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Key points..... 5

Recommendations from this research are to:

and discussion about the way forward particularly with organisations already working in this area and with parents and impact assessment, including pilots of the most promising approaches better , pooling knowledge and resources so that organisations can collectively add value to what is possible when they work alone.

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.

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

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

The review found two

. 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.

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.

(a telephone advice line with the potential to offer face to face to 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.

, including transition events

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.

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

. Future strategies should build on existing relationships and provision. Professionals also require further development to promote better transitionsation

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.

as there
is insufficient existing evidence about parent development initiatives and how/how well they work.

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.

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.

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

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

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

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.

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.

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.

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

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)

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

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

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:

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

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

A number of qualitative studies included in the review considered how parents have overcome some of the issues affecting transition



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.

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

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 vT/F111.04 Tf1 0 0 1 101.9 392.21 Tm0 g0 G(d)3(e)9(v)-4(eI(IY)/F1 710 0 1

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

- 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].

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

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

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.

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.

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.

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].

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:

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.

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].

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].

. 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

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.

its focus on implementing actions and 'doing' rather than just developing plans. The greatest

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.

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

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-

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.

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.

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

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

also have the capacity to handle face-to-face, telephone and electronic enquiries. These services are

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.

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).

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

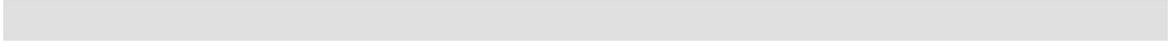
My Family, Our Needs run a website for families with any children with an additional need from birth to age 25.¹³ It was established two years ago by parent company Care Choices (a privately owned publishing company) when it converted its print magazine Progress (for young disabled people) into an online 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)

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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

employment ready because of support they had received from the Real Opportunities project (discussed in Chapter 4) which

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

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.

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

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.



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 the

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.

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.

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

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

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-

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

maximum usefulness, any pilots must be appropriately funded, have a clear focus on improving

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.

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.

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

program" OR "mother
programme" OR "mothers
training" OR "mothers

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.

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