

Learning and development for family/unpaid carers of children/young people with a learning disability and/or autism: rapid evidence review and mapping study

Report to Skills for Care

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Key points

Preparing for adulthood and transition is a scary time for all young people but also an opportunity for them to try new things and work out what they want for their future. Having a good understanding of the opportunities available in a local community and the chance to try out different activities is vital. So too is having people around who understand and value their strengths and abilities and what support they will need to succeed. Friends and relationships for young people with SEND are particularly important to enable them to develop a sense of belonging and well-being.

The system may aim to fully involve young people with SEND and their parents in transition planning and utilise a person-centred approach, but this is often not the reality. Parents often feel undervalued and underutilised during planning and can feel unheard and anxious. They are concerned about their children's safety and futures and how well the system will support their needs. Parents must research and co-ordinate the transition process whilst also continuing to provide care.

There is evidence from a range of established parenting programmes that tailored support and development for parents of children with learning disabilities and/or autism can be effective in improving parenting behaviour, increasing parental confidence and improving child behaviour. Little or no evidence exists about the role such programmes play in longer-term outcomes and **little work has been done to utilise these programmes with older children or young adults.**

There is emerging evidence from the US that **tailored development opportunities for parents of transition age children with autism spectrum disorder can be beneficial.** These courses have positive results, but more evidence is needed (e.g. how well do they work with parents of children with other disabilities). UK based initiatives have had positive results using key workers and a broader support package to work with families. **Developing parents is one way of addressing the difficulties faced during the transition period, but there are others.**

Parent's access to development opportunities is currently driven by geography rather than level of need. Development opportunities tend to draw on elements from more established parenting programmes and have often been co-designed by parents working with experienced professionals. However, there is **little evidence about what impact these programmes have on transition outcomes** and a more robust evidence base is required before firm conclusions on the best way to support parents can be drawn.

The **benefits of developing parents**, rather than taking another approach are that this:

- promotes parental **skills and resilience** acting as a low-level preventative measure
- creates **strong peer support networks** when parents learn together
- can be relatively **self-sustaining** when parents go on to support others, act as parent trainers or work to influence practice
- promotes skill development amongst a **lifelong unpaid care workforce**
- is potentially a **cost-effective** way of helping parents.

There are a number of common elements of existing development opportunities, these include: providing clear, accessible and practical information; working with families well before their child turns 18; bringing parents together; coverage of legal rights and responsibilities; developing advocacy and/or mediation skills; using person-centred planning techniques, and; promoting parent resilience. However, **more evidence is needed on what impact these initiatives have and how they work.**

Recommendations from this research are to:

- **engage in further consultation** and discussion about the way forward particularly with organisations already working in this area and with parents
- **promote better evaluation** and impact assessment, including pilots of the most promising approaches
- better **coordinate local and national efforts**, pooling knowledge and resources so that organisations can collectively add value to what is possible when they work alone.

Executive Summary

Details of the research

The transition into adulthood for young people with a learning disability and/or autism can be a difficult and complex process. Despite a range of law, regulation and guidance, families and young people often have negative experiences at this point in their lives.

This research was undertaken between October 2018 and April 2019 by Research Partners on behalf of Skills for Care. It was commissioned to explore the available evidence about the impact of tailored learning and development activities for parents of children with a learning disability and/or autism, and whether such activities support families through the process of transition into adulthood. The study included both a rapid evidence review and a consultation with individuals from a range of relevant organisations. Many of those responding as professionals also had lived experience of parenting a child/young person with a learning disability and/or autism and a small number of parents also shared their stories.

The research focussed on three main areas.

- What do we know about the experience of transition from the perspective of parents and families of young people with LD and/or ASD?
- What do we know about the established parenting interventions for family carers of young people with LD and/or ASD?
- What interventions exist to support parents during transition?

Parental experience of transition.

Transition is a difficult time for parents. Parents of young people with a learning disability and/or autism are required to take on a dual role during transition. In addition to the role they already play in supporting their child with care and domestic tasks, they also need to act as a coordinator of their child's care and opportunities. This latter role includes a range of additional planning, liaison and research tasks. The developmental process of transition can also pose additional challenges for parents as their child grows physically and emotionally at the same time as significant changes to their educational setting and statutory support occur. Not surprisingly parents can find the demands placed on them during this period overwhelming and their own lives can be significantly compromised as a result.

Parents play a crucial but undervalued role. Transition works best when parents are fully involved in the process and families are a vital source of support which the state relies on them providing. Despite this, parents often feel that they receive inadequate information about the options available to their children and that they are not fully involved in decision making. Parents may not feel that their unique perspective on the needs, aspirations and skills of their children are recognised or utilised during transition. They can, therefore, feel anxious and uncertain about the future and it can be emotionally and practically difficult to coordinate the transition process whilst also feeling unheard and ignored.

Person-centred planning is not a consistent reality. Person-centred planning offers a strengths-based approach to discussing preferred future options. It should be fully accessible to young people and their families and help them feel included in the process whilst focussing directly on what young people really want and need. The reality is that the current system can struggle to fully adopt a person-centred approach. Professionals can lack relevant experience, the system can be too inflexible or paternalistic, the process starts too late, and the options are too limited for young people and their families to be placed at the heart of the transition process. Parents

can also find it difficult to adopt a strengths-based approach when working with professionals because they have spent years working within a system that focusses on their child's disability rather than their abilities.

Transition is often a time of conflict. All parents feel some degree of conflict about their child becoming more independent, but when that child has a learning disability and/or autism there are other factors to consider. Parents often fear that their children will receive a poor quality of care/support/options and lack faith in the transition process. They also have, often understandable, concerns about safety. Such concerns can lead parents into conflict with professionals many of whom are not fully trained in how to work successfully with parents. Poor relationships between professionals and parents become a further barrier to a successful transition.

Complex system which hands over rather than transfers young people into adult services. Adult services are not always fully involved in transition planning, and transition is linked to a range of policy areas (i.e. housing, health, social care, education) which mostly operate independently of one another. Knowledge built up over years of joint working between families and child services can be lost. A systematic approach to managing the transition process, transitional workers, formal intra- and inter-agency working and a case management approach have all been shown to support more successful transitions. For many families, however, the reality is poor agency coordination, and a lack of clarity and information about planning and options. Parents, therefore, need to navigate the transition alone, but this requires a range of skills and resources which not all parents have.

Parents value clear and written plans, high-quality information and access to emotional support. Parents define a good experience of transitions as related to supportive services which lead to informed decision making and realistic and satisfactory options after school and which promote strong social and community networks. Parents can struggle to find the information they need, lack the resources necessary to act as effective advocates for their child and/or find it hard to support their child's social networks and social skill development. Meeting with other parents and being given the tools for self-care are important support mechanisms. However, the emotional and financial resources available to parents, combined with their knowledge of systems and networks can be key in overcoming barriers.

Established parenting programmes

Established parenting programmes are proven to have a positive impact, but little evidence on their role in transition. Evidence was examined for four established parent training programmes which have been adapted or tested on parents of children with learning disabilities and/or autism. They provide useful indications of some of the elements which have been proven to have a positive impact on parents but there is little or no evidence regarding their impact on transitions through either their use with parents of older children or longer-term tracking of transition outcomes. Despite recognition that the needs of children with learning disabilities and/or autism change as they age, research is yet to fully examine the role of parent training in the transition of children into adulthood.

The programmes share core characteristics. All the programmes offer support through psychoeducation and skill development to improve parenting skills and tackle challenging behaviour and are typically delivered in a group format.

Parents value these programmes and find them useful. There is a consensus that the programmes provide benefits in terms of improved parenting behaviour, increased parenting confidence and improved child behaviour although most evidence is from outside the UK. The group format and chance to meet others in a similar situation is seen as an important component

of the training. There is also evidence that a tiered approach can be used to offer tailored support based on need.

Other ways of supporting parents

The review found two **UK based initiatives have had positive results using key workers to support families**. These programmes both involved a key worker as a single point of contact for families acting as a coordinator, adviser and system navigator. In both cases, the keyworker was part of a broader support package, although the precise role of the keyworkers varied between projects. Evidence from the evaluation of these initiatives suggests positive transition outcomes as a result of the interventions, particularly because they went beyond planning for transition and focussed on achieving desired transition outcomes.

US studies of training interventions to develop parents also suggest positive results. The review found two US studies focussed directly on developing parents of young people with autism spectrum disorder with transition using (primarily) group delivery methods, although one also included a distance learning element. Both aimed to develop the advocacy skills of parents, with one also covering other topics related to transitions (e.g. behavioural management strategies, negotiation of service systems and long-term planning). There is positive evidence from both programmes, but further research is necessary to fully determine their impact and to investigate their utility with parents of children with other disabilities.

Current initiatives to support parents

Each local authority must support a parent carer forum and provide an Information Advice and Support Service (a telephone advice line with the potential to offer face to face support) as part of their local offer. Funding levels for these services are locally determined, as is the decision to support other services for parents/families. There are examples of good practice, such as offering a dedicated Transition Support Service, but in some areas, provision is limited.

National organisations offer a range of services related to transition, including transition events and resources designed to inform and educate parents about the transition process or their child's development at this time. The National Autistic Society also offers a specific 'Transition Support Service' which offers bespoke advice and support to families on transition issues. For parents of children with other disabilities, however, no such service is available, although other condition-specific charities can help parents through transition if they are approached.

Local organisations, generally third sector, have developed a range of training and development interventions for use with families. Some of these focus specifically on transition issues and are supported by other specially designed resources. There is little evidence of joint working between these organisations and some have developed similar interventions independently of one another.

Access to support is driven largely by geography rather than need. Whether parents have access to learning and development is largely determined by the funding position taken by their local authority and the level of funding local third sector organisations can secure from a range of sources. Many community organisations would like to expand their work to more people or cover more/different transition topics if funding was available to enable them to do so.

Many interventions are co-designed by parents working with experienced professionals. The development opportunities currently available share characteristics with established parenting programmes and certainly look and feel like good practice. Each organisation may be working with only small numbers of parents, but some organisations have developed sustainable models (e.g. programme graduates go on to become parent trainers). There are also examples of parent graduates working together to provide mutual support in the longer-term.

More robust evidence is needed before firm conclusions about the best way to support and/or develop parents can be drawn. Whilst most organisations collect parent satisfaction data, few have been able to compile robust data on the impact of their programme. For this to happen it is likely that organisations will need to be encouraged and supported to both coordinate their efforts and work towards measuring meaningful indicators of impact. At a time when resources in the third sector are already under pressure, any co-ordination/evaluation efforts will most likely need to be accompanied by financial support to be successful.

Caveats and scope

Before going on to discuss the conclusions of this research it is important to clarify its scope.

Development work with parents is not discussed in this research as a replacement for other forms of support or ways of improving transitions. Future strategies should build on existing relationships and provision. Professionals also require further development to promote better transitions and young people need to play a more meaningful role in transition planning. These issues are an important backdrop for this research but beyond its scope. Developing parents is also only one of many things that could be done to promote more successful transitions (e.g. use of keyworkers) but this research has focussed on how parents can be helped to help themselves.

The focus on parental development in no way implies that parents are not already doing everything they can. Parents are not 'the problem', and have a range of unique skills, experience and perspectives that could be more effectively utilised during the transition process. The development activities discussed in this report are not about being better parents or about parents doing more, rather they focus on providing parents with a broader range of information and strategies to support them with their existing, challenging, role in the transition process.

Conclusions

Developmental opportunities for parents have the potential to:

- give parents the information, skills and resilience they need to work positively through the transition process
- establish and promote positive peer networks
- provide lifelong carers with techniques they can use throughout their lives
- be a cost-effective way of supporting parents.

Despite these observed benefits, there is a lack of solid evidence about the impact of developing parents. We cannot say whether access to an established parenting programme early in life leads to more successful transitions into adulthood, for example. Similarly, whilst many initiatives which directly target parents during the transition period seem to demonstrate good practice and can claim examples of excellent outcomes, there is a lack of systematic evidence about the impact of different programmes or about their relative merits. There is, however, a great deal of collective knowledge in the public and third sector, strong views on what works and what doesn't and a range of promising approaches already in place. It will be important that any future work builds on this.

There is a degree of consensus on elements that parents want and find useful, these are:

- clear, accessible and practical information focussed specifically on the transition process
- working with parents at an early stage to avoid crises when the young person reaches 18
- allowing parents to learn together, support one another and share experiences, insights and information
- coverage of legal rights and responsibilities so that families can speak authoritatively about their entitlements
- techniques to help parents prioritise and promote their own well-being and resilience

- developing advocacy and/or mediation skills
- person-centred planning techniques.

Future development work must capitalise on existing networks, reputations, knowledge and skills whilst also promoting a more consistent offer for parents. Development opportunities must also be made fully accessible if they are to help those families whose needs are greatest.

Recommendations

This paper should be viewed as a starting point for further consultation and discussion as there is insufficient existing evidence about parent development initiatives and how/how well they work.

Our recommendations at this stage are therefore that:

- Any next steps or firm recommendations about how best to support parents in future should be created in tandem with organisations already working in this area and with parents. Co-production must be a reality.
- Local and national third sector organisations should be brought together to capitalise on their collective knowledge and to allow them to share resources. It is not necessary to invent a new way of doing things, organisations are already likely to have the answers, but a coordinated national network would facilitate greater collaboration and be a good way to reach consensus on what is likely to work best.
- Once consensus is reached regarding the most promising models of parental learning and development, these must be properly piloted and evaluated. Using evaluation evidence from these pilots a set of actionable, costed alternatives can be developed and used to set out a clear way forward.

1. Project method and policy background

Key points

The research was commissioned in response to feedback that Skills for Care had received that if families received tailored learning and development, they would be better able to support young people with learning disabilities and/or autism through their transition into adulthood. The project took place between October 2018 and April 2019.

The aim of the research was to investigate the available evidence on learning and development for parents of young people with learning disabilities and/or autism during the transition into adulthood. A rapid evidence review was conducted of academic and other literature alongside a series of interviews with representatives of organisations with expertise in the area. The purpose of the consultation was to determine what support currently exists for parents and to map the national picture.

1.1. Introduction

This report presents the results of a research project commissioned by Skills for Care and conducted by Research Partners. The research took place between October 2018 and April 2019.

A regular message given to Skills for Care is that if families caring for a child or young person with a learning disability and/or autism had access to tailored learning and development, then those families would be better equipped to support their son, daughter, sibling, grandchild, friend etc. as they move from children's services to adult life. Skills for Care set out to determine what published evidence, if any, existed to support this idea.

1.2. Project aims

The aims of the project were to investigate the available evidence on:

- the knowledge and skills family and/or unpaid carers require
- the availability of learning and development for families and carers
- the impact of existing learning and development, particularly on individuals, their care, support delivery and the impact that this has on service use.

1.3. Definitions

Transition

The term transition is used to describe a range of different life events in different contexts. The transition into adulthood is both a developmental process which occurs for all children but which for children with learning disabilities and/or autism, coincides with a move from child to adult services.

Planning for this stage in life can begin at any age, but a formal process should begin by the time a young person with Special Educational Needs and Disability (SEND) is in Year 9. The transition planning process should involve all the services that support young people's needs in relation to health and social care; mental health; education; financial benefits for the young person and their family; work, and; housing.¹

¹ According to [NHS.co.uk](https://www.nhs.uk)

Development activities

In examining current work and existing practice which supports families and unpaid carers, this research has not been prescriptive on what constitutes developmental activities. A range of different approaches to the development of family and unpaid carers are therefore examined. These include taught courses, seminars, support groups, advocacy work, telephone helplines and other mechanisms whereby information, advice or support is provided to families and/or which empower them to act on their own behalf.

1.4. Study methodology

There were two main research stages; a review of existing academic and other literature, and a consultation process to map out existing training, development and support for parents. The focus of both phases was on initiatives to support parents during the transition of the young people they care for into adult services. Each of these two research stages is discussed in turn.

Rapid evidence review

A rapid evidence review was conducted. This means that the study was designed to cover key papers rather than be a comprehensive or systematic review of all relevant literature. The review started with a search of academic literature. A search was conducted using an agreed list of search terms. The search terms were designed to include all papers of interest, namely ones that:

- focussed on people with learning disability and/or autism
- were concerned with the needs of children or adolescents and improving their care
- discussed the training and/or development of parents/family/unpaid carers.

These search terms were entered into two online citation databases (PubMed and EBSCOhost), which revealed a substantial body of evidence regarding parent training interventions. However much of this focussed on interventions for parents of very young children, or on the reduction of symptoms or behaviours associated with autism or Autism Spectrum Disorder (ASD) rather than on improving the care that children and young people receive and supporting their needs at/during transition. There were concerns that by focussing solely on this literature, the review would fail to meet its aims.

A decision was therefore made, in consultation with Skills for Care, to refocus the review into three key areas.

- What do we know about the experience of transition from the perspective of parents and families of young people with learning disabilities and/or autism?
- What do we know about the established parenting interventions for family carers of young people with learning disabilities and/or autism?
- What interventions exist to support parents of children with learning disabilities and/or autism during their transition to adulthood?

A purposive review was then conducted for each topic which focussed on existing evidence reviews, but which also included primary research if it was felt to be relevant. In tandem with the team's search and sift activities for the review ten academic experts were contacted and invited to provide input to the review and four of these provided recommendations for key studies and these were also included in the review. During the consultation process, respondents also suggested the research team consider a range of additional evidence and this too was included in the review.

The search, expert inputs and consultation identified approximately 1,300 separate pieces of evidence which were sifted down to 67, 58 of which have been referenced in this report. A full methodology for the review is provided in Appendix 1 and a reference list provided as Appendix 2.

Consultation

Following the completion of the review, a consultation process was undertaken to map out the developmental activities currently available to the parents/unpaid carers of young people with learning disabilities and/or autism which support them with the transition process. The consultation took place between January and April 2019.

Process

The researchers contacted 113 individuals or organisations by email or phone to invite them to take part in the research. Potential participants were identified in several ways:

- Skills for Care provided a list of individuals that they had worked within the area of learning disability and/or autism, and highlighted organisations that were likely to have a view on the research questions
- an internet search was conducted to find potentially relevant organisations working in this area
- research participants suggested other individuals or organisations to contact based on their experiences and networks
- a number of key documents/databases were reviewed for details of relevant organisations²
- several organisations publicised the research project on their website. This resulted in three parents contacting the research team to share their experiences.

In addition to responding in a professional capacity, many individuals involved in the research in were also able to draw on their personal experiences of caring for a child or young person with a learning disability and/or autism when discussing the issues affecting families.

Participants

36 individuals were involved in the consultation. These included representatives of government departments and non-departmental public bodies, private and not for profit organisations, national and local charities, local government, universities and parents. Appendix 3 provides the names of organisations whose staff participated.

This process gathered a range of perspectives on the research topic. However, the results do not provide full and complete mapping of all provision available, and participants are in no way a representative sample of individuals or organisations with an interest in this topic. It is, therefore, the recommendation of the research team that this report forms the basis for a wider and deeper consultation/involvement process before firm recommendations are made to policy makers. The research, for example, did not include any discussions with young people.

1.5. Legal and policy background

There is both a legal framework and national guidelines which act as an important backdrop to this research and which set out the process that young people and their families should go through to prepare them for transition. This section aims to provide the lay reader with an overview of these policies and an outline of the role that young people and their families should play in the decision process about their future. It does not provide complete coverage of all relevant policies or legislation. As will become apparent throughout the remainder of the report, guidelines and the spirit of the law are not always followed, affecting the experiences of families going through transition.

² The specification for Transforming Care (Annex B of which provides case studies of good practice), the Skills for Care Experts by Experience Directory for Transforming Care Partnerships and the National Autism Society Services Directory.

The Care Act 2014

The Care Act 2014 sets out local authorities' duties in relation to assessing people's needs and eligibility for publicly funded care and support. The Act addresses the role of local authorities in prevention, the provision of information and advice, and in shaping the market of care and support services. It also created a single, consistent route to establishing entitlement to public care and support for all adults with needs for care and support, created an entitlement for carers, and describes the steps that must be followed to work out this entitlement. Also, within the Act is a description of the assessment process by which local authorities determine whether a person needs care and support to help them live their day to day lives.

The Act highlights the highly individual needs for care and support that exist and how these needs can be met in different ways. It gives local authorities a new legal responsibility to provide a care and support plan (or a support plan in the case of a carer) and gives individuals the right to a personal budget which must be included in every plan alongside the detail of what has been agreed during the planning process. Individuals can then ask for a direct payment based on this budget.³

The Act also states that if a child, young carer or an adult caring for a child is likely to have needs when they, or the child they care for, turns 18, the local authority must assess them if it considers there is 'significant benefit' to the individual in doing so. This is regardless of whether the child or individual currently receives any services or their likely eligibility for state-funded care. In conducting this assessment, local authorities must:

- focus on the person's needs and how they impact on their wellbeing and desired outcomes
- involve the person in the assessment and, where appropriate, their carer or someone else they nominate
- provide access to an independent advocate to support the person's involvement in the assessment if required
- consider other things besides care services that can contribute to the desired outcomes (e.g. preventive services, community support).⁴

Children and Families Act of 2014

The Children and Families Act 2014 is a landmark and wide-ranging act designed to reform services for vulnerable children. It does this by giving them greater protection, paying special attention to those with additional needs, and by helping parents and the family as a whole. The largest part of the Act considers the laws and provisions that relate to children with SEND. Major changes involved giving families more control over the welfare of their child, with new provisions for:

- an Education, Health and Care (EHC) Plan based on a single assessment procedure which supports children, young people and their families until the age of 25
- services for children, young people and families that are jointly commissioned, planned and run by health services and local authorities
- the right to a personal budget for the support of children, young people and families
- the involvement of families and children in discussions and decisions relating to their care and education.
- local authority funded services which provide impartial advice, support and mediation.

³ Adapted from materials available at Gov.uk

⁴ As described on SCIE.org.uk

Local authorities, schools and Clinical Commissioning Groups (CCGs) must work together in joint assessments of need. EHC plans must include a provision to prepare for adulthood. SEND provision can extend up to age 25 if the young person is still in education (except university) which is also intended to support a smoother transition to adulthood.

SEN Code of Practice 2015

This is a statutory code which details the legal requirements and statutory guidance relating to the duties of local authorities, health bodies, schools and colleges in England to provide for those with SEND under part 3 of the Children and Families Act 2014. The code outlines how the assessment and planning process should enable parents, children and young people to express their views, wishes and feelings and be part of the decision-making process.

Chapter 4 of the code explains that local authorities must publish a local offer setting out in one place information about what provision they expect to be available for children and young people in their area who have SEND, including those who do not have EHC plans. The local offer should provide clear, comprehensive, accessible and up to date information about the available provision and how to access it. In addition, there must be direct involvement of children and young people with SEN or disabilities as well as parents/carers, in the development and review of the offer.

Chapter 8 of the code covers the preparation for adulthood from the earliest years and set out how professionals across education, health and social care should support children and young people with SEN or disabilities to prepare for adult life. It highlights the need for consideration of how to achieve the best outcomes in employment, independent living, health and community participation. Local authorities must ensure that the EHC plan review at Year 9, and every review thereafter, includes a focus on preparing for adulthood.

NICE Guidance 2016: Transition from children's to adult services for young people using health or social care services

NICE Guidance Transition from children's to adult services for young people using health or social care services. This guideline covers the period before, during and after a young person moves from children's to adult services. It aims to help young people and their carers have a better experience of transition by improving the way it is planned and carried out and covers both health and social care.

The guidance states that groups not covered by health, social care and education practitioners should start planning for adulthood from year 9 but that planning should be developmentally appropriate, taking into account each young person's capabilities, needs and hopes for the future. There should be an annual meeting to review transition planning, or more frequently if needed. The meeting should involve all practitioners providing support to the young person and their family/carers, alongside the young person and their family/carers, and inform a transition plan that is linked to other plans the young person has in respect of their care and support. There should also be a single practitioner who acts as a 'named worker' to coordinate their transition care and support. The named worker should be someone with whom the young person has a meaningful relationship (e.g. youth worker, health, social care or education practitioner, an allied health professional, their GP or an existing keyworker, transition worker or personal adviser - dependent on the young person's needs).

The young person should be asked regularly how they would like their parents or carers to be involved throughout the transition, including when they have moved to adult services. The transition should be discussed with the young person's parents or carers to understand their expectations about the transitions. This should include recognising that the young person's preferences about their parents' involvement may be different and should be respected. In

addition, discussions with parents should consider the young person's capacity, following the principles of the Mental Capacity Act. This Act aims to protect people who lack capacity and maximise their ability to make decisions or participate in decision-making.

Preparing for Adulthood

A programme of support called Preparing for Adulthood (PfA) is run by the National Development Team for Inclusion, funded by the Department for Education. PfA identifies a core set of outcomes across Health, Employment, Community Inclusion and Friends, Relationships and Community which reflect what disabled young people say is important to them. It works with the Department for Education and its partners to ensure that young people with SEND achieve paid employment, independent living and housing options, good health, friendships, relationships and community inclusion as they move into adulthood. It does this via the development of good practice, information sharing and partnership working via events and networks.

In 2017 PfA produced a supportive tool to promote consideration of the four PfA outcomes. The tool looks at aspiration, activity and provision that can support progress towards the outcomes at various stages of development, including the specific needs of 16 to 19-year-olds. The guide not only sets out a range of age-appropriate indicators for each PfA outcome but also references a range of useful resources.

PfA has identified a number of challenges that face young people as they transition from childhood to adulthood, including [1]:

- Different thresholds for children's social care and adult social care. Thresholds for adults are generally higher than for children although this is not always the case. There are also different criteria for health support which can be confusing for both families and professionals.
- Planning for transition not happening early enough, often despite local areas knowing about children and young people coming through.
- Different working cultures of Children's and Adults' Services. A risk-averse approach can lead some Children's Services to struggle to think about what children need to support them to be as independent as they can be in adult life. There can also be concerns when costly placements (often out of area) are arranged ahead of Adults' Services becoming financially responsible for the young person once they turn 18.
- Different legislation that impacts on children, young people, adults and their families. It can be a challenge for practitioners who are steeped in one piece of legislation and assessment framework to understand the link across to the other.

2. Experiences of the transition process

Key points

During the transition of young people with learning disabilities and/or autism into adulthood, parents must continue to support their child's care through a period of physical and emotional development. At the same time, they need to coordinate a range of additional planning, liaison and research tasks to support their child's future options. The demands placed on parents during this time can be overwhelming.

Parents play a crucial role in transition and are relied upon to do so, but their vital inputs are often undervalued, and they are often not fully involved in decision making. This can lead to anxiety and uncertainty about the future. The unique perspective that parents have regarding the needs, aspirations and skills of their children is not always appreciated or utilised, and they are required to coordinate the transition process whilst feeling unheard.

Person-centred planning is not a consistent reality. The current system can be too inflexible or paternalistic, the process starts too late, professionals lack the necessary skills and the options are too limited for young people and their families to be placed at the heart of the transition process. Adopting a strengths-based approach can also be difficult for parents when they have been required to focus on their child's shortcomings previously when seeking support.

Parents often fear that their children will receive a poor quality of care/support/options when they leave school, have concerns about their safety and well-being and lack faith in the transition process. When professionals interpret these concerns as over-protectiveness this can lead to conflict and barriers to a successful transition. Professionals themselves can lack the experience and skills to deal with families and their concerns effectively.

The transfer between child and adult services can be managed well with a systematic, joined up approach. The reality for many families, however, is a disjointed handover rather than a smooth transition. Families therefore often feel that they are required to navigate the system alone but can lack the resources they need to do this effectively.

Families want clear information provided in a timely manner but seldom feel that they receive this. Emotional support, through parent peer networks and/or self-care techniques, can help by supporting parental resilience. The emotional and financial resources available to parents, combined with their knowledge of systems and networks can be key in overcoming barriers.

2.1. Introduction

This initial chapter describes the transition process from the perspective of parents. It is based on a rapid review of exploratory research from the UK and beyond involving interviews and survey work with parents to gauge their experiences of, and views about the transition process and the support they receive or would like to receive, during it. It also draws on the views of those involved in a consultation process conducted specifically for this project. The chapter covers both parent's experience of the process of transition and evidence about what works to support them.

2.2. Parental experience of transition

The point of transition into adulthood can be a challenging time for all families. Where the young person transitioning has learning disabilities and/or autism there can be additional concerns and considerations that make the process more difficult, not least the need to move from child to adult services.

2.2.1. Multifaceted role

For families with disabled children, the process of leaving school can mean leaving behind important sources of support and information, including those which support positive health and wellbeing outcomes (e.g. physical or speech therapy), a lack of access to meaningful daytime activity and decreased opportunities for social contact [2]. The process can be stressful and isolating, difficult emotionally and psychologically, and the move into adult health and social care can pose challenges (e.g. poor inter-agency communication, confusing transition planning) and lead to problems going unidentified.[2]

There is recognition in the literature of the dual role that parent carers assume as their children move into adulthood. In one study [3], parents of young people with autistic spectrum disorders described this in terms of:

- A coordination role where they are responsible for planning and securing service provision in adult health and social care and securing opportunities in employment and education. The tasks involved in this are varied including researching post-school options and support and chasing service staff for help and information.
- A life-supporting role where they continue to be responsible for the young person's care and domestic tasks, promoting personal hygiene and dressing, providing daytime occupation, helping young people organise themselves, teaching about money management and assistance with decision making.

Not only does transition require parents to assume the additional co-ordinator role, but the life supporter role can also become more difficult at this time. Moving into adulthood has the potential to result in increased support needs (due to health, mental health or challenging behaviour needs). Care tasks, for example, can become more difficult for larger and stronger young adults. The gap between young people's intellectual development and their emerging sexuality can also be a concern. Increasing care demands also need to be placed in the context of parents becoming older and potentially less able to meet the needs of young people and them having to provide this care until the end of their lives [4].

Parents assume the coordination aspects of this role in what they perceive as an absence of statutory services support, or where the support available does not meet the needs of their child. Not surprisingly parents struggle to take on these roles and feel emotionally challenged by doing so, in addition to having their own lives compromised as a result. In one study parents described themselves as acting as their young person's transition worker with acute consequences for individual and family well-being [5]. Parents have also expressed how they find dealing with bureaucracy difficult, including managing a range of different professionals and services [6]. Also common amongst parents are concerns about what would happen to their children once they were unable to continue to be strong advocates [4]. Adequate service provision can help make the transition less problematic because parents are then required to take on less of a coordinator role.

One consultation respondent described the situation as follows:

"The reality is that it shouldn't fall on the parent to be case managing but public services are so stripped back that that's what happens and that's what they have to do. We're expecting a lot of parents, but the more capable ones are the ones that make transition work. We see

time and time again that it's the most vulnerable families that come out of these things the worst. " (National charity)

2.2.2. Parents crucial but undervalued

The evidence is clear and consistent that transitions work best with the involvement of the parents (e.g. parental involvement has been found to relate to better healthcare transition outcomes [7]) and participation and user involvement are placed at the centre of present UK policies, particularly in relation to employment and education outcomes. Families are a vital source of support in successful transitions [6] and are relied upon to perform a major role during the process, resulting in substantial disruptions to family routines and responsibilities [8]. However, even though families are a key facilitator for successful education and employment transition planning, social and family networks are largely underutilised during the process [9].

To perform the critical role expected of them during transition, families and young people need to be kept informed throughout the transition process, but many families feel they have been left 'in the dark' and/or receive a lack of information about the options available to young people [10]. Parents are the main support system for young people but often feel overwhelmed and anxious about the future and need support and recognition to be involved across levels of decision making and to have greater access to information and involvement in service delivery [6]. Parents also require more substantial support to advocate and care for their children [4].

The literature documents how parents feel they lack information to support the planning of, and the actual, transition process and how complex the process can be. As a result, parents need to be fully involved in the transition planning process early enough to support their efforts. This includes being given all the options available post-school. This is important because how informed carers are about the process will affect, in part, how successful the process is. Despite policy aims for a co-operative approach to transition (e.g. careers advice providers, care managers, the young person and their parents), evidence suggests that there is still a lack of coordination between the relevant agencies and little involvement of the young person [10].

Parents have a unique perspective on the needs of the young person going through transition in relation to any healthcare needs [7] but also the aspirations, skills and support needs of their child. A recent qualitative study [6] described how parents of disabled children feel about the process of transition and revealed how emotionally demanding it can be for them. In this study, parents described how their experience of supporting their child can be ignored once they reach adult services and they can feel unheard despite their role in organising appointments etc. Parents also described how emotionally difficult it was to coordinate the transition process whilst feeling unheard. As adult services involve parents less than children's services parents felt that this could add to concerns about their children. Parents also feared that without their role in coordinating services the young person would not access them.

One of the parents involved in our consultation described their battle to find out information which would help them to support their child:

"I've ordered the SEN code of practice from Amazon to go through it. You have to train to be a solicitor. Nobody is prepared to give you the information... You have to dig and really find out what this missing thing is why your child can't get what they're entitled to." (Parent)

2.2.3. Person-centred planning

Person-centred planning (PCP) should be adopted in school reviews for students with a Statement of Special Educational Need from Year 9 onwards. This is so that parents and young people can have a meaningful role in the transition process. PCP takes a strengths-based approach by discussing what is liked and admired about the person and what is important to them now and in the future. This is done alongside a discussion of their support needs and the

production of an action plan to help achieve their aspirations. The process should be truly accessible to young people and their families by avoiding jargon and encouraging young people to express themselves. PCP should, therefore, help parents feel included in the transition process as well as focus on the young person themselves.

There is, however, a lack of evidence on the effects of PCP, particularly for people with learning disabilities [11]. In practice, PCP may not be accessible to service users or be a paper exercise with service staff still paternalistically driving the process. PCP also cannot tackle problems of service delivery. The literature suggests that PCP planning may most realistically lead to temporary improvements in planning pathways into conventional service structures, rather than having a more transformative role [12]. PCP needs to be combined with consistent involvement of all relevant stakeholders across professional boundaries during planning if further improvements are to be made [12].

During our consultation, one respondent described the problem as follows:

"There is an inability of the current system to meaningfully include young people in the conversation. This is sometimes a function of the short-termism that exists in a lot of the organisations that they are transitioning to and the need to meaningfully include the young people means that it needs to be done at a pace that's appropriate and in a way that manages the amount of information being exchanged...Quite often the situation is that 'we don't have time or resources or budget to do that, so we're just going to make the decision and then worry about communicating that decision'. They take communicating about the decision to be including them, but they're not actually being included, they're just being told about it afterwards." (Researcher)

The fact that transition reviews do not truly involve PCP was a common complaint from those involved in the consultation. As a result, equipping parents with PCP skills was a central component of many of the development initiatives available to parents (examples of some of these opportunities, identified via the consultation process, are discussed in Chapter 5). Most of those involved in the consultation expressed the view that achieving a more person-centred focus in transition planning was critical in achieving better outcomes for young people. Providing parents with the skills necessary to drive the PCP process was thought to be one way of achieving this.

"The problem is that families of disabled children are not a homogenous group. We need to stop fitting people into service models and be person-centred so we start with where that particular family is at and support them and empower them to express their real feelings about what's important to them and then plan for outcomes and put in support that is relevant to them. We're trying to move away from a service specification model to a person-centered model." (National charity)

There was some discussion in the literature about the use of a more holistic planning approach - person-family interdependent planning - for young adults with severe learning disabilities. This process recognises the influence that the family system has on young people, and that, whilst young people with severe learning disabilities can control decisions in their lives, some level of external support may be necessary for them to make complex decisions. The approach recognises the uniqueness of families and considers their environment, culture, values, preferences and needs in transition planning, alongside those of the individual [13]. This may not be appropriate for all young people, particularly if their aspirations for transition are not shared by their parents. However, there is clearly a need for greater recognition of the role that families play in supporting young people to achieve successful transitions, and that they themselves need support to do this well.

2.2.4. Parental aspirations

Parental aspirations about the transition to adulthood for young people with learning disabilities and/or autism are often no different than those of most parents of young people without disabilities or who are neurotypical. One US study found that parents of children with intellectual disabilities or developmental delay prioritised their child: having an occupational or functional role in society; moving out of home; having relationships with peers; achieving the skills required for daily functioning; continuing with education and/or general intellectual stimulation, and; achieving some form of independence [14]. However, the same study found that many of these aspirations were not addressed by formal transition planning. What families and young people valued most for success in adulthood tended to be more nuanced and expansive than conventional perspectives.

One of the parents involved in our consultation process described the situation as follows:

"Someone once said to me "Parents of children with disabilities aren't after a Rolls Royce, they just want a Ford Focus that gets you from A to B and is reliable in a morning." That's true really. We don't want to have services at all we just want to be able to live the same lives as everyone else and sometimes we need a bit of help to do that for our young people. People expect that their child is going to grow up, get some work, meet somebody and be happy. That's really all we want. We don't necessarily want anything different from anybody else it's just getting the support to enable them to do that". (Parent Carer Forum member)

Another issue which emerged from the consultation was that parents can need encouragement to be optimistic, forward-looking and aspirational. Parents spend years working within a system that requires them to prove their child's eligibility for support by focussing on their disability and not on them. The transition process then asks them to switch to a strengths-based approach which may not, by this stage, feel natural. Having access to a community of other parents was suggested as one way to help people overcome their negative experiences and develop the skills necessary for more successful engagement in the transition process.

2.2.5. Time of conflict

The period of transition can be one of conflict for parents. Firstly, in terms of their child achieving independence. Professionals can see parents as being unwilling to relinquish control or let go, but this can be driven by, understandable, concerns about the perceived lack of support and services available to meet their child's needs and achieve their aspirations [5]. For example, moving out of home is a complex issue with parents advocating for the independence of their children and their right to move out of the home on the one hand, but with concerns about the poor quality of care outside the home on the other [4].

Our consultation suggested that parents can fear the risks associated with transition and that this is exacerbated because they have no faith that the process will work for them and their child.

"Families are utterly distressed, burnt out, feeling that they have to fight for their children. We want to get to the place where families can be families and not having to do all the other stuff that they have to do. The system itself and providers should be easy for people, it shouldn't be the fight that it is now. People often don't know what they're entitled to and what they can ask for." (National Charity)

Another type of conflict can occur between parents and professionals. Parental concerns about transition can lead to them being labelled as 'over-protective' [10] and prevent their full involvement in the planning process. A parent involved in our consultation process described her experiences as follows:

"If you try and fight a bit you get deemed as an unreasonable mother. That's what I'm trying to avoid. I'm not an unreasonable mother, I'm the opposite, I'll try and do everything I can.

But...unfortunately once you get tarred with that brush because it's a small community here, you'll find that they're very unwilling to deal with you at all. They just basically shut the doors on you." (Parent)

The literature suggests that the aspirations of carers for the lives of young people with learning disabilities can depend on their relationship with service providers. Whilst tension between parents and professionals can be a barrier to successful transitions, individual professionals can also be important support systems [5]. As one review states:

"Studies have shown that carers tend to express general dissatisfaction with professionals but that more positive relationships are possible when professionals provide clear and appropriate information and interventions and acknowledge the parents' needs, expertise and involvement." [10, pg 96]

Our consultation also highlighted that working with families and engaging in PCP can be challenging for professionals. One academic researcher discussed how there was currently no best practice or evidence-based approach to doing this. Professionals often have every intention and desire to engage in person-centred planning and do this as best they can, but lack the necessary systems, skills or resources to do so effectively. Another respondent described how social workers, for example, can lack family work skills or knowledge of techniques/strategies that families could find useful unless they have worked in a specialist disability service. Generic workers without specific qualifications in learning disabilities and/or autism can struggle to guide people through a process that they themselves don't understand. The consultation also suggested that when parents do not receive good support from professionals, trust can be lost, and relationships break down. These issues can be exacerbated by staff turnover which means that families feel they are effectively 'starting again' when new staff come on board.

2.3. Supporting a successful transition

At a system level, transition in the UK has been described as a low funding priority with short term planning, organisational complexity, poor systemic coordination and a considerable gap between policy and implementation [15]. Understanding what elements of the process support a more successful experience, including from the perspective of parents, is, therefore, an important step to supporting parents more effectively.

2.3.1. System elements

The transition process is complex and can be difficult for professionals and parents alike to navigate. It covers a range of different policy areas (e.g. housing, health, social care, education) which are not always well linked. Children's services are required to prepare young people for transition, but often without the full involvement of adult services, for example. Some young people face a considerable change in how much support they receive after the age of 18 due to different thresholds rather than a sudden change in need [6]. One review [10] described the problem in terms of the process being a handover, rather a meaningful transition. It describes a 'chasm' between child and adult services whereby knowledge about what works for the individual is not forwarded to or used by, adult services staff and how families and young people often have to navigate this transition on their own.

There are ways the system can be used to support a more successful transition, however. One review [5] found moderate evidence in support of: transitional workers/teams; services such as adolescent health services; formal intra- and inter-agency liaison and agreements; frameworks for fostering accessibility of services, and process components including a systematic approach to managing the transition process (e.g. holistic assessment, care planning/review and the active involvement of young people and their families), and; case management approaches.

The same review presented evidence about elements of the transition process that can act as barriers to a successful transition. These included limited options post-school in terms of housing and supported employment, but also factors related to the support that parents and young people were given during the process and the way that the different agencies involved in transition work together. The review found that: poor staff attendance at meetings; a lack of clarity on the responsibilities for service provision; poor coordination between agencies; limited capacity of transition workers/high staff turnover, and; a lack of information about planning and options were all linked to poor transitions. It also highlighted how young people do not always receive a transition plan, causing stress and uncertainty for families.

"It's very very rare that transition planning starts at 14. Either in the context of education, health or social care. It's really unusual. It just generally doesn't happen. We know that public bodies are stripped back to the minimum and frankly planning and doing that sort of preparation - there's just no capacity for it and so it doesn't happen. We often see that it's rushed at 18 and parents are ill-prepared for it. There's also a really unfair burden placed on families who themselves might be very vulnerable". (National charity)

The lack of a co-ordinated approach to transition was highlighted by most respondents in our consultation. Parents spend many years developing relationships with people working in child services and required to start this whole process again with a range of professionals in adult services. The lack of an adequate transition to adult services means that the expertise and viewpoint of parents are lost and families who are used to seeing the same person regularly no longer receive that level of service. Respondents suggested that parents, therefore, need to become their own care navigators and whilst some parents are well equipped to take on this role, others cannot. In such cases, it was suggested, an independent advocate may be useful support. Such advocates could be professionals or other parents, for example, but need to have the best interests of the young person and their family at heart.

2.3.2. Factors that parents feel aid a successful transition

Our evidence review included a range of studies which examined parental perspectives on what constitutes more successful transitions (as defined by parents themselves). Elements of the planning process that parents valued or found helpful included:

- having a written transition plan and a transition process in place [16]
- having access to the right information at the right time and being able to ask questions [3]
- a co-ordinated approach, for example via a transition worker of some kind or another single point of contact and source of information [5]
- early support to achieve transition aims (e.g. early consideration of work options and then work experience to support work aspirations [17])
- emotional support and, for some, advocacy [5].

Research into the experiences of parents of young people with autism spectrum conditions in the UK found that: *"Parents defined good transition support from services as that which had yielded realistic and satisfactory post-school options, and which supported and enabled them to make informed decisions."* [5, pg 104]

Our consultation also found that where young people and their families reported good experiences, they had been involved, they were clear about the process, they felt well supported by a key worker, lead professional or dedicated transitions service and they often had access to a youth-centred provision that helped young people prepare for adulthood and expand their social and community networks. However, one research study found that young people, parents and professionals all agreed that young people with learning disabilities are still expected to slot into services that already exist, with limited options if the available services do not fit their needs [6].

During our consultation, one parent described the importance of a holistic view of transitions:

"There are lots of elements to this. I have to be creative and look for a solution that will make this person's life more satisfying in the long term. It's not just about getting a qualification".
(Parent)

Parents would also value more transparency and clearer pathways to responsibility and accountability - there are many different professionals involved in decision making but their roles are not always clear. Meetings are typically arranged through school whilst funding decisions lay with social workers, for example. Families also struggle to understand how budget decisions are made and this can increase tensions between families and professionals [4]. Whilst individualisation and self-directed support can allow parents to create the most suitable care packages, organising this can be stressful and demanding. A number of respondents to our consultation highlighted specific problems that parents face in managing personal budgets including a lack of flexibility on how these can be spent and a high level of bureaucracy attached to them.

There is also a danger that by focussing on transition, the continuous support needs of parents are ignored. Parents see transition as an ongoing process and anticipate further transitions due to changing needs (of the individual and/or their family), reviews of care providers or services ceasing to support the young person in their mid-20s [5].

2.3.3. Equipping parents for transition

The expectations, involvement and knowledge of families play a critical role in successful transitions. However, families find understanding and navigating a complex system of services and support related to employment, college and community life challenging.

During the consultation, several respondents discussed how the term 'transition' could become a 'buzzword' that lacks clarity and substance. One respondent highlighted that it is important to acknowledge that the period of transition covers both a period of personal development as well as a period of service change. Parents could, therefore, be provided with support to deal with one or other, or both, these aspects, although operating a system which is so complex that parents need specific training about their role within it was, understandably, described by the same respondent as 'perverse'.

"These are two separate questions. Should we just be training families more in different types of interventions, different types of support regardless of whether their child is in transition or not? Should we be training families on how to navigate the system? You might go for one or more of these things...We don't do enough to educate parents about the types of interventions and support that are available for your child." (Non-Departmental Public Body)

Several aspects of the process of transition have been identified as key roles parents are required to take on, and which they may, therefore, need support to fulfil, such as:

- knowledge management by finding out about available options. A lack of knowledge directly impacts the opportunities families know about and therefore pursue [18] and our consultation consistently included discussions about how difficult it can be for families to access the information they need
- advocacy where families have to strongly champion the needs of their child. However, it can require privilege in economic and educational terms for parents to be able to assume this type of role [8]
- helping young people develop social skills and social connections (including appropriate behaviours and strategies for further education and/or work). However, parents are often unclear about how to support this [19].

A recent parent survey highlighted parents' own needs for support during the transition planning process including emotional and information support and, for some, advocacy [5]. The need for

parents to be given tools which support their own self-care also emerged as a consistent theme from our consultation.

2.3.4. Parental responses to the challenges of transition

A number of qualitative studies included in the review considered how parents have overcome some of the issues affecting transition or how they feel this could be achieved. Some suggestions were relatively simple, such as making a list of local services available to help parents understand options and choices [4], whilst others were more nuanced. One study [20] discussed the needs of parents of young people with profound intellectual disabilities during the time of transition to explore realistic solutions based on their perspectives. Parents identified a range of needs, including informational, material and emotional support. Table 1 presents some of the suggests from parents on how to meet these needs.

A further study [21] examined how parents had worked together with other parents to support transition through 'parent projects'. These projects focus on a range of issues and highlight the complex and multi-faceted nature of the transition process. Projects included:

- connecting with others for personal support (social and emotional support as well as sharing ideas for the transition)
- equipping the young adult for adult life and independence (e.g. through cooking, cleaning, personal care and hygiene skills, and managing finances, technology and transport with parents teaching, monitoring and rewarding the young adult)
- equipping the young adult for employment (e.g. helping each other learn how to navigate the system across different agencies to support their young person's job search)
- equipping the young adult for social relationships (e.g. facilitating opportunities for the young person to spend time with friends or to have romantic relationships)
- providing the young adult with a focus on safety (e.g. coaching about safety practices to avoid being taken advantage of, principles of safe sex)
- managing the day to day whilst preparing for the future (e.g. balancing daily household needs with the immediate needs of the young adults, as well as interacting with various agencies).

For these parents, the emotional and financial resources available to them, as well as their system knowledge and networks, were key to being able to overcome barriers. Parents who spent most of their time managing daily life had fewer resources available to devote to transitions. However, parent networking increased resilience and the study found value in ongoing parental relationships to facilitate the transition and encourage social service and health professionals to support them.

Table 1: Parental needs at transition and proposed solutions

Needs of parents	Suggested parental solutions
Informational support	Knowledge sharing (e.g. web-based transition planning document setting out necessary steps for transition linked to important dates and contacts for people in various organisations)
	Use of thematic conferences involving experts in various fields of transition
	School-based professionals to attend new settings and facilitate information sharing about new staff, young person's abilities, preferences, needs etc.
Material support	Access to concrete resources and services to help meet life's needs and solve practical problems
	Planning to begin at least 3 years before the end of school and involve all professionals involved pre- and likely to be involved post-transition alongside parents
Emotional support	Support before, during and after the transition to counter anxiety
	Opportunities to socialise with other parents to reduce feelings of isolation
	Moderated discussion groups with other parents of transition age young people

Adapted from Gauthier-Boudreault C, Couture M, Gallagher F. How to facilitate transition to adulthood? Innovative solutions from parents of young adults with profound intellectual disability. J Appl Res Intellect Disabil. 2018;31(Suppl. 2): 215–223

3. Established parenting programmes

Key points

The rapid evidence review identified four established parent training programmes that have been adapted or tested on parents of children with learning disabilities and/or autism. Most of these have not been used to specifically support parents with transition or at this point in a child's life. However, they provide useful indications of some developmental elements which have been proven to have a positive impact on parents.

These programmes all offer support through psychoeducation and skill development to improve parenting skills and tackle challenging behaviour and are typically delivered in a group format. Whilst most of the evidence for these comes from outside of the UK, there is a consensus that they provide benefits in terms of improved parenting behaviour, increased parenting confidence and improved child behaviour.

The acceptability of these programmes amongst parents is high. Many value the information provided and found the training useful. Parents particularly value the group format of the programmes and the chance to meet others in a similar situation to themselves. There is also some evidence that programmes can be tiered so that parents receive only the support they need, and those in the greatest need receive the most support.

These programmes have traditionally been designed and tested on parents of young children – either pre-school or primary school age – and little is known about how well they work with parents of adolescents. Any follow-up reported in these papers tended to be within a year of the intervention completing so no evidence is available to track the longer-term outcomes (e.g. on transition) of parents having received these interventions. Despite some recognition that the needs of children with learning disabilities and/or autism change as they age, research is yet to fully examine the role of parent training in the transition of children into adulthood.

3.1. Introduction

The review found four established parent training programmes relevant to the research topic. These four programmes are all published interventions accompanied by a manual to allow them to be repeated. They have all been tested with parents of children with learning disabilities and/or autism in countries around the world. A number of those involved in our consultation discussed how these types of interventions are 'trusted' by parents and providers working with families of children with learning disabilities and/or autism and some run these courses as part of their portfolio of supportive work.

The programmes reviewed during this research were:

- Incredible Years Programme (developed in the US, commonly delivered across the UK)
- Stepping Stones to Triple P (developed in Australia, now commonly available across the UK)
- Parents Plus (developed and most commonly available in Ireland, but also available in some areas of the UK)
- Early Bird and Early Bird Plus (developed in, and delivered across, the UK).

Each of these programmes is described in turn, alongside evidence of their effectiveness.

The four programmes all bear similarities. They all include psychoeducation (an evidence-based therapeutic intervention that provides information and support to better understand and cope with disability and resulting behaviours) in tandem with the development of positive parenting skills. All four programmes also involve, or can involve, group sessions whereby parents learn alongside others in a similar situation to themselves.

All four programmes have demonstrated high levels of satisfaction amongst participating parents and there is strong parental support for the acceptability of the programmes [22,23]. If an intervention is considered acceptable, participants are more likely to adhere to recommendations and to benefit from improved outcomes. The evidence suggests that most parents are satisfied with the content and format of programmes and feel that their needs are met by them.

3.2. The Incredible Years Suite of Programmes

There is consistent evidence of the effectiveness of the Incredible Years programmes, although some evidence is from relatively small trials or pilots.

3.2.1. Programme details

The Incredible Years Parent Training Programme (IYPT) was originally developed in the US for non-disabled children. IYPT is delivered over 12 weeks using 2.5-hour sessions in which groups of 8 to 12 parents participate. The sessions cover topics such as play, praise, rewards, limit setting, and handling challenging behaviour. Techniques such as group discussion, videotapes of parent-child interactions, role-playing, taught elements, and weekly homework assignments are used.

This programme has been also adapted to make it applicable to children with learning disabilities aged 2 to 5 years (IYPT-DD). IYPT-DD was developed from the toddler version of the original programme following pilot work and input from community stakeholders. Modifications included discussing with parents which key points could and could not be generalised to their children with developmental delay; excluding content on 'time-out'⁵; focussing on predicting and avoiding problem behaviour, and; providing informational handouts on developmental disability resources in the community [24].

Another version has been produced for those with autism and/or language delay aged 2 to 5 years (IYPT-ALD). It is delivered in 14-16 weekly, two-hour sessions and includes eight topics: child-directed narrated play; pre-academic and persistence coaching; social coaching; emotion coaching; developing imagination through pretend play; promoting children's self-regulation skills; using praise and rewards to motivate children, and; effective limit setting and behaviour management. The programme uses video vignettes that include examples of parents and children on the autism spectrum, role play to practice skills, and home activities [25].

The Incredible Years Programme has also been offered as a tiered service to parents of children with developmental disabilities. Depending on the level of need, parents can be offered a combination of (a) self-administered reading material, (b) group training, and (c) individualised video feedback sessions [26].

3.2.2. Evidence of effectiveness

A trial of the IYPT-DD with families of young children (ages 2 to 5) with developmental disabilities [27] found that after receiving the training, parents demonstrated a number of positive outcomes compared to those in a waitlist control group. These included greater decreases in observed inappropriate or negative parenting behaviours and modest declines in parent-reported behaviour problems amongst their children. Another small pilot study [28] (without a

⁵ Time out is a behaviour strategy which takes children away from interesting activities and attention.

control group) tested the IYPT-ALD with parents of children aged 2 to 5 years who either had a diagnosis of autism or were awaiting assessment (conducted with 9 families in Wales). Parents reported a significant increase in the pro-social behaviour of their children and a significant reduction in their peer problems.

On further small-scale study [26] tested an adapted tiered version of the Incredible Years programme delivered to parents of children with developmental disabilities, where parents received just the amount of support they needed. Participants who appeared to need more support after the first tier and second tiers were offered the next level of support. This trial included only eight families, with children aged 2 to 4 years, but nonetheless found improvements in the use of positive parenting strategies, which were maintained for families over three months. This has been interpreted as preliminary evidence that the IYP can be tailored to needs, thus making service delivery more efficient.

3.3. Stepping Stones Triple P (STTP)

There is consistent evidence of the effectiveness of a number of variations of the STTP approach, including from randomised control trials.

3.3.1. Programme details

Triple P - Positive Parenting Program - originated in Australia. Stepping Stones Triple P (SSTP) was specifically designed for parents of pre-adolescent children with disabilities, both intellectual and physical [29]. SSTP interventions can be delivered in individual, group, or self-directed learning formats with or without telephone assistance. Like other programs within the Triple P system, SSTP is tiered and offers different levels of intervention strength depending on the needs of the family.

On review [22] described the empirical studies involving families with children with intellectual disabilities. These had been conducted at the following levels:

- Selected - specific advice to parents on common child development issues and minor behaviour problems through brief contact with a practitioner (e.g. 2 sessions for 20 mins each) or seminars.
- Standard - 8 to 10 sessions focused on identifying the causes of child behaviour problems, training in 14 child development strategies (e.g. quality time, praise, tangible rewards, activity schedules, incidental teaching⁶, behaviour charts) and 11 behaviour management strategies (eg diversion, setting rules, planned ignoring, clear and direct instructions, logical consequences, time-out), and active practice and individualised feedback from a therapist in these techniques.
- Enhanced - additional sessions to address parent adjustment or family dysfunction (e.g. adjustment to a child's disability, parent coping skills, marital distress, social support).

In a recent study, STTP was developed into Building Bridges Triple P (BBTP), an eight-session behavioural family intervention designed to meet the needs of parents with an adolescent with ASD [30]. This included five 2-hour group sessions and three 30-minute telephone sessions covering topics such as understanding teenage behaviour, encouraging appropriate behaviour, managing problem behaviour and parenting routines, getting teenagers connected and teaching survival skills.

⁶ Incidental teaching involves creating an environment in which students' interests are easily fostered and nurtured, and one in which students can be most successfully motivated.

3.3.2. Evidence of effectiveness

Four main studies provide evidence of the efficacy of STTP from randomised control trials (RCTs) [31,32,33,34]. Three of these studies looked at the standard form of STTP for parents of children, involving a number of group sessions, whilst one involved parents receiving just two 90-minute seminars. In three of the studies, the children had a learning disability, whilst in another, the children were all autistic, and the age of children across the studies ranged from pre-schoolers to primary school age.

The RCTs all found positive effects of the standard version of SSTP on child behaviour problems (although not always consistently across similar measures) and some improvements in parenting style or perceived competence relative to the wait-list controls. Child and parenting outcomes were generally maintained for intervention families at follow-up six months or one year after their training.

One study [31] also compared SSTP-standard (8-10 sessions) with SSTP-enhanced (8-10 sessions plus additional sessions to address parent adjustment and family dysfunction) and found few significant differences in outcomes across the two interventions. However, the authors noted that since families had not been selected based on the presence of parental distress or relationship adjustment they may not have required the additional support in the areas that the enhanced programme offered. Another study [34] found that just two 90-minute seminars for parents could be effective at reducing child behaviour problems and improving parenting practices compared to wait-list controls. This was at both six weeks after intervention and at three months follow up. This has been interpreted as indicating how a cost-efficient programme can be beneficial to parents and their children [29].

The Building Bridges Triple P programme has been tested with a small sample of nine parents with children aged 12 to 16 with ASD [30]. Participating parents reported significant reductions in their adolescent's behaviour problems, increased parenting confidence, decreased lax and over-reactive responding, and decreased symptoms of depression and stress following the intervention.

3.4. Parents Plus (PP)

There is consistent evidence of the effectiveness of PP programmes, including from control trials. The evidence is less clear about the differential impact the programmes have on children/young people with learning disabilities when compared to those without disabilities or who are neurotypical.

3.4.1. Programme details

Parents Plus (PP) is a set of group-based parenting interventions originally designed in Ireland for parents of children ages 1 to 16 with conduct problems, including those with developmental disabilities [35]. The current approach has revised this into three separate programmes tailored to different age groups: PP Early Years Programme (ages 1 to 6), PP Children's Programme (ages 6 to 11), and PP Adolescent's Programme (ages 11 to 16). Each is delivered as a structured course for small groups of parents utilising DVD input, booklets, group exercises and homework.

The programmes involve 6 to 9 sessions spanning 2 to 3 months, with 8 to 12 parents. Each session is around two hours long. The groups follow solution-focused principles⁷, and centre on client goals with an emphasis on clients' strengths and resilience. The topics covered in the sessions vary by age. Participants in the adolescent group training cover topics such as:

⁷ This type of work is future-focussed, goal-directed and focusses on solutions rather than on problems

- getting to know and connecting with your teenager
- communicating positively and effectively
- building your teenager's self-esteem and confidence
- negotiating rules and boundaries
- teaching teenagers responsibility
- positive discipline for teenagers
- managing conflict
- solving problems together.

All three programmes are usually conducted in a group format although individual parent practice and feedback sessions are also incorporated into the revised programmes, especially when delivered in a clinic setting. During individual sessions, parents are videotaped interacting with their child and therapists provide strength-based feedback to parents. Parents Plus has also been tested with families of children with developmental disabilities [23, 36].

3.4.2. Evidence of effectiveness

A number of reviews referenced studies which included parents of children with learning disabilities in PP programmes. The original PP programme was tested with parents of children aged 4 to 7 with developmental disabilities using a controlled trial [37] and this found the programme had a positive effect on child behavioural problems relative to families in the wait-list control group. These effects were maintained at a 10-month follow-up. However, the same study found no differences in family functioning, parenting stress, or social support. A separate study on PP Early Years for children aged 3 to 6 (both with and without learning disabilities) [38] found it effective at improving the child's behaviour and reducing parental compared to a control. These positive results were found for both children with and without developmental delays, and there were no differences in intervention effects between the two groups.

A similarly designed evaluation of the PP Children's Programme for parents of children aged 6 to 11 found significant reductions in conduct problems, decreased parental stress, increased parental confidence and improvements in parent-defined problems and goals for the intervention group compared to the control [39]. In this study, the effects were smaller for children with learning disabilities than for those without, although only a relatively small number of children with developmental disabilities were included in the study.

Further positive results are available from a more recent RCT of an adapted version of the PP Children's Programme given to families of children with developmental disabilities (aged 6 to 12) attending a special school [40]. Compared to wait-list control, the treatment group in this study showed significantly greater improvement on a range of measures after their involvement in the programme. These included children's problem behaviour, parent satisfaction, and decreases in parent stress. An additional unpublished study [41] involved parents of adolescents with disruptive behaviour disorders, emotional and developmental disabilities who were attending a mental health clinic. These parents received the PP Adolescent Programme or were allocated to a wait-list control group. The study found greater improvements for the PP Adolescent Programme group compared to the control on a range of measures that were maintained at follow-up. However, it is unclear from the review whether all children in this study had developmental disabilities.

A recent meta-analysis demonstrated that the effect size of PP was comparable with other established interventions such as Incredible Years and Triple P.⁸ However, some of the studies

⁸ An effect size of 0.57 emerged from a meta analysis. Cited in [36]

included in the meta-analysis had treated parents with non-disabled children, and figures were not reported separately for those with learning disabilities.

3.5. EarlyBird and EarlyBird Plus

There is consensus support for the effectiveness of EarlyBird and Early Bird Plus but there is no evidence from RCTs and some research has been conducted with small sample sizes.

3.5.1. Programme details

EarlyBird and EarlyBird Plus are two parent training programmes designed by the UK's National Autistic Society (NAS) in 1997 and 2003 for parents of children under five years old (EarlyBird) and those aged 4 to 9 years old (EarlyBird Plus) with a diagnosis of autism. Both programmes work on understanding autism, building confidence to encourage interaction and communication and analysing and managing behaviour. They both consist of 12, 2.5-hour sessions, including eight group sessions with a maximum of six families in each group, three home visits and a follow-up session held three months after the programme [42]. In the EarlyBird Plus programme, parents can invite a professional who regularly works to attend the programme.

3.5.2. Evidence of effectiveness

Evaluations of the EarlyBird programmes demonstrate that these programmes can increase parental knowledge of ASD, increase confidence in parenting their child, decrease parental stress, improve communication and behaviour in children [42]. However, none of this data is from RCTs and some effects were only observed on small sample sizes.

3.6. The use of these programmes with parents of older children

There is insufficient evidence regarding the use of established parenting programmes for parents of older children to draw firm conclusions about their effectiveness.

The most established parent training programmes have, generally, been designed for and tested on parents with young children. In most of the studies reviewed, the child of the parent was either a pre-schooler or at primary school. Furthermore, none of the studies looked at long-term outcomes for those that go through the programmes; any follow-up tended to be within a year of the intervention completing. One review [43] concluded that whilst there are some good examples of longitudinal studies in this field, not enough of these throughout the world examine families' experiences and how those experiences influence adaptation at the time and in the long-term.

The PP Adolescent Programme and a recent revision of the STTP called Building Bridges Triple P (both discussed above) have both been trialled with parents of older children. However, the evidence on the effectiveness of both programmes is limited. Within the confines of our search, only one study was identified which examined the impact of each programme. One of these studies was unpublished and unclear on whether all the participants had learning disabilities [41] whilst the other was based on just nine cases without a control group [30].

3.7. Most effective components of these interventions

An interesting question for this research was to try and draw out which components of the various existing parenting interventions were most effective. Factors to consider in the design of interventions for parents of children/young people with learning disabilities and/or autism include:

- **Providing a course of sufficient length to allow new techniques to embed.** One review [44] found that studies with fewer sessions had lower effect sizes and reflected that behaviour management techniques take time for parents to learn effectively. Another review [45]

recommended that programmes allow parents sufficient time to practice new skills, and therefore suggested that parents be taught strategies they can use in their daily routines. However, other evidence has found a positive impact from just two sessions [29] so shorter courses can have merit, depending on the topic.

- **Tailoring development opportunities to meet the needs of participating parents.** Tiered programmes (e.g. tiered version of Incredible Years and STTP which have been tested and found effective) are one way of achieving this [46].
- **Including parent stress management training** with parental behaviour management training in order to have an effect on parental stress levels [47]. Tackling parental stress is seen as important because stress can moderate the effects of an intervention and parents may not benefit from intervention if they have high stress levels at the start [45]. Recent evidence suggests that adding stress reduction strategies into a training programme for parents can be beneficial [48].
- **Using group delivery methods.** Whilst evidence on the relative impact of individual versus group delivery methods of parental intervention is mixed, and more direct comparisons are necessary to clarify the issue [22], there are other valued benefits of group delivery. Group programmes provide major advantages in terms of cost-effectiveness and have additional benefits for parents in terms of social support and stress reduction. Studies on established parenting programmes reported that the group format had been viewed favourably by parents [45]. Parents see the group setting as both a source of support and a forum for skill development [36]. Other benefits for parents of a group-based intervention include being able to discuss coursework with other parents, learning how to ignore unwanted behaviours and meeting other parents [28].

Whilst the primary aim of this research is to consider the impact on the care and support of young people, it is also important to acknowledge the potential that parenting programmes have to simultaneously enhance parental well-being. This is well covered by the literature and perspectives on "looking after yourself" often form part of services provided for families, alongside information about disabilities and available services [43].

4. Other supportive and/or developmental programmes for parents

4.1. Introduction

Our evidence review included interventions which supported families in a variety of ways through the process of transition. Some of the interventions were primarily focussed on parents whilst others involved parents/families in broader programmes of work to support young people. These initiatives include programmes which have supported families with the transition process, but which have not directly attempted to develop the skills of parents, as well as parental development initiatives. This chapter presents details of four initiatives identified by the evidence review alongside the available evidence of their effectiveness.

4.2. My Way

This an ongoing UK programme which has been independently evaluated using qualitative methods and found to lead to a range of positive outcomes for young people which reduced the cost of their care packages overall. No data are available from RCTs.

4.2.1. Programme details

My Way⁹ offers a personalised approach to transition which encourages mutual help within communities. It is available to young people aged 15 to 24 with any disability although a large proportion of those using the service have learning disabilities. My Way works closely with the young person as well as their family, friends, their circle of support, teachers, support staff and various external organisations to gather information, create a transition plan and then provide practical support to help them put the plan into action. This is an ongoing approach.

My Way aims to offer something different from a traditional care manager approach which assesses needs and matches these to currently available services. My Way Facilitators take on a multi-faceted role working with and on behalf of the family. Facilitators act as co-ordinators for professionals; a single point of contact for families; listeners; navigators; advocates and; facilitators. They provide practical support with filling out forms and attend meetings. They also provide information and advice to young people, their families, other professionals and organisations (e.g. schools). In addition, they act as a broker to find out what is available and/or create opportunities and make the actions in transition plans happen.

This goal-focussed work is described as 'going one step further' and is achieved through a range of activities such as writing service specifications, supporting young people to access social activities they are interested in, gathering information from other organisations and visiting other professionals and sharing information about different options and ways of working. Facilitators also support people to harness existing social assets by bringing young people together to give opportunities for friendship, peer support and links to share support or housing solutions.

4.2.2. Evidence of effectiveness

Evaluation evidence is available for a specific project that ran My Way in tandem with a local authority between 2010 and 2012 and which involved 75 young people. An independent evaluation was conducted based on interview data with professionals, families and young people [49]. The findings showed positive outcomes for young disabled people using the programme and reduced costs to commissioners. The success of the My Way programme seemed to result from

⁹ <https://www.macintyrecharity.org/for-children/transition/>

its focus on implementing actions and 'doing' rather than just developing plans. The greatest progress was made in terms of young people moving out of the parental home, improving their social relationships and work. The majority of participants reported successful transitions supported by the programme, and that it had strengthened the partnership between young people and their families. The programme was either cost neutral compared to the status quo or was cheaper than other care packages. My Way facilitators were also able to engage with young people and their families more intensely than traditional care managers despite taking on a similar role.

The evaluation concludes that: "*The My Way approach is more effective than traditional care management at enabling people to turn their PCPs into reality and in a way that is cost-effective.*" (49, pg. 133)

4.3. Real Opportunities Project

The Real Opportunities Project was well received and achieved a range of positive outcomes for participants. No data are available from RCTs.

4.3.1. Programme details

The Real Opportunities Project operated in 9 local authorities in Wales from 2011 to 2014 and engaged with 1,766 people over its lifetime, funded for this period by the European Social Fund (ESF) The project set out to address the lack of support for employment and people with learning disabilities and/or ASD. It implemented a range of approaches identified by the literature as beneficial in transition to adulthood, particularly into employment. The project was designed to fill a gap in existing provision and establish what could be delivered through a comprehensive, well-staffed approach to transition support.

The project was driven by a person-centred approach, offered an integrated service which linked with schools, and hands-on support to help young people achieve transition goals. It supported young people by providing access to social activities, mentoring and work preparation. Families and young people were supported by independence teams including a Transitions Key Worker (TKW) with responsibility for PCP, and who acted as a single point of contact and information and who managed communication between the staff involved with the family. These workers also supported visits to post-school options (e.g. colleges) and travel training. TKWs had pushed, on behalf of young people, for more resources to support choices. They had also taken up a role for the young people who were not eligible for a social worker to assist in planning.

The overarching evaluation of the project [50] concludes that "*roles such as Transition Key Worker are central to the success of a person-centred approach. They are flexible, able to take a hands-on approach in helping people see potential placements and develop practical ideas for the future. The trust of families is important. Being able to come to the family, to help them build confidence and independence, and to provide an independent source of advice and guidance to young people with learning disabilities and/or ASD are key to winning that trust.*" [pg. 27]

4.3.2. Evidence of effectiveness

The project was subject to an independent evaluation and a range of papers published considering individual components of the programme, as well as an overarching programme evaluation. Young people and parents participating in the programme were involved in a range of survey and qualitative work to gauge their reactions to the service and their views on the transitions achieved. The approach was well received by families, young people and professionals. Families reported that the involvement of TKWs had had an impact on the way other services were working with the young people and family, and the resources and choices available to them [50]. A final follow-up survey of families suggested that the end of the project

represented a significant loss to them. The evidence from this evaluation is also suggestive of a positive impact on the employment prospects of young people who had gone through the supported work experience element of the programme.

4.4. Parent Advocacy Training

This is a new programme which has been tested with a small RCT in the US. The initial results are promising.

4.4.1. Programme details

The Volunteer Advocacy Program (VAP) was developed in the US and has trained parents and other individuals to develop the knowledge and skills needed to advocate effectively for school-aged children with disabilities within special education. This programme has been shown to boost attendee's knowledge about rights and their advocacy skills [51]. A new approach has been tested which adapted VAP to emphasise the needs of young adults with ASD and focus on advocating for adult disability services. The Volunteer Advocacy Program-Transition (VAP-T) introduces parents to person-centred planning and discusses adult-disability topics (e.g. the benefits system).

VAP-T is a 30 hour, 12-week training intervention delivered in a group setting with access to remote technology. Traditional teaching is combined with family-sharing activities, case studies and group discussions. The course is directed by an experienced group facilitator, a clinical social worker, trained in PCP who is aided by content experts for specific topics. The VAP-T programme works to empower and provide the knowledge necessary for parents to advocate on behalf of their transition age children with ASD. The programme focussed on a person-family interdependent model of planning which acknowledges the importance of person-centred planning but which requires the involvement of parents as service navigators.

4.4.2. Evidence of effectiveness

The VAP-T approach was tested using an RCT involving 41 parents of young people with ASD within two years of leaving high school, 21 of whom were assigned to a wait-list control [51]. Outcomes, collected before and after the intervention, included parental knowledge about adult services, advocacy skills-comfort, and empowerment. After participating in the VAP-T, intervention parents (compared to controls) knew more about the adult service system, were more skilled/ comfortable advocating, and felt more empowered.

The course was delivered flexibly to accommodate the needs of parents and allow remote access. The trial found that distance learners learned similar amounts of information as those who attended in person. However, many families valued the group format and opportunities to meet and network with other parents, and the workshops encouraged families to share their experiences. Also, the more sessions attended with the group, the higher the advocacy skills and sense of empowerment that parents reported. The evaluation suggests this may be due to the social-emotional components of being a successful advocate which are potentially best supported by learning with others.

Whilst the approach requires further testing, the evaluation suggests that it might become, in due course, part of a suite of interventions aimed at individuals which can be used in tandem or as needed. The project builds on the multi-dimensional approaches used in the established parenting programmes already discussed.

An accompanying discussion paper reflects on the process of implementing VAP-T and sets out key considerations when conducting interventions of this type [52]. These include:

- Timing - when is an intervention likely to be most effective -is this when or before a person needs the knowledge and skills covered by the course. This is likely to depend on the course content.
- Mode of delivery - what is the best way to present the information. Distance technology offers many benefits, but some course elements may be strengthened by a group dynamic or benefit from in-person skills and social support.
- Measuring outcomes - how best are initiatives to be judged if they succeed in empowering adults to advocate for services but in an area where there is a lack of service? The focus needs to be on whether individuals achieve meaningful real-life change as a result of their involvement.
- Inclusive design - this may be challenging when dealing with individuals of varying abilities and whose children have differing abilities.
- Level of intervention - parents are often required to act as brokers for their children due to the complexity of the adult system which is not always conducive to PCP. Interventions which focus on parents, therefore, need to include the needs and perspectives of young people with disabilities and may need to include coverage of PCP approaches with parents as a first step.

4.5. Transitioning Together

There are some positive indications of the effectiveness of this US-based programme, but the evidence base is still limited, and further research is needed.

4.5.1. Programme details

Transitioning Together is specifically concerned with assisting parents and young people through the period of transition into adulthood. Like the established parenting programmes (discussed in Chapter 3), this is a psychoeducational programme, and its design was based on evidence from longitudinal research and feedback from families of individuals with ASD.

This 10-session programme includes two individual family sessions focused on goal-setting for the adolescent, followed by eight multifamily group sessions (held in separate rooms for parents and adolescents) that covered a range of topics including: the developmental course of ASD; negotiation of service systems; exploration of behavioural management strategies; advocacy; parental well-being, and; long-term planning for the adolescent (eg employment and college planning).

4.5.2. Evidence of effectiveness

An early feasibility study of Transitioning Together [53], which involved 10 families in the US, provided encouraging results on parental understanding of the child's disability and service system as well as improvements in the parent-child relationship.

A more recent RCT of Transitioning Together [54] involved 45 adolescent-parent dyads. The adolescents involved were aged 14 to 16 and had high-functioning autism. This US study found that the programme had benefits for parent well-being, parent-child relations and social outcomes for adolescents. Furthermore, parents who received the intervention reported that the information presented and the interactions with other families were both valuable. This programme demonstrates that it is possible and effective to target interventions at the period of transition. The evaluation concludes that more interventions aimed at this stage in the child's life, and for a greater range of learning disabilities, are required.

5. Opportunities currently available to parents

Key points

The Children and Families Act (2014) places a statutory duty on local authorities to publish a Local Offer and to consult with/involve parents, children and young people. Parent Carer Forums receive funding from the Department for Education and local authorities must offer an Information Advice and Support Service (IASS). Both are well received and useful provision but the resources allocated to these services vary significantly between local authority areas. So too does the scale and nature of other elements of the local offer and the extent to which individual authorities prioritise and coordinate SEND provision.

Across the UK a diverse range of people and organisations are actively working to promote better transitions, many of these third sector organisations. National charities, both pan-disability and those which provide specialist support to individuals with a particular disability have an important role to play, but not all offer specific transition services. Local organisations similarly offer a range of services and training including generalist support to carers, specific provision for parents of disabled children and/or specialist resources for children with a specific disability.

Collectively these organisations provide national, regional or local helplines some of which focus specifically on transition issues, run events which focus on or include transition topics, provide resources or courses which inform parents about transition issues. These combined efforts aim to inform and support parents emotionally and practically. Organisations are also working, with parents, to develop and change agendas and affect commissioning decisions relating to transition. There are also examples of strong existing parent support networks, both local and national, and of parents who, having completed developmental activities, are actively working to support others as a result.

These initiatives have often been co-designed by parents and professionals with a huge amount of experience. There are therefore numerous organisations involved in delivering a range of initiatives that look and feel like good examples of how to develop parents to better manage transition. Many of which use techniques that have been proven to work when used to support parents of younger children (i.e. in the established parenting programmes highlighted in Chapter 3). However robust evaluation evidence about the impact of these initiatives is lacking. We know that parents appreciate the initiatives and feel that they get a lot out of their involvement and that the organisations involved are convinced that they are useful. However, more evidence is needed before firm conclusions about the best way to support and/or develop parents can be drawn.

There is significant geographical variation in the support and development opportunities available to parents. Much of what is available is offered by small, local organisations who are reliant on short-term funding and key individuals. There is a lack of co-working across these organisations and many have developed their own versions of similar tools independently of one another. There are therefore opportunities for these organisations to coordinate their activities more effectively.

5.1. Introduction

The research set out to map out what learning and development activities are currently available in this country to families of young people with learning disabilities and/or autism to support them through the transition process. In practice, full mapping was not possible. We discovered that provision is fragmented, much of it delivered locally rather than nationally, and providers in one area were often not linked to those in other areas. All this made it difficult to uncover what is out there, certainly within the constraints of the research (time and budget).

Rather than a complete mapping of the national picture, therefore, in this chapter, we discuss a range of different approaches to supporting parents using examples provided by those who participated in the consultation process. There are undoubtedly other examples of well informed, well planned and successfully implemented initiatives out there which we have failed to capture. The research team were, however, privileged to speak to some incredibly committed individuals and we can now highlight some of the work done by their organisations. Case studies have been provided to highlight a range of different relevant approaches to working with parents.

5.2. Statutory services

The legislative and policy background (discussed in Chapter 1) means that local authorities are required to offer families and young people with SEN a range of support. However, exactly what is offered in each local authority varies significantly. This section discusses the common elements of local authority support that parents across England can access as well as some of the differences.

5.2.1. The Local Offer

The Children and Families Act (2014) places a statutory duty on all local authorities in England to develop and publish a Local Offer. This sets out the support they expect to be available for local children and young people with SEND [55]. The offer should focus on the provision that 'will actually be available' and must cover the provision available to assist in preparing children and young people for adulthood. The support must include information about preparing for and finding employment, finding somewhere to live and participating in the community.

Some respondents to the consultation expressed concern about how well the local offer fulfils its brief to provide information and had concerns about how and what information is provided on local authority websites. This was felt to particularly affect how useful the local offer was to families seeking general information or who didn't know what they were looking for. The consultation suggests that a lot of local authorities provide a list of organisations that offer different services or support. However, there was a feeling that this wasn't enough and that local authorities need to go beyond this to more effectively support families.

"In an ideal world the local offer in every local authority would be so good that you could just type in 'local offer' and you would get a wealth of information when you needed it. Most local offers are not good and certainly haven't done what they were expected to do." (Parent carer forum member)

One respondent who has been working nationally to support local authorities described a situation where all were at different points in their journey towards the new way of working described in the SEN Guidance. Their view, however, was that no local authority is at the point where they have successfully implemented every aspect of this work. Delivery pressures make prioritising strategic work difficult, including joint commissioning and identifying transition pathways. Clear leadership support is required to drive through successful approaches to the way that children and families with SEND are supported. Greater awareness across different local authority departments is also required so that they can all deal with the needs of people with SEND in a connected way rather than working in silos.

Our consultation included representatives of three different local authorities. Each of these described a different approach. One local authority had a dedicated post to manage the transition process (see Case Study 1), another focussed on supporting families through a carers service that had not, yet, dealt specifically with transition issues but which supported a range of parent-led groups to do so, whilst the third had a distinct split between the support offered by children's and adult services with transition, seemingly, being caught in the middle.

Case Study 1: Enfield Borough Council's Moving On Service

Moving On¹⁰ is a joint initiative between children's and adult services supported by a dedicated transition co-ordinator post which has been supporting families for over 10 years. The service is built on the principle of co-production and parents are continually involved in the design and running of the programme. Moving On includes a series of workshops on core transition topics, an annual marketplace conference involving a wide range of providers offering presentations on key topics. Young people with learning disabilities and parents also talk about their experience at this event. A Moving On booklet is produced and widely publicised which sets out what should happen in the transition process and when.

Parents are encouraged to attend events from when their child reaches 14. The service promotes the events and booklet heavily with the transitions worker hosting coffee mornings at all local special schools accompanied with a parent where booklets are handed out and events publicised. Booklets are also given out to professionals and published on the borough's website. Moving On also links with the borough's parent carer forum.

*"We try really hard to provide people with information so that they have a choice and can make informed decisions. It's about providing the information - that's the important thing".
(Transition worker)*

Each of the two-hour workshops is run by an expert in the specific topic, in venues across the borough throughout the academic year. Parents are given information, offered the chance to ask questions and can be signposted to further support as appropriate.

The service also compliments other aspects of the system. Young people receive a Moving On assessment at the age of 16 which considers all four PfA Outcomes and the resulting information is considered by a group which includes both children's and adult services. If the child is eligible for adult services a Care Co-ordinator is appointed who then works with the family to develop their care and support plan in adult services.

The service is working to widen its reach beyond young people who are likely to be eligible for social care in adulthood. The transitions co-ordinator is developing a specific programme for SEND students in mainstream schools. The borough has also recently developed a supported internship programme for all young people with SEND using a two-year DfE grant with encouraging early results.

5.2.2. Information Advice and Support Services

The Care Act 2014 also requires local authorities to establish and maintain a service for providing people in its area with information and advice about the adult care and support system. This service must be dedicated and easily identifiable, impartial, confidential and accessible. It must

¹⁰ <https://new.enfield.gov.uk/services/children-and-education/local-offer/young-people/young-people-over-14/#1>

also have the capacity to handle face-to-face, telephone and electronic enquiries. These services are provided by a network of locally commissioned SEND Information, Advice and Support Services (IASS) which support parents, carers and young people up to the age of 25. The services act to help people become better informed, know their rights and help with EHC plans and tribunals. IASS are funded by local authorities but operate as an impartial service, even where they are operated by in-house teams. The amount of funding allocated to services is determined by each local authority and varies significantly.

One IASS provider discussed their work with us. They described the majority of what they do as providing information and advice with much of this relating to questions about school or college, EHC plans, annual reviews, benefits entitlements and local options for education and supported housing. The service provides advice about making choices, services and where to go for different things. This organisation provides IASS services in two different, neighbouring local authorities and the funding levels for each service are very different. Where the funding is less, the service becomes a light touch phone line only, whereas with more funding they can offer an enhanced service including casework. Transition issues make up around 15% of their helpline calls and 13% of their casework. The service also assists people with queries about Disability Living Allowance (DLA) and Personal Independence Payment (PIP), and the IASS provider identified the transition in benefits at age 16 as a key issue for parents and young people. The service supports PIP claims, but this is very time-consuming.

IASS are well respected but their capacity is restricted by the level of funding that they receive. One respondent (from a national not for profit) described IASS as the "*the most informed part of the system*". Their knowledge about the whole system (i.e. health, social care, education) makes them a potentially valuable source of support to parents. Similarly, one parent representative described IASS as a '*trusted voice*'. However, they are mostly small services in high demand.

5.2.3. Parent Carer Forums

There is a grant available for a parent carer forum in every local authority area in England from the Department for Education (DfE) to support their development and strategic involvement in local services. The aim of these forums is to involve as many parents as possible and work on co-production with the local authority. Parent Carer Forums are developed by parents themselves and bring parents together to support one another.

There is a National Network of Parent Carer Forums (NNPCF)¹¹ which is made up of all of the parent carer forums from across England. The NNPCF ensures that local parent carer forums are aware of national developments and promotes opportunities for the voice of parent carers to influence at a national level. The NNPCF works closely with the Department for Education and the Department of Health.

Consultation respondents described forums as being well used and having a significant supportive role but that this is achieved despite relatively low funding levels. Respondents also discussed how the quality of the co-production work in an area can be determined by the quality of the relationship between parents and the local authority. The relationships in some local authority areas were described as 'antagonistic', making co-production difficult to achieve in practice. However, where parent forums and authorities work well together there is the opportunity for parents to have a real local voice.

"For parents, it's the focus on co-production that's really important. Co-producing your child's support. Families should be at the table when producing local strategy". (National not for profit organisation)

¹¹ <http://www.nnpcf.org.uk/>

5.3. National organisations

There are a range of national organisations working to support people with disabilities and their families. Some of these organisations work across different disabilities whilst others focus on a specific disability. The extent to which they address the needs of transition age young people and their families varies significantly. Some examples are provided below of the work of organisations who took part in our consultation.

5.3.1. National Autistic Society (NAS)

The NAS is the UK's leading charity for autistic people and their families. Their goal is to help transform lives, change attitudes and create a society that works for autistic people.¹² Within their broad portfolio of work they influence, support and campaign on behalf of people with autism. They also offer a specific service to support families through transition (see Case Study 2).

Case Study 2: NAS Transitions Support Service

The NAS Transitions Support Service is a free UK-wide telephone helpline for families. It supports any family with an autism diagnosis or where they believe their child might be on the autism spectrum. The service is staffed by specially trained volunteer advisers. Volunteer training takes place over 7 distance learning modules (e.g. education and social care, the benefits system, mental capacity and the ability of people to make their own decisions and be given the opportunity to do so) with each module taking 5 to 7 hours to complete depending on prior knowledge. Volunteers then receive 2 days of face to face training before going on to actively work with families.

It can be difficult to solve problems related to the transition process during a single phone call. After their first call families are given an email and phone number that they can use to contact the same adviser more easily in future. If that adviser isn't available, then other co-ordinators will step in. The main channel into the service may require up to 5 days for a call-back, but after the first call, they then have direct access to the volunteer advisers. Some families only use the service once or twice, but other families call in on an ongoing basis with questions.

"The thing about transitions is that it is a long process. If you've got someone at 14 who wants to go on to specialist college and they won't be leaving for years and will be going through various stages of transitions and what the changes mean for them. As long as we have the funding we'll be here." (Service Manager)

The NAS feel that it is important that the service is volunteer-led and bespoke. The training process allows advisers to offer a personal service and meet individual needs. Families, therefore, receive information that is of benefit to them and their child. The service is also able to explain the transition process from an autism point of view.

"It's key to make the advice you provide meaningful to each family. It's not about just getting the right information it's making sure that they understand and can act on that information proactively. It can be overwhelming so it's important that we offer that ability to get back in touch and hopefully with a consistent person". (Service Manager)

¹² <https://www.autism.org.uk>

In last year the service has worked with around 500 new families and is growing quickly with an average of 50-60 new families a month recently. They also continue to work with families that are part of their caseload. Each of the six volunteers spends around 4 hours a week speaking to families and researching solutions for them. Another 5 volunteers have recently been trained, with a further 6 completing the training process. The helpline highlights aspects of statutory care and guidance so that families then feel empowered and validated in seeking support and solutions.

5.3.2. Mencap

Mencap is a large national charity focussed on supporting people with learning disabilities and their families. Their focus is on improving the lives of people with a learning disability and their families now, and to work with them to achieve a better future. They aim to reduce stigma and discrimination, promote early intervention, make a difference to people's lives through social care, support friendships and relationships, improve health and employment. Their work includes campaigning activities and offering personalised support in areas such as health, housing and work, as well as supporting people with learning disabilities to access leisure opportunities they enjoy. Mencap also operates a telephone helpline which focusses on providing advice and information on a range of issues, and support with legal issues. The helpline advisors will also signpost on to other advice and information providers where appropriate

Reflecting the organisation's strategic prioritisation of legal support, Mencap has recently developed a Legal Network. This is a collaboration of a range of organisations including service providers and local Mencap groups. Mencap acts as a hub providing legal education and early legal help (including through pro-bono clinics and a pro-bono Barristers' panel) on a subscription basis. The money paid in subscriptions is related to the level of support the organisation requires and is used to fund additional caseworker support. The network aims to increase the legal capabilities of frontline staff alongside providing high volume early legal help. The Legal Network also collects data to identify trends in unlawful behaviour which it uses to influence decision makers and bring about local and national change. The Legal Network is seeking to expand membership to Advocacy Organisations.

Another element of the Legal Network is the development of a Legal Chatbot which is currently being tested and prepared for launch. This has already been programmed with 500 questions and answers and complex dialogue flows. It uses natural language processing and is capable of speech recognition. It provides initial information and suggests template letters which users can fill in and send off. The Chatbot is the result of a collaboration between Mencap and the private sector, academics and legal experts. It already contains reference to legislation relevant to transition and SEND issues are starting to be programmed in. Whilst still in its early stages, Mencap hope this has the potential to support a large number of people and be a useful resource which will be publicly available for use across the sector. Mencap sees the Chatbot as tackling less complex legal problems in a different, highly efficient way, with more complex cases still able to be referred on for intensive support from their other services.

The Legal Network represents one way of promoting collaboration and a consistent approach across the sector. Achieving collaboration in this way has relied on building strong relationships. Mencap also funded a pilot of the service which provided evidence about the potential impact of this approach and this was used to create interest and commitment across the sector.

5.3.3. My Family, Our Needs

My Family, Our Needs run a website for families with any children with an additional need from birth to age 25.¹³ It was established two years ago by parent company Care Choices (a privately owned publishing company) when it converted its print magazine Progress (for young disabled people) into an online presence. The website has two sections: 1. for parents coming to the website to find out about their disabled child (e.g. diagnosis, education advice and a broad range of topics) and; 2. highlighting support for parents. It provides resources to help parents manage their lives outside of the young person and their disability. The website provides lists of local support groups and bloggers talk about their lives and share their stories. The aim is to create an online community.

Another aspect of their work is the transition events that they run annually (see Case Study 3). They also run an awards event in partnership with Bringing Us Together- Bloody Awesome Parents Awards (BAPS awards). This is the only blogging award for just SEND parents and recognises their valuable contribution to raising awareness of additional needs, both within the SEND community and wider society. The event is a chance for people who have met on the internet to meet up in person. There is also a My Family Our Needs Facebook group which parents use. Expert speakers who present at the transition events also write features for the website about various aspects of the transition process (e.g. education deadlines). Readers then email questions to these experts and receive responses.

"The biggest thing is that people just don't have a clue what's out there. People might not have enough money to advertise what they do, or they work locally or regionally rather than nationally. Parents just don't know what's out there and if you don't know what's out there you don't know what to look for". (Service manager)

Case Study 3: My Family, Our Needs Transition Events

My Family, Our Needs runs two Transition Events annually, one in the Midlands and one in the East of England. The Transition Event Midlands has been running for over 10 years and the events aim to help parents put the information provided on the My Family, Our Needs website into practice. The events are for parents/carers and for professionals and young people who are bussed in from their schools (both mainstream and special schools, but more of the latter). Events typically have around 100 delegates.

The events offer an exhibition room where parents can meet service providers and other relevant organisations and groups. There is a speaker programme which runs in tandem with practical workshops where parents can have individual time with expert speakers to discuss their specific situation.

The expert speakers change year to year, but the content of the events remains similar. Experts present on a number of 'core' topics, these tend to be:

- Progress from statement to EHCPs. Parents should ideally get everything in place that their child will need by the age of 16 with regard to EHCPs because after this it will be more difficult to get those needs met if they haven't been met already.
- Educational transitions such as from school to college, or to university.
- Housing and transitioning from living at home to more independent living. The talk discusses housing options that are available such as supported living, shared lives or

¹³ <https://www.myfamilyourneeds.co.uk/>

residential care. The focus is on finding alternatives to residential care which people may not have heard of (e.g. house shares).

- Employment. How young people can get a job when they're ready after school.

Other topics that they have covered include mental capacity and how this might change, assisted technology, sex and relationships. There are organisations that can help with various aspects of the transition process, but families are often unaware that these organisations exist and the events help bring providers and families together.

5.3.4. Autism Initiatives

Autism Initiatives¹⁴ operates some of its services across the UK with others focussed in the North West. It offers a range of free training to parents to equip them with the information they need at various points in the life of their child. The organisation also offers one to one support to families from primary age onwards. When families hit 'brick walls' they can come back to the charity for further support and often receive requests from young people over the age of 18 to maintain their support due to an absence of support from statutory services. The charity talks things through in an 'autism therapeutic way' to help people realise what they can do and achieve.

One aspect of their training is to take a forward look towards transition, including consideration of how fearful people with autism or ASD can be when considering their futures. They offer parent training on the pathway to adulthood which looks at routes for the young person, parent fears and which takes a whole family approach involving siblings. Autism Initiatives tries to link their training with pathways into employment and to help families look at next steps.

5.3.5. Prader Willis Syndrome Association (PWSA)

This organisation¹⁵ provides a range of services to support children and adults to Prader Willi Syndrome (PWS). This a rare condition so the organisation believes that specialist support is a necessary counterpoint to the generalist services available to parents. The syndrome results in a range of difficulties as young people go through their teenage years. Whereas many young people with PWS cope well in primary school as their developmental differences become apparent at around 10/11 years old they can need more specialist support and may move into special schools from mainstream provision.

PWSA offer families access to: a telephone, email and facebook helpline for those in crisis or needing help, mediation, information and support (this often involves helping families with issues relating to transition); an information hub providing information about about PWS in an accessible, engaging and relevant form; Familynet: a regional network of peer support groups, with a programme of family events within safe environments; training courses for professionals working with those with PWS; funding for research throughout the world and opportunities to take part in research.

Parents often contact PWSA when they are turned down for support and PWSA offers a range of support with processes. For example, they offer support in making applications and can write to local authorities in support of an application. Parents can lack basic understanding of the process of applying for support (e.g. they don't know that they can appeal decisions or that they don't have to wait a year to review a plan). The specialist support PWSA offer is also important for the

¹⁴ <https://www.autisminitiatives.org/>

¹⁵ <https://www.pwsa.co.uk/>

EHCP (e.g. PWS individuals have a high pain threshold, low base temperature and find it hard to vomit).

PWSA run a biannual conference for parents and professionals which include a programme of sessions providing support. The first day is for parents of children under the age of 18 and childcare is provided for the whole day. The second day is for parents/carers of those over 18. Professionals can attend either day. The last conference covered 10 different topics including some related to transitions. Having conducted focus group work with young people with PWS, PWSA have identified key information that these young people want to know and will work to make this accessible. They have also produced sex education videos for young people to watch with their parents/carers.

5.3.6. Engage to Change

Engage to Change¹⁶ operates throughout Wales. They run several programmes that relate to the period of transition. They have a 5-year lottery funded employment programme to support young people between 16 and 25 with learning disabilities and/or autism by helping them find work experience, meaningful employment and/or paid work. The programme aims to ensure that they enter the world of work and has a target for how many long-term jobs they can create. It will work with around 1,000 people over its lifetime. The project uses a supported employment model and targets work-ready young people. There are also work co-ordinators who act as a single point of contact for the young person throughout their employment and are available for as long as the project is funded.

Families are recognised as an important part of the project and are interviewed with family support workers available. Young people can access a range of support to help them move into employment such as hygiene courses or clinical psychology to reduce anxiety for parents and young people relating to a change in circumstances (particularly important for young people with autism). The ongoing support also helps to address some of the social aspects of work which young people can struggle with. The Engage to Change website also has a specific section for families.

Through their experience of running the project, the main issues that families require support with include:

- Transport. Parents have concerns about the safety of their child and how using public transport can make them vulnerable. The project uses Access to Work money to pay for taxis when appropriate but focusses on helping young people travel independently where possible.
- Benefits. Their project has encountered a huge issue around benefits and the better off cap. Families have concerns about how many hours young people can work before they're better off. Benefits also span the whole family so the project supports parents to see how they will be better off if the young person is working and promotes moving from benefits reliance to a working tax model.
- Lack of aspiration. Families have spent many years proving to the DWP how incompetent their child is. There can, therefore, be a disconnect when they are then asked to think about young people's skills and aspirations during transition

The organisation also runs a paid work placement scheme and Project SEARCH which works with employers to provide an internship programme. Project SEARCH has a great deal of family involvement during the selection process. Many of the young people in South Wales have been

¹⁶ <http://www.engagetochange.org.uk/>

employment ready because of support they had received from the Real Opportunities project (discussed in Chapter 4) which finished its work in 2015, but which also had a substantial element of family support. People supported by Real Opportunities are now old enough to be eligible for support by Engage to Change. Future cohorts who have not had Real Opportunities support may, therefore, be less employment ready.

5.3.7. Books Beyond Words

This national charity produces wordless books which tell a story using pictures so that they are accessible to people with a learning disability and others with communication difficulties or who just prefer pictures to words. The books cover a range of topics (e.g. depression, health screening, starting periods, making friends) some of which are directly relevant to the period of transition. The books are extensively trialled before publication.

They can be read alone or with peers, and help individuals understand different aspects of life and relationships, including for example, the impact of their behaviour (e.g. indiscriminate hugging). The books help parents to talk about some difficult topics with their children and could form the basis of a training course for parents and others with a care role. Each book has a 4 to 8-page text at the back which is designed for family carers and support workers or other professionals, depending on the topic. This section sets out what they need to know, why it matters and what to do about it.

5.3.8. Partners in Policy Making

Partners in Policymaking¹⁷ is a leadership course for parents and relatives who have a disabled child up to the age of 15, and disabled adults. From Partners in Policymaking, sister courses have been developed aimed at families who have a disabled relative, alongside the people who support them through their work in health social care and education. Originally developed in the US, Partners in Policy Making is run under license in the UK and gives families the strategies they need to work in partnership. Courses have been offered locally and nationally for the last 23 years.

The model is that those who have completed the course go on to support others in their local community and beyond. There are now over 3,000 graduates from the programme in the UK who are in contact with one another via a coordinated email network which can be used to get tips and support. Courses are operated within a single local authority area so that people can be brought together who live locally and are invested in that area. Whilst service workers move on, families tend to stay, so investing in families makes sense in the longer term. The programme therefore provides both local and national peer support.

"Have parents who know exactly what they are talking about. They're not recipients, they're partners. They don't wait for people to do things. If somebody wants a meeting and there's no agenda we will write the agenda. We will say what outcomes do you expect from this meeting? We give parents the strategies and then the back up from other families across the country". (Programme Founder)

The training consists of eight residential sessions, each two days long, approximately one month apart over 128 hours of sequential instruction. Local, national and international experts on disability issues present information and interact with the participants, to share state-of-the-art ideas and equipment and current best practices. Topics include: exploring why things are the way they are at present; understanding and relating to the systems; getting information on what is

¹⁷ [http://www.in-control.org.uk/related-pages/about-us/the-team-\(bios\)/lynne-elwell,-partners-in-policymaking.aspx](http://www.in-control.org.uk/related-pages/about-us/the-team-(bios)/lynne-elwell,-partners-in-policymaking.aspx)

possible and what is available; getting the right support, and; making change happen locally and nationally.

The core Partners in Policy Making has been adopted into a range of other courses such as 'Altogether Better' which can accommodate parents of young people of all ages and professionals working in health and social care. Other courses could also be developed with a different focus, such as specifically on transitions topics if funding was available. The founder of Partners in Policy Making UK has recently published 'Rights of Passage' which has been designed as a handbook to help young people and their families prepare for adulthood. A course with the same name has also been developed which works with young people going through transition.

"Transition always seems to be about fitting the person into where they might fit rather than looking at what their gifts and passions are and starting from that. What I would do is put a course together that more about person-centred planning and get some families together and come out of the other end with some solutions and a plan and a support plan." (Programme Founder)

The Partners in Policy Making programme in the UK was evaluated in 2006 by Lancaster University [56] using a follow-up survey of programme graduates. This found that participants were highly satisfied with the programmes and that most graduates stayed in contact with one another after the courses had finished. The evaluation concluded that *"Partners in Policymaking programmes are highly effective in terms of helping to generate wide-ranging positive outcomes for individuals, families, local services and increasingly national policies."* (56, pg. 8)

5.4. Local provision

There is also a broad range of organisations who work to support families and people with disabilities at a regional or local level. These are often third sector organisations, some of which receive funding from local authorities and/or rely on grant funding. A range of these organisations participated in the consultation and the services they offer are outlined as examples of the local services that parents can access in some areas.

5.4.1. Autism West Midlands

Autism West Midlands¹⁸ operate across the whole of the West Midlands but what they can offer in each local authority varies significantly.

"It's a bit of a postcode lottery, you wouldn't find a consistent body of evidence about impact because it's so variable as to what gets delivered in different areas" (Service manager).

They would like to work towards a broader universal offer in the entire region, but at present, the services offered across the whole of the West Midlands is limited to the helpline, detailed information guides and some training courses. Ideally, they would extend their services, possibly by offering more intensive support over the phone/by Skype, or online training which is available to everyone. Then, when LAs are prepared to fund more they would buy additional local provision. They have been able to develop strong networks in some local authorities to support their work.

"The local provision is what makes the biggest impact. If you have a presence in the area and you're joined up. For transition, if you can join up with the transition teams for social services and do some joint work this can make a big difference, but you can't do that unless you have that local presence and funding base". (Service Manager)

¹⁸ <https://www.autismwestmidlands.org.uk/>

The main emphasis of all the services they provide for families is empowering and upskilling parents, giving them early information and light touch support along the way when they can. Rather than work intensively with a small number of families their model is to offer repeated activities to groups of people to engage as many families as possible and they reach thousands of families across the region. It is very difficult, however, for them to find the funding required for any universal offer.

Autism West Midlands offers established parenting programmes such as Early Bird and their own course 'Rising to the Challenge' which covers similar topics, but only where the local authority funds this. They also offer one-off workshops on specific topics such as teenage issues and developing independence skills and work with groups of young people. They hope to extend their provision for young people but need to secure funding in order to do so. Ideally, they would work with parents and young people simultaneously to support transition and put in place the same model of support for young people as they already offer adults. Early consideration of transition is necessary to promote true independence (e.g. transport - by taking their children on buses from an early age, families can prepare their young people for independent travel more effectively). Their courses cover practical issues alongside understanding autism and behaviour management strategies.

5.4.2. Oxfordshire Family Support Network

Oxfordshire Family Support¹⁹ was set up in 2007 by family carers of people with learning disabilities who wanted to use their experiences to help others in the same situation. They are a peer-led charity and everyone that works with them, and their Trustees are family carers. They operate an expert by experience peer support model across Oxfordshire and have built strong local partnerships and working relationships with statutory organisations.

The charity runs a small team of Family Advocates who are all family carers of children or adults with learning disabilities. Each advocate has skills in different areas and can support families, such as during meetings with professionals, or through signposting. The charity has also produced a series of guides and workshops to support parents through transition into adulthood (see Case Study 4) and feels it is very important to train families and help them develop skills so that they can help themselves and others. These materials could also be adapted for use in other local areas if area-specific information was edited.

"We are parents supporting other parents, but we are parents who have had positive experiences and know our stuff. We know the legislation; we know what your rights and responsibilities are as a parent, but we tell them it warts and all and we tell them what to do if...this happens. So, if you're told 'no' how to manage that. We show how it's good to negotiate rather than fight. It helps parents be able to calmly negotiate with professionals from a position of knowledge, knowing that there are other families that are there to support you should you need that help". (Programme Manager)

They have also developed a six-session Open College Network accredited course called 'Family Champions' which covers legislation alongside person-centred thinking, approaches and planning and how to use these in a practical way. They have run two of these courses now and have 9 family carers actively working with the charity, as a result, each specialising in a different area (e.g. becoming a co-trainer, understanding the legislation). The courses support families to think about their child in a person-centred way but also helped to move family carers into paid work for the charity to support other parents. The aim is to deliver a course annually from now on.

¹⁹ <https://www.oxfsn.org.uk/>

The charity also works to bring families, decision makers and service providers together such as running events which bring together professionals and parents (e.g. a recent World Café²⁰ event) to influence professionals and change the way they work. They have also run a series of training sessions for health and social care providers, called Working with Families in which parents (who have previously completed a course with the charity) share their experiences and discuss how they'd like to be treated. It is hoped that these interactions can help families and professionals problem solve together.

Case Study 4: Oxfordshire Family Support Network's 'Getting a Life' guides and workshops

Oxfordshire Family Support Network has produced five guides each of which covers a different transition topic, and which can be used as the basis for a workshop session with parents. These are:

- **Getting Started.** This includes a 'jargon buster', introduces person-centred thinking, planning and approaches, the Year 9 review and which encourages parents to start thinking about transition.
- **Education Matters.** This discusses the options for staying on at school or going to college including residential colleges, adult education and lifelong learning.
- **Finding the Right Support.** This covers how to find good support and includes things to think about and questions to about the type of support the family are looking; finding and checking out support providers, employing your own staff and keeping safe.
- **Becoming an Adult.** This covers the Mental Capacity Act and supported decision making.
- **Social life, Having Fun, Friends and Relationships.** This covers the things that parents can do to help young people stay in touch with the people that are important to them and make new friends. It also covers sex education, relationships and keeping safe.

5.4.3. Greater Manchester Autism Consortium Project

The Greater Manchester Autism Consortium (GMAC)²¹ is a partnership between the ten local authorities in Greater Manchester and the NAS. It carries out work on a variety of issues, including transition.

At the request of the Department of Health, the consortium conducted research into the transition of young people from childhood to adulthood in Greater Manchester, the results were published in 2012. One of the key recommendations was that parents of young people going through transition should have better, and timely, access to information about the kinds of services available and eligibility criteria for these services so that they can navigate the system better.

GMAC can be contacted via a telephone information line and their website. They tend to work with people when they feel they have nowhere else to go and/or where young people have totally disengaged from education. Often families can be helped with relatively basic information about how the process works and what they are entitled to, particularly if the young person has attended mainstream school. Other local provision tends to be support groups rather than developmental activities.

²⁰ This is a technique to facilitate the inputs of large groups of people in a way that support small group working and insights

²¹ <https://www.autismgm.org.uk/>

GMAC offers a parent seminar programme primarily to family members of under 16s (although they have had attendees of parents of older children with learning disabilities) covering: managing anger; understanding sensory needs, and; understanding autism. Their seminars are advertised locally so that parents can self-refer. Local schools and CAMHS teams can also call and book a space for parents.

GMAC also funds and steers the Family Services Development Project (FSDP) which supports the development of local services for families, carers and people with autism or Asperger syndrome in each of the 10 local authorities. The FSDP has developed and piloted a two-day transition workshop for parents covering issues such as working with services, the transition to college and university, employment, entitlement to benefits and health and social care support. Running the course over 2 days also allows parents to come to terms emotionally with some of the issues being raised. At present they lack the funding necessary to roll this out alongside the other workshops but would like to do so.

GMAC currently have a contract to develop and write an autism strategy for Greater Manchester. Although Greater Manchester is joined up in some ways, people's experience from diagnosis and all the way through their lives can be very different from borough to borough. The strategy aims to achieve some consistency. The strategy will cover diagnosis onwards. The current strategy is a 14+ strategy because most of the funding comes from adult services and a lot of the focus is on transition, but they hope to make it an all age strategy. The strategy will have various headings such as Access in the Community, Criminal Justice, Housing, Transition and Employment. For all topics, they will set up an implementation group with key people from each sector to scope out what is already happening within the region and identify gaps. These groups will provide recommendations on how to improve things in a practical way.

5.4.4. Amaze

Amaze²² is a charity based in Sussex which provides information, advice and support to families of children and young people with SEND. They provide the IASS service for Brighton and Hove and East Sussex, operate the disability register in Brighton and Hove and West Sussex. They operate these registers up to age 25 and link them to a leisure discount card this allows them to stay in touch with families throughout transition.

Amaze offers a range of training and support for parents including workshops on Personal Independence Payment (PIP) or seminars on the Mental Capacity Act. They have also developed a series of six courses called Insiders Guides including one which is focussed on transition age young people (see case study 4).

Amaze offer parent befriending at the time of diagnosis but also at times of difficult change. They believe that this is a powerful model and that it would be useful for families of older young people. They also run a Dad's group, a breakfast club which brings parents together, including parents whose children are in transition, and outreach coffee mornings in more socially deprived areas. These events provide a vehicle for people to come together. Amaze also runs Amazing Futures which is a peer support project for young people. This has a knock-on effect for parents but is focussed on young people being trained to be peer supporters for people with SEND. Almost everyone being trained has additional needs. This runs in Brighton and Hove and East Sussex.

"There's something about offering a mix of things. Everything we do (apart from SENDIASS which came down from the government) has come out of what parents and young people have expressed needs and we've looked at ways of meeting them." (Service Director)

²² <https://amazesussex.org.uk/>

Case study 4: Amaze Insider Guide - Course for Parents of Teens

The Insider Guide courses are carried out over six, three-hour sessions. A worker and a parent-trainer co-facilitate the course which is focussed on topics that parents have fed back they want. One of the courses focusses specifically on the parents of young people over the age of 12. The morning sessions combine emotional and practical information. The workshops are designed to help individuals to maintain resilience to carry on and cover specific topics such as socialising and relationships and skills in working with others and getting the most out of other people in meetings. Everything is focussed on moving onto adulthood.

Insiders Guides focus on how parent carers can sustain themselves and the sessions mix information, talking about feelings and the journey so far as well as offering practical support. Feedback from participants demonstrates that parents value being with people going through the same experience and who can provide emotional support. The aim is to help people be better able to cope and to acknowledge that they need time to look after themselves and that they should be asking other people for support with various things.

The course is based on four fundamental assertions:

1. Parents are key to improving child and family outcomes
2. Parents of children with SEND travel a unique journey
3. Parents enter a frequently unfamiliar world of disadvantage directly related to having a child with SEND
4. The best can be achieved for a child when parents and practitioners work together.

The courses are run annually funded by both Brighton and Hove Council and the Big Lottery. They each attract 12 to 14 parents which are considered by project staff to be the right size group for work of this kind. Amaze feel that the demand is there to run at least one other course in the area if funding was available to do so.

The programme has been run in several different geographical areas and has been collectively evaluated using data from surveys, standardised scales, stakeholder events and meetings. An independent evaluation [57] concluded that the project achieved a significant range of impacts on participating parent carer learners, on their families, and on parent carers and practitioners who worked as co-facilitators, on practitioner co-facilitators. It states that *"Parent carer learners reported significant changes for themselves and their families as they became equipped, informed and confident. The resilience elements were of particular importance for parent carers coming to understand the need to attend to their own health and wellbeing in order to continue caring for their children with additional needs in the long term."* (pg. 5) The evaluation also acknowledged that a longer evaluation timescale would be needed to track these changes further.

5.5. Main gaps

As the examples presented in this chapter demonstrate there are already interesting and innovative approaches to supporting parents with their struggles with some of the problems presented by the transition process. There are therefore no gaps in aspiration, particularly amongst parent-led third sector organisations, and hugely committed and passionate people are

working hard with and for parents on this topic and others. Having said that, there are three key difficulties with the status quo identified by this research, and which are discussed below.

5.5.1. Major geographical differences

As a minimum, parents have access to a telephone advice line and parent carer forum in their area. The offer in some local authorities goes beyond this and some councils fund a regular programme of events for parent carers. There are also other free information events focussed on transitions that parents can access but which may require them to travel to a different region. In some areas/regions, there are also active community-based organisations providing courses, workshops, advocacy and support. Some national charities also provide specialist support for parents of children with specific disabilities.

This description may suggest that there is a wealth of opportunities available to individuals seeking support and that may be true if we judge the country as a whole. However, for an individual parent, the support that they can access locally is often limited not by the level of their need, but by their address. This postcode 'lottery' reflects a picture of fragmented provision, hugely different levels of funding by area, reliance on community and voluntary sector groups often supported by short-term funding and therefore a complete lack of consistency. This creates massive complexities for any family trying to work out what to do and what support they can access.

Given these differences, local networks and partnerships can be extremely important. The consultation found examples of organisations using their networks to support influencing work. Parent (and young person) involvement in these activities was seen by consultation respondents as a vital component in changing the perceptions and agendas of local commissioners. Similarly, bringing parents together to share knowledge and experiences of how the system works within any one area was also felt to be very important.

5.5.2. Lack of joined up working

We found a range of organisations who were already actively supporting families through transition or thinking about how best to do so. Our consultation suggests, however, that there is limited joint working between organisations across the country. Many of the local organisations we spoke to, for example, were unaware of what other similar organisations in other areas offered. A number of organisations have also developed their own courses relating to transition issues but done so independently of one another. Bringing together the experience, knowledge and ideas of these organisations would, therefore, be a useful first step in determining how best to support parents in future to avoid 'reinventing the wheel'.

It is important to recognise the importance of local knowledge, networks and trust that smaller organisations have already developed. These things make them ideally placed to work with parents, but they also have vulnerabilities (e.g. their funding base is often piecemeal and short-term and they are often reliant on key staff or founders). It may, therefore, be worth considering whether there is any way to provide infrastructure to better support a range of small organisations in a way that would help to develop a more consistent offer nationally for parents and to do so in a sustainable way. One consultation respondent, for example, felt that their organisation, a national charity, would be well placed to provide back office support and take on a coordination role in relation to smaller local charities. The approach of Mencap in bringing together a Legal Network offers another template of how to do this.

5.5.3. Limited evidence base on what works

The consultation revealed a range of ways in which organisations are currently supporting/developing parents in ways which aim to promote more positive transitions. Broadly speaking, the approaches available to parents currently involve some combination of:

- peer-support networks
- telephone-based information, sometimes also with advice and guidance and/or bespoke casework as appropriate
- seminars or short information sessions delivered face to face
- longer taught courses, mostly with interactive elements.

The available evidence suggests that these programmes are well received and that parents believe they benefit as a result of their involvement. There is, however, a lack of robust evidence about which approaches are most effective. Better research and evaluation is therefore required to assess and demonstrate what works and how and to determine the impact of these programmes on the transitions of young people. Without this evidence, it is not possible to make clear recommendations on how to support parents in a way that best promotes successful transitions.

Tailored learning/development is certainly one way of helping parents, but whether this is more effective, or cost-effective, than doing things some other way is not clear. Similarly, organisations have taken a variety of approaches to developing parents, with a range of courses covering similar transition-related topics already on offer but it is not possible to directly compare the outcomes and impact of these different courses due to a lack of evidence.

This lack of evidence does not necessarily indicate a lack of impact and the existing development programmes certainly seem to be doing all the right things and have received positive responses from parents. The logical next step is therefore to promote the collection of more robust evaluation data rather than to redesign or develop more interventions. However, organisations who excel in working with families often lack the skills or resources necessary to implement such evaluations on their own. Finding out from these organisations what support would enable them to evaluate their efforts more effectively, and how best to help them coordinate their efforts would be a useful interim step.

6. Conclusions

6.1. Study scope and caveats

There is a range of challenges facing families during the transition of a loved one with learning disabilities and/or autism into adulthood. Many of these relate to the way that the current legislation and guidelines are implemented and reflect broad systemic issues which are beyond the scope of this research. It is an acknowledgement of these system failures that drive the desire to find a better way to support and develop parents, but such systemic issues are beyond the scope of this research. Development work with parents is not being discussed in this research as a replacement for other forms of support and it is our view that future strategies should build on existing relationships and provision.

It is also important to acknowledge that the 'system' is not the people who work within it. Professionals are consistently being asked to do more, with less, and can lack the training and experience they need in order to offer the quality of service they aspire to. Not referencing the need for professional development, when discussing how to improve the situation, would, therefore, be a grave omission. Again, however, how best to support professionals is outside the remit of this project.

Similarly, by focussing on developing parents, that does not mean that young people should play any less of a role in making decisions about their future. Rather, the aim of developing parents is that they are then better able to advocate for and represent their children's true aspirations and desires and work more effectively to find creative solutions to attain these. However, the system also needs to make strides in involving young people in a more meaningful way in the transition process, but this is not something this research addresses.

Another important point to make is that in no way does the focus on parent development in this research imply that parents are 'the problem' or that their struggles during the transition period reflect a lack of capabilities, strengths or potential. It is also not driven by any suggestion that parents need to do more, the evidence is clear that they are already doing so much that their health and well-being are at risk as a result. However, parents may benefit from doing things differently, having a broader range of information and strategies at their disposal and from access to emotional support or strategies on emotional self-care. This is particularly true for parents who are vulnerable themselves.

Parental development work is also not the only way that parents could be supported. There are clear indications from the literature, and our consultation, that families appreciate, and that transition outcomes can be influenced by, someone working on their behalf. Having a single point of contact from outside the family to help them navigate the system, advocate for the rights of the young person and their family, co-ordinate the input of professionals and help formulate creative support packages would be one of a number of alternative ways of addressing the issues family face during transition. The focus of this research project, however, is on how parents can be supported to do these things more effectively themselves.

6.2. Benefits of developing parents

The consultation suggests that there is a wide degree of support for the idea of working to develop parents and that it is a valuable approach (given the caveats above). There was much discussion during the consultation about the role of low-level preventative support for families in preventing crises. Developing ways in which parents can be supported to have the resilience and skills necessary to work positively through the transition process may, therefore, have significant potential to act as a preventative measure.

Development initiatives also typically have an element of peer support. Creating and sustaining these networks is another benefit of working directly with parents. There are examples of long-standing networks currently operating, developed by graduates of development programmes connecting with each other. These networks appear to provide significant support to their members, including, but not limited to, support during transition. There are also benefits of having local peer experts or simply well-informed parents who have been through transition and can share approaches and information which has local relevance, particularly given the geographic variations in provision that exist.

There are also examples of relatively self-sustaining models of parental development programmes. By informing and empowering parents, development programmes can lead to parent advocates, parent trainers and parent representatives working in their communities to support others and influence practice. This is a unique benefit of offering development opportunities to parents.

Another benefit of developing parents, rather than professionals, is that they will be working with their child/young person throughout their lives. Investing in parents is, therefore, investing in a long-term unpaid care workforce without fears about staff turnover or skill loss. However, developing parents requires a different approach to traditional workforce development primarily because parents generally only work with their own children and therefore need tailored support which meets their specific needs.

An additional consideration is that developing parents is likely to be a cost-effective way of improving the transition process. Providers are certainly currently offering courses and other support using very little funding. Parental development, however, can only ever be part of the solution and other forms of investment are necessary to deal with the many systemic issues affecting transitions.

Despite these observed benefits, there is a lack of solid evidence about the impact of developing parents. We cannot say whether access to an established parenting programme early in life leads to more successful transitions into adulthood, for example. Similarly, whilst many initiatives which directly target parents during the transition period seem to demonstrate good practice and can claim examples of excellent outcomes, there is a lack of systematic evidence about the impact of different programmes or about their relative merits. There is, however, a great deal of collective knowledge in the public and third sector, strong views on what works and what doesn't and a range of promising approaches already in place. It will be important that any future work builds on this.

6.3. Potential elements of support

Putting aside the lack of evidence about existing transition-focussed parent development programmes, it is possible to draw out some key themes which characterise what is currently available. This is not to say that these elements should necessarily form part of any future curriculum but there is a degree of existing consensus on elements that parents want and find useful.

Common elements of parental support and development initiatives include:

- the provision of clear, accessible information which focusses specifically on practical issues related to the transition process
- working with parents at an early stage to avoid families slipping into crisis when the young person reaches 18
- bringing parents together to learn, support one another and share experiences, insights and information

- coverage of legal rights and responsibilities so that families can understand their entitlements and be able to spot unlawful behaviour and challenge it
- techniques to help parents prioritise and promote their own well-being and resilience
- developing advocacy and/or mediation skills
- person-centred planning techniques.

It is also clear that small third sector organisations are particularly good at involving parents in co-production and building up strong local relationships, credibility, goodwill and trust. This forms the basis of much of their work and parents engage with them on that basis. The challenge is to capitalise on all these strengths whilst attempting to provide parents with a more consistent offer.

An additional issue is that parents are not a homogenous group. The resources available to parents, both emotional and financial, will vary greatly, as will their skills and abilities. Some parents will, for example, have learning disabilities and/or autism themselves whilst others are far less connected to traditional support systems than others (e.g. parents of children in mainstream rather than special education provision). Development opportunities must be made fully accessible if they are to help those families whose needs are greatest.

6.4. Recommendations

This paper should be viewed as a starting point for further consultation and discussion. The evidence reviewed is not strong enough to provide solid recommendations on the most effective approach to developing parents in relation to the transition of their children with learning disabilities and/or autism into adulthood. There is also a lack of evidence which allows the impact of parent development programmes to be compared with the impact of other approaches to promoting successful transitions.

The current development initiatives detailed in this report, however, provide a useful snapshot of what informed and engaged organisations believe works and share a range of key characteristics. Many of these shared elements have been proven to work in supporting parents of younger children via established parenting programmes. There is, therefore, a great deal of existing expertise, experience and commitment to developing and supporting parents through transition and this should be utilised in the formulation of meaningful next steps. Much of this is based on the best available evidence about what works.

If the evidence base is to be strengthened in the future, it is important to support organisations who are already offering parent development opportunities to better evaluate what they are doing. These organisations will need guidance on what indicators to focus on and how to measure their progress against these indicators. Greater clarity about how, why and in what way the different approaches support parents is needed alongside an assessment of how providing support and development for parents impacts on the transitions of their children.

It would also be useful to better coordinate what is happening across the country by bringing different providers together to pool resources, discuss their approaches and develop ways of working together that add value to the status quo. This also has the potential to help parents as it could lead to greater consensus in provision and clarity about what is available and where. There are examples (e.g. Mencap's Legal Network) of co-ordinated work in the sector but this requires not only action at a central hub but also within each spoke. At a time when third sector organisations already feel squeezed, it is likely that some organisations will need additional resources if they are to effectively respond to opportunities for co-ordinated working.

Such a network of providers would be well placed to develop well-designed pilots to test out and compare specific approaches to parent development and its impact on transitions. To achieve

maximum usefulness, any pilots must be appropriately funded, have a clear focus on improving the evidence base and be run over a realistic time frame

Our recommendations are therefore that:

- Any next steps or firm recommendations about how best to support parents in future should be created in tandem with organisations already working in this area and with parents. Co-production must be a reality.
- Local and national third sector organisations should be brought together to capitalise on their collective knowledge and to allow them to share resources. It is not necessary to invent a new way of doing things, organisations are already likely to have the answers, but a coordinated national network would facilitate greater collaboration and allow some consensus to be reached on what is likely to work best.
- Once consensus is reached regarding the most promising models of parental learning and development, these should be properly piloted and evaluated. Using evaluation evidence from these pilots a set of actionable, costed alternatives can be developed and used to develop a clear way forward.

Appendix 1: Review methodology

This research included a rapid evidence review which took place in two stages. Our review represents the start of an ongoing process and is a response to the need for timely, indicative information to be shared with Skills for Care at this stage in their work. It is a foundation on which Skills for Care can build in the future. The final research report references 58 separate publications or other evidence sources.

Stage 1: Academic literature search

A list of search terms was compiled covering specific types of learning disability and a full range of terms used to denote 'learning disability', autism, child or adolescent and 'parent training' - see Table A2.1 for further details. In November 2018, these were entered into a search of abstracts or titles in PubMed and EBSCOhost, selecting only literature published since 1st January 2008 and in the English language. The full list of selection criteria is included in Table A2.2. The search identified 345 articles in total – 312 from PubMed and 34 from EBSCOhost. Abstracts for all these articles were screened to see whether they were of relevance to the topic of interest, and any duplicates removed.

Table A2.1: Search terms for use in review

S1 = learning disability/autism	S2 = child	S3= parent/carer interventions
"learning disability"	child*	"parent training" OR
"learning disabilities"	"young person"	"parent education" OR
"intellectual disability"	"young people"	"parent support" OR
"intellectual disabilities"	adolescent	"parent program" OR
"intellectual impairment"	infant	"parent programme" OR
"profound and multiple disability"	pre-schooler	"parents training" OR
"profound and multiple disabilities"	preschooler	"parents education" OR
"developmental disability"	Teen*	"parents support" OR
"developmental disabilities"		"parents program" OR
"developmental delay"		"parents programme" OR
"pervasive developmental disorder"		"parenting training" OR
"oppositional defiant disorder"		"parenting skills training"
"oppositional defiance disorder"		OR "parenting education"
"down syndrome"		OR "parenting support" OR
"downs syndrome"		"parenting program" OR
"down's syndrome"		"parenting programme" OR
"fragile x syndrome"		"family training" OR "family education" OR "family support" OR "family program" OR "family programme" OR "families training" OR "families education" OR "families support" OR "families program" OR "families programme" OR "mother training" OR "mother education" OR "mother support" OR "mother
"prader willi syndrome"		
"turners syndrome"		
"turner syndrome"		
"turner's syndrome"		
"tuberous sclerosis"		
"william's syndrome"		

<p>"williams syndrome" "william syndrome" "low intelligence" "low functioning" "foetal alcohol syndrome" asperger Autism Autistic "pathological demand avoidance" "sensory processing disorder" "acquired brain injury" "acquired brain injuries"</p>		<p>program" OR "mother programme" OR "mothers training" OR "mothers education" OR "mothers support" OR "mothers program" OR "mothers programme" OR "father training" OR "father education" OR "father support" OR "father program" OR "father programme" OR "fathers training" OR "fathers education" OR "fathers support" OR "fathers program" OR "fathers programme" OR "informal carer training" OR "informal carer education" OR "informal carer support" OR "informal carer program" OR "informal carer programme" OR "informal carer training" OR "informal carers education" OR "informal carers support" OR "informal carers program" OR "informal carers programme" OR "unpaid carer training" OR "unpaid carer education" OR "unpaid carer support" OR "unpaid carer program" OR "unpaid carer programme" OR "unpaid carer training" OR "unpaid carers education" OR "unpaid carers support" OR "unpaid carers program" OR "unpaid carers programme" OR "guardian training" OR "guardian education" OR "guardian support" OR "guardian program" OR "guardian programme" OR "guardians training" OR "guardians education" OR "guardians support" OR "guardians program" OR "guardians programme"</p>
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Table A2.2: Inclusion criteria for the review

Inclusion criteria	Exclusion criteria
Published after 2008	Research published before 2008
All UK studies, international reviews of evidence or high-quality quantitative studies from other countries Grey literature from the UK only	Primary qualitative studies conducted outside of the UK Grey literature from outside the UK
Published in English	All publications not available in English
Type of study (review of reviews, systematic review, meta-analysis, large scale studies, small scale qualitative studies, needs analysis, learning needs analysis, case studies)	Expert opinion and commentaries
Involves development activities for parents/unpaid carers of children/young people with autism and/or learning disabilities up to the age of 18	Development only involves: <ul style="list-style-type: none"> • professional carers • carers of adults • carers of children with other needs/ disabilities
Interventions which support (directly or indirectly) the achievement of better care standards, or outcomes for those cared for, through development activities for carers	Interventions aimed solely at the needs of carers Respite care, care breaks or similar provision

The screening process identified a substantial body of research on parent training, specifically in relation to training for parents of young children with autism. Most of this research originated from the US or Australia, with very few studies from the UK. However, none of the papers identified looked at the impact of parent training on transitions of the child with a learning disability and/or autism into adulthood. In addition, it was felt that many of these papers could be excluded since the interventions were either aimed at addressing the core features of ASD (eg social interaction, communication, imitation and play skills) or common co-occurring behavioural problems (eg sleep disturbance, food refusal and toileting problems), rather than improving care outcomes for the child.

Using an established taxonomy of parent training for autism [58] we categorised interventions in the literature according to whether they were ‘parent support’, where the parent is the main beneficiary of the intervention, or ‘parent-mediated interventions’, where the parent is an active agent assisting their child in gaining new skills (thus making the child the main beneficiary). Parent support programs intend to provide an indirect benefit to the child by supporting the parent as caregiver and increasing parental knowledge about ASD and may include some care coordination (ie how to navigate services for the child) and psychoeducation (ie promoting knowledge gains around the child’s ASD diagnosis). In parent-mediated interventions, the parent is taught skills (often based on applied behavioural analysis) that are traditionally used by a therapist in order to allow the intervention with the child to continue in the home environment.

Our screening of the 345 abstracts revealed that most of the research on parent training was focused on parent-mediated interventions for parents of young children with autism, rather than parent support. Again, most of these originates outside of the UK. However, the screening

process identified some parent programmes that offer a hybrid of interventions – mainly parent support alongside skills to deal with key areas, particularly challenging behaviour – and cover a range of learning disabilities rather than just autism. A few of these were adaptations of established parenting programmes, including the Incredible Years Programme and The Triple P Programme, both of which were originally developed for parents of non-disabled children.

Whilst these interventions do not aim directly to improve transitions, this literature was reviewed in order to understand the impact of these types of parent interventions on care outcomes more generally.

Stage 2: Wider search

Whilst the review of established parenting programmes was felt to be useful, it did not address the need to understand parent requirements during the transitions process. Following the initial screen of abstracts, a decision was therefore made, in consultation with Skills for Care, to refocus the review into two key areas:

- What do we know about the established parent support interventions for family carers of young people with learning disabilities and/or autism?
- What do we know about the parental experience of transition and initiatives that support parents during this time?

Each piece of evidence was reviewed by only one individual but this was done using a data extraction template to maximise consistency.

Phase 1: What do we know about the established parent support interventions for family carers of young people with LD and/or ASD?

A purposive review was conducted whereby only existing review papers on established parent support interventions identified in the initial search were included, alongside any key primary research papers. In total 12 review papers from the initial search of academic literature were considered. In addition, 14 primary studies were included due to expert recommendation or because they were a key reference from a review paper.

A full list of the included papers can be found in Appendix 2. References from phase 1 are included as items 22 to 48 in the reference list.

Phase 2: review of evidence about transition and transition-related initiatives

A second search was undertaken to find literature which examined the parental experience of transition and/or interventions designed to support/develop parents during this time. The search was conducted across a wide range of electronic databases in order to include grey literature alongside published research.

Searches were made of:

- EBSCO SO index
- PubMed
- SCIE, NICE, NHS evidence search tool and IRISS and other organisational websites.

In addition, a call for evidence was published on the Skills for Care website. Four academic experts commented on the approach and suggested additional papers for inclusion in the review. Other consultation respondents also highlighted other evidence which was also included.

This identified 1,100 papers. Given the scale of information available, the research team focussed on identifying existing review papers alongside other key papers (determined on the basis of relevance to the research topic). A total of 32 pieces of evidence on the experience of transition,

or on initiatives which specifically support parents through this period, have been included in this report: 12 review papers and 22 other pieces of evidence. Many of the latter were suggested by respondents to the consultation or by the academic experts.

Evidence regarding the experience of transitions is referenced as items 1 to 21 in the reference list and evidence about approaches to supporting parents with the transition are presented as items 49 to 57.

Appendix 2: Reference list

1. Pointer J " Preparing young people with special educational needs and disabilities for a good adult life" *Research in Practice for Adults* December 2018
<https://www.ripfa.org.uk/blog/preparing-young-people-with-special-educational-needs-and-disabilities-for-a-good-adult-life/>
2. Young-Southward G, Philo C, Cooper SA. What Effect Does Transition Have on Health and Well-Being in Young People with Intellectual Disabilities? A Systematic Review. *Journal of Applied Research in Intellectual Disabilities* 2017; 30, 805–823.
3. Spiers GF. Choice and caring: the experiences of parents supporting young people with Autistic Spectrum Conditions as they move into adulthood. *Children & Society*. 2015; pp. 546-557.
4. Jacobs P, MacMahon K, Quayle E. Transition from School to Adult Services for Young People with Severe or Profound Intellectual Disability: A Systematic Review Utilizing Framework Synthesis. *Journal of Applied Research in Intellectual Disabilities*. 2018; 31, no. 6: 962–82.
5. Beresford B, Moran N, Sloper T, Cusworth L, Mitchell W, Spiers G et al. Transition to Adult Services and Adulthood for Young People with Autistic Spectrum Conditions, Department of Health Policy Research Programme. 2013; ref: 016 0108.
6. Children's Commissioner for Wales. Don't Hold Back: Transitions to adulthood for young people with learning disabilities. Welsh Government. 2018.
7. On behalf of the Transition Collaborative Group, Colver A, McConachie H, Le Couteur A, Dovey-Pearce G, Mann KD, McDonagh JE et al. A longitudinal, observational study of the features of transitional healthcare associated with better outcomes for young people with long-term conditions. *BMC Medicine*. 2018 16, 111.
8. Foley KR, Dyke P, Girdler S, Bourke J, Leonard H. Young adults with intellectual disability transitioning from school to post-school: A literature review framed within the ICF. *Disability and Rehabilitation*. 2012; 34, 1747–1764.
9. Westbrook JD, Fong CJ, Nye C, Williams A, Wendt O, Cortopassi T. Transition Services for Youth With Autism: A Systematic Review. *Research on Social Work Practice*. 2015; 25, no. 1: 10–20.
10. Kaehne A, Kiernan J, Ridley J, Maden M, Onochie D, Pilkington M. Rapid Review Transition for Young People with Learning Disabilities in Housing, Social Care, and Health Care, Education/Training, and Employment, Evidence-Based Practice Research Centre. 2018.
11. Beyer S, Kaehne A, Meek A, Pimm C, Davies A. Regional SEN Transition to Employment Initiative (Real Opportunities): Impact of the Real Opportunities project, Welsh Government. 2014.
12. Davies A, Meek A, Beyer S. Regional SEN Transition to Employment Project (Real Opportunities): The Influence of HUB Teams on the Quality of Person Centred Planning, Cardiff University, Real Opportunities and Welsh Government. 2014.
13. Kim KH and Turnbull A. Transition to Adulthood for Students with Severe Intellectual Disabilities: Shifting Toward Person-Family Interdependent Planning, *Research and Practice for Persons with Severe Disabilities*. 2004; Vol 29, No. 1, 53-57.

14. Henninger NA, Taylor JL. Family Perspectives on a Successful Transition to Adulthood for Individuals with Disabilities. *Intellect Dev Disabil.* 2014; 52, 98–111.
15. Hudson B. Making and missing connections: learning disability services and the transition from adolescence to adulthood. *Disability & Society.* 2006; 21, 47–60.
16. Hatfield M, Ciccarelli M, Falkmer T, Falkmer M. Factors related to successful transition planning for adolescents on the autism spectrum. *Journal of Research in Special Educational Needs.* 2018; 18, 3–14.
17. Beyer S, Kaehne A, Grey J, Sheppard K and Meek A. What Works? Transition to employment for young people with learning disabilities. Shaw Trust. 2007.
18. Carter, EW, Harvey MN, Taylor JL, Gotham K. 'Connecting Youth and Young Adults with Autism Spectrum Disorders to Community Life'. *Psychology in the Schools.* 2013; 50, no. 9: 888–98.
19. Geller L, Greenberg M. Managing the Transition Process From High School to College and Beyond: Challenges for Individuals, Families, and Society. *Social Work in Mental Health.* 2010; 8(1):92-116.
20. Gauthier-Boudreault C, Couture M, Gallagher F. How to facilitate transition to adulthood? Innovative solutions from parents of young adults with profound intellectual disability. *J Appl Res Intellect Disabil.* 2018;31(Suppl. 2):215–223.
21. Young RA, Marshall SK, Stainton T, et al. The transition to adulthood of young adults with IDD: Parents' joint projects. *J Appl Res Intellect Disabil.* 2017;00: 1–10.
22. Petrenko, CLM. A Review of Intervention Programs to Prevent and Treat Behavioral Problems in Young Children with Developmental Disabilities. *J Dev Phys Disabil.* 2013; 25.
23. Matson JL, Mahan S, LoVullo SV. Parent training: A review of methods for children with developmental disabilities. *Res Dev Disabil.* 2009; 30, 961–968.
24. Webster-Stratton C. *The Incredible Years: Parents, Teachers, and Children Training Series. Leader's Guide.* 2001.
25. Webster-Stratton, C. *Manual for the Incredible Years Autism Spectrum and Language Delays Programme for Parents with Preschool Children* Seattle, US: Incredible Years Inc. 2015.
26. Phaneuf L, McIntyre LL. The Application of a Three-Tier Model of Intervention to Parent Training. *J Posit Behav Interv.* 2011; 13, 198–207.
27. McIntyre LL. Parent training for young children with developmental disabilities: randomized controlled trial. *American Journal on Mental Retardation.* 2008; 113, 356–3368.
28. Hutchings J, Pearson-Blunt R, Pasteur M, Healy H, Williams M. A pilot trial of the Incredible Years® Autism Spectrum and Language Delays Programme. *Good Autism Practice.* 2016; 17, 15-22.
29. Einfeld SL, Tonge BJ, Clarke KS. Prevention and early intervention for behaviour problems in children with developmental disabilities. *Curr Opin Psychiatry.* 2013; 26, 263–269
30. Mazzucchelli TG, Jenkins M, Sofronoff K. Building Bridges Triple P: Pilot Study of a Behavioural Family Intervention for Adolescents with Autism Spectrum Disorder. *Res Dev Disabil.* 2018; 76, 46–55.
31. Plant KM, Sanders MR. Reducing problem behavior during care-giving in families of preschool-aged children with developmental disabilities. *Research in Developmental Disabilities.* 2007; 28, 362–385.
32. Roberts C, Mazzucchelli T, Studman L, Sanders MR. Behavioral family intervention for children with developmental disabilities and behavioral problems. *J Clin Child Adolesc Psychol.* 2006; 35, 180–193.
33. Whittingham K, Sofronoff K, Sheffield J, Sanders MR. Stepping Stones Triple P: an RCT of a parenting program with parents of a child diagnosed with an autism spectrum disorder. *J Abnorm Child Psychol.* 2009; 37, 469–480.
34. Sofronoff K, Jahrel D, Sanders M. Stepping Stones Triple P seminars for parents of a child with a disability: a randomized controlled trial. *Research in Developmental Disabilities.* 2011; 32, 2253– 2262.

35. Sharry J; Hampson G; Fanning M. Parents Plus Early Years: A Practical and Positive Guide to Parenting Young Children Aged One to Six. Manual and videos. Dublin: Mater Hospital. 1997.
36. Carr A, Hartnett D, Brosnan E, Sharry J. Parents Plus Systemic, Solution-Focused Parent Training Programs: Description, Review of the Evidence Base, and Meta-Analysis. *Fam Process*. 2017; 56, 652–668.
37. Quinn M, Carr A, Carroll L, O’Sullivan D. Parents Plus Programme 1: Evaluation of Its Effectiveness for Pre-School Children with Developmental Disabilities and Behavioural Problems. *Journal of Applied Research in Intellectual Disabilities*. 2007; 20, 345–359.
38. Griffin C, Guerin S, Sharry J, Drumm M. A multicentre controlled study of an early intervention parenting programme for young children with behavioural and developmental difficulties. *International Journal of Clinical and Health Psychology*. 2010; 10(2), 279-294.
39. Coughlin M, Sharry J, Fitzpatrick C, Guerin S, Drumm MA. Controlled Clinical Evaluation of the Parents Plus Children’s Programme: A Video-based Programme for Parents of Children Aged 6 to 11 with Behavioural and Developmental Problems. *Clinical Child Psychology and Psychiatry*. 2009; 14, 541–558.
40. Hand A, Raghallaigh CN, Cuppage J, Coyle S, Sharry J. A controlled clinical evaluation of the Parents Plus Children’s Programme for parents of children aged 6–12 with mild intellectual disability in a school setting. *Clinical Child Psychology and Psychiatry*. 2013; 18, 536–555.
41. Beattie D, O’Donohoe P, Guerin S, Fitzpatrick C. An Evaluation of a Parent Management Training Program as a Treatment for Adolescents Attending a Child and Adolescent Mental Health Service. Dublin, Ireland: School of Psychology, University College Dublin (unpublished manuscript) 2011. Reported in Carr et al (2017) op cit.
42. Dawson-Squibb JJ, Davids EL, de Vries PJ. Scoping the evidence for EarlyBird and EarlyBird Plus, two United Kingdom-developed parent education training programmes for autism spectrum disorder. *Autism*. 2018; Volume: 23 issue: 3, page(s): 542-555.
43. Glidden LM, Floyd FJ, Hastings RP, Mailick MR (in press). Family Impact and Adjustment: Parents. Abbeduto L, McIntyre LL, Tasse M (Eds.), *APA Handbook of Intellectual and Developmental Disabilities*. Washington, DC; American Psychological Association Publications.
44. Postorino V, Sharp WG, McCracken CE, Bearss K, Burrell TL, Evans AN, Scahill L. A Systematic Review and Meta-analysis of Parent Training for Disruptive Behavior in Children with Autism Spectrum Disorder. *Clin Child Fam Psychol Rev*. 2017; 20, 391–402.
45. Steiner AM, Koegel LK, Koegel RL, Ence WA. Issues and Theoretical Constructs Regarding Parent Education for Autism Spectrum Disorders. *J Autism Dev Disord*. 2012; 42 (6).
46. McIntyre LL, Phaneuf LK. A Three-Tier Model of Parent Education in Early Childhood: Applying a Problem-Solving Model. *Topics Early Child Spec Educ*. 2008; 27, 214–222.
47. Singer GHS, Ethridge BL, Aldana SI. 2007. Primary and secondary effects of parenting and stress management interventions for parents of children with developmental disabilities: a meta-analysis. *Ment Retard Dev Disabil Res Rev*. 2007; 13, 357–369.
48. Pennefather J, Hieneman M, Raulston TJ, Caraway N. Evaluation of an online training program to improve family routines, parental well-being, and the behavior of children with autism. *Research in Autism Spectrum Disorders*. 2018; 54, 21–26
49. Broadhurst S, Yates, K, Mullen B. An evaluation of the My Way transition programme, Tizard Learning Disability Review. 2012; 17(3), 2012, pp.124-134
50. Beyer S, Kaehne A, Meek A, Pimm C and Davies A. Regional SEN Transition to Employment Initiative (Real Opportunities): Impact of the Real Opportunities project, Welsh Government. 2014.
51. Taylor JL, Hodapp RM, Burke MM, et al. Training parents of youth with autism spectrum disorder to advocate for adult disability services: results from a pilot randomized controlled trial. *Journal of Autism and Developmental Disorders*. 2017; 47: 846–857.

52. Burke MM, Waitz-Kudla SN, Rabideau C, Taylor JL, Hodapp RM. Pulling back the curtain: Issues in conducting an intervention study with transition-aged youth with autism spectrum disorder and their families. *Autism*. 2018; 23 issue: 2, page(s): 514-523.
53. Smith LE, Greenberg JS, Mailick MR. Adults with autism: Outcomes, family effects and the multi-family group psychoeducation model. *Current Psychiatry Reports*. 2012; 14, 732-738.
54. DaWalt LS, Greenberg JS, Mailick MR. Transitioning Together: A Multi-family Group Psychoeducation Program for Adolescents with ASD and Their Parents. *J Autism Dev Disord*. 2018; 48, 251–263.
55. Department for Education and Department for Health. Special educational needs and disability code of practice: 0 to 25 years. Statutory guidance for organisations which work with and support children and young people with have special educational needs or disabilities, Department for Education. 2015.
56. Hatton C. Partners in Policymaking North West England: An evaluation. Institute for Health Research, Lancaster University. 2006.
57. Britton C. Insider's Guide: Journeys for Living and Learning. 2012. Adult and Community Learning Fund Final Report.
58. Bearss K, Burrell TL, Stewart L, Scahill L. Parent Training in Autism Spectrum Disorder: What's in a Name? *Clin Child Fam Psychol Rev*. 2015, 18, 170–182

Appendix 3: List of participating organisations

We would like to thank the representatives of the following organisations for their support with this project and for sharing their insights, advice and experiences. We would also like to thank the three parents who shared their personal stories.

Amaze Sussex

Austism Initiative

Austism West Midlands

Autistica

Bangor University

Books without Words

Cardiff University

Choice Support

Council for Disabled Children

Department of Health and Social Care

East Sussex County Council

Enfield Borough Council

Engage to Change programme

Extratime

Greater Manchester Autism Consortium Project

Health Education England

Mencap

My Family, Our Needs

National Autistic Society
National Network of Parent Carer Forums
Oxfordshire Family Support Network
Partners in Policy Making
Portsmouth City Council
PWSA UK
Skills for Health
The National Development Team for Inclusion
University College London