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Helping the most vulnerable out of the poverty trap and reducing inequality: Policies, strategies, and services for individuals with Autism Spectrum Disorder, including intellectual and neurodevelopmental disabilities: Benchmarking Autism Services Efficacy: BASE Project (Volume 4) Qualitative data analysis

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BASE PROJECT (VOL. 4) QUALITATIVE DATA ANALYSIS

DILLENBURGER, K., MCKERR, L., & JORDAN, J-A.
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Professor Karola Dillenburger
Centre for Behaviour Analysis
School of Education
Queen's University of Belfast
69/71 University Street
Belfast BT7 1HL
Northern Ireland

Scientific Consultation

Professor Mickey Keenan,
School of Psychology,
Ulster University Coleraine
Coleraine BT52 1SA
Northern Ireland.

Professor Dennis Moore
School of Education
Monash University
Melbourne, Australia

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Helping the most vulnerable out of the poverty trap and reducing inequality: Policies, strategies, and services for individuals with Autism Spectrum Disorder, including intellectual and neurodevelopmental disabilities

(Working title: Benchmarking Autism Services Efficacy: BASE Project)

The BASE project aims to provide baseline data for individuals with autism against which the effect of the Autism Act (NI) 2011 and associated Autism Spectrum Disorder (ASD) strategy can be measured. The five integrated Volumes of this project include

Volume 1: Comprehensive literature review using a systematic approach on outcomes for individuals with autism and the policies designed to improve those outcomes;

Volume 2: Northern Ireland Life and Times (NILT) Survey Autism module to survey public attitudes, knowledge and awareness of autism (n=1200); and

Volume 3. Secondary data analysis of all relevant NI governmental and related departmental etc. datasets focusing on education, employment and poverty;

Volume 4. Qualitative study using interviews and focus groups with individuals affected by autism and key professionals (e.g. educationists, employers, policy makers).

Volume 5. Final project report to funder including process and outcome record of the BASE Project.

This report (Volume 4) represents the qualitative research phase, using interviews, surveys and focus groups with individuals affected by autism and key professionals (e.g. educationists, employers, policy makers). The research reported here is in line with guidance from the United Nations General Assembly (2012) that encourages Member States to ‘undertake to collect appropriate information on ASD, developmental disability (DD) and associated disabilities’ (p.3).

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Abbreviations

ADD Attention Deficit Disorder

ADHD Attention Deficit Hyperactivity Disorder

ASD Autism Spectrum Disorder

CWA Child with Autism Spectrum Disorder

DEL Department for Employment and Learning

DES Disability Employment Service

DLA Disability Living Allowance

ESA Employment Support Allowance

ELB Education and Library Board

FE Further Education

GP General Practitioner

HE Higher Education

HSCT Health and Social Care Trust

IQ Intelligence Quotient

ITT Initial Teacher Training

IRAS Integrated Research Application System

MLD Moderate Learning Disabilities

PGCE Postgraduate Certificate in Education

RQIA Regulation and Quality Improvement Authority

Chapter 1: Executive summary

This executive summary is based on the qualitative study phase of the BASE project. The extensive literature review (Volume 1) had identified the mechanisms that have the potential to help individuals with autism and their families out of the poverty trap and thereby reduce inequality; these include increased public awareness, appropriate and accessible staff training across the public and private sector, timely diagnosis, availability of early intensive behaviour interventions, quality of education and training, and availability of employment, with appropriate support. Volume 2 reported on a survey of public attitudes, knowledge and awareness of autism, while Volume 3 described the comprehensive secondary data analysis of all relevant NI autism related datasets that focused on education, employment, and deprivation and poverty.

The present volume (Volume 4) adds a qualitative perspective to the project by exploring the experiences of individuals with autism, their parents or carers and the staff (both public and private sector) who are tasked with supporting service users affected by autism. Volume 4 reports on how autism policies and strategies translate into services that aim to help vulnerable individuals and their families out of the poverty trap and social exclusion.

Summary of main findings

Participants

Surveys, interviews and focus groups took place with a range of key professionals (e.g. educationists, health care professionals, doctors, policy makers), individuals affected by autism, parents of children affected by autism, as well as employers of adults with autism.

Professionals (n=798), including staff from all Health and Social Care Trusts (HSCTs) and Education and Library Boards (ELBs), teachers, General Practitioners (GPs) and private and public sector employees took part in a short online survey about awareness, knowledge and training in autism. A number of these professionals also took part in individual interviews.

Service user experiences were sought in individual interviews, focus groups, or surveys. This allowed individuals with autism and the parents of children and young adults with autism to outline their experiences. Eight children with autism who attended secondary school (mainstream and special schools) took part in focus groups while ten students with autism who were currently enrolled in Further and Higher Education courses completed on-line

surveys. Five adults with autism, three men and two women, and fourteen parents (including two couples) of children with ASD took part in individual semi-structured interviews.

Information about professionals' autism awareness, knowledge, and experience, as well as autism training was sought through a range of on-line surveys that established base-line levels of existing autism awareness and training levels, before resources were committed to address gaps in knowledge or training needs. Results therefore can be used by policymakers to target resources directly where there is a need to make available accurate and effective information to preparation for engaging with individuals with autism.

1.1 Professional autism awareness, knowledge, and experiences of autism training

The first Strategic Priority of the Autism Strategy and Action Plan (Northern Ireland Executive 2014, p. 51) is

‘To work in partnership with representatives from all government departments to access a range of awareness training which will support the public and private sector in providing services to people with autism, their families and carers’.

According to the ASD coordinators in Northern Ireland, health, social care and education sector, post-qualifying staff training in autism is categorised at 3 Levels or Tiers (terms are used interchangeably) along the lines of the National Autism Society autism training (NAS, 2015).

- Level/Tier 1 equates to brief autism awareness sessions, usually lasting no more than 1-2 hours. For education professionals, this is aimed at teaching and non-teaching staff (including office staff, governors, and caretakers, catering staff, drivers / transport staff and escorts, e.g., see INSET training).
- Level 2/Tier is usually a one-day seminar, aimed at staff who directly support a child with autism and, for education professionals, this covers more specifically classroom based strategies and is suitable for teaching assistants, lunchtime staff and teachers.
- Level 3/Tier commonly takes 1-2 days and aims at building on existing knowledge for staff, who are taking a lead in autism provision.

In addition, advanced autism training is offered by both Universities at Undergraduate and Masters levels (e.g., MScASD at Queens University Belfast (QUB); MScABA at Ulster University (UU) and at QUB), in addition there are Open Learning courses at QUB and professional development courses at UU.

The on-line staff surveys were designed to gauge the level of autism training in the health, social care, education and the public and private sectors in Northern Ireland and therefore could be used to inform policy.

The surveys also gathered qualitative information from professionals on their personal practice and recommendations for the future direction of services for individuals with autism, which provided context for the experiences of service users and key education professionals who also contributed to this phase of the BASE project

Professional contact with individuals with autism

- Half of the professionals who responded knew someone with autism personally, consistent with NILT data showing that 50% of the general population knew someone with autism personally (BASE Report Volume 2);
- All teachers who took part in the survey had contact with children with autism; two thirds of teachers on a daily basis, the remaining one third of teachers had less frequent contact;
- Nearly a quarter of other ELB participants had daily contact, while nearly half of ELB staff had no contact with children with autism;
- Over half of HE/FE staff respondents had no contact with individuals with autism. Only one tenth of HE/FE staff had professional contact with a student with autism on a daily basis;
- Fewer than a sixth of HSCT staff respondents had daily contact with individuals with autism, while about three in ten had no contact with individuals on the autism spectrum; individuals with autism can be expected to access the same health and social care services (such as accident and emergency units, clinics, specialist surgical procedures, general nursing and social work interventions) as the rest of the population, yet policies and practices can be generated by staff members with no contact with individuals with autism.

Professional experience of autism training

- None of the GPs who participated in this research had received any autism training through their employer, although respondent numbers were small; this subject perhaps deserves further research as GPs are one of the 'gatekeepers' for autism referrals (both for children's and adults' pathways) and also the point of contact through which many people will access other services;
- None of the teachers who completed the questionnaire had attended Level 3 training and only 13% had attended Level 2 training, which covers adaptations to

- professional practice, something many felt would be useful;
- Only one in ten of HSCT staff questioned had received Level 2 autism training (usually lasting 1-2 days) and many felt that their working environment could be better adapted to meet the needs of individuals with autism.
 - Education staff participants felt that at times, classroom assistants had more training in autism than teachers, but for some this was regarded as a very valuable resource, as staff were willing to share good practice;
 - Educational professionals who took part in the interviews generally enjoyed the ‘challenge’ of working with pupils with autism, and loved the ‘quirkiness of their personalities’.
 - Participants did not appear to be fully aware of advanced University training options in ASD and thus this resource remains potentially under-used locally.
 - Professionals who responded felt that training should be tailored to their specific roles and it should contain more ‘real-life’ examples of specific situations involving people with autism; the need for more realism to improve awareness was raised by participants from the private sector who represented potential employers, as well as service providers.
 - Overall, participants felt training should be more accessible, delivered in a variety of formats and should be informed directly by service users.

1.2 Identification of vulnerability: Autism diagnosis and service response

The identification of those most vulnerable to poverty and social exclusion is necessary prior to any intervention. Diagnosing autism, as well as participants’ experiences with health and social service responses were assessed in interviews and focus groups. Accurate and timely diagnosis is important to allow families affected by autism to move out of the poverty trap and social exclusion because a diagnosis gives access to benefits, allows for early intervention to start building skills in the child, and consequently, for parents to maintain (or return to) employment.

Diagnosis

- Recent figures (4th quarter of 2014) show that approximately 200 referrals for an autism diagnosis are made per month (range 188-210) to HSCTs across Northern Ireland;
- Approximately 50% of these referrals lead to a full-diagnosis of autism (range 84-119 per month), with the other 50% of cases either being placed on a watch-and-wait list or discharged without a diagnosis.
- Diagnosis is important as it improve chances of better individual and parental financial, physical, and mental health.

- For the majority of parents there were clear early indications of developmental delays or other concerns about their children (cf. BASE Project Vol. 3).
- All the adults with autism who participated in the interviews recognised that they had difficulties from childhood (particularly in social situations and at school).
- Adult diagnosis can give access to educational or employment supports.

Challenges with diagnosis

- Many parents spoke of their frustration with the diagnostic process, including lengthy delays associated with getting a diagnosis and patchy professional knowledge, particularly with regards to diagnosing autism in girls.
- Parents reported problems with communication and feeling judged by professionals during the diagnostic process, e.g., they were frequently asked to repeat themselves or were not asked the right questions and left sessions feeling that important issues had not been covered.
- In addition, a small number of participants felt concerned that some professionals viewed them as ‘bad’ parents.
- For some participants it appeared that professionals were poorly trained or ill-informed and thus not prepared to deal with autism as it was manifested in adults, particularly when these adults were able, articulate, and had family lives.

Support

- Parents who participated in the interviews were the main care-givers for their children, providing personal and emotional care and organising social activities to a much greater extent than that which might be expected for their peers.
- Most parents reported that they had limited access to statutory services overall, but some thought that Direct Payments had provided worthwhile respite opportunities.
- The post-diagnostic support network for individuals with autism (children and adults) and their families included family, peers, self, voluntary, private and statutory sectors.
- Knowledge shared by others was thought to be very valuable; many participants belonged to parent or other peer support groups, and others used social media to seek solutions or to offer advice to others.

Challenges regarding support

- Despite the fact that early intervention is recommended and significant in securing better outcomes, very few parents received any early intervention for their children following diagnosis.
- Some parents reported that they were steered towards self-help or to the voluntary sector, because no early intervention was available in the statutory sector.
- Almost half of parents who participated had found they needed to adjust their lifestyle either by leaving employment or reducing their hours because of their caring responsibilities.
- While appreciating DLA, some participants found it difficult to access as they found the forms so complex.
- Only two parents reported that they received Carer’s Allowance, although the

majority of participants were not in employment or worked part-time.

- Allocation of statutory support (which varies between Trusts) can have a cut-off point for individuals with an IQ above 70, which disadvantages those with learning disabilities or serious social and emotional problems whose IQ exceeds this limit.
- Parents of school leavers found that whatever support they had received discontinued once their child approached adulthood.

1.3 Education and training

Education and training are the foundations that enable vulnerable people to move out of poverty and into social inclusion. Children, students and adults with autism, and the parents of children with autism reported their experiences of education (from nursery to third level) and FE and HE training.

School and college/University experiences

- When support provision for children with autism in schools was tailored to the child's individual needs this was particularly successful.
- In general parents felt they were able to communicate effectively and comfortably with their child's school placement, if needed.
- Of the children with autism who took part in the study and who were currently attending school, most had a statement of special educational needs.
- Good communication between parents and teaching and support staff and good staff training were seen as major factors in a successful educational placement at all levels.
- Appropriate support structures and a curriculum that met individual academic demands, and peer group awareness of autism, all contributed to a good experience for students.
- The majority of parents felt their child's school placement was able to meet his or her academic needs.
- Focus group pupils identified the provision of support for individual needs and opportunities to develop new interests (or build on existing academic skills) as the main strengths in transferring to secondary education.

Addressing independent living needs

- Many professionals in both mainstream and special schools recognised the need to promote independence for individuals with autism, although some parents and school students would like to see this given greater priority. Educational professionals mentioned a range of activities that aimed to improve the social skills of some children with autism, such as buddy systems and links with other classes.
- Most parents felt that their child's school or college was making a positive effort to enhance social skills, although almost half believed this could be undertaken much

more proactively.

- Social skills groups for school and FE/HE students can offer valuable support.

Challenges related to support needs

- Challenges at school or college included lack of staff training, lack of resources, difficulties with interacting and focusing on tasks, and lack of staff skills in dealing with students' behaviour challenges.
- Some parents had challenged Education and Library Boards (ELBs) to have specific support needs met.
- The focus on academic achievement could at times detract from teaching independent living skills.
- None of the adults with autism who participated had been diagnosed while at school, and therefore had not been supported in their school days. Overall, their school life had been very difficult in terms of engaging with staff and peers.
- A minority of parents felt that school was not meeting their child's academic needs, in part because the school was not ambitious for students with autism.
- None of the school pupils had sought or been offered careers advice from their schools, although the younger participants were aware of the provision, and expected to have some contact in the future.

Third level education and training

- School pupils who participated were looking forward to moving in to third level education, while students currently attending FE or HE institutions reported that overall it was an enjoyable experience.
- Parents whose children were attending/had attended FE/HE courses were confident the placements offered the best opportunity for their children to achieve their goals, although there was less formal support in place.
- The most commonly mentioned forms of support for respondents to the student survey included technology (such as live scribe pens, laptops and software), financial support and Asperger's tutors.
- Saturday jobs and work experience were very helpful if matched with career expectations and interests.
- The majority of respondents in the student survey felt that university/college had been a comfortable and worthwhile experience, and for many this was identified with greater independence and meeting new friends.

Challenges regarding third level education and training

- Both parents and school students reported very little engagement with transitions services.
- Adults with autism reported very unsatisfactory transitions; of the five participants, four had entered third level education but none felt prepared.
- The diminishing input of parents, who knew their sons' and daughters' individual strengths and challenges, could affect the support offered in third level education.
- Learning social skills in the real world could present challenges for students with

autism.

1.4 Employment and quality of life

Service users' reports of their plans for the future offer insights into the challenges and advantages of futures and career planning, work experience and employment, daily living and quality of life.

Futures and career planning

- As their sons and daughters grow older, parents wanted them to move into the adult world with as many opportunities as possible, building on their individual skills and interests.
- Parents hoped their children would achieve some measure of independence, living and working with as much (or as little) support as they needed but acknowledged that finding the resources and services to make this possible was likely to be difficult.
- Young people with autism were optimistic about the future, and looked forward to leaving school or college and entering adult life in a variety of careers; half of them were considering moving away from Northern Ireland.

Developing skills and gaining employment

- Work experience was perceived as useful; where this was a more significant part of the curriculum, and appropriately supported, it is likely to be more useful.
- For adult participants in employment finding the right balance of support and challenge in the workplace had been rewarding.
- For the adult participants seeking employment, undertaking further appropriate training and volunteering were seen as steps towards finding a satisfying job.
- One participant was self-employed, for which there is little statutory support, but it has been rewarding, and one in which he is fully in control of the outcomes.
- A supported work placement offered one young person with more severe disabilities further training opportunities, supported by an experienced voluntary organisation; computer training was useful and enjoyable outside the workplace.
- Two employment case studies, based on in-depth interviews with employers, showed that given suitable support systems employment does not have to be an elusive aim for adults with autism.

Barriers to employment

- Adults and young people with autism who were at school or college had received very little formal support in making career decisions.
- Parents and adults with autism recognised that gaining employment included having relevant experience, filling in application forms and taking part in interviews and therefore could be challenging even for the most able young people with autism.
- For those with learning disabilities or behaviour issues, obtaining employment or

work experience was viewed as even more difficult because employers would be concerned about managing people with such problems in the workplace.

- Participants identified the major barriers to employment as lack of autism awareness and understanding both in the application process and in the workplace.
- All participant groups felt there should be more emphasis for employers on the positive aspects of autism that individuals could bring, such as attention to detail, enthusiasm, creativity and honesty.

Daily living and quality of life

- Some parents expressed concerns about the sense of responsibility which would pass on to siblings as parents aged, but all anticipated their children could move away from the family home, although they realised that this might need to be accomplished gradually.
- A number of young people in third level education and all the adults who participated were living independently.
- The great majority of participants living away from a parental home had found they could manage financially, that is, they had enough money to pay for basic needs such as food, clothing, accommodation costs and heating.
- Adults with autism who had engaged with the benefits system had mixed experiences, with some reporting very negative encounters with staff and delays in payment while others had found staff supportive at times.

Challenges in employment and daily life

- Parents realised that some of their adult sons and daughters with autism would need on-going support and mentoring as they remain vulnerable adults.
- Overall, parents felt there was a distinct lack of signposting from social services; any information they had acquired was through their own research on the internet or through contacts with parent support groups and other voluntary organisations.
- A number of parents were aware of excellent specialist provision for those with other conditions, or within other Trusts, but there seemed to be no overall regional plan for the type of accommodation which would be suitable for adults with autism.
- Adult services are at a very early stage of development with Trusts and the majority of the adult participants could not rely on the level of provision which might be expected through Children's services. This places an additional onus on families and voluntary organisations to fill the gaps.
- Employers emphasised that employing an individual with autism demanded considerable additional time commitment from employers.
- In the short-term, employers were prepared to 'go the extra mile' to offer employment opportunities individuals with autism, however this was not feasible in the long-term without being adequately resourced.

Recommendations

The following recommendations emanated from the qualitative research findings. In the present economic climate, it should be recognised that many require additional resources (or more effective use of resources currently available) and implementation will be a matter for individual departmental consideration.

Recommendations regarding diagnosis

1. Early and timely diagnosis should be made available more widely to avoid delays in intervention and benefit support for families vulnerable to poverty and social exclusion;
2. Adult diagnostic services should be available more efficiently; necessary resources should be available in all Trusts;
3. Care Pathways should include triage systems for those on the waiting list for urgent need as many intervention services are not offered until a diagnosis is obtained;
4. A more expedient solution may be to outsource triage and diagnosis to the voluntary or private sector (see Adult Diagnostic Research Centre in Southampton; <http://www.adrc.co.uk>);

Recommendations regarding training

5. Autism training should go beyond autism awareness; the minimum departmental requirement specified in the Autism Strategy (Strategic Priority 1) and where appropriate for staff and carers, the focus should be on practical interventions and skills training, e.g., how to manage and support individuals with autism; this should be facilitated in-service by Boards and Trusts who already have the options to access or 'buy-in' training and by DEL through the Universities;
6. University-based autism training should be endorsed and commissioned as key qualification in autism for education and healthcare staff, and information on such courses should be widely available through employers (e.g., HSCTs, ELBs and DENI);
7. There should be more information on where to access training, for example by featuring this regularly on staff intranet/ communications.
8. In order to improve accessibility, training should be accessible on-line (e.g., Northern Health and Social Care Trust; QUB and UU courses);

Recommendations regarding education and intervention

9. Early intensive behaviour analytic intervention programmes should be embraced as evidence-based practice by the statutory sector; NB: although some health and education professionals already draw on behaviour analytic principles, for example in parent training and managing challenging behaviours, very few are trained to the international standards to deliver behaviour analytic, individually tailored intensive interventions; alternatively, these specialist services could be outsourced to the voluntary or private sector, although this would require additional resources.
10. Autism support groups (both for academic and social skills) should be made available in school;

11. Awareness programmes should be offered to all pupils at school to promote inclusion and reduce bullying; autism related training should be integrated during initial teacher training (ITT) (e.g., in PGCE);
12. Courses (which include peers without autism) should be made available specifically for life skills and relationship skills, preferably on school premises;
13. More flexibility for the 'spectrum' of needs; schools should avoid the predominant 'one-fits all approach', i.e., visual schedules are not needed by all children with autism;

Recommendations regarding employment and quality of life

14. Employers should be aware of, and focus on, the potential for specific skills of individuals with autism; employer specific awareness training should be promoted by DEL/DES;
15. Self-advocacy for adults with autism should be made available, i.e., ask what they want, not make decisions for them. This should be mandatory practice for all adult autism service providers and can be delivered at no extra cost after relevant autism training;
16. Employment support can provide job stability and enhance self-confidence, and uptake of specialist support programmes should be targeted for increase by DEL/DES through their on-going strategies such as Access to Success/Pathways to Success and the proposed Economic Inactivity Strategy (as noted in Strategic Priority 7 of the Autism Strategy);
17. Specialist groups for women with autism should be made available to offer effective support, if necessary by offering 'seed funding' and/or advice (including support for suitable external funding applications) for establishing these through HSCT adult autism services;
18. Access to specialist autism counselling/advocacy service should be made available; for children this should be accessible through school referrals and on school premises where possible, and for school leavers aged 16-19 years, this should be available through the HSCT adult autism service.
19. Policy makers should listen to parents. They are the people who know what they need, but many parents who are involved in the day-to-day care of their children with autism do not have the time or energy to respond to lengthy consultation documents or join committees. Opportunities to contribute to strategies should be offered by a variety of means (including on-line forums, Twitter and Facebook) as well as the input from committed user groups organised through the Autism Strategy;
20. Personal budgets/Direct Payments should be allocated so parents/individuals with autism can plan/decide on flexible services tailored to individual need. This is already identified as a key action for HSCB/HSCTs in the Autism Strategy (Strategic Priority 3), although within the policy recommendations for Transforming Your Care, the need for structural support in implementing any increased uptake has been emphasized.

Chapter 2: Introduction and research methodology

Autism Spectrum Disorder (ASD) pervasively affects communication and social interactions as well as flexibility in thoughts and behaviour patterns, often but not always with intellectual and/or other co-occurring neurodevelopmental disability. While some individuals on the autism spectrum are able to function in mainstream society without additional supports, most require intensive services.

The estimated prevalence rate of autism across all age groups is approximately 1 in every 88 (Elsabbagh et al., 2012); in Northern Ireland, 2% of school children are on the autism spectrum (DHSSPS, 2014). This figure is likely an underestimation given that parents of 3.5% of 11-year-old children in the UK (including NI), who took part in the Millennium Cohort Study (n= 13,287), were told that their child had autism (Dillenburger, Jordan, McKerr, & Keenan, 2015); confirming these findings for Northern Ireland, 3.1% of 16 year-olds, who took part in the Young Life and Times Survey (YLT; total n=1,034), self declared as having autism (Dillenburger, Schubolz, McKerr, & Jordan, 2015), and 2.7% of the children (aged 11 years of age) who took part in the Kid Life and Times Survey (KLT; total n= 2319) self-declared as having autism (Dillenburger, Lloyd, McKerr, & Jordan, 2015).

Despite recent advances in brain imagery and discovery of certain genetic linkages, presently there are no medical tests that reliably identify individuals with ASD and consequently diagnosis is based purely on behavioural data, such as direct observations and parental/caregiver reports (Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010).

The number of people diagnosed with ASD has risen dramatically over the past decade. Whether this is caused by diagnoses becoming more precise, over-diagnosing, or an actual rise in incidents is a much-debated issue. In any case, recent studies have estimated that, if not adequately treated, the lifetime cost to care for an individual with an ASD can amount to as much as £1.5 million (Buescher, Cidav, Knapp, & Mandell, 2014).

Therefore, issues of staff awareness and training, timely identification (i.e., diagnosis), and appropriate and effective responses to diagnosis are very important; getting it right can save enormously, not only fiscally but even more importantly, it has major impact both socially and emotionally, i.e. in terms of quality of life and relative poverty for individuals and their families and therefore society as a whole (Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2010) as the behaviours which impact on their economic and social exclusion (such

as problems with communication and social interaction, challenging behaviours, low academic achievement and poor life skills) are addressed.

In Northern Ireland, the Autism Act (NI) 2011 aimed to address these issues and mandated the development of a cross-departmental autism strategy within two years of the Act coming into force. The Autism Act (NI) 2011 includes an amendment to the Disability Discrimination Act 1995 (c.50) in its application to NI, by inserting at the end of paragraph 4(1) of Schedule 1 ‘(i) taking part in normal social interaction; or (j) forming social relationships’ and it places a duty on the Department of Health & Social Security (DHSSPS) to act as the lead government agency in producing, reviewing and implementing a cross- department strategy for Autism. In addition, the Autism Act (NI) 2011 places a duty upon all Government Departments to clearly detail how the needs of individual with ASD, their families, and their carers are to be assessed and addressed (Northern Ireland Executive, 2014). The Autism Strategy (2013-2020) and the Autism Action Plan (2013-2016) were launched in January 2014.

This report builds on previous research on the needs of families affected by Autism Spectrum Disorder in early childhood (Dillenburger & McKerr, 2014; Dillenburger, McKerr, & Jordan, 2014) and futures planning of parents caring for their disabled son or daughter in later life (i.e., 60+ years old) (Dillenburger & McKerr, 2009, 2011). These studies clearly point towards the need to ensure policies, strategies, and services produce tangible results when combating social exclusion and poverty.

There are five Volumes of BASE reports that have explored the academic literature and policy context (Volume 1), reported results from the NILT Survey autism module about public awareness, knowledge, and attitudes in Northern Ireland (Volume 2), presented the evidence from numerous secondary data analyses on prevalence as well as social and educational outcomes which impact on individuals with autism and their carers (Volume 3), and summed up the research in an abbreviated final report (Volume 5).

The present volume, Volume 4, draws together qualitative reports (through focus groups, interviews, and/or questionnaire surveys) about knowledge, training, and practical experiences of the following stakeholder groups:

- Health and social care professionals
- Educationalists
- Policy makers

- Employers
- Young people and adults with ASD, including those with intellectual and neurodevelopmental disabilities
- Caregivers/parents of individuals with ASD

Participants were asked to make recommendations based on their own experiences in work, at home, or in educational settings and this information led to a number of clearly defined policy and service recommendations.

A number of qualitative research methodologies were used:

- For service providers, including health and social care professionals, educationalists, policy makers, and employers individual interviews and a number of bespoke on-line surveys were used. The online surveys were a useful way to collect data from professionals because they were anonymous, offered the opportunity to comment on aspects of professional experiences, and allowed for recommendations for service improvements without prejudice. Interviews with employers of adults with autism facilitated a small number of in-depth case studies and examination of the factors which impacted on supported work placements and the challenges that can arise. They also allowed for suggestions for measures to increase employment opportunities in the future.
- For service users, including young people and adults with ASD and their caregivers/parents, focus groups and individual interviews were used to allow for in-depth explorations of their experiences, whether these relate to school, transition to adulthood, tertiary level education, employment, or daily living. Interviews with caregivers/parents added perspectives on service provision and also gave an insight into some of the social, emotional and economic impacts of caring for children and young people with autism. Ten students attending FE/HE institutions opted to complete an on-line survey on their experiences rather than participate in focus groups.

Given that the focus of the research was on helping vulnerable individuals out of poverty and social exclusion, findings are reported along the lines of the model developed by the UN Convention of the Rights for individuals with disabilities, including autism (UNCRPD, 2006; see Figure 1 for a fuller explanation). First, professional awareness and knowledge of autism,

gained either by qualifying or post-qualifying training is explored; then, the identification of those most vulnerable to poverty and social exclusion (i.e., diagnosis of autism) is addressed in terms of early markers, the diagnosis process and the eventual diagnostic determination. Clearly, once vulnerable individuals and their families are identified, social and health care interventions are important stepping-stones to alleviate descent into poverty and exclusion. However, ultimately, the quality and access to education and employment opportunities are the decisive factors of bringing the most vulnerable out of poverty and social exclusion and afford them good quality of life and their rightful place in society.

Figure 1: UNCRPD: Rights for individuals with disabilities, including autism.



Given the importance of well-trained professionals in supporting the most vulnerable out of poverty and into social inclusion, Chapter 3 presents the results related to autism awareness and training of professionals (n=798) from organisations across the public and private sectors, offering a ‘snapshot’ of the range of expertise both in quantitative and qualitative terms. In addition, more detailed views of twelve professionals who were experienced in working with children and young people with autism in a variety of educational settings, provide a further qualitative dimension regarding the autism awareness and staff training.

Chapters 4-6 represent the views of service users (n=41), using survey, focus group and individual interview with children, young people and adults with autism that were related to school, transition to adulthood, tertiary level education, employment or daily living. Chapter 4 reports on identification, diagnosis and health and social care support, Chapter 5 focuses on education and training of individuals on the autism spectrum and Chapter 6 explores employment, planning the future, and quality of life.

2.1 Participant background

Professionals

Short on-line surveys tailored for specific professional sectors were completed by a total of n=798 professionals; those represented included health and social care, education, public sector and private sectors. In addition, twelve education professionals from across the sector took part in in-depth interviews.

The gender ratio of public sector respondents was 50/50 (male/female); the other groups of professionals were primarily female. Responses to all surveys represented a wide age group (18-65 years), with average age for the professional groups ranging from 40-46 years. Full details of the gender and age breakdown of the participant groups are included in Appendix 2.

Health and Social Care Trust (HSCT) staff: Of the HSCT respondents (n=569), the majority came from the South Eastern (35%), Western (27%) and Northern (26%) Trusts, with fewer respondents from the Southern (6%) or Belfast (4%) Trusts¹ (Figure 2). A small percentage of individuals were classified as ‘other’ because they either worked for more than one Trust or for the Health and Social Care Board and related agencies.

¹ Breakdown of responses is detailed in Appendix 4

Figure 2: HSCT respondents by Trust area

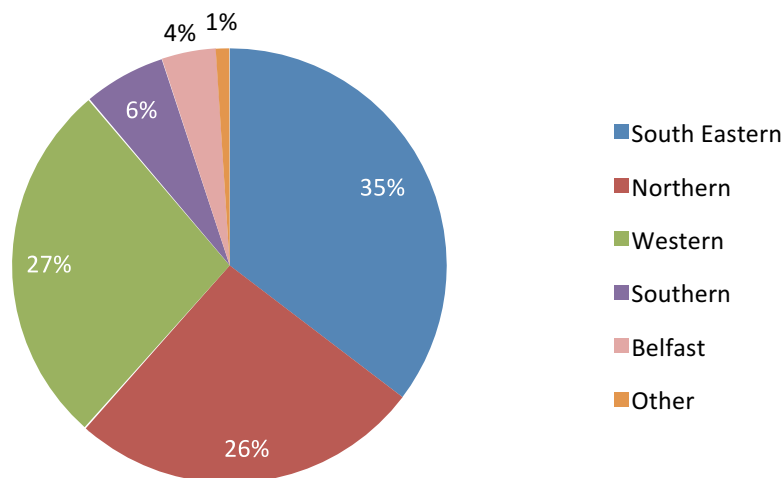
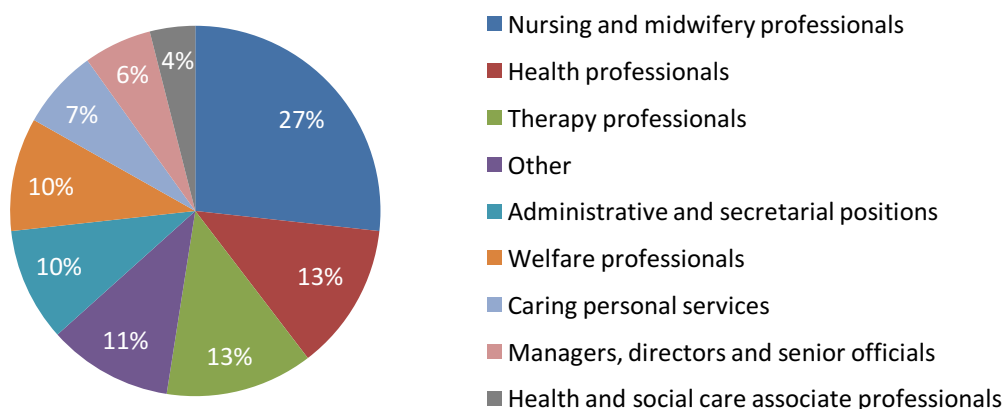


Figure 3 shows occupational breakdown of HSCT participants. Almost a third of the respondents were nursing and midwifery professionals (27%), while others included health, e.g. medicine and psychology (13%), therapy, e.g. occupational therapy, speech and language therapy and physiotherapy (13%), welfare, e.g. social work (10%), and administrative and secretarial (10%), and others (11%). The very low response rates from Southern and Belfast Trust staff were due to the absence of the ASD co-ordinators in these Trusts at the time of the study that lead to very lengthy delays in governance approvals to carry out the survey.

Figure 3: Occupations of HSCT respondents



Education and Library Board staff: Of the Education and Library Board (ELB) professionals who participated in the survey (n=48), 75% were employed in the Western Education and Library Board and 25% were either general ‘C2k’ (technology support providers) or from Belfast (BELB), North Eastern, (NEELB), or Southern (SELB) Education

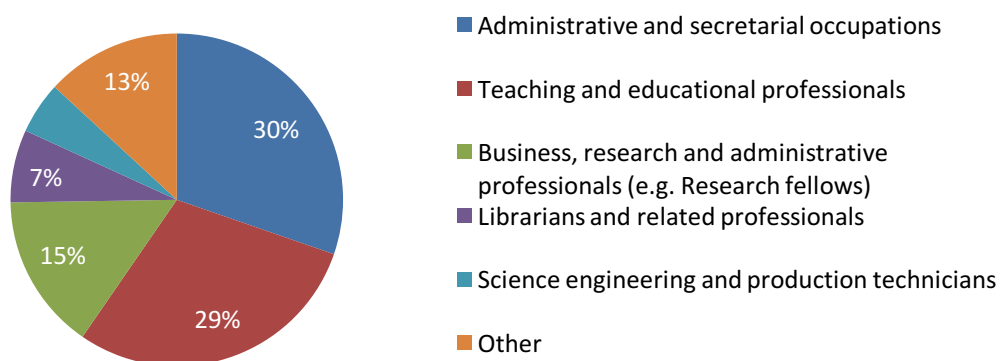
and Library Boards.

Twelve educational professionals took part in semi-structured interviews, which offer an in-depth perspective on some of the issues identified in the surveys. Participants included teaching staff and lecturers as well as those working in roles related to coordinating support for individuals with disabilities. Half of the respondents had been in their current post for over 10 years, one third had only been in post for 2-4 years, and the others had been in post for 5-10 years. All participants currently worked with at least one student with autism. Three quarters of participants had contact with individuals with autism on a daily/weekly basis.

Five respondents were working in the post-16 sector, while the others worked mainly in post-primary education. Three quarters of professionals were working in special education. The vast majority of participants had completed some form of teaching qualification.

Further and higher education staff: The majority of respondents of the Higher Education and Further Education (HE/FE) staff survey were employed at Queen’s University Belfast (89%) and with the remainder employed at Further Education colleges (11%). The majority of participants were either in administrative/secretarial (30%) or teaching and educational (29%) professions². The occupational breakdown is presented in Figure 4³.

Figure 4: Occupations of FE/HE respondents



² HE/FE occupations were coded using Standard Occupational Classification (SOC) 2010 codes

³ Breakdown of occupational groups is presented in Appendix 3

Employers

Round table discussions were held with a group of employers (n=21) and two employer case studies were based on in-depth interviews with employers. The first case study involved a cross-border rural development pilot project, offering supported employment as an alternative to day care for adults with learning disabilities or mental health problems, some of whom had autism. Twenty rural businesses took part in this pilot project providing placements for one to three individuals (total, n=66), for at least one day each week. The owners of two of these businesses (three individuals) participated in the BASE project (Case Study 1).

Case Study 2 had a long history in the culture, arts and leisure sector, offering public access as well as maintaining an international research facility. Staff included students and visiting researchers (n=40) people; at the time of the interview with the director, two individuals with autism were on work placements for one day each week.

Service users

Children with autism: Focus groups were held at a mainstream secondary school (School 1) and a school for children with special educational needs (School 2), both in urban settings. A total of n=8 children participated in the focus groups, three at School 1 and five at School 2. The participants were all male and the majority were aged between 15 and 16 years of age (NI secondary school years 11 and 12). Group discussions were lively, articulate and relaxed, and the children talked easily about their wide range of interests and hobbies.

Further and higher education students with autism: Students with autism in further or higher education completed a short online questionnaire about their educational experiences (n=10). The sample was quite diverse in terms of academic interests; subjects studied included: maths, physics, biomedical engineering, computer science, history, politics and creative media and hobbies and interests.

Adults with autism: Five adults with a diagnosis of autism, three males and two females, aged between 41-57 years of age, took part in semi-structured interviews. Three participants were married, with young children; the wife of one participant (A) took part in the interview with her husband, at his request. Two of the participants were employed within the public sector and one was self-employed; the other two participants were actively seeking work.

Parents of children with autism: Fourteen parents of children with ASD participated in semi-structured interviews, representing n=15 children. Nine families had one child with autism, three families had two children diagnosed with autism, and in two of the families both parents took part. Parents were aged between 37-59 years; half were in employment (five in full time and two in part-time jobs). Six others were not in paid employment and one was retired.

Eleven of their children were males, aged 8-27 years and other four were females aged 3-20 years; the term 'children' used in the following section is therefore a generic term which also covers sons and daughters who are over 18 years of age. Thirteen of the children lived at home with their parents and two lived away from home. Twelve of children had one or more co-occurring conditions; three had learning disabilities, two had Attention Deficit Hyperactivity Disorder, three had dyslexia, two had dyspraxia, two had sleep disorders, and one each had anxiety, Tourette's syndrome, asthma, and eczema.

Chapter 3: Staff autism awareness, knowledge, and training

Staff awareness and knowledge, gained through effective qualifying and post-qualifying training are an essential pre-requisite to preparing professionals for their role of supporting the most vulnerable out of the poverty trap and social exclusion.

In the Autism Strategy and Action Plan a strong focus was put on autism awareness with a strategic priority to ‘deliver a comprehensive autism awareness training programme for frontline staff in government departments and their arm’s length bodies’ (Northern Ireland Executive 2014, p.10). This is a key part of the overall aim of improving services and addressing disadvantages for individuals with autism and their families.

Baseline levels of autism awareness in the general population were explored in the autism module that was included in the Northern Ireland Life and Times Survey (NILT). This established autism awareness in the general population to be 82%, with half of the adults (51%) having personal contact with an individual with autism (BASE Project, Volume 2; Dillenburger, McKerr, Jordan, Devine, & Keenan, 2014).

In order to gauge the baseline of autism awareness levels of professionals before the onset of the Action Plan, an on-line autism awareness and training survey was carried out with key professionals⁴.

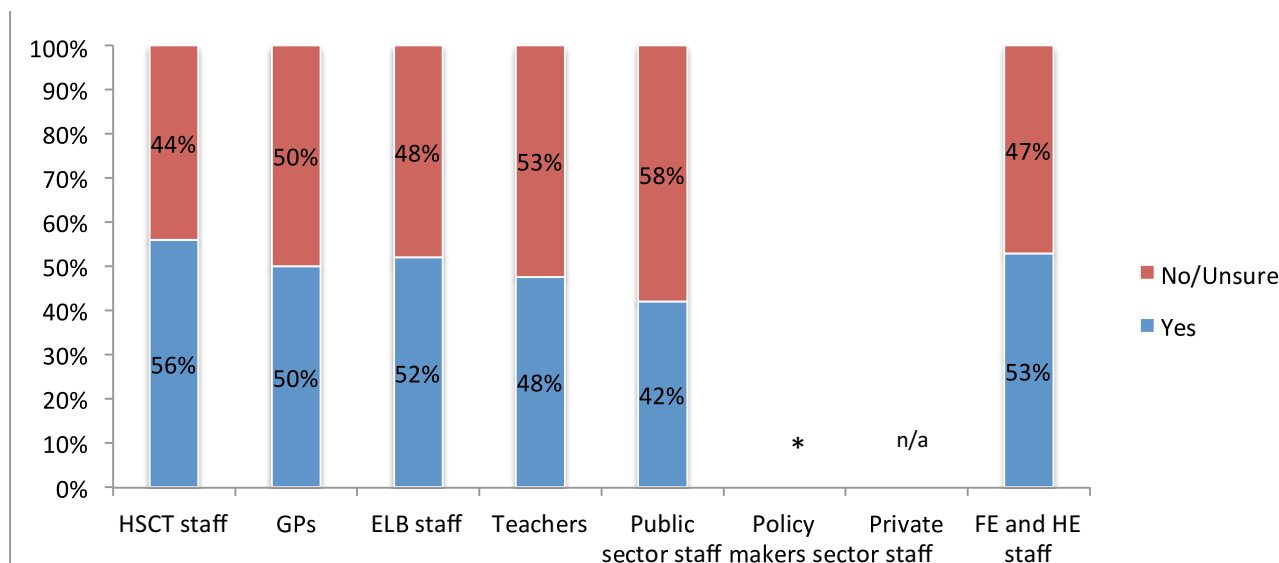
3.1 Professional autism awareness

Autism awareness levels of professionals were consistent with the NILT Survey data, establishing that about half of the teachers and ELB, HSCT, and HE/FE staff knew someone with autism personally⁵ (Figure 5). Numbers in other staff categories were too small to make even tentatively generalizable statements.

⁴ Technical information is presented in the technical appendix.

⁵ Breakdown of the responses is shown in Appendix 6

Figure 5: Professionals who know someone with autism



Proportions are calculated with prefer not to say/missing responses excluded. Cells suppressed due to small values (1 or 2) for personal information – denoted by *. Question not asked to this participant group denoted by n/a

More than two-thirds of teachers had contact with individuals with autism on nearly a daily basis (Table 1) with the remaining teachers having some level of contact, either once or twice a week or less frequently. In contrast, the majority of FE/HE staff (57%) had no contact with individuals with autism or were unsure. Less than one in ten of HE/FE staff said they had professional contact every day with individuals with autism⁶.

Table 1: Frequency of contact with service users who have autism

	Almost every day	Once or twice a week	Infrequently	Never/ unsure	Total
Teachers	68%	24%	8%	0%	38
Private sector staff	33%	0%	38%	29%	21
ELB staff	23%	20%	15%	43%	40
HSCT staff	16%	18%	39%	27%	459
HE/FE staff	9%	14%	20%	57%	65
GPs ²	-	-	-	-	-
Public sector staff ²	-	-	-	-	-
Policy makers ³	n/a	n/a	n/a	n/a	n/a

¹Proportions are calculated with prefer not to say, 'other' responses that could not be recoded, and missing responses excluded.

²Cells suppressed due to small values for personal information – denoted by a dash.

³ Question not asked to this participant group

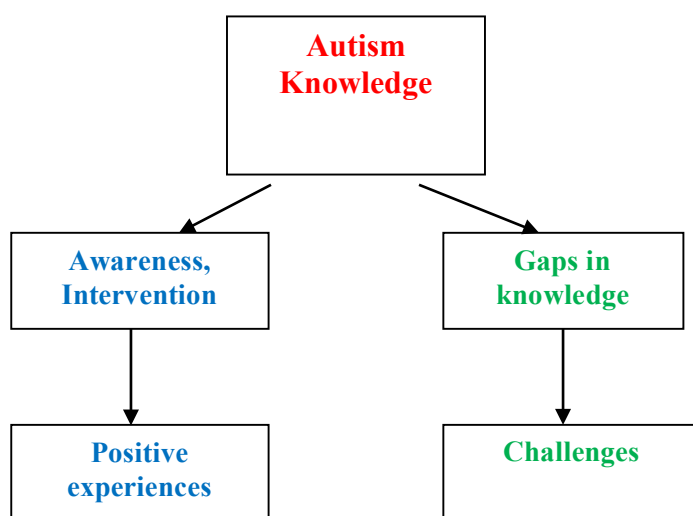
⁶ Full breakdown of figures is presented in Appendix 7

3.2 Professional knowledge of autism

Professional knowledge of autism and intervention strategies came from several sources, including knowing someone with autism personally, completing initial teacher training, in-service training, personal reading, or voluntary sector training. This knowledge provided the foundation of educational supports through staff working as a team, working with parents, providing structure and organisation, providing exam support, orientating students, providing social skills support, enabling communication and promoting independence.

Professional participants, especially those within education, identified gaps in their own knowledge of autism that led to challenges, such as difficulties in balancing expectations and resources and having to deal with challenging behaviours (see Figure 6).

Figure 6: Knowledge about autism of educational professionals



The majority of participants had some form of contact with individuals with autism outside work and participants talked about how their working experiences had affected their interactions with individuals with autism outside their professional role. Yet the relationship between personal experience and experiences in work appeared to be bi-directional, as participants also described how knowing someone with autism had affected their work practice.

'I can see where, before I had this job, I would have just, you know 'You're not on my wavelength' and now I know it's me that's not on his wavelength...' (Professional 7)

'I think because of [son] I'm more clued in to the fact that they need things clearly explained. Definitely, if it weren't for [son], I'd probably be like my colleagues. 'Oh he's strange'. 'Wish he wasn't on the course' (Professional 11)

3.3 Professional autism training

Professional qualifying courses for teachers, speech and language therapists (SLT), occupational therapists (OT), psychologists, nurses, and other allied health and medical professionals offer very limited input on ASD, with a maximum of between one and three hours of lectures. Most pre-qualifying courses offer no training in ASD (Dillenburger, Röttgers, et al., 2014).

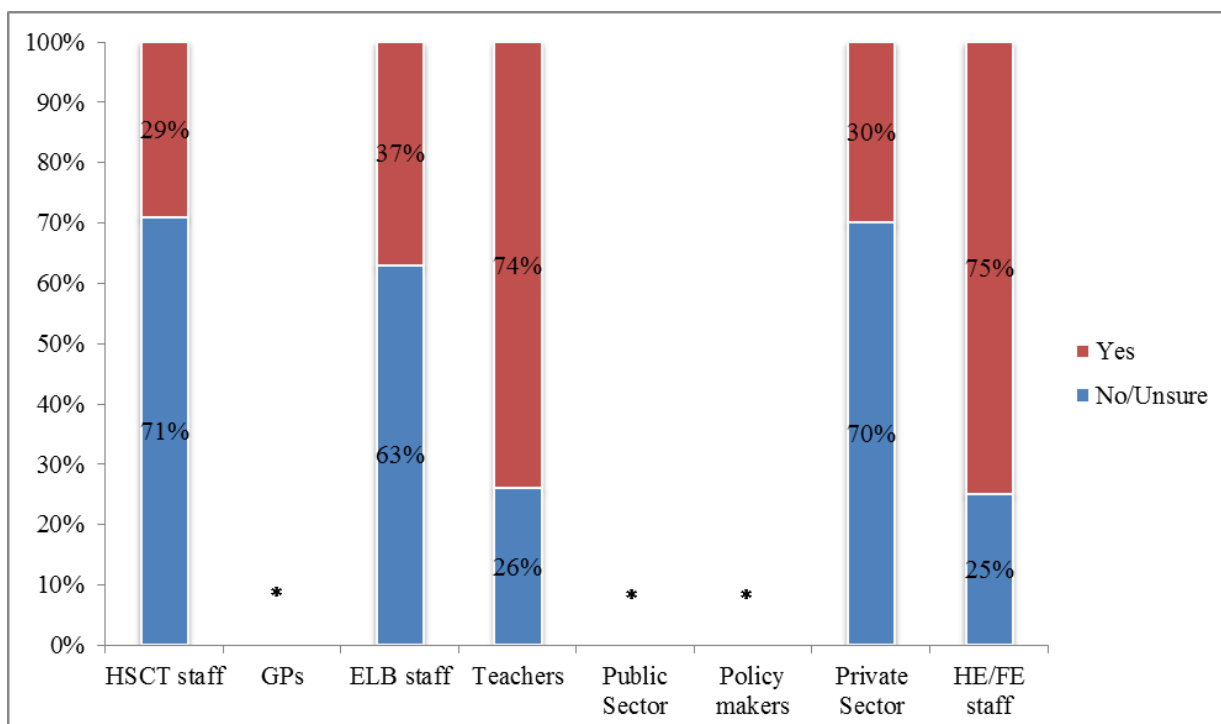
In Northern Ireland, HSCT and Department of Education provide very basic in-service autism training at three post-qualifying levels (BASE Project Report Vol. 1).

- **Level/Tier 1** equates to a brief autism awareness session, usually lasting no more than 1-2 hours and for the education sector is aimed at teaching and non-teaching staff (including office staff, governors, caretakers, catering staff, drivers/ transport staff and escorts, e.g., see INSET training);
- **Level/Tier 2** is usually a one-day seminar aimed at staff who directly support a child with autism. For education professionals, this covers some classroom based strategies and is suitable for teaching assistants, lunchtime staff and teachers;
- **Level/Tier 3** commonly takes 1-2 days and aims at building on existing knowledge for those who are taking a lead in autism provision.

At Higher Education levels, Queen's University as well as Ulster University and the Open University offer undergraduate level or professional development courses in ASD. Advanced post-qualifying training is offered at Queen's University Belfast in the MSc/ PGDip/ PGCert. in Autism Spectrum Disorders (MScASD) and the MSc/ PGDip Applied Behaviour Analysis (MScABA) and at Ulster University in the MSc Applied Behaviour Analysis (MScABA). University courses are either funded by employers or self-funded by students.

Figure 7 shows that three quarters of the teachers had received in-service autism awareness training (74%)⁷. Other (non-teaching) professionals were less likely to have received autism awareness training (25% - 37%). As noted earlier, the numbers of some of the groups who responded were too small to make generalisations overall, or were potentially disclosive, and these were not included in Figure 7. None of the participants mentioned having received University-based training.

Figure 7: Existing autism training of professionals



Proportions are calculated with prefer not to say/missing responses excluded.

Cells suppressed due to small values for personal information – denoted by *.

Note that most of this training was at Level 1 (see Table 2)

Half of the teachers indicated that the autism awareness training they had received was at Level 1 (1-2 hours) (47%); none of them had received Level 3 training. Just over one quarter of ELB (27%) and fewer HSCT (19%) and HE/FE (12%) staff confirmed that they had undertaken Level 1 autism awareness training, while 19% of the ELB staff had received up to Level 3 (1-2 days) autism awareness training.

This kind of autism awareness training is usually delivered sequentially (from Level 1 through to Level 3), however this is not mandatory and since approximately one quarter of

⁷ Full breakdown of training responses is provided in Appendix 8

ELB staff had completed Level 2 (1 day seminar) and one fifth of them had received Level 3 training (1-2 day seminar), it is possible that these professionals had a certain level of autism awareness prior to their appointment to post, which meant that when they were able to access in-service training at a somewhat higher level. However, since some staff indicated that they had been offered autism training, but then did not indicate the level at which this training was delivered, it is also possible that some of them simply indicated the highest level of training received rather than detailing all the training they had received (see Table 2).

Table 2: Level of existing autism awareness training

	Total who received training ¹	Level 1	Level 2	Level 3
Teachers	74%	47%	13%	0%
ELB staff	37%	27%	28%	19%
Private sector staff ²	30%	-	-	-
HSCT staff	29%	19%	10%	3%
HE/FE staff ²	25%	12%	5%	-
Policy makers ³	0%	n/a	n/a	n/a
Public sector staff ²	-	-	-	-
GPs	0%	0%	0%	0%

¹Proportions are calculated with prefer not to say/missing responses excluded.

²Some cells suppressed due to small values for personal information – denoted by a dash.

³ Where question not asked to this participant group-n/a

3.4 Future staff training needs

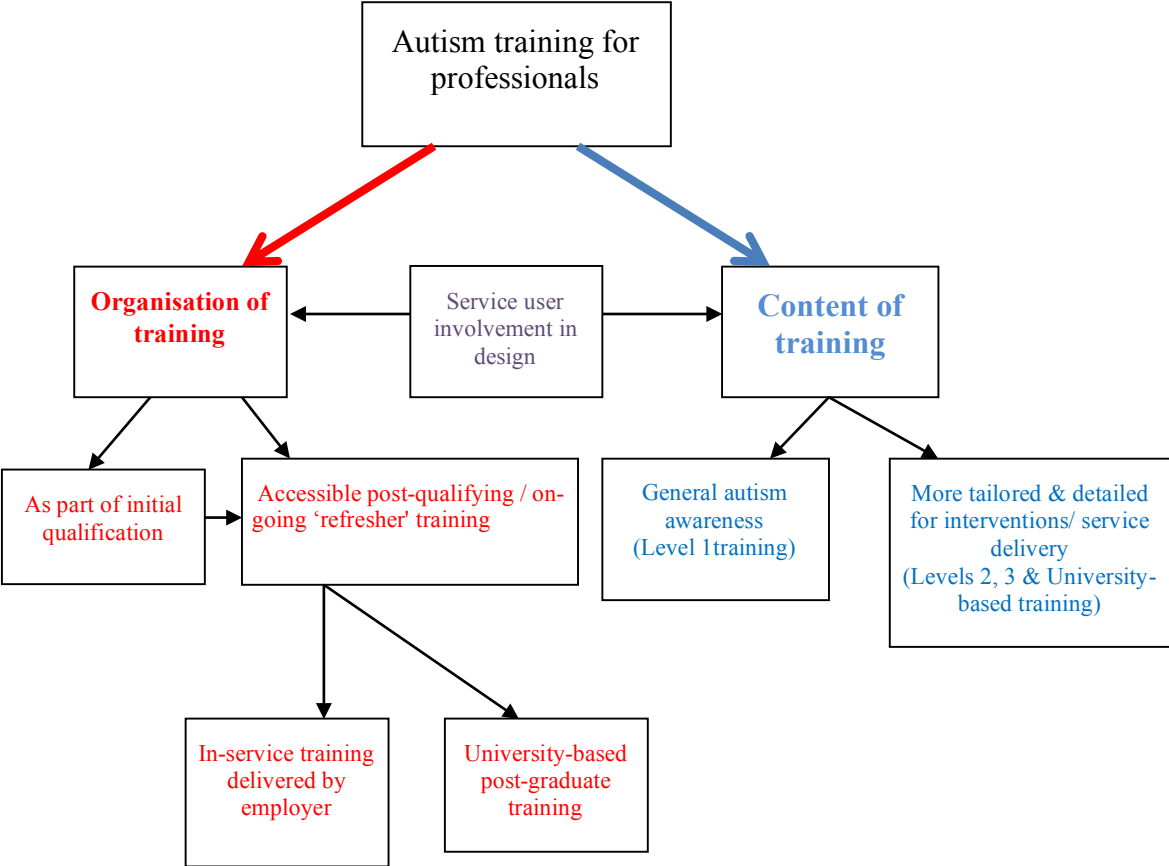
Participants were asked about their future training needs with regards to autism; 175 HSCT participants responded to this open question. Only a very small minority (n=12) stated that they had no suggestions or that they were happy with the training that had been provided to them. The vast majority (n=163) felt that more training was needed.

Fifteen (just over 1/3) of the teachers who responded to the survey made at least one suggestion. Twenty FE and HE respondents emphasised the need for more general in-service autism awareness training. Fifteen ELB respondents felt they would benefit from more information, provided by their employer, about autism and twelve staff from the private

sector emphasised the need for more training, and the use of ‘real-life’ situations to inform employers. Six public sector staff also commented on lack of autism training.

With regards to proposed improvements for future training a number of themes emerged around the *organisation* (i.e. when and how it was delivered) as well as the *content*, based on the role of the service provider, of training (see Figure 8).

Figure 8: Structuring autism training for professionals



Organisation of training

In terms of the organisation of autism training, a number of suggestions were made, including that it should be mandatory, provided early in people’s careers, provided regularly and for all staff, easy to access, and that there should be a designated ‘expert’ who could be consulted for advice. It was also felt that there should be service-user involvement where possible.

The current position within HSCTs and ELBs is that training is optional. A number of respondents commented that they felt a certain level of autism training should be mandatory to all staff working with individuals with autism.

‘I feel training and updates should be mandatory as we encounter people with Autism frequently as service users and some colleagues.’ (HSCT participant)

Fourteen of the FE and HE respondents emphasised the need for employers to provide and promote general autism awareness training.

‘Yes! Mandatory for advisors of study and teaching staff, research supervisors.’ (FE /HE participant)

Qualifying training: The majority of the educational professionals thought that their initial qualifying teaching had not been effective in preparing them for working with students with autism.

‘I completed my PCGE [early 2000s] ... so maybe there weren’t so many students, you know, mainstream at that time..., it’s really this last seven years I suppose, just thinking of the first autism student that I encountered in mainstream.’ (Professional 10)

Newly qualified educational professionals were more likely to have heard of autism during their initial training, however, they indicate that this was very basic and that there is much room for improvement in terms of postgraduate training coverage of autism.

‘There might have been one lecture to be honest with you about autism and what it is... what is the spectrum and you know just maybe having awareness of what it is but I feel in terms of preparing you, if you had a child with autism in your class, I don’t think we had sufficient you know training.’ (Professional 5)

It was felt that training should either be incorporated into professional training or should form part of staff induction, so that staff have the training they need when they start a new post. One third of the teachers felt that autism related training should be integrated during their initial teacher training (ITT).

‘I think it should be included in basic nursing training. We are not always made aware when referrals are put through that there has been a diagnosis of autism and training would assist us to recognise it.’ (HSCT participant)

*‘Automatic appropriate and practical training within ITT [initial teacher training].’
(Teacher)*

It was also suggested that students and teachers at an early stage in their careers could benefit from working alongside experienced classroom assistants who were supporting children with autism. One respondent drew attention to the uneven distribution of support within a classroom where other pupils may need help, but this was not being provided.

‘Any extra help in the classroom should be spread across the classroom as team teaching rather than a qualified teacher at times sitting with one pupil.’ (Teacher)

‘There needs to be more common sense in spreading of resources where less able pupils in the class also need support but do not get it.’ (Teacher)

Some of the respondents indicated that the need for further training was greater amongst teachers than classroom assistants.

‘...as a classroom assistant, I do have ample opportunity for training. I do not think there is enough training for teachers, and I am convinced of that.’ (Professional 8)

Two respondents felt that their training had been effective, however, they commented on the need for continuing professional training or experience after qualifying.

Post-qualifying training

Delivered by employers in-service: The vast majority of respondents had been offered some form of autism training by their employer (mainly Level 1 training). Many respondents considered the training that they had completed to be useful albeit ‘basic’ and more was needed.

‘Certainly not in-depth. It was a morning session, so you’re talking about one to 1 ½ hours. I think it was just for raising the awareness and helping us maybe see it from an autistic child’s point of view.’ (Professional 10)

‘I was maybe thinking I need some different kind of training. I’m not even sure what I would have been looking for, but certainly some of the training that I was being given just wasn’t relevant to that age group. So there’s maybe a good bit around for Primary school children.’ (Professional 8)

The highest level of autism related training that educationalists had completed was Level 2 (<one day). While they were pleased with the training they felt that educational

professionals would benefit from higher-level training.

‘Super, absolutely wonderful and afterwards, it was rolled out to all the staff! If courses are useful, I’ll either bring them in or staff will go out. Level 3 isn’t being offered any more, I think there is a problem with funding. If it was offered, I would take it. I would welcome Level 3 training for all teachers and classroom assistants.’ (Professional 1)

Regular in-service training and refresher courses were highlighted as important, especially as some long-standing staff may have missed out on training opportunities. The vast majority of respondents had at least one other source of support or information if required, such as external autism supports.

‘The ‘younger generation’ of professionals have probably had some training or at least awareness raising about autism. Some updating required for more senior (in age) staff.’ (HSCT participant)

‘Web-site with useful resources e.g. to access accessible information etc.’ (HSCT participant)

‘Many employers may not know of the help/ assistance available through disability organisations, more awareness raising required.’ (Private Sector participant)

‘We have autism advisory, the behaviour team, and we work very closely too with social workers and parents. We have OTs for maybe some of our kids would have sensory [problems] ... and you have physios and you have speech and language therapists which are great.’ (Professional 4)

Those who did not have this kind of support were unsure about where to go and for one participant the restructuring of support services within their institution had negative consequences for students and for staff.

‘...a new and smaller team of qualified staff were to be in place. By qualified I mean be graduates rather than folk with hands on personal experience of dealing with these circumstances, so it’s caused a lot of concern, not just with us as support people, but also within the disabled community at [organisation], who feel they have had a raw deal out of it...’ (Professional 12)

Training delivered by Universities: Seeking knowledge outside core professional and employment support was commonly reported by educational professionals, with many doing over and above what was expected of them to gain further knowledge of disabilities and autism. Specifically, some educational professionals had gained knowledge through further training outside their work, forming links with charities, extensive reading, and carefully selecting teacher training placements and project topics. A number of respondents felt it

would be useful if there were a designated expert in autism within their field of practice that they could approach for advice.

‘My degree, there was a special needs placement... so I did two days a week here which was amazing. So probably coming into this job then, I had a good grounding for what behaviours to expect, knowing that maybe the kids don’t come and they don’t sit on their seats and they don’t... You have to work with them and be very patient...’ (Professional 4)

However, professionals showed a lack of knowledge about University-based post-qualifying training. None of the basic or the advanced University-based autism training was mentioned in the interviews or in the Autism Strategy (2013-2020).

‘...beneficial to have specialist practitioner in ASD available to professionals, particularly when they have individuals with ASD and associated learning difficulties on their caseloads.’ (HSCT participant)

Content of training

Autism awareness training: A number of respondents felt there would be value in providing all staff working in HSCT with autism awareness training, not just in ‘core features’, but in how an individual with autism can react to different situations. On-line staff training has recently been made available within the NHSCT, but is not yet available in other Trusts.

‘Any person working with service users with autism not only professionals should have a lot more basic training and continuous training. And as much training as possible about how autism affects a person’s behaviour and personality and how they see the world around them’ (HSCT participant)

Many respondents felt that autism training should cover the diversity of autism, and not just focus on one end of the spectrum or only on males with autism.

‘Awareness raising about the whole spectrum. Perceptions of autism are based on Rainman movie generally!’ (Private Sector participant)

‘I feel emphasis should be placed on the differences between individuals on the ASD scale and degrees of severity, specific info relating to females with ASD diagnosis would be helpful as this is a significant grouping who I feel get less attention than their male peers.’ (HSCT participant)

'[a]n acceptance that people with autism have much to offer as well as experiencing many challenges in life.' (HSCT participant)

Intervention skills: Some of the HSCT workers suggested that training should cover practical strategies, so that they would learn how to adjust their working practices appropriately. None of the participants were aware of the importance of learning about the theoretical roots and underpinnings of intervention strategies or the importance of functional assessments.

'As with any lifelong diagnosis, practical strategies to address the difficulties... from the point of view of children's services, topics such as toileting issues, feeding issues, sleeping issues, sensory sensitivities and anxiety management are the most recurring topics raised that require further support.' (HSCT participant)

Six of the HE /FE respondents made concrete suggestions about tailoring the training to meet the specific needs of further and higher education staff, including the use of video examples of 'real-life' situations and how to best use resources in one-to one sessions with students.

'Most training only provides what are the signs/symptoms of ASD, not actually how do deal with a student with ASD in your classroom.' (FE HE participant)

Private sector staff as well as ELB staff also emphasised the utility of the use of 'real-life' situations to inform employers.

'Need to see real examples e.g. videos as I would not have imagined what it would be like until the person actually came in and we learned on the job.' (Private Sector participant)

'Video behaviour analysis and video interactive guidance strategies to help professionals/students/parents see what they should do in certain situations.' (ELB participant)

Difficulties in communicating are regarded as a key diagnostic feature of autism spectrum disorders. The most common suggestion regarding training was that the content should include a section on communicating with individuals with autism.

'... a short introduction of main ways to communicate and tips for interaction with individuals would be useful at induction.' (HSCT participant)

Sensory issues and problems in adjusting to routines can have a major impact on how some individuals with autism interact with health professionals, and the possibility of the need for

environmental adjustments was singled out by one participant, who noted that there was a need to

‘... adapt services for people with autism i.e. looking at the environment we offer (face-to-face interview rooms may prove challenging for people with autism).’ (HSCT participant)

Some participants commented on the need for training regarding how to support individuals with autism in the workplace. Specifically, HCST training should be more tailored for those working with adults with autism and in the mental health sector.

‘Better training for staff working in Mental Health services on working with people with autism. This is important as Asperger’s Syndrome now falls within mental health services whereas previously this came under learning disability services.’ (HSCT participant)

The development of specific services for adults with autism, and the wider recognition that the condition is not restricted to children, is a relatively recent development within the HSC sector. Some health professionals felt that they would benefit from more training on dealing with adults with autism, and this was seen as particularly relevant to those working within the mental health services.

Services for individuals with autism differ significantly across HSCTs, e.g., at the publication of this report (March 2015) only two Trusts (Northern and Belfast) had established an Adult Autism Advice Service (NAAAS and BAAAS). An independent evaluation of these services was underway by QUB.

A number of social workers felt that they needed to be made aware of localised support services for individuals with autism and their families so that they could pass this information on and make referrals where appropriate, especially since some Trusts imposed limits on certain services, based on service user IQ.

‘Would be helpful to know what resources/support/services exist for individuals with autism and how this fits with funding criteria/eligibility for services.’ (HSCT participant)

Public sector staff commented that autism training should also take into consideration that adults with autism work in the public sector, and colleagues should receive tailored training (the generally ‘autism-friendly’ environment of the civil service was noted by two of the

adults with autism who took part in individual interviews).

‘The training that we undertook focused on dealing with external clients with autism, whereas I think the training should look equally at dealing with colleagues with autism.’ (Public Sector participant)

Staff working in clinics felt they needed advice on how to help individuals with autism deal with waiting for their appointments in busy clinics and on how to pass on relevant health care information.

‘I feel people with Autism should be triaged as a priority as I have seen how distressing it is both for carers and patients sitting for many hours in a waiting area not knowing when they are going to be treated.’ (HSCT participant)

Their needs may be better met with an extended community service where possible, as one participant suggested:

‘There is a definite need for greater flexibility in the provisions of services e.g. the ability to do home visits on a regular basis or at short notice.’ (HSCT participant)

Advanced issues: At present in Northern Ireland interventions are based on an eclectic model (DENI, 2002). There has been much critique of this model internationally and the evidence shows that it is not the most effective model of intervention (Howard, Sparkman, Cohen, Green, & Stanislaw, 2005; Howard, Stanislaw, Green, Sparkman, & Cohen, 2014). DENI has not been able to provide published evidence in favour of the eclectic approach.

In contrast, in the USA and Canada, autism interventions are based on advanced applications of science of behaviour analysis and a significant evidence-base as well as cost-benefit analysis have shown the benefits of individuals with autism, their families, as well as for health and social service policy (Diament, 2014; Jacobson, Mulick, & Green, 1998; Motiwala, Gupta, Lilly, Ungar, & Coyte, 2006; Surgeon General, 1999). None of the participants seemed aware of these more advanced issues (cf. Dillenburger, McKerr, & Jordan, 2015).

Regardless of the sector they worked in, the vast majority of participants felt that educational professionals could benefit from gaining further knowledge of autism, and that this should be appropriately structured and accredited.

‘I know it’s part of the syllabus, but from what I hear from staff going through it, it’s

skimmed over, it's not, sort of seen as a core skill and I would like, even if it's a case of some way when they come back, or when they finish their course, or as part of their course if they would do an assignment on it, that something makes them go and investigate it a bit further.' (Professional 7)

Service user involvement

The importance of involving of service users/caregivers in the development and delivery of autism training was highlighted by some health professionals. The involvement of service users (i.e., parent/ and caregivers and individuals on the autism spectrum) in developing autism training is likely, in turn, to have an influence on the content of training. Therefore, service users' input is of relevance to both the organisation and content of autism training. Insights offered by individuals and their families can improve not only an understanding of how best to adapt provision and approaches, but also awareness that autism is indeed a 'spectrum' condition which can present in many different ways (and not always negatively).

'Service user stories and experiences- essential range of behaviours and skills- need to be specific to individual.' (HSCT participant)

Summary of staff training needs

Respondents from all sectors felt that training should be more widely available, especially during qualifying and early career training and the content should be tailored to their specific professional situations. People with autism use the same 'core services' as everyone else and their needs may not be met if staff cannot recognise or communicate with them effectively.

Participants also felt that levels of training should be more advanced. Methods of delivery should be more accessible (such as on-line or on-the-job training) and meaningful examples of 'real-life' situations captured through video footage. For specific professions where contact with individuals with autism was frequent (e.g. within health, social care and education), mandatory initial and accessible 'refresher' courses were seen as desirable.

The ultimate aim of effective staff autism training is to equip service providers with the skills to address issues that may impact on individuals with autism and their families, within their own professional roles. Health, educational attainment, employment opportunities, access to benefits and social activities can all be negatively affected by the characteristic impairments in communication, social interaction and responses to novel

situations associated with autism. Where such issues are not being effectively addressed, individuals with autism and their families face a lifetime of restricted financial and social opportunities. Clearly, poorly trained staff can do little to prevent poverty and social exclusion of some of the most vulnerable in society.

More advanced level autism training is available at the Universities in Northern Ireland, where this training is validated to international standards and delivered in a variety of accessible forms (on campus, online, and blended), using real life examples and stemming from an academic and practice research base. However, very few of the professionals referred to this training, which indicated that the relevant information was not readily available to teachers, HSCT, ELB, and other staff. The onus lies within all relevant staff training departments (especially DE, DHSSPS, and DEL) to seek and commission University-based staff training and to inform staff of these options.

Participant's recommendations

Participants were asked to suggest changes that could improve the present systems of delivering autism training to education professionals, and their recommendations are summarised below.

- Autism related training should be integrated during initial teacher training (ITT); not just autism awareness, but practical skills (e.g., in PGCE).
- More awareness of where to access training, e.g., many were not aware that Universities offered training at different levels.
- More direct skills training, e.g., how to manage and support individuals with autism.
- Training to have greater depth, coverage and be delivered more frequently.

Chapter 4: Identification of vulnerability: Autism diagnosis and service response

This chapter reports on issues related to the identification of vulnerability, i.e., autism diagnosis, as well as the experiences of participants with health and social service responses aimed to address this vulnerability. Accurate and timely diagnosis is important to allow families affected by autism to move out of the poverty trap and social exclusion because a diagnosis gives access to benefits, allows for early intervention to start building skills in the child, and consequently, for parents to maintain (or return to) employment. Adult diagnosis gives individuals access to educational or employment supports. The consequences of early and timely diagnosis are improved chances of individual and parental financial, physical, and mental health. In this chapter professional and service users give their views about the diagnostic process in Northern Ireland.

4.1 Autism diagnosis

Recent figures (4th quarter of 2014) show that approximately 200 referrals for an autism diagnosis are made per month (range 188-210) to HSCTs across Northern Ireland; approximately 50% of these referrals lead to a full-diagnosis of autism (range 84-119 per month), with the other 50% of cases either being placed on a watch-and-wait list or assessed and discharged without a diagnosis. There were significant regional variations, e.g., the Southern HSCT received considerably fewer referrals, while the Northern HSCT (which covers the largest geographical area) received significantly more referrals than the other Trusts, and the South Eastern HSCT had the most efficient referral to diagnosis rate (Table 3, figures supplied by DHSSPS, 2015).

Parental experiences

Many parents spoke of their frustration with the diagnostic process, including lengthy delays associated with getting a diagnosis and patchy professional knowledge, particularly with regards to diagnosing autism in girls. Parents reported problems with communication and feeling judged by professionals during the diagnostic process, e.g., they were frequently asked to repeat themselves or were not asked the right questions and left sessions feeling that

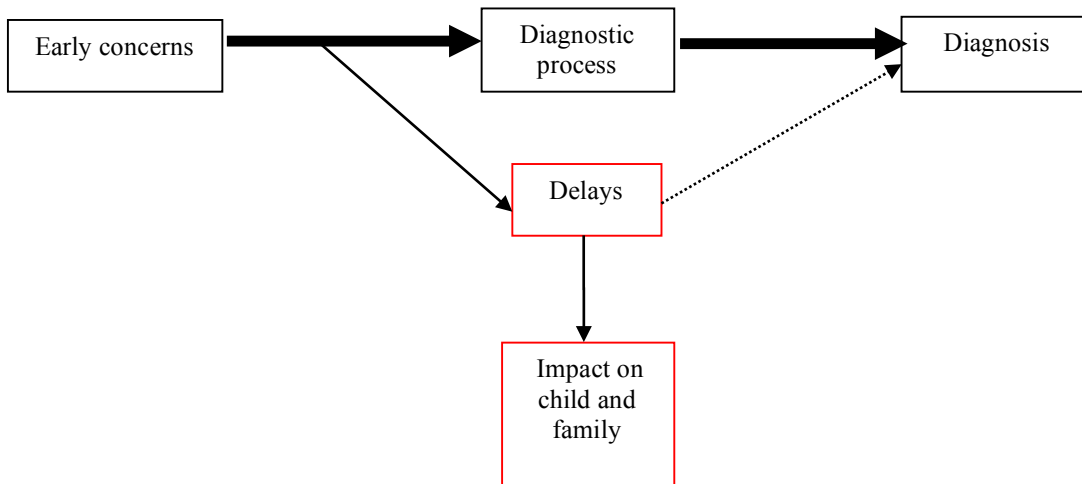
important issues had not been covered. In addition, a small number of participants felt concerned that some professionals viewed them as ‘bad’ parents.

Table 3: Number of autism referrals and diagnosis per Trust in last Quarter of 2014

Trust	Oct 14		Nov 14		Dec 14		Total	Quarter
	Referral	Diagnose	Referral	Diagnose	Referral	Diagnose	Referral	Diagnose
Belfast	47	19	54	25	50	23	151	67
Northern	71	37	71	27	66	18	208	82
S.Eastern	32	32	30	27	21	21	83	80
Southern	28	15	16	8	17	4	61	27
Western	32	16	31	14	34	18	97	48
Reg. average	42	24	40	20	38	17	120	61
Total	210	119	202	101	188	84	600	304

Overall, both delays in the diagnostic process and in receiving the diagnostic designation had a negative exclusionary impact on individuals, parents, and families as a whole. Only very few parents agreed with the ‘watchful wait’ approach taken by some HSCTs and felt it was important to be careful not to label children too early (for full discussion about diagnosis see BASE Project Vol.1).

Figure 9: Diagnosis process



Early concerns: For the majority of parents there were clear early indications of developmental delays or other concerns about their children, while all the adults with autism who participated in the interviews recognised that they had difficulties from childhood (particularly in social situations and at school). For many parents and also for adults with autism, these concerns were based on personal experiences, information from family, and from their own internet research.

‘He was just turned 3, it was quite early...my mum is a teacher and she sort of highlighted some issues that she flagged up to us... so we kind of had an idea from pretty early on.’ (Parent 1)

Three of the adults with autism had young sons diagnosed with autism, and two had other close relatives who had characteristics of autism, although not necessarily formally diagnosed, and this background led them to seek a diagnosis.

‘I went and saw the GP, and I said to the GP ‘I believe I’m autistic, because of [son]’s diagnosis, that I match up quite a bit to how he is, and stuff.’ (Adult A)

Diagnosis process: For some, actually getting a referral for diagnosis was a challenge, especially for parents of girls, as girls with autism often behave very differently from boys. Parents were very aware that there were issues with their daughters, but felt professionals did not have the experience or appropriate knowledge to diagnose autism in girls. One parent paid for two private assessments for her daughters to avoid the stress of statutory HSCT diagnosis. Two other girls, who had received a private diagnosis, were subsequently re-diagnosed by HSCT teams, indicating that commissioning diagnostic services from the private sectors may be an option to be considered by HSCTs who want to avoid delays.

‘Yes, we suspected from about 15 to 18 months that [name] had autism, it took us quite a while to get her on to the waiting list to be diagnosed, so we actually took her privately ourselves... [t]hen we got her on to the waiting list to be diagnosed...’ (Parent 3)

Obtaining an assessment was also an issue for the adults with autism who participated in the interviews; none of them had received a diagnosis until later in life, although they had experienced considerable difficulties throughout life and all had experienced mental health problems. In part, for them the delay was due to the policy emphasis on childhood diagnosis and the absence of a dedicated adult autism service in Trusts; very few professionals had received training in adult diagnostic techniques.

Whole-time equivalent (WTE) staff numbers and roles of HSC Trust staff who are specialising in working with adult clients with ASD are extremely low (DHSSPS, Hansard, Feb 15, 2015).

The most recent figures available indicate that only four out of the five regional HSCTs are operating an adult diagnostic service (AQW 41410/11-15). The Southern HSCT does not have ‘any specialists who can undertake this role’ (ibid.), despite the allocation of adult services funding through the Regional Autism Spectrum Disorder Network [RASDN].

The other HSCTs have teams with varying Whole Time Equivalent (WTE) allocation for adult autism services, between 1 and 0.025 WTE. Across the four Trusts with adult diagnostic services, only three posts (out of eighteen) are full time (1 WTE) (Table 4).

Table 4: Whole-time equivalent staff numbers and roles of HSCT staff who are specialising in working with adult clients with ASD

Professional	Belfast	Northern	Southern	S. Eastern	Western
Cons./Principal Clinical Psychologist	0.4	0.6	0	0.2	0.025
Clinical Psychologist	0.5	0.2	0	0	1.0
Psychiatrist	0.025	0.025	0	0	1.0
Occupational therapist	0.5	0.2	0	0.7	0
Psych. Therapist/Associate	0	0	0	1.5	0
Speech & Language Therapist	0	0.1	0	0	0
ASD Co-ordinator	0	0.1	0	0	0
Board Certified Behaviour Analyst	0	0	0	0	0

It is clear that Trusts are finding it difficult to resource the increasing demand for adult autism diagnosis and adult services (e.g., all of the adults with autism who participated in BASE Project interviews (n=5) received their diagnosis recently).

...so the GP was like ‘we’ll try and get you someone to see in the Psychology department’ and he says ‘but I daren’t put autism down because they might just simply say Oh, we don’t diagnose for that, and you wouldn’t get seen for any trouble’ so it took a long time for that... (Adult A)

It had been particularly problematic for the two female participants to obtain an autism diagnosis and both felt diagnosticians had a very ‘stereotypical’ view of autism.

‘The GP wrote off...but suggested that because I was married and had a job there was ‘No hope [of a diagnosis]’...I took an ADOS⁸ test, and an IQ test. They said ‘no’ ... I took the whole day off work to attend [Trust clinic]. [Trust diagnostician] said, if I had Asperger’s I wouldn’t have done that, but I was so anxious...’ (Adult D)

However, where professionals were pro-active or supportive, a number of parents and adults with autism reported that they felt relieved that their concerns and worries were taken seriously.

‘...the Educational Psychologist... she was lovely, and she kept saying to me ‘I know how important it is to get [older son] diagnosed before he leaves school, before he’s out of the system, before he’s out of support’ and she pushed’ (Parent 14)

Given the late diagnosis for all the adults who participated, and the difficulties in getting assessed for some, it was also important to feel that the professional understood the needs of individuals with ASD, and presented this in a confident and positive manner.

‘[Diagnostician] was able to say on the spot ‘Yes, there is no doubt about it, most certainly you are on the spectrum’...he presented it to me in a very positive way. It was sort of almost like ‘Congratulations you are part of an elite.’ (Adult B)

Delayed diagnosis: Not all professionals agree with the importance of an early diagnosis and some Trusts have an explicit watchful-wait policy that, at times, conflicts with the interests of parents, who are living with their child and who can find their concerns undermined or dismissed (Dillenburger, 2014).

Parents found that many children were placed on waiting lists, or referred for further appointments, e.g., in 2014, 1300 children were waiting for a diagnosis in NI (cf. Connolly, 2014). When children were presenting with what parents saw as clearly identifiable needs, they wanted answers and could not understand why professionals were reluctant to make a definitive diagnosis. The delay in diagnosis did not only prohibit benefit claims (disability benefits are only available for claimants with a diagnosis), it also meant that early interventions were not available to the child, thus increasing the likelihood that the child and their family would remain in poverty and socially isolated.

⁸ Autism Diagnostic Observation Schedule

On the other hand, due to lack of expertise in the statutory sector (Associate Notes, 2008; Hughes, 2008), and despite the fact that this was noted in the Task Group on Autism Report as early as 2002, none of the statutory bodies in NI were in a position to offer early intensive behaviour analytic interventions, that are considered medically necessary ‘treatment as usual’ in the USA and Canada (Autism Speaks, 2014).

‘...from then it took two to three years to get the diagnosis ...it’s quite frustrating because you see so many people and you just go over the same details again, when did he talk, when did he walk...’ (Parent 8)

The small number of parents who felt that for their child a delay in diagnosis was possibly appropriate were concerned that the label ‘autism’ could perhaps become a barrier in later life. They were worried that once a child was diagnosed this could not be reversed.

[Younger son] doesn’t need the same level of support ... and in some ways I would think it would be to his detriment to have that diagnosis because with him it would become nearly like a label ... there probably are some barriers... we were told not to push too hard at the moment for a diagnosis...’ (Parents 9 & 10)

This opinion is frequently expressed by professionals in NI, although it stands in contrast to international evidence, which shows that with the right intervention at the right time and intensity, a significant number of children no longer meet the diagnostic criteria for autism (Fein et al., 2013; Orinstein et al., 2014). However, parents who were worried about a labeling effect also thought that there could be the possibility that, over time, their view about diagnosis could change.

Impact of diagnosis and delays on child and parents: Parents of children with autism are at higher risk of health problems, including mental health and stress-related problems, than parents of children without disabilities (Smith, Seltzer, & Greenberg, 2012). Delays and repeated visits to diagnostic centres over a lengthy period of time within the pediatric assessment process added to the stress and some parents viewed the process as hostility from service providers. Seeking a diagnosis became a ‘fight’ or a struggle with the relevant statutory bodies and it was particularly difficult for parents when their child engaged in unusual or challenging behaviours. Communication from the statutory bodies was perceived as poor and some parents felt they were being judged as inadequate.

‘Oh, every assessment was a nightmare, I mean he just used to scream and yell, and roll round the floor, and totally not co-operate. Well, it didn’t help that the medical officer at the time gave me every impression of thinking that he was just a spoiled little brat, and that he just needed stronger discipline. That was the distinct impression that I got from her, which was very sad ...’ (Parent 4)

A relatively recent development is the ‘neurodiversity’ movement that focuses positive attention on the difference of people with autism (when compared to neuro-typically developing individuals) in areas such as information processing, thinking, learning and social functioning (Dubin, 2011; Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013). However, only one parent reported that her son was proud to have a diagnosis of autism.

‘He loves his autism. He is a champion for it, he thinks it’s the best thing ever... he said he knew anyway, he knew he was different, but he thinks he is great, and if ‘I could take the autism away I wouldn’t because it’s me’...and then I, I can’t wish it away for him then, because he loves it’ (Parent 8)

For the majority of adults with autism who participated, the resultant diagnosis was overall not a negative experience but confirmation of their own research and observations.

‘I would say the diagnosis was, not a relief but... when you read testimonies of people with autism, Asperger’s, you know... your life fits the description.’ (Adult C)

Adult diagnosis

Adult participants with autism pursued a diagnosis when other family members and personal research indicated that they may ‘fit’ the diagnostic criteria. Most of these adults initially engaged with the statutory sector to get diagnosed, however, while some of them received a diagnosis, in some cases this proved problematic; to evade issues in the statutory sector, both women with autism had sought privately funded diagnosis, and this reflects the situation for girls with autism discussed previously. After receiving a diagnosis, regardless of the diagnostic route taken; i.e., private or statutory, most of the participants felt relieved that ‘questions had been answered’.

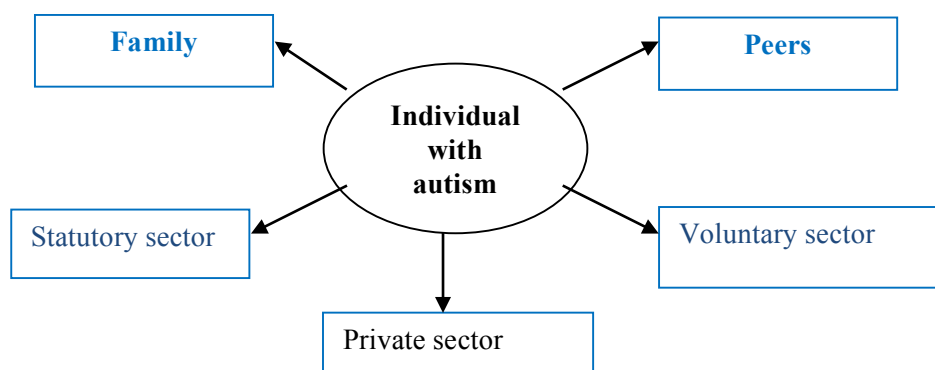
Participants were knowledgeable about autism for a number of reasons, including having other family members who had been diagnosed with autism and personal research on the topic. All participants were fairly certain that they were on the autism spectrum prior to seeking diagnosis. However, professional knowledge did not always keep pace with the greater awareness of autism at all stages in the life course; for some participants it appeared

that professionals were poorly trained or ill-informed and thus not prepared to deal with autism as it was manifested in adults, particularly when these adults were able, articulate, and had family lives.

4.2 Post-diagnostic issues

Parents who participated in the interviews were the main care-givers for their children, providing personal and emotional care and organising social activities to a much greater extent than that which might be expected for their peers. As such post-diagnostic issues, such as parenting a child with autism and health and social care interventions play an important role in the prevention of poverty and social exclusion. The post-diagnostic support network for individuals with autism (children and adults) and their families included family, peers, self, voluntary, private and statutory sectors (Figure 10).

Figure 10: Post-diagnostic systems of support for individuals with autism



Family

For the most part, important support was offered by well-informed family members, friends, or, at times, neighbours. A third of parents had reduced their hours or left work to cope with the demands of parenting a child or young person with autism. Most of the parents who remained in employment required flexibility from their employers.

Personal care: Twelve of the children with autism had additional needs (such as learning disabilities, Tourette's syndrome, asthma and dyslexia). The majority of parents provided personal care for their children, such as help with tasks such as washing, eating and dressing. While this is to be expected for the younger children, some degree of help with personal care was still necessary for children with autism aged eight years and upwards and for those who had left school.

'I have to guide him as to the time that he should get up. I have to advise him as to what clothes he should wear ... I'm constantly having to reinforce how he needs to wash, and the fact that he can't wash if he doesn't use soap...I don't go into the shower with him any longer, I haven't done for many years. So it's a constant reminding him as to all those basics.' (Parent 4, whose son is an adult)

Administering medication: A number of children had been prescribed medication, primarily for sleep disorders, and it was up to parents to administer this. Sleep disorders are quite common in individuals with autism; these can be disruptive both for the individual (particularly in terms of affecting overall performance at school, college or work) and for the parents whose sleep is also interrupted. This has a detrimental effect, particular for parents who have to go to work the next morning.

'[Son] did always only sleep for about 4 hours in the evening, but the wanderinghe gets up and wanders around and as he has got bigger and bigger it's hard for me to get him back up the stairs and into bed... because he is quite a big lad, and he is quite strong, so the melatonin has been increased from just before exam period so that's made things a little bit easier ...' (Parent 13)

Organising: Organising activities such as the school run, dealing with minor crises at school and providing transport for work or college placements, medical appointments and social opportunities is particularly time consuming for most parents, and at times it can be mentally and emotionally exhausting. It can also prevent parent from engaging in gainful employment.

'...every time the phone went it was the school, and I felt like I was on speed dial, the headmaster, like we were on first name terms...because I was like 'he can't be doing something again', it did feel more mentally than physically draining. Sometimes it feels you are in a relationship, you know, you would divorce a partner, if you had that relationship with them.' (Parent 8)

Planning for change: For some families, it was also important to plan in advance for changes that were to take place in the household, as some children or young people with autism found interruptions to their routine very difficult, which in turn had an impact on the

rest of the family by requiring time and resources.

'... we have to try to have a schedule on our kitchen cupboards so that he can see pretty much what is happening every day...for years that was a nightmare if anything changed at all, if anybody was late to collect him, he just couldn't cope with any of that...but he can get over it a bit quicker than he used to.' (Parent 4)

Supervising play and leisure time: Some parents reported that their children also required a lot more direct supervision, as they were not aware of the risks they take, or they have issues with social behaviour that needed careful monitoring. One parent discussed her conflicting feelings about wanting to encourage her son's independence and social inclusion.

'He so craves independence and wants to be allowed, but whenever I give him independence he lets himself down ... like he says 'I want to go out with my friends and play' so I'm out there looking and the next minute he is on top of someone's roof and you are like, well that's the end of it. I tried.' (Parent 8)

Supervision outside the home was not always possible as young people with autism tried to lead increasingly independent lives at school and in social situations. They were vulnerable because they frequently did not read social danger signals, and thus become victims of bullying. Two families reported violent situations that resulted in actual physical or psychological harm for their children.

'He has been assaulted before a few times... Adults have got quite angry with him, irate at him because he's ... just doesn't act normal. And he comes across as cheeky... if you don't know him.' (Parents 5 & 6)

'They have damaged her too much. The school didn't know how to deal with bullying ... she has been [time] out of school now, but still has nightmares every night. She has no friends, just the horses. She will never fully recover.' (Parent 7)

Free time: Parents found that most of their time was spent in providing care or support for their children with autism at home; for many parents, other household, leisure, or work-related tasks had to take second place. The actual amount of time varied depending on circumstance, e.g., more time was needed in crisis situations or for homework and school assignments.

'...when they come home from school, that's it, there is nothing else can be done as such, so if housework needs done or (husband) needs paperwork done for the business or anything like that if it's not done when they are at school, it's not going to be done' (Parent 11)

This related to all the aspects of care discussed above; for children at school, completing homework and generally keeping them occupied were major factors. For older children, supporting their leisure activities or dealing with their emotional or social needs took up a lot of time and at times parents had to step away a little to find some time for themselves.

‘Well, it’s all your time until you take time out for something else... you have to take time out for something else, otherwise you’re all consumed, you know, that’s just the way it is’, (Parent 14)

Other family members: Sometimes, as relatives get older, they move from being care-givers and supporting family members with autism to needing care themselves, and this was the case for some participants, who then had to find time and energy to look after an older parent as well as their child with autism. A number of participants were also caring for other young people; three families had two children with autism, and another had a child with mental health problems.

‘Well, I used to have help from my mum, but she took a brain infection last year so I’ve been caring for her the past year or so as well... [daughter] has her own difficulties, she would be quite OCD, and high anxiety.’ (Parent 1)

Adjusting work and home life: For some parents it was very difficult to cope with the demands of parenting a child with autism while holding down a job. Almost half of parents had found they needed to adjust their lifestyle either by leaving employment or reducing their hours because of this.

‘I had to give up my job to look after my children, because they came out of education. I used to be a project manager, I worked on a project with links to kids with ASD and challenging behaviour, but the child in most need was in my house.’ (Parent 7)

One participant said directly that caring responsibilities had limited her choices for a career path, and in fact this parent had retired early to better support her son once he reached adulthood.

‘I have always said that I would never work too far away from home or from the school that he was at, so that if there was a crisis on anything that I could get back very quickly... I partly took early retirement because I didn’t have the energy to work full time and fight for what [son] needs for his future, and so my work and paid employment had to go.’ (Parent 4)

Peer support from friends, family or neighbours

When other people such as family, friends or neighbours were able to support parents in caring for children with autism, or able to help adults with autism it had positive benefits for all recipients; most participants reported that they had some level of support from others.

Family members with availability and knowledge to help: For parents, in order to feel confident about asking others, they needed to be sure that their child's needs would be met and that they were not imposing on people who may not be able to cope. Some family members took part in autism training to be able to provide the right support.

'My parents, yeah, they are fantastic... my mum and dad, they are in their 70s you know, but they are quite active...[my mum] has went to some of the courses, she is brilliant ... it definitely helps us then when I am working and I know there that he is not stressed going to them.' (Parent 2)

Most parents reported that they had some level of support from close family members. Having confidence in the way their child is looked after, knowing that the support was reliable and caring, allowed parents to remain in employment.

'...both my family and my husband's family would be very good with her. They look after her while we work. ...My sisters would be very good, they would babysit for us sometimes, but it's mostly parents.' (Parent 3)

Other parents however were reluctant to ask for help from relatives whose understanding of autism meant they would find it difficult to cope. As children grew older, their original support networks tended to diminish; relatives died or moved away, took on other responsibilities or needed care themselves. For some parents, having a small family circle further reduced the potential for support.

'No and this is a huge issue I think... for ourselves, I'm an only child, and my husband's only brother lives {name of place}. So we have literally no extended family, and we have never had any support from anybody other than my mother, my husbands' parents both died before I even met him.' (Parent 4)

For most of the adults with autism who participated, there was now limited help from close family members. However, two participants had found family support invaluable in their own role as parents; three families had children with autism themselves.

'We're getting on OK but I have to say my mum helps. She minds [son] in my house, and

she does a lot of housework. ' (Adult D)

One family had recently lost that support quite suddenly due to their aging parents' need for care; the situation was made more difficult by the fact that other close relatives also had children with autism or health problems.

'We did up until about last year. My mum and dad would have been good, but my mum has recently been diagnosed with Alzheimer's, and my dad, he goes into hospital every second week for treatment, as an outpatient, he's barely able to walk so really, we don't leave the kids with them at all now... And my sister... she's got fibromyalgia... her younger son, he's got Asperger's and the younger daughter, she's not diagnosed but we're pretty certain she's got autism as well ... she's got enough going on in her house without taking on our two as well...' (Adult A's wife)

It has been established that there are increased familial risks with autism (Sandin, Lichtenstein, Huja-Halkola, Larsson, Hultman & Reichenberg 2014) and it is possible that other families would find their support networks affected by intergenerational occurrence of autism. This does not necessarily have to be negative; Adult A had a unique insight into parenting a child with ASD, and found he could support his partner when their son's behaviour was causing problems.

'Yes, at times I've had to tell [wife] to just leave him alone... I'm like 'Just leave him' ... and you just wait until he calms down, and tell him what he's done wrong, he's got to fix whatever he's done ... but at the same time, I probably don't let him away with as much as [wife] will...' (Parents 9 &10/ Adult A)

Limited help from friends or neighbours: Most parents did not ask friends or neighbours for any regular help in looking after their child, although many would be comfortable asking for occasional support if needed. Some parents felt that others did not really understand what the issues with autism could be, or that they had responsibilities of their own such as work and families, and asking for help would be an imposition.

'No, most of my friends... just the way things have worked, most of my friends would be parents with children with autism, so you kind of... it's a bit more difficult.' (Parent 1)

All the adults with autism who participated could call on 'informal' support- family members, friends, colleagues, support groups (peer and voluntary organisations) or neighbours, at times. However for many, this support was limited and generally they would not depend on it.

'I get some informal support from friends... psychological support, moral support I suppose it's called, isn't it, though it's a bit of a misnomer isn't it... there's no danger of my morals slipping! Anyway, they have helped kind of decorate ... when it's been appropriate and helped with the garden and stuff.' (Adult E)

Advice from peers: The knowledge shared by others was thought to be very valuable; it was informal and accessible, and most participants felt comfortable about both sharing and seeking advice from their peers. Many participants belonged to parent or other peer support groups, and others used social media to seek solutions or to offer advice to others. Such groups were viewed as a resource where other (e.g. statutory) support was limited or unavailable.

'You really have to hunt for everything. Our autism group... [Son] is going to a computer programming club ... one of the parents found out about this ... usually, if there is one of us having a problem with say eating, eating green things or something like that who do you turn to ... the other parents say 'well I know she went through this so that's the way that we go round it.' (Parent 8)

With adult participants, shared experiences meant that some people could communicate more easily within a specialised support group.

[Name of practitioner] started a female group once a month ... It's good to be there with other women, I could sit and relax but I could see how creative they are- I don't have anything I am 'good' at, so a panic attack...but it's good support so I would recommend that. There is no [other] support out there.' (Adult D)

Voluntary sector

The majority of parents accessed a range of support from voluntary groups. For some, it was useful for information and for others it was practical training in addressing behaviours associated with autism.

'We've been going to [charity] meetings, we've been going to their training and things like that, and I suppose other parents, and seeing other children, and I suppose seeing that way, and we also go to [another charity]' (Parent 3)

For parents setting up and dealing with Direct Payments or work placements for school leavers, the support offered by voluntary organisations made a great difference in how they coped with these demands. One parent of a young adult had found the transition to adult services very difficult, and the practical help from a voluntary group had been invaluable.

‘... without it post-19, I just dread to think what would have happened, there aren’t enough [name of organisation] around. I mean if that hadn’t been there and so handy to us... they found him all those work placements, supported him through them and still support him now because he needs support at work.’ (Parent 4)

The majority of adults with autism who responded had also found voluntary organisations helpful for advice or temporary practical support after diagnosis.

‘at the beginning ... I received help from an autism charity... a floating support service, but I don’t use it now ... it was valuable, but I need to make my own schedule- it’s a bit disorganised, but it’s OK.’ (Adult C)

Two adults who were also parents of young children with autism had found the respite or out of school activities offered by voluntary organisations very useful, even if this was short-term.

‘...[voluntary group] organise respite, they are trying to ‘wean’[son], it took 4 weeks to get him to play Crazy Golf- [son] craves one-to-one so he’s loving the attention, but it’s only for 6 months.’ (Adult D)

Absence of early intervention⁴: Despite the fact that early intervention is recommended and significant in securing better outcomes, very few parents received any early intervention for their children following diagnosis; some parents reported that they were steered towards self-help or to the voluntary sector as there was no early intervention available in the statutory sector.

‘We have had to seek out everything ourselves... where I get all my information is online, obviously, Facebook pages, [autism charity] those sort of things, but I don’t think, I don’t believe we have had one leaflet, letter or anything, not bar the board’s [Trust’s] courses that they run.’ (Parent 11)

One parent of a young adult with more severe disabilities felt that the family had been neglected since her child first received a diagnosis (initially, of learning disabilities) some twenty years previously.

‘I have felt that the health service has abandoned us throughout our entire parenting’ (Parent 4)

Many parents felt it was necessary to undertake intervention or private treatment programmes, such as occupational therapy, speech therapy and ABA-based interventions for

⁴ i.e., early intervention that exceeds a once-of post-diagnosis visit.

their children, as their Trust did not offer suitable interventions. This involved considerable time and expense, and some families resorted to legal action to have some of the costs met for the successful specialist home-programme provision to be continued in school.

‘We started an ABA programme ... and he did the programme for about 5 years, and in the meantime we went to the high court... we won our case... funding for term time, we paid for it during the summer ourselves...it was incredibly stressful, they took it off us then the next year, and we had to go back to an educational tribunal 12 months later, and we won that as well, so then they funded us until we decided to stop...’ (Parents 5 & 6)

Support outside the statutory sector

Of the 14 parents who participated in interviews, half were in employment (five of them full-time; two of them part-time), while six were not in paid employment and one was retired. Interviewees reported mixed experiences in terms of employer support; some parents felt their employers were flexible and were able to adjust to the different demands of caring, while others felt unsupported to the point where they changed their hours or left employment.

Three adults with autism who took part in the interviews were in employment, and two of them felt their employers were very aware and happy to make reasonable adjustments; one was self-employed and enjoyed the control that this allowed over day-to-day decisions around work. Two parents had children with autism in the workplace; one was just commencing a full time job in a profession allied to medicine, and the other worked part-time in supported employment.

Where employers were knowledgeable about autism, and where appropriate disability policies were in place, adults in the workplace felt supported (cf. Chapter 5).

‘The Civil Service is a supportive environment. That’s Civil Service policy- an element of ‘having to’, and involvement with a Disability Officer’ (Adult D)

One parent felt that employers would perhaps be more supportive if they had been more aware of the issues in looking after a child with autism.

‘It was Christmas Eve, staff were encouraged to bring their child in for a couple of hours, ... but I would have done that and he loved to see where I worked and he loved to wander around the corridors and meet people and it was the only time that people actually met [son], my colleagues actually met [son], and yeah it did increase understanding a bit.’ (Parent 4)

For those parents who were working outside the home most had found that their employer

was prepared to be flexible and supportive when they needed time for appointments or other interruptions to working routine. Having a supportive employer during particularly stressful times allowed parents to continue working full-time once the issues were resolved.

‘...once [son] got diagnosed, they were absolutely brilliant.... I was allowed to take any time off during the day that I wanted, it was all organised...at senior level...if they needed to get people in they would pay people to come in...honestly, they were unbelievable.’ (Parents 5 & 6).

However, one parent did not find her employer supportive, and at times this increased the strain on what was already a difficult situation in going through the diagnostic process, particularly as the parent’s job involved working anti-social hours.

‘...I was going to these appointments without going to bed in the morning, but it was trying to fulfil all that ... my job can be very stressful too, but they weren’t willing to accommodate that, and you know, it wasn’t said like this but that it kind of came across, well, you are not the only mother and you are not the only one with children who have issues or problems or difficulties...’ (Parent 2)

Statutory sector

In terms of health and social care, most parents reported that they had limited access to services, but some thought that Direct Payments had provided worthwhile respite opportunities. Three families had to pay privately for consistent and effective early intervention programmes to address behaviour issues, as this was not available through their local Trust. Financial supports were limited to Direct Payments and other benefits.

Direct Payments: Direct Payments are allocated directly to an individual with disabilities (or their representative) to allow them to organise their own support provision, following assessment by a social worker. Three parents had accessed Direct Payments in order to organise respite care that was flexible and matched the needs of their child or young person better than the provision available through Trust services.

‘... there was ...a residential home, where they can go for a weekend or so ... it’s not fit for purpose, the whole building isn’t fit for purpose. There were no other options like family placement, adult family placement ...[I said] I’m sorry, I’m not prepared to go with this particular residential place and [son] said ‘Well I will go for my tea but I’m not staying over here’, and that’s why we went for Direct Payments.’ (Parent 4)

Using such services, though usually limited to a few hours per week, provided a welcome break for parents and siblings as well as offering a range of activities outside the home for

sons and daughters.

'So you can use that then to pay somebody come in... study with him...when he gets older. Or mind the other ones so we can take [son] out and you can save up time, so if [wife] and I want to go away for a weekend... That's one service that has been brilliant, and you know a lifeline, I think a lifeline for maybe others with more severe children than [son], you know.' (Parents 5 & 6)

Other benefits: All the children and young people received Disability Living Allowance (DLA), as did three adults with autism, the majority at low mobility/middle rate care; one young person and two adults also received Employment Support Allowance or Incapacity benefit. Issues around claiming benefits had quite a serious impact on the daily living experiences of the majority of adults with autism who participated.

While appreciating DLA, some participants found it difficult to access. Two parents relied on their support group to signpost or help them complete the forms as they found them so complex.

'[DLA] ... It's a terrible form as well. It's like the worst application form you could imagine, it took me like a good couple of weeks to do it. I know a lot of parents who just can't do it, other parents in the group would help with...they just can't go through it, it's very distressing to do it.' (Parent 8)

Carer's Allowance: Carer's Allowance was a means tested benefit payable to a person who was caring for more than 35 hours each week (including weekends) for someone receiving a recognised disability benefit (e.g. DLA at middle or highest care rate)⁵. All of the interviewees provided care for at least 35 hours (including weekends); of these eight were not in employment or worked part-time and one person had retired, yet only two reported that they received Carer's Allowance.

Statutory services in Health and Social Care

Services for individuals with autism delivered through Health and Social Care fell into two broad categories: health related services and social care.

⁵ www.nidirect.gov.uk/index/information-and-services/caring-for-someone/money-matters/carersallowance/carers-allowance-eligibility.htm

Health related services: Very few children with a diagnosis of autism received on-going therapeutic or health-related services through their Trusts. Two children received medication for sleep disorders, and three children received speech and language or other therapy organised through their Trust; for two of these, therapy had continued at school although one parent also had to make time to attend after school appointments.

‘...she was assessed as not being suitable for the kid’s team so that was why she was transferred to the Speech and Language...but it’s after school, so we have to take her after school, but I have to say her Nursery have been very good, they do one to one with her during the day.’ (Parent 3)

A number of parents felt that at times there seemed little point in requesting help, and one parent had opted out of seeking support because of disillusionment with statutory provision.

‘We get no help, but I don’t want that kind of help, I have no energy for it.’ (Parent 7)

The majority of adult participants did not have access to regular statutory health and social care services. In part this was because some did not request or want such help.

‘Initially I didn’t sort of go seeking diagnosis immediately ... it probably wouldn’t be from the point of view of seeking further services or intervention... I think there probably is a significant unmet demand, including among people who have a much greater need for services or support than I would.’ (Adult B)

However, one participant, who had struggled with addiction problems, found the on-going support he had received through his Trust had been invaluable.

Yes, I still have my occupational therapist... she has been with me for maybe 2 or 3 years... and she can keep an eye, she can support me (Adult C)

One parent felt that there should be more specialist provision for dental treatment; the family practitioner’s inability to offer appropriate treatment for her younger son led to a very expensive private consultation. Specialist dentistry is an area highlighted for individuals with learning disabilities both in the Bamford report *Equal Lives* (DHSSPS 2005) and in the post-consultation report for *Transforming your Care* (DHSSPS 2013).

‘... there’s a thing they should do, get ASD dentists! ... Our dentist said ‘I cannot deal with that ’ and referred us to this private dentist, and we thought it would be a couple of hundred pounds... £600 I think he charged us, for fillings and X-rays, he gave him like a whole work-up once he got us in there.’ (Parent 14)

Given the potential for sensory issues and problems in adjusting to novel events that can be experienced by some individuals with autism, it is surprising that measures to improve appropriate dental or other key health services (e.g., eye care, podiatry, etc.) do not appear in the key priorities for well-being set out in the Autism Strategy. Private healthcare is costly; for families already struggling financially (e.g. where one or both parents are unemployed), the extra expense can further restrict the money they have available for household expenses and for leisure activities which would offer opportunities for social inclusion.

In effect this sets up a 'two-tier' system of access to services, where families cannot access statutory services because providers cannot tailor these to meet the needs of individuals with autism, and the poorest cannot afford to opt for suitable private treatment, which results in increasing health inequalities.

Social care services: Most parents and adults with autism who took part in the interviews did not receive statutory social care support. Only few participants sought out social services, but some did feel it could be useful, particularly where multiple needs were involved, such as on-going mobility problems.

I've heard tell there are such things as disability social workers, I think they're as rare as hen's teeth, I think that would probably be of benefit.' (Adult A's wife)

Disability social workers are often 'gatekeepers' for other services such as respite, Direct Payments and out of school schemes. Some participants who would find such support helpful discovered their circumstances did not meet the strict criteria governing service allocation of statutory support, which can vary between Trusts. Services can have a cut-off point for individuals with an IQ above 70, which disadvantages those with learning disabilities or serious social and emotional problems whose IQ exceeds this limit.

'[Son]'s IQ is 80/81... I was at (university) last year doing a course and one of the girls there was from the [different] Trust... and she said to me; 'What do you mean you don't have a social worker? You just said your child was diagnosed?' ... so different Trusts I suppose are different.' (Parent 2)

A minority of parents reported that they had received direct support from social services. For one parent this was very consistent, and was flexible enough to accommodate changes in circumstances, although for others the support was limited or short-term.

'[Son] had a Disability social worker from he was quite a young age... she's very good, she sort of fought to get the 3 hours a week, because [daughter] was due to go to university ... so I couldn't rely on her for extra help...I think it's a family care plan as opposed to just my care plan. I think it's reviewed annually, and then other bits are put in, sort of as and

when necessary.’ (Parent 1)

For some who were receiving services, there is a threshold which can be age-related; this is particularly difficult for young people who were previously receiving support who then find this is removed as they approach the ‘transition’ period, when they are expected to leave school and move into adult life.

‘...there’s a cut-off age, she would no longer be his social worker, once he reached 16, but I don’t remember seeing [name] the last year, it might even have been 14, or 12... because when he got to a certain age, she no longer was his social worker, because he didn’t fit the criteria.’ (Parent 14)

Crisis care: A number of parents reported that they had received short-term care following a crisis or family emergency but this was not continued once the initial situation had been addressed.

‘We did have a social worker come round once because [son] was quite down at school, a suicidal type of thing... He was just having a bad day, and he said ‘I could get this pen and stab myself with it and then everybody would be happy’, and that was immediate, the social worker was here literally within hours, I bet you if I wanted one I wouldn’t have saw one.’ (Parent 8)

However, when one family asked for behaviour support in a domestic crisis, this was not provided at the time; this family had been moved out of their home to allow for renovations, and were under pressure because changes in routine and environment had been detrimental both for their son and for the father (Adult A), who also had autism.

‘[Son] for a week at least...three times a night was trashing the place, pulling the spare mattress off the bed, trashing everything basically. We asked for support, that was October, and they didn’t come out to see us until January, February time...That’s serious stuff... when you’re crying out, saying you need help, and that’s the length of time you’re having to wait.’ (Parents 9&10)

For a family like this, where both parent and child have a diagnosis of autism, or a parent also has a physical disability, the system may be too inflexible to cover such different support needs, and they reported another occasion where the communication between social care service providers and themselves was very unsatisfactory.

No, it ended up I lost the plot... I ended up smashing a plate and running it up and down on my arm... luckily I didn’t actually do any damage. Whenever I did calm down, I think it was the next day, I phoned up Social Services, I said we need some help, and it was basically ... ‘it’s not our problem’ (Adult A)

Transition support: Parents of school leavers found that whatever support they had received discontinued once their child approached adulthood and for one of the young people the sharp change in routine and services had a significantly detrimental impact on his life.

‘The contrast between what happens pre-19 and post-19 is a total disgrace, total disgrace... Shocking- the money just stops, and everything stops and [son] had severe mental health problems from when he knew he had to leave school... and then everything else dried up, all the money for his social life, everything.’ (Parent 4)

None of the adults with autism who participated had received a childhood diagnosis; consequently, they had not been in receipt of either childhood or ‘transition’ support leaving them more vulnerable to poverty and social exclusion as they might have been with support services (cf. Chapters 5 and 6). Yet, most of the adults with autism who participated in the interviews did not seek services after diagnosis. Rather, they sought confirmation and explanation of previous difficult life experiences, including relationship problems, and hoped that this would help them adjust to the future. While three adult participants accessed statutory services to seek advice, one participant and his wife also wanted to improve future provision for adults, especially for their own children as they grew up and moved on from children’s services.

Key points

- Delays in diagnosis should be addressed through increasing resources in terms of staff allocation, knowledge, and training, including autism in females and in adults
- Early, and timely diagnosis should be a key priority; a policy of watch-and-wait should be discontinued
- Early intensive behaviour analytic interventions should be offered to all those who require intensive levels of early intervention.
- Appropriate resources should be directed to evidence-based interventions both for children and for adults (including HE based post-qualifying training for staff; cf. Chapter 2).
- Disability support should not be determined by IQ threshold; rather by inability to “(i) taking part in normal social interaction; or (j) forming social relationships” (Autism Act NI 2011, Amendment to Schedule 1 to the Disability Discrimination Act 1995 (c. 50))
- Adult autism services should be adequately resourced, to ensure adults with autism receive necessary support.
- Employment support is necessary for parents to remain in the workforce, and this

remains the case as children move into adulthood; employer awareness training should be a priority.

- More flexible and effective support provision can be achieved by use of Direct Payments

Chapter 5: Education and training

This chapter addresses issues of education and training that lay the foundations that enable vulnerable people to move out of poverty and into social inclusion. Children, students and adults with autism, and the parents of children with autism, were asked about their experiences of education (from nursery to third level) and FE and HE training. Eight school children participated in two focus groups and ten FE/HE students completed an on-line survey, while five adults with autism and fourteen parents (two jointly with a spouse) took part in interviews (cf. quantitative information about education and training is available in BASE project report Vol. 3).

Most of the children and young people with autism who took part in the study needed support to help them make the most of their education and training opportunities. Parents felt school, third level education and employment placements were not always addressing their children's specific needs in terms of academic progress, independent living skills, social inclusion and future employment (cf Chapter 6).

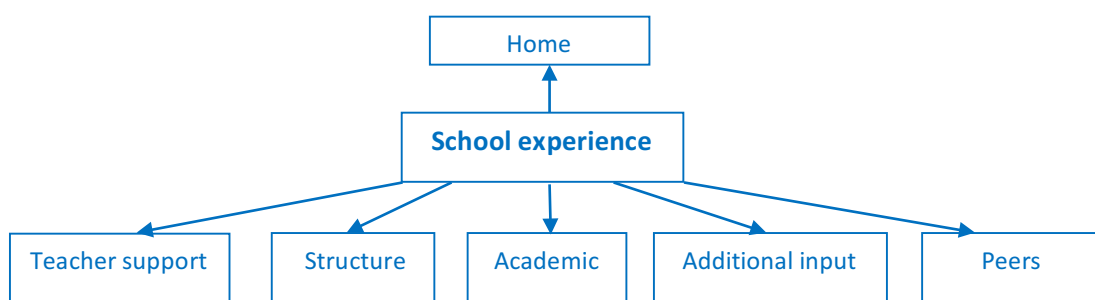
5.1 Factors that contributed to success in schools

When support provision for children with autism in schools was tailored to the child's individual needs this was particularly successful, although some parents felt that they had to challenge Education and Library Boards (ELBs) to have specific support needs met. In general parents felt they were able to communicate effectively and comfortably with their child's school placement, if needed. Of the children with autism who took part in the study and who were currently attending school, most had a statement of special educational needs.

Factors that contributed to a successful placement were close working relationships and good communication between parents and teaching and support staff, good staff training, knowledge and awareness of autism, appropriate structures and academic demands, additional supports, and peer group awareness of autism. None of the adults with autism who participated had been diagnosed while at school, and were therefore not supported in any way. Overall, their school life had been very difficult in terms of engaging with staff and peers, and they had been very unhappy at school.

Figure 11 illustrates the themes that emerged when discussing what contributes towards a good school experience for children with autism and their families

Figure 11: Factors related to positive school experiences of children with autism



School was experienced as positive when educational professionals supported students with autism in a number of ways, including working closely with parents and colleagues, providing structure and academic support, offering some additional inputs with a specific focus on communication, promoting independence, and promoting good peer relationships.

Working closely with parents and colleagues: Parents reported overall that they had a good relationship with their child’s school. The key to this would seem to be good home-school communication, both formally and informally.

The most common formal communication took place in annual educational reviews and in parent-teacher meetings that allow parents and staff to discuss the child’s progress throughout the year. Good communication also included instances where home-school diaries allowed a day-to-day overview of achievements or problems, and parental input for the child’s Individual Education Plan (IEP) was welcomed.

‘They have us in roughly every 6 weeks or so, just to speak to the teacher... The IEPs and stuff like that, it’s always got me in mind. At the moment we are doing a star based system to try to help with the handwriting but I can give some comments on what he feels at home or what is going on at home or if he had just refused to do it that night so, any input I have they are always willing to listen.’ (Parent 8)

Most parents felt they could talk to teachers without having to go through a formal contact process, and this was very helpful, particularly in discussing on-going strategies to improve their child's progress in class.

'If we have any issues, officially I think you're meant to make an appointment or whatever, but usually you can just knock on the teacher's door first thing in the morning, or at the end of school, and say 'Can we have a quick chat for 5 minutes' and they know you're not there to have a go at them, because there's no reason to. They know we'll raise something if we feel it's a problem, or just to get their take on it.' (Parents 9 & 10)

Although none of the parents reported that they felt uncomfortable or unwilling to engage with the school, or that staff were hostile, some parents did feel that communication could be improved; one parent noted that for non-specialist staff, contact could result in what her child perceived as a patronising response.

'..they seem to forget at the start of each term that [son] has Asperger's, some of the teachers ...but I have had to request at the start of each term that the teachers are emailed and told but then [son] was getting quite annoyed about that...because they start talking to him li-ke he is re-eal-ly st-up-id, like that there. And I am like 'Ach, son they are not that bad, and he went 'You are not there, you don't hear the way they talk to me'.' (Parent 13)

This is a matter not just of communication between the special needs professionals and general staff but also of autism awareness in the school; this could be addressed by better autism training for all staff, rather than just those with a specialist role and it is an issue which education professionals themselves have noted (see Chapter 3).

Around half of the focus group pupils mentioned the role their parents had in communicating with their former primary school, although some of these recalled the relationship was more formal and infrequent, limited to the annual progress review.

'My parents would come to the school and they would be given like a progress review for like annually, so they would but that was about it really.' (School 2 pupil)

A small number of parents also had close links through employment or governance roles

'In my first primary school my mum was on the chair of the primary school so she would have been there all day anyway.' (School 2 pupil)

Parental contact in secondary school appeared more limited and was seen in terms of general support, both initially and for older pupils, in transition arrangements, something which will be discussed more fully in the next section.

‘When I started here I know my mum and dad helped, they were very helpful.’ (School 1 pupil)

In terms of personal or parental input regarding their education, the majority of adults with autism who participated felt they had little guidance, and would not necessarily have expected their parents to have been very involved with school decisions, or to have challenged school authority.

‘No ... My parents were very hands-off as far as school went... they failed me in a sense. I don’t hold it against them, I’m not blaming them, just recognising, you know, that they could have done things differently.’ (Adult E)

Educational professionals reported that in order to effectively support students with autism, they needed to work together as a team. Working as a team allowed knowledge of autism to be shared. Many participants acknowledged that supporting students with autism involved developing a good relationship with parents. They felt that it was important to make sure that parents were advised of the child’s educational needs and a consistent approach was applied at home and in school.

‘I think another thing is keeping that good key relationship with parents, and communicating. It’s about keeping all relationships are key and sort of making sure we are reading off the same page, you know to get the best for that child, for consistency too and it’s so important that we do that.’ (Professional 5)

Working with parents when a student with autism becomes an adult (18+ years old) was considered more difficult due to data protection laws. However, the role of parents in supporting 18+ year olds was considered important and professionals did their best to engage with parents while working within the law.

‘Managing parents as well can be very, very difficult... the data protection. Sometimes I think parents actually play a very, very valuable role in those first few weeks. If you can get the parents support in the right way it can be very, very helpful, now I like working with them and I always try to encourage them to be involved, but yeah it’s certainly challenging.’ (Professional 3)

Teachers also talked about how important it was to work together with the classroom assistants to effectively support students with autism as often they had done more autism training than teachers.

'You know the classroom assistants have gone on autism training, [classroom assistant name] has gone on quite a lot, and she's worked with children for years and years and years... She could write a book. She's gone on a course, she could give the course!' (Professional 9)

'I also advise teachers and classroom assistants. I also attend the annual reviews, and children are engaged with that from day one. They are invited, but they don't have to attend. Also, if the rest of the class are briefed on the needs of the child - with permission- it works better.' (Professional 1)

Where the school placement was successful, parents, children and young people identified the knowledge, personal research and training of staff as a key factor.

'Understanding, the teachers need to understand what Asperger's is, you know at the start take a class in what people have and what makes them different, and then they can understand more when they get confused in class and get annoyed!' (School 1 pupil)

Providing structure and academic support: Most of the educational professionals made efforts to create a structured environment for their students with autism; for particular classroom activities this can mean careful planning to encourage completion of potentially challenging tasks.

'The boys in my class operate on schedules, so I would have one boy on a picture schedule, which he really needs... He finds transitioning from a preferred activity to a non-preferred activity very difficult so we would do... 'you know, if you move from that, if you do this thing for me then after you will get a reward or you will get something that you like.' (Professional 4)

Some mainstream professionals pointed out that structure was incorporated into the school environment for all pupils, so as not to marginalise students with autism; in one secondary school, all the pupils coming from primary school received the same initial support in familiarising themselves with their new routines.

'All the pupils in year 8 have colour-coded timetables, so they don't feel any different.' (Professional 1)

Those in charge of organising support and reasonable adjustments for students with autism in school and at University (e.g. SENCOs, disability officers) mentioned that some students with autism benefitted from reasonable adjustments, such as extra time during exams, breaks, readers or scribes in exams. Also, some students were facilitated in their exams in a separate room (e.g. green room) on their own and this was perceived as useful for students who found that the noise and number of people in a regular exam room affected their performance. School experience was improved by the provision of well-matched, consistent one-to-one support, where necessary.

‘I think the exams process is incredibly challenging for them. For exam support as well they get extra time. Most of them will do exams and, yes, they do get stressed and all but they will do them, and we can organise support and get them a scribe and an individual room as well which is really important for a lot too, for the noise factor.’ (Professional 3)

‘[Older son’s] current placement is outstanding, absolutely outstanding... [The Principal] told me when she took him into the P7 year that she would be able to fulfil his needs, if he had a full-time classroom assistant, and if she could match him up with a particular practitioner that she thought would be able to accommodate him.’ (Parent 12)

Navigating around the school and the classroom was considered difficult for some children with autism. Some teachers reported using inductions/visual strategies to help students with autism learn their way around the building and find the different classrooms and new buildings could be purposefully ‘autism-friendly’ (McNally, Morris and McAllister 2014).

‘I think we have started to try and put that round the school, do you know the wee visual pictures, and like every door has it where you go.’ (Professional 6)

‘The way our school’s laid out...that corridor is science and maths which helps me because people are like ‘Oh you need to go to science’ and I know the classrooms for science, and then this corridor is English.’ (School 1 pupil)

The majority of parents felt their child’s school placement was able to meet his or her academic needs. They found staff were generally knowledgeable and would tailor the classroom environment, where necessary. They would also engage with parents about strategies that proved useful at home, and keep parents informed.

‘And if there is something he doesn’t understand with regards academic, they would try and do it differently for him to suit his needs, what works for [son]. They give him time out, like headphones...or they have like crayons and smelling objects because he has sensory issues.’ (Parent 2)

For the pupils at secondary school who participated in focus groups, accommodation of their individual needs was also important; all the participants were preparing for (or had completed) GCSE examinations and they recognised the academic challenges this presented, particularly for the pupils at the school for pupils with complex needs and/or learning disabilities (School 2). However, pupils from both schools identified the provision of support for their individual needs and the opportunities to develop new interests or build on existing academic skills as the main strengths in transferring to secondary education.

‘The level of work seems to be ...not just the amount but the quality of work that’s expected and required really, that can have a big impact on someone’s education and their well-being really because ... stress and with homeworks and such piling up.’ (School 2 pupil)

‘Work these days is quite good. It’s a bit challenging which I always like ... I was quite proficient at maths back in primary school, so I was given quite good expectations in terms of maths, so that was quite a good thing to come to.’ (School 2 pupil)

A minority of parents found that school was not meeting their child’s academic needs. In part, they felt this was because the school was not ambitious for students with autism.

‘I think he has moved into the special school system, that they don’t push them at all, now don’t get me wrong there are lots of things that are very important [but] ...We had him up to a certain level, and then you are relying on teachers to push them you can see that they are not being pushed at all, honestly... if you talk to any parents in most MLD¹⁰ schools, they will say the same.’ (Parents 5 & 6)

In one instance, a parent had to insist that her son was allowed to sit more than one GCSE, as she felt not only was he able to undertake the work, but missing out on the qualifications would have been detrimental for his chosen career in media studies.

‘No, I don’t think they were ever expected to amount to very much, to be honest...So they did a course on Life Skills, how to cook for themselves, how to work with money... but I don’t think they were expected to have a plan. [Younger son] was the first person ever in [school] to do GCSEs, to do two GCSEs, and pass both of them.’ (Parent 14)

Two families also felt that their child’s one-to-one assistant was being used as a more general classroom resource, which diminished the tailored educational support that should have been provided.

¹⁰ Moderate Learning Disabilities (see http://www.deni.gov.uk/sen_categories.pdf for a more detailed explanation)

'[son] would have talked about this other child kind of sitting beside him and [classroom assistant], you know and I went straight to the school and said because I fought really hard for [son] to get those hours that he did... I appreciate that maybe some other child had difficulties but that was up to their parents and the school together to put something in place for him.' (Parent 2)

Sharing classroom assistance was an issue which was identified by other professionals in Chapter 3 as a more effective use of resources; however, if a one-to-one assistant is specified in a child's Statement of Special Educational Needs ('Statement') then that is exactly what is required. This difference in perspective would not occur if adequate resources were available for other children who had special needs but who did not have a Statement, or whose Statement did not specify the support actually needed.

Some pupils from School 2 who participated, while generally very happy with their placement, did suggest more support would be helpful. In addition, some felt that they wanted more choices about what they could study, as they were following a common academic pathway.

'I'm thinking maybe ...the school could set up a support group, maybe like a little tutor thing maybe in the evenings or such to like help students with their... the subjects that they struggle with.' (School 2)

'We should be able to pick our GCSEs because here we don't get to pick our GCSEs.' (School 2 pupil)

For adults with autism, there was no specialist provision at the schools the participants attended, either in terms of examination or classroom support. All were academically able, and in general, where participants were performing well in class, this was not an area where they felt they had needed support; given the very low level of autism awareness at that time, did not feel their schools could have provided any. However, where they had additional needs such as anxiety or dyslexia (which would have been evident at the time) they felt they had been disadvantaged.

'Just had to get on with it. Dyslexia wasn't picked up on then but it was always commented on that I had ... it was called then 'word blindness'... I've always known that my spelling was atrocious.' (Adult A)

For some, this was particularly true in examination situations; Adult A recalls writing in capital letters because he was afraid the examiners would not be able to read his answers, while another participant could not focus on the questions because of anxiety issues.

‘... well, I underperformed in quite a few of the exams because I was having anxiety problems during them, so I was spending quite a lot of energy in controlling myself, and not freaking out... (Adult E)

Offering some additional inputs: Although most parents felt that the school placement addressed their child’s needs overall, specialist ASD support (e.g. from Education and Library Boards or specialist centres) was not always available when it was needed. Even where support was in place, there were mixed responses regarding effectiveness. Where there was a ‘joined-up’ approach by the autism advisory service this was viewed as very helpful.

‘I do feel, so much more could have been provided from outside coming in.’ (Parent 2)

‘...we’ve been getting good help from the Board, [name] who’s with the autism advisory service through the Board, would come in and work with [daughter] as well in the nursery and give the nursery things that can help her.’ (Parent 3)

Focus group participants from School 2 reported that staff at their primary schools (i.e., schools for pupils with recognised complex or special needs) had been particularly understanding of issues or difficulties. Many individuals with autism have sensory issues and specialist accommodation, whether for quiet study or for taking examinations when needed, also contributed to a good school experience.

‘Our classroom assistant, [name] she had really good understanding of both of us and everybody else in the class in the class who had ASD.’ (School 2 pupil)

‘Well, when we were doing the exams, we’re part of special needs, we go to a different room, it’s quieter and it helps a lot, because obviously you don’t actually have to listen to people moving their chairs, or coughing.’ (School 1 pupil)

However, another parent of an older pupil at mainstream secondary school had found specialist provision was not timely or appropriate.

‘...they were supposed to come in and do sessions to prep [son] on how to study, on how to organise study skills... I said ‘but he is doing his mocks next week surely you should have been in to prep before the mocks’. They came in after the mocks and were in with him for 20 minutes...showed him how to do a spider diagram ... so it was left to me.’ (Parent 13)

While the majority of the young people were in favour of a specialist autism support group in their school, they saw it as a matter of choice. Some pupils felt that not everyone with autism would actually want to be part of a specific group, especially if it was after school hours.

‘...it would be your choice to go to it, like, but I actually talk to my friends or go out with them and go to the gym which helps me get rid of stress and stuff... It’s not that you feel uncomfortable, it’s that you just don’t want to be in the school any longer!’ (School 1 pupil)

At school, educational professionals mentioned a range of activities that aimed to improve the social skills of some children with autism, such as buddy systems and links with other classes.

‘We do integration with other groups, which is important I think for social skills for children and encouraging you know even whether its choice picking, showing everyone what they like to do, and you know even listening as well.’ (Professional 5)

Difficulties with social interaction are a characteristic feature of autism, and considering that children and young people spend so much of the day at school or college with their peers, this is an area which can cause problems, but can also offer opportunities for improvement. While most parents felt that their child’s school or college was making a positive effort to enhance social skills, almost half believed this could be undertaken much more proactively. Some parents felt that schools did not effectively address behaviour issues which impeded taking part in social activities. One participant noted that her child was being excluded from planned social groups because of his non-compliance, something she felt the school should have anticipated and addressed before expecting him to participate.

‘... he’s missed three out of four social skills groups...because of behaviour issues, but trying to explain to them that social skills are a difficulty, so you are going to get these behaviours when trying to get a child with autism to engage in social activities...not throw them into a group of 8 children who have their own additional needs and expect them to sit and learn social skills when they already have other difficulties.’ (Parent 1)

A social skills group had been set up between the universities to assist students with autism, and students valued the support this provided.

‘...the feedback seems to have been very, very good. The difficulty again, I suppose as with everything else, is getting the student to engage. When I have done initial assessments with

a few of the students, I have said to them about the social group and they have just gone aw mm...and ironically then those are the students who would probably benefit most from it. (Professional 2)

For others, interventions were offered in a different setting, which may have involved taking time out of school; this meant missing out on other learning opportunities, and some groups were of such limited duration and scope that little improvement was likely.

'It was like 45 minutes every day after school or maybe he was taken out of school, for four days, and they said afterwards 'He is fine, go', and that was it. In 45 minutes, 4 days? No [there was no difference]. I think they were put in the room and told to play and share and things ... and that was it.' (Parent 8)

Overall, pupils with autism who participated in the focus groups found that school had enhanced their skills in terms of self-esteem, confidence and social skills, and some they felt they had made real gains.

'Well, school has taught me to have more self-belief and confidence in myself than when I left [name of primary school], and they've also helped me get over my social anxiety and get out and socialise and that kind of thing' (School 1 pupil)

However, most pupils expressed some concerns about interacting with peers who were not their friends. They also felt that it was important to be open about having autism, as it was not something people should hide away from, and one participant considered it was in fact something very positive. The older pupils raised the issue that schools should be preparing them for relationships, particularly where partners did not understand the complexities of autism.

'Wherever you go, don't be afraid to say that you have Asperger's, because I see it as a gift, to be honest' (School 1 pupil)

'I think more people should just know, because my girlfriend's like 'What? What is that?' you know? I gave her a booklet on Asperger's, 'Just read that'...'' (School 1 pupil)

While many professionals specifically expressed the view that social groups were useful, one participant felt that they could be counterproductive and could hinder successful inclusion.

'One of our main objectives is we want them to feel part of the student body, and you know, feel that they are part and parcel of that. To then set up a group that says 'you're different' is flying in the face of that objective, you know?' (Professional 7)

Participating educational professionals working in special schools felt that a key part of supporting lower functioning students with autism was enabling communication by alternative non-verbal means. A range of non-verbal communication strategies were used including a Picture Exchange Communication System (PECS), sign language (e.g., Makaton), and allowing students to type on iPads. One of the participants who were working in the mainstream sector pointed out that adjustments to communication methods were also useful for some higher functioning individuals with autism.

‘So they come in and verbally tell their news from the weekend and that’s a big challenge even to know...We have our PECS cards, iPads are coming in handy as well, some of them use that to speak. They could tell you the answers to things but when it comes to hand writing or spelling like written they just clam up, so there comes a point where you have to say right well, you know you could type your word.’ (Professional 6)

‘...they need things clearly explained, one-to-one, and look for feedback. The way I’m trained to teach foreign students, I would say ‘what is it you’re doing?’, so they can say it back, rather than just asking if they understand and getting a ‘yes’, when they don’t...and make sure it’s written down, because oral instructions don’t work.’ (Professional 11)

Promoting good peer relationships: Many professionals in both mainstream and special schools recognised the need to promote independence for individuals with autism. In special schools, this was done by giving children with autism responsibilities within the school (e.g. giving out milk and returning registers to the office) and also building life skills into their Individual Education Plans (IEPs), and demonstrating these in a very practical way.

‘... their IEPs, one of them is to encourage independence and dressing themselves... A big thing is to encourage ‘you take off your jumper’ and you know just lots of prompting, lots of encouragement ‘taking off jumper’ ‘taking off jumper’ and showing them, modelling how it’s done and then encouraging them to get to do it.’ (Professional 5)

Anxiety, stress and anger management were areas that also affected some of the young people with autism who participated and some pupils had specific concerns about how their own personal issues and difficulties would impact on settling in to a new situation. Most mainstream schools were unable to provide on-site effective specialist support, which would have been helpful.

‘... for my anger I did counselling, there last year with [name of organisation]... they helped, they knew ... there were people there like with Asperger’s, well, their funding got cut off, and it’s pretty bad now, you can’t really get counselling... I don’t like ‘normal’

counsellors, because they don't really understand. I came into the counsellor here one day and she kept saying 'Why?' to me and I just walked out.' (School 1 pupil)

In mainstream post-primary and post-16 education the focus was much more on enhancing employment prospects of students with autism. For school students, work experience is usually arranged towards the end of Year 11; students with autism may need additional support in finding and in carrying out this type of placement. At university, where campuses can be very large, campus assistants play an important role in helping students navigate their environment and orientation support is particularly important during the first week of term where not just the environment but many of the tasks are novel.

'...most students would find their own placements. Obviously students that need that extra bit of support will be supported and a placement will be found for them.' (Professional 10)

'A big aspect of the support is orientation at the beginning of the year, so they are given the access to the campus assistant to help them get used to the change in environment.....one of the things that we try to find is assistance to get support with registration and all because that is really daunting for them.' (Professional 3)

All professional participants reported having positive experiences with students with autism. In many cases the educational professionals explicitly stated that these positive experiences were as a result of seeing students flourish due to the implementation of effective support. In addition, many educators appreciated the unique personalities of individuals with autism and the interaction with peers.

'Yeah I love it, love it. I think I enjoy the challenge of it like getting them to do, to achieve things that maybe... their parents thought or they thought they couldn't do. I love the quirkiness of their personalities too and how they look at things and there's just something really lovely and genuine about them.' (Professional 4)

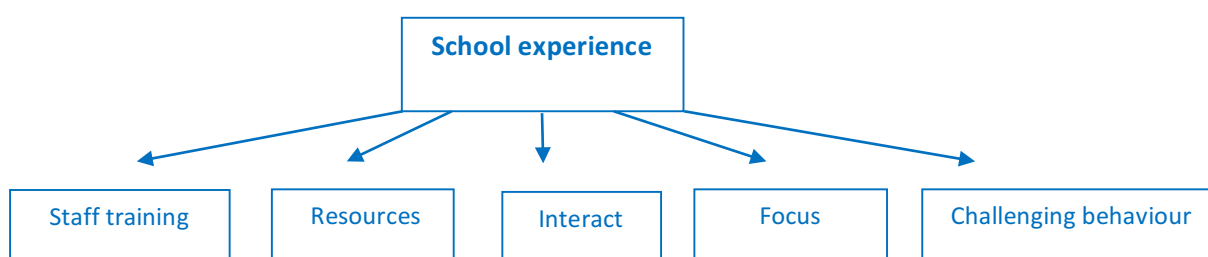
Adults with autism who participated recalled that interactions with other students could be uncomfortable, and overall, most participants did not enjoy school. Two people recollected being bullied continually, an experience which they have never forgotten.

'...I was bullied all the way through school, which now looking over it, saying ' You know, I have autism' would make more sense, the fact that I was that... bit different.' (Adult A)

5.2 Factors that present challenges in education

Despite some good practice, there were some significant challenges to schooling and education of children with autism in mainstream as well as in special schools. The key challenges were concerned with lack of staff training (i.e., most education staff had only received Level 1 autism awareness training equating to a lecture or talk lasting 1-2 hours, cf. Chapter 2), lack of resources, difficulties with interacting and focusing, and lack of educational staff skills in dealing with child behaviour challenges (Figure 12).

Figure 12: Factors presenting challenges for school experiences of children with autism



Lack of staff training: Given the lack of staff training with regards to autism and intervention strategies (cf. Chapter 2) it is not surprising that the importance of good autism training was reinforced through the comments the professionals made about the challenges involved in working with students with autism.

Adults with autism who participated had all attended mainstream secondary schools in the 1970s and 1980s, when there was very little awareness or understanding about autism, and schools were not set up to cope with additional needs. Interactions with some teachers and other students were uncomfortable, and overall, most adult participants said they did not enjoy school.

‘Yeah, they very definitely could have done, but they didn’t have any mechanisms in place for that at all... at Senior school, it was just chaos...I just hated that aspect of it...’ (Adult E)

‘...you felt left behind, especially if you are quiet- I hated, really hated it’ (Adult D)

Lack of resources: Many educational professionals commented on how they had to balance

resources, such as their time and lack of support staff, with the needs and expectations of their students with autism. Most concerns related to having enough time to implement the support that their students needed without discouraging independence. As students grew up and wanted to be more independent, some become resistant to accepting support.

'I'm sure I could improve. There probably are different things I could be doing and should be doing... When you're teaching 125 kids a day, it's difficult to take on board new things...' (Professional 10)

'Some won't have talked to their tutor, maybe self-conscious, don't want to be different, and at different times of the year. They might realise later they are struggling a bit and ask for help.' (Professional 11)

Difficulties with interacting and focusing: The majority of professionals highlighted interacting with students or helping them to interact with teachers and peers was a challenge. This can be particularly problematic for those students who are non-verbal, and in some situations it is a challenge for staff to find effective means of helping them to communicate their needs and feelings.

'Some of our children that wouldn't have the speech and things, you know, they are ... I don't like using the word, but they are just sort of so highly autistic that the frustration can set off challenging behaviour...that's sort of hard, that would be a challenge.' (Professional 6)

However, difficulties can occur for individuals across the spectrum and supporting academically able students who find social situations difficult also presents challenges, particularly when other students (or staff members) are insufficiently aware. A number of parents were concerned that their children's peers were not being educated about disabilities in a way that would encourage more inclusion. Three parents mentioned that their children had been bullied at mainstream school because they had autism and were seen as being different by some of their peers; the schools had not addressed these issues.

'We have students who find it so difficult just to come through the doors. The main challenge is staff and students who don't understand ... Students can be quite cruel particularly younger ones. Older ones are much more inclusive, but certainly younger students can be very childish. The problem's not the student with autism; it's the students with no sense.' (Professional 7)

'She had a lot of absences and bullying at school...Her peers pushed her in front of cars, tried to hang her upside down by the ankles... I told the school, but they did not deal appropriately with it. All they did was call in the bullies and talk to them, instead of giving a general talk to all pupils about how people should treat each other.' (Parent 7)

For adults with autism, all the participants had found engaging with the social side of school life was very difficult. Some found the transition from primary school particularly problematic, having to make new friends and fit in to a very different style of organisation, while others were picked on and bullied. Their schools made no attempt to address any of these issues, although at times some of the participants felt that there should have been awareness or sensitivity from school staff on a general level, even if knowledge of autism was almost non-existent. One participant felt an informal support ('buddy') system would have been very helpful at first.

'So it was okay in primary school because everything is very structured and supervised ... but in secondary school you know, break times, lunch times you are kind of left to it yourself...I found it difficult to participate properly in the social side of things... Looking back I think there are things I could have used support with particularly in first year, a buddy or a mentor, somebody who I could have gone to for a bit of help' (Adult B)

Education staff reported that students with autism at times got 'stuck' in their own routine and it was difficult to ensure they engaged in different activities or moved onto another task. The challenge was on focusing on the 'important' task as opposed to the task that the student 'prefers'. Education professionals realised that student motivation can change quickly, i.e., what was of interest one day may not work the next. For this reason educational professionals needed sufficient training and skills in different methods of supporting students with autism.

'Trying to get him to change what he was doing was also a bit difficult. He would get into a bit of a routine and want to keep on at it until he could make it work.' (Professional 12)

'Some days...they really love the sand and you can get them to do their work based on a motivator about that and then by tomorrow they don't like the sand so...I think it's not being afraid to try something new and if this works great and if it doesn't... and it will not work for all of them either.' (Professional 4)

Dealing with challenging behaviours: Several educators reported that dealing with challenging behaviours was difficult. Challenging behaviours appeared to be a particular issue in special schools where this can be associated with children who have co-occurring conditions. These highlight issues around teaching practice which can be addressed by effective interventions and appropriate training.

'I think particularly in severe special needs, because the children mightn't just have autism. It's a range of learning difficulties that they might have... so there will be a lot of throwing themselves on the ground, maybe hitting out, lashing out, frustrated that they

can't tell you why... what they want to do and why they are annoyed or something is sore.... The main challenges I would find are the behaviours.' (Professional 4)

Challenging behaviours were also an issue in mainstream education, but not to the same extent. Here, the comments regarding challenging behaviours suggested they were infrequent and generally manageable, particularly when professionals involved with the student were knowledgeable, and working together.

'If you work with them, you know with their classroom assistant, there's not really any challenging behaviour in that sort of way.' (Professional 10)

Although none reported being bullied, focus group participants mentioned concerns when talking about transferring to secondary school. A number of pupils said they had been worried about bullying or unpleasantness from others. One student mentioned that he had been unsettled by negative media portrayals of secondary school life. They also felt that pupils with autism could play an important role in providing more accurate and useful information about what it was like to actually be on the autism spectrum, and the issues that affected them directly.

'... like I wasn't bullied or anything at primary school, but just with moving, I'd heard about bullying and stuff at secondary schools and so I was a bit worried.' (School 1 pupil)

'If I am honest I think it was mostly from TV shows and such...' (School 2 pupil)

'You see, the way the pupils in my [primary] school found out ... is from a small speech by the principal, talking about ASD in a well-meaning but misinformed way, talking about how we only see things in black and white, in a figurative manner, but then people took it literally and they started asking me if I was colour blind... so I think better education for the pupils would be a good idea.' (School 1 pupil)

A number of parents experienced finding the right school and the most appropriate teaching support as very difficult and stressful; some had challenged their ELB, and one family reported that they had undertaken legal action to get the appropriate support provision for their child.

'...I fought really hard for [son] to get those hours that he did...I mean I fought with the education board until I could fight no more to get that in place for him.' (Parent 2)

'We have fought with the education board, haven't fought so much with the school but we have fought with the education board for years and years. We have been to the high court,

we have been to the SEN tribunal as well... You are sitting there with a lady who is a barrister, it's just the intimidatory factor, you get what you ask for.' (Parents 5&6)

For one parent, the engagement was particularly hostile, and she eventually withdrew her daughter from school. Her child's private diagnosis of autism was not accepted by the ELB and the support provision requested was not forthcoming; as a result her daughter had an extremely negative school experience. Her mother felt that this was due to a lack of professional understanding of how girls with autism can be very different from the stereotypical perceptions of the condition. Another parent, whose son was in mainstream secondary school, felt that the absence of a statement of special educational needs impacted negatively on the type of support that was provided, limiting the specialist resources.

'The ASD service in the [name] ELB wouldn't talk to the parent or the child, only to the school. Teachers at school just don't understand... Girls have a different profile, so you have autism, and Asperger's, and Asperger girls etc...The multidisciplinary team were failing to protect my child. There was bullying, and the school failed to act appropriately...' (Parent 7)

'I think the school do a good job with the resources they have and it would be nice if they had more resources, but they can't do that because there is not a statement.' (Parent 13)

5.3 Addressing independent living needs

The term 'independent living' covers a wide range of skills, from the basics of personal care to reading a timetable, organising homework tasks, managing money, eating out, using public transport and cooking. Parents reported that their children generally received encouragement in tasks which helped them cope with school routines but these were not necessarily all the skills needed in 'real-life' situations. However for younger children, very basic skills such as toileting and eating at the table were being improved.

'She's picking up a lot of skills in school that she didn't have before she started school, eating as well. She would have been very much a finger eater, but, yeah the knife and fork has come into play more in school... I suppose because her classroom assistant is there to constantly remind her ...which is good...and her toileting has improved since she went to school actually, because that was a huge worry.' (Parent 11)

Where a student's needs were not being met, one parent felt that absence of autism awareness and training among general staff (as opposed to the learning support staff) was a major contributory factor to a lack of consistency in addressing independent learning skills.

'...his organisation skills are woeful... like homework diaries and stuff he loses them all the time, or misplaces them or leaves them in different classrooms, and instead of the school trying to reinforce one kind of system of that they will just shout at him or tell him he has to go and pay for another one...like all the teachers seem to do something differently, and if they were all doing the same thing it might reinforce him, he might learn quicker' (Parent 13)

The pupils who took part in the focus groups were worried about the lack of life skills training and subsequently their experience in practical aspects of independent living, such as paying bills, and the subject came up again when asked what they felt would improve their educational experience. Overall, they agreed that this should be more widely available across all schools in Northern Ireland; one pupil noted that students in other jurisdictions, e.g., the USA, received more training in life skills.

'More life skills classes really in terms of like what I mentioned earlier, paying taxes, rent, yeah.' (School 1 pupil)

'I would like to have that everywhere, like every school. They have that over in America.' (School 1 pupil)

Again, given the time period (some 30 or 40 years previously) adults with autism did not feel their schools considered this type of support to be of relevance; one parent with ASD compared the situation with that of her child's in the present day. A number of parents felt that in general, independent living skills were not a priority for mainstream schools; even in schools for children with moderate learning disabilities (MLD) very basic skills had to make way for a more academic curriculum.

No- now, [son] has classroom assistance at school, and a home school diary, he needs organised...[my school] could have done more to address my confidence, I was seen as so shy- everyone was labelled as shy but I wasn't shy, I just didn't want that.' (Adult D)

'...he used to be in [another school] which is an SLD¹¹, and they would have done...make their own break and brush their teeth in between, and teach them to tie their laces but those things are kind of put to the wayside because it's slightly more academic in MLD, and then if you were to go up to mainstream again it's more to the academic and less on

¹¹ Severe Learning Disabilities (see http://www.deni.gov.uk/sen_categories.pdf for a more detailed explanation)

your self-help skills. So I have brought it up with the school but I think they're just limited in what they can fit in.' (Parent 1)

Balancing life skills training with academic curriculum is not easy; e.g., some parents felt that special schools were not always academically ambitious enough. However, where provision was individually tailored for children, it was possible to ensure that students were leaving school with the skills necessary to enter further education, training or work, including both academic and daily living skills (whether these were personal care, use of money, anger management, confidence in using transport or any other activities we expect other young people to carry out).

School pupils themselves raised a number of issues about preparing for independent living, as half of those who participated in the focus groups wanted to move away from home to study at university or college and felt there was little preparation for this. Some felt that school should be offering courses that prepared young people with ASD (and also their peers) for dealing with practical issues such as personal finance and general living skills, rather than, as one pupil noted, the more abstract aspects of mathematics.

'Well, I suppose the skill of being able to live on your own, in a university, kind of having to look after yourself is something that could be learned, a skill that could be acquired before leaving to university or college.' (School 1 pupil)

'I mean we are sitting there learning things like algebra...when will you ever use that one thing...I would prefer...not just for us but for everyone is that we actually learn some life skills like how to do like taxes, paying rent ...personal finance.' (School 2 pupil)

Adults with autism who participated all drew attention to the fact that preparing students for adult life was not a priority for the schools they attended, regardless of any additional needs they may have had. The focus appears to have been very much on academic achievement with the aim of gaining entrance to university or college. There was no preparation for any of the changes that such a transition would make in terms of independent learning, living away from home or making new friends, and it seems all students were just expected to follow a fairly standard pathway, without questioning whether that was what they wanted or could cope with.

'No...I don't think they ever prepared anyone for the real world, it was just pure ... academic, getting you through your qualifications, and that was it- it was just a standard state school.' (Adult A)

Those parents whose children had attended special schools reported that some of these schools provided a wider range of activities to promote independent living skills, and could include specialist counselling for issues like anger management to help students cope with difficult or frustrating situations.

‘He would go to anger management classes... He was given the tools to control his temper, not that he was ever violent or bad-tempered...But he was given the tools to deal with his frustration and things, you know, if you get very frustrated at some things you end up getting quite loud, and aggressive, and they taught him all that, and money management.’ (Parent 14)

5.4 Third level education, training and employment

Of the parents who responded, eight of their children attended nursery or primary school. Three of these families felt their children were too young to focus on future employment and training; however a number of parents had noticed teachers steering children towards areas where they showed a particular interest or talent. One parent considered future employment needs could be addressed more fully and felt that lack of autism awareness among general teaching staff was the main issue.

‘...they have started already with her on her computer skills and typing, which is great. Whereas the rest of the class don’t type, but [daughter] is able to type her name and all at this stage...They are really focusing on that and trying to encourage it with her.’ (Parent 11)

‘The special needs department and the guys in the [support unit] seem to be on a completely different page from the rest of the school... I said ‘[son] is not going to college...I have already discussed it with the year head, the SENCO, and they want [son] to stay in school because the support structure in school will be much better for him, he doesn’t need to fill in a college application’, ‘well just in case’ (careers teachers response), ...’ (Parent 13)

The focus group pupils felt that work experience was useful for career development, especially if it built on existing skills and interests. The older students had all undertaken this, and for two students it had been useful in helping them decide what they did **not** want to do, even if the experience had been interesting. Four of the pupils had, or were about to start, part-time jobs, and most saw this as a stepping stone to a future career.

‘Yes, I’ve done work experience, because originally I wanted to be a game designer and stuff, and I went to a place called [name]... and it was really good, but when I did it, it wasn’t my type of job.’ (School 1 pupil)

‘I actually have a Saturday job... I went to [name of FE College] ... they had like an open day... there was hairdressing and everything and I talked to a girl and she said it would be good if you could get a Saturday job in a really good salon, she said that that would help’ (School 2 pupil)

None of the pupils had sought or been offered careers advice from their schools, although the younger participants in School 2 were aware of the provision, and expected to have some contact in the next academic year.

Moving into adulthood can be a challenging period for young people with autism, and parents who participated remained a consistent supportive presence in their lives. Four young people had left school and had attended FE Colleges, university and vocational courses; one had a part-time job, and another was just about to begin in a full-time post following his university training. School pupils who participated were looking forward to moving in to third level education, while students currently attending FE or HE institutions reported that overall it was an enjoyable experience.

Parents were confident the placements offered the best opportunity for their children to achieve their goals, although there was less formal support in place. The majority of these parents felt that transition support at schools was inadequate, and that despite, rather than because of this, the experiences in further or higher education were positive; they commended the flexibility of systems that allowed tailored support for their children with autism. Adults with autism reported very unsatisfactory transitions; of the five participants, four had entered third level education; none felt prepared, and the majority had been unhappy. Important issues included transitions from school to work, work experience placements, the diminishing input of parents, third level education, and learning social skills in the real world.

Transitions from school to work

Transitioning from school to adult placements was a very difficult time for some young people with autism, as they face leaving the familiarity and routine of school that had been a major part of their life to date. The Transitions service¹² (organised through the Education and Library Boards) was intended to help young people with special educational needs

¹²<http://www.education-support.org.uk/parents/special-education/transition-service/>

leaving school and prepare them for adult life. This service included planning courses, establishing contact with services, and advocating for students and parent/carers where necessary. One young person had withdrawn from school before engaging in transition services, but for the others, parents did not find the Transitions team particularly useful.

‘...definitely for [younger son] I met the Transitions team a couple of times... it was a waste of my time, complete waste of time. They were only interested if I was sending him to Tech to do a Transitions course. ... He knew what he wanted to do, and because he knew what he wanted to do they had no information for him. They only had information for people who didn't know what they wanted to do.’ (Parent 14)

Of the focus group pupils, only one participant had any knowledge of a Transitions Service provided through the ELB. None of the boys recalled any personal contact despite the fact that the service claims to involve the pupils closely. The year 12 pupils from School 1 thought that their parents would be dealing with the transitions process.

‘I don't even know what that is -Transitions team, what is that? My mum probably knows, I've never heard of that.’ (School 1 pupil)

Work experience placements

Parents reported that three young people had taken part in school-based work experience programmes. In mainstream or MLD schools, this tended to be brief and perhaps of limited value in terms of real work experience, as prioritising other areas of the curriculum leaves little time. For one parent, whose son had attended an SLD school, work experience placements were timetabled and planned through a voluntary group specialising in supported employment, and they were more consistent and longer-term.

‘[Younger son] it's a theatre and they do workshops and all... he went on a work placement there. [Older son] did a work placement with school... it was just a week somewhere.’ (Parent 14)

‘... It was the very start of probably the transition planning, it was quite early on there and they worked very closely with [organisation]. We were very lucky to have [organisation]... and they got some work placements and [son] would have been, probably the last two years going to [organisation] at least one day a week, to try to adjust to that transition even though it didn't work, but at least we tried. And he got various work placements and would have been supervised in those.’ (Parent 4)

In the literature review (BASE Volume 1) it was noted that success of employment placements depended not only on matching the skills of the young person to the position, but also on the support and knowledge in the workplace (Howlin, Alcock, & Burkin, 2005; Howlin & Moss, 2012). Parent 4 felt that this ‘joined-up’ approach was lacking in some of the placements for her son.

‘... [son] was stacking shelves somewhere and halfway through the job someone asked him to change and wipe the floor, and that was just a nightmare. In the work placements I think there could have been better autism awareness training around what stresses out people on the spectrum.’ (Parent 4)

The two older focus group pupils had engaged with work experience programmes and found them worthwhile, as noted earlier in the section on future employment support. After a disappointing earlier experience, one pupil found his subsequent placement very useful. Although the younger students (Year 11 and below) had not yet been on arranged programmes, they were clear that work experience should build on their existing skills and interests and would be useful for their future career development.

‘Well, when I was in fourth year I really wanted to be a journalist, so I went to the [local paper] ... they had me doing typing out, now it was really detailed type of stuff, not even a cup of tea after it, and then in year 12, a wholesalers, because I’m interested in business and so I went there and it made me think I’d maybe go into the business side of things, when I’m a bit older.’ (School 1 pupil)

‘... the job I’m wanting to get into, Northern Ireland, we’ve conveniently got [name] on pretty much everybody’s doorstep, in fact we drive past the headquarters to get here, so I think going for a job experience, say there, before I leave secondary school would be a good idea.’ (School 1 pupil)

The diminishing input of parents

For parents, communication with college, university or the workplace was much less structured than at school; in addition, once young people were considered adults, parents had very little input. For some parents this was not a major concern especially in areas where they feel their child was coping well.

‘For [younger son], the social side, [school] addressed all that for him, and he’s only been at the Tech for a year...and he’s quite... he’s a totally different social butterfly. But he’s socially strong enough to say ‘That’s what I want to do’, where [older son] would never do that, and I don’t feel the need, that I have to discuss his social skills with the Tech.’ (Parent 14)

However, some parents wanted continuing contact, and this was something which, while usually helpful, could also be problematic given restrictions on sharing information. They were used to a supportive role and had unique insights into their sons'/daughters' behaviours that could be helpful in post-secondary settings, which was appreciated by support staff. For one parent, where a voluntary group organised a placement this was viewed as a useful channel for dealing with problems, and also getting positive feedback about work issues; at times informal contact with staff was also viewed as useful.

'[organisation] were the intermediary ...it was all through them and they provide the disability awareness training ... but I have sort have done it myself indirectly just through going to events and chatting to the senior manager and explaining, so it's been fine but I have done it my own way.' (Parent 4)

Third level education

Three parents had children who had already left school and entered third level education or training. In general, they felt the supportive environment and the fact that the subjects were directly relevant to future career plans had allowed their children to achieve their academic potential. Further education colleges had been flexible when asked to take into consideration the needs of the young people with autism, and they had achieved well academically.

'[Younger daughter] attended [FE] College. She did 'Essential Skills' from home ... They asked 'what do you need' and she made a list and the College did every one of them. She could work at home, and she had separate rooms for exams, with her parents there. [Name of partner] did the Essential Skills course with her, and sat the exam with her... We have been doing 'unschooling', learning what the child is interested in.' (Parent 7)

Of the ten students who had responded to the survey on their experiences in third level education, the most commonly mentioned forms of support included technology (such as live scribe pens, laptops and software), financial support or help applying for financial support, and Asperger's tutors. Exam related support such as having extra time, alternative forms of assessment and having a separate room was reported by half of participants. A similar number also reported having a note taker or scribe. The majority of respondents felt that university/college had been a comfortable and worthwhile experience. When asked about what had made it comfortable and worthwhile, the main theme to emerge was *greater independence and meeting new friends*.

For the young person who had just finished his vocational course, the structure, and the availability of a mentor throughout the study and work period, had made the experience at university enjoyable.

‘The whole way through his training he had a mentor in the [team], there was one person he would go to, so this person would also have followed his report for uni, and he got one-to-one and got on really well with this mentor. So, he was supported in that as well, which everybody gets, so it seemed to be a good place for him too.’ (Parent 14)

Four of the adults with autism who participated had gone on to third level education and two had gone on to study for higher degrees. For all but one of the participants it was not an entirely happy or intellectually satisfying experience, largely because of the particular challenges with organisation, routine and social engagement which can be experienced by individuals with autism.

‘... then when I went to university that was another very difficult transition because again it’s a higher level of autonomy ... you organise your own study and plan that yourself...’ (Adult B)

As none of the participants had been diagnosed with autism at that point, there would have been very little effective support available, but two individuals had associated mental health problems which impacted on their work, and were not addressed.

‘... I was much more OCD and much more presenting as bipolar... very manic, in those days, so I kind of had nervous exhaustion three times and I did a lot of what on the face of it seemed weird things, like hiding most of my work from the tutors... So I got told off about that, and ... but they did like the work that I did, they just didn’t understand why I had hidden it.’ (Adult E)

Social skills in the real world

Once young people left school the opportunities for teaching social skills more formally (e.g. in small groups or in the classroom) diminished. Instead, they had to learn to interact with people in more naturalistic settings, and some needed parental support. Having come from a relatively well-supported school environment, students found that colleges and universities had fewer formal structures to encourage inclusion for young people with social skills needs.

‘It’s not like they’re saying ‘Oh let’s all go and have a chat’ like they would have done in the supported unit ... [younger son] still has no friends from college that he sees outside of college just yet... and I say to him. ‘You know, you have people in your class with the same interests. You should say ‘Why don’t we go out and do a bit of filming, or do you want to meet up for a cup of tea or a soft drink or something’, you know, and generate some friendship with people in your class.’ (Parent 14)

The majority of students who responded to the survey emphasised that the social side of starting a university or college course was the issue that had concerned them the most. One parent explained how difficult it was for her older son to fit in with his peers, particularly as his course was at a mainland university and involved a work placement. As he was not interested in joining 'typical' student activities, this further limited his opportunities for social interaction.

'Mixing with a new group of people. Making new friends. Having to move away from home and adapt to living with 'strangers'. (Student survey respondent)

'...[older son] just did not click with the rest of the students at all, and they'd be partying when he came in from work ... So the first year, social-wise, was horrible, I don't remember him meeting any friends from the halls or the uni... You know, when he finished his course, and he went out for a drink with the fellas from his course, and I think he would have done that twice in the two years he's been in [university] so it wasn't a regular occurrence. He doesn't like to drink...' (Parent 14)

Some however found the new opportunities for social interaction, along with increased independence, very rewarding and as noted above, many had found third level education enjoyable. Among suggestions for improving the experience for other students was that more social support from the institution would be useful in addressing initial difficulties they could face when settling in.

'The mixture of quasi-independent autonomy and large-scale socialising was a powerful catalyst for my own personal development.' (Student survey respondent)

'More student events which are autism-friendly. More support whenever an autistic student is moving into University accommodation for the first time.' (Student survey respondent)

A need for more support with the social aspects of university was something the adults with autism who participated had also identified as a critical factor in their experience, which for the majority had been unhappy and uncomfortable; for one participant, this led to further social problems.

'... then I began a PhD but... it finished early because I was starting to drink heavily, it was my fault, and my work wasn't good enough... that time, like many people with Asperger's, they want to leave because it's not working... it's terrible... I don't know, because of the social demands... I stayed in my room...' (Adult C)

Key points

The key features for positive experiences in education were close working relationships and good communication between parents and teaching and support staff, good staff training, knowledge and awareness of autism, appropriate structures and academic demands, additional supports, and peer group awareness of autism.

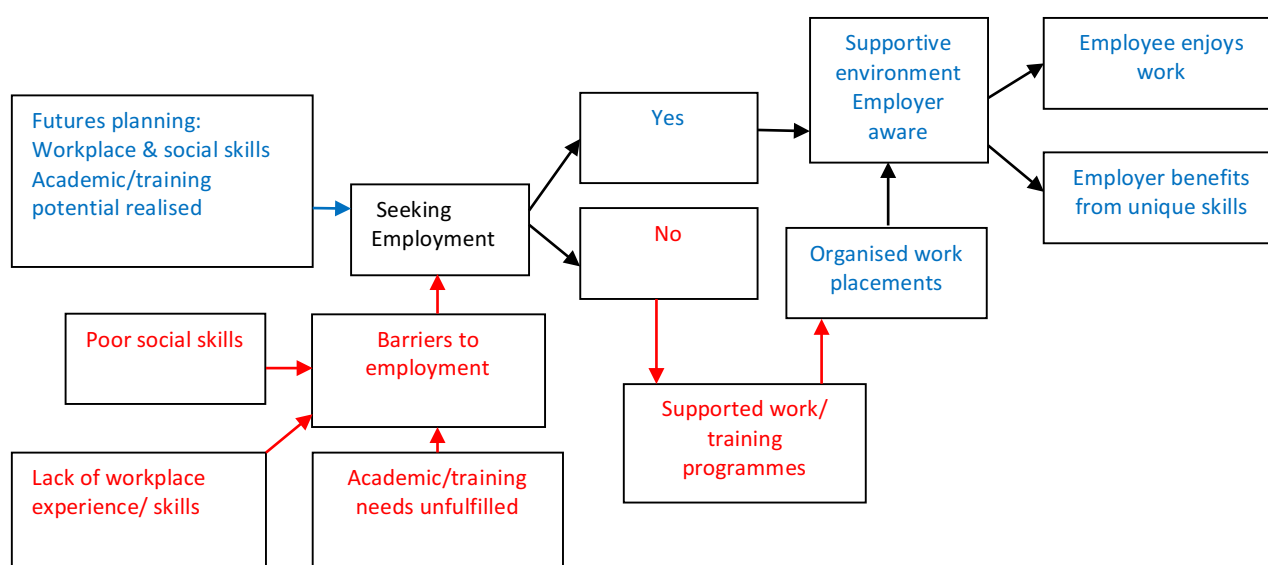
The major challenges for the education system concerned with lack of staff training, lack of resources, difficulties with interacting and focusing, and lack of educational staff skills in dealing with child behaviour challenges.

- The balance between academic achievement and life skills should be individually tailored for school students with autism.
- More autism training and support (where requested) for general staff is required, and good practice in SEN provision should be shared throughout the school.
- Schools should consider how their environment can best be adjusted to the needs of students with autism without necessarily incurring additional expense (e.g. provision of dedicated quiet study spaces and all students to have colour-coded timetables and a school floor plan which complements this).
- Schools, colleges and universities should consider instituting a ‘buddy’ or mentor system for new students.
- Social skills training should be tailored for the individual pupil/students and this should include a programme for generalisation of skills acquired in small group settings.
- Work experience at school, college and university should be arranged with appropriate support, if necessary from voluntary sector organisations with suitable expertise.

Chapter 6: Employment and quality of life

In this chapter, the parents, school children and young people with autism who participated in the study talk about their plans for the future, and adults with autism offer insights into the challenges and rewards of futures and career planning, work experience and employment, and daily living and quality of life. Figure 13 illustrates the pathways to employment which can help alleviate poverty and potentially improve quality of life for individuals with autism and their families.

Figure 13: Pathways to successful employment experiences



As their sons and daughters grow older, parents wanted them to move into the adult world with as many opportunities as possible, building on their individual skills and interests. Parents hoped their children would achieve some measure of independence, living and working with as much (or as little) support as they needed but acknowledged that finding the resources and services to make this possible was likely to be difficult. Young people with autism were optimistic about the future, and looked forward to leaving school or college and entering adult life in a variety of careers; half of them were considering moving away from Northern Ireland.

Participants identified the major barriers to employment as lack of autism awareness and understanding both in the application process and in the workplace; they felt there should be more emphasis for employers on the positive aspects of autism that individuals could bring,

such as attention to detail, enthusiasm, creativity and honesty. However adults and young people with autism who were at school or college had received very little formal support in making career decisions. Despite this, work experience was perceived as useful, and for adult participants in employment finding the right balance of support and challenge in the workplace had been rewarding.

Some of the parents expressed concerns about the sense of responsibility which would pass on to siblings as parents aged, but all anticipated their children could move away from the family home, although they realised that this might need to be accomplished gradually. They also realised that some of their adult sons and daughters with autism would need on-going support and mentoring as they remain vulnerable adults. Overall, parents felt there was a distinct lack of signposting from social services; any information they had acquired was through their own research on the internet or through contacts with parent support groups and other voluntary organisations. A number of young people in third level education and all the adults who participated were living independently, and the great majority of participants living away from a parental home had found they could manage financially, that is, they had enough money to pay for basic needs such as food, clothing, accommodation costs and heating. Adults with autism who had engaged with the benefits system had mixed experiences, with some reporting very negative encounters with staff and delays in payment while others had found staff supportive at times.

6.1 Futures and career planning

All the parents who participated were ambitious for their child's future, and the majority of parents found it easy to discuss career and other life options with their son or daughter. Parents of very young children felt that they really were not ready to start thinking about the long-term future, but they explored ideas about growing up through play and leisure activities. When talking about the future with older children the focus was often about educational stages and about planning the transition to secondary school or university.

'Oh yeah, we would talk through play I suppose. We would say, 'you are going to be a doctor.' You know it's very much dependent on what she is into at the time. Obviously she wanted to be a doctor for a while, and just really... [like] 'normal' children. Whatever tickles their fancy...' (Parent 11)

'Yes, we've talked to him about the choices for secondary school, and the reason that he

would choose them because of what he wants to do when he's older. I think it helps having [daughter] about and she's going to university and he's seen her go through [grammar school]... and I really would encourage him to think ahead, and not try to put any limits on what he will do.' (Parent 1)

Only a few parents mentioned that they had discussed 'relationships' with their children, but they expected them to have the same opportunities as their peers; the parent of young adults felt in her case it was also necessary to be very direct about sexual health. For the parents of a child at primary school, conversations about adult relationships were age-appropriate.

'You don't skirt around things, you know, especially when they started dating. [Older son] and [friend] would be walking out the door and I'd be shouting 'Wallets, combs, condoms!' and [friend] would laugh and [older son] would go 'Mum shut up!' I mean they're 18, 19, and it makes you sort of say 'This could happen.' (Parent 14)

'He does talk about getting married. He has a girlfriend who he's had from P1 and he's very distressed because somebody else has now said he wants to marry her too! So, he thinks very much ahead of himself and gets himself in a tizzy.' (Parents 9&10)

For a minority of parents, talking about the future was difficult, especially if the prospect of major changes at home was broached as parents got older. They said that most of their sons had very fixed ideas of what the future should hold and were unwilling to consider alternatives. For one parent this caused a lot of distress, made more difficult by the limited possibilities for future provision.

'No, it's hell, it's hell! Because he actually usually walks out of the room; because he doesn't want things to be any different... But you can't promise things that may not be able to happen and it breaks my heart. We talked to him a wee while back... (respondent got upset and interviewer suggested a break or moving on). It's okay, please, [they] need to know how hard it is. I even drive around town and think that would be a good location for him. I just want to know where and who is going to look out for him. His name has been down on the [Housing Executive] list for nine years.' (Parent 4)

School children with autism who participated talked confidently and with ambition about their future plans. When they completed their current studies, the majority of the pupils intended to go on to either Further Education (FE) or Higher Education (HE); a number of pupils saw FE college as a stepping stone, either to a career or to university. The courses they wished to follow demonstrated their wide range of interests and skills. Half of the pupils planned to leave Northern Ireland, either to study or to work abroad.

'I would probably want to move away somewhere yeah. Apparently over in Scandinavia

the colleges are free so that's something, maybe go over to Germany as well because I have a bit of a soft spot for Germany... I am already learning a slight bit [of German].' (School 2 pupil)

They had different reasons for doing so; some had family connections that would be helpful in their careers while others had spent time abroad and decided that Northern Ireland offered them fewer opportunities, due to the economic or political situation. They all had firm ideas on a future career path.

'[Name of NI university] are good, however, they're about a half hour drive from here which is my only problem with going... this country is somewhat of a shambles, I don't want to stay here any longer than I have to, frankly.' (School 1 pupil)

6.2 Developing skills and gaining employment

Having meaningful employment that provides a regular routine and generates self-esteem was an important factor in moving towards independence. Figure 13 above illustrates the issues identified on the path to employment for individuals with autism.

Planning a career: The majority of parents who participated felt their children had definite ideas about a future career based on individual interests and skills. For their children who were still at school or college, career interests included architecture, computer programming, retail (in a computer store), equestrian training, photography, science, engineering, and film-making.

Academically, she's very intelligent. She has 3 paths open to her: horses, graphic design and photography. She could have her own studio here. She is interested in 'Intelligent Horsemanship'. She will be self-employed.' (Parent 7)

'[older son] wants to go to Cambridge and study aeronautical engineering. We know that now, so we'll help him build those things in, if we can.' (Parent 12)

Planning a career involved the development of skills and qualifications. Two young people wanted to learn to drive a car; one of them wanted to learn to drive as he planned to work for a Pizza delivery chain. Learning to drive was also something many of their peers in secondary school were talking about. Autism in itself is not an automatic barrier to driving. Disability driving assessments and information on specialist instructors are available in NI¹³

¹³ For details of the range of services from the NI Mobility Centre, see <http://www.disabilityaction.org/services-and-projects/driving/>

and obtaining a driving license is a major step in achieving independence and also opening up career options.

‘He wants to learn how to drive. This is a new thing. It’s because everyone his age is talking about them kind of things.’ (Parent 13)

In terms of a career, all pupils had definite aspirations and were planning their futures quite clearly, both in terms of university or college courses and work experience, making use of their skills and interests. Their chosen employment areas were diverse, ranging from media-related careers to entertainment (drama and music), hairdressing, computing, business and engineering. None of the focus group participants had sought or been offered careers advice from their schools, although the younger participants in School 2 were aware of the provision, and expected to have some contact in the next academic year, as noted in Chapter 5. The majority of the pupils intended to go on to either Further Education (FE) or Higher Education (HE). Interestingly, two of the pupils also wanted to be involved in counselling and autism support at some point in the future.

‘I just want to be an entertainer, because I like making people smile and laugh.’ (School 1 pupil)

‘...I would like to have something to do with counselling so I would like helping people with problems because that’s something that I ...just the feeling of knowing that you have helped someone to do better with their life, it’s just something that you can’t really experience anywhere else.’ (School 2 pupil)

While the majority of FE/HE students who completed the survey wanted to undertake further study or gain employment after completing their course, only three reported being offered any employment advice. Most students felt that it would be useful for them to gain further skills to help them when they enter the job market, and two had part-time jobs. When asked about what specific skills would be useful, the main theme was a need to improve their social and communicative skills, and also to acquire practical experience.

‘How to deal with handling the tasks required in a new job. How to interact with those who are in authority... How to get used to working in a full-time job.’ (Student survey participant)

A number of parents were very positive about the skills some young people with autism could bring to the workplace. Two young people were already in work, one part-time and one moving into a full-time capacity after training and they enjoyed their jobs. Both parents and adults with autism stressed that employers could benefit from the individual skills of those with ASD but were not always aware of this.

‘They don’t know the strengths that people with autism have and the benefits of having people with autism in certain job roles would be. Like the scientists, and forensics, and all these sort of things where it’s a very black and white, either it is or it isn’t sort of response or whatever. People with autism would be fantastic, so suited to those roles.’ (Parents 9 & 10)

The adult participants with autism also felt they could bring something positive to the workplace. They identified a number of positive employment skills, such as intense focus on detail that would benefit those who employ adults with autism. Participants considered that having autism should be seen by employers as an advantage in many aspects of work, rather than focusing on perceived or expected deficits. Strengths they mentioned included compliance with good employment practices such as honesty, punctuality, diligence and attention to detail and also the ability to discern patterns and linkages that allows them to deliver solutions to problems.

‘I do think it’s important to recognise and celebrate the things that are positive about Asperger’s, the fact that we are people who are honest, sincere, hardworking, diligent, and yes, there are blind spots and things you need to look out for, but on the whole I think people on the spectrum have a lot to offer.’ (Adult B)

Both of those individuals who were still seeking work would be keen to develop a career based on their interest in IT; they had completed additional training and had been involved in volunteering programmes using IT skills while they were looking for a job.

‘In the meantime I am volunteering for a charity. I fix computers. One of the psychiatrists said to me ‘Even if you are autistic, you need social contact’, and it keeps me busy. It’s good all round, because they like to work on filing systems. I can do things that are interesting for me and it can be useful. If I go to work in an IT company, it is good, you know.’ (Adult C)

6.3 Barriers to employment

Many participants were also aware of some of the barriers faced by people with autism when they went to look for jobs or training opportunities, that either lay with the employee or the employer. Work placements allowed participants to gain experience that increased the chances of gaining employment.

Employee based challenges: Some parents recognised that there could be practical problems when their sons or daughters with autism were applying for jobs; the process itself included having relevant experience, filling in application forms and taking part in interviews and therefore could be challenging even for the most able young people with autism. For those with learning disabilities or behaviour issues, obtaining employment or work experience was viewed as even more difficult because employers would be concerned about managing people with such problems in the workplace.

‘How can you go into an interview with autism, how can you? I know, Down Syndrome, it’s visible and you are going to be nice to somebody with Down Syndrome, and if you see them in Sainsbury’s you go ‘aren’t you doing a great job’ and all this here, you know and you are nice to them. Somebody with autism, you expect them to be ‘normal’, that’s the problem.’
(Parents 5 & 6)

‘I know some other parents have found it difficult to get their kids work experience ... without being obvious about it, there’s definitely an apprehension to take on those, particularly those with behavioural difficulties, fearful about what they’ll do, I suppose’
(Parent 1)

Actually getting through the initial processes of application and interview, rather than in maintaining the job, was also considered one of the main challenges to finding work by adults with autism. They felt perceptions by employers, a narrow focus on generalist attributes and the actual stresses of taking part in the interview process (even as part of work experience) were significant barriers.

‘Probably getting to the [job]... some questions for instance. They ask a lot about social performance, you know? They ask ‘How would you work in a team’ ... and I did that more or less but for me, I know I focus on a different aspect of things.’ (Adult C)

‘We had to take part in mock interviews. That killed me! I didn’t do well in those at all.’
(Adult D)

For another individual who was seeking work, the challenges lay primarily with his physical health, and the resultant possible strains on capacity for any employer. The workplace itself was considered a challenging environment for individuals with autism. Parents were aware that the social demands of dealing with colleagues or the public could be particularly difficult.

‘My [physical chronic condition] is one of the first challenges, then probably the autism as well. I can appreciate from the employers’ sides, like the last job I had, there was five members of staff. Because the operation needed five members of staff, so you don’t employ as sixth person as a ‘spare’... I mean bigger organisations to a degree can get away with it, but on the whole, no-one really does any more, like they used to years ago, just taking on people.’ (Adult A)

‘I think it depends, obviously, if her social skills still aren’t that great, I would worry about her in employment, you know. I’ve heard about a lot of schemes, different schemes that are run for employment, so I suppose we would look at those but I suppose it depends on how she does with her skills. I think there can be barriers but it depends on how severe the autism is.’ (Parent 3)

For adults with autism, good communication, understanding and flexibility in employer attitudes were seen as key factors in providing a supportive working environment. Where work support was provided, placements needed careful consideration of individual skills to be successful and again, good communication between all parties. Two participants worked in the public sector and found this a very supportive environment. Strategies could be employed to negotiate work challenges, if necessary through a support worker, and overall, they enjoyed their jobs

‘Yes, I enjoy it- work have been supportive... management are supportive. The panic attacks are in our ‘contract’ and [employment support worker] checks up on it- sometimes things need clarified- she’s in touch with my line manager’. (Adult D)

Certain aspects of the work proved particularly challenging, but participants were confident that in general they were able to negotiate appropriate adjustments with their employer and address specific issues, e.g., by changing their working routines or placement.

‘I really don’t like confrontation, but sometimes when you are responsible for delivering things and other people have competing agendas you have to be quite assertive and forceful and that. I can do it but it takes a lot of energy to do it...I try to manage my time in such a way that if I know I am going to have a difficult meeting in the morning, I will have an easier afternoon.’ (Adult B)

Employer-based challenges: Half of the parents who participated identified the lack of awareness and understanding of employers as an area that was likely to prove a barrier for sons and daughters with autism not just in acquiring any job, but one which was meaningful and which reflected their capabilities. Focus group pupils were generally optimistic about their career prospects, as noted above. One pupil did worry about the potential of discrimination against individuals with autism in the workplace, with employers offering preferment to other employees.

‘I would assume that because so many people I have come across have very little understanding of autism, employers would be the same... about sort of doing jobs that are very maybe demeaning and low paid. They all have something that they can bring and the barrier there is autism, and people maybe don’t look beyond that, you know and there are lots of things...’ (Parent 2)

‘...one thing that actually concerns me quite a bit... is the fact that people may be discriminated over by employers as well as employees. Like say you do a higher quality of work than someone who doesn’t have autism, although they could potentially be picked over you solely due to the fact that they don’t have autism...I think that’s something that could potentially happen and may already happen in the world...’ (School 2 pupil)

Employment support had proved useful to those participants who had availed of it. This type of specialised support (offered by voluntary groups) works best when there is a good match between the skills of the employee and the demands of the job; one adult with autism with a Master’s degree who is currently unemployed had been disappointed by the low expectations of an employer when he was placed on a work scheme for people with autism.

‘...it was a laptop repair shop, because one of my interests it was IT, computers, but they did nothing to make me feel included... I’m very interested in the technical spec of things, ... I like to work with an open source system, something called Linux [but] ...people see computers like a black box... they just want to push the buttons ... and the way they speak to me... ‘No [name], terminate the computer, brush the floor’... I’m probably exaggerating, but...’ (Adult C)

Subsequent placements were more successful, and were supervised by a specialist occupational therapist; although the part-time and short-term nature of these positions does not help build up a particularly useful CV for future job applications, the participant saw this in a positive light as steps towards a full-time paid position and raised self-esteem.

One participant was self-employed, which perhaps is a route that is not commonly pursued by individuals with autism and for which there is little statutory support, but it has been rewarding, and one in which he is fully in control of the outcomes.

'I basically found a job where people would tell me what they want ... and then they would leave me alone... and I could get on with it [laughs]. So doing [craft] is very good, you know, I'm an expert in it... it's all controlled and I don't get any paradoxical situations... I like the fact that I'm in control, with it, and it's definable, and then occasionally there's... you get a moment where what you do far surpasses what people expect, and they come in and go 'Wow' and then, that's great. (Adult E)

One of the issues discussed in the previous chapter was school support and direction for future careers; parents had noted where schools were encouraging particular aptitudes in their children, but a number felt that the careers advice and transitions support was lacking. While the focus group participants had felt their work experience (which they arranged themselves) was useful, none of the year 11 or 12 pupils had seen a careers advisor, as noted earlier.

Of the five adults with autism who participated, only one felt that he had been given sufficient transition support for his future career options. The others had compromised with their post-school choices, either to please parents or because they had been set on a course which directed them to university without referring to their own interests.

Any careers advice was very general, and as none of the participants had been diagnosed with autism at that point, no account could be taken of any specific needs in third level education or employment.

'They were all concerned about university, and pushing you that way- you found that in a grammar school- they didn't address 'normal' jobs. My sister went to secondary school and did typing- you weren't supposed to be a secretary, you were meant to be the boss.' (Adult D)

'The careers advisor teacher was just hopeless, that was the start of it, you kind of got the feeling he ended up doing that because nobody else wanted to do it. He knew nothing about any, you know, vocations in any detail. He was just basically saying 'Oh if you want to be a lawyer you'll need Latin and you'll need history', or 'you want to be a chemist you'll need chemistry, and maths.' and that's basically all he did' (Adult E)

Work experience placements: A supported work placement offered one young person with more severe disabilities further training opportunities; computer training in particular had proved not just useful but enjoyable outside the workplace. The voluntary organisation

supporting the placement had worked closely with the family for a number of years, and the parent felt confident that they would help her son make the most of any future opportunities.

*‘...he did a computer course at [FE college] and he really enjoyed it, it opened up the world of computers to him because before he wouldn’t touch them, so that helped him a lot with that... There was a time when [name of organisation] were keen for us to go to some initiative where he increased his work hours and he would have got more training to work his way up the organisation, which is a lovely idea in theory but in practice there was nowhere for him to work up to... he is happy, he is really happy doing what he is doing ...’
(Parent 4)*

Employment: Fully paid employment clearly is the aim for most young people who have completed their school education and further training. It is an important factor in helping vulnerable people out of poverty and social exclusion. While it may not be possible for all adults with autism to gain fully paid employment most adults with autism are able to be employed at some level. Two employment case studies, based on in-depth interviews with employers, showed that given suitable support systems employment does not have to be an elusive aim for adults with autism, and the options can be much wider and more stimulating than traditional centre-based activities.

In the employment settings that are described in the case studies, adults with autism carried out a range of jobs in a supportive environment and had the opportunity to engage in employment which also benefitted employers. For those with more complex conditions (such as additional learning disabilities), initial support needs were high, but over the course of the employment this was gradually reduced (see Appendix 9 for full details of all interviews).

Case Study 1 combines the views of two from the same industry sector (rural development).

Case Study 1: Rural development project

This was a cross-border rural development project offering employment experience as an alternative to day care for adults with learning disabilities or mental health problems. Owners of two rural businesses in the pilot scheme, who offered placements of one day a week to a total of six adults with autism, took part in interviews.

Reasons for offering employment opportunities

- Value-led decisions based on personal and/or professional knowledge and understanding.
- Owners had researched the background to current provision for adults in Northern Ireland
- Examples of good practice in Republic of Ireland and mainland Europe
- Natural continuation of traditional rural community practices of inclusive employment and social responsibility.
- May enhance opportunities to maintain existing social networks in rural communities

‘Very, very disappointed with what was available in Northern Ireland ...all of the people on (name of project) had autism and we’d seen how happy they were... We thought, right we will try and replicate it for others and particularly then in the longer view for our [family members].’

Recruitment

- Worked closely with Health and Social Care Trust services and voluntary sector providers
- Matched interests and skills of the individuals to each placement.
- Assessment process identified individual support needs, and ensured these were met.
- Work was meaningful and grounded in the everyday life of the business
- Range of activities which improved work skills and enhanced social and independent living abilities

Adjustments to the working environment

- Need for accurate, on-going risk assessments tailored to the individual
- Clear planning structures and visual strategies when appropriate
- Provision of a slower working environment and allowing time to ‘de-stress’ if required.
- Structuring the working day and addressing behaviours due to deficits in social skills.

Positive aspects

- Very positive personal impact for families, neighbours and the individuals who participated
- Fostered a sense of inclusivity in the wider community
- Development of the project could have longer-term economic benefits for businesses in rural areas

Negative aspects and future barriers

- Autism was not a barrier or limitation to employment in itself
- Project did not meet full economic costs to businesses
- Emotional impact of project termination on the participants, with nothing similar to put in place
- Restricted capacity of individual businesses to expand, as there was limited extra work for individuals
- Rural transport infrastructure was not designed to meet participants’ future placement needs

Employing more people with autism

- More strategic approach from government departments, to deliver meaningful day opportunities
- Opportunities should be clearly signposted to allow more people to become aware of their options
- Financially support individual choices through increased provision of Direct Payments
- Increase the numbers of small businesses taking part, rather than turning into large enterprises

‘The scalability of it. If you want to get the central statistics office for Northern Ireland and look how many [rural businesses] there are and you scale that out, and that’ll tell you how many day opportunities could be offered.’

Case Study 2 is based on an interview with a long-standing employer of individuals with autism in the science and research sector.

Case Study 2: Scientific research centre

Case Study 2 was an organisation with a distinguished history within the Northern Ireland Culture, Arts and Leisure sector, offering public access as well as maintaining an international research facility. Two individuals with autism undertook work experience placements for one day each week.

Reasons for offering employment opportunities

- For the benefit of the person with autism, rather than the organisation directly.
- In fulfilment of the overall departmental goal of increasing therapeutic work experience
- Beneficial in helping to fulfil charitable status objectives

Recruiting individuals with autism

- Organised through voluntary sector organisations
- Does not recruit across the spectrum as work demands skills in communication and administration
- Preparation for placements is the responsibility of the voluntary organisations
- Individuals carry out a number of specific administrative tasks matched to their interests and abilities
- Tasks have to be meaningful and contribute to the overall work of the organisation.

Opportunities for staff to undertake further training and qualifications

- Offers a range of training for all staff, but no specific programme for individuals on placement
- Autism training for other staff not currently in place, but organisation is considering this in future.

Adjustments to the working environment

- Very few adjustments necessary; the only concern for both placements was their mobility
- Need for more supervised, structured working practices than would normally be in place
- Projects had to be planned carefully to meet the specific needs of individuals

Positive aspects

- Extra work undertaken increases the capacity of the organisation
- Benefits in the contact between other staff members and the placement individuals
- Regular work routine and sense of inclusivity for the individual with ASD.

Negative aspects and future barriers

- Individuals do not yet have the skills to work completely independently
- Supervision can be an issue if the allocated staff members are absent
- No external funding available
- Placements are limited by the absence of a designated member of staff

Employing more people with autism

- Adjust regulatory employment requirements, interviews in particular would be an obstacle for individuals with autism.
- Specific funding in place, and dedicated staff roles to optimise benefits for individuals and for the overall work of the organisation.

'...it would have to be able to 'wash its face' in the full economic costs sense, so salary and other costs would need to be met... you could create genuinely useful positions and their 'employment' then becomes a more virtuous circle. But it would be essential to employ a member of staff with the background interest and experience.'

6.4 Daily living and quality of life

Obtaining gainful employment is a key factor that helps vulnerable people move out of poverty and social exclusion. However, there are a number of other factors of daily living that contribute to independence and overall quality of life, such as deciding on appropriate accommodation, finding available accommodation, and financial and statutory support.

Deciding on appropriate accommodation: Inevitably, as parents grow older and their own situations change, staying in the family home may not be an option for some adults with autism; others will wish to move out and live as independently as possible, perhaps with families of their own. Participants identified issues that they felt could present barriers for independent living for people with autism.

Parents who participated wanted to see their sons and daughters with autism settled in a house or flat of their own. The majority of parents had children of school age and therefore had not begun to explore housing options in detail, although a number of them had thought about the future living arrangements of their sons/daughters with autism. Most parents felt this was a challenge their children would have to meet in the future and that it would take some preparation.

‘I would like for him to be as independent as possible, and we work on that a lot in the house... ‘That’s another step towards my independence Mummy’. ..It’s maybe a bit soon for me to judge where that would be but I would really hope he would be independent in his own place, maybe somewhere with a warden to start off with, and then hopefully on his own.’
(Parent 1)

For those with other sons and daughters, there were concerns for some parents about how they would feel about taking on a supportive role when their sibling was an adult. While parents appreciated this was a natural concern for their other children, they were concerned that siblings felt that they would be automatically expected to take on the role, although if they were able to be part of a wider support network this would be welcomed.

‘...I know my eldest son has had this concern. He actually spoke to my GP about this just after [younger son] was diagnosed. He is kind of jumping ahead to the future and thinking what happens when [son] is older and anything happens to mum and dad. ‘What if I am married, where does that leave me? He is my brother and I’m the oldest and I would want to care for him and help. But, what if you are married and have a family of my own. What if your wife doesn’t want that?’ **(Parent 2)**

Three parents had children who had left school and they had all begun to explore the options available for independent living. One young adult was already living away from home, although his mother did feel he and his brother would continue to need more support than others of their age. Another parent had already made firm plans to provide a home for her daughter by building a new house for the rest of the family next door.

‘I expect them to develop, naturally. I’d expect that to be the next step for them, like everybody else, you know. They’d maybe be home a bit longer. I’d maybe go visit them more than anybody else’s mammy might, if they needed it, at the start...’ **(Parent 14)**

‘We have a plan- we will get her to be independent, she will live here and we will be next door.’ **(Parent 7)**

Three of the ten students in third level education who participated were living in independent accommodation, but the majority were living in the family home and travelling to attend their courses (something which is not unusual for many ‘typically developing’ students in NI).

All the adults with autism who participated lived in standard housing; two rented their homes through the same publicly funded housing organisation, and three owned their own houses. Three participants were parents of school-age children and shared their homes with the children and a spouse. Of the two who lived alone, one was divorced and the other was single. For the majority of participants, their accommodation suited their needs, and while there might be certain aspects that they would like to change, overall they were happy with where they lived.

‘I’m happy here, but the accommodation is a bit small. These were built for two persons ... We know that because the bathroom wall had been moved a few years ago to create a second bedroom, so these aren’t designed [for a family].’ **(Adult A)**

‘It’s OK... I’m not glad, but grateful. It’s not much but it’s home. Because you know, I met people [living] on the streets, and they say you don’t want to do that, because it’s terrible.’ **(Adult C)**

The situation is more complex when a young adult has learning disabilities that make independent living problematic. Planning the right level of support, and trying to locate accommodation which is tailored for her son’s specific needs, has been very difficult for one parent. The type of accommodation needed is not readily available; her son has been on a

Housing Executive list for nine years but gets no priority. This parent drew attention to the need not just for accommodation but for the expertise of a supported housing provider.

‘... It’s the general social housing list that the Housing Executive have, with no knowledge of their requirements, or their needs. There is absolutely no sense to the way that they send every year this blanket form to everybody on the social housing list... The type of accommodation that [son] would require, there is one such property where there is a little enclave and there would be some flats, a couple of houses with maybe 3 or 4 people in it. But it’s not available... You would have to be very careful who he would share with and I think that would be a big issue... and then to have an organisation that has a great deal of understanding, because the bricks and mortar is the least important thing.’ **(Parent 4)**

Finding appropriate accommodation: Some parents expressed concerns that accommodation tailored to the needs of young people with autism was unlikely to be available when their child needed it. A number of parents were aware of excellent specialist provision for those with other conditions, or within other Trusts, but there seemed to be no overall regional plan for the type of accommodation which would be suitable for adults with autism.

‘Because I haven’t looked into that I’m not really sure, but again I assume maybe there is not enough support out there to allow... I mean, I work in mental health and we have several different types of accommodation where people with severe mental health problems can go and live independently and they have excellent support coming in there to allow them to do that. I don’t know if that is available for people with autism. I would probably tend to think it’s not.’ **(Parent 2)**

Parents were aware that certain criteria would have to be met to apply for housing in the future and this may exclude their sons/daughters. Again, the implementation of an IQ threshold does not take into account the support needs of individuals with autism who do not have severe learning disabilities.

‘...the health and social care[should] have to provide the numbers and that includes people with Asperger’s who badly need supported housing as well and they have to broaden it because it’s not just people with social workers... I know some people who have got Asperger’s who didn’t meet the IQ criteria for getting a social worker... they couldn’t exist on their own, they would need supported housing, and with the Autism Act that has to be considered as well so they need the numbers, they need forward planning.’ **(Parent 4)**

Financial and social support: Some parents were concerned that supported housing options would be expensive; in particular, individuals with autism may find it difficult to share accommodation with others who are unfamiliar to them. It was felt that that this would place a limitation on availability. These parents were not aware of available supported living

options which were specifically planned to increase inclusion or reduce the possibility of bullying or harassment, although one parent had followed up the issues through her own research and had discovered a lack of planning for suitable housing. A number of parents felt that young people with autism living away from the family home could be vulnerable in social situations and that neighbours and casual acquaintances could prove unhelpful or even unpleasant.

‘I suppose there’s always the barriers of funding. There seem to be places like that, but it’s finding a place on them. I suppose with their funding they can only take a limited amount of people, so it’s finding a place, and finding somewhere she’s be happy, so I suppose those are the big issues.’ **(Parent 3)**

‘... But maybe if there was enough there, you could feel easier about that and again it would be that social thing. Other people living around... You would worry that they would be maybe teased by children in the area or even older people. They would be aware that this person... There is something wrong they will maybe not know what it is but there is something wrong there, and you know it does happen unfortunately.’ **(Parent 2)**

‘It’s been shown in lots of research that people with learning disabilities can’t really integrate into the social housing complexes and they very often get bullied and harassed, so it needs to be planned separately for those with supported housing and you are not talking big numbers. You are talking small numbers but with huge housing needs and there is no planning. The Housing Executive don’t know the numbers and very few housing associations are really thinking learning disability, so it’s just not happening.’ **(Parent 4)**

Most parents had very limited contact with benefits agencies, although all were familiar with the application process for Disabled Living Allowance (DLA) and some had found this quite difficult. Adults with autism felt the attitudes of public sector staff and the flexibility of services were seen as generally falling short of best practice. Of the five participants with autism, two received no benefits on their own behalf. Three received DLA and they also reported that they received Employment Support Allowance (ESA) or Incapacity Benefit; two received Housing Benefit, but there were problems with the regularity of payments.

‘Incapacity Benefit is the main one, and then I’ve had DLA at the low rate of care... and I’ve had high rate of mobility, which I’ve swapped for a car so I can get about... at the moment we get full Housing Benefit, but it keeps changing every couple of months... our income doesn’t change but our help constantly changes and we get ... it gets stopped quite regularly.’ **(Adult A)**

Those who had contact with the benefits system reported mixed experiences. Three had found benefits advisory or voluntary group support helpful, particularly with filling in forms, either for themselves or for a child.

‘No, I got help... I was living in a hostel, there was a social worker, and they contacted a benefit advisor ... I was on Income Support, and switched to ESA... [assessment] was a bit intimidating, which is why I received good advice from the benefit advisor... it’s very blunt...but I think if you are in genuine need, then generally it’s ok.’ **(Adult C)**

For others the process was more problematic. These participants had a very clear understanding of the departmental regulations and to them it seemed benefits staff at times did not appear to either understand or follow their own guidelines, communication was poor and decisions on payments seemed arbitrary. When challenging or questioning decisions, two participants reported they had found staff hostile or obstructive at times

‘...they do not understand their own rules, and I had to send them the information four times. One of those times I went into DSS¹⁴ and handed it in to a person , you know, over the counter and I went over and said ‘Hello’, and she didn’t speak ... that’s not normal. I just thought, maybe she’s having a bad... maybe something’s happened ... I just put it to one side and carried on, and said what I needed for her to fax these things, and as I went out I thought ‘She’s not going to do that’ , and lo and behold, they couldn’t find the documents. I sent them four times, they stopped my benefits for 6 months ... so I ended up [in debt], it’s supposed to be a safety net for people.’ **(Adult E)**

Overall, the majority of participants with autism considered they were able to manage financially. One participant felt that her financial position was better because the skills associated with autism increased her employment opportunities.

‘I think I am in a better job than I would have been if I didn’t have Asperger’s. I am the only member of my family who made it into third level education. They did a lot better socially but they didn’t do well in exams and it limited their options in terms of work prospects.’ **(Adult B)**

They regarded financial management as a priority, especially when relying on state benefits, but generally found this a challenge they were well-prepared to meet by careful budgeting. Those who were not in paid employment were able to cope financially although it took careful money management to make ends meet.

‘When you are on benefit you have enough money for food, to pay for the gas. You go to the shop to buy food, yes, it’s a tight budget but I look out for bargains. Then I cook, and I can save a lot of money! For instance, I stopped smoking and I don’t spend on booze...If you are on benefits, you have to take time to look for the best bargain. It’s interesting because I have time to do that, if I was working, I wouldn’t have the time.’ **(Adult C)**

¹⁴ ‘DSS’ (Department of Social Services) is used by participant as an abbreviation for ‘Jobs and Benefits office’

The only participant who reported financial issues (Adult E) had recently experienced family problems and had considerable difficulties in communicating his situation to benefit officers, as noted earlier. This held up the full assessment of his entitlement for six months and he could not afford to heat his home in the winter.

‘...I don’t really know at the minute whether I’m OK or not. At the moment my outgoings exceed my income. I am building up a debt but I don’t see that there’s any other way forward. I ran out of money last year, [voluntary organisation] got me some oil at one point.’ **(Adult E)**

Statutory support: None of the parents had been offered any advice on planning for the future from statutory agencies. In part this may have been because very few had regular contact with social workers. Social workers are the gatekeepers to many additional services; therefore, lack of contact with social services meant lack of access to services. Some parents actively sought out relevant information by attending conferences, training sessions, voluntary support groups and researching on-line.

‘I think, looking after [son] over the years I’ve come not to expect it. If I have an issue, I look it up first, find out where I can go, and then ask. I would have had to seek it out myself. I’ve been to Transitions conferences and different things. I’m involved with a local autism charity. I’ll go to as many as they offer me and I have the free time to do it. So, I’ve contacted quite a few agencies, find out what they’re offering, in this area.’ **(Parent 1)**

The majority of adults with autism who participated did not have access to regular formal support by statutory or public sector services, although in some cases this was due to the fact that they did not request such help. For others, help at a critical time was not available, e.g., a family where both parent and child had a diagnosis of autism or a parent who had a physical disability remained unsupported due to inflexibility in the cover of such different support needs. This family also reported unsatisfactory communication between health and social care service providers and themselves.

‘When [son] was, I think, 6 months at the most, my back was playing up. [Wife] was down with the flu. We got in contact with Social Services and said ‘Look my back’s gone, I can’t do anything, whatever. I’ve a child here needs help’. ‘Oh there’s nothing we can do, to be honest the most I could do is come out. Although that won’t be for a few days, and we’re not allowed to touch your child.’ **(Adult A)**

Not only that. Children’s services said ‘It’s not our remit’, adult services said ‘no, that’s not our remit either’. **(Adult A’s wife)**

Adult services are at a very early stage of development with Trusts and the majority of the adult participants could not rely on the level of provision which might be expected through Children's services. This places an additional onus on families and voluntary organisations to fill the gaps; the majority of adult BASE participants could call on some informal support from family, friends or neighbours if needed, and all had contact with voluntary organisations or support groups which helped with advice and practical support at times.

Key points

- Greater access to futures planning and improved signposting to services is required (achievable through the model of current Adult Autism Advice Service (AAAS) pilot schemes)
- Transitions services and careers advice should be provided by teachers or agency staff with specialist autism training
- Co-ordinated planning (using up-to-date prevalence figures and research on social integration) needs to be in place for specialist housing options to meet future needs
- Difficulties with social interactions and relationships recognised by the Autism Act (2011) as a disability should pertain to social housing provision in terms of availability, inclusion and personal safety, rather than IQ thresholds alone
- Benefits staff should have more appropriate and targeted autism awareness training
- Autism training for social care providers should include awareness of the 'trans-generational' and multiple needs within a household
- Employment regulations should be flexible enough to accommodate the specific needs of individuals with autism during selection procedures
- Employer awareness training should focus on the benefits as well as the challenges of employing individuals with autism
- Day opportunities for adults currently delivered from specialist centres should include more work placement options
- Supported employment providers should receive autism training at a minimum of Level 2.

Chapter 7: Discussion

This report (BASE Project Volume 4) focused on the findings from the qualitative phase of the project, including focus groups, interviews, and/or surveys with young people and adults with ASD, caregivers/parents of individuals with ASD, educationalists and health care staff, policy makers, and employers. A total of N= 848 participants were included in this phase of the research.

Findings reported here reflect findings from the literature review reported in BASE Project Report Vol. 1, the quantitative research reported BASE Project Report Vol. 2 (general population survey) and BASE Project Report Vol. 3 (secondary data analysis). When findings were triangulated across the qualitative and quantitative findings of the overall BASE Project a relatively coherent picture emerges. Data from BASE Project offer a baseline that pinpoints some of the most important issues related to helping some of the most vulnerable individuals and families out of the poverty trap and reduce inequality. This baseline leads to benchmarks that can be used to develop policies, strategies, and services for individuals with Autism Spectrum Disorder, including intellectual and neurodevelopmental disabilities (cf. BASE Project Vol. 5).

Autism awareness was found to be good across the general population (BASE Volume 2) and this was reflected also in the views of members of most professional groups who responded to the BASE surveys, apart from public sector staff, where autism awareness was less than half of that in the other groups. It is likely that the relatively high levels of autism awareness in the other groups was due to personal experience with people with autism, as over half of the population knew someone with ASD personally (BASE Vol. 2). It seems likely that high-profile autism awareness campaigns carried out by major international and national charities (e.g., such as the iconic *Autism Speaks* ‘Light it Up Blue’ events) and a number of campaigns by local charities have also played their part.

Autism awareness amongst education staff who responded, was over 80% reflecting the same levels of awareness of the general population (BASE Project, Vol. 2). Half of the educationalists, health care staff, and policy makers knew someone with autism personally, consistent with NILT data showing that 51% of the general population knew someone with autism personally (BASE Report Volume 2; Dillenburger, McKerr, Jordan, et al., 2014). However, public sector staff autism awareness was 40%, less than half that of the autism

awareness in the general population (82%; see BASE Report Volume 2; Dillenburger et al., 2013; Dillenburger, Jordan, McKerr, & Keenan, 2014). Therefore, this research suggests that any further autism awareness should be focused on specific groups in the public sector, such as front-line staff.

Staff training: Where it existed, staff training was of the most basic level (i.e., Level 1), equating to 1-2 hour talks about ASD, rather than adequate professional training. Of particular concern was the lack of any relevant or significant autism related behavioural skill training for teachers. Although the great majority of teachers who responded were offered training by their employers, this was only to Level 1 (general awareness) for most and specialist behaviour support (where available) had to be sought by staff themselves from external providers (e.g., Universities), when needed for dealing with increasing numbers of pupils with ASD in mainstream settings.

Lack of teacher training in ASD and behaviour management meant that individually tailored evidence-based teaching programmes that rely on data-based decision making (e.g. behaviour analysis based educational practices) generally were not available and pupils experienced restrictive ‘one fits all’ approaches e.g., picture schedules or basic structural methods adapted from the TEACCH approach (Ospina et al., 2008), which has been widely adopted in NI since a license for training was granted to Autism NI in 1997 (Autism NI, 2014).

A recent study (Dillenburger et al., 2010) indicated that there seemed to have been little development in relation to behaviour analysis based practices in the statutory sector, since the Task Group Report on Autism (DENI, 2002) identified the aspiration for expansion in this area by stating ‘when parents seek support for such a service the boards are dependent on external providers and have not taken steps as yet to become self-sufficient in this respect’ (DENI, 2002, 3.21). The parents interviewed in the present study who used behaviour analysis based intervention programmes for their children (n=4) had sought support from the voluntary sector; in one instance, the family had taken legal action to pay for and continue the programme within their child’s school.

None of the GPs who participated had availed of autism training, although the number of responses from GPs was too small to make generalisations about autism training amongst these professionals. Responses from policy makers are not reported here as they could potentially be disclosive. These findings are consistent with a recent exploration that found

very low levels of training in ASD in qualifying training in multidisciplinary teams, especially for speech and language therapists, occupational therapists, psychologists, psychiatrists, social workers, and educationalists (Dillenburger, Röttgers, Dounavi, et al., 2014).

Despite this extremely low level of ASD related training, educational professionals generally enjoyed the ‘challenge’ of working with pupils with autism, and loved the ‘quirkiness of the personalities’ of the children in their care. Not surprisingly, professionals made clear recommendations how training delivery and content should be matched to their needs and the needs of the service users. They felt that autism related training should be integrated during initial teacher training (ITT, e.g., in PGCE) and that it should not just focus on autism awareness, but focus on teaching practical skills. They thought that there should be more information of where to access training, e.g., many were not aware that Universities offered training in ASD at undergraduate and postgraduate/Masters levels. Participants proposed that more direct skills training was required, e.g., how to manage and support individuals with autism, and generally wanted training to have greater depth, coverage and be delivered more frequently.

Advanced training, such as that offered by both Universities in Northern Ireland (e.g., MSc in Autism Spectrum Disorder at QUB; MSc in Applied Behaviour Analysis at both QUB and UU), was neither included in the *Autism Strategy* (2013-2020) nor in the *Action Plan* (2013-2016). It was therefore not surprising that this was not signposted to professionals working in the field who were seeking training despite the fact that staff were keen to avail of more advanced training, specifically ASD related behaviour skill training, and that University training costs compare favourably with other training providers.

Autism diagnosis: Diagnosis was key to identifying those with the greatest potential to be most vulnerable to poverty and social exclusion. Approximately 100 children were diagnosed with autism every month in Northern Ireland (in 2014). However, this is around 50% of those referred for assessment every month (n=200). The other 100 children who are referred for diagnosis were either put on a watching waitlist or assessed as not autistic. The children placed on the watch-and-wait list are of great concern as they are losing out not only on potential early intervention but also on financial support. As such they are particularly vulnerable to poverty and exclusion. Early and timely diagnosis could be achieved through outsourcing diagnostic services to the private or voluntary sector. This is a practice that has proved very successful in Southampton, where the Autism Diagnostic Research Centre

(shortlisted for the National Autistic Society's Award for Clinical Excellence in 2013-201; <http://www.adrc.co.uk>) accepts direct referrals through the NHS and other sources. In NI, strict criteria for diagnosis are available in the Six Steps to Autism Care and the Adult Care Pathway developed by RASDN and would be need to be adhered to by outsourced providers.

The majority of parents and caregivers identified early concerns about their children, well before they were diagnosed with autism. Delays in obtaining a diagnosis worried many parents. Parents of girls with autism were concerned that there was a lack of recognition and skills in diagnosing ASD in girls. Due to delay in diagnosis, early interventions were not available. None of the statutory bodies in NI offered early intensive behaviour analytic interventions that are considered medically necessary 'treatment as usual' in the USA (Surgeon General 1999) and Canada (Motiwala, Gupta, Lilly, Ungar & Coyte, 2006). These interventions are based on over 40 years of international research, evidencing transferability to the UK (Remington et al., 2007; Grindle et al., 2012) and Northern Ireland (Elliott & Dillenburger, 2014; Keenan, Henderson, Kerr, & Dillenburger, 2005). There is evidence that lack of these services has detrimental long-term outcomes in the UK (Howlin, Goode, Hutton, & Rutter, 2004; Howlin, Savage, Moss, Tempier, & Rutter, 2014).

Yet in NI, these services are not available in the statutory sector and those who seek behaviour analysis based interventions are referred to the voluntary sector. In fact, parents of children with autism are more knowledgeable about applied behaviour analysis (ABA)-based interventions than professionals (Dillenburger, Keenan, Doherty, Byrne & Gallagher 2012).

Most adults with autism in this study had sought diagnosis based on having an experience with another family member with autism, i.e., often after their own child was diagnosed. Generally, the adults with autism who participated in the BASE interviews were not satisfied with delays in the statutory diagnosis system, and two out of five had sought a private diagnosis. Adult women with autism had even more difficulties getting diagnosed than adult men.

Adults with ASD did not necessary expect services following diagnosis. In many cases, they wanted the diagnosis to help them 'explain' life experiences and problems they had in the past. Many of the adults with autism had unhappy memories of school days. They felt unsupported, not included, and bullied at times. They thought that many of their teachers equated good grades with good performance, regardless of lack of social skills or unhappiness. Adults with autism recommended buddy systems and improved teacher training

to help pupils with autism succeed within the school system.

Early intervention: Early intervention is a key recommendation not only in the Autism Strategy but also in the recent review of health and social care (DHSSPS 2011, 2013) and in the framework for addressing social exclusion (OFMDFM 2012). It is widely acknowledged that improving health, well-being and life opportunities as soon as possible will produce the best outcomes in later life (ibid.), and for children with autism in particular, this should reduce the need for support services in adulthood. Early intensive behaviour analytic interventions, such as those recommended internationally, that are based on extensive research evidence were not available in the statutory sector in Northern Ireland. This stands in stark contrast to USA, Canada, and Norway, where behaviour analysis-based interventions are considered ‘treatment as usual’ and are widely available through statutory health and education sectors.

Although the Six Steps Pathway to Care outlines the provision of ‘tailored interventions’ as a guiding principle (RASDN 2011, p. 5), and includes Early Intervention programmes in Step 5 in the care pathway, it did not define what constitutes an effective intervention, and includes ‘ASD information sessions’ among ‘interventions’. Clearly, there is a big difference between once-off ASD information sessions offered by the Trusts (usually 1-3 hours) and early intensive (usually 15-40 hours per week), long-lasting (usually 2+ years) behaviour analytic interventions (Cooper et al., 2007).

A recent report into community services indicated that parents of children with autism expressed concerns overall about ‘access to, coordination of and continuity of services’ (Regulation and Quality Improvement Authority [RQIA] 2014, p.4) and noted deficits in autism intervention services, which contributed to unmet need. Parents who participated in interviews for the BASE project felt that they had received very little statutory support and many relied on voluntary group or peer support; those who had implemented tailored early intervention programmes had done so through an autism charity or not-for-profit organisation outside the statutory sector. Not surprisingly in Northern Ireland, both parents and pupils were more ambitious for good educational outcomes than most teachers or healthcare professionals (cf. Lamb, 2009). Positive outcomes were achieved when parents were in a position to privately fund diagnosis and early behaviour analytic interventions, or to support work placements or FE/HE training. Most students with ASD lived at home and thus availed of parental as well as college-based supports.

Parents experienced difficulties in communicating with professionals and at times were frustrated with professional ‘hostility’, when looking for answers. Lack of availability of professionals who were well trained in ASD heightened the emotional impact of diagnosis. These findings confirm earlier findings from a needs assessment of families affected by ASD that was conducted in Northern Ireland, prior to the Autism Act (NI) 2011 (Dillenburger et al., 2010; Keenan et al., 2010; Munteanu & Dillenburger, 2009) that found that the needs of families affected by autism were not met adequately in Northern Ireland.

Education: All teachers who responded to the survey had contact with children with autism; two-thirds of them on a daily basis, the remaining one-third less frequently; nearly a quarter of other ELB staff had daily contact, while just over two-fifths (43%) of ELB staff had no contact with children with autism. Yet the majority of these teachers had not received any autism training higher than Level 1 which equates to listening to a 1- or 2- hour talk. Many had received no autism training at all. Classroom assistants had more training in autism than teachers, although this training was also restricted to Level 1.

For young people with ASD, teacher and staff awareness and knowledge about ASD was important, however teachers’ knowledge about subject areas was equally important and academic and creative challenges were enjoyed. Friendships within peer groups were the major contributory factors for positive school experience and specific special needs pathways led to more positive experiences, especially in primary school. Having autism made children vulnerable to bullying in mainstream schools more so than in special schools. The children’s hobbies were the same as those enjoyed by other children, such as playing musical instruments, ranging from drums to guitar, computer games, social media and other technology, going to the gym and to football matches and going out with friends.

Transitions into secondary school were supported through visits to the new school, peer education about autism, and teacher support. None of the children with autism aged 14+ recalled having engaged with the Education and Library Board Transitions team and career advice was perceived as not useful. Generally, they felt that peers and teaching staff tended to categorise people with autism in a very uninformed and stereotypical way, using ‘standardised’ approaches that were not always relevant to real-life situations. Both the children and the parents who participated were much more ambitious for the future than many of their teachers/career advisors, as evidenced in their enthusiasm to enter third level education after leaving school.

Further and Higher Education: Over half of FE/HE staff had no contact with individuals with autism. Only 1/10 of HE/FE staff had professional contact with a student with autism on a daily basis. The majority of the ten Further and Higher Education students with ASD who responded to the survey lived at home with their family. They considered good support networks and support structures, friendliness and inclusivity as important. Disability support facilities offered through colleges, such as live scribe pens, note taker, laptops and software, financial support or help applying for financial support, Asperger's tutors, and exam related support were important to their success at FE and HE.

Students with ASD who responded said they enjoyed the improved independence and social life that came with FE and HE. Work-related placements were particularly welcomed and they felt that more employment -related skills and training, especially to improve social and communicative skills, were required. Four of the five adults with autism who participated had entered higher education and while they felt that they could meet higher education demands academically, socially many failed. The majority reported that they had found the experience very stressful, and one participant consequently dropped out of a PhD programme.

Employment: For some of the adults with ASD, gaining and maintaining employment was difficult and work placement programmes were considered worthwhile. For those in employment (whether in the public sector or self-employed) work was enjoyable. Most of the adults with autism were content with their housing situation; the majority of participants found they could manage their finances although those on benefits found it could be a challenge at times, and two had experienced serious delays and poor communication when dealing with benefit claims.

Employers of adults with ASD saw the advantage of employing individuals with autism for the individual, other employees, and business. They realised that employing an individual with autism could demand considerable additional time commitment. In the short-term employers stated that they were prepared to 'go the extra mile' to employ individuals with autism, however this was not feasible in the long-term without being resourced. The Case Study participants found the employment support provided from statutory or voluntary organisations was a key part of a successful placement, as they felt they would not have the resources or expertise to identify and meet additional support needs, although over time, the need for this should diminish. Future development of workplace opportunities could be enhanced by resourceful use of personal budgets; this could provide adults –particularly those with additional needs- more meaningful choices and life-long learning opportunities.

Employers were keen to help and offer work experience for adults with ASD. They saw the benefits and as such findings reported here concurred with findings from the NILT survey (BASE Project Vol. 2), where 12% of respondents said they would shop more frequently in businesses with an explicit policy to employ people with ASD. Employers also saw the demands that employing someone with ASD placed on them in the longer term and were realistic that they may not be in a position to offer employment unless this was externally resourced. Obviously, the level of support needed depended on the level of ability of the individual with ASD, and that is also dependent on their education. Of particular relevance is the need for adequate life-long education and training opportunities for individuals with co-existing learning disabilities or complex needs. Post-19 support (i.e. for young people leaving SLD schools) is an area of concern, and parents report a sharp-often unsupported- transition into adult services which are generally much poorer than those for children (Post-19 Lobby Group 2013). This issue was raised by one parent in the interviews for this report, and also by two of the case study employers, particularly in respect of the day opportunities provision for adults with autism, funded by HSC Trusts.

Transforming Your Care (DHSSPS 2011) sets out the aims of a person-centered programme to augment-and where possible, replace-day care offered within purpose-built centres (p.95).

The post-consultation document '*Transforming Your Care: Vision to Action*' (DHSSPS 2013, p. 84) sets out a number of key proposals for service improvement for individuals with learning disabilities (which can include some who also have autism). These include improved access to a wider range of respite options (Key Proposal 2), increased uptake of 'self-directed support and individual budgets' to allow greater choice (Key Proposal 3), the continued development of 'creative and age-appropriate day opportunities to promote independence and choice, such as access to employment, leisure and educational activities' (Key Proposal 4) and enhanced 'involvement of carers in care planning and service planning to bring their experience to bear on these functions' (Key Proposal 5). Findings reported here support and extend these aims. However, they should not result in a limited set of options drawn up in lieu of traditional institution-based care but provide meaningful choices based on the interests and building on the skills of the service users themselves- who, given the opportunities to articulate those choices, want to experiment and re-assess their long-term goals as much as any other individual (Dillenburger & McKerr 2014).

Conclusion

The Autism Strategy (2013-2020) and Action Plan (2013-2016) clearly identified strategic priorities for all Departments. It is clear from this research that at baseline (prior to the full roll out of the Autism Strategy), a ‘joined -up’ process was not in place and international best practices were not utilised.

There is no doubt that the prospects of individuals with ASD are intimately linked from early diagnosis to early intervention through to schooling and employment. Where this is effective, young people leave school ambitious and skillful, and ready to enter the job market (with appropriate support, where needed). Although no accurate employment figures are available for individuals with autism in Northern Ireland, reports from elsewhere suggest that unemployment rates are high (Rosenblatt 2008) and a guide for employers by the NAS (2011) estimated that there were some 17,000 people with autism in NI, of whom 15 % were in employment. Obviously enabling employment can be regarded as one of the best ways to *help the most vulnerable out of the poverty trap and reducing inequality*; the government Social Inclusion Strategy has recognised that ‘work is the best route out of poverty for people of working age’ (OFMDFM 2006, p.11), and improved ‘Employability’ is Strategic Priority 7 of the Autism Strategy. Increased independence (both financial and social) can lead not only to positive outcomes for individuals with autism, it releases parents and carers from responsibilities which have held them back in terms of a career (for a discussion of parental employment figures derived from the Millennium Cohort Study, see BASE Volume 3) and enhances the well-being of the whole family.

In Northern Ireland diagnosis was delayed, early intensive behaviour analytic interventions were not available through statutory agencies, and the burden of care lay firmly with parents, who had to actively research autism services, primarily drawing on peer networks rather than statutory advice. Despite their best intentions, most teachers were not adequately trained and therefore ill prepared for inclusive practice with children on the autism spectrum. University based advanced ASD training was not signposted to staff.

Ultimately, it was not surprising that few adults with ASD who responded were in full-time gainful employment. Official employment statistics for individuals with autism are not available in the UK, because a question on autism does not feature in employment surveys (Dillenburger, Jordan, & McKerr, 2014). However, there is evidence that employment

prospects of individuals with autism (and those of their carers) are limited and can vary considerably depending on factors such as autism specific symptoms, variations in economy and the nature of support being received (Howlin & Moss, 2012; see BASE Volume 1 for a fuller discussion).

In order to optimise the life chances of individuals with ASD in Northern Ireland and help them out of the poverty trap (or ensure they do not enter it), a holistic joined-up approach is needed that is based on evidence-based practice. This should be delivered by a well-trained workforce and targeted to empower people affected with ASD and their families with the skills necessary to lead fulfilled lives.

Recommendations

The following recommendations emanated from the qualitative research findings. In the present economic climate, it should be recognised that many require additional resources (or more effective use of resources currently available) and implementation will be a matter for individual departmental consideration.

Recommendations regarding diagnosis

1. Early and timely diagnosis should be made available more widely to avoid delays in intervention and benefit support for families vulnerable to poverty and social exclusion;
2. Adult diagnostic services should be available more efficiently; necessary resources should be available in all Trusts;
3. Care Pathways should include triage systems for those on the waiting list for urgent need as many intervention services are not offered until a diagnosis is obtained;
4. A more expedient solution may be to outsource triage and diagnosis to the voluntary or private sector (see Adult Diagnostic Research Centre in Southampton; <http://www.adrc.co.uk>); a cost-savings analysis should be conducted to aide decision-making.

Recommendations regarding training

5. Autism training should go beyond autism awareness; the minimum departmental requirement specified in the Autism Strategy (Strategic Priority 1) and where appropriate for staff and carers, the focus should be on practical interventions and skills training, e.g., how to manage and support individuals with autism; this should be facilitated in-service by Boards and Trusts who already have the options to access or 'buy-in' training and by DEL through the Universities;
6. University-based autism training should be endorsed and commissioned as key qualification in autism for education and healthcare staff, and information on such courses should be widely available through employers (e.g., HSCTs, ELBs and DENI);
7. There should be more information on where to access training, for example by featuring this regularly on staff intranet/ communications.
8. In order to improve accessibility, training should be accessible on-line (e.g., Northern Health and Social Care Trust; QUB and UU courses);

Recommendations regarding education and intervention

9. Early intensive behaviour analytic intervention programmes should be embraced as evidence-based practice by the statutory sector; NB: although some health and education professionals already draw on behaviour analytic principles, for example in parent training and managing challenging behaviours, very few are trained to the international standards to deliver behaviour analytic, individually tailored intensive interventions (cf., www.bacb.com); alternatively, these specialist services could be outsourced to the

voluntary or private sector, although this would require additional resources; a cost-savings analysis should be conducted to aid decision making.

10. Autism support groups (both for academic and social skills) should be made available in school;
11. Awareness programmes should be offered to all pupils at school to promote inclusion and reduce bullying; autism related training should be integrated during initial teacher training (ITT) (e.g., in PGCE);
12. Courses (which include peers without autism) should be made available specifically for life skills and relationship skills, preferably on school premises;
13. More flexibility for the 'spectrum' of needs; schools should avoid a predominant 'one-fits all approach', i.e., visual schedules are not needed by all children with autism;

Recommendations regarding employment and quality of life

14. Employers should be aware of, and focus on, the potential for specific skills of individuals with autism; employer specific awareness training should be promoted by DEL/DES;
15. Self-advocacy for adults with autism should be made available, i.e., ask what they want, not make decisions for them. This should be mandatory practice for all adult autism service providers and can be delivered at no extra cost after relevant autism training;
16. Employment support can provide job stability and enhance self-confidence, and uptake of specialist support programmes should be targeted for increase by DEL/DES through their on-going strategies such as Access to Success/Pathways to Success and the proposed Economic Inactivity Strategy (as noted in Strategic Priority 7 of the Autism Strategy);
17. Specialist groups for women with autism should be made available to offer effective support, if necessary by offering 'seed funding' and/or advice (including support for suitable external funding applications) for establishing these through HSCT adult autism services;
18. Access to specialist autism counselling/advocacy service should be made available; for children this should be accessible through school referrals and on school premises where possible, and for school leavers aged 16-19 years, this should be available through the HSCT adult autism service.
19. Policy makers should listen to parents. They are the people who know what they need, but many parents who are involved in the day-to-day care of their children with autism do not have the time or energy to respond to lengthy consultation documents or join committees. Opportunities to contribute to strategies should be offered by a variety of means (including on-line forums, Twitter and Facebook) as well as the input from committed user groups organised through the Autism Strategy;
20. Personal budgets/Direct Payments should be allocated so parents/individuals with autism can plan/decide on flexible services tailored to individual need. This is already identified as a key action for HSCB/HSCTs in the Autism Strategy (Strategic Priority 3), although within the policy recommendations for Transforming Your Care, the need for structural support in implementing any increased uptake has been emphasized.

Technical detail

Survey results

Valid responses

Respondents were excluded from the survey analysis if the respondent:

- 1) Clicked disagree on the electronic consent page; or
- 2) For the majority (over 75%) of questions selected ‘prefer not to answer’ or provided no response. The exclusion of this type of response pattern was designed to eliminate people who were ‘testing’ the link before distributing.

Table 9: Valid and excluded survey responses

	Total responses	No consent	Prefer not to answer/missing responses throughout survey	Valid responses
HSCT staff	645	16	56	573
GPs	7	0	1	6
ELB staff	58	1	8	49
Teachers	52	1	7	44
Public sector staff	22	0	10	12
Policy makers	15	0	9	6
Private sector staff	32	1	8	23
FE & HE staff	100	1	14	85
FE & HE students	16	0	6	10

Suppression of small values

Government Statistical Service (GSS) survey guidance recommends that where small values exist (i.e. 1 or 2) then the whole row of data should be suppressed to protect the personal data of individuals. This policy has been adhered to in this report, and where this has been done the data values in the row are replaced by ‘-’. Consistent with the GSS guidance where it was possible to combine categories containing small values instead of using suppression this was done instead.

‘where the sample size of a total or subtotal is one or two, suppress the whole row to which the total refers, including any zero cells (or combine neighbouring categories)’.

As this policy generally only affected the presentation of data where response levels were low, this also provides a degree of quality control.

SOC 2010 coding for FE/HE and HSCT respondents

The majority of FE/HE and HSCT trust respondent job titles were coded under the most relevant SOC 2010 minor code. However, as there were a number of SOC 2010 minor codes for administrative jobs these were combined and recorded under the SOC 2010 major category, ‘Administrative and secretarial occupations’. SOC 2010 minor codes that were less common and could not be aggregated under a higher level SOC 2010 major group category were combined and recorded under an ‘other’ category.

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Appendices

Appendix 1: Methodology

Recruitment and sampling

Purposive sampling was used (i.e., non-random selection of particular groups whose experiences were directly relevant to the research questions; see Teddlie and Yu, 2007). Participants with ASD and their carers were recruited using agency and voluntary sector contacts as gatekeepers, and snowballing methods were also applied. This process was aided by consultation with Steering Group members, stakeholder groups (e.g., autism charities) and statutory organisations, such as relevant Departments. This sampling methodology applied to individuals with autism and their families, as well as to employee/employer/service provider/policy maker surveys. Gatekeepers were approached from organisations such as Health and Social Care Trusts, government departments involved in the Autism Strategy and also voluntary and private sector organisations with a focus on disability (see Table 1.1).

Table 1.1: Direct gatekeeper contacts for BASE project

Gatekeeper	Number of organisations
Autism and carer voluntary organisations and networks (including social media)	9
Educational institutions and professional bodies	12
Private sector professional/workplace organisations and specialist groups	11
Public sector governance and professional organisations	18

In total, 50 gatekeeper organisations were approached, of which 47 agreed to disseminate information to members/colleagues. Of these, a number were ‘umbrella’ associations; a further 34 organisations or institutions were allied with the parent organisations. In addition, a short presentation was made to an employers’ group.

Individuals with a diagnosis of autism and their principal family caregivers were recruited through contact with autism and carer’s organisations and networks, including those at Further and Higher Education institutions. Inclusion criteria specified that participants had

the capacity to give informed consent and also possessed a basic proficiency in the English language (NB; budget did not allow for translation cost). Individuals whose first language was not English, or who used an alternative communication strategy (such as sign language or Picture Exchange Communication) were invited to take part, where unpaid facilitators were available.

The use of the term ‘child’ or ‘children’ in interviews was qualified, where appropriate with terms such as ‘school-age’. In parent interviews, where offspring were aged 18+years, reference was made to ‘adult sons or daughters’.

Service providers and policy makers were identified by contacting key gatekeepers in policy and service management from relevant government departments and agencies, particularly those concerned with employment, inclusion, and education. This included all Departments engaged in the Autism Strategy Group (e.g., Department of Health, Social Services and Public Safety, Department of Education, Department of Employment and Learning, etc.), the five regional Health and Social Care Trusts (Belfast, Northern, South Eastern, Southern and Western HSCTs), the five regional Education and Library Boards (ELBs) and General Practitioner (GP) organisations. Distribution of the relevant survey link by HSCTs and ELBs was subject to their research governance regulations. For the HSC Trusts, this required a very time consuming and complex application through the Integrated Research Application System (IRAS), despite the fact that the survey was not seeking patient information.

Employers and employees were recruited from major employer organisations and through employer groups provided by ASD and disability groups or charities. A number of case studies were used to examine in detail job placement schemes and projects for individuals with autism. As well as compiling information on participant’s profiles, job preparation and support systems, employers from these schemes participated in a short semi-structured interview to explore the role of management in creating effective placements. For reasons of confidentiality organisations, groups, or charities from which participants were recruited were anonymised, i.e., given identification numbers.

Educationalists were recruited from schools and other educational organisations through professional bodies and staff intranet/media links. For reasons of confidentiality institutions from which participants were recruited were anonymised, i.e., given identification numbers.

Sample size

As in any qualitative research, participation was voluntary and therefore due to self-referral. Although theoretically, sample size should be limited at the upper end by ‘data saturation’ (i.e., the point at which no new themes or data will be observable) in practice this can be difficult to determine accurately in advance (Guest, Bunce, & Johnson 2006). Actual sample size in each category is displayed in Table 1.2.

Table 1.2: Sample size ranges

Category	Total
Individual interviews (face to face and self-completion) <ul style="list-style-type: none"> • Focus groups participants: n=8 • Individuals with autism and their carers: n=17 interviews (19 participants) • Educational professionals: n=12 	N= 37
On-line questionnaires: <ul style="list-style-type: none"> • Employees and further education/training and higher education staff: n=108 • Individuals employed in Government departments participating in the Autism Strategy (e.g., DHSSPS, DE): n=18 • Students in FE/HE institutions: n=10 • Individuals employed in provision of education and health and social care services such as Education and Library Boards, teachers, GPs and Health and Social Care Trust employees: 672 	N= 808
Case Studies (Individual interviews): <ul style="list-style-type: none"> • Managers of job placement for individuals with ASD: n=3 interviews (4 participants) 	N=3
Total participants	N= 848

Research Tools

The main research tools consisted of

1. Semi-structured interviews;
2. Questionnaires (alternative interview format and on-line surveys);
3. Focus group schedules (see appendix 10 for full version of various research tools).

The tools were developed specifically for the purpose of this research and were based on previously used research tools (Dillenburger et al., 2013, 2010; Keenan et al., 2010). All tools were based on best-practice guides for qualitative research design. Peer review feedback was requested on all research tools from the BASE advisory group, which included service users and a voluntary sector provider, and where specialist advice was applicable, from the Autism Co-ordinators of the five regional Health and Social Care Trusts and from GP advisors. Furthermore, feedback from local and international scientific advisers as well as the relevant OFMDFM Project Committee was integrated.

All research tools were pilot tested and no changes were necessary. The interview schedule for adults with ASD and the carers of individuals with ASD were altered (plural was added) to allow for joint participation by spouses.

Following advice by Further Education/Higher Education (FE/HE) gatekeepers, the relevant focus group questions were adapted to an on-line survey (SurveyMonkey), and the link was distributed by the gatekeepers.

Research procedure

Individual interviews (face to face and self-completion) were conducted by both researchers, either in the participants' home or office, whichever was preferred. All but three interviews were –audio-recorded; interviewers made contemporaneous notes in lieu of recording and all were subsequently transcribed.

On-line questionnaires were posted on SurveyMonkey. Links were distributed to gatekeepers who then circulated the link directly to their staff or members either via emails, staff newsletters, or online, using staff intranet services. Trust and ELB governance procedures

were undertaken before these organisations agreed to distribute information about the link to their staff. A reminder was sent after a couple of weeks to encourage responses. Online questionnaires were open to be completed up to an agreed deadline date. The deadline was extended by 3 weeks to allow for delays in receiving governance approval from some Trusts.

Individual case studies interviews were held in the organisations and lasted 1 -1 ½ hours each. Two were audio-recorded, (by request one was not recorded) and subsequently transcribed.

Risks assessment for participants

Overall, there was minimal risk for participants and they were informed that they could withdraw from the data collection process at any time, without any adverse effects. For service users and their families, questions covered topics such as diagnosis as well as employment, financial circumstances, social relationships and assessment of services they receive. Responding to such questions should not be distressing but may be regarded as potentially intrusive. If individual interview questions appeared to cause distress, participants could either discontinue the interview or leave out a response to the particular topic. Where applicable, the questionnaire alternative gave the option of ‘prefer not to answer’ for all questions, none of the participants requested this. For service providers, there was minimal risk as the questionnaire/interview was primarily auditing existing services and autism training, and asking for suggestions for improvement.

Risks assessment for researchers

Personal contact with participants was conducted in safe environments; individual interviews took place at an arranged time and place that was logged by the researchers (i.e., text message sent to team leader at beginning and end of interview), and two interviewers were present. Interviews within education institutions were carried out by researchers individually. Focus groups were carried out in a venue agreed by the gatekeeper organisation and logged by the research team.

Researchers were briefed at team meeting prior to the onset of the fieldwork; at these meetings, ethical and personal safety issues, as well as fieldwork practicalities were discussed. De-briefing occurred at these regular Team meetings during the fieldwork phase;

if any issues had arisen that distressed the interviewer(s), staff counselling was available through QUB Human Resources (Occupational Health and Safety). No such issues arose.

Appendix 2: Gender and age of participants in on-line autism awareness and training survey

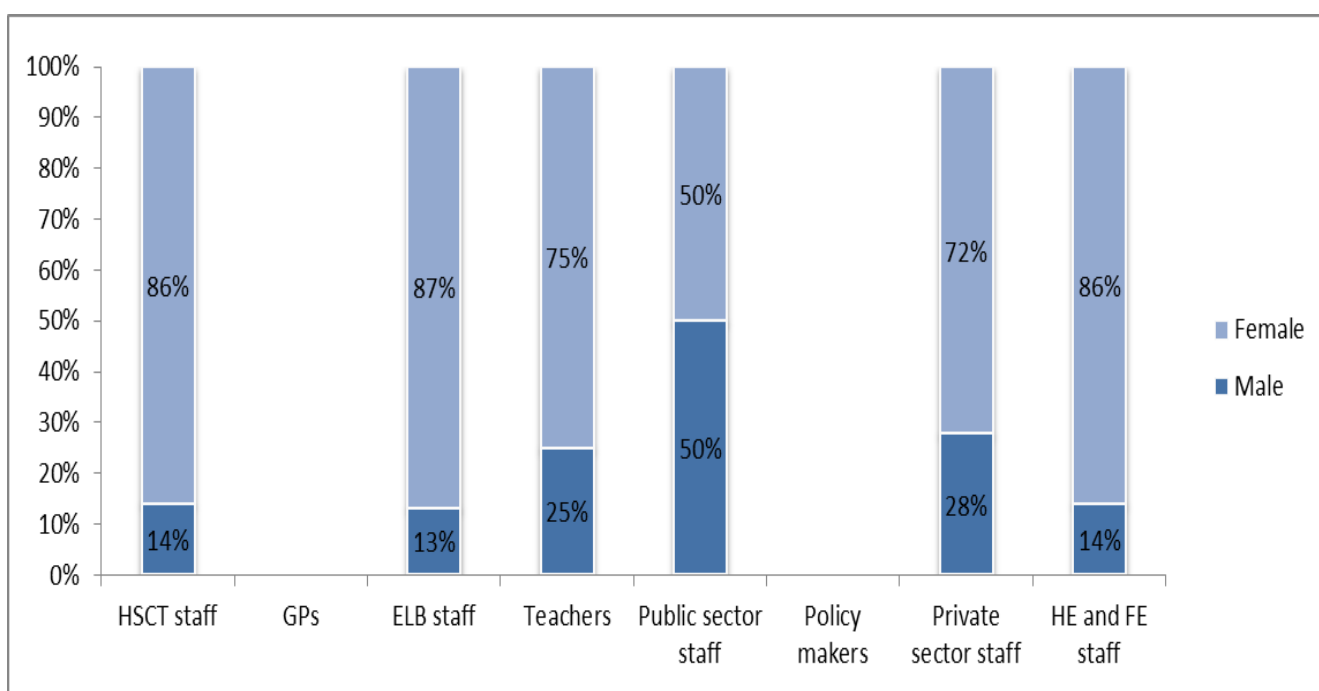
NB: Some questions were not compulsory and not all respondents answered all questions on the survey. This is indicated in results for individual questions.

	Gender ²		Age (years)	
	Male	Female	Average	Range
HSCT staff	61 (14%)	372 (86%)	41.37	18-65
GPs ²	-	-	45.50	-
ELB staff	5 (13%)	33 (87%)	43.62	25-60
Teachers	9 (25%)	27 (75%)	43.24	27-63
Public sector staff	6 (50%)	6 (50%)	42.90	26-58
Policy makers ²	-	-	-	-
Private sector staff	5 (28%)	13 (72%)	43.86	26-58
HE and FE staff	8 (14%)	49 (86%)	39.84	24-59

¹Proportions are calculated with prefer not to say/missing responses excluded.

²Cells suppressed due to small values for personal information – denoted by a dash.

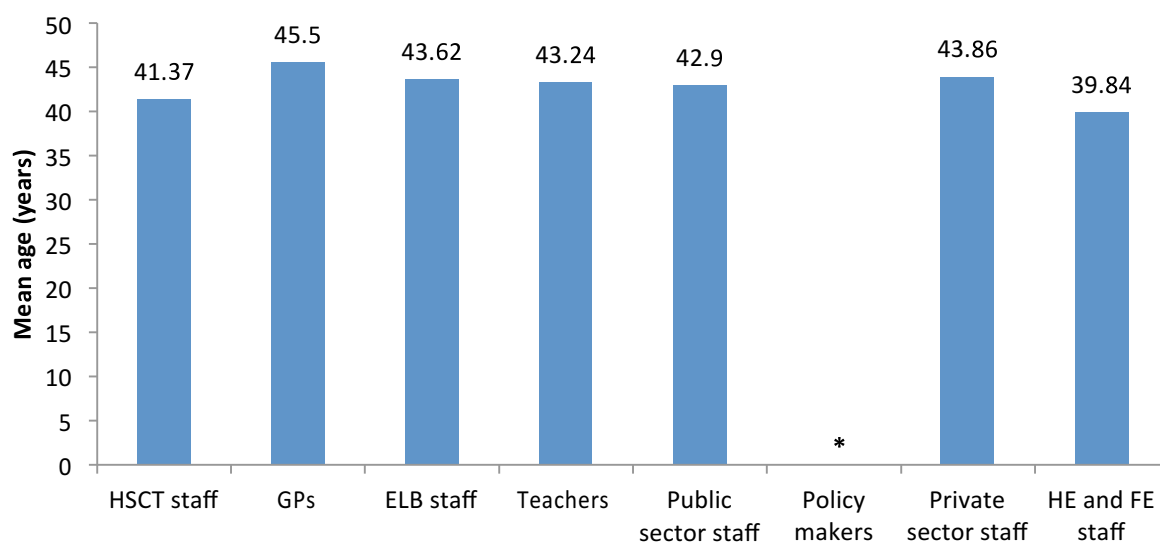
Figure 2.2: Gender breakdown of the professional groups



¹Proportions are calculated with prefer not to say/missing responses excluded.

²Cells suppressed due to small values for personal information – denoted by *.

Figure 2.2 Age breakdown of the professional groups



¹ Cells suppressed due to small values for personal information – denoted by * .

Appendix 3: Occupational breakdown for FE/HE respondents

Occupation	n	%
Administrative and secretarial occupations	25	30%
Teaching and educational professionals	24	29%
Business, research and administrative professionals (e.g. Research fellows)	12	15%
Librarians and related professionals	6	7%
Science engineering and production technicians	4	5%
Other	11	13%
Total	82	100%

Appendix 4: Health sector respondents by Trust

Trust	n	%
Belfast	25	4%
Northern	147	26%
Southern	34	6%
South Eastern	200	35%
Western	156	27%
Other	7	1%
Total	569	100%

Appendix 5: Occupational breakdown for health sector respondents

Occupation	n	%
Administrative and secretarial positions	51	10%
Caring personal services	37	7%
Health and social care associate professionals	20	4%
Health professionals	71	13%
Managers, directors and senior officials	30	6%
Nursing and midwifery professionals	142	27%
Therapy professionals	67	13%
Welfare professionals	54	10%
Other	57	11%
Total	529	100%

Appendix 6: Proportion who know someone with autism.

	Yes	No/Unsure	Total
HSCT staff	275 (56%)	214 (44%)	489 (100%)
GPs	3 (50%)	3 (50%)	6 (100%)
ELB staff	22 (52%)	20 (48%)	42 (100%)
Teachers	19 (48%)	21 (53%)	40 (100%)
Public sector staff	5 (42%)	7 (58%)	12 (100%)
Policy makers ²	-	-	-
Private sector staff ³	n/a	n/a	n/a
FE and HE staff	37 (53%)	33 (47%)	70 (100%)

¹Proportions are calculated with prefer not to say/missing responses excluded.

²Cells suppressed due to small values (1 or 2) for personal information – denoted by a dash.

³ Question not asked to this participant group

Appendix 7: Frequency of contact with service users who have autism

	Almost everyday	Once or twice a week	Once a fortnight, few times a year	Never/ unsure	Total
HSCT staff	75 (16%)	83 (18%)	178 (39%)	123 (27%)	459 (100%)
GPs ²	-	-	-	-	
ELB staff	9 (23%)	8 (20%)	6 (15%)	17 (43%)	40 (100%)
Teachers	26 (68%)	9 (24%)	3 (8%)	0 (0%)	38 (100%)
Public sector staff ²	-	-	-	-	-
Policy makers ³	n/a	n/a	n/a	n/a	n/a
Private sector staff	7 (33%)	0 (0%)	8 (38%)	6 (29%)	21 (100%)
HE/FE staff	6 (9%)	9 (14%)	13 (20%)	37 (57%)	65 (100%)

¹Proportions are calculated with prefer not to say, 'other' responses that could not be recoded, and missing responses excluded.

²Cells suppressed due to small values for personal information – denoted by a dash.

³ Question not asked to this participant group

Appendix 8: Proportion offered autism training by employer

	Yes	No/Unsure	Total
HSCT staff	166 (29%)	403 (71%)	569 (100%)
GPs	0 (0%)	6 (100%)	6 (100%)
ELB staff	18 (37%)	31 (63%)	49 (100%)
Teachers	32 (74%)	11 (26%)	43 (100%)
Public sector staff ²	-	-	-
Policy makers	0 (0%)	3 (100%)	3 (100%)
Private sector staff	7 (30%)	16 (70%)	23 (100%)
HE/FE staff	21 (25%)	63 (75%)	84 (100%)

¹Proportions are calculated with prefer not to say/missing responses excluded.

²Cells suppressed due to small values for personal information – denoted by a dash.

Appendix 9: Employment for adults with autism: Case Studies (Full version)

Case Study 1: Rural development project

The first case study is a cross-border rural development project which was piloted between June 2013 and April 2014, offering employment experience as an alternative to day care for adults with learning disabilities or mental health problems. Twenty rural businesses took part in the pilot study, and each of these provided a placement for between one and three individuals, for at least one day each week. In total, 66 participants were engaged with the project on a weekly basis. On behalf of the BASE project, the organisers of the rural development project contacted business owners in Northern Ireland who had offered placements to adults with autism, inviting them to participate in the Case Study employer interviews. Initially the owners of four businesses came forward and expressed interest in BASE; due to other commitments at the time, two could not participate, but interviews were carried out with the owners of two rural businesses in the development pilot.

Business 1

This family business is run on two sites, both of which offered opportunities to participate in day-to day activities for people with mental health or learning disabilities. The owners are a married couple who also have two family members diagnosed with ASD. Their business involves horticulture, marketing and livestock maintenance. They have offered placements to 13 individuals, four with autism, in the period between 2011 and 2014. One of the partners also works in health care provision and has a professional as well as a personal understanding of autism.

Business 2

Again, this is a family business, with less emphasis on horticulture than in Business 1. The owners are a married couple, and they have offered placements to four individuals, two of whom have autism, in a ten month period between 2013 and 2014. As with Business 1, one of the partners works in health care provision and has a professional understanding of autism.

Reasons for offering employment opportunities to individuals with autism

The owners of both businesses had made value-led decisions to offer placements to individuals with autism and/or mental health issues, based on personal or professional knowledge and *understanding*.

‘We have a good understanding of people on the autism spectrum. I was involved in setting up the autism team for (name of area) so whenever I was involved in that, I would have went on every bit of training that...so I got a good grounding in what’s required for somebody with autism, and then we ended up with [family members] with autism, so as well as having my professional training, I have the personal aspect of it.’ (Business 1)

In addition, the owners of Business 1 had researched the background to current provision for adults, and they had found an example of good practice in the Republic of Ireland, which had made them interested in pursuing the possibility of offering employment placements for adults with disabilities such as autism.

‘We looked to see what was available for adults with autism, regarding work and living, and was very, very disappointed with what was available in Northern Ireland ...all of the people that we’d seen on (name of project visited) had autism and we seen how happy they were...for very often people with autism have no work ...very much closed in their bedroom ...not able to socialise, so it was quite a very positive experience and we thought, right we will try and replicate it for others and particularly then in the longer view for our [family members].’ (Business 1)

For both businesses, being involved in the pilot project seemed a natural continuation of traditional rural community practices of inclusive employment and social responsibility. It is an approach that may even enhance the opportunities to maintain existing social networks in dispersed settlements, developing contacts which lead to an improved quality of life for rural communities

‘But we always would have had people with you know, learning difficulties, working ...in my father’s time and then before that in my grandfather’s time...there would have been people with ... you know war veterans and stuff coming back from the First World War...’ (Business1)

‘This role of being a hub in the community, where you have maybe older neighbours and you have to call in to them and you do other stuff. There’s some money attached to it, and that makes it, that actually gives you time, because I don’t have to worry about becoming super-profitable and efficient.’ (Business 2)

Recruiting individuals with autism

The overall project worked closely with statutory Health and Social Care Trust services and contracted voluntary sector providers, as an active part of Day Opportunities, matching the interests and skills of the individuals to each placement. Both businesses were happy to offer placements to people with a range of skills across the autism spectrum, but made clear that the assessment process had to identify the individual's support needs, and provide a mechanism to ensure these were met. This should involve a tailored plan which aimed to reduce support over time if appropriate

'They have to make sure that they get the appropriate support to some with them... we can as [business owners] plan the activities and do the activities, and tailor the environment and activities for the person but we can't actively you know give them the one to one support.' (Business 1)

Preparation for the placement was managed in both businesses by the service providers. As well as matching the individual's skills to the activities, each person on the programme visited the business site beforehand. Support provision was tailored to each person's needs, and reviewed to allow for increasing independence, but in all cases the service providers carried out assessments and put plans in place.

'There's a person-centred plan, every year, and it goes through the sort of issues and supports and the future... there is a statutory process, that's what I'm finding out.' (Business 2)

Jobs that were carried out by individuals with autism

The placement opportunities had to fit in with the daily and seasonal activities associated with the rural businesses. Where possible the individuals on placement were encouraged to participate in all aspects of the daily routines, although that sometimes required more specific organisation than was usual with employees. The strength of the programme lies in offering a normal working environment and the participants learning to fit in to that; one of the business owners felt that to create artificial opportunities ran against the core values of the overall project.

'On this [business site] anyway, we have never manufactured an activity... just what needs done... and if it's raining you come in and take tea because that's what I do... or you can go up to the local shop ... very much for me it's about inclusion into your family life.' (Business 2)

The participants understood the work was meaningful and grounded in the everyday life of the business, and this reinforced the sense of achievement the placements gave them.

‘They always love bringing things home with them, one guy in particular. He lived with an elderly mum, he had to have a pot of jam or some potatoes or onions, but he used to go home to his day care centre and he used to show this off. This was what he did...he just loved this, it really helped his self-esteem and his pride that he had done a busy day’s job.’ (Business 1)

As the activities varied, considerable advance planning (including for ‘unplanned’ activities which could arise) and communication strategies were needed, as these were areas where the owners recognised individuals with autism may have difficulties.

‘And in the morning too, to help the people with autism, we’d have a white board, so you would write down, structure... what they’re doing today.’ (Business 1)

As the tasks were seasonal as well as weather-dependent, there were a range of activities planned, which gave participants the opportunity to improve not just their work skills but also gradually enhanced their social and independent living abilities, which previous placements (or living at home) had not always encouraged.

‘A lot of them because they came from the traditional day centre where they basically sat round a table and did whatever activity was on for that day, they wouldn’t have walked a lot... so this was a real challenge for them to walk.’ (Business 1)

‘I made tea, and put the tea on the table, this took a week or two, and went out you know, ‘do you take sugar’, next day was ‘There’s the sugar and the spoon’. At the end it was ‘put on the kettle [name] we’ll have a cup of tea’. But the day his mother came [she poured the tea and stirred it]... and gave it to him, and she didn’t even see it.’ (Business 2)

Opportunities for staff to undertake further training and qualifications

Specific training opportunities were not built into the pilot programmes, but the owners of both businesses saw the incorporation of training programmes on site as an important developmental step in rolling out future projects.

‘If we had participants back again, to link up with the local college, we have been speaking to them because very often they do [rural industry] activities for people with autism but...it’s so far removed from the reality ... whereas then if they could come out to [the business], they would actually see the reason why they need to plant things.’ (Business 1)

However the issues around funding any training programmes and setting up appropriate structures to allow full participation would need dedicated multi-agency support. As with the

overall aims of the project, business owners saw relevant training as an important development of the individual's needs and interests within a placement rather than a 'one-size-fits-all' approach.

'One particular young man, and he has a learning disability ... [provider] got him jobs like working in the hospital as a porter, and he hates it, he wants to be out... they have a farm at home and he'd like to learn to drive a tractor... I spoke to this guy [from training college] and maybe if we can put something together we could come out with a qualification, or show something ... that's how I would see [project] going.' (Business 2)

Autism training for other staff was not a particularly relevant issue, as both businesses had a partner who had received professional training. Support staff members were trained by the service providers, and any other employees in the business such as casual labour, recruited for seasonal requirements, did not receive formal training.

Adjustments to the working environment

The businesses had both made a number of adjustments to accommodate the specific needs of the individuals with autism who were on work placements. As the daily tasks could include outdoor work on uneven terrain, the use of tools and equipment and occasional unexpected changes to routine, the most fundamental undertaking was the need for accurate, on-going risk assessments that are tailored to the individual.

'Safety isn't something where 'Right I've signed the induction sheet and I've identified all the risks' and that's you done. Safety on [business] or anything really, especially with people who maybe aren't used to [business] or maybe might forget... It's full-time, you're full-time switched on... you're aware.' (Business 2)

Particularly in businesses where sudden changes to routine may occur because of weather or minor interruptions, strategies such as the use of clear planning structures formed part of the daily schedule as noted earlier. In specific circumstances, visual strategies may be appropriate

'[Whiteboard to give structure] you know, in this climate sometimes it rains and all ... You can clearly score it out, 'we are unable to do that because of the weather' and if they can't read you can draw wee symbols, it's raining, cloud, and that helps to de-stress ... because things do change.' (Business 1)

In terms of business management, the most significant adjustment for the needs of participants was the provision of a slower working environment and allowing time to 'de-stress' (as noted above) if required.

‘Other placements they have been on they have displayed really negative behaviours, not coped, whereas [in this business] you have so much space, you don’t need to be around people because that usually stresses them more. So usually for those kind of mornings with people with autism, you can just go to the orchard, where they have got space, time.’ (Business 1)

Extra expenditure and funding

Support provision from trained staff is organised and funded by the service providers (the Health and Social Care Trust or the voluntary organisation which undertakes the placement allocation). During the working day, the extra allocation of time needed for supervising work plans for individuals with disabilities (including autism) and ensuring they can carry out tasks safely carries costs in itself; although no major outlay in terms of equipment is needed, at times other work has to be put on hold and these hidden costs may not be fully met.

‘The [project figure] was £40-50 per person and I would say you would nearly need 3 or 4 people a day to make it you know useful so that’s really [the business owner] getting about £120 per day minimum. So we felt well that was the bare minimum just to cover yourself for your time and your materials and we always had to have a plan B, you know like a wet day programme.’ (Business1)

Longer-term, sustainable funding from statutory bodies would be necessary to roll out the programme across Northern Ireland, but the businesses recognised that the present structures for provision of day opportunities were unlikely to result in an immediate solution.

‘We’re as a society paying for meaningful day opportunities and policy says it should be meaningful day opportunities, not day care. [This project] is day opportunities and all policy says ... it’s all saying the same stuff, people have to get person-centred planning, and so. The money is there, and statutory services say ‘yes, we know that but it’s all tied up in our current budgets or whatever’.’ (Business 2)

Areas requiring most support

The areas requiring most support for individuals with autism were in structuring the working day and addressing behaviours which occurred due to deficits in social skills. These issues were approached creatively and with understanding by the business owners, such as providing the right environment for ‘unstructured’ events like breaks

‘Lunch breaks and tea breaks can be a challenge also for people with autism but again you can get round it very easily. Give them a staggered break. Some of them don’t like sitting round the circular table. So the people with autism, we just give them soft chairs away from the main table, and that’s where they chose to sit, so they could be part of the conversation if they wished to.’ (Business 1)

Positive aspects in offering employment opportunities to people with autism

Business owners identified aspects of the project as having a very positive personal impact for their families and neighbours, as well as for the individuals with autism who had participated in the placements.

‘I think it’s good for our family that they see other people and have different people calling and being part of our family unit. I think it’s good for our neighbours to see people with disabilities, because a lot of our neighbours wouldn’t know anybody, have never any interaction with anybody with a disability.’ (Business 1)

The project at times had very practical advantages for other community members, as the participants helped out neighbours at holiday times, and it also fostered a sense of inclusivity which benefitted the participants who may not otherwise have had the opportunity to take part in everyday activities.

‘They are at home, their social skills mightn’t be great. They wouldn’t maybe go to all the local events. Maybe then they go to a special service ... and they are bussed to there, and then bussed home kind of thing. I know some of the other [project business owners] will bring them to the mart if they could cope, you know bring them to country fairs and things so they have to interact with the local community.’ (Business 1)

The development of the project could also have longer-term economic benefits for more businesses in rural areas

‘What we can offer is unique, and it’s... There’s a whole infrastructure, it’s amazing, there’s some people there could offer maybe a day or two a week, it’s good for them and it’s a good feel to it. The other side of the relationship, if you move a little bit of money it suddenly makes that [business] sustainable.’ (Business 2)

Negative aspects in offering employment opportunities to people with autism

Very few negative aspects in offering employment opportunities were identified. There were some initial issues around interpreting behaviours which might otherwise seem rude or unresponsive as identified earlier, but this was a matter of getting to know the individuals, and was relatively easily addressed. The financial issues remain a problem however, as such projects cannot be adequately funded at present, and if this pilot scheme is to be developed as a meaningful alternative to ‘day care’ then business owners need to have their economic costs met.

‘I suppose there’s financial outlay for us at the minute because I would say we give a lot more than we ever got back financially and you can do that for a short time but you can’t continue to do that all the time, we’d be out financially because it just doesn’t work.’ (Business 1)

In common with other short-term projects, the termination of the pilot scheme had emotional impact on the participants. For almost a year, they had an employment routine which gave them a sense of purpose, job satisfaction and improved self-esteem. Not only was the contact with the placement businesses severed, there was nothing similar to put in place, and all the hard-won skills would almost certainly decline. This had a direct personal effect on all concerned.

‘It was quite hard for the participants to understand why they couldn’t continue because they had really seen that they nearly couldn’t be done without, and that was a sad bit of it that we couldn’t just continue to have them without the structures in place.’ (Business 1)

Barriers to employing more people with autism

No-one identified autism as a barrier or limitation to employment in itself. For those involved in the project, there were issues around the capacity of individual businesses to expand, as there was limited extra work for individuals.

‘Maybe for some [businesses], if you got to a situation where you know, you decided to expand and you were going to employ people, I would see no barriers in employing somebody who had progressed to the point. We wouldn’t have enough work at this time, but I wouldn’t see a barrier, no.’ (Business 2)

Again, the negative aspects of acquiring funding were seen as a barrier, in particular the nature of allocating departmental funding, despite recent legislation regarding autism services.

‘I know that was the idea of the Autism Bill, I suppose the legislation is there but the practicalities on the ground of these departments, working together and maybe sharing monies and sharing pots of money isn’t there yet.’ (Business 1)

As the businesses were rural, many operating along minor roads without regular public transport, the issue of access for people with disabilities was raised as an issue that could become problematic unless reliable transport was available.

‘Transport could be an issue... but there should be a budget there for that, [people can be] transported from rural areas into urban congregated settings. So you know, it doesn’t take a whole lot of creative thinking to think, well you can do it in reverse, in to out.’ (Business 2)

Measures to encourage employing more people with autism

It was felt by the owners of both businesses that a more strategic approach from government departments was needed in order to co-ordinate and deliver effective day opportunities and meaningful employment for individuals with autism, which would also free up social and economic opportunities for their carers. These should be clearly signposted to allow more people to become aware of their options, and they could financially support their choices through the increased provision of Direct Payments.

'Maybe one person needs to be employed to make all these people work together. Very often families, particularly people with autism get very isolated and they're not aware of what's out there for them. They are too busy managing their son and daughter and very often they have to stay at home because their son and daughter refuse to leave. There is nothing available for them to leave to. That person then would need to try and educate the families, what is available and where they can get employment.' (Business 1)

Participants felt that offering more employment opportunities should not detract from the overall values that lie behind the project and should not replace what was often seen as institutionalised 'day care' offering few choices with similarly organised day placements.

'If you isolate them in a building out there and you build a purpose built building, that's day care in a field, it really is.' (Business 2)

It was felt that developing the pilot programme, or offering more employment opportunities, should not turn participant businesses into large enterprises in their own right but could be accomplished by increasing the numbers of small businesses taking part.

'The scalability of it. If you want to get the central statistics office for Northern Ireland and look how many [rural businesses] there are... and you scale that out, and that'll tell you how many day opportunities could be offered.' (Business 2)

General advice for those considering employing people with autism: in their own words

'You have to be flexible, you have to be willing to change things. Coffee breaks and tea breaks might have to be adapted, and staggered a little and encouragement and give tasks like, you know like leadership tasks, you know feel that they are in control you know...in a controlled environment, responsibility that's the word I'm kind of thinking of... because they are very good...people with autism have brilliant skills ... once they learn... if the job is a very you know A plus B equals C job and that's the task that will be everyday..and they are very good with attention to detail ...those skills... just hone in on those really, really, good skills and then support them with...they are going to need support around social skills and... if they are feeling stressed those kind of days and be willing to adapt and change those days but you know they have excellent, excellent skills.' (Business 1)

‘Yeah, I’d say, why not? Ask yourself, instead, as Mr Kennedy says! The initial reticence on the project, from everyone, is ‘What if? What if? What if?’ But nobody would swim if we all said ‘What if we drowned?’ You know what I mean, somebody has to, sort of, get wet! But you manage those risks, you manage them in conjunction with services and the families and the people, do you know what I mean... To create something that manages, that has core values on that, that’s key to the success and it’s the key to success for people with autism who can maybe tap into it as a day opportunity, because it’ll be value based... we’re[rural businesses] and we produce and we do things, there’s capacity in [rural businesses] in Northern Ireland to offer day opportunities to people and it’s structured, controlled with statutory services to complement what goes on, not in competition to it... But it’s in complement to what the existing services, that’s what I see, that [rural business] as a sector could play a part... you guys write the report, and give it to [Minister] and say to him ‘[Minister], this is ...!’ (Business 2)

Case Study 2: Scientific research centre

Case Study 2 is an organisation with a distinguished history within the Northern Ireland Culture, Arts and Leisure sector, offering public access to its resources as well as maintaining an international research facility. Staff included students and visiting researchers, a number of whom would be present on short-term funding; approximately 40 people were employed. In the past 10 years, the organisation offered placements for up to four individuals with autism; currently, at the time of interview there were two individuals with autism undertaking work experience placements for one day each week.

Reasons for offering employment opportunities to individuals with autism

The organisation offers placements in fulfilment of the overall departmental strategic goal of increasing therapeutic work experience. Ultimately this is for the benefit of the person rather than the organisation, but the work that is undertaken is useful, and may not otherwise have been done

‘There is also a benefit to staff in meeting such people. The [organisation] is recognised as a charity in Northern Ireland, and this is beneficial in helping to achieve our charitable objectives.’

Recruiting individuals with autism

The placements were organised through a voluntary sector organisation and an ASD specialist organisation respectively, although support provision had changed for one individual, whose placement was managed by a national charity. In contrast to Case Study 1,

the organisation did not recruit across the spectrum, as the work demanded certain skills in communication and office administration.

‘The individuals have to be verbal, and capable of following instructions. Some individuals with autism would not be able to do this, for example they may have limited speech and/or limited ability to follow instructions.’

As with the business owners in Case Study 1, the voluntary organisations which arrange the placements played a very important role, as the organisation was not in a position to carry out necessary assessments. Preparation for the placements was the responsibility of the voluntary organisations.

‘We couldn’t do it on our own, we would need a funding line, and it would be better to have an external provider to match the student to the project, as they have the experience.’

The placement organised through the charitable trust was in fact one of a range of activities which they organised for that individual. The national charity which managed the second placement had a more formal and measurable support process that was geared towards increasing his independence. There was good communication between the support provider and the organisation, and they sought to address minor workplace issues to improve his skills.

‘The other individual is now supported by [national charity], which has been very professional. They have, for example, provided us with formal risk analysis forms, and a timetable to review the placement.’

After two years, the organisation of support for the first individual on placement also changed. His parents had arranged a package of support measures (through individual funding from DHSSPS) and managed this budget themselves.

Jobs carried out by individuals with autism

The individuals on placement carried out a number of specific administrative tasks which were matched to their interests and abilities as closely as possible. As with the work undertaken by the businesses in Case Study 1, the tasks had to be meaningful and contributed to the overall work of the organisation.

‘One works on the extraction/analysis of historic documents (from the 20th century), transferring information from a box of staff archives to text files. This is handy, because we don’t have an archivist and the resulting text file can be readily searched...If we had more support, he could do more, as he is a very fast typist. The other individual ... came to

us with a different interest, so we gave him a project that we felt would align with this interest... we thought that [he] could become involved in making observations and photographic images of the flora and fauna in the grounds... Such work would not otherwise happen and the leaflet will be a tangible output.'

Opportunities for staff to undertake further training and qualifications

The organisation offered a range of training, including work experience for school students, international placements for undergraduates, post-graduate positions and general in-service training for employees. The individuals with autism who were on placement were able to obtain further qualifications if they wished, but there was no specific programme for them. Autism training for other staff was not in place, although the national charity which organised one of the placements had offered to train staff, and the organisation was considering taking this up in the future.

Adjustments to the working environment

The organisation had found very few adjustments necessary; the only concern for both placements was their mobility, but otherwise the working environment was suitable.

Extra expenditure and funding

As with the previous Case Study, support needs of the individuals on placement were met by the voluntary organisations which organised the positions; however, there were additional overhead costs to the organisation. The supervisory roles required allocation of other staff, and as well as time management, there were additional costs to be factored in.

'We would ideally need a dedicated project supervisor, as it does take a bit of time. In short, our involvement with these kinds of individuals does put a certain amount of overhead on the organisation, and anticipating financial difficulties we have in the past put forward 'micro-bids' to cover the cost of a member of staff for one or two days a week.'

Areas requiring most support

The only area of increased support identified was the need for more supervised, structured working practices than would normally be in place for other staff members. The project each individual was involved with had to be planned carefully to meet their specific needs

Positive aspects in offering employment opportunities to people with autism

On a managerial level, employment of individuals with disabilities allowed the organisation to meet the required Departmental targets. Staff benefitted from working with individuals with autism, and the participants had an inclusive work environment, where their work is valued.

‘We meet our [overall Departmental] targets; also the points raised earlier about staff benefits and the opportunity of getting work done which wouldn’t otherwise be possible owing to other work pressures.’

The extra work undertaken increased the capacity of the organisation; following staff shortages, the individuals on placement carried out or helped with projects which may not otherwise have been done. There were also benefits in the contact between other staff members and the placement individuals, not least of which was the regular work routine and sense of inclusivity for the individual with ASD.

Negative aspects in offering employment opportunities to people with autism

The placement individuals, while otherwise very competent, did not have the skills to self-monitor or work completely independently and therefore the need to provide supervision was an issue if the allocated staff members were absent, given the reduction in overall staff numbers. Replacement for supervisors or mentors proved bureaucratic as it had to be done at Departmental, rather than organisational, level and appeared intrusive or disruptive to staff when the organisation was otherwise considered autonomous.

‘Due to austerity measures, we have several vacant posts, but these are currently frozen. So the amount of useful work that these people do is limited more by the lack of staff to develop and supervise certain projects, even if the individual can do quite a lot on his own. You have to make sure there is cover to provide these people with work. If the nominal supervisor is away, it can be tight getting someone to step in if we have no reserves.’

Barriers

A number of potential barriers to offering more placements or paid employment to people with autism were identified. The issue of funding was raised in respect to organising placements, which were limited by the absence of a designated member of staff.

‘Yes, funding. We could take on more people if we had a designated member of staff to look after them and find projects.’

It was felt that the organisation should not have to find this money, either through grant applications or from its existing allocated budget; the extra costs involved should be externally funded.

‘It has to be funded externally. Overhead costs have to be recognised, as there are overheads on the organization as well as on the supervisor.’

However, funding was not the only limiting factor. Employment legislation made the application for a paid position very difficult for an individual with autism as the organisation recognised that interviews in particular would be an obstacle for them.

‘If we had a ‘high performing’ person in, we would have to advertise any jobs, and they may not get the job as an interview would be difficult for them. That is an issue. Every case should be taken on its merits.’

In addition, an employer needed to be aware of the effects any part-time wages would have on existing benefit payments, and should they recruit volunteers the organisation has to be careful not to place itself in a position where it inadvertently breaches minimum wage regulations.

‘With the minimum wage, you might have volunteers who wanted to help but the employer could be charged with exploitation. It should not be a ‘one size fits all’ approach.’

Measures that would encourage employers to employ staff members with autism

The organisation acknowledged there were benefits to offering such placements, but with the situation with respect to redundancies there were limits. To enable the organisation to take on more staff members with autism, they were clear that there would have to be specific funding in place, and dedicated staff roles to optimise the benefits for individuals and for the overall work of the organisation.

‘Although it has a positive benefit, it would have to be able to ‘wash its face’ in the full economic costs sense, so salary and other costs would need to be met.’

General advice for those considering employing people with autism

The organisation offered general advice to those considering employment of individuals on the autism spectrum, such as ensuring that autism awareness and external supports were

available.

'You need to make sure you have external support, and you need to take it gently, both for yourself, the designated supervisor and other staff...You need to be aware that 'autism' covers a huge range. One person's idea of autism can be a million miles away from another's, and none of us always gets it right.'

Appendix 10: Research tools

10.1 Participant Information Sheet and Consent forms for service users (adult individuals with ASD)

School of Education
Queen's University Belfast
Research Project

PARTICIPANT INFORMATION SHEET

You are being invited to take part in a research study. Before you decide whether you want to take part or not it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

The BASE Project (Benchmarking Autism Services Efficacy)

This research aims to find out how effective current government policies and strategies are at delivering the services needed and wanted by individuals with Autism Spectrum Disorder (ASD), their carers, teachers and lecturers and employers. We hope to be able to inform

policy makers, professionals, individuals with autism, and parent/carers about these important issues. The Research Ethics Committee of the School of Education, Queen's University Belfast reviewed and approved this research. You have been chosen to take part in the study as an individual with ASD. If this does not apply to you, please let us know immediately.

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. Your decisions either way will not affect any services you receive.

If you decide to take part you will meet the researcher for an interview at a place which is convenient for you, and you will be asked for your views on support services at home, in education and in the workplace. This interview will normally be recorded but if you prefer, you can ask for the researcher to make notes instead or you can request a questionnaire to complete yourself (either in hard copy or on computer). It should take no longer than 45 minutes to complete in any format.

All information that is collected about you during the course of the research will be kept strictly confidential (except as might be required by law). Any information about you will have your name removed so that you cannot be recognised from it. Once the study is completed, results will be presented in written papers and in oral presentations, and the final report will be available on our website: <http://www.qub.ac.uk/research-centres/cba>. I am the Principal Investigator on this project and if you have any further questions you can contact Professor Karola Dillenburger by e-mail at k.dillenburger@qub.ac.uk, or you can contact Dr Lyn McKerr at 02829541991 or Dr Julie-Ann Jordan at 02890973177.

Thank you very much for reading this information sheet.

(Form to be on headed paper)

CONSENT FORM

Title of Project: **BASE Project** (Benchmarking Autism Services Efficacy)

Researcher: Professor Karola Dillenburger

Research Team: Dr Julie-Ann Jordan and Dr Lynne McKerr

Name of Researcher: xxxxxxxxxxxxxxxx

Please tick and initial box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without services or legal rights being affected.
3. I understand that the researchers will hold all information and data collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in the study (except as might be required by law) and I give permission for the researchers to hold relevant data.
4. I agree to my interview being taped. (*Not applicable for those completing questionnaire*)
5. I agree to take part in the above study.

_____	_____	_____
Name of Participant	Date	Signature

_____	_____	_____
Name of Researcher	Date	Signature

1 for participant; 1 for researcher

10.1.1 Semi-structured interview questions for adult individuals with ASD

Semi-structured interview questions

BASE: for adults with ASD

Interviewer instructions:

Before interview, print out for each interviewee: **Participant information sheet and consent form, and interview schedule**. Ensure that your tape-recorder is working.

At beginning of interview: Get interviewee to read the participant information sheet and sign the consent form (read it out if necessary). Only proceed if interviewee has signed the consent form. If not, discontinue and thank the participant for taking time to consider contributing to research.

During interview: If consent form signed, switch on tape recorder. Read out each question and give time to answer in full. Make sure that all questions are covered, but remember that all prompts (ancillary questions in italics which are **not** in bold) are there to aid the flow of the interview but should not be automatically read out. Feel free to add any clarifying questions as necessary. Make notes during the interview on the interview sheet e.g. especially name and date etc. Start interview by saying:

“Thank you very much for agreeing to take part in this interview. The interview should take between 30 and 45 minutes in total but we can take a break at any point if you wish; if there are any questions you would prefer not to answer, they can be left out. I hope you don’t mind if I tape-record this interview so that I can be sure not to miss out on anything you say.” [If this has been previously agreed]

Location: Urban/rural

Education and Library Board /Health and Social Care Trust Area:

The first few questions are about you and your family, and the type of accommodation you live in.

1. About you:

What is your age?

Gender:

If you are comfortable with talking about it, please tell me something about your diagnosis of autism and when it was obtained.

What are your hobbies and interests?

2. Please describe the type of accommodation you live in

E.g. number of bedrooms, flat or house, whether it is Parental home, Owned by you, Rented from a private landlord, Rented from a housing association, Provided through social services (such as group home)

**If parental home- who else lives there, e.g., parents, brothers/sisters?
*In total, how many people live with you?***

If 'independent living' /sheltered accommodation- who else lives there, e.g., spouse/partner, children, flatmates? *In total, how many people live with you?*

Is this your preferred type of accommodation? If not, what kind of accommodation would you prefer and what do you think are the barriers to obtaining more suitable living arrangements for the future?

3. What support do you have with regard to your living arrangements?

E.g. Support worker/parents/other family members/social worker help with domestic arrangements, shopping, gardening, repairs etc.

4. Do friends or neighbours help out?

Who helps and what do they help with?

The next few questions are about your educational experience

6. Are you currently studying at a college or university?

If not, is this something you have previously done, or would like to do in the future?

If so, what subjects are you studying? Is this in Northern Ireland, in the UK mainland or elsewhere?

7. I'd like to ask you now about your experience of the education system at secondary school.

Was this a mainstream placement, in a specialist unit attached to a mainstream school or in a Special School?

What qualifications did you obtain at school?

A levels: 3 or more (or equivalent), 2 (or equivalent), 1 (or equivalent)

GCSEs: 5+ A*-C (or equivalent) including English and Maths: GCSEs: 5+ A*-C (or equivalent): 1-4 A*-C (or equivalent) including English and Maths: 1-4 A*-C (or equivalent), Other grades (1+ D-G); No GCSEs

Do you feel the examinations system made reasonable adjustments for your needs- and if so, what were these adjustments?

Do you feel that having autism had any impact on your school attendance? If so, what impact has it had?

Did you have a diagnosis of autism while at school?

If so, did you have a Statement of Special Educational Needs?

Note to interviewers: for those without diagnosis/ Statement of Educational Needs while at school, for questions 8-13 please insert 'In view of the fact that you did not have a diagnosis/Statement of Special Educational Needs' as necessary

8. How do you feel your school addressed your academic needs?

Do you feel you have had enough input into your education choices?

Did the school involve your parent/carers in choices?

9. Do you feel your school addressed your independent living needs outside the school environment?

If yes/partially, how were these needs addressed?

What else, if anything, do you think the school could have done?

10. Do you think your school addressed your needs in terms of future training and employment?

If yes/partially, how were these needs addressed?

Again, what else, if anything, do you think the school could have done?

11. Do you think your school addressed your needs in terms of social skills and inclusion?

If yes/partially, how were these needs addressed?

Once again, is there anything else you think your school could have done?

12. Were you able to discuss any of these specific needs –educational, independent living and social inclusion- with someone at your school? *If so, who was this (role- SENCO, form teacher etc)*

13. Before you left school, were you in contact with the Transitions Service in your Education and Library Board (*this is a service to support young people and their parents/carers in finding information and guidance on moving from school into adulthood*), or on any work experience programmes? *Have you had any advice from the careers advisor when you were at school about future employment support through e.g. Job Centres?*

The next few questions are about your current employment situation

**14. Are you currently in paid employment?
If so what is your job and is this full-time or part time?**

**Are you self-employed?
*If so, what were your reasons for choosing this type of employment?***

Did you have any support finding and keeping this job *e.g. from a Job Centre, from a business support organisation or from an autism voluntary organisation?* **If so, what kind of support did you get and how easy was this support to access?**

Do you enjoy your job? If so, what aspects do you enjoy?

Do you find your job challenging? If so, what do you find challenging?

[Interviewer to filter]

**15. If not employed, are you seeking employment now?
How long have you been seeking employment?
Are you enrolled in any work schemes to help you find employment?
*What sort of job are you looking for/ would you prefer?***

Do you think that obtaining a suitable job will be/is challenging? If so what do you think these challenges will be/are?

16. Are you currently receiving any benefits- (*such as Housing Benefit, Disabled Living Allowance [DLA], Employment Support Allowance [ESA] or Jobseekers Allowance etc.*)?

**If so, were you or your family offered any support in completing forms and arranging appointments at benefits offices?
*How did you find the staff at benefits offices responded to your situation ?***

Do you feel that you are living in real financial hardship or do you generally have enough money for the things you really need? *e.g. household essential bills, heating food etc.-or anything else participant identifies as necessary*

17. Finally, is there any advice you would offer to other people about living and working with someone with autism?

If so, what advice would you offer?

Thank you very much for participating in this interview. Your answers were very informative and helpful. Once the study is completed results will be presented in written papers and in oral presentations, and the final report will be available on our website. The details for this web site are on the Information Sheet you were given earlier.

Interviewer instructions: After interview: Please file signed consent sheet and interview schedule with handwritten notes securely. E-mail anonymised digitised interview recordings (as email attachment) to k.dillenburger@qub.ac.uk.

10.1.2 Questionnaire alternative for adult individuals with ASD

Alternative interview questions

BASE Project

This questionnaire is an alternative to an individual interview, and you have chosen this format because you are more comfortable with writing down your responses. The questions are exactly the same in both formats.

Once you have read the Participation Information Sheet and indicated on the Consent Form that you are happy to proceed, please answer the following questions. You may type directly onto the document, or write on a printed copy.

If there are any questions you would prefer not to answer, this is perfectly acceptable and please say so in the space provided beneath the relevant question. We hope the questionnaire will take no longer than 30 minutes in total to complete, but you may want to take several breaks rather than finishing it all at once.

The first few questions are about you and your family, and the type of accommodation you live in.

1. Please fill in the following details about yourself:

1a.Name: _____ Gender: *Male /Female*

1b.Age: _____

1c.Location: *Urban /Rural*

1d. Education and Library Board (if known):

Belfast

North Eastern

Western

Southern

South Eastern

1e. Health & Social Care Trust (if known):__

Belfast

Northern

Western

Southern

South Eastern

1.f *If you are comfortable with writing about it, please tell me something about your diagnosis of autism and when it was obtained.*

1g. What are your hobbies and interests?

2. Please tick the type of accommodation you live in

Flat

House

How many bedrooms are there?

2a. Please indicate if it is

Parental home

Owned by you

Rented from a private landlord

Rented from a housing association

Provided through social services (such as group home)

If parental home- who else lives there, e.g., parents, brothers/sisters?

In total, how many people live with you?

If 'independent living'/sheltered accommodation- who else lives there, e.g., spouse/partner, children, flatmates? In total, how many people live with you?

2b. Is this your preferred type of accommodation? YES/NO

If not, what would be your preferred accommodation and what do you think are the barriers to obtaining more suitable living arrangements for the future?

3. What support do you have with regard to your living arrangements?

E.g. Support worker/parents/other family members/social worker for help with domestic arrangements, shopping, gardening, repairs etc.

4. Do friends or neighbours help out? YES/NO

If YES, who helps and what do they help with?

The next few questions are about your educational experience

5. Are you currently studying at a college or university? YES/NO

If not, is this something you have previously done, or would like to do in the future?

If so, what subjects are you studying? Is this in Northern Ireland, in the UK mainland or elsewhere?

6. I'd like to ask you now about your experience of the education system at secondary school.

Was this

A mainstream school

In a specialist unit attached to a mainstream school

In a Special School?

6a. What qualifications did you obtain at school?

A levels

3 or more (or equivalent)

2 (or equivalent)

1 (or equivalent)

GCSEs

5+ A-C (or equivalent) including Maths and English*

5+ A-C (or equivalent)*

1-4 A-C (or equivalent)*

Other grades (1+ D-G)

No GCSEs

6b. Do you feel the examinations system made reasonable adjustments for your needs?

YES/NO

If so, what were these adjustments?

6c. Do you feel that having autism had any impact on your school attendance? YES/NO

If YES, what impact has it had?

7. Did you have a diagnosis of autism while at school? YES/NO

7a. Did you have a Statement of Special Educational Needs? YES/NO

For those without a diagnosis/ Statement of Educational Needs while at school, for questions 8-13 please feel free to comment on what difference (if any) a diagnosis or Statement may have made in addressing your needs.

8. How do you feel your school addressed your academic needs?

Do you feel you have had enough input into your education choices? YES/NO

Did the school involve your parent/carers in choices? YES/NO

9. Do you feel your school addressed your independent living needs outside the school environment? YES/NO/PARTIALLY

If yes/partially, then how were these addressed?

9a. What else, if anything, do you think the school could have done to address your independent living needs?

10. Do you think your school addressed your needs in terms of future training and employment? YES/NO/PARTIALLY

If yes/partially, then how were these addressed?

10a. Again, what else, if anything, do you think the school could have done to address these needs?

11. Do you think your school addressed your needs in terms of social skills and inclusion?

YES/NO/PARTIALLY

If yes/partially, then how were these addressed?

11a. Once again, is there anything else you think your school could have done to address your needs in terms of social skills/inclusion?

12. Were you able to discuss any of these specific needs –educational, independent living and social inclusion- with someone at your school? YES/NO

If so, was this a careers teacher, a teacher who was the designated special needs co-ordinator (SENCO), a form teacher or someone else?

13. Before you left school, were you in contact with the Transitions Service in your Education and Library Board (this is a service to support young people and their parents/carers in finding information and guidance on moving from school into adulthood)? YES/NO

13a. Were you on any work experience programmes at school? YES/NO

13b. Have you had any advice from the careers advisor when you were at school about future employment support through Job Centres? YES/NO

The next few questions are about your current employment situation

14. Are you currently in paid employment? YES (please go to question 14a)

NO (please go to question 15)

14a. What is your job?

Is it FULL-TIME/PART-TIME?

Are you self-employed? YES/NO

If YES, what were your reasons for choosing this type of employment?

14b. Did you have any support finding and keeping this job (e.g. from a Job centre, from a business support organisation or from an autism voluntary organisation)? YES/NO

If you had support, please explain what kind of support you got

Was it easy to access? YES/NO

14c. Do you enjoy your job? YES/NO/SOMETIMES

If so, what aspects do you enjoy?

14d. Do you find your job challenging? YES/NO/SOMETIMES

If so, what do you find challenging?

If you are not currently in paid employment please answer q.15.Otherwise please go to q.16

15. Are you seeking a job now? YES/NO

15a. Are you enrolled in any work schemes to help you find employment?YES/NO

15b. What sort of job are you looking for?

15c. How long have you been searching for a job?

15d.Do you think that obtaining a suitable job will be/is challenging? If so what do you think these challenges will be/are?

16. Are you currently receiving any benefits- (such as Housing Benefit, Disabled Living Allowance [DLA], Employment Support Allowance [ESA] or Jobseekers Allowance etc.)? YES/NO

If YES,what benefits do you receive?

16b. *Were you or your family offered any support in completing forms and arranging appointments at benefits offices? YES/NO*

16c. *How did you find the staff at benefits offices responded to your situation?*

16d. *Please give details if you had support in claiming benefits.*

16e. *Do you feel that you are living in real financial hardship or do you generally have enough money for the things you really need, such as household essential bills, heating food or anything else you feel is necessary?*

17. *Finally, is there any advice you would offer to other people about living and working with someone with autism? YES/NO*

If so, what advice would you offer?

*Thank you very much for completing this questionnaire. Your answers will be informative and helpful. Once the study is completed results will be presented in written papers and in oral presentations and the final report will be available on our website:
<http://www.qub.ac.uk/cba>*

10.1.3 On-line survey template incorporating information and consent forms for FE/HE students with autism (replaced focus group questions).

The BASE Project (Benchmarking Autism Services Efficacy)

This research aims to find out how effective current government policies and strategies are at delivering the services needed and wanted by individuals with Autism Spectrum Disorder (ASD), their carers, teachers and lecturers, and employers. We hope to be able to inform policy makers, professionals, individuals with autism, and parent/carers about these important issues. The Research Ethics Committee of the School of Education, Queen's University Belfast reviewed and approved this research. You have been chosen to take part in the study as an individual with ASD currently attending college/university. If this does not apply to you, please let us know immediately.

It is up to you to decide whether or not to take part. If you decide to take part you will be asked for your views on support services in education and in the workplace. All information that is collected about you during the course of the research will be kept strictly confidential (except as might be required by law). Any information about you will have your name removed so that you cannot be recognised from it. Once the study is completed, results will be presented in written papers and in oral presentations, and the final report will be available on our website: <http://www.qub.ac.uk/research-centres/CentreforBehaviourAnalysis/>

I am the Principal Investigator on this project and if you have any further questions you can contact Professor Karola Dillenburger at k.dillenburger@qub.ac.uk, or you can contact Dr Lyn McKerr at 02829541991, or Dr Julie-Ann Jordan at 02890973177.

Thank you very much for reading this information. By proceeding to the survey, you have indicated your consent to taking part in the research.

Introduction: *Recent figures indicate that as many as 2% of children are currently being diagnosed with autism, which means a lot of young people with ASD will eventually be making choices about their future in education and in the workplace. The government funds a variety of services for people with autism, and their families, across the life course, so your experiences and your views are important in helping them plan for effective use of their spending.*

1. Please give details of the course you are currently doing.

2. What are your hobbies and interests when you are not studying?

3. What do you think makes a school or college a good place to be for young people with autism?

4a. Thinking back to when you were at secondary school, do you think your teachers and other staff had a good understanding of what it was like for a student with autism?

Yes

No

4 b. Did they ask you what would be helpful in class or in examinations?

4c. Did they involve you and your parents in e.g. reviews of your progress?

5. Do you think your teachers were ambitious for you in terms of academic subjects?

5a. Did you have the opportunity of going for work experience?

6. What were the issues- positive and negative- around applying for a place at college/university? (please select all that apply)

Choosing subject/ place to study

Filling in application forms for courses

Writing a student statement

Applying for a student loan/funding for fees

Accommodation/travelling

Mixing with a new group of people

Other (please give details)

7. Which of these were the most concerning to you at the time?

8. This question looks at support services and benefits which may be available for students with autism at college/ university.

8a. What student support services does your college/university currently offer?

8b. How easy was it to access those services?

8c. Have you asked for help in applying for benefits, and if so what happened?

8d. Have you ever been refused benefits or had to appeal a decision?

8e. Do you have a part-time job?

**9. Are you living in
student accommodation,
independent flats/houses
*with family?***

10. Do you have enough money for your basic needs, (e.g., food, rent, clothing, heating in the winter, transport from your house to college/university, books etc)? Please give details

11a. Has your time at college/university been a comfortable and worthwhile experience?

Yes

No

12b. If yes, what has made it comfortable and worthwhile?

12c. If no, what problems did you experience?

12d. Is there anything about college/university life which you think could be improved?

13. What do you want to do once you complete your current course of study?

14. Has your college offered you employment advice?

Yes

No

15a. Are you aware of any support schemes for finding work or training placements for young people with autism?

15b. If so, which ones are you aware of?

16a. Are there any other skills you would like to acquire which might be useful in the job market?

Yes

No

16b. If so, what are these?

17. What advice would you offer about the process of applying for a college place or finding job to

a. other young people with autism

b. people who make policy decisions

18. Is there anything else you would like to say about your college/university experience?

Thank you very much for taking part in this survey; your input is very important to us and when the research is complete we will be making the report available on our website- the details are in the introduction to this survey.

10.2 Participant Information Sheet and Consent forms for interview with parent/carer of child/ adult with ASD

School of Education

Queen's University Belfast

Research Project

PARTICIPANT INFORMATION SHEET

You are being invited to take part in a research study. Before you decide whether or not to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

The BASE Project (Benchmarking Autism Services Efficacy)

This research aims to find out how effective current government policies and strategies are at delivering the services needed and wanted by individuals with Autism Spectrum Disorder (ASD), their parents/carers, teachers and lecturers, and employers. We hope to be able to inform policy makers, professionals, individuals with autism, and parent/carers about these important issues. The Research Ethics Committee of the School of Education, Queen's University Belfast reviewed and approved this research. You have been chosen to take part in the study because you are the parent/carer of an adult/child with ASD. If this does not apply to you, please let us know immediately.

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. Your decisions either way will not affect any services you receive.

If you decide to take part you will meet the researcher for an interview at a place which is convenient for you, and you will be asked for your views on support services at home, in education and in the workplace. This interview will normally be recorded but if you prefer,

you can ask for the researcher to make notes instead. It should take no longer than 45 minutes to complete in any format.

All information that is collected about you during the course of the research will be kept strictly confidential (except as might be required by law). Any information about you will have your name removed so that you cannot be recognised from it. Once the study is completed results will be presented in written papers and in oral presentations, and the final report will be available on our website: <http://www.qub.ac.uk/research-centres/cba>

I am the Principal Investigator on this project and if you have any further questions you can contact Professor Karola Dillenburger at k.dillenburger@qub.ac.uk, or you can contact Dr Lyn McKerr at 02829541991, or Dr Julie-Ann Jordan at 02890973177.

Thank you very much for reading this information sheet.

CONSENT FORM as for 8.1.

8.2.1 Semi-structured interview questions for parent/carer of school leaver/adult individual with ASD

BASE: parent/carer interviews for those with sons and daughters who have left school

Interviewer instructions:

Before interview, print out for each interviewee: **Participant information sheet and consent form and interview schedule**. Ensure that your tape-recorder is working.

At beginning of interview: Get interviewee to read the participant information sheet and sign the consent form (read it out if necessary). Only proceed if interviewee has signed the consent form. If not, discontinue and thank the participant for taking time to consider contributing to research.

During interview: If consent form signed, switch on tape recorder. Read out each question and give time to answer in full. Make sure that all questions are covered. Feel free to add any clarifying questions as necessary, but remember that all prompts (ancillary questions in italics which are not in bold) are there to aid the flow of the interview but should not be automatically read out. Make notes during the interview on the interview sheet e.g. especially name and date etc. Start interview by saying:

‘Thank you very much for agreeing to take part in this interview. The interview should take no longer than about 45 minutes, and if there are any questions you would prefer not to answer, these can be left out. I hope you don’t mind if I tape-record this interview so that I can be sure not to miss out on anything you say’[if this has been previously agreed].

1. About you and your family:

What is your age?

Are you in paid employment? If so, what is your job and is this full-time or part-time?

Is your husband/wife /partner living with you? Is he/she in paid employment? If so, what is his/her job and is this full-time or part-time?

How many children do you have?

What is the name, gender and age of your child/ren with autism? Of course, we won’t be using anyone’s name in our report.

What are the ages and gender of your other children (if appropriate).

Please tell me something about the diagnosis of autism and when it was obtained?

*Does [name of son or daughter with autism] live at home all the time? **If not**, where does s/he live and in what type of accommodation?*

2. What type of care do you provide? (e.g. personal care such as dressing, washing, toileting, supervision/ administration of medicines / cooking and washing clothes/ organising activities, financial management or any combination of these).

How much time does this take up throughout the week?

3. (For individual interviews) Are you the principal carer? If not, who would be the principal carer, or do you consider you are a joint carer?

(For joint interviews) Would one of you be considered the principal carer, if so who, or do you consider you are joint carers?

Do you receive any support in this from other family members?

***If so**, what is their relationship and how do they help?*

Do friends or neighbours help out?

What aspects of care do they help with?

*If you are in paid employment, have you found your employer is prepared to adjust conditions to take into account your caring responsibilities? **If so**, how? Are there any other adjustments that employers could make that you would find useful? **If so**, what are they?*

4. Do you receive any help with caring for [name of son/daughter] from Social Services (*such as a care worker to help you look after [name of son/daughter] or with cooking and cleaning, a day care facility or a supported work placement for [name of son/daughter], respite if you request it*)?

Do you have a 'Care Plan'? This will be drawn up by e.g. your son or daughter's social worker to detail the services that are available to help with your child's specific requirements.

If so, how was that decided? How often is it reviewed?

5. Does your son/daughter receive Disability Living Allowance [DLA]?

If so, at what rate?

Does he/she receive any other benefits (*e.g. Employment Support Allowance [ESA] , Housing Benefit*)?

Do you yourself receive any benefits, and do you receive a specific Carer's Allowance for your caring role?

Have you been offered a Carer's Assessment by your Health and Social Care Trust?

6. Is your son/daughter currently in an educational/work placement?

***If so,** is this e.g. a mainstream placement, in a Further Education or Higher Education setting, in a specialist centre or in a supported employment programme- **if the latter,** which programme?*

***If not,** have they previously been in an educational or work placement?*

***If so,** was this e.g. a mainstream placement, in a Further Education or Higher Education setting, in a specialist centre or in a supported employment programme- **if the latter,** which programme? How long were they involved and when did it finish?*

7. How do you feel this placement addresses/addressed his/her academic needs?

Do you feel you have /had enough input into his/her education programme?

8. Do you feel the placement addresses/addressed your son/daughter's independent living needs?

If yes/partially, how were these needs addressed?

If no/partially, how and ideally, what else do you think the placement should be doing/have done?

9. Do you consider the educational/work placement addresses /addressed your son/daughter's needs in terms of future training and employment?

If yes/partially, how were these needs addressed?

If no/partially, how and ideally, what else do you think the placement should be/have been doing?

10. Do you consider the placement is addressing /addressed your son/daughter's needs as far as social skills and inclusion is concerned?

If yes/partially, how were these needs addressed?

If no/partially, again, is there anything else you think the placement should be/have been doing?

11. Were you able to discuss any of these particular needs –educational, independent living and social inclusion- with the placement organisers?

12. Before your son/daughter left school, were you in contact with the Transitions Service in your Education and Library Board? *(A transitions service supports young people and their parents/carers in finding information and guidance on moving from school into adulthood)*

If so, what was their advice?

Had your son/daughter been on any work experience programmes before leaving school?

If so, where/what kind of programme?

Have you been in touch with any Further Education Colleges or Universities to discuss what support they might offer for students with autism?

If so, please explain.

Have you had any advice from the careers advisor at school about future employment support through e.g. Job Centres?

if so, please explain.

13. What are your son's/daughter's plans for the future?

E.g. In terms of education and employment?

In terms of family life?

Have any agencies offered you any advice about the future, or have you had to seek it out for yourself?

Are you able to talk about choices for the future with [name of son/daughter]?

14. In the future, as you yourself grow older, what sort of accommodation/living arrangements would you like for [name of son/daughter]?

Have you begun to explore these options?

Does your local area provide the choices you would like?

What do you think are the barriers to obtaining suitable living arrangements for the future?

15. What advice would you like to offer other parents of children with autism?

Thank you very much for participating in this interview. Your answers were very informative and helpful. When the research is complete we will be making the report available on our website- the details are on the information sheet we gave you earlier.

Interviewer instructions: After interview: Please file signed consent sheet and interview schedule with handwritten notes securely. E-mail anonymised digitised interview recordings (as email attachment) to k.dillenburger@qub.ac.uk.

10.2.2 Parent/carer interviews for school age children with ASD

BASE Project

Parent/carer interviews for school age children with ASD

Interviewer instructions:

Before interview, print out for each interviewee: **Participant information sheet and consent form, and interview schedule**. Ensure that your tape-recorder is working.

At beginning of interview: Get interviewee to read the participant information sheet and sign the consent form (read it out if necessary). Only proceed if interviewee has signed the consent form. If not, discontinue and thank the participant for taking time to consider contributing to research.

During interview: If consent form signed, switch on tape recorder. Read out each question and give time to answer in full. Make sure that all questions are covered but remember that all prompts (ancillary questions in italics which are **not** in bold) are there to aid the flow of the interview but should not be automatically read out. Feel free to add any clarifying questions as necessary. Make notes during the interview on the interview sheet e.g. especially name and date etc. Start interview by saying:

“Thank you very much for agreeing to take part in this interview. The interview should take no longer than about 45 minutes, and if there are any questions you would prefer not to answer, these can be left out. I hope you don’t mind if I tape-record this interview so that I can be sure not to miss out on anything you say [if this has been previously agreed].

1. About you and your family:

What is your age?

Are you in paid employment? *If so*, is this full-time or part-time?

Is your husband/wife /partner living with you? Is he/she in paid employment?

How many children do you have?

What is the name, gender and age of your child/ren with autism? Of course, we won't be using anyone's name in our report.

What are the ages and gender of your other children (if appropriate).

Please tell me something about the diagnosis of autism and when it was obtained?

*Does [name of son or daughter with autism] live at home all the time? **If not,** where does s/he live and in what type of accommodation?*

2. What type of care do you provide? (e.g. personal care such as dressing, washing, toileting, supervision/ administration of medicines / cooking and washing clothes/ organising activities, financial management or any combination of these).

How much time does this take up throughout the week?

3. (For individual interviews) Are you the principal carer? If not, who would be the principal carer, or do you consider you are a joint carer?

(For joint interviews) Would one of you be considered the principal carer, if so who, or do you consider you are joint carers?

Do you receive any support in this from other family members?

***If so,** what is their relationship and how do they help?*

***Do friends or neighbours help out?** What aspects of care might they help with?*

***If you are in paid employment,** have you found your employer is prepared to adjust conditions to take into account your caring responsibilities? **If so,** how? Are there any other adjustments that employers could make that you would find useful? **If so,** what are they?*

4. Do you receive any help with caring for [name of son/daughter] from Social Services (such as a care worker to help you look after [name of son/daughter] or with cooking and cleaning, a day care facility or a supported work placement for [name of son/daughter], respite if you request it)?

Do you have a 'Care Plan'? This will be drawn up by e.g. your son or daughter's social worker to detail the services that are available to help with your child's specific requirements.

If so, how was that decided? How often is it reviewed?

5. Does your son/daughter receive Disability Living Allowance [DLA]?

If so, at what rate?

6. What is your son/daughter's current educational placement?

Is this a mainstream school, in a specialist unit attached to a mainstream school or in a Special School, home schooling, or another placement, e.g. residential?

Does your child have a Statement of Special Educational Needs?

7. How do you feel the placement addresses his/her academic needs?

Do you feel you have enough input into his/her education? For example, if your child has an annual review, do you attend?

8. Do you feel the placement addresses your son/daughter's independent living needs?

If yes/partially, how are these needs addressed?

If no/partially, ideally, what else do you think the school could be doing?

9. Do you consider the school placement addresses your son/daughter's needs in terms of future training and employment?

If yes/partially, how are these needs addressed?

If no/partially, how and, ideally, what else do you think the school could be doing?

10. Do you consider the school is addressing your son/daughter's needs as far as social skills and inclusion is concerned?

***If yes/partially**, how are these needs addressed?*

***If no/partially** again, is there anything else you think the school could be doing?*

11. Were you able to discuss any of these particular needs –educational, independent living and social inclusion- with the school?

12. What are your child's plans for the future?

***Have you been in contact with the Transitions Service in your Education and Library Board?
(Children 14+)***

***If so**, what was their advice?*

Has your child been on any work experience programmes? (Children 14+)

***If so**, where/what kind of programme?*

Have you been in touch with any Further Education Colleges or Universities to discuss what support they might offer for students with autism?

***If so**, please explain.*

Have you had any advice from the careers advisor at school about future employment support through e.g. Job Centres?

***If so**, please explain.*

Have any agencies offered you any advice about the future, or have you had to seek it out for yourself?

Are you able to talk about choices for the future with [name of child/]?

***If so**, please explain who you discuss this with.*

Are there barriers for young people with autism to finding employment and training opportunities?

***If so**, what are they?*

13. Once your child leaves school, what sort of accommodation/living arrangements would you like for him or her?

Have you begun to explore these options? Does your local area provide the choices you would like?

Are there barriers to obtaining suitable living arrangements for the future? If so what are they?

14. What advice would you like to offer other parents of children with autism?

Thank you very much for participating in this interview. Your answers were very informative and helpful. When the research is complete we will be making the report available on our website- the details are on the information sheet we gave you earlier.

Interviewer instructions: After interview: Please file signed consent sheet and interview schedule with handwritten notes securely. E-mail anonymised digitised interview recordings (as email attachment) to k.dillenburger@qub.ac.uk).

10.3 Participant Information and Consent form incorporating survey instructions for stakeholders (professionals)-on-line questionnaires.

On-line Information and Consent Form:BASE (Benchmarking Autism Services Efficacy) Project

This research is funded by the OFMDFM and has been approved by the School of Education (Queen's University Belfast) and the Office for Research Ethics Committee (OREC) ethical procedures for research involving human subjects.

The purpose of this project is to evaluate the current provision of autism services. This is a research project being conducted by Professor Karola Dillenburger in the School of Education at Queen's University Belfast. You are invited to participate in this research project because you work in a setting that provides education, health care, or social services for individuals with autism and their families. If this does not apply to you, please do not complete the on-line questionnaire, instead contact us to find out other ways in which you can take part in this research.

Your participation in this research study is voluntary. You may choose not to participate. If you decide to participate in this research survey, you may withdraw at any time. If you decide not to participate in this study or if you withdraw at any time, that's fine, there are no negative consequences.

The procedure involves filling an on-line survey that will take approximately 10 minutes. Your responses will be confidential and we do not collect identifying information such as your name, email address or IP address. The survey questions will be about autism awareness, the provision of staff training courses in autism offered by your employer and your perception of their effectiveness.

All data are stored in a password protected electronic format. To help protect your confidentiality, the surveys will not contain information that will personally identify you. The results of this study will be available in a final report (free download from www.qub.ac.uk/cba after completion of the project) and in subsequent academic publications/presentations.

If you have any questions about the research study, please contact Professor Karola Dillenburger, School of Education, Queen's University Belfast, e-mail at k.dillenburger@qub.ac.uk.

ELECTRONIC CONSENT: Please select your choice below.

Clicking on the "agree" button below indicates that:

- You have read the above information
- You voluntarily agree to participate
- You are at least 18 years of age

If you do not wish to participate in the research study, please decline participation by clicking on the "disagree" button.[NB ' agree' ticked for illustrative purposes only]

- agree
- disagree

INTRODUCTION to QUESTIONNAIRE:

Thank you for taking the time to complete this survey for the BASE project. Your opinions are important to help us advise policy makers on improving services for individuals with autism and their families.

This survey should take about 10 minutes of your time. Your answers will be completely anonymous. The survey results will be published in the final report, copies of which will be widely disseminated to politicians and policy makers, Directors of Autism Services and ASD Co-ordinators and will be available for free download at <http://www.qub.ac.uk/cba>

Any questions marked with an asterisk (*) require an answer in order to progress through the survey.

If you have any questions about the survey, please contact us at k.dillenburger@qub.ac.uk.

In order to progress through this survey, please use the following navigation buttons:

- Click the Next button to continue to the next page.
- Click the Previous button to return to the previous page.
- Click the Exit the Survey Early button if you need to exit the survey.
- Click the Submit button to submit your survey.

10.3.1 Questions for stakeholders (professionals) - on-line questionnaires

10.3.1.1 Public Sector employees

Autism awareness and training: Including **Health and Social Care Trusts**

The first two questions are about your employment

Q.1. Please indicate where you are employed:

Health and Social Care Trust: **Belfast/Northern/Southern/South Eastern/Western**

Education and Library Board: **BELB/NEELB/SEELB/SELB/WELB**

Government Department (name the department):

.....

Other Agency/voluntary organisation (name the organisation):

.....

Q.2. What is your job title?

The next few questions deal with professional autism /ASD training courses

Q.3. Were you offered autism training provided through your employer?

Yes /No

If you answered ‘**No**’ please go to **Q.7.**

If you answered ‘**Yes**’ please go to **Q. 4.**

Q.4. Did you undertake Level One (basic awareness) training?

Yes/No

If you answered ‘**No**’ please proceed to **Q. 5**

About level 1 training undertaken:

Did this give you an adequate knowledge of what autism is? **Yes/No**

Did this advise on how to adapt work practices? **Yes/No**

What was the duration (how many sessions/how much time was allocated per session)?

Which organisation provided the training?

Is this training accredited, and if so, by whom?

Q.5. Have you undertaken specific autism training at Level 2 (e.g. in dealing with problem behaviours, evidence-based interventions, effective communication etc.)?

Yes/No

If you answered ‘**No**’ please proceed to **Q. 6.**

About level 2 training undertaken:

Did this give you a more in-depth knowledge of the issues around engaging with individuals with autism? **Yes/No**

Did this advise on how to adapt work practices? **Yes/No**

What was the duration (how many sessions/what was time allocated per session)?

Which organisation provided the training?

Is this training accredited, and if so, by whom?

Q.6. Have you undertaken specialist autism training at Level 3 (diagnostic/assessment, e.g. ADOS/ADI-R, DISCO)?

Yes/No

If you answered 'No' please proceed to **Q. 7.**

About level 3 training undertaken:

Did this cover all the situations in which you currently engage with individuals with autism (e.g. group assessments)? **Yes/No**

Did this advise on how to adapt work practices? **Yes/No**

What was the duration (how many sessions/how much time was allocated per session)?

Which organisation provided the training?

Is this training accredited, and if so, by whom?

The next questions are more general queries about contact with individuals with autism

Q.7.a. . In a typical week, how many clients/pupils/students/patients with autism do you see?

Q.7.b. How often do you see clients/pupils/students/patients with autism? (Tick one).

Almost every day

About twice a week

About once a week

About once a fortnight

About once a month

Only a few times a year

I never see clients with autism

Don't know

Q.8. Do you have personal contact with anyone with autism?

No.

Yes - Family member/ friend/ colleague/ acquaintance (please indicate all that apply)

Q .9.a. Have you found your general professional (*i.e. non-autism specific*) training has been effective in preparing you for working with patients with autism? Please indicate **one** of the options below

Yes/Somewhat/No/Not applicable

b. Have you found autism specific training has been effective in preparing you for working with clients/pupils/students/patients with autism? Please indicate **one** of the options below

Yes/Somewhat/No/Not applicable

c. Did you experience informal 'on-site' training through observation and practice with experienced staff? Yes/No/Not applicable

Q.10. Is there anything you feel should be included to improve future training for professionals working with individuals with autism, either as clients/pupils/students/patients

or as colleagues?

Finally, although the survey is completely anonymous we understand that you may not wish to give personal information, and the following two questions are optional

Q.11 Please indicate your **age**: _____ years

Q.12 Please indicate your gender: **male/female**

Thank you for taking the time to complete this questionnaire. When the research project is finished we will send a copy of the final report to each participating Trust ASD Director and Co-ordinator and it will also be available on www.qub.ac.uk/cba.

10.3.1.2 Private sector employees

Autism awareness and training: Private Sector

The first two questions are about your employment

Q.1. Please indicate the sector in which you are employed

Agriculture, Forestry & Fishing

Mining & Quarrying

Manufacturing

Electricity, Gas, Steam & Air Conditioning Supply

Water Supply; Sewerage, Waste Management & Remediation

Construction

Wholesale & Retail Trade; Repair of Motor Vehicles & Motorcycles

Transportation & Storage

Accommodation & Food Services

Information & Communication

Financial & Insurance

Real Estate

Professional, Scientific & Technical

Administrative & Support Service

Public Administration & Defence; Compulsory Social Security

Education

Human Health & Social Work

Arts, Entertainment & Recreation

Other services

Activities of Households; Goods- & Services-Production for Own Use

Activities of Extraterritorial Organisations & Bodies

Not Known

Q.2. What is your job title?

The next three questions deal with professional autism /ASD training courses

Q.3. Were you offered autism training provided through your employer?

Yes /No

If you answered '**No**' please go to **Q.6.**

If you answered '**Yes**' please go to **Q. 4.**

Q.4. Did you undertake Level One (basic awareness) training?

Yes/No

If you answered '**No**' please proceed to **Q. 5**

About level 1 training undertaken:

Did this give you an adequate knowledge of what autism is? **Yes/No**

Did this advise on how to adapt work practices? **Yes/No**

What was the duration (how many sessions/what was time allocated per session)?

Which organisation provided the training?

Is this training accredited, and if so, by whom?

Q.5. Have you undertaken specific autism training at Level 2 (e.g. in dealing with problem behaviours, effective communication etc.)?

Yes/No

If you answered 'No' please proceed to **Q. 6.**

About level 2 training undertaken:

Did this give you an adequate knowledge of the issues around engaging with individuals with autism? **Yes/No**

Did this advise on how to adapt work practices? **Yes/No**

What was the duration (how many sessions/what was time allocated per session)?

Which organisation provided the training?

Is this training accredited, and if so, by whom?

6

The next questions are more general queries about how your work brings you into contact with members of the public with autism

Q.6a. In a typical week, how many clients with autism do you see? _____

Q.6.b. How often do you see clients with autism? (Tick one).

Almost every day

About twice a week

About once a week

About once a fortnight

About once a month

Only a few times a year

⁶ Erratum: Question re Level 3 training missing.

I never see clients with autism

Don't know

Q.7. Do you have personal contact with anyone with autism?

No.

Yes - Family member/ friend/ colleague/ acquaintance (please indicate all that apply)

Q .8.a. Have you found your general professional (*i.e. non-autism specific*) training has been effective in preparing you for working with employees/clients with autism? Please indicate **one** of the options below

Yes/Somewhat/No/Not applicable

b. Have you found autism specific training has been effective in preparing you for working with employees/ clients with autism? Please indicate **one** of the options below

Yes/Somewhat/No/Not applicable

Q.9. Is there anything you feel should be included to improve future training for professionals working with individuals with autism, either as clients or as colleagues?

Finally, although the survey is completely anonymous we understand that you may not wish to give personal information, and the following two questions are optional

Q.11 Please indicate your **age**:_____years

Q.12 Please indicate your gender: **male/female**

Thank you for taking the time to complete this questionnaire. When the research project is finished a copy of the final report will be available on www.qub.ac.uk/research-centres/cba

10.3.1.4 Policy makers

Government Departments: autism policies

The first two questions are about your employment

Q.1. Please indicate the Government Department or Agency in which you are employed

Q.2. What is your job title?

The next questions deal with your role as policy maker/advisor

Q.3. Which of the following sources of evidence do you use? Please tick all that apply.

Articles in peer-reviewed journals on autism issues

Departmental briefings

Academic books

Newspaper articles

Articles on national or international autism voluntary group websites

Articles on local autism voluntary group websites

Information from the All Party Group on Autism

Information from the Health Committee

Personal meetings with local autism voluntary groups

International conferences on autism issues

Local conferences on autism issues

International guidelines on autism

Other (please give

details) _____

Q.4. In preparing policy documents with respect to autism, who do you consult with?

Individuals with autism

Parent/carers of individuals with autism

Service providers (government agencies)

Service providers (voluntary groups)

Autism advice organisations (voluntary groups)

Other (please give details)

Q.5. Does your Department consult with other government departments in preparing autism policies?

YES/NO

If you answered **YES**, please list an example of cross-departmental working

Q.6. Does your Department evaluate the effectiveness of autism policy?

YES/NO

If you answered **YES**, please indicate the data you collect and how these are used.

The next questions deal with professional autism training and experience of living or working with individuals with autism

Q.7. Were you offered autism training provided through your employer?

YES/NO

If you answered '**YES**' please go to **Q. 8.**

If you answered 'NO' please go to Q.9.

Q.8. About autism training offered by your employer:

Did you undertake this training? **YES/NO**

(If you answered 'NO' please go to Q9).

Did this give you an adequate knowledge of what autism is? **YES/NO**

Did this advise on how to adapt work practices for people with autism? **YES/NO**

What was the duration (how many sessions/what was time allocated per session)?

Which organisation provided the training?

Is this training accredited, and if so, by whom?

Q.9. Do you have personal contact with anyone with autism?

NO.

YES- Family member/ friend/ colleague/ acquaintance (please indicate all that apply)

Finally, although the survey is completely anonymous we understand that you may not wish to give personal information, and the following two questions are optional

Q.10 Please indicate your **age**: _____ years

Q.11 Please indicate your gender: **male/female**

Thank you for taking the time to complete this questionnaire. When the research project is finished we will send a copy of the final report to each participating Government department/agency and it will also be available on www.qub.ac.uk/cba.

10.3.2 Participant Information Sheet and Consent form for education sector professionals

School of Education

Queen's University Belfast

Research Project

PARTICIPANT INFORMATION SHEET

You are being invited to take part in a research study. Before you decide whether you want to take part or not it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

The BASE Project (Benchmarking Autism Services Efficacy)

This research aims to find out how effective current government policies and strategies are at delivering the services needed and wanted by individuals with Autism Spectrum Disorder (ASD), their carers, teachers and lecturers, and employers. We hope to be able to inform policy makers, professionals, individuals with autism, and parent/carers about these important issues. The Research Ethics Committee of the School of Education, Queen's University Belfast reviewed and approved this research. You have been chosen to take part in the study as you work with students with ASD. If this does not apply to you, please let us know immediately.

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. Your decisions either way will not affect any services you receive.

If you decide to take part you will meet the researcher for an interview at a place which is convenient for you, and you will be asked for your views on support services at home, in education and in the workplace. This interview will normally be recorded but if you prefer, you can ask for the researcher to make notes instead or you can request a questionnaire to

complete yourself (either in hard copy or on computer). It should take no longer than 45 minutes to complete in any format.

All information that is collected about you during the course of the research will be kept strictly confidential (except as might be required by law). Any information about you will have your name removed so that you cannot be recognised from it. Once the study is completed results will be presented in written papers and in oral presentations, and the final report will be available on our website: <http://www.qub.ac.uk/research-centres/cba>. I am the Principal Investigator on this project and if you have any further questions you can contact Professor Karola Dillenburger by e-mail at k.dillenburger@qub.ac.uk, or you can contact Dr Lyn McKerr at 02829541991 or Dr Julie-Ann Jordan at 02890973177.

Thank you very much for reading this information sheet.

Consent form as 10.1

10.3.2.1 Template semi-structured interview for Education sector professionals who work with students with autism

Interviewer instructions:

Before interview, print out for each interviewee: **Participant information sheet and consent form, and interview schedule**. Ensure that your tape-recorder is working.

At beginning of interview: Get interviewee to read the participant information sheet and sign the consent form (read it out if necessary). Only proceed if interviewee has signed the consent form. If not, discontinue and thank the participant for taking time to consider contributing to research.

During interview: If consent form signed, switch on tape recorder. Read out each question and give time to answer in full. Make sure that all questions are covered. Feel free to add any clarifying questions as necessary. Make notes during the interview on the interview sheet e.g. especially name and date etc. Start interview by saying:

“Thank you very much for agreeing to take part in this interview. The interview should take between 30 and 45 minutes in total but we can take a break at any point if you wish.” If the participant has agreed on the consent form to the interview being taped then also say.. *“I hope you don’t mind if I tape-record this interview so that I can be sure not to miss out on anything you say.”*

The first few questions are about your current job, and your professional qualifications.

Q.1. Which sector are you are employed in?

Pre-School/Primary/Secondary/Further Education/Higher Education

Sector specific information-Education and Library Board area/ institutional organisation

Q.2. What is your job title, and how long have you held that position?

Q.3. Which professional qualifications do you hold?

E.g. Diploma, Bachelor's/Master's/Doctoral/ degree, postgraduate teaching qualification etc.

Q.4. Have you found your general professional (i.e. non-autism specific) training has been effective in preparing you for working with students with autism?

Did your general professional training include topics such as autism? If so can you tell me something about this?

The next questions are about your work with students with autism

Q.5. Do you work directly with students with autism in a formal setting (e.g. in class/one-to-one advisory or teaching/seminar group/counselling session)?

If so, how many students with autism do you work with?

And how often do you work with students with autism?

(E.g. Daily, several times a week, monthly)

And what support do you provide to students with autism?

Do you engage with students with autism in less formal settings (e.g. /pastoral care/assembly hall/playground/ library /examination hall/sports/study group)? [Question will be framed according to setting]

How often, in a typical week, do you engage with students in this way?

What age groups of students with autism do you work /engage with?

Do you enjoy working with students with autism?

If so, what do you enjoy the most?

Do you find that there are the challenges when working with students with autism?

If so, what are the main challenges?

Q.6. Were you offered autism training that was provided through your employer?

If so was this at Tier⁷ One (basic awareness), Tier 2 (dealing with problem behaviours, effective communication etc.), or Tier 3 (Targeted training for teachers of pupils referred to ASD service)?

Did this give you an adequate knowledge of what autism is?

Did this advise on how to adapt work practices?

How long was the training course?

How useful did you find it?

*Which organisation provided the training, and is it accredited? **If so**, by whom?*

Q.7. Have you undertaken any other autism training (e.g. postgraduate course in autism education, training through a voluntary group).

If so, please tell me about it

Did you finance this yourself or did your employer assist with fees or arrange study leave?

How useful did you find it?

Q.8. Does your employer provide on-going support (e.g. through the ELB Autism Support Team, such as Autism Advisory and Intervention Service (AAIS), Multi Agency Support Team for Schools (MASTS) or through Student Support/Guidance centres etc.)

If so, how frequently is this available?

Do you find it has been useful?

Q.9. Apart from your students, do you have personal contact with anyone with autism?

E.g. Family member/ friend/ colleague/ acquaintance

⁷ Erratum; this should have been Level not Tier

If so, do you think this has affected your working practices?

Q.10. Do you feel that there are positive aspects of the learning environment for students with autism in your institution/school?

If so, what are these?

Do you think that any part of the learning environment could be improved for students with autism in your institution/school?

If so, what could be improved?

Does your institution/school place any emphasis on non-academic areas of the curriculum e.g., social/daily living skills and employment experience [where appropriate]?

If so, how useful do you think this is for students?

Q.11. Finally, is there anything you feel should be included to improve future training and support for professionals working with individuals with autism?

Thank you very much for participating in this interview. Your answers were very informative and helpful. Once the study is completed results will be presented in written papers and in oral presentations, and the final report will be available on our website. The details for this web site are on the Information Sheet you were given earlier.

Interviewer instructions: After interview: Please file signed consent form and interview schedule with handwritten notes securely. E-mail anonymised digitised interview recordings (as email attachment) to k.dillenburger@qub.ac.uk.

10.3.3 Participant Information Sheet and Consent forms for interview with Case Study Employer

School of Education

Queen's University Belfast

Research Project

PARTICIPANT INFORMATION SHEET

You are being invited to take part in a research study. Before you decide whether or not to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

The BASE Project (Benchmarking Autism Services Efficacy)

This research aims to find out how effective current government policies and strategies are at delivering the services needed and wanted by individuals with Autism Spectrum Disorder (ASD), their parents/carers, teachers and lecturers, and employers. We hope to be able to inform policy makers, professionals, individuals with autism, and parent/carers about these important issues. The Research Ethics Committee of the School of Education, Queen's University Belfast reviewed and approved this research. You have been chosen to take part in the study because you are the employer of an individual/ individuals with ASD. If this does not apply to you, please let us know immediately.

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. Your decisions either way will not affect any services or support your organisation receives.

If you decide to take part you will meet the researcher for an interview at a place which is convenient for you, and you will be asked for your views on employing individuals with ASD, and on workplace issues such as funding, training and support services. This interview

will normally be recorded but if you prefer, you can ask for the researcher to make notes instead. It should take no longer than 45 minutes to complete in any format.

All information that is collected about you during the course of the research will be kept strictly confidential (except as might be required by law). Any information about you will have your name removed so that you cannot be recognised from it. Once the study is completed results will be presented in written papers and in oral presentations, and the final report will be available on our website: <http://www.qub.ac.uk/research-centres/cba>

I am the Principal Investigator on this project and if you have any further questions you can contact Professor Karola Dillenburger at k.dillenburger@qub.ac.uk, or you can contact Dr Lyn McKerr at 02829541991, or Dr Julie-Ann Jordan at 02890973177.

Thank you very much for reading this information sheet.

CONSENT FORM as for 10.1

10.3.3.1 Semi-structured interview questions for case-study employer of individual (s) with ASD

Semi-structured interview questions

Interviewer instructions:

Before interview, print out for each interviewee: **Participant information sheet and consent form, and interview schedule**. Ensure that your tape-recorder is working.

At beginning of interview: Get interviewee to read the participant information sheet and sign the consent form (read it out if necessary). Only proceed if interviewee has signed the consent form. If not, discontinue and thank the participant for taking time to consider contributing to research.

During interview: If consent form signed, switch on tape recorder. Read out each question and give time to answer in full. Make sure that all questions are covered but remember that all prompts (ancillary questions in italics which are **not** in bold) are there to aid the flow of the interview but should not be automatically read out. Feel free to add any clarifying questions as necessary. Make notes during the interview on the interview sheet e.g. especially name and date etc. Start interview by saying:

“Thank you very much for agreeing to take part in this interview. The interview should take no longer than about 45 minutes, and if there are any questions you would prefer not to answer, these can be left out. I hope you don’t mind if I tape-record this interview so that I can be sure not to miss out on anything you say [if this has been previously agreed].

1. Firstly, some brief questions just to put together some general information about your organisation:

Nature of business:

Your position:

Number of employees overall:

Number of people known to have autism currently employed: Full-time

Part-time

How many of these positions are permanent?

2. Can you tell me the reasons your organisation specifically employs individuals with autism?*E.g. personal decision by management, based on family circumstances, potential benefits such as work fitted with profile of individuals with autism*

How long have you had a policy of specifically employing people with autism?

How many people with autism (that you know of) have worked in your company to date?

3. Can you tell me something about how your organisation currently recruits individuals with autism? *E.g. through Job Centres, through partner company or voluntary*

agency

Do you recruit across the spectrum? Or e.g. recruit only individuals with learning disabilities, or those who are 'high-functioning'?

4. What jobs do staff with autism carry out in your company?

Are there opportunities for staff-including those with autism- to undertake further training and qualifications? If so, what is the uptake among staff?

5. Do your employees with autism have a pre-placement programme? If so, can you tell me something about this? Does another organisation carry this out? Who funds this?

6. Have you made any adjustments to your working environment to accommodate staff with autism? If so what are these? E.g. quiet work areas, structured breaks, special equipment etc.

If so, did they require any extra expenditure, and how was that funded?

7. What areas (if any) do you find your staff with autism need most support with? E.g. transport to work, executive function skills (organisation, time keeping, staying on task, appropriate behaviour in the workplace) managing stress etc

Do you have a support programme in the workplace for each staff member with autism?

If so, who advises you on this, and how is it funded?

8. Have you offered autism training for other staff?

If so, how is this delivered, and by whom? How do you judge if it is effective?

9. Can you outline any particularly positive aspects for your company in employing people with autism?

10. Can you outline any particularly negative aspects for your company in employing people with autism?

11. Are there any barriers which prevent you employing more people with autism? If so, what are these?

12. Are there any measures which would encourage you to take on more staff members with autism? E.g more pre-placement training or more accurate pre-placement profiling, more funding/longer term funding for support in the workplace etc.

13. Finally- can you offer any general advice for other employers who might be considering employing people with autism?

Thank you very much for participating in this interview. Your answers were very informative and helpful. When the research is complete we will be making the report available on our website- the details are on the information sheet we gave you earlier.

10.4 Participant Information Sheet for child (aged 14 -17) with ASD in school setting

[Note to researchers: cartoon images may be omitted for older students]

Insert picture of
researcher here.

Note: you can
expand/contact the
size of this box to fit
your picture

School of Education Queen's University of Belfast
BASE Research Project

My name is xxxxx and I am working as part of a team at Queen's University Belfast, looking at how government policies affect the services available for children, young people and older people with autism (sometimes called ASD- Autism Spectrum Disorder). You can contact me at [Insert e-mail address of researcher in picture]

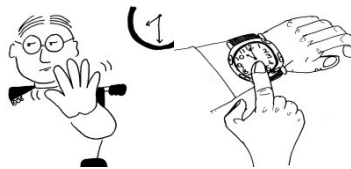
BASE project

No one knows what it is like at home, at school or college for someone with autism as much as you do. We are asking a number of people, including parents/carers, children and some adults with autism, what services they use, about school, work and college opportunities, and how they like to spend your spare time.

Some people in my work have looked carefully at our ideas (they are called the 'Ethics Committee' of the School of Education at Queen's University) and think that it's ok to do this research. If you agree to take part, we will organise a 'focus group' where you together with a number of other young people with ASD from your school or college can give your views on the issues that matter to you about education, social life and plans for the future

I ask you to take part in this research because we would really like to hear about your experiences as a young person with autism. We have chosen you because you are at school or college and your parent/carers help look after you. We will tell no one your exact name or where you live, so you don't have to worry about what you say. We will tell only that 'someone' has told us, not that it was you. I will only tell your teachers or your family what you say, if there is anything that makes me really worried about you.

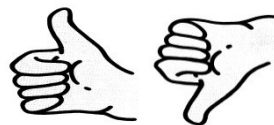
You can ask to leave the focus group at any time. You don't need to explain or worry about leaving if you don't want to stay. It should take no longer than half an hour, but if people want to talk for longer, then that is fine.



I will read this form to you, or you can read it yourself so you know what to expect.



Then you can make up your mind if you want to take part or not. You can say yes or no. It is up to you whether you take part.



If you would like to talk to me, I would be very grateful if you could sign the attached form and then we can talk.



If not, you can keep this sheet and let me know if you change your mind later on.

If you would like to know more about the project after I leave, please give e-mail me or you can speak to the Principal at your School/College



Thank you for taking the time to read this letter and for your help.

¹⁵ Images and format are adapted from University of Lancaster forms available on <http://www.lancs.ac.uk/researchethics/1-4-samples.html>

(Form to be on headed paper)

CONSENT FORM

Title of Project: **BASE Project**

Name of Researcher: Dr Julie-Ann Jordan/ Dr Lynne McKerr

Please tick each box

- I have read and understand the information sheet and have asked any questions I need to
- I know that I don't have to take part if I don't want to and nothing bad is going to happen.
- I understand the interview will be recorded
- I agree to take part in the above study.

Name of Participant	Date	Signature
---------------------	------	-----------

Name of Researcher	Date	Signature
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1 for participant; 1 for researcher

Preparatory information: to be completed before focus group begins

Venue:

Date and Time:

Researchers:

Recording equipment:

Participant details:

First name	Year Group	Age

10.4.1 Focus Group questions for Students at Secondary school

Pre- session introductions: This will include the names of researchers, a brief background to BASE and an explanation of the consent process. All individuals will have received a copy of this documentation in advance but consent forms will be signed in the presence of the researchers. Students will add their first names, Year Group and ages on an information sheet, and stick-on name badges will be distributed.

Aims: *We want to discuss some of the services for students with autism provided by government agencies such as Education and Library Boards, Health and Social Care Trusts and by voluntary organisations. We are particularly interested in how you feel the Education and Health/Social Care system is preparing you for the transition from school, and for adult life.*

Guidance for how this works: *We hope you will feel you can take part fully and we will respect the comments of everyone round the table. There are no right or wrong answers, and please feel free to join in with your opinion. I will be asking questions and making sure that everyone has a chance to put their point of view, and [Researcher] will be taking notes and recording answers. What you say here is important for our research and we may quote certain phrases that you use in the final report but there will be nothing published that can identify you.*

Method of recording: *We will be using a voice recorder, flip chart & note taker (unless a request not to use the voice recorder has been received at the Participant Information/ Consent form stage)*

Topics

Introduction: *Recent figures indicate that as many as two in a hundred children are currently being diagnosed with autism, which means a lot of young people with ASD will eventually be making choices about their future in education and in the workplace. The government funds a variety of services for people with autism, and their families, across the life course, so your experiences and your views are important in helping them plan for effective use of their spending.*

Opening question:

1. It's great to see you here today- I'm XX, and I'll be asking for your opinions about the topics we are interested in and this is my colleague YY, who will be taking notes, and we are both from the School of Education at Queen's University. Just to help us get

to know each other a little better, I'd like to ask each of you in turn to tell us your first name and the subjects you are currently doing -and also about your hobbies and interests when you are not studying.

Introductory question:

2. What do you think makes a school or college a good place to be for young people with autism?

Transition questions:

3. Thinking back to when you were at primary school, do you think your teachers and other staff had a good understanding of what it was like for a student with autism?

Did they ask you what would be helpful in class or in examinations?

Did they involve you and your parents in e.g. reviews of your progress?

4. Do you think your primary school prepared you for the experience of secondary education?

Did you have the chance to visit or spend the day at your chosen secondary school before you transferred?

Did you have a choice about how you would travel to your new school?

Key questions

5. What were the issues- both positive and negative- around transferring to this school?

e.g. Choosing new subjects

Getting used to the school building and school rules

Travelling to school

Mixing and making friends with a new group of people

Parting with old school friends who were going to different schools

Change of support staff

6. Which of these were the most concerning to you at the time?

7. Have you talked about/ taken on work experience opportunities through school?

Have you asked for careers advice?

Have you had any contact with the Transitions team (specifically for those aged 14+)

Do any of you have a part-time job at holiday times or after school?

8. Has your time at this school been a comfortable and worthwhile experience?

If Yes, what made it comfortable/

What made it worthwhile?

Is there anything about school life which you think could be improved?

9. What do you want to do once you complete your current course of study?

Has your school offered you employment advice?

Are you aware of any support schemes for finding work or training placements for young people with autism?

Are you considering going to college or university?

Are you aware of the range of benefits which may be available for students with autism at college?

Are there any other skills you would like to acquire which might be useful in the job market?

Ending the session.

10. Finally- have you any advice for other young people with autism – or for the people who make policy decisions- about how to make the most of opportunities at school or in social activities?

Is there anything else you think we should have talked about, but didn't?

Thank you very much for taking part in this focus group: your input is very important to us and when the research is complete we will be making the report available on our website- the details are on the information sheet we gave you earlier

10.4.2 Letter incorporating Participant Information Sheet and Proxy Consent forms for parent/guardian of child aged 14-17

(To be on headed paper)

Centre for Behaviour Analysis
School of Education
69-71 University Street
Belfast BT7 1NN
DATE

BASE Project (Benchmarking Autism Services Efficiency)

Dear Parent/Guardian

My name is Professor Karola Dillenburger and I am leading research on the BASE project reviewing autism services. The Principal of your son or daughter's school/college is aware of our research and has identified young people who would be able to and are interested in taking part. The study has been approved by the Ethics Committee at Queen's University Belfast, and the researchers have Access NI clearance.

We plan to talk to students with autism from your child's school (as part of a Focus Group) on issues around education and employment support services and also about their hobbies and interests. We intend to tape record the Focus Group session to help write a report. However, the discussions will be confidential and the only people who listen to the recordings will be the research team. No one will be named in the report, and no details that might allow someone to be identified will be included. Once the study is completed results will be presented in written papers and in oral presentations, and we will notify your child's school/college when the final report is available on our website: www.qub.ac.uk/cba

We have asked the students themselves for consent to being interviewed. Staff members who know your son/daughter have helped explain the study to them, and I enclose copies of the Participant Information Sheet that they received. If you are willing to agree to your son or daughter taking part, I would be very grateful if you could sign the attached form and return it to school/college. If you would like to know more about the project, I would be very happy to explain it further. If you wish to do this, please feel free to contact me by e-mail at k.dillenburger@qub.ac.uk.

Many thanks for taking the time to read this letter and for your help.

Yours sincerely

(To be on headed paper)

Consent Form

Re: BASE Project

I am aware that my son/daughter * (print name).....
has agreed to take part in BASE Project

I wish my child to take part in the project.

Signed.....Parent/Guardian

Please print your name.....

10.5 Letter incorporating Participant Information Sheet for Principal /Board of Governors of participating educational establishments of students (see 10.1 and 10.4).

(To be on headed paper)

Centre for Behaviour Analysis
School of Education
69-71 University Street
Belfast BT7 1NN
DATE

Dear Principal/Chair of Board of Governors,

We are currently carrying out a research project which will involve setting up focus groups with young people with autism, and have previously been in contact with you/the Principal to discuss the possible participation of your school/college in this study. As agreed, I am sending you information on the project so that you can consider if your school can participate in the research by allowing us to approach your students to see if they would be interested in taking part in a focus group.

The BASE Project (Benchmarking Autism Services Efficacy)

This research is funded by the Office of the First Minister/Deputy First Minister (OFMDFM) and aims to find out how effective current government policies and strategies are at delivering the services needed and wanted by individuals with Autism Spectrum Disorder (ASD), their carers, teachers and lecturers and employers. We hope to be able to inform policy makers, professionals, other individuals with autism and parent/carers about these important issues. The Research Ethics Committee of the School of Education, Queen's University Belfast reviewed and approved this research.

If you do decide to facilitate this research, students will be given the attached information sheet to keep and be asked to sign a consent form. If they decide to take part, they are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect any services they receive.

If they decide to take part they will meet the researchers in an informal focus group setting in a familiar environment within school/college premises, and they will be asked for their views on support services in education and in the workplace; the outline focus group schedule is attached.

This session will normally be recorded but if anyone prefers otherwise, the researcher will make notes instead. It should take no longer than 45 minutes to complete.

All information that is collected about students during the course of the research will be kept strictly confidential. Once the study is completed results will be presented in written papers and in oral presentations, and we will notify you when the final report is available on our website: www.qub.ac.uk/cba

I am the Principal Investigator on this project and if you have any further questions you can contact me at k.dillenburger@qub.ac.uk.

Thank you very much for considering participating in this study.