functioning that build the profile of an individual developing in a particular context. The findings stemming from this thesis call for further training of professionals and practitioners with the task of developing tools for eliciting the voices of children and young people, irrespective of their SEND, writing holistic EHC plans that reflect the dimensions of functioning considering as well the environment in which the individual develops, in order to develop outcomes and provision consistent with their individual needs and aspirations.



## **9. Summary of findings and conclusions**

### **9.1 Introduction**

This chapter summarises the main findings stemming from this study in relation to how young people with ASD viewed and experienced their transition to life beyond compulsory education, together with their views, needs and outcomes as portrayed in their EHC plans. Methodological considerations and limitations of the current study are put forward, followed by suggestions for further research. The implications of this study for policy and educational and professional practice are also discussed.

### **9.2 Overview of findings related to the views of young people with ASD in transition to post-secondary destinations**

This strand of study contributes novel findings with regards to how young people with ASD see and experience their transition to post-secondary destinations, through the complementary perspectives obtained by semi-structured interviews (Chapter 4), the analysis of EHC plans (Chapter 5) using the ICF-CY as a coding system, and the exploration of the extent of the match between these sources of data (Chapter 6). Four research questions pertained to this line of enquiry:

- a. What are the views of young people with ASD about their transition to post-secondary destinations?
- b. What are the ICF-CY functioning dimensions identified as the views of young people with ASD as extracted from interviews?
- c. What are the methods used to capture the views of young people with ASD in their EHC plans?

- d. What are the functioning dimensions identified in the EHC plans as the young person's views, wishes and aspirations?

### **9.2.1 *The views of young people with ASD***

Participants provided insightful accounts on their experiences and aspirations of independence, autonomy and participation, the challenge of facing new settings with new people while at the same time facing feelings of loss by leaving their current setting; addressing ambivalent feelings about their own future, experiences of bullying, and the importance of the support they received from family, friends and school staff. The themes that emerged from this study highlight the complexity and interconnected dimensions of transition for young people, and stress the contrasting experiences of transitioning *from* environments and people that constitute a 'safe haven' for individuals with ASD, and the experiences of loss and anxiety concerning their transition *to* post-secondary destinations. Albeit this, post-secondary destinations could be construed as a bridge towards opportunities of further autonomy and wider participation. As such, these findings have important implications for transition planning in its role to equip and prepare the young people with skills that would help them navigate the change of setting in an assertive manner. This also calls for greater collaboration among service providers to help smoothen the journey to post-secondary destinations.

This study has also identified a series of commonalities and differences concerning the views of young people as explored through interviews and EHC plans. Overall, the views of young people had a focus on engagement in routines and involvement in life situations, as shown in the large number of codes identified from the ICF-CY's activities and participation component. However, the scope of activities and participation differed from EHC plans to interviews, with the latter focusing on gaining further autonomy and participating in everyday life situations in the domains of mobility, self-care, domestic life, and major life areas. EHC plans, however,

emphasised other dimensions of functioning such as learning and applying knowledge, and general tasks and demands. This finding points towards the fact that EHC plans are documents with an educational focus and relevance for the school context, where dimensions of participation could be seen as circumscribed to learning.

### ***9.2.2 Capturing the voices of young people with ASD***

Research has consistently reported that engaging young people in conversations about their future and transition from early stages of their school journey, and including the development of skills that would foster independence and confidence, such as domestic life skills, self-care skills, decision-making and community participation constitute effective ways of supporting the transition process (Carter et al., 2010; Robinson et al., 2018). In addition, multi-agency collaboration and involving families and relevant support staff are also seen as crucial in aiding transition of young people with SEND (Davies & Beamish, 2009). The principles adopted by the new SEND Code of Practice resonate with these suggestions, and have a direct link to the development of EHC plans. The Code of Practice emphasises the need to review the EHC plans every year, and to incorporate discussions about transition from year 9 (13-14 years of age), to develop plans and provision that are forward-looking and person-centred focusing on participation and wellbeing, and that involves multi-agency collaboration and the participation of all stakeholders in the process, most importantly, the child (DfE & DoH, 2015).

This study revealed a series of inconsistencies in the ways schools and LAs elicited and documented the views of young people with ASD in Section A. Findings of this study have shown that not all EHC plans had included the actual voice of the young person, and that the inclusion of their actual own views, wishes, and aspirations in more than half of the cases analysed was only assumed. Given the gravitas of voice

in the context of SEND reform, these findings are concerning. Firstly, as a starting point of an EHC plan and given the statutory duty for schools and LAs to have regards to the views of children and young people in the EHC planning process, these inconsistencies suggest that at practitioner-implementation levels improvement further guidance are required. Harrington and colleagues (2014) emphasise the prominence of practitioners' capacity to capture the voices of young people with ASD as critical to an in-depth understanding of their experience. In this respect, this study responds to the need for more in-depth understanding of the lived experiences of young people with ASD, while also highlights on the possibilities that the methods adopted to elicit, capture and analyse the views of a group of young people with ASD have for practitioners working with children and young people with SEND.

In order to make justice to the statutory right of young people to get involved, be given the opportunities to have a say about and shape their future in light of their own wishes, aspirations and goals, developing and delivering training for both school staff and practitioners involved in the EHC plan process is crucial. The efficacy in the use of communication tools that enable capturing the views of children with ASD depends on practitioners' knowledge of ASD and understanding which is the individual's preferred medium of communication (Fayette & Bond, 2018; Lloyd, 2015). It has been suggested that in the case of children with SEND, there might be an underlying assumption of limited capacity which could lead to their views being more readily ignored or less valued (Harris, 2009). This study has shown that with the support of visual stimuli from the Talking Mats framework (Cameron & Murphy, 2002), participants were able to engage in research interviews, and shared their aspirations, concerns and views about a range of areas of their lives at a significant point in their lives, irrespective of their communication difficulties.

Another significant finding from this study is that the voices of young people with ASD were not taken into account in their entire scope in the development of EHC

plans. Findings stemming from both interviews and the analysis of EHC plans have shown some contrast in the way young people themselves discussed their views, experiences and aspirations for the future, and the dimensions of functioning that emerged from analysing both interviews and Section A of EHC plans using the ICF-CY system. In particular, these differences emerged in relation to the role of environmental factors in acting as barriers or facilitators of functioning and participation in the lives of these young people. Although some recognition to contextual factors was given in the EHC plans, this did not represent the force with which young people referred to these aspects in interviews. This highlights that EHC plans emphasise functioning dimensions that are more likely to be located 'within the child', rather than accounting for the interplay of the environment in their functioning. Furthermore, this 'ceiling' in representing the actual voice of young people with ASD in these documents extends beyond Section A of EHC plans and is reflected as well in the section concerning the outcomes sought for this group at a time of transition. These issues are considered in section 9.4 of this chapter.

### **9.3 Overview of findings related to the nature of the content and functioning dimensions identified in the EHC plans of young people with ASD**

The use of the ICF-CY as a system for coding the content of EHC plans allowed representing this content in a universal language (Lollar & Simeonsson, 2005; WHO, 2007). The exploration of the content of EHC plans, particularly that of the needs of young people with ASD, using the ICF-CY taxonomy was guided by the following research question:

- a. What are the functioning dimensions identified in the outcomes sought for young people with ASD?

In doing so, it was possible to identify salient functioning dimensions in each analysed section of EHC plans. A common denominator across sections was the



predominance of codes from the activities and participation component to describe the views, the needs and the outcomes sought for a group of young people with ASD, followed by body functions codes, and lastly environmental factors. The identification of activities and participation codes suggests that the descriptions of young people focused on the execution of tasks (or limitations in this respect) and participation (as involvement in life situations, or restrictions in their involvement). Of particular relevance were those referring to mobility, self-care, and domestic life, suggesting that the move to post-secondary destinations for young people with ASD translated into aspirations of further autonomy and involvement in everyday life situations. In this respect, the role of environmental factors should also be underlined, as support and relationships, and attitudes of other people were signposted as vital components in the lives of young people with ASD in transition.

Concerning the needs of young people with ASD, through the use of the ICF-CY system to analyse the EHC plans it was possible to observe the interactive nature of functioning domains that appeared within and across the sections of education (Section B), health (Section C), and social care (Section D) needs. Evidence emerging from this study showed the difficulties arising from separating the needs of young people in these discrete terms. The activities and participation component, together with the body functions component were linked to a number of meaning units across sections of the EHC plans that were also linked to environmental factors. In this respect, evidence suggests that the description of the young people's needs is not circumscribed to 'within' individual characteristics, but inextricably linked to aspects of involvement in everyday life situations in a particular context. Moreover, the breadth of the ICF-CY codes identified in the needs' sections suggest that developing holistic EHC plans requires describing the individual and their functioning across life areas, rather than circumscribing their identified needs to specific services. The person-centred approach advocated by the SEND Code of Practice calls for the development of support that is built based on the individual's strengths, needs, and

goals to achieve (Beadle-Brown, 2006); thus, separating needs in this categorical terms could constitute a barrier in the development of truly person-centred provision.

#### **9.4 Overview of findings related to the outcomes sought for young people with ASD at time of transition**

Five research questions were identified for the exploration of outcomes sought for young people with ASD at time of transition to post-secondary destinations:

- a. What are the functioning dimensions identified as the outcomes sought for young people with ASD?
- b. What is the overall quality of outcomes defined for young people with ASD in their EHC plans?
- c. Does the quality of outcomes vary depending on the LA that produced them?
- d. Does the quality of outcomes vary depending on the type of setting that the young person attended?
- e. Does the quality of outcomes vary depending on the year group the young person attended?

There are two significant findings that need to be highlighted with regards to the outcomes sought for young people with ASD in their EHC plans. The first one is related to the overall quality of these outcomes; the second concerns the scope of the outcomes described for these young people. With regards to the quality of outcomes for young people, this study found that overall they were of poor quality, presenting variations in dimensions of quality from LA to LA, and significant differences were found with regards to the type of setting (special or mainstream), and year group to which they belonged. A series of arguments were put forward to try to understand these occurrences, covering differences in socioeconomic characteristics of the

context, to higher level of detail and expertise in specialist settings in comparison to mainstream settings. What is evident is the lack of guidance and direction from the new SEND Code of Practice in producing high quality EHC plans, something that professionals have stressed with regards to the implementation of the new SEND policy (Boesley & Crane, 2018, Norwich, 2014; Palikara et al., 2018a). One of the consequences of the marketization of the education system is the viewpoint that the decentralisation of services would lead to creating and improving a local offer responsive to the needs and characteristics of a specific area, with their users at the core (Lamb, 2013). In the case of EHC plans, Allan and Youdell (2017) emphasise the existence of a double edge to this process: the Code of Practice mandates a series of systems, actions, timelines and practices while ghosting its own regulatory content, making the local state responsible for materialising these, with the expectation that doing so would result in the identification of best practices. This point also raises concerns in relation to issues about equality, fairness and comparability of provision across the country, when the instrumentation of these is dependent on the specific demands, resources and responses of a local area.

As stated in section 9.2 of this chapter, it seems that the voice of young people with ASD has a 'ceiling' when it comes to their EHC plans, in particular with regards to the sections of their voices (Section A) and that of the outcomes (Section E). This became clear when analysing the extent of the match between the views and aspirations of young people as portrayed in Section A, and the resulting outcomes reported in Section E of their plans. While the EHC plan process offers a space – as a statutory requirement – to include the voice of young people about matters affecting their lives, this space has a 'ceiling' when it comes to designing outcomes to guide provision for transitioning students. The wishes and aspirations of young people in this study focused on dimensions of functioning related to increasing participation in day to day life; while the SEND Code of Practice recognises that EHC plans should be forward-looking and that efforts should concentrate in preparing young people for

adulthood from age 14 (DfE & DoH, 2015), outcomes for a group of 23 young people with ASD predominantly focused on targeting academic skills, particularly concerning with reading, writing and numeracy skills, improving attention and communication.

A number of reasons could help understand this phenomenon. The first one is that, in spite of the change of name, EHC plans are still predominantly educational plans (Boesley & Crane, 2018; Norwich & Eaton, 2015). The promise of a radically new system that would encompass the integration of services to reflect broad life areas, and the extension of provision until the age of 25 are principles that have been well received by professionals working in SEND, but practice has proven difficult to fully embrace these (Boesley & Crane, 2018; Palikara et al., 2018a). Another reason for this could be the fact that schools are the ones who write a considerable proportion of the EHC plans; the pressures that schools face with regards to attainment and progression of pupils might help account for the academic focus of outcomes. Engaging in post-secondary settings was seen by participants as a bridge towards further autonomy and participation in wider society, yet outcomes proposed at this stage for these young people seemed to fall short of participatory value, as they did not address the core of their wishes and aspirations for post-secondary life.

## **9.5 Methodological considerations and limitations**

Inevitably, conducting a piece of research comes with a series of limitations. The socially constructed nature of the views of the young people, the content of their EHC plans, and the researcher's methodological choices for data collection, analyses and interpretation indicates that this particular study, together with its findings represent the work and reflection of this researcher with a particular group of young people, in a particular place, at a particular time (Heasley, 2017). In other words, it was not within the aims of this study to produce findings that would be applicable to all young people with ASD. Nevertheless, this study aimed at deepening understanding on the views of a group of young people at a critical time in their lives,

and how these were also portrayed together with their needs and outcomes in the context of SEND policy change, so that practitioners, professionals and all stakeholders involved in the development of EHC plans might be able to incorporate these views in their practice by steering the conversation of transition towards what is meaningful for young people. This section of the chapter addresses those aspects of the study which could be done differently if the study were to be redone. These concern the selection of participants, documents, and broader methodological considerations.

### **9.5.1 Participants**

As outlined in Chapter 3, the number of schools, and therefore potential participants, approached to conduct the study was much larger than the researcher was able to recruit: only one in 11 schools contacted ultimately took part in the project. The process of identifying potential participants encountered an array of reasons for schools and parents alike to decline access to or the participation of their children in the study. Some schools referred to the fact that year 11 was a crucial year for students as it was the last year of secondary school, therefore they were not willing to allow students to miss a class period for research purposes. On other occasions, schools highlighted that the researcher was a stranger for the young people, and that for that reason the young people would not be prone to engage in conversation about their lives with a stranger. Schools sustained this line of argument in spite of the researcher's reassurance and offer to meet the potential students first with a familiar person prior starting the recruitment process. Other schools fed back positively to the request to recruit participants from their student body, but were turned down by parents, who did not want their child to miss class, or who thought that meeting another unfamiliar adult would be a burden to their child, as they were already seen by a number of professionals. On occasion, and mainly mainstream settings, schools

responded that the students with ASD in their schools were under the SEN support and therefore did not hold an EHC plan. One of the most unforeseen reasons for declining to take part in the project was given by a specialist school; this school argued that in the context of moderate to severe communication difficulties, conducting a study concerning the voice of young people would not be appropriate as the students would not be able to say anything to the researcher.

From the reasons presented above, a series of questions emerged. The first one related to whether the views that had arisen from this particular group of young people were different from those of individuals with ASD who did not take part in the study. The nature of this study and the sample size and composition suggest that generalisation of findings was not within reach, so it is not inconceivable that different views may emerge from within the population of young people with ASD.

### **9.5.2 Documents**

The fact that one selection criterion required having an EHC plan in place in order to take part in the study raised the question of whether the views of young people with ASD with EHC plans were shared by those without an EHC plan. These questions could also be extended to incorporate the extent to which the views, needs and outcomes of those young people with an EHC plan differed from those who did not hold an EHC plan, and therefore did not qualify for participation in the study. The selection requirement of having an EHC plan may have favoured the recruitment of participants from specialist settings as the majority of special schools include having an EHC plan as part of their admission criteria. In this respect, another question that emerged referred to the extent to which the views of individuals with an EHC plan in mainstream settings were represented in the same breadth than those in special schools; the vast majority of participants with EHC plans (20 out of 23) were attending specialist settings.

Nevertheless, from the outset this study was located within the significant policy changes in SEND introduced in England. Thus, it was deemed pertinent for the purposes and scope of this study to include EHC plans as a source of data to explore these changes. The Code of Practice suggests the development of individual learning plans (ILP) or individual education plans (IEP) for those pupils identified as having SEND but who do not require an EHC plan (DfE & DoH, 2015). These documents, however, are not statutory, they do not provide the same detailed information, and are not subject to the same stringent procedure in their development as EHC plans. Including young people with ASD *without* EHC plans would have, very likely, diversified the breadth of views about transition to post-secondary destinations from. In keeping consistence throughout procedures and analyses, these young people were not considered.

The delays faced by LAs in converting previous statements of SEND into the new EHC plans was another unexpected occurrence throughout the study that had an effect in the researcher's aim to explore and analyse the content of the plans of all recruited participants. In spite this limitation, the 23 EHC plans collected for this study provided rich information about young people with ASD at this particular time of their lives, and significant insights were gained with regards to the implementation of the new policy for SEND and its practical translation into these new statutory documents, as discussed in section 10.3 and 10.4.

### **9.5.3 Methodology**

The present study used individual semi-structured interviews with 28 young people with ASD and collected their respective EHC plans when available. Through the use of tools such as Talking Mats to enhance engagement and communication in the interview process, to using the ICF-CY system to analyse the data from interviews and plans it was possible to obtain in-depth, rich information about the life situation of

young people with ASD at the point of transition to post-secondary life. However, one of the disadvantages of these methods is that they captured participants' experiences in one specific point in time. In light of the aspirational emphasis of the transition period, and the anticipated changes that participants would be facing throughout this phase of their lives, a longitudinal approach to studying this phenomenon would be advantageous. Due to time constraints, such approach was not possible to adopt. Approaching transition to post-secondary life longitudinally would produce a much more detailed picture of the actual transition process that young people go through, and the factors that facilitate or constitute barriers to successful transitions and participation in life after secondary school. It would be interesting to explore the evolution of the views of young people and the content of their EHC plans over a period of time, to examine the changes in their respective views, and EHC plan content in terms of aspirations, needs, and outcomes.

Moreover, this study only focused on participants located mainly in the Greater London area, and so the built picture of young people with ASD, and their respective EHC plans represent a local snapshot of their transition in the scope of the changes introduced by the new SEND policy. Palikara and colleagues (2018a) found differences in the methods to elicit the views of children with a wide range of SEND in EHC plans, and variability in the nature of their content. The present study also found variability in these domains and in other analysed sections for a group of young people with ASD. In light of these findings, it would be interesting to explore this phenomenon on a larger scale across England, where the current SEND Code of Practice applies. Doing so could help highlight problematic areas of the plans, and identify best practices in the development of these documents, both in eliciting the views of children and young people and incorporating them to the plans, and in the language used to describe them.



## **9.6 Suggestions for future research**

A number of questions have arisen from the limitations presented in the previous section, and as a result of conducting this study. There is a recognition that research in ASD has primarily focused on childhood, and yet investigations in late adolescent and adulthood remains scarce. The young people with ASD who took part in this study provided valuable accounts of their views and experiences of transition to post-secondary settings in the scope of the new policy for SEND in England. Future research should investigate further stages of the lives of individuals with ASD and their participation in other spheres of life associated with becoming an adult, such as higher education and employment, family and domestic life, and financial independence, to name a few.

Albeit increasing research interest on the new SEND policy and the EHC plans, there is still dearth of information with regards to the content, development and evaluation of EHC plans for children and young people with SEND that allow a national representation of the policy's implementation. This study explored the content of a small number of EHC plans in Greater London, to identify functioning dimensions that related to the views, needs and outcomes of young people with ASD. Future research should aim to develop a national picture concerning the content of the EHC plans, and to analyse their content longitudinally, particularly before and after significant transitions, to examine whether their content reflect the changes experienced by individuals, their needs and outcomes.

The young people that took part in this study are among the first groups of individuals who would transition to adulthood under the new policy. In light of the extension of statutory provision until the age of 25, future research should examine the availability and quality of services provided for young people and emerging adults who have SEND and an EHC plan. This could involve assessing the provision

stipulated in the local offer, allowing comparisons of services across local areas and nationally.

Lastly, evidence from this study highlighted that there is still plenty to do to capture the voices of children and young people with SEND, in the case of this study, young people with ASD. More research is needed concerning processes and effective practices of eliciting the voices of children and young people in the scope of the new SEND Code of Practice. In addition, it would be interesting to examine these representations captured in Section A of EHC plans at other transitioning points in the journey of children and young people, to explore commonalities and differences of different transition periods and age groups.

### **9.7 Implications for policy and practice**

This study has provided concrete insights into what transition to post-secondary destinations looks and feels like for individuals with ASD from their own perspectives; it has shown in detail the domains of functioning covered by EHC plans across a series of sections which allowed building a picture of the current life situation of a group of young people with ASD in the 15-19 age range, at a crucial time in their lives. Facing the end of compulsory education brought a series of challenges and opportunities for transitioning young people which, if addressed through well-rounded, person-centred transition planning and provision, could contribute to enabling the realisation of young people's aspirations and the achievement of outcomes sought for them. Moreover, this study has also identified a gap between what young people with ASD aspire to at the end of their compulsory education journey, and what their EHC plans described as their wishes and outcomes for this critical period. While the relevance of academic skills should not be undermined, LAs and practitioners should and must acknowledge that life skills for participation are central components of aspirations of young people for post-secondary life, and these should be acted upon

as crucial elements of preparation for adulthood. The literature has recognised that there is no recipe or 'one-size-fits-all' approach to transition to adulthood and to elicit pupil's views (Fayette & Bond, 2018); nevertheless, it has reported consistently on the need for services to be responsive to the needs of emerging adults with ASD (Shattuck et al., 2012b), and highlighted engagement of individuals in their transition planning as an effective way of making transitions to post-secondary life smoother (Robinson et al., 2018; Wei, Wagner, Hudson, Yu, & Javitz, 2016). It is crucial for practitioners to gain a deeper understanding and training on different strategies to elicit the views of children and young people with ASD, irrespective of their difficulties, and to ensure that those views are recorded and incorporated into the EHC planning process.

Concerning the development of EHC plans, it has been argued that the ICF-CY constitutes a sound system aptly aligned to the principles set by the Children and Families Act 2014 to serve as a framework and universal language to record the characteristics of children with ASD (and SEND), incorporating all dimensions of life in a cross-disciplinary language (Castro & Palikara, 2016; Castro, Palikara, Gaona & Eirinaki, 2018; WHO, 2007). Indeed, one of the strengths of the ICF-CY is that it allows the description of abilities and disabilities in a holistic manner, across disciplines and social contexts. In this respect, the ICF-CY has the potential to address vagueness or lack of clarity found in some descriptors of young people, particularly with regards to the needs and outcomes sought for them. The iterative nature of EHC plans, starting from the views of young people and finishing with the section concerning provision, requires a language specific enough to provide a clean, accurate description of the child throughout, that could be read and produced by all stakeholders taking part in the development of these documents. By using a holistic, cross-disciplinary language, the boundaries between the sections of education, health and social care become unnecessary to these biopsychosocial descriptions, as needs are described in terms of the dynamic interaction between the individual's body functions and structures,

their activities and participation, and the environments in which they are embedded. Thus, the introduction of these three areas of need in EHC plans (education, health and social care) creates artificial boundaries among needs, which are no less than the result of these previously described interactions; and do not necessarily respond exclusively to one particular domain of service provision.

## **9.8 Closing remarks**

The first two chapters of this thesis highlighted the paucity in research concerning the voices of young people with ASD and the transition to post-secondary destinations in the context of the new policy for SEND, the Children and Families Act 2014, and the new SEND Code of Practice. The value of this work resides in the exploration of these underrepresented voices in the growing and changing landscape of SEND and ASD research, and in the shown potential of the ICF-CY to enhance the overall quality of EHC plans by allowing a close-up description of the young people in all life areas, in a cross-disciplinary language. This study has shown that the WHO's ICF-CY (2007) as a biopsychosocial framework could support the implementation of the Children and Families Act 2014 and the new SEND Code of Practice by providing a system to record the dimensions of functioning relevant for young people with ASD, in order to develop provision that responds holistically to their views, needs and aspirations.

These findings could improve practice for young people and their families, and front-line professionals involved in the documentation and operationalisation of the views, needs and outcomes for children and young people who have SEND and require specialist provision in the English context.



## APPENDICES

### List of appendices

Appendix A	Interview Schedule
Appendix B	Examples of Talking Mats from interviews
Appendix C	Extracts from interviews with initial coding
Appendix D	Extracts from Education Health and Care plans with coding using the ICF-CY
Appendix E	List of all ICF-CY codes identified in all interviews and EHC plans
Appendix F	Examples of outcomes coded with the Goal Functionality Scale
Appendix G	Social Communication Questionnaire
Appendix H	Introductory letter for schools, colleges and organisations
Appendix I	Information sheet and consent forms
	I.1 Information sheet and consent form for headteachers
	I.2 Information sheet and consent form for parents
	I.3 Information sheet and consent form for young people
	I.4 Information sheet and consent form for young people – adapted version



## **Appendix A. Interview schedule**

Thank you for meeting me today. I am conducting a study on the views and experiences of young people at the end of secondary school and in post-16 education, so this is what we are going to talk about today. I will record our conversation so that I don't forget what we talk about. I will not tell or show anyone what we say, and all this information, including your name and other personal details, will be safely stored. This means I will be the only one who has access to it and that no one will be able to identify you in any report of this study. We can stop or take a break at any time you need it, just let me know or use the stop sign.

### **Changes from secondary school/college to post-16/employment**

1. How do you feel about finishing secondary school/post-16?
2. Do you know what you will do after secondary school/post-16? [ prompt: *studying, working, other; part time, full time, don't know*]
3. Why did you choose this destination? [*decision process – support?*]
4. What are the things that you like the most about this destination? (work/course) Why?
5. Is there anything you would like to change? Why?
6. Have you expressed concern for the things that you like the least?

There are some young people that find the change from secondary school/college to college/work/etc easy, and some of them find it quite hard.

7. How do you think this change will be/has been for you?
8. What are your hopes/aspirations for the future? What would you like to do when you finish this course/training?
9. What would you like to achieve in the next year?
10. Do you get any kind of support in your school/college/workplace? [situations on which support was needed – people involved – helpfulness]
11. What needs to improve to make your [student] life easier?
12. What will you miss most from your this school/college? Why?
13. Can you describe a typical day at school/college/work? [routines, free time]
14. How do you get to school/college/work? [prompt: transport, going out alone, mobility]

### **Family**

15. Who do you live with?



16. Do you have any siblings? How many? Ages?
17. When you have any kind of problem or concern, do you turn to anyone for support? Who? If/Why do you choose that person?
18. When you are happy or excited about something, do you share this with anyone? Who/Why?
19. When you need to make decisions about your life, how do you decide? [is there a family member/friend/support that helps you decide?]

### **Friends**

20. How important is friendship to you? Why?
21. Do you have any friends from your school? What do you do together? *[prompt on activities, common interests, length of relationship]*
22. When you have a problem or a concern, how do you try to sort it out? *[support from friends?]*
23. What do you do in your free time?
24. Do you go out on your own? Do you tell your parents [or other as appropriate] where you are going and when you are coming back?
25. Is there anything else you would like to share with me today?

## Appendix B. Examples of Talking Mats to support interviews



Figure B.1 Talking Mat from participant YP 17

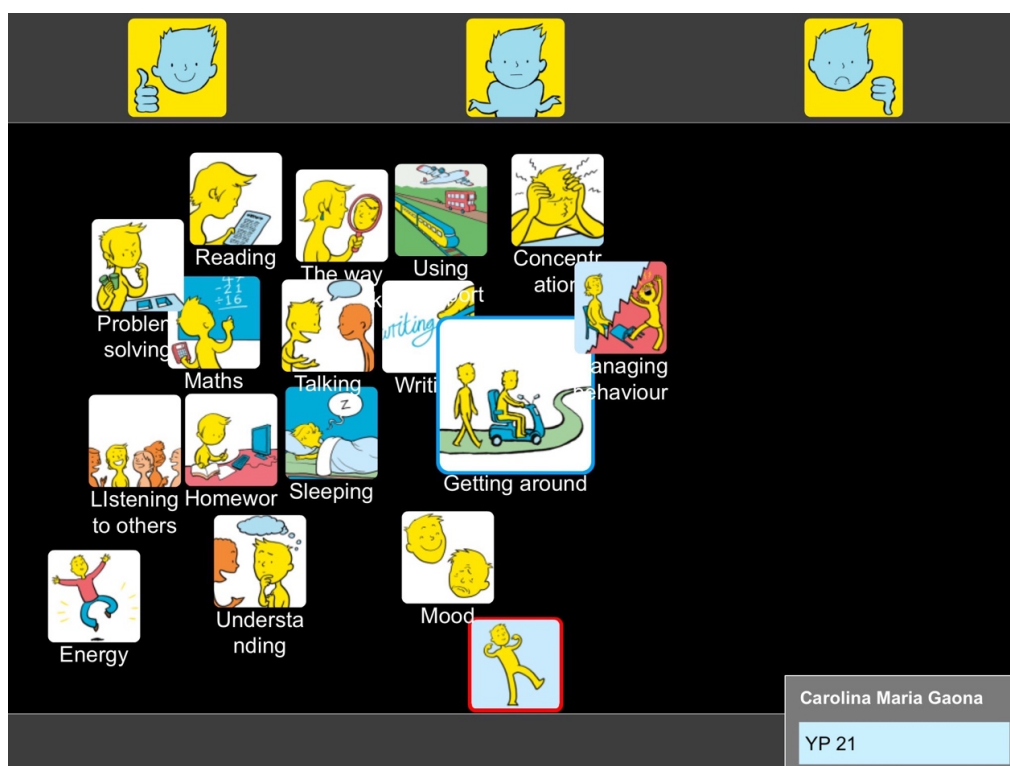


Figure B.2 Talking Mat from participant YP 21

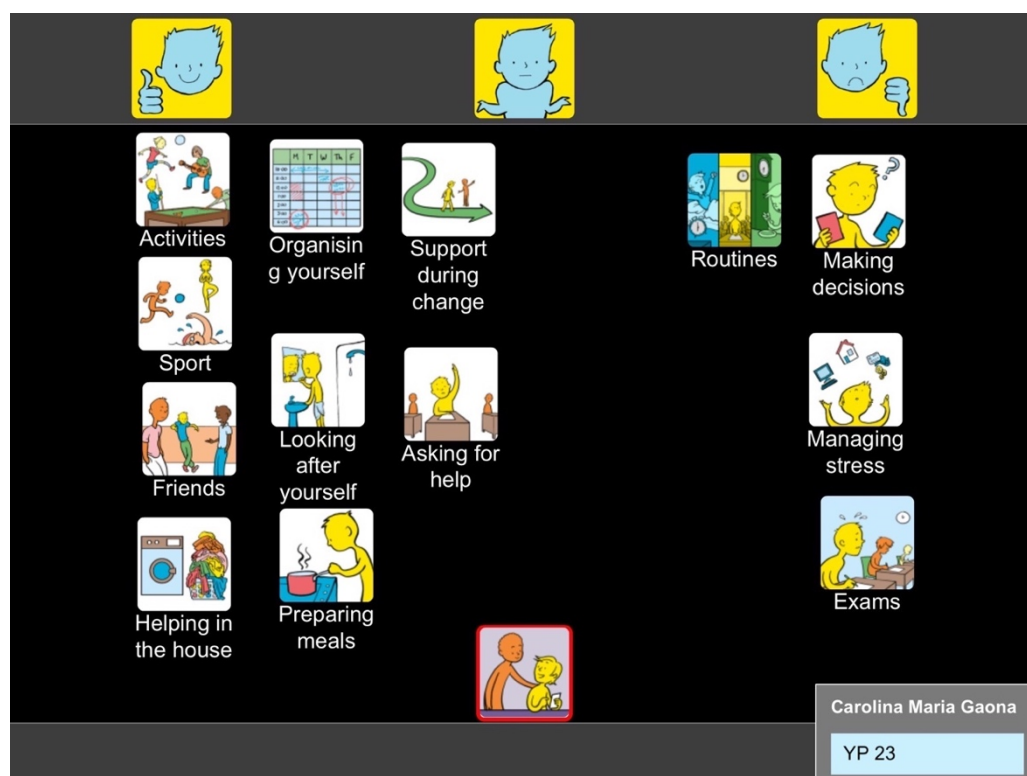


Figure B.3 Talking Mat from participant YP 23

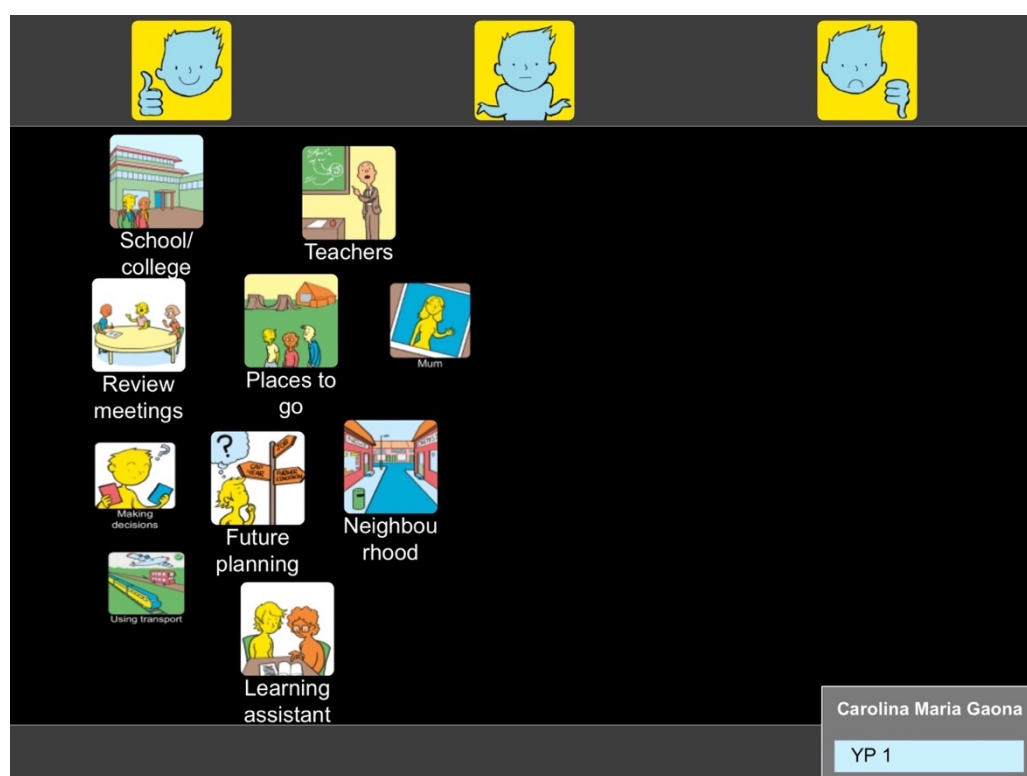


Figure B.4 Talking Mat from participant YP 1

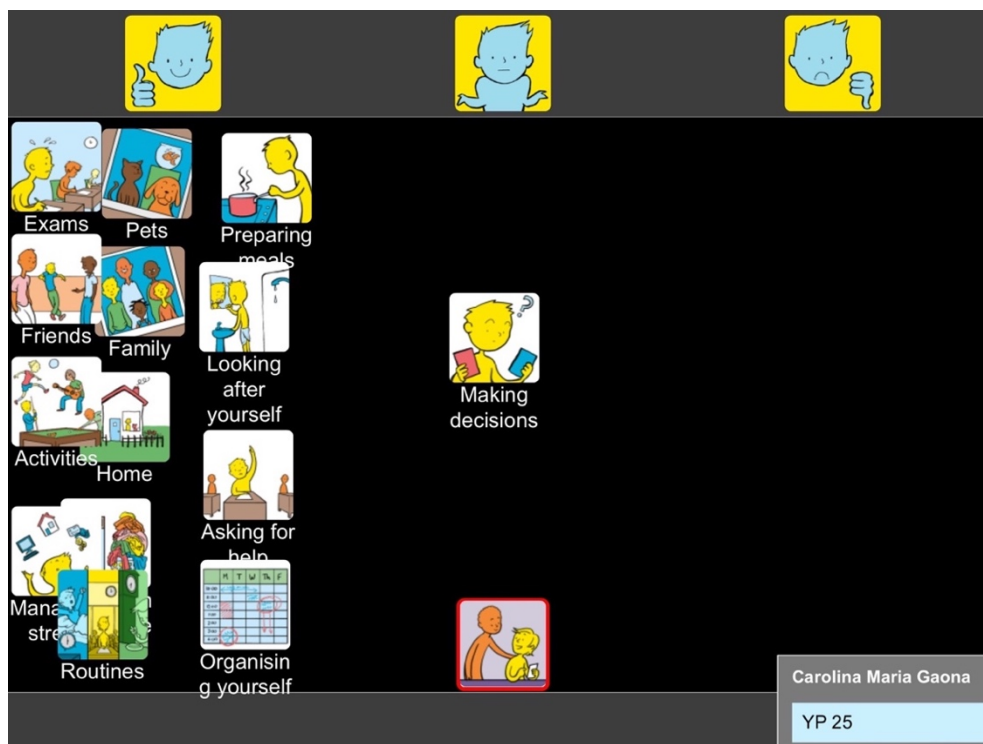


Figure B.5 Talking Mat from participant YP 25

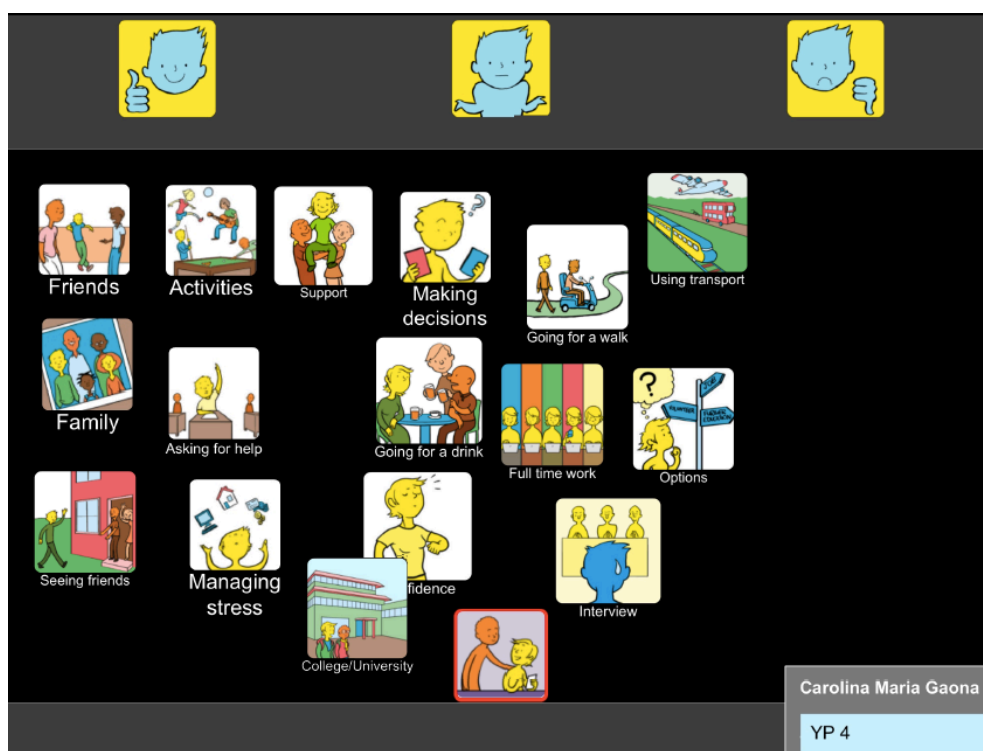


Figure B.6 Talking Mat from participant YP 4



## Appendix C. Extracts from interviews with initial coding

Interview extract	Theme coding
'Well, I am likely going to miss this school since I've been here for quite a long time now... but the university I'm going to move to is really nice'	Feelings about leaving school/future
'I'm scared I will turn out to have a bad future, I might not even get a job!'	
'I don't know... initially I felt pretty excited, but um... I'm not really sure now. I mean, right now, I definitely feel a lot of pressure. It is mostly pressure'	Feelings about future
'At first it is kind of daunting, like, this new path, trying to remember to go this way, and then go that way, and then take the bus, and all that... but it grows on you and you can begin to remember it better'	Independence, mobility
'I like to see my friends, and go to a friend's house and play. I like table tennis'	Free time, friendship
'It is actually kind of nice coming to the club and have something to do than rather just being indoors. I am only allowed to walk around my block, cross the street, the shop that is near my block, and I guess that's it.'	Mobility, free time
'That's something I would like to achieve, definitely. Stuff of how to be free and go where I please'	Independence
'We are always there for each other, we have each other's backs. So having this relationship with another person, it's just very special'	Friendship, support
'I am still anxious about it because it's a new place and I haven't been there before, and I'm going to miss this school... they helped me a lot building confidence'	Future placement, support

Interview extract	Theme coding
'I don't like the students there... I don't know what they can do to me or say to me, they would definitely pick on a guy like me... so I don't want to go there'	Future, bullying
'I told you, there is this guy that takes your money, and what can I do about it? If I say anything it will be worse for me, so...'	Bullying

**Appendix D. Extracts from Education Health and Care plans from participants,  
with coding using the ICF-CY**

EHC plan extract	ICF-CY coding
'In the classroom I need a person with me to explain the lesson when I don't understand, to refocus when I become distracted, and to help me work independently when possible'	e340, d160, d210
'D would to be more independent and have a job one day'	ND, d845
'J can easily get upset.'	b152, b1251
'T lives at home with his mum, dad, and sister. He has a large extended family from which he benefits.'	e310, e315.
'F would like to consolidate his maths and English skills, improve his reading age and at 16, undertake further education with a vocational training option.'	b1301, d140, d150, d825
He will develop a better understanding of his emotions and how to regulate them so he is better able to manage his behaviour	b1521, d250
'C is an active and friendly student, who has significant global developmental delay'	b126, ND
'D finds it difficult to deal with peer and adult relationships.'	d7504, d740
'He talks with confidence in a wide range of contexts'	b1266, d330





**Appendix E. List of all International Classification of Functioning – Children and Youth version (ICF-CY) codes identified in 28 interviews and 23 Education Health and Care (EHC) Plans**

<i>Code</i>	<i>Code description</i>	<i>Interviews (n=28)</i>	<i>Section A</i>	<i>Section B</i>	<i>Section C</i>	<i>Section D</i>	<i>Section E</i>	<i>Total Frequency</i>	<i>Total frequency only EHC PLANS</i>
Body structures (s)									
<i>s110</i>	Structure of the brain		2		1			3	3
<b>1 code</b>		<b>0</b>	<b>2</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>0</b>	<b>3</b>	<b>3</b>
Body Functions (b)									
<i>b1</i>	Mental functions			1				1	1
<i>b114</i>	Orientation functions		1					1	1
<i>b1140</i>	Orientation to time		1	1			1	3	3
<i>b1141</i>	Orientation to place		1					1	1
<i>b11420</i>	Orientation to self		1					1	1

<i>Code</i>	<i>Code description</i>	<i>Interviews (n=28)</i>	<i>Section A</i>	<i>Section B</i>	<i>Section C</i>	<i>Section D</i>	<i>Section E</i>	<i>Total Frequency</i>	<i>Total frequency only EHC PLANS</i>
<i>b1144</i>	Orientation to space			1				1	1
<i>b117</i>	Intellectual functions		4	1				5	5
<i>b122</i>	Global psychosocial functions		1					1	1
<i>b125</i>	Dispositions and intra-personal functions	15	12	2				29	14
<i>b1250</i>	Adaptability	3	8	2				13	10
<i>b1251</i>	Responsivity		1					1	1
<i>b1252</i>	Activity level	1						1	
<i>b1253</i>	Predictability		5	2				7	7
<i>b1254</i>	Persistence			1				1	1
<i>b1255</i>	Approachability		4	1		1		6	6
<i>b126</i>	Temperament and personality functions	21	24	5				50	29
<i>b1260</i>	Extraversion	3	7	6		2	1	19	16
<i>b1261</i>	Agreeableness		21	4				25	25
<i>b1262</i>	Conscientiousness	1	11	4				16	15
<i>b1263</i>	Psychic stability	8	1	7		3	2	21	13
<i>b1264</i>	Openness to experience	1	4	4				9	8

<i>Code</i>	<i>Code description</i>	<i>Interviews (n=28)</i>	<i>Section A</i>	<i>Section B</i>	<i>Section C</i>	<i>Section D</i>	<i>Section E</i>	<i>Total Frequency</i>	<i>Total frequency only EHC PLANS</i>
<i>b1265</i>	Optimism	1	4	1		1		7	6
<i>b1266</i>	Confidence	7	9	10		3	14	43	36
<i>b1267</i>	Trustworthiness		1					1	1
<i>b130</i>	Energy and drive functions	2		2			1	5	3
<i>b1300</i>	Energy level	3	1	3				7	4
<i>b1301</i>	Motivation	90	87	16	1	1		195	105
<i>b1302</i>	Appetite	1	1	1				3	2
<i>b1303</i>	Craving		1					1	1
<i>b1304</i>	Impulse control					1		1	1
<i>b134</i>	Sleep functions	7	2	1	2		1	13	6
<i>b140</i>	Attention functions	7	2	5				14	7
<i>b1400</i>	Sustaining attention		1					1	1
<i>b144</i>	Memory functions		4	2				6	6
<i>b1440</i>	Short-term memory		1	4				5	5
<i>b1442</i>	Retrieval and processing of memory			4				4	4
<i>b147</i>	Psychomotor functions		4	3			2	9	9

<i>Code</i>	<i>Code description</i>	<i>Interviews (n=28)</i>	<i>Section A</i>	<i>Section B</i>	<i>Section C</i>	<i>Section D</i>	<i>Section E</i>	<i>Total Frequency</i>	<i>Total frequency only EHC PLANS</i>
<i>b1470</i>	Psychomotor control		1	1			1	3	3
<i>b152</i>	Emotional functions	88	35	50	3	3	7	186	98
<i>b1520</i>	Appropriateness of emotion						1	1	1
<i>b1521</i>	Regulation of emotion		2	12		1	17	32	32
<i>b156</i>	Perceptual function		1	1		1	1	4	4
<i>b1560</i>	Auditory perception			1				1	1
<i>b1561</i>	Visual perception			2	1			3	3
<i>b1564</i>	Tactile perception			1				1	1
<i>b1565</i>	Visuospatial perception			1				1	1
<i>b160</i>	Thought functions	2	8	4				14	12
<i>b1600</i>	Pace of thought			1				1	1
<i>b1603</i>	Control of thought		1					1	1
<i>b163</i>	Basic cognitive functions			1				1	1
<i>b164</i>	Higher-level cognitive functions		3	5			2	10	10
<i>b1640</i>	Abstraction			2				2	2
<i>b1641</i>	Organisation and planning	6	4	1			1	12	6

<i>Code</i>	<i>Code description</i>	<i>Interviews (n=28)</i>	<i>Section A</i>	<i>Section B</i>	<i>Section C</i>	<i>Section D</i>	<i>Section E</i>	<i>Total Frequency</i>	<i>Total frequency only EHC PLANS</i>
<i>b1642</i>	Time management	1	1					2	1
<i>b1643</i>	Cognitive flexibility		5	6			1	12	12
<i>b1644</i>	Insight		4	4				8	8
<i>b1646</i>	Problem-solving	10	2	1				13	3
<i>b167</i>	Mental functions of language		5	3			1	9	9
<i>b1670</i>	Reception of language		1	3				4	4
<i>b1671</i>	Expression of language		4	1				5	5
<i>b180</i>	Experience of self and time functions						1	1	1
<i>b1800</i>	Experience of self			1		1		2	2
<i>b1801</i>	Body image			1				1	1
<i>b2</i>	Sensory functions and pain			3				3	3
<i>b230</i>	Hearing functions		1	1				2	2
<i>b2300</i>	Sound detection			1				1	1
<i>b235</i>	Vestibular functions			2			1	3	3
<i>b2401</i>	Dizziness				1			1	1
<i>b2403</i>	Nausea associated with dizziness or vertigo				1			1	1

<i>Code</i>	<i>Code description</i>	<i>Interviews (n=28)</i>	<i>Section A</i>	<i>Section B</i>	<i>Section C</i>	<i>Section D</i>	<i>Section E</i>	<i>Total Frequency</i>	<i>Total frequency only EHC PLANS</i>
<i>b265</i>	Touch function		1	1				2	2
<i>b3</i>	Voice and speech functions		2	1				3	3
<i>b320</i>	Articulation functions			2				2	2
<i>b330</i>	Fluency and rhythm of speech functions		2	1	1		1	5	5
<i>b3300</i>	Fluency of speech			3				3	3
<i>b3302</i>	Speed of speech		1		1			2	2
<i>b340</i>	Alternative vocalisations functions			1				1	1
<i>b5</i>	Functions of the digestive, metabolic and endocrine systems		1					1	1
<i>b510</i>	Ingestion functions		1					1	1
<i>b5153</i>	Tolerance to food				1			1	1
<i>b530</i>	Weight maintenance functions	1	1					2	1
<i>b7</i>	Neuromusculoskeletal and movement-related functions		1					1	1
<i>b710</i>	Mobility of joint functions		1					1	1
<i>b730</i>	Muscle power functions			1				1	1
<i>b735</i>	Muscle tone functions			2				2	2
<i>b760</i>	Control of voluntary movement functions		1	4				5	5

<i>Code</i>	<i>Code description</i>	<i>Interviews (n=28)</i>	<i>Section A</i>	<i>Section B</i>	<i>Section C</i>	<i>Section D</i>	<i>Section E</i>	<i>Total Frequency</i>	<i>Total frequency only EHC PLANS</i>
<i>b7602</i>	Coordination of voluntary movements						2	2	2
<i>b765</i>	Involuntary movement functions		1	1				2	2
<i>b7652</i>	Tics and mannerisms		1	2		1		4	4
<i>b7653</i>	Stereotypies and motor perseveration		2	1				3	3
<b>89 codes</b>		<b>279</b>	<b>319</b>	<b>224</b>	<b>12</b>	<b>19</b>	<b>59</b>	<b>912</b>	<b>633</b>

#### Activities and Participation (d)

<i>d1</i>	Learning and applying knowledge	4		2				6	2
<i>d110</i>	Watching	3	6	2				11	8
<i>d115</i>	Listening	5	6	7			4	22	17
<i>d131</i>	Learning through actions with objects			1				1	1
<i>d132</i>	Acquiring information		3	2			1	6	6
<i>d133</i>	Acquiring language		2	1			3	6	6
<i>d1330</i>	Acquiring single words or meaningful symbols						1	1	1
<i>d1332</i>	Acquiring syntax			5			1	6	6
<i>d134</i>	Acquiring additional language		1					1	1



<i>Code</i>	<i>Code description</i>	<i>Interviews (n=28)</i>	<i>Section A</i>	<i>Section B</i>	<i>Section C</i>	<i>Section D</i>	<i>Section E</i>	<i>Total Frequency</i>	<i>Total frequency only EHC PLANS</i>
<i>d135</i>	Rehearsing	3	1	3				7	4
<i>d137</i>	Acquiring concepts	2	2	2			2	8	6
<i>d140</i>	Learning to read		1	3			1	5	5
<i>d145</i>	Learning to write			2	1			3	3
<i>d1450</i>	Acquiring skills to use writing implements				1		1	2	2
<i>d1452</i>	Acquiring skills to write words and phrases			1				1	1
<i>d150</i>	Learning to calculate		1	3			1	5	5
<i>d1502</i>	Acquiring skills in using basic operations			2			1	3	3
<i>d155</i>	Acquiring skills	13	3	2		1		19	6
<i>d1551</i>	Acquiring complex skills	3	1					4	1
<i>d160</i>	Focusing attention	1	3	12			5	21	20
<i>d161</i>	Directing attention		2	4				6	6
<i>d163</i>	Thinking		2	7			1	10	10
<i>d166</i>	Reading	5	7	7			14	33	28
<i>d1660</i>	Using general skills and strategies of the reading process						1	1	1
<i>d1661</i>	Comprehending written language			5			1	6	6

<i>Code</i>	<i>Code description</i>	<i>Interviews (n=28)</i>	<i>Section A</i>	<i>Section B</i>	<i>Section C</i>	<i>Section D</i>	<i>Section E</i>	<i>Total Frequency</i>	<i>Total frequency only EHC PLANS</i>
<i>d170</i>	Writing	8	4	7			12	31	23
<i>d1701</i>	Using grammatical and mechanical conventions in written compositions		1	2			2	5	5
<i>d1702</i>	Using general skills and strategies to complete compositions		1					1	1
<i>d172</i>	Calculating	26	5	3		1	12	47	21
<i>d1720</i>	Using simple skills and strategies of the calculation process			1			1	2	2
<i>d1721</i>	Using complex skills and strategies of the calculation process			2				2	2
<i>d175</i>	Solving problems	15		3				18	3
<i>d177</i>	Making decisions	57	6	4			5	72	15
<i>d210</i>	Undertaking a single task		7	7			1	15	15
<i>d2100</i>	Undertaking a simple task		1					1	1
<i>d2102</i>	Undertaking a single task independently		3				3	6	6
<i>d2103</i>	Undertaking a single task in a group			2			1	3	3
<i>d220</i>	Undertaking multiple tasks	1	2	11	1		2	17	16
<i>d2202</i>	Undertaking multiple tasks independently	1	2	2				5	4
<i>d2203</i>	Undertaking multiple tasks in a group		1				1	2	2
<i>d2204</i>	Completing multiple tasks independently		1					1	1

<i>Code</i>	<i>Code description</i>	<i>Interviews (n=28)</i>	<i>Section A</i>	<i>Section B</i>	<i>Section C</i>	<i>Section D</i>	<i>Section E</i>	<i>Total Frequency</i>	<i>Total frequency only EHC PLANS</i>
<i>d230</i>	Carrying out daily routine	25	14	5			3	47	22
<i>d2300</i>	Following routines		1					1	1
<i>d2301</i>	Managing daily routine		1				1	2	2
<i>d2302</i>	Completing the daily routine	2						2	
<i>d2303</i>	Managing one's activity level	2		1				3	1
<i>d2304</i>	Managing changes in daily routine	4	10	11		2	4	31	27
<i>d2305</i>	Managing one's time	2	3	1		1	1	8	6
<i>d240</i>	Handling stress and other psychological demands	24	4	7	2		8	45	21
<i>d2400</i>	Handling responsibilities		1	1			1	3	3
<i>d2401</i>	Handling stress	5	1	3	1		1	11	6
<i>d2402</i>	Handling crisis	6	1					7	1
<i>d250</i>	Managing one's own behaviour	17	9	12		4	12	54	37
<i>d2500</i>	Accepting novelty		1	5		1	1	8	8
<i>d2501</i>	Responding to demands		1	2		1	1	5	5
<i>d2502</i>	Approaching persons or situations	2		5			3	10	8
<i>d2503</i>	Acting predictably			9				9	9

<i>Code</i>	<i>Code description</i>	<i>Interviews (n=28)</i>	<i>Section A</i>	<i>Section B</i>	<i>Section C</i>	<i>Section D</i>	<i>Section E</i>	<i>Total Frequency</i>	<i>Total frequency only EHC PLANS</i>
<i>d2504</i>	Adapting activity level		1	5			2	8	8
<i>d3</i>	Communication	1	5	7			11	24	23
<i>d310</i>	Communicating-receiving	7	6	9			2	24	17
<i>d3101</i>	Comprehending simple spoken messages			1			1	2	2
<i>d3102</i>	Comprehending complex spoken messages		4	5			3	12	12
<i>d315</i>	Communicating with-receiving- nonverbal messages			2				2	2
<i>d3150</i>	Communicating with -receiving- body gestures		2	1			1	4	4
<i>d3151</i>	Communicating with -receiving- general signs and symbols		1	1			1	3	3
<i>d325</i>	Communicating with-receiving- written messages		1					1	1
<i>d330</i>	Speaking	6	15	15			6	42	36
<i>d335</i>	Producing nonverbal messages			1				1	1
<i>d3350</i>	Producing body language		1					1	1
<i>d3352</i>	Producing drawing and photographs	1						1	
<i>d345</i>	Writing messages	2	2	1				5	3
<i>d349</i>	Communication - producing, other specified and unspecified			1				1	1
<i>d350</i>	Conversation	15	7	6			7	35	20

<i>Code</i>	<i>Code description</i>	<i>Interviews (n=28)</i>	<i>Section A</i>	<i>Section B</i>	<i>Section C</i>	<i>Section D</i>	<i>Section E</i>	<i>Total Frequency</i>	<i>Total frequency only EHC PLANS</i>
<i>d3500</i>	Starting a conversation		3				3	6	6
<i>d3501</i>	Sustaining a conversation	1	1	1			2	5	4
<i>d3502</i>	Ending a conversation			1				1	1
<i>d3509</i>	Conversation, unspecified		1					1	1
<i>d355</i>	Discussion	6	2	2			1	11	5
<i>d360</i>	Using communication devices and techniques	2	4					6	4
<i>d4</i>	Mobility	1	1					2	1
<i>d430</i>	Lifting and carrying objects	1						1	
<i>d440</i>	Fine hand use				1		5	6	6
<i>d4402</i>	Manipulating				1		1	2	2
<i>d4503</i>	Walking around obstacles	2						2	
<i>d455</i>	Moving around	1						1	
<i>d4552</i>	Running			2				2	2
<i>d4553</i>	Jumping			1				1	1
<i>d4554</i>	Swimming		2					2	2
<i>d460</i>	Moving around in different locations	31	9			3	5	48	17

<i>Code</i>	<i>Code description</i>	<i>Interviews (n=28)</i>	<i>Section A</i>	<i>Section B</i>	<i>Section C</i>	<i>Section D</i>	<i>Section E</i>	<i>Total Frequency</i>	<i>Total frequency only EHC PLANS</i>
d4601	Moving around within buildings other than home	2	4					6	4
d4602	Moving around outside the home and other buildings	13	5	1		2		21	8
d469	Walking and moving, other specified and unspecified	1						1	
d470	Moving around using transportation	24	15	2		5	8	54	30
d4701	Using private motorised transportation	12	1					13	1
d4702	Using public motorised transportation	15	4			4	2	25	10
d475	Driving	1	1					2	1
d4750	Driving human-powered transportation		2					2	2
d4751	Driving motorised vehicles		3					3	3
d5	Self-care	4	3	3		4	5	19	15
d510	Washing oneself		2	3		5		10	10
d520	Caring for body parts	1	1	1		2		5	4
d5201	Caring for teeth		2			1		3	3
d530	Toileting		1	1				2	2
d540	Dressing			1				1	1
d5402	Putting on footwear			1				1	1

<i>Code</i>	<i>Code description</i>	<i>Interviews (n=28)</i>	<i>Section A</i>	<i>Section B</i>	<i>Section C</i>	<i>Section D</i>	<i>Section E</i>	<i>Total Frequency</i>	<i>Total frequency only EHC PLANS</i>
d5404	Choosing appropriate clothing		2			2	1	5	5
d550	Eating	1	3		1			5	4
d5500	Indicating need for eating		1					1	1
d5501	Carrying out eating appropriately		2					2	2
d560	Drinking				1			1	1
d570	Looking after one's health	3	5		1			9	6
d5701	Managing diet and fitness	4	3	1	5		5	18	14
d5702	Maintaining one's health	1	1		2		7	11	10
d57020	Managing medications and following health advice		1					1	1
d57021	Seeking advice or assistance from caregivers or professionals	9	1				1	11	2
d571	Looking after one's safety	4	4	2			6	16	12
d6	Domestic life	1				1		2	1
d610	Acquiring a place to live	3	4					7	4
d620	Acquisition of goods and services	6	1			2		9	3
d6200	Shopping	6	6			3		15	9
d630	Preparing meals	14	10			4	1	29	15

<i>Code</i>	<i>Code description</i>	<i>Interviews (n=28)</i>	<i>Section A</i>	<i>Section B</i>	<i>Section C</i>	<i>Section D</i>	<i>Section E</i>	<i>Total Frequency</i>	<i>Total frequency only EHC PLANS</i>
<i>d6300</i>	Preparing simple meals		1			3		4	4
<i>d6301</i>	Preparing complex meals	1						1	
<i>d6302</i>	Helping prepare meals		1					1	1
<i>d640</i>	Doing housework	3	4			4	1	12	9
<i>d6402</i>	Cleaning living area	2						2	
<i>d6403</i>	Using household appliances	1						1	
<i>d6404</i>	Sorting daily necessities					2		2	2
<i>d6406</i>	Helping to do housework	7				3		10	3
<i>d650</i>	Caring for household objects	1						1	
<i>d6503</i>	Maintaining vehicles		1					1	1
<i>d6505</i>	Taking care of plants, indoors and outdoors	1	2					3	2
<i>d6506</i>	Taking care of animals	6	2					8	2
<i>d660</i>	Assisting others	7	8	1				16	9
<i>d6606</i>	Helping in assisting others	1						1	
<i>d710</i>	Basic interpersonal interactions	8	8	18		2	7	43	35
<i>d7100</i>	Respect and warmth in relationships	1		1				2	1



<i>Code</i>	<i>Code description</i>	<i>Interviews (n=28)</i>	<i>Section A</i>	<i>Section B</i>	<i>Section C</i>	<i>Section D</i>	<i>Section E</i>	<i>Total Frequency</i>	<i>Total frequency only EHC PLANS</i>
d7101	Appreciation in relationships	1		2				3	2
d7102	Tolerance in relationships	1		2			2	5	4
d7103	Criticism in relationships		1			2		3	3
d7104	Social cues in relationships			4			1	5	5
d71040	Initiating social interactions			1				1	1
d7105	Physical contact in relationships			1				1	1
d7106	Differentiation of familiar persons		4	2				6	6
d720	Complex interpersonal interactions	16	9	6			5	36	20
d7200	Forming relationships	3	6			1	16	26	23
d7201	Terminating relationships	1						1	
d7202	Regulating behaviours within interactions	3		6		1	1	11	8
d7203	Interacting according to social rules			3		2	2	7	7
d7204	Maintaining social space			2				2	2
d729	General interpersonal interactions, other specified or unspecified			2				2	2
d730	Relating with strangers	1	5			1		7	6
d740	Formal relationships	1		2			1	4	3

<i>Code</i>	<i>Code description</i>	<i>Interviews (n=28)</i>	<i>Section A</i>	<i>Section B</i>	<i>Section C</i>	<i>Section D</i>	<i>Section E</i>	<i>Total Frequency</i>	<i>Total frequency only EHC PLANS</i>
<i>d750</i>	Informal social relationships	4	5	1				10	6
<i>d7500</i>	Informal relationships with friends	6	4	3			1	14	8
<i>d7502</i>	Informal relationships with acquaintances	1						1	
<i>d7504</i>	Informal relationships with peers	1	2	2				5	4
<i>d760</i>	Family relationships	2	4					6	4
<i>d7600</i>	Parent-child relationships	2						2	
<i>d7601</i>	Child-parent relationships	4	1					5	1
<i>d7602</i>	Sibling relationships	7	3					10	3
<i>d770</i>	Intimate relationships	2	4					6	4
<i>d8</i>	Major life areas	1	1					2	1
<i>d8150</i>	Moving into preschool educational programme or across levels		1					1	1
<i>d820</i>	School education	21	3	3		1	1	29	8
<i>d8200</i>	Moving into educational programme or across levels	2		1		1	1	5	3
<i>d8201</i>	Maintaining educational programme	4	1		1			6	2
<i>d8202</i>	Progressing in educational programme	18	24	3			14	59	41
<i>d8203</i>	Terminating educational programme or school levels	13	2				1	16	3

<i>Code</i>	<i>Code description</i>	<i>Interviews (n=28)</i>	<i>Section A</i>	<i>Section B</i>	<i>Section C</i>	<i>Section D</i>	<i>Section E</i>	<i>Total Frequency</i>	<i>Total frequency only EHC PLANS</i>
<i>d825</i>	Vocational training	23	7				5	35	12
<i>d8250</i>	Moving into vocational training programme or across levels	3						3	
<i>d8251</i>	Maintaining vocational training programme	1						1	
<i>d8252</i>	Progressing in vocational training programme	1						1	
<i>d830</i>	Higher education	7	6					13	6
<i>d8300</i>	Moving into higher education or across levels	6	3				1	10	4
<i>d8302</i>	Progressing in higher education programme	1						1	
<i>d835</i>	School life and related activities	6	1	1			2	10	4
<i>d839</i>	Education, other specified or unspecified						2	2	2
<i>d840</i>	Apprenticeship (work preparation)	6	6	1			4	17	11
<i>d845</i>	Acquiring, keeping and terminating a job	27	18			1	2	48	21
<i>d850</i>	Remunerative employment		2			1	1	4	4
<i>d8501</i>	Part-time employment		1					1	1
<i>d855</i>	Non-remunerative employment		1					1	1
<i>d859</i>	Work and employment, other specified and unspecified		1				6	7	7
<i>d860</i>	Basic economic transactions	3	4	3		5	8	23	20

<i>Code</i>	<i>Code description</i>	<i>Interviews (n=28)</i>	<i>Section A</i>	<i>Section B</i>	<i>Section C</i>	<i>Section D</i>	<i>Section E</i>	<i>Total Frequency</i>	<i>Total frequency only EHC PLANS</i>
<i>d870</i>	Economic self-sufficiency	1	3				1	5	4
<i>d8700</i>	Personal economic resources	1						1	
<i>d880</i>	Engagement in play	13	2					15	2
<i>d8800</i>	Solitary play	2	6	1				9	7
<i>d8801</i>	Onlooker play		1					1	1
<i>d8803</i>	Shared cooperative play	1						1	
<i>d9</i>	Community, social and civic life	1	1					2	1
<i>d910</i>	Community life	1	5				1	7	6
<i>d9100</i>	Informal associations	5	6	1			3	15	10
<i>d9103</i>	Informal community life	2	1				2	5	3
<i>d920</i>	Recreation and leisure	12	8	2		1	2	25	13
<i>d9200</i>	Play	8	1	1				10	2
<i>d9201</i>	Sports	31	17	3			3	54	23
<i>d9202</i>	Arts and culture	41	21	2			1	65	24
<i>d9203</i>	Crafts	2	2					4	2
<i>d9204</i>	Hobbies		1					1	1

<i>Code</i>	<i>Code description</i>	<i>Interviews (n=28)</i>	<i>Section A</i>	<i>Section B</i>	<i>Section C</i>	<i>Section D</i>	<i>Section E</i>	<i>Total Frequency</i>	<i>Total frequency only EHC PLANS</i>
<i>d9205</i>	Socialising	41	8	1			2	52	11
<i>d9209</i>	Recreation and leisure, unspecified	1						1	
<i>d930</i>	Religion and spirituality		1					1	1
<b>204 d codes</b>		<b>839</b>	<b>519</b>	<b>339</b>	<b>19</b>	<b>80</b>	<b>301</b>	<b>2097</b>	<b>1258</b>
Environmental factors (e)									
<i>e110</i>	Products or substances for personal consumption		2		1			3	3
<i>e1100</i>	Food		1	1				2	2
<i>e1101</i>	Drugs	1	1	1	7			10	9
<i>e115</i>	Products and technology for personal use in daily living		2					2	2
<i>e1150</i>	General products and technology for personal use in daily living						1	1	1
<i>e1152</i>	Products and technology used for play	4	3					7	3
<i>e120</i>	Products and technology for personal indoor and outdoor mobility and transportation		1					1	1
<i>e1201</i>	Assistive products and technology for personal indoor and outdoor mobility and transportation	1						1	

<i>Code</i>	<i>Code description</i>	<i>Interviews (n=28)</i>	<i>Section A</i>	<i>Section B</i>	<i>Section C</i>	<i>Section D</i>	<i>Section E</i>	<i>Total Frequency</i>	<i>Total frequency only EHC PLANS</i>
e1208	Products and technology for personal indoor and outdoor mobility and transportation, other specified					1		1	1
e125	Products and technology for communication	4	2	1				7	3
e1250	General products and technology for communication			1				1	1
e1251	Assistive products and technology for communication			3			1	4	4
e130	Products and technology for education	3	2	2				7	4
e1300	General products and technology for education	5	2	4				11	6
e1301	Assistive products and technology for education		5	6			2	13	13
e140	Products and technology for culture, recreation and sport	6	2	2				10	4
e1400	General products and technology for culture, recreation and sport	5						5	
e150	Design, construction and building products and technology of buildings for public use	4	1					5	1
e155	Design, construction and building products and technology of buildings for private use	1						1	
e165	Assets			1				1	1
e220	Flora and fauna	1						1	

<i>Code</i>	<i>Code description</i>	<i>Interviews (n=28)</i>	<i>Section A</i>	<i>Section B</i>	<i>Section C</i>	<i>Section D</i>	<i>Section E</i>	<i>Total Frequency</i>	<i>Total frequency only EHC PLANS</i>
e250	Sound		3	9				12	12
e3	Support and relationships	30	18	32	2	2	4	88	58
e310	Immediate family	118	41	3	2	5		169	51
e315	Extended family	4	3					7	3
e320	Friends	58	22					80	22
e325	Acquaintances, peers, colleagues, neighbours and community members	17	4					21	4
e330	People in positions of authority	63					1	64	1
e340	Personal care providers and personal assistants	3	7	8		1	1	20	17
e345	Strangers		1					1	1
e350	Domesticated animals	11	3					14	3
e355	Health professionals	2	4	4				10	8
e360	Other professionals	19	5	10			3	37	18
e4	Attitudes	3	1	1			1	6	3
e410	Individual attitudes of immediate family members	24	3			1		28	4
e420	Individual attitudes of friends	11	1	1				13	2

<i>Code</i>	<i>Code description</i>	<i>Interviews (n=28)</i>	<i>Section A</i>	<i>Section B</i>	<i>Section C</i>	<i>Section D</i>	<i>Section E</i>	<i>Total Frequency</i>	<i>Total frequency only EHC PLANS</i>
e425	Individual attitudes of acquaintances, peers, colleagues, neighbours and community members	18	4	3	1	1	1	28	10
e430	Individual attitudes of people in positions of authority	7	1					8	1
e440	Individual attitudes of personal care providers and personal assistants				1			1	1
e445	Individual attitudes of strangers	6	2					8	2
e450	Individual attitudes of health professionals	4						4	
e455	Individual attitudes of other professionals	5	1					6	1
e460	Societal attitudes	2						2	
e5	Services, systems and policies	1					2	3	2
e525	Housing services, systems and policies					1		1	1
e535	Communication services, systems and policies		1					1	1
e5400	Transportation services	1				1		2	1
e5500	Legal services				1			1	1
e5550	Associations and organisational services, systems and policies		2					2	2
e5700	Social security services		1			3	1	5	5
e575	General social support services, systems and policies		1					1	1



<i>Code</i>	<i>Code description</i>	<i>Interviews (n=28)</i>	<i>Section A</i>	<i>Section B</i>	<i>Section C</i>	<i>Section D</i>	<i>Section E</i>	<i>Total Frequency</i>	<i>Total frequency only EHC PLANS</i>
e5750	General social support services, systems and policies		1				1	2	2
e580	Health services, systems and policies	1	2					3	2
e5800	Health services, systems and policies		3	2	6		2	13	13
e585	Education and training services, systems and policies	5	4					9	4
e5850	Education and training services	5						5	
e5851	Education and training systems	2						2	
e5852	Education and training policies	2						2	
e5853	Special education and training services	30	18	2				50	20
<b>59 e codes</b>		<b>487</b>	<b>181</b>	<b>97</b>	<b>21</b>	<b>16</b>	<b>21</b>	<b>823</b>	<b>336</b>

**Appendix F. Extracts of outcomes from EHC plans coded with the Goal  
Functionality Scale III (GFS III)**

Outcome	Participation in routines (a)	Measurability (b)	Necessity or usefulness (c)	Acquisition criterion (d)	Meaningful acquisition (e)	Generalisation criterion (f)	Timeframe (g)
He will feel more confident in asking for help if needed, and initiating new conversations. This will help him develop the social skills which will be important to him when working and living independently	2	3	4	2	1	1	4
To prepare for further education	1	1	1	1	1	1	4
He will use today, tomorrow and yesterday in his speaking activities. Then given a given date or event on a calendar, he will independently identify it as happening today, tomorrow or yesterday.	2	4	4	4	2	1	4
He will independently participate in a class conversation through three or more communicative exchanges with various partners	3	3	4	3	2	1	4
He will take daily exercise to try and maintain a healthy weight	1	2	1	1	1	1	4
He will demonstrate an understanding of 80% of common non-literal phrases taught, with minimal adult prompting	2	3	3	2	1	1	4
She will have developed her language and communication skills	1	2	2	1	1	1	4

Outcome	Participation in routines (a)	Measurability (b)	Necessity or usefulness (c)	Acquisition criterion (d)	Meaningful acquisition (e)	Generalisation criterion (f)	Timeframe (g)
I have developed my literacy and numeracy skills which support me to be as independent as possible with daily living skills	1	2	3	1	1	1	4
I understand what is available to me in the local community	1	1	1	1	1	1	4
M will have developed awareness of appropriate behaviour	1	1	2	1	1	1	4
C will have developed her attention, listening and concentration skills	1	1	1	1	1	1	4
To increase self-esteem	1	1	2	1	1	1	4
He will be able to use paragraphs and extend his writing	1	2	1	1	1	1	4
He will improve understanding of new methods in maths.	1	1	2	1	1	1	4

## Appendix G. Social Communication Questionnaire

### Social Communication Questionnaire (SCQ) – Current form

Michael Rutter, MD, FRS; Anthony Bailey, MD; Sibel Kazak Berument, PhD; Catherine Lord, PhD; Andrew Pickles, PhD.

Name of Subject:	Gender:
Date of Birth:	Age:
Date of SCQ Completion:	
Name of Respondent:	Relationship to subject:
School:	

#### Directions

Thank you for taking the time to complete this questionnaire. Please answer each question by circling yes or no. A few questions ask about several related types of behaviour; please circle yes if any of these behaviours were present during the past 3 months. Although you may be uncertain about whether some behaviours were present or not, please answer yes or no to every question on the basis of what you think.

- |    |   |     |    |
|----|---|-----|----|
| 1. | Is she/he now able to talk using short phrases or sentences?<br>If <i>no</i> , skip to question 8.  | yes | no |
| 2. | Do you have a to and fro 'conversation' with her/him that involves taking turns or building on what you have said?  | yes | no |
| 3. | Does she/he ever use odd phrases or say the same thing over and over in almost exactly the same way (either phrases that she/he hears other people use or ones that she/he makes up)?                                   | yes | no |
| 4. | Does she/he ever use socially inappropriate questions or statements? For example, does she/he ever regularly ask personal questions or make personal comments at awkward times?   | yes | no |
| 5. | Does she/he ever get her/his pronouns mixed up (e.g. saying <i>you</i> or <i>she/he</i> for <i>I</i> )?   | yes | no |
| 6. | Does she/he ever use words that she/he seems to have invented or made up herself/himself; put things in odd, indirect ways; or use metaphorical ways of saying things (e.g., saying <i>hot rain</i> for <i>steam</i> )? | yes | no |
| 7. | Does she/he ever say the same thing over and over in exactly the same way or insist that you say the same thing over and over again?  | yes | no |
| 8. | Does she/he ever have things that she/he seems to have to do in a very particular way or order or rituals that she/he insists that you go through?  | yes | no |

9.	Does her/his facial expression usually seem appropriate to the particular situation, as far as you can tell?	yes	no
10.	Does she/he ever use your hand like a tool or as if it were part of hers/his own body (e.g., pointing with your finger or putting your hand on a doorknob to get you to open the door)?	yes	no
11.	Does she/he ever have any interests that preoccupy her/him and might seem odd to other people (e.g., traffic lights, drainpipes, or timetables)?	yes	no
12.	Does she/he ever seem to be more interested in parts of a toy or an object (e.g., spinning the wheels of a car), rather than in using the object as it was intended?	yes	no
13.	Does she/he ever have any special interests that are <i>unusual</i> in their intensity but otherwise appropriate for her/his age and peer group (e.g., trains or dinosaurs)?	yes	no
14.	Does she/he ever seem to be <i>unusually</i> interested in the sight, feel, sound, taste, or smell of things or people?	yes	no
15.	Does she/he ever have any mannerisms or odd ways of moving her/his hands or fingers, such as flapping or moving her/his fingers in front of her/his eyes?	yes	no
16.	Does she/he ever have any complicated movements of her/his whole body, such as spinning or repeatedly bouncing up and down?	yes	no
17.	Does she/he ever injure her/himself deliberately, such as by biting her/his arms or banging her/his head?	yes	no
18.	Does she/he ever have any objects ( <i>other</i> than a soft toy or comfort blanket) that she/he <i>has</i> to carry around?	yes	no
19.	Does she/he have any particular friends or a best friend?	yes	no
20.	Does she/he ever talk with you just to be friendly (rather than to get something)?	yes	no
21.	Does she/he ever <i>spontaneously</i> copy you (or other people) or what you are doing (such as vacuuming, gardening, or mending things)?	yes	no
22.	Does she/he ever spontaneously point at things around her/him just to show you things (not because she/he wants them)?	yes	no
23.	Does she/he ever use gestures, other than pointing or pulling your hand, to let you know what she/he wants?	yes	no
24.	Does she/he nod her/his head to indicate <i>yes</i> ?	yes	no
25.	Does she/he shake her/his head to indicate <i>no</i> ?	yes	no
26.	Does she/he usually look at you directly in the face when doing things with you or talking with you?	yes	no
27.	Does she/he smile back if someone smiles at her/him?	yes	no
28.	Does she/he ever show you things that interest her/him to engage your attention?	yes	no
29.	Does she/he ever offer to share things other than food with you?	yes	no
30.	Does she/he ever seem to want you to join in her/his enjoyment of something?	yes	no

31.	Does she/he ever try to comfort you if you are sad or hurt?	yes	no
32.	If she/he wants something or wants help, does she/he look at you and use gestures with sounds or words to get your attention?	yes	no
33.	Does she/he show a normal range of facial expressions?	yes	no
34.	Does she/he ever spontaneously join in and try to copy the actions in social games, such as <i>The Mulberry Bush</i> or <i>London Bridge is Falling Down</i> ?	yes	no
35.	Does she/he play any pretend or make-believe games?	yes	no
36.	Does she/he seem interested in other children of approximately the same age whom she/he does not know?	yes	no
37.	Does she/he respond positively when another child approaches her/him?	yes	no
38.	If you come into a room and start talking to her/him without calling her/his name, does she/he usually look up and pay attention to you?	yes	no
39.	Does she/he ever play imaginative games with another child in such way that you can tell each child understands what the other is pretending?	yes	no
40.	Does she/he play cooperatively in games that need some form of joining in with a group of other children, such as hide-and-seek or ball games?	yes	no



## Appendix H. Introductory letter to organisations



**Research Project: The Voices of Young People with Autism Spectrum  
Disorders in transition to Post-16 education**

**Researcher: Carolina Maria Gaona**

**Supervisors: Dr Susana Castro & Dr Olympia Palikara**

Dear Sir/Madam,

I am writing to introduce myself and inform you of a research project that we are conducting for the School of Education at the University of Roehampton. The **Voices of Young People with Autism Spectrum Disorder in transition to Post-16 education** is a 2-year research project to investigate the views and experiences of post-16 education and employment of young people with ASD, following the introduction of the new Education, Health and Care plans. These plans give a significant role to the views and wishes of the young person and their families, and extend provision until the age of 25.

The present study will focus on describing how the young people themselves see and experience their transition to post-16 destinations. It will also explore how these views,



and the overall functioning of the young people are depicted in their newly developed EHC plans.

In addition, we hope that the findings of the study will inform future education policy and practice for young people with ASD following their transition to post-16 education and employment, and that for this reason your organisation will be interested to participate.

We are approaching a number of schools, colleges and organisations working with young people with special educational needs, and we hope that you will be interested in taking part. Therefore, we would like to arrange an initial meeting with you to introduce ourselves and to discuss the details of our project. The identification stage will take place from September 2016 to March 2017. Throughout the project we would be happy to communicate with you to describe our research, disseminate our findings and provide feedback, both orally and in written form.

We hope this information is helpful but if you would like further details please do not hesitate to contact us using the contact details below.

**Thank you for your support on this project. One of us will call shortly to arrange a time for a meeting.**

Kind regards,

Carolina Maria Gaona

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## **Appendix I. Information sheet and consent forms**

### ***I.1 Information sheet and consent form for headteachers***



#### **HEADTEACHER/PRINCIPAL INFORMATION SHEET AND CONSENT FORM**

**Title of Research Project: The Voices of Young People with Autism Spectrum Disorders in transition to Post-16 education**

#### **Brief Description of Research Project, and What Participation Involves:**

The changes introduced by the Children and Families Act and the new Education Health and Care (EHC) plans have given a new and significant place to the views of young people with Special Educational Needs (SEN) and their families. Furthermore, the extension of provision for SEN until the age of 25 places transition to adulthood planning in a compelling position.

The study of the Voices of Young People with Autism Spectrum Disorders (ASD) in transition to Post-16 education is a 2-year research project to investigate the views

and experiences of post-16 education and employment of this group through their own voices, following the introduction of the new EHC plans.

This study aims to explore young people with ASD's views through two complementary strands. The first strand consists on one to one, 30-45 minute interviews, with 30 Young people with ASD in the 15-19 age range. The second strand consists of collecting the EHC plans of this same group to analyse the way their views and their functioning are portrayed in these plans. This study will focus on the International Classification of Functioning, Disability and Health for Children and Youth, a classification system for disability and special needs that was published by the World Health Organisation in 2007, as a framework to analyse the data, highlighting functioning aspects rather than diagnostic categories.

We hope that the findings of the study will inform future education policy and practice on the significance of the views of young people with ASD following their transition to post-16 education. Findings from this research will be published in journal articles and conference presentations.

Participation in the study will involve the participant attending an individual interview with the researcher, and collecting their respective finalised EHC plan. Interviews will last between 30 and 45 minutes each. These encounters will be audio recorded and will take place in the participant's preferred environment (i.e. at home, school, work). If the chosen environment is school, these encounters will take place during school hours, at a time convenient for you and the participant, and agreed with both of you. Additionally, it will involve collecting the participant's EHC plan for analysis. No names or identifying personal details will be fed back to the University or given in any presentation of the findings, and it should not be possible for anyone to recognise you, your school or the participant in any report of the project.

There is no pressure or compulsion to take part in this project. You will be free to withdraw from the study at any time without giving a reason. If you decline to take part or subsequently withdraw from the study, you will not be adversely affected.

**Consent Statement:**

I agree to take part in this research, and am aware that I am free to withdraw at any point without giving a reason, although if I do so I understand that my data might still be used in a collated form. I understand that the information I provide will be treated in confidence by the investigator and that my identity will be protected in the publication of any findings, and that data will be collected and processed in accordance with the Data Protection Act 1998 and with the University's Data Protection Policy.

Signature .....

Name .....

On behalf of (name of School) .....

Date ...../...../.....

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Tel: 020 8392 3768

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the investigator (or if the researcher is a student, you can also contact the Director of Studies). However, if you would like to contact an independent party please contact Deputy Director of Research.

**Deputy Director of Research Contact Details:**

Professor Andrew Stables

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## ***1.2 Information sheet and consent form for parents***



### **PARENT PARTICIPANT INFORMATION SHEET AND CONSENT FORM**

#### **Title of Research Project: The Voices of Young People with Autism Spectrum Disorders in transition to Post-16 education**

#### **Brief Description of Research Project, and What Participation Involves:**

The changes introduced by the Children and Families Act and the new Education Health and Care (EHC) plans have given a new and significant place to the views of young people with Special Educational Needs (SEN) and their families. Furthermore, the extension of provision for SEN until the age of 25 places transition to adulthood planning in a compelling position.

The study of the Voices of Young People with Autism Spectrum Disorders in transition to Post-16 education is a 2-year research project to investigate the views and experiences of post-16 education and employment of this group through their own voices, following the introduction of the new EHC plans.

This study aims to explore young people with ASD's views through two complementary strands. The first strand consists on one to one, 30 to 45 minute interviews with Young people with ASD in the 15-19 age range. The second strand

consists on collecting the EHC plans of this same group to analyse the way their views and their functioning are portrayed in these plans.

We hope that the findings of the study will inform future education policy and practice on the significance of the views of young people with ASD following their transition to post-16 education. Findings from this research will be published in journal articles and conference presentations.

Participation in the study will involve your child attending an individual interview, and collecting their respective EHC plan. Interviews will last between 30 and 45 minutes. These encounters will be audio recorded and will take place in your child's preferred environment (i.e. at home, school, work), at a time convenient for you and agreed with you or the head teacher/principal of your child's school. Additionally, it will involve collecting your child's EHC plan for analysis. No names or identifying personal details will be fed back to the University or given in any presentation of the findings, and it should not be possible for anyone to recognise your child in any report of the project.

In order to adapt and tailor the research process to the profile of each participant, parents are kindly requested to answer a questionnaire on Social Communication, which is attached to this letter. The questionnaire is very simple, and it takes about ten minutes to complete.

There is no pressure or compulsion to take part in this project. You will be free to withdraw your child from the study at any time without giving a reason. If you decline to take part or subsequently withdraw from the study, your child will not be adversely affected.

**Consent Statement:**

I agree to take part in this research, and am aware that I am free to withdraw at any point without giving a reason, although if I do so I understand that my data might still be used in a collated form. I understand that the information I provide will be treated in confidence by the investigator and that my identity will be protected in the publication of any findings, and that data will be collected and processed in accordance with the Data Protection Act 1998 and with the University's Data Protection Policy.

Signature .....

Name .....

Name of my son/daughter .....

School/College .....

Date ...../...../.....

**Investigator Contact Details:**

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Tel: 020 8392 3768

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the investigator (or if the researcher is a student, you can also contact the Director of Studies). However, if you would like to contact an independent party please contact Deputy Director of Research.

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### ***1.3 Information sheet and consent form for young people***



## **PARTICIPANT INFORMATION SHEET AND CONSENT FORM**

### **Title of Research Project: The Voices of Young People with Autism Spectrum Disorders in transition to Post-16 education**

#### **Brief Description of Research Project, and What Participation Involves:**

The study of the Voices of Young People with Autism Spectrum Disorders in transition to Post-16 education is a 2-year research project to explore the views and experiences of post-16 education and employment of a group of young people with ASD through their own voices, following the introduction of the new Education Health and Care plans.

This will be done in two different ways:

- Through individual interviews, ideally one at the end of secondary education or in their post-16 destination. The interview will last between 30 and 45 minutes.
- Through their EHC plans. This is to see how their views and their functioning are depicted in these plans.

We hope that the findings of the study will inform future education policy and practice on the significance of the views of young people with ASD following their transition to post-16 education. Findings from this research will be published in journal articles and conference presentations.

Participation in this study involves:

- An individual interview with you
- Collecting your EHC plan

These encounters will be audio recorded and will take place in your preferred environment (i.e. at home, school, work). These encounters will take place during school/work hours, at a time convenient for you, and agreed with you and your parent/headteacher/manager.

No names or identifying personal details will be fed back to the University or given in any presentation of the findings, and it should not be possible for anyone to recognise you, your school or workplace in any report of the project.

There is no pressure or compulsion to take part in this project. You will be free to withdraw from the study at any time without giving a reason. If you decline to take part or subsequently withdraw from the study, you will not be adversely affected.

Thank you for your time.

**Consent Statement:**

I agree to take part in this research, and am aware that I am free to withdraw at any point without giving a reason, although if I do so I understand that my data might still be used in a collated form. I understand that the information I provide will be treated in confidence by the investigator and that my identity will be protected in the publication of any findings, and that data will be collected and processed in accordance with the Data Protection Act 1998 and with the University's Data Protection Policy.

Signature .....

Name .....

School: .....

Date ...../...../.....

**Investigator Contact Details:**

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Tel: 020 8392 3842

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Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the investigator (or if the researcher is a student, you can also contact the Director of Studies). However, if you would like to contact an independent party please contact Deputy Director of Research.

**Deputy Director of Research  
Contact Details**

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#### ***1.4 Information sheet and consent form for participants – adapted version***



### **Participant information sheet and consent form**

## **THE VOICES OF YOUNG PEOPLE WITH AUTISM IN TRANSITION TO POST-16 EDUCATION AND EMPLOYMENT**

Hello! My name is Carolina.



I am a student researcher at the University of Roehampton.

I am carrying out a study to find out about the views and experiences of young people with Autism about finishing secondary school and life in post-16.

I would like to know:

- What **your views** are about your life after secondary school.
- What **your wishes and aspirations** are for the future.
- How you see **yourself, your life**, and how you cope with problems.

- How your Education Health and Care plan describes you.

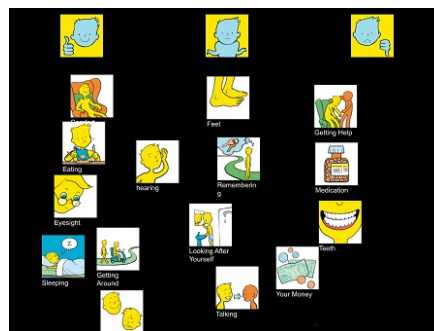
I would like you to help me. If you agree to help me, I will/can use Talking Mats to help you tell me what you think and feel.

This is a picture of someone using Talking Mats with a tablet.



**I will not share your views with anyone unless you want me to.**

You can get a copy of your Talking Mat to keep.



If you agree to help, I will meet you one time for about 30 to 45 minutes.

I will see you at a place that is comfortable and familiar to you, like School.



I will ask you about your life and changes after secondary school.

I will audio-record our conversation using this recorder.



Your **name** and **all** you share with me will be kept safely.

No one will be able to recognise you in any report of the findings.



If you change your mind at any time you can tell me to stop.

It is OK if you don't want to take part.

This will not harm you in any way.



You can contact me at:  
School of Education  
University of Roehampton  
Roehampton Lane  
SW15 5PJ  
Telephone: 020 8392 3842

[gaonac@roehampton.ac.uk](mailto:gaonac@roehampton.ac.uk)

Carolina Gaona

If you have questions or concerns about this study, you can ask me or my Director of Studies:



Professor Debbie Epstein

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[Debbie.Epstein@roehampton.ac.uk](mailto:Debbie.Epstein@roehampton.ac.uk)  
Telephone: 020 8392 3768

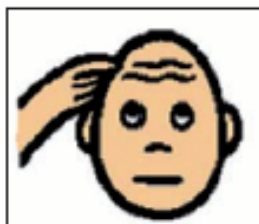
If you want to ask questions or talk about this study with someone else at the University, you can contact the Deputy Director of Research:



Professor Andrew Stables

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## PARTICIPANT CONSENT FORM



Have you read the information sheet, or had it explained to you?

**YES**

**NO**



Do you understand that it is your choice to take part in the study?

**YES**

**NO**



Do you understand that I will use your EHC plan, an audio recorder and a tablet as part of the study?

**YES**

**NO**



Do you understand that what we discuss will be stored safely and that no one will have access to it?

**YES**

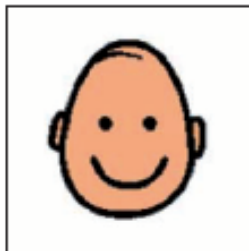
**NO**



Do you understand that you can stop at any time? (You do not have to say why you want to stop)

**YES**

**NO**



Are you happy to take part in the study?

**YES**

**NO**

Signature .....

Name .....Date.....

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