Brighton & Hove, East Sussex, Hampshire and West Sussex

What Works for Us:

The case for meaningful independent support

Partnership team of Amaze Brighton, Hampshire Parent Carer Network, Brighton & Hove Parent Carers' Council, West Sussex Parent Carer Forum and East Sussex Parent and Carers' Council

Report for Evidence Gathering and Build Phase of Independent Support Programme:
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REPORT A:
What we know about families

Foreword

Our starting point lies in families' experiences and family based evidence about what works and does not work because effective Independent Support (IS) must attend to the interconnectedness and positive outcomes for all family members. Our core focus, workers and families alike, is enabling children and young people with additional needs and/or disabilities to achieve and thrive in the long term, and not just survive the turmoil of a reform programme.

We are pleased to evidence positive perspectives of parent carers, young people with additional needs and/or disabilities and workers who have experienced elements of the Special Educational Needs and Disability reforms (SEND). Partnership working between all parties and co-production are seen as key. However we also record raised levels of anxiety, and huge variations in levels of knowledge and local practice around the SEND reforms which come into place in three months' time.

A second significant issue for all of us, are the daily consequences of austerity, including service and benefit cuts and a reduced workforce. In the context that there are 2 million children and young people with additional needs and or disabilities in England[1], in order to use the £30 million investment of the IS programme effectively, we must understand and show we have learnt from existing research evidence, and the wider Pathfinder experience so that with all partners, as stated at the heart of the reforms, we can together build on what families say works and does not work.

Therefore in Report A of this report we set out a landscape based upon existing evidence about the lived reality for families, and core principles related to workforce knowledge, skills and cultural change. In Report B we explore the SEND reforms specific experiences about what is working and not working, keeping in mind sustainable outcomes for families that could make a difference in the longer term, not just the 2 year term of the Independent Support programme. In Report C, we describe options for the delivery of IS and discuss key risks and benefits of different approaches.

And finally, our reports includes evidence about progress in defining positive outcomes for children and young people with additional need which is a difficult task for both workers and families, and is an essential focus of the IS role. In keeping with the reforms, the outcomes are far wider than just educational attainment, but rather as the Chief Medical Officer in her 2012 annual report recommends that services at national, local and individual levels should be shaped by the needs, wishes and aspirations of both children and their families. She also recommends that all services for disabled children should be underpinned by their legal rights and aim to maximise their health, wellbeing and life chances, and that services should promote opportunities for social participation and the chance to lead an ordinary life.

The evidence about children and young people with additional needs and disabilities is both patchy and repetitive. There remain gaps in our knowledge and it seems there is little investment in plugging the knowledge gaps. Where we do have evidence, it often restates core messages time and again about transparency, impartiality, family focus, whole life outcomes and meaningful participation. However for us as a team, it makes us more determined to raise aspirations and standards, to highlight where and how successful outcomes are possible, and to notice the enormous efforts made by the young people themselves, and their parents, and working with wider teams of supportive practitioners and commissioners. The reforms play a part in this progress, but we know, it is down to how people respond to the challenges individually too. Our commitment remains to work in partnership together to achieve more than just ordinary lives for this generation of young people and their families.

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[1] Department of Education March 2011: Support and Aspirations: a new approach to special educational needs and disability

EXECUTIVE SUMMARY

What works for us

The IS programme was announced in January 2014 with £30M to be used to recruit and train a pool of independent supporters' – champions drawn from the independent voluntary, community and private organisations to help families of children and young people with Special Education Needs (SEN) arising from the Children and Families Act 2014. Is this area, the SE7 Pathfinder, which championed co-production which has been an important foundation to our commitment to partnership working and together using a solution based approach.

This report gathers the evidence about the existing landscape for families of children and young people with additional needs and/or disabilities; it examines the experience of what works or does not work for parent carers and young people relating to the Special Education Needs and Disability reforms (SEND); and offers two models for an Independent Support Programme (IS) with associated material.

Our partnership included an independent project manager, researcher, Amaze Brighton (a long established and award winning parent support organisation), and four parent carer forums (Hampshire Parent Carer Network, West Sussex Parent Carer forum, East Sussex Parent and Carers' council, and Brighton & Hove Parent and Carers Council). This combination is uniquely well placed to collate the experiences from families involved in the SE7 pathfinder phase of the reform process. We have greatly appreciated the contributions from members of two young people groups (CHAOS and AHA) and the assistance from colleagues at Parent Voice in Hampshire, Parent Partnership Services in Hampshire and Brighton & Hove, and Learning Difficulty/Disability Advisers at the Youth Employability Service in Brighton, and school SENCO's.

In **Report A**, we set out national evidence base about longstanding common issues and needs of families of children and young people with additional needs and/or disabilities. We establish the centrality of family focussed support and the interconnectedness between young people and parent carers' wellbeing, and set out what parents and young people say works for them. We offer an evidence based narrative about how the IS programme could make a wider and more resilient enhancing impact on parents and young people than just the delivery of information and support around the Education Health and Care Plan process. We offer a model of this enhanced approach.

In **Report B** we set out the national, regional and local evidence about what works for parents and young people around the reforms. The core change relates to personalisation, and the opportunity to shape both outcomes and solution focussed plans that are co-ordinated and co-produced. The emphasis is that 'one size does not fit all', and parent carers and young people tell us what works or does not work, and what matters most to them regarding supporting their daily lives. Young people want more occupation and social participation opportunities. We organised a regional workshop with SE7 colleagues to explore the values, practices and potential ways an IS programme could operate and respond to local need across the different local authority areas. We note that much of the historical, pathfinder, regional and local data is repetitive which may indicate how common issues stated by families are still unresolved, or how complex this arena is, or how local complexity and restructures have got in the way of progress, but it seems that previous investment for whatever reason, has not yet produced anticipated improvements. We recognise that there are huge expectations for the IS programme and that considerable levels of unmet need are likely to remain.

Our evidence based recommendations at the end of these two reports include the key elements for our enhanced model, which are:

What parent carers say works

What young people say matters

Family focussed information, advice and support

Outcomes and effective strategies and resources to achieve them

Building a legacy of resilience

In order to complete the terms of this project we have collated in **Report C** two potential organisational structures for an IS programme in this area, with supplementary material. The IS team will need a range of knowledge, experience, skills and qualities across its workforce. We have included a risk analysis that records the issues if the workforce management, recruitment and supervision are inappropriate according to our evidence for this demanding arena at this critical time of change. To be effective the Independent Supporters will need an in-depth understanding about local arrangements, provision and links, offer a range of approaches to meet individual needs and have proven experience of engaging effectively with families, parent carers and young people in a way that builds confidence, skills, networks and resilience.

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Our steering group members were:

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1 INTRODUCTION – What works for us

This eleven week project gathers local, regional and national research and practice evidence about models of service and support which parents and young people with Special Educational Needs and Disabilities (SEND) say works well and why, together with information about what they say does not work well and why.

Our evidence gathering work aims to inform the Independent Support Programme initiated by the Department of Education and managed by the Council for Disabled Children. One of thirteen contracts awarded to Community and Voluntary Sector organisations across England, we believe our collaborative project strength is disseminating what parents and young people are saying currently, and is underpinned by existing research.

The project was co-ordinated by Amaze (an award winning parent led charity providing information, advice and support for parent carers in Brighton and Hove), and brings together four neighbouring parent carer forums (Brighton & Hove Parent and Carers' Council, East Sussex Parent and Carers Council, Hampshire Parent Carer Network, West Sussex Parent Carer Forum) who have been active partners in the South East Seven (SE7) Pathfinder which is a national and regional champion for the SEND reforms. Amaze and the parent carer forums, working with an independent project manager, a project researcher, and partner organisations, have explored families' experiences and sought their views about a diverse range of support services across conditions and disabilities, age groups and locations, solutions and a range of ideas.

1.1 What we did

We have examined the learning, from the four areas, about effective support for both children and young people and parent carers in relation to:

- Conversions to Education, Care and Health Plans (ECHPs) and person-centred, outcomes-focused planning
- Preparing for adulthood
- Rolling out of personal budgets
- Building parent carer confidence and resilience.

We collected a range of local reports of what parents and young disabled people have said either works or does not work in their areas, and then gathered new evidence about their views on the implementation of the SEND reforms. To do this we chose to assemble cameos and case studies from parents, young people and workers, conducted parent and young people focus groups and completed an online transition survey across the four areas.

While the network of young people's participation groups is not yet as developed as parent forums, this project builds on the work of the SE7 Pathfinder by utilising its Young People Participation Framework. We have facilitated two engagement and activity sessions with a range of disabled young people, and collected a wide-range of young people's and workers experiences.

Across the region, a variety of service providers, commissioners and practitioners are involved in the SE7 Pathfinder, to gain as rounded a view of current provision as is possible and we have drawn on this data, to collectively shape our regional recommendations for future provision via the Independent Support service. We also organised a regional SE7 conference to provide an opportunity for a wide range of parent carer and young people representatives and professionals to come together to consider the new IS role, how this might best complement existing services in local areas and how it might be structured.

1.2 More about the Independent Support Programme

In January 2014, the Government announced the release of £30million to support local areas to prepare for and implement the new SEND reforms. This involves recruiting and training a pool of approximately 1,800 Independent Supporters, to support families through the change. This is a twenty month programme to provide additional support to young people and parents during the implementation of the SEND reforms. It is focused around the assessment and EHCP planning process to:

- New entrants to the system
- Children with a statement converting to an EHCP
- Young people with an Learning Disability Assessment (LDA S139a) converting to a plan

The service is to be targeted at families most in need of support, tailored to meet the particular needs of a family but time limited (over 20 weeks) and the support should:

- Building the family's resilience
- Provide positive outcomes and demonstrate cost savings later on in the process in order to ensure the role becomes sustainable by Local Authorities (LAs) in the future.

1.3 More about the SEND reforms within the Children and Families ACT 2014

The Children and Families Act 2014 comes into force in September and is underpinned by the SEND Regulations and the Code of Practice which set out the practical requirements and guidance. The new SEND legislation will cover the age range 0 to 25 years and includes children and young people with special educational needs and/or disabilities. Here are the main points from the reforms:

- replacing special educational needs statements and learning disability assessments with a new birth-to-25 education, health and care plan – setting out in one place all the support families will receive
- requiring better co-operation between councils and health services to make sure services for children and young people with SEND are jointly planned and commissioned
- requiring councils to publish a 'local offer' showing the support available to all disabled children and young people and their families in the area – not just those with educational needs
- introducing mediation for disputes, giving children and young people the right to appeal if they are unhappy with their support
- introducing a new legal right for children and young people with an education, health and care plan to express a preference for state academies, free schools and further education colleges – currently limited to maintained mainstream and special schools
- 16+ changes including their wishes taking priority, but family still to be included and helped to build independent living skills.

With regard to the 'Impartial Information and Advice and Support' (IAS) service the Draft Code of Practice (April 2014 draft version) states it should be:

- A dedicated and easily identifiable service;
- Can be built on existing Parent Partnership Service and/or any other local services for young people to create an Information, Advice and Support Service;
- Young people must be able to access independently from their parents;
- Should be impartial, confidential, arms length, free and accessible
- Promote independence and self advocacy
- Inform policy and practice

The expectation is that many children and young people will receive IAS via or alongside their parents but local authorities need to also ensure that they (children and young people) are able to receive information, advice and support separately from their parents.

A key change is in Section 26 with regards to joint commissioning duties which direct education, local authority, health and other partners to jointly commission services and work better together. These include arrangements for considering and agreeing what advice and information is to be provided about education, health and care provision.

1.4 More about NHS, health and social care changes

The NHS Constitution establishes the principles and values of the NHS in England. It sets out the rights to which patients, public and NHS staff are entitled. The NHS is committed to achieve these, together with responsibilities which the public, patients and staff owe to one another to ensure that the NHS operates fairly and effectively. This includes how patients access health services, the quality of care patients receive, the treatment available to patients, confidentiality of personal information and the right to complain if things go wrong. All NHS bodies and private and third sector providers supplying NHS services will be required by law to take account of this Constitution in their decisions and actions. The pledges the NHS makes to patients can be viewed by downloading the NHS Constitution[1]

The Health and Social Care Act 2012

This requires CCGs and Commissioners in NHS England to enable:

- Patients and Carers to participate in planning, managing and making decisions about their care and treatment through services it commissions.
- The effective participation of the public in the commissioning process itself so that services provided reflect the needs of local people.
- shifted responsibility for provision of Independent Complaints Advocacy Services from the Secretary of State for Health to local authorities from April 2013

The Care Bill 2014

This requires local authorities to establish and maintain a service which must provide information and advice relating to care and support for adults and support for carers. Parent carers are also now to be included in the enhanced rights to assessment and support and this will be outlined in the Children and Families Act Regulations.

2. EXISTING EVIDENCE about what does and does not work for families

This report starts from the premise that designing an IS programme that is fit for the purpose of achieving positive outcomes for disabled children and young people, relies on a commitment to both empower and promote resilience with children, young people and their families and adopting an equalities perspective.

By this we mean there is substantial evidence that children and young people with additional needs and /or disabilities and their families, face additional financial hardship, lack of opportunities, more intense and longer-term caring responsibility, multiple bureaucratic procedures, access barriers, stigma and discrimination, and often have to negotiate with and manage multiple ineffective, underfunded and unresponsive professionals and services, often reported to work in a disjointed fashion. After all, in 2011 in the case for reforms made in the by Ministers in the Support and Aspirations Green Paper (DfE 2011) stated:

> **'Children and young people with SEN don't achieve as they could –**
> **by the time they leave school these young people are more than twice as likely to be**
> **out of education, training or employment as those without. That is wrong.**
> **We are letting these children and young people down'.**

While we know that there is a strong link between disability, exclusion and socioeconomic inequality (Blackburn et al. 2012, Hosseinpoor et al. 2013) and the implications for children and young people with disabilities depend on the nature of their disability, where they live, their culture, socioeconomic status and gender (DWP 2012, CMO 2012, UNICEF, 2013b), disabled children and young people CAN achieve good outcomes. For example:

- more children with serious illnesses and disabilities are surviving into adulthood (Ludvigsen and Morrison 2003; Nessa 2004);
- in the second quarter of 2012, 46.3% of working-age disabled people were employed (compared to 76.4 % of non-disabled people);
- 3.2 million disabled people are in work and 11.5 % of all employed people are disabled;
- over half (55%) of disabled people play an active role in civic society by formal volunteering, civic activism, civic participation and consultation (ODI Indicator E2);
- in the year 2009/10, 33% of young disabled people at the age of 19, were in Higher Education (although this compares with 44% non disabled young people);
- and there are reported improvements, albeit small, in public attitudes about disability (DWP 2012).

Parents are key to the process of improving the life chances of disabled children and young people and their significance is strongly confirmed by local surveys conducted in the south east with disabled young people too (KIDS SE7 2013, Meechan 2014, Focus group findings with CHAOS gathered during this project). Given that the overwhelming majority of disabled children and young people live at home with their families, for much longer than their typically-developing peers (Buckner and Yeandle 2006, Kagan et al. 1998), it crucially matters how parents are assisted to facilitate good outcomes and advocate with and on behalf of their disabled children.

Clearly, parent carers have diverse individual backgrounds, resources and preferences and how they cope with the additional demands of caring for their disabled child/ren will be influenced by many factors. While this can include many factors like, their internal capacity to manage challenges, their pattern of communication and problem sharing and value and belief systems, and their resilience will be greatly influenced by the external support and resources available to them and the extent of the adversity they face.

Resilience is the ability to withstand and recover from stressful life challenges, strengthened and more resourceful. As Michael Ungar, internationally renowned for his resilience research and practice work with children and families, and others (Hart et al., 2007) states, resilience is often mistakenly defined as residing solely within individuals, rather than as a dynamic interplay between people and their environments. He defines this complex concept in the following way:

“In the context of exposure to significant adversity, resilience is both the capacity of individuals to navigate their way to the psychological, social, cultural, and physical resources that sustain their well-being, and their capacity individually and collectively to negotiate for these resources to be provided and experienced in culturally meaningful ways (Ungar, 2008, p. 225).

There is little doubt that parent carers of disabled children and young people often lack crucial information about matters that significantly affect their lives (Smith 2014, Clarke 2013, Barzotti and Pike 2013, Dixon et al 2012, Martin 2011).

However the IS programme has to be more than imparting information and advice. It is a unique opportunity to facilitate better outcomes for children and young people by providing families with timely, supportive and accurate information that assists them to navigate and negotiate for the resources and support they need. While the primary task is to help parent carers and their children to navigate the new SEND statutory process, it has the potential to do so in a way that will contribute significantly to building resilience and sustaining families in the ongoing task of maximising good outcomes.

2.1 The Context

The new Children and Families Act 2014 and the updated SEND Code of Practice described earlier have been drafted with the aim of reinforcing good practice. Together they provide a framework that introduces changes to the SEND system that promote certain ideals: personalisation, putting children young people their families at the heart of decision making, to build confidence, strategic participation of parent carers and co-production, and ensuring collaborative working across all sectors.

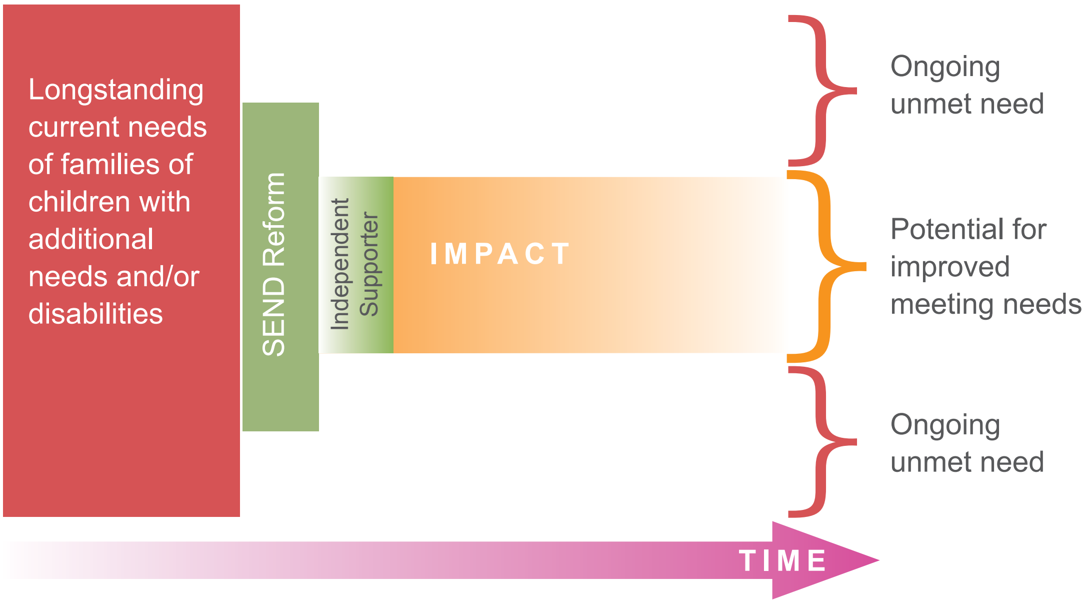
The task of the IS will be to assist families to understand and engage with the new education, health and care assessment and planning process, as outlined in Part 3 of the Children and Families Act. The framework aspires to offer a new joined-up approach for children with SEN from 0-to-25, ensure that support is made available at the earliest possible point, involve children and young people in decisions about their care and what they want to achieve, and introduce the new Education Health and Care Plans (EHCP) for those with more complex needs.

We know from the literature and data we have collected locally, which records the voice of 1,000s of parent carers, that many have experienced the process of securing support for their children as an unwelcome battle. They tell us that they work very hard to find out about their entitlements, even when they know that they may not meet the criteria for provision, or there is little guarantee that what is offered will fit with what they or their children require.

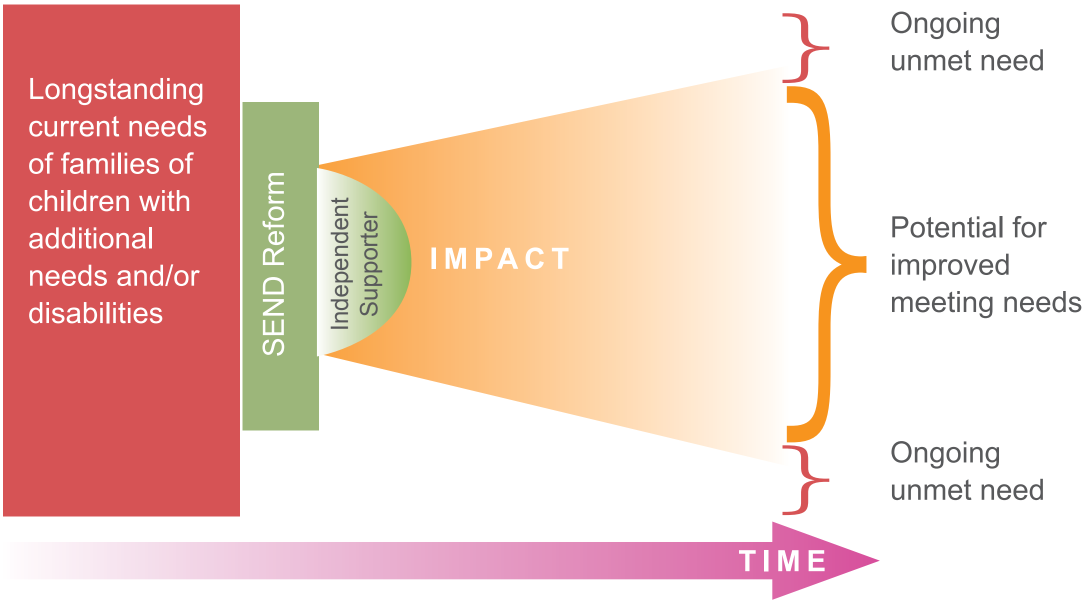
While the SEND reforms should rightly raise our levels of expectation, there is a danger that they will signal a promise of increased resources when relatively little additional practical and tangible help is likely to be available. Overlaying new reforms onto a system that already has flaws or as Mayer states “denied access to the tools needed for self-sufficiency” (Mayer, 2003, p. 2) presents real challenges for the IS programme.

For us, the challenge of the IS programme must be to inform young people, parents, and families about statutory rights and how the reforms work locally but more importantly enable families to learn requisite skills and applied knowledge to effectively manage the challenges of daily life. The contact with services at this point is the front door to other support and resources, not just the time and task bound activity related to one part of the reforms.

Model one: Basic IS version with limited impact on families



Model two: Enhanced IS version with greater potential impact on families



Clearly, there has been and continues to be unmet need that the SEND reforms are not designed to meet. However, the IS programme has a unique opportunity to assist and empower families, scaffolding and encouraging their ability to navigate and negotiate for the support they need. Programmes that understand and appreciate: the context/backdrop; social ecological ways of promoting resilience that call for the people and service systems around families to support their needs; the common needs, problems and issues for children and young people and parent carers; and the services and provision that disabled children and young people and parent carers tell us they value, could add significant worth to the investment in IS support for families, over the coming two years.

2.2 Common needs, problems and issues for families

What do we know about parents and carers?

Numerous studies and the experience of the core team involved in this project collaboration consistently confirm that parent carers share in common a distinct set of experiences that set them apart from parents of children without special needs (Contact a Family 2011, DCSF 2009, McKay and Atkinson 2007, Gammon and Rose 1991, Russell 1991, Worthington 1994). A quick glance at some of the national research findings which are further substantiated by our local parent carer surveys, clearly show how the odds are stacked against disabled children, young people and their families and look certain to worsen as reduced UK public, community and voluntary sector funding looks set to continue. Organisations such as Scope, the National Deaf Children's Society, Action for Children, Royal National Institute for the Blind and the Children's Society, have all published recent accounts of how the current cuts threaten to increase the burden placed on families. Understanding the social determinants of health and well being can help us to see what needs to be done to promote resilience by boosting protective factors and reducing the risks for families.

The latest report 'Forgotten Families', published in December 2011 by Contact a Family, again confirms many of these themes and in a survey of 1,148 families of disabled children across the UK shows that:

Parents report that:

72% of parent carers experience poor mental health such as anxiety, depression or breakdown

65% feel isolated frequently or all the time

over half **(56%)** reported that the cause of their isolation is due to lack of support from statutory services

Almost half **(49%)** reported feeling so unwell that they have asked their GP for medication or to see a counsellor

and **54%** say that not having the time or money to do things that other families do makes them feel isolated

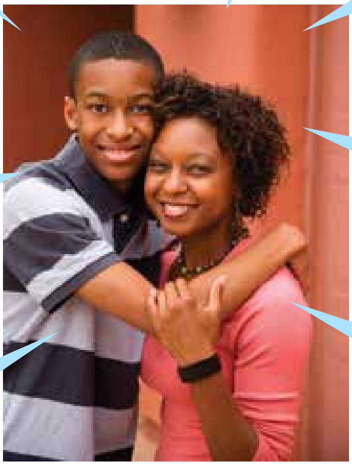
21% say that isolation has lead to a break up of their family or marriage

Only **50%** of families receiving DLA

Costs **3** times more

32% are single parents (22% in nondisabled households)

4 in 10 **(40%)** disabled children live in relative income poverty, once the additional costs of their disability is accounted for (compared to 3 in 10 (or 30%) of all children)



Only **8%** of families (1 in 13) get regular support from their local authority

16%
mums in work
(61% others)

63%
dads in work
(86% others)

Carers are twice as likely to suffer ill-health as those not providing care

While we may share an understanding of the terms parent and parental role, in the context of disabled children and young people, it is important to recognise the additionality involved when parenting a child or young person with a disability. We use the term 'parent carer' to distinguish the added complexity and challenge that is experienced when parenting in this situation.

Appreciating the experience of families as they continually adapt to the additional demands of their caring role, can assist services to adjust the way in which they provide information and support for parents.

The table below shows fluid themes shown in research studies, and suggests a common but dynamic sequence that can happen over days, months or years. Parents report feeling back to the beginning when faced with new complications or other changes.

Unique Family Journey of Parents of Disabled Children

- **Early Stage:** anxiety and effort to secure diagnosis; shock and feelings of helplessness; denial; guilt; crisis as life will now be different; eagerness to put child in hands of expert; isolation.
- **Middle Stage:** coping with conflicting advice; realising things cannot always be fixed; noticing unsustainable physical and emotional effort; emergence of chronic sorrow; navigating service systems; exposure to disability discrimination and lack of opportunities.
- **Later Stage:** reframing 'normality'; drawing on range of expertise; developing confidence; connecting with other families; being able to celebrate; advocating for services.

Britton 2001

Caring for disabled children makes demands on families over and above those usually expected of other families and survey findings across the country repeat the same story identified by our local consultations. For example, of the 341 parents who responded to a Brighton and Hove survey about their caring role, 66% said that they provided 20 or more extra care hours a week over and above their usual parenting duties and 15% said it was 100 hours or more (Amaze 2013). Access to appropriate short break support is a key factor for many families yet provision is under pressure from austerity cuts in services.

Given the extra demands of caring for disabled children without the necessary resources and support, it is not surprising that parent carers are particularly vulnerable to poor health outcomes. Stress related illnesses such as anxiety, depression and neurotic symptoms are widespread amongst parents carers (Gannon 2004, Hirst 2004, Singleton et al 2002, Wallander and Varni 1998) and increased levels of stress double the chance of illness or injury for carers (Shared Care Network 2006).

Locally in Brighton and Hove, 58% of the 341 parents who completed a survey about their caring role, said they feel depressed, anxious or stressed some of the time and a further 18% feel that way all or most of the time. Only 33% said that they usually got a good night's sleep (Amaze 2013).

While only a few UK studies establish a connection between having a disabled child and relationship breakdown (Contact a Family 2011, Hatton et al. 2009, Clarke and McKay 2008), there are a number of extensive national and local parent and carer surveys that illustrate the strain on families and the 'breaking point' many are living with on an ongoing basis (Carers UK 2012, Amaze 2013, Walker and Streatfield 2012, Martin 2011, Amaze 2010, DH/DfES 2004, Contact a Family 2004, Mencap 2003 and 2006).

Cost effectiveness of family based support

Stress on families is cited as one of the causes of children going into social care or residential educational placements (DoH NSF 2004). While difficult to measure the cost effectiveness of family support, the average price of a residential placements is estimated at £2,639 per week and foster care placements at about £676 per week (Berridge et al 2010, Copps and Heady 2007). Support for families before they can no longer cope is clearly less costly and emotionally preferable to looking after children following a family breakdown. In the same way, easily accessible community based family support makes economic sense. For example, the cost of caring for children with poor epilepsy control (due to medication and hospital admissions) is more than twice that of caring for children in whom seizure control is good (Beghi et al 2005).

Carers UK working with the University of Leeds calculated that carers (which includes parent carers of disabled children) make a huge contribution to the economy. By taking into account the cost of providing alternative care outside of the home, they estimated that in 2011, this unpaid workforce saved the national economy approximately £119 billion a year, or perhaps easier to conceptualise, £18,472 for every carer in the UK (Carers UK, 2011). The UKs Chief Medical Officer cites many examples of the cost benefits for supporting disabled children and their families and states clearly that “The evidence base increasingly suggests that failure to invest does not make economic sense… the very group in our population on which science suggests we should be focusing investment is the group that we disadvantage the most” (CMO 2012, p13).

All of this information about the strain on families needs to be understood in the context of recognising that the overwhelming majority of disabled young people remain at home for much longer than their non-disabled peers and that disabled children and young people report relying on their families as their regular and often preferred source of ongoing support (Meechan 2014, KIDS SE7 2013, Stalker and Moscardini 2012). There are obvious economic benefits and financial savings for society, from improved health in disabled children and young people and their parent carers.

What do we know about children and young people with additional needs and disabilities?

In the past three decades there have been substantial changes in the way we understand and define disability. Crucially there is a challenge to move away from a single focus on a child’s impairment or medical condition and instead a greater emphasis on the disabling role of contextual factors (social model of disability). Hence the experience of disability results from the interaction of individual’s impairments and the conditions with the context in which they live. The implication from this is that any attempt to improve the situation for disabled children and their families through service provision and other means needs to be based on an understanding of the children and young person’s individual conditions, the environment in which they live and on the dynamic relationship between the two (CMO/DoH 2013). This is why understanding all aspects about the family context of the child matters so much, and is shown to be the strongest determinant about the outcomes for each child and young person.

Many children and young people do not have disabilities but still have difficulties with learning, and about a quarter of children with disabilities do not have special educational needs (Porter et al. 2008).

Definitions and Data

According to the UK Equality Act 2010, a person is disabled if they have a physical or mental impairment that has a substantial effect on their ability to carry out normal day-to-day activities. In total there are 0.8 million disabled children and young people in the UK aged 0-8 (6% all children). However a lack of reliable data sources makes it hard to secure specific detail. The difficulties related to capturing information about children with disabilities are well documented in a study by York University (2009): DH Aiming High for Disabled Children: Improving Data, Final Report, and even repeated again by the Chief Medical Officer, Sally Davies, in her 2012 Annual Report published in 2013.

Her report presents the following key statistics regarding children with neurodevelopmental disabilities, sometimes called neurodisabilities. This is the largest group of children with disabilities and include children with ADHD (estimated as 3-9% school aged children), autism, specific, moderate and severe learning difficulties, epilepsy, and cerebral palsy). These children and young people frequently have other conditions and complex medical and support needs. A detailed break down of the percentages of different conditions within the group ‘neurodevelopmental disabilities is reproduced in Table 1, and a table of the functional impairments are found in the Appendix.

There are **0.8 million** disabled children and young people aged 0-18 in the UK, 6% of all children.[1]

Children with neurodevelopmental impairments and conditions are the largest group of disabled children and young people. The estimated prevalence of neurodevelopmental impairments and conditions is around **3-4%** of children in England.[2]

Autism is thought to occur in at least **1%** of children and young people in the UK.[4]

The household income for a household with a disabled child has been shown to be around **13%** lower than for those with non-disabled children.[5]

Attention deficit hyperactivity disorder (ADHD) is the most common neurodevelopmental condition in the UK and is estimated to affect **1-2%** of children and young people, if the narrower criteria of International Classification of Diseases-10 are used.[3]

The most common functional limitations reported for disabled children and young people concern mobility **(18%)**, communication (22%) and memory, concentration or learning (24%).1

Children in socio-economically disadvantaged households in early childhood are twice as likely than the least disadvantaged children to develop a disabling condition in later childhood.[6]

Some **32%** of disabled children and young people live with a lone parent compared with 22% of their non-disabled peers.[5]

Almost half of disabled children and young people, as compared with a fifth of non-disabled children and young people, live with a parent who is also disabled.[5]

Some **28%** of disabled children and young people experience barriers to education, leisure or play. Barriers include unsuitable environments, lack of money and the attitudes of others.[7]

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What do we know about children and young people with additional needs and/or disabilities

Outcome trends

While children and young people with additional needs and /or disabilities can lead full and fulfilling lives, for many, disability is associated with limited development and social participation, and with poor educational, health and employment outcomes (Department for Work and Pensions 2013). The population of children and young people 0-25 includes those with a range of severity and complexity, and each with individual characteristics and potential.

However, we do know that disabled people do less well than non-disabled people across a wide range of indicators and, whilst there have been improvements in some areas, it is still the case that outcomes for disabled people in terms of education, employment and income are significantly lower than for non-disabled people (DWP 2012). Outcomes for many disabled people are not improving as far or as fast as they should (EHRC 2010).

Increase in numbers of children surviving with complex learning needs and other issues

Prematurity can be a causal issue: the EPICure1 study of children born very preterm in 1995 showed that 11 years later 45% now have a moderate or severe impairment or condition. Other advances in medical treatment mean that children with trauma (like head injury), complex needs or chronic illnesses (like cystic fibrosis, or heart and lung disease) are surviving longer and so for some groups of young people they are the first cohorts to transition into adult services. This means a steep learning curve and service providers, for often longer provision of substantial care by parents in the family home.

Barriers to taking part in different areas of life

There is widespread agreement that disabled children, young people and their families face significant social, attitudinal, environmental and financial barriers to full participation and life chances (DWP 2012, Family Resources Survey 2010/11, CMO 2012).

Break this down a little and there is evidence suggesting that disabled children and young people are more likely than their non disabled peers to experience barriers to social participation in sport, education, leisure, personal relationships and the use of public transport (Jones et al. 2012, CMO 2013). Commonly reported hurdles are lack of money, unsuitable physical environments and the attitudes of others.

In addition, the type and severity of impairment is also associated with levels of inclusion, with those experiencing pain and more severely impaired mobility, fine motor skills, communication and intellectual abilities, experiencing lower levels of participation (Jones et al. 2012). Disabled people are often vulnerable to secondary health conditions. Alongside this can be the difficulty for a young person or child to notice early indications of common illnesses, like chest or throat infections and so they may only gain medical attention once they have become severe.

For children and young people with learning disabilities, the prevalence rate of a diagnosable psychiatric disorder was 36%, compared with 8% of those who did not have a learning disability. These young people were also 33 times more likely to be on the autistic spectrum and were much more likely than others to have emotional and conduct disorders, which in itself becomes a barrier to social integration and positive outcomes (Emerson et al. 2011). This is in the context of a wide recognition of a serious lack of appropriate mental health provision to meet these needs (UK National Screening Committee (2013) Screening in

England 2011/12). Parents who had used child mental health services noted problems both in the quality and availability of the treatment and the functionality of the tier system. This resonated with the work of Sin et al. (2010) and our own local surveys (Dominey 2014, Mortensen et al. 2012), suggesting that access to Child and Adolescent Mental Health Services (CAMHS) is very uneven with some local services showing no clear care pathways.

School Absences and Exclusion

Children with additional needs and disabilities are likely to have more absences from the classroom due to assessments and interventions by others. They may also need to attend appointments in hospital for treatment and monitoring or undergo more protracted care in hospital and require recuperation at home, all of which takes them away from the classroom. These absences interrupt learning, peer friendships and participation and can reduce a sense of belonging.

What works?

Work and meaningful occupation

This is an area often raised by young people themselves, many of whom aspire to work (KIDS SE7 2013). Although the realities of being able to work are especially challenging in this time of austerity and general youth unemployment, evidence suggests that for those of working age, whether or not a person is in work has a major impact on poverty and social exclusion (DWP 2012). In the SEND reforms this is one of the targets for improving outcomes and alongside improving the process of transition, is known to be an essential tool for improving life outcomes for these groups of young people.

As already mentioned, the largest group of disabled young people are those with neurodisability and a recent study explored theirs and their parents' views.

Key findings from Beresford's study with parents and young people 'Transition to adult services and adulthood for young people with autistic spectrum conditions (SPRU 2013)

- Some localities had developed systems which ensured all young people with a diagnosis of ASC were supported in preparing for and planning leaving school.
- College careers could be foreshortened because mainstream colleges struggled to support young people with ASC, particularly managing behavioural issues.
- Young people and their families lacked autism-specific advice and support as they anticipated leaving further education.
- The absence of any meaningful daytime occupation, and the increased vulnerabilities associated with greater independence, were enormous worries for parents.
- A lack of appropriate employment opportunities and insufficient (specialist) support to gain and maintain employment, were key barriers to paid work.
- Young adults endorsed the benefits of autism-specific, preventive or 'low intensity' support. Peer support opportunities were highly valued.
- Parents found themselves, often reluctantly, assuming a key-worker role. They felt unskilled and uninformed in this role.

Meeting peers

Children and young people highly valued peer support and shared time as indicated in the Autism Strategy 2010 which arose from the Autism Act 2009. This emphasised the need to develop evaluate systems for peer support for these young people (Beresford 2013). The young people in this study said they liked just being able to do the things, and access the places that other young people do. The importance of building a culturally and practically inclusive community is therefore seems a priority if they are to socially participate in our communities and workplaces.

Choice and control

The young people tell us that they like to be given real choices, and for it to be clear where there are in fact no choices. The opportunity to live independently was a recurring theme in studies, and to be able to work and have normal family lives. In the transition study by Beresford (2013) young people with autistic spectrum disorders showed that while there were in some areas systems which ensured all young people with ASC were supported in preparing and planning for leaving school, sometimes college careers were foreshortened because mainstream colleges struggled to manage particularly the behavioural issues. This study showed the lack of daytime occupational, relevant volunteering or appropriate employment opportunities options for these young people.

A recurrent theme emerging in this study was that parents appeared to be very much involved in supporting their son or daughters lives, and yet struggled to about knowing how best to support their son or daughter's to acquire independent living skills. The accounts from the young people interviewed in this study suggest the high levels of parental involvement in their lives were not, typically, unwanted. However, this was not a role parents usually wanted to assume but happening in the absence of effective support.

3 The Evidence about current services families use and value

3.1 Overview

Like ordinary parents, those with disabled children and young people carry the main responsibility of care for their children's development, health and well being. But this is parenting plus and as parent carers travel this unique journey, they often gather significant levels of expertise in relation to what they and their children need and find coping strategies along the way that we would be wise to take note of.

For example, a synthesis of parent surveys across the UK (Li et al 2003; Robinshaw and Evans 2001; Jennings 2008; Bennett 2009; King et al 1999) identified that the services most valued by parent carers are ones that are able to provide:

- support at time of diagnosis
- access to information and advice
- assessment that takes on board family views
- effective and stress-free service coordination
- an efficient and not over-prolonged statementing process
- a service that considers and meets the needs of the whole family
- targets and developmental milestones to work towards
- evidence of achievements
- rapid and obstacle-free access
- ideas and suggestions for activities
- a knowledge base on which parents can rely for informed treatment options
- help to enable parents, especially mothers, to enter or return to work skills for parents.

Unpick this list a little more and consult the detailed comments parents have provided in response to our local consultations, and what emerges is a clear message about ways in which the IS Programme can effectively support disabled children, young people and families. The following diagram sets out the core elements that we believe will underpin a good quality IS programme.

Core elements needed to underpin an IS programme

A support base that:

- Empowers
- Promotes resilience
- Adopts an inequalities lens

Information and advice: that tells it how it is rather than how it ought to be

With me – not about or for me: because it's our lives, and we know something about what helps

Co-ordinated support: is always important especially at transition times

Choice and range: because we need different things at different times and some of us need more

The way support is given: can be as important as what is given

Meeting other parents: in the same situation can reduce isolation and provide us with the best source of tips

Champion our corner: because getting the right support and promoting inclusive communities would turn our lives around

Information and advice

Information and advice are related but slightly different activities requiring slightly different skill sets. In simple dictionary terms, information is the communication of items of knowledge, facts and ideas whereas advice is an opinion or recommendation regarding a course of action. Often overlapping, parents tell us that they need both. They say that sometimes, they want access to details about what they need to know and at other times, they want guidance as to how to go about doing and getting support or provision. Either way, having accurate information at the right time or being guided to know and take the next step, can help build family confidence and contribute to improving life immeasurably.

Parents want information that helps to access services and support (DCFS 2009). They want to access it from a single point of contact that coordinates the information and is not only about education processes and the SEND reforms. A one stop shop approach to information provision that is joined up, independent and impartial is highly valued. Only some want information via websites, leaflets and booklets and there are specific geographically and economically deprived communities who have little access to online technology (Amaze 2012). The majority of families want to be able to speak to someone who is knowledgeable, can tell it how it is, is able to say when they don't know and can signpost. Many parents are well aware of the limits on resources but appreciate it when workers make the tensions transparent.

With me, not about or for me

Despite the 'Valuing People' phrasing 'nothing about me without me' (DoH 2001) parents still report a pattern in this sector, of decisions being made by others who may be unknown to the family, where neither the child, parent or young person are able to represent their views. So, 'with me, not about or for me' operates at two levels and is about meaningful participation, partnership and personalisation – where the individual is actively at the heart of the process, not a bystander or recipient of it.

'Nothing about me without me' being a catch phrase used in health service development for the past five years about including 'patients' in health related decisions and implies the same imperative that the people most directly impacted by decisions need to be meaningfully engaged in those decisions. Here it is about individual choices or decisions with a child or young person and their family. Most young people will develop their decision making capacity wherever possible over time. Locally, Triangle, a specialist organisation working with disabled children and young people across the country (http://www.triangle.org.uk/), report that time and again children and young people say:

What matters is:

- Communicating with them about their wishes and feelings
- Communicating their rights and choices to them
- Supporting children and young people to join in and feel included
- Supporting children and young people with their futures and independence
- Being treated the same as other children and young people.

What adults should do when they are with children and young people, is:

- Listen and talk the right way
- Take time
- Take care of you
- Learn and help support people better
- Think about how it feels when people around you don't understand
- Find out how to help us
- Find out how that person is feeling

We know from understanding the unique parent carer journey that there is an early stage when the parent can be desperate to seek help, answers, information and solutions and their own expertise and confidence takes time to evolve. Some parents for a wider range of reasons may not develop confidence in their own abilities and will need ongoing help and guidance. Most parents seek to work in partnership, where there is mutual recognition of skills.

In parallel there has been a development of embedding representative voice, mostly through parent carer forums, in strategic decision making so that planning, delivery and monitoring activities are co-produced as outlined in the SEND Code of Practice. The SE7 pathfinder in particular developed a framework and practice guidance based on co-production which has helped change relational values and created a greater understanding between service providers, commissioners and families who use those services.

Co-ordinated support

There are a number of important transition periods in the lives of families that time and again generate additional strain and stress (Dominey 2014, ECM Common Core of Skills and Knowledge DfES 2005, Baldwin and Carlisle 1994), so it is no surprise that parents value key working as a way of co-ordinating family support. However, parents also tell us that they often become their child’s keyworker, despite feeling unskilled and uninformed to do so, because there is no other option available to them (Beresford et al 2013). While key worker strategies are relevant throughout a disabled child’s lifespan, effective key workers are particularly valued at the early stages and at adult transition.

Key workers improve the quality of life of families by ensuring quicker access to support and benefits, reduced levels of stress and greater empowerment (C4EO 2009, DCFS 2009). Parent carers value the regular contact, supportive relationships, a single point of contact and a family-centred, rather than a child-centred approach. They say good practice is when key workers recognise the families’ strengths and represent the families’ interests rather than those of their employing agencies. The range of skills and qualities parents valued in key workers (Greco 2005) and likely to be highly relevant to the workforce development of the IS programme and are listed below in the section about the way support is given. The research study on the Parent Advisor Model and the benefits for families conducted back in 2001 spells out the importance of training and support for this role (Davis et al. 2002).

Choice and range

There is a gap sometimes between what research and surveys report, and what people want to know and learn about when working in the messy complexity of trying to support families. It can be difficult to identify what works for whom, in what circumstances, in what ways and how and so it can be tempting to design a one size to fit all approach for ease and simplicity.

While parent carers tell us they share in common a range of experiences, they also tell us that they need access to different types of support at different times and some need more support than others. Research shows that parents of children with a moderate severity of additional needs, or a combination of needs often feel that accessing support is especially difficult because their child does not reach the criteria for high need services from anywhere, and therefore struggle to manage. The complexity of needs across the family warrants better consideration, perhaps where more than one child had additional needs, so that even if neither child has the most complex needs, the overall care task for the family is huge.

We know that many parents find navigating their way through the maze of services a frustrating, time-consuming, repetitive and distressing process (Dominey 2014, Brawn and Rogers 2012, DCSF 2009, PMSU 2005). The IS programme might be able to guide parents through the new process of securing a EHCP clearly and smoothly, but it won’t be much use if it doesn’t also incorporate a co-ordinated approach (DCSF 2009) that helps parents to know their rights and how to exercise them, supports them to ask useful questions about what’s available and how to access provision, and equips them with transferable skills that they can use for the long term.

Parents are not one homogenous group, and just as two young people with the same health condition may experience illness and impairment differently, the way in which parent carers experience the demands of caring can also vary. In the face of such diversity, a flexible approach that respects individual parents and children’s wishes is required. So again there will need to be a range of resources, and a range of ways of delivering support.

The way support is given

While no amount of sensitive care and concern will mask that assessments and service criteria can be narrowly resource driven, many parents, over years of research, report that how support is provided can be as important as what is provided.

Parent carers value a family centred approach that takes into account the views, needs and support of each family member. Having a disabled child in the family effects everyone and siblings and dads can frequently get left out of the frame even though they can experience social and emotional isolation, provide extra care and are coping with the additional demands (Netbuddy and Scope 2012, Burke and Burke 2004).

When the Social Policy Research Unit at the University of York explored different models of key worker services across the UK, they enquired further into what parent carers valued about these roles and identified the following list of characteristics:

Skills and attitudes	
• Good communication skills	• Negotiation skills
• Demonstrate respect for parent expertise	• Ability to work with team
• Ability to step back	• Knowledge of other agencies
• Ability to step outside your discipline	• Knowing what's available
• Diplomacy	• Say when you don't know
• Family focus	• Time management
• Empathy	• Ability to plan
• Rapport	• Good organiser
• Listening skills	• Understand disability issues *(Greco et al. 2005 p.157)*

While quite a daunting list, parents cite many examples of meeting workers with this collection of skills and attitudes. Having just half of these talents would go a long way towards creating a good quality IS service.

Meeting other parents

One of the features we've noticed as we have collected in data, read the literature and scrutinised our parent surveys, is that time and again parent carers comment on how helpful it is to meet other parents and attend organised groups that are designed specifically for them. They say often the best support and most useful tips come from other parents. However, they also say that it can be hard to find this type of group support. For example, the recent wave of Local Authority funded parenting programmes rarely if ever included programmes for parents of disabled children and young people. There is a gap between what's delivered and what's needed and opportunities to reduce a sense of isolation and meet other parents in similar situations, are thin on the ground.

Given how helpful many parent carers find peer-to-peer parent support, delivering information and advice in group settings can be an efficient and powerful way to kick start long lasting parent networks. Very little of this type of support is rigorously evaluated however we found evidence that the community sector can be best placed to source and organise this activity and that courses designed by and for parents such as the Face to Face programme and the Insiders' Guide parent support course can have lasting effects, are cost effective and build parent carer resilience (Barzotti and Pike 2013, Britton 2012, Graham and Elton 2013).

Advocates and champions

Some of the most difficult experiences reported by families are not an inevitable consequence of their children having impairments (DWP 2012, Bennett 2009). In the Contact a Family survey where 615 families were asked what makes them stronger, almost 70% said that understanding and acceptance of disability from their community is poor or unsatisfactory; over 60% said they were not listened to by professionals and over 60% said they don't feel valued by society in their role as carers (Bennett 2009). It is not hard to understand that feeling a sense of belonging and connection builds resilience and makes a positive difference to life (Britton 2012, Aumann and Hart 2009).

There is agreement that disabled children, young people and their families face significant social, attitudinal, environmental and financial barriers to full participation and life chances (DWP 2012, CMO 2012, Family Resources Survey 2010/11) and we have highlighted the disadvantage families are living with on a daily basis. The way in which an IS programme is planned and delivered can play a part in helping to reduce social and material barriers and actively help to promote supportive and enabling environments. Families need workers to assist them to champion equality of opportunity for their disabled children and young people. Understanding the social determinants of health and well being could be a good place to start if the IS programme aims to assist families to navigate and negotiate for the support they need.

REPORT B: The SEND Reforms – what families say works or does not work

This report is one of three that combine to present the evidence gathered about what parent carers and young people say works or what does not work regarding information and support services which could underpin the Independent Supporters programme:

Report A – evidences the key features of the landscape currently experienced by families and the teams who support them; Report B– is about the Special Educational Needs and Disability (SEND) Reforms and what families are saying works well and not so well and should be read alongside this material which together sets the context for Report Three, which offers two models for an Independent Supporters programme.

1 Study Findings

During this 11 week project (4 weeks of which included school holidays) we were pleased to be able to collect material from:

- Three short case studies
- Nine short cameos from individual parent carers
- Two parent carer focus groups
- One focus group of parents of young people aged 19 years plus
- Transition survey with 155 families across the four areas with three cameos and two young people focus groups about what did and did not work for them.
- Additional material about school based work was also collected.

Figures for all these activities were low due to the timescale and the huge demand to attend meetings, on families who were already engaged in the reform process.

The three family case studies were about the pre-reform services and illustrated the range and inter-connectedness many of the issues explored in Report A and all the data is found in Appendix 1. The Local Offer and aspects of the Education Health Care Plans (EHCP), and an effective Independent Support (IS) service may assist these families in the future; meanwhile here are some of their comments:

Parents' summary about familes' experience

- Fighting for Services – lack of working together – lack of emotional understanding or support.
- Information is hidden – parents find things out by speaking to other parents.
- Struggled to find information and support over the years. Professionals not open and forthcoming with options and information and seemed to take opposing positions rather than a partnership approach.
- Lack of (or badly delivered) information at key points (birth, diagnosis, school transitions, move to adult services) led to parents feeling unsupported meaning increased stress.
- Generally good early years support but poor advice and information on school choice led to the child being incorrectly placed for a year. Some frustration with waiting times and lack of info in some areas.

Parent carer ideas to improve things in the future examples

- More delicacy and warning when delivering initial diagnosis at birth.
- To have been better prepared about seeing the baby after surgery.
- To be able to make informed choices about schooling and not being presented with what would happen.
- To receive emotional as well as practical support.
- To have had access to a social worker when requested, without having to threaten legal action.
- To have been more involved in decisions over adult services.
- To have been informed earlier about banking and court of protection.
- Professionals being open and honest.
- Written information in the early days.
- A partnership approach rather than gate keeping resources.
- Someone to go through the statementing forms with (or to have been told about Parent Partnership). Better information, prospectuses etc. on school choices.

2 Overview of SEND Reforms and Pathfinder experiences

2.1 Introduction to SEND reforms

The SEND reforms (see Report A, sections 1.3 and 1.4 for further detail) combine with other changes in both health arrangements and social care to address poor outcomes for children and young people with special educational needs and disabilities and tackle family's experience of an adversarial and disconnected system of support.

This report (number two of three), gathers evidence about the key features of the reforms with a specific focus on what young people and parent carers say does or does not work for them and their families. We have drawn on three data sets to do this:

1. The findings from Pathfinder areas who have been exploring and trialling the new approaches since September 2011
2. Existing evidence from work undertaken within our region
3. New evidence and material gathered during this 11 week project.

2.2 Introduction SE7 Pathfinder

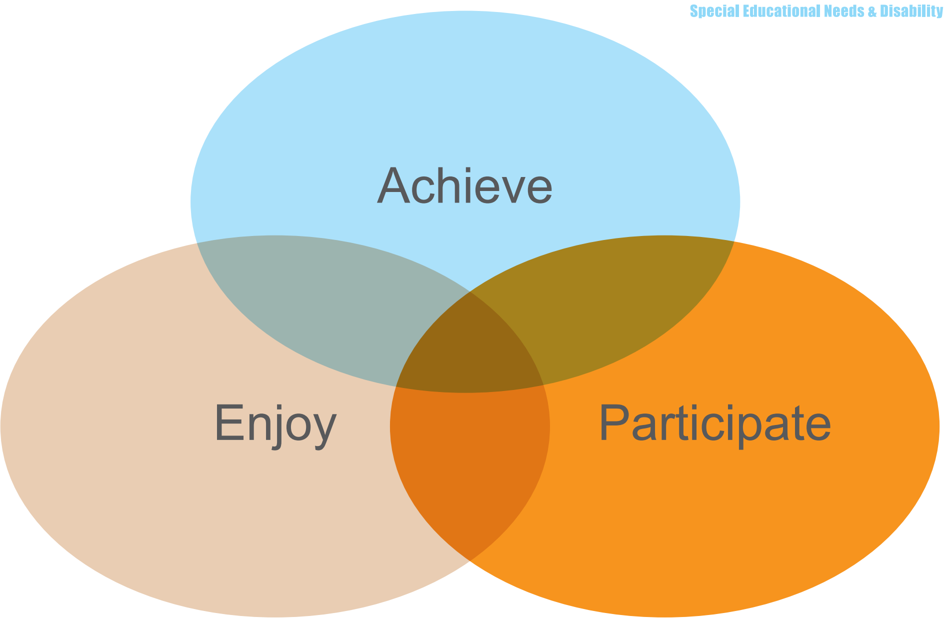
The SEND reforms are led by the Department of Education, but are a combined endeavour with the Department of Health. Local authority areas and health service colleagues were invited to volunteer to path find for the reforms, and 22 Pathfinders (comprising 36 local authorities as some worked in groups) were selected. A collaboration of local authority areas working in the South East, was one of these successful groups. South East Seven (SE7) is a collective of teams from across seven neighbouring local authority areas (Brighton and Hove, East Sussex, Hampshire, Kent, Medway, Surrey and West Sussex), working together with parent carer forums, young people, community and voluntary organisations, health, education and social care colleagues to influence the design and delivery of the SEND reforms. Further information about the work of the Pathfinders, parent carer forums, delivery partners and others is available at www.sendpathfinder.co.uk and http://www.councilfordisabledchildren.org.uk.

The core team for this project include Amaze (an award winning parent led charity providing information, advice and support for parent carers in Brighton and Hove) and the four parent carer forums in Brighton and Hove, East Sussex, Hampshire and West Sussex all part of SE7. Our partners include Parent Voice and the Parent Partnership Services, both based and Hampshire, and CHAOS and AHA young people's groups.

Pathfinder work began in September 2011 and the SE7 has produced a huge amount of material and useful frameworks about how it has worked in a co-productive way to shape the local reform process (www.se7pathfinder.co.uk). Some families and practitioners from across the area have experience of the early trial phases of different aspects of the reforms and we have drawn on this work to illustrate many of the points we make in this report. Approximately 10% of the families recruited nationally to pilot the reforms were from the SE7 region, although a consistent concern has been that the sample size itself has been very small considering the total number of families who will be impacted by the reforms (Spivack et al. 2012).

One of the key discussion across all sectors, and participants within SE7 lead to an agreement that the high level outcomes we collectively sought for children and young people were all our responsibility and were:

South East 7
Special Educational Needs & Disability



2.3 General national overview of pathfinder experiences

The Impact Evaluation commissioned by the Department of Education undertaken by SQW show that the numbers of families in the initial stages were very low, often included families who volunteered their involvement, and that because the Pathfinder areas adopted different values, approaches, frameworks and processes there was little comparable data between the groups of families in the different Pathfinder areas (Spivack et al. 2012).

However nationally overall there was evidence to show that the changed approaches have:

- Increased choice and control for families. For example this was seen in their involvement in the development of outcomes for their children and agreeing the plan to achieve these outcomes.
- Keyworkers found development of outcomes based plans challenging and so further workforce development and support is needed.
- Pathfinders that engaged with parent carer forums early in the process developed less conflicted and better working relationships with parent carers. There was less progress working with young people although SE7 commissioned KIDs to co-ordinate engagement with young people and their finding has provided useful evidence.
- The new approach needs services to work together and there were positive examples of joined up planning leading to issues being resolved or services being allocated more efficiently. However some concerns remain, especially as health reforms mean that groups are still finding their feet. Joint commissioning duties in the Act should help.
- Many areas underestimated the level of resourcing required to deliver the reforms and huge pressures on resources remain.
- Take up of personal budgets was not as high as expected and relatively few SEN direct payments agreed. The main issues were the development of a robust and transparent process, reliable information about unit costs for existing services.
- There was an appetite among parents to be involved in the decision making around support for their child, and to have more choice and control but relatively low parental demand of personal budgets.

3 What works for us in this region

3.1 Information, advice and support

The feedback from forums and school staff in each area has been a sense that the majority of families are still not aware of the changes coming and how they might affect them. It is essential that there is clear, impartial, independent and accurate advice about how the new legal process should work. Guidance and proactively making this information available, accessible and user friendly for all is crucial. The Department of Education are developing information about the SEND reforms and producing a version for parents. Another Guide to the Code of Practice suitable for young people, is being prepared with help from young disabled people from EPIC (the group recruited and hosted by CDC), but much work is still needed as the words on the page are translated into real change on the ground.

Effective information sharing is essential for the smooth implementation of the reforms, but the task has a very compact timeframe in which to do this so that families and the diverse workforce impacted by the changes experience confidence in the new system.

Delivery partners and grant-aided oganisations had to ‘hit the road running’ when the Pathfinders began. They tried to introduce plan templates and models in a one-size-fits-all approach, which perhaps did not allow for co-production or adequate responsiveness to local areas and teams (Spivack et al. 2014). There were huge gaps in targeted audiences, for example leading to poor reform awareness in schools, myths and misleading information that added to anxiety and confusion for families and workers, and some groups were bombarded with information from all directions. Part of the confusion stemmed from Pathfinders creating their own pilot approaches, and so information and experience from one area might conflict with measures in the neighbouring authority.

Ten national ‘Together is Better’ workshops were delivered in which Christine Lenehan, Director of the Council for Disabled Children (CDC), promised to ensure improvements in getting quality updated information to parent carers, their forums and workers at the same time so that we could all benefit from informed collaborative working. Since then, CDC were appointed strategic partner for the delivery of the reforms and we are optimistic that this promise will be realised. This is an exciting opportunity to really improve the quality of information and information routes between all parties especially with the social media tools now available.

SE7 example

SE7 developed a website early in its work to share all the frameworks and materials being developed across the region. There was a Question and Answer section which helped address common concerns or information needs, and also helped dispel some of the myths and misinformation. SE7 used a co-production approach to all its work and the production of materials, and made the operational decision to be transparent and open. Through working together on a suite of information booklets and frameworks, single cost effective materials in simple English that everyone could use and rely on were produced. Parents and workers report that these have been very useful, especially as they included plenty of illustrations which became familiar images and helped to explain the contents. The full set of materials remains available on the SE7 website www.se7pathfinder.co.uk.

In this report, we have gathered further detail about what young people and parent carers tell us is important about getting information right, in the right formats, at the right time, to the right people. There are a number of local studies with parent carers and young people that describe what they want regarding information and advice within the Local Offer. Here are a few examples:

What local parent carers say?

When the University of Chichester evaluated the impact of support provided by five small parent led organisations in West Sussex, they consulted with 312 parents and found that accessing support services can have an impact on: skills and knowledge, dealing with professionals, shaping services, effect on family life and emotional health and well-being (Barzotti and Pike 2013).

Peer group learning and support

Parents need more than information and signposting. They tell us about the significance for them of meeting together and as a group learning the skills and approaches, for example in the Early Bird programme, and Time Out and the mentoring approach of Face to Face operated by Scope and Early Support. The activities of the local parent carer forums facilitate these opportunities and help build a community experience. These few course that exist do offer more than information; they are an opportunities for parent carers to share perspectives and experiences and practise new knowledge and skills that will equip them for the challenges of daily life.

Local Example Insiders' Guide Parent Carer Support course

As part of this project we undertook two courses of 6 sessions in Hampshire and West Sussex, with a total of 27 parent carers. Each course specifically aims to equip parents to build more resilient lives for themselves and their families and is co-facilitated by a worker and a parent so that partnership working and solution-finding are demonstrated throughout. The value base of the course is that parents are key to improving child and family outcomes, that the best can be achieved for a child, when parents and practitioners work together and address the common parental experience of entering an unfamiliar world of disadvantage directly related to having a child with additional needs. Insiders' Guide has been fully evaluated by the University of Brighton and by using a Social Return on Investment approach, where its social value was shown to reach 9 times for each £1 invested (Britton 2012). In this research the main outcomes achieved by Insiders' Guide for the parent carers, the facilitators and the organisations that deployed this programme were:

1. Parent carer improvements were in: confidence, securing more help and support, willingness to ask for help, feelings of isolation versus connectedness to others, use of new ideas and strategies in everyday situations, more positive general outlook for the future, and greater interest in joining other learning situations in the future, as evidenced by pre and post measures.

In the current 2014 group a West Sussex parent described the benefit being ***"Able to evaluate my journey so far and how I can do things differently for both the well-being of myself and family."***

2. Parent carers reporting significant impacts and changes in thinking and actions arising from attending the course particularly in securing more timely help and support for family, friends and service providers as evidenced in self reporting evaluation forms and diaries.

A parent said ***"I realised that I am doing a good job in difficult circumstances plus that it's ok to ask for help. It's made me less critical of my child but also more focused on how to get the help he needs."***

3. Parent carer re-engaging with learning and accessing other learning or civic engagement opportunities, evidenced in co-facilitator survey, manager and commissioner survey, and a job satisfaction survey.

4. Impacting parent carer and practitioner partnership working, and more holistic approaches across service boundaries.

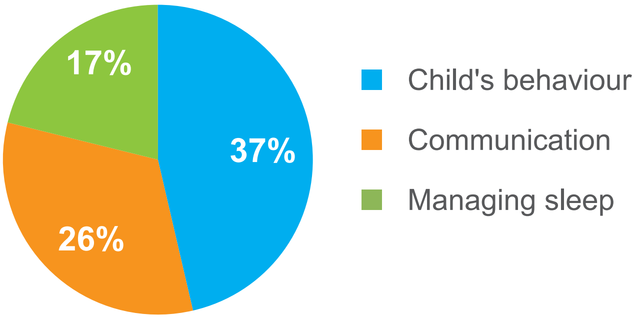
5. Wider cultural shift that nurtures collaborative and creative efforts to meet the families' needs. Workers felt hugely encouraged that this work bore results.

During the SROI research, a manager said ***"At last! after twenty years working with different parent support courses where little change happens, in Insiders' Guide we have a course that makes a visible and real difference for parent carers. It's the best thing I've done and it's been a privilege to take part in."***

Local Example

In West Sussex, 62% of the 592 parents responding to the Aiming High parent survey (Martin 2011) said they did not use services because they did not know about them! The top priority for services ranked by parents was information.

When asked what aspects of family life parents/carers would like help or advice with, the most frequent replies were:



Interestingly, as a point of comparison between what parents say in different local areas, when Amaze asked Brighton and Hove parents, only 13% said that they wanted more information while getting more information was the top priority for Hampshire parents. This may reflect the difficulties of getting information to families in such a huge county like Hampshire compared to a condensed unitary authority and urban area like Brighton & Hove. Or it could relate to the legacy of commissioner investment in Amaze to deliver information and support to parents over the past 17 years.

Local Example:

In Brighton and Hove, 73 parent carers completed a survey about their own mental health and well being (Amaze 2014) and identified specific types of information provided by Amaze (they were not asked about information from other organisations) that they felt had supported their mental health. Their responses were:

84.4% Compass leisure card for their children

62.5% DLA/benefits casework

56.3% Parent newsletter

51.6% Parent information handbook

40.6% Helpline advice

This is another example of parents saying they need far more information about local events and opportunities and support, as well as practical help managing daily challenge like advice about maximising household income as many parents were unable to fulfil the same work commitments as families with non-disabled children. In the requests for handbooks parents were looking for a range of information in one resource they can take home and dip into as needed, rather than just online material.

Local Example:

In a different survey, 341 parents in Brighton and Hove commented on their caring role. 85% said they had not been offered a Carer’s Assessment. While the Child Development Centre explained these are always carried out as part of a family’s integrated assessment, it tends to suggest that parent carers are not aware of having their needs assessed and … something about making assessments explicit is a consciousness building mechanism.

What local young people say:

During this project we completed a focus group Havant with 10 young people aged 18-32 years. These young adults were members of CHAOS a parent led organisation offering day time activities for young adults with additional needs in based in Hampshire.

They commented mostly on how information is delivered rather than the types of information they wanted.

We like it when people who are meant to help us are:

- friendly
- kind
- patient
- positive
- tell us when we're doing well
- happy
- polite
- fun and can have a laugh
- has clear boundaries
- good at listening,
- understanding,
- explain things clearly and take time to get to know us
- sorts things out

We don't like it when people who are meant to help us are:

- angry
- bossy
- swear
- lazy
- don't listen to us
- don't help when I am being bullied
- has favourites
- are not around much
- tell us what to do over and over again
- too many people at meetings who we don't know

The young people also said that:

- Nearly all of us still live at home with our families
- Our parents help us with important decisions and information
- Our parents help us with things like sorting our benefits out
- We don't work at the moment but there are lots of jobs we'd like to do
- We don't use the Internet much at home to get information
- None of us are on Facebook but we look at YouTube a lot

What came across strongly from the group discussion, was just how much the young people rely on their parents to find out information on their behalf and to get the support and help they need in all aspects of their lives. They want people to listen to them and they thought that the people who were most helpful were people who took the time to get to know them. Very few of the young people used the internet at home and none of them were on Facebook. They said they use YouTube to find things out when they are at CHAOS and some said they found things out from books and leaflets.

3.2 Personalisation and joint commisioning

The national agenda to encourage personalisation – where individuals are actively at the heart of the decision making process about their lives – is enshrined in the new Children and Families Act 2014. Personal budgets are one of the key mechanisms widely promoted to make personalisation a reality.

3.3 The Local Offer

This is one of the key changes useful for all families of children and young people with additional needs or disabilities from 0-25 years. Local authorities will be required from September 2014 to publish and keep under review information about services they expect to be available for children and young people with special educational needs and disabilities aged 0-25. This is the Local Offer.

The intention of the Local Offer is to improve choice and transparency for families. It must include information about the provision the local authority expects to be available in its own area as well as outside of its area for the children and young people for whom it is responsible, regardless of whether or not they have EHCPs. It will also be an important resource for professionals in understanding the range of services and provision in the local area. A further key role for the local offer will be to inform the joint commissioning for families by setting out in a single place what is available locally.

The Local Offer should be a dynamic resource of updated information and advice for families about nurseries, schools, colleges, health services, social care provision, community and voluntary sector organisations and the widest range of resources. The local authority must work together with children and young people, parent carers and local services, including the voluntary and community sector, to develop their offer and keep it under review. This is co-production.

The inclusion of eligibility is an important feature of this new information requirement. However, a key finding from the SQW Impact Evaluation of the reform process was that there were still issues around the information available to families which has emphasised the importance and challenge of getting the Local Offer right (Spivack et al. 2014).

School Action and School Action Plus categories of the SEND reforms within schools will be replaced by a single category of SEND support. This will mean a more graduated approach to meeting children’s needs with a mainstream school setting from within existing school budgets, rather than children being into specific category of support. Schools will be expected to involve parents and young people in identifying needs and planning support. All schools will be required to clearly communicate with support they will make available for children with SEND in their school.

The Local Offer will cover:

- Education, health and care provision for children and young people with SEND (which should include information about its quality and the destinations/outcomes achieved by those who use it);
- Arrangements for identifying and assessing children and young people with SEND, including arrangements for requesting an EHCP needs assessment;
- Other education provision (outside of schools or colleges such as sports or arts provision);
- Training provision, including apprenticeships;
- Arrangements for travel to and from schools, post 16institutions and early years providers;
- Support to help children and young people in moving between phases of education and to prepare for adulthood.

Similarities with a directory…

- It will provide contact details for services in the area.
- It will be a comprehensive record of services in the area.

Differences from a directory…

- I t will provide threshold and referral information.
- It will provide detail on schools and colleges and how they do things.
- It will have reference to the legislation underpinning the services.
- It will set minimum expectations for schools and colleges.
- It will be searchable for stuff you don’t know you need to find.
- It will have a feedback facility.
- It will inform joint commissioning. (SE7 2014)

What local parent carers say about information?

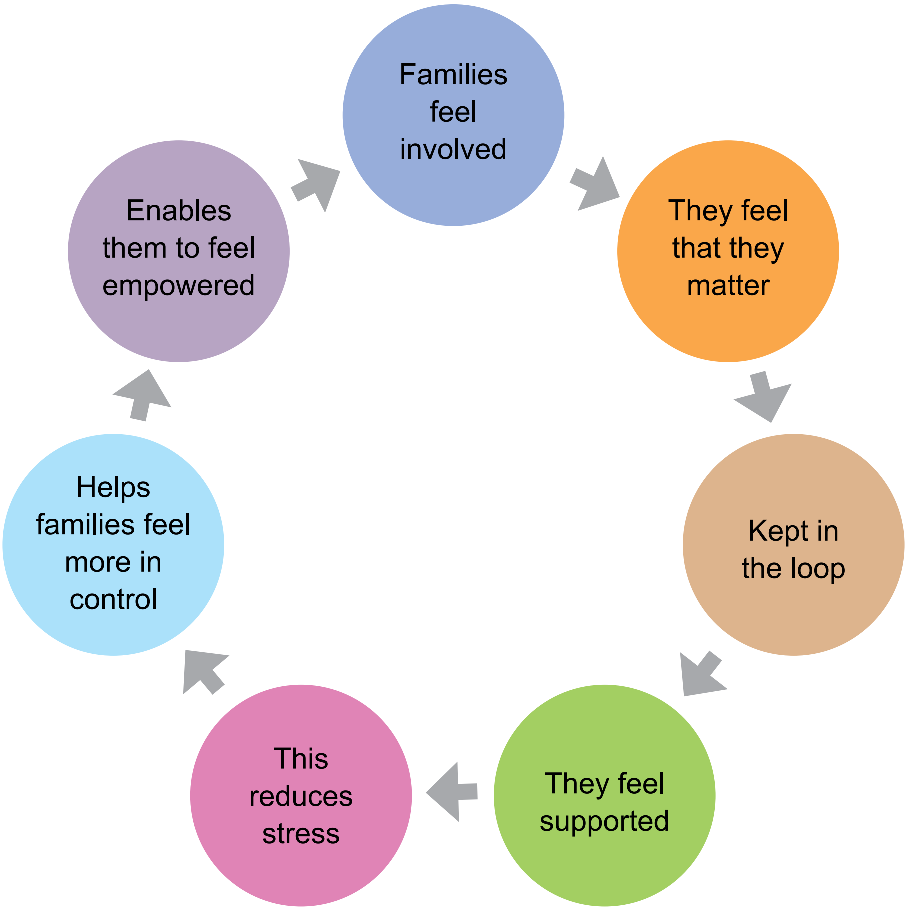
A local survey completed by 170 Hampshire parent carers and interviews to develop the Local Offer, identified the top five things families ‘would have liked’ (Clarke 2013):

78%	**• Someone to sit down with and talk through the process**
67%	**• To be listened to**
53%	**• Signposting when not eligible for a service, signposting in general**
50%	**• A single point of contact or key worker**
43%	**• Options and choices, making decisions together**

In the brief report from this Parent Journey exercise parents said the following were important in information giving:

- Parent friendly websites, leaflets and printed booklets
- Having options and choices – being involved in the decision making
- Having information prior to appointments knowing who's who, what they do and what they can expect
- Professionals working together
- Information from other parents and support groups
- Independent Assessments Therapies and Support

The significant role information can play in meaningfully supporting parent carers is illustrated by this diagram, which summarises the impact of when having information works well:



Parents in this study also said that online information is not enough
and has to be supported by 'real people' who can act as a single point of contact

What children and young people say about information?

Although the Local Offer should provide some information about local leisure opportunities, and encourage social participation, the comments of disabled young people themselves clearly demonstrate the internal and external barriers they face. The following survey results illustrate the limits of only providing young people with information. What they are telling us is that they cannot access things so the support provided needs to supply information in a way that addresses ways of getting over these hurdles.

A summary of responses to just a few of the questions a survey of 149 school aged children and young people with additional needs and/or disabilities across the SE7 region is included below (SE7/KIDS 2013):

What stops you from doing the things you like?

While 31 of the respondents provided no response, of the remainder:

24% said no money or no help

14% said no transport or that they didn't know

12% said family

8% said no information

4% said bullying

There is a message here about removing obstacles. Resilience research with the most vulnerable children shows very clearly that they heal best when we shape their environments to meet their needs (Jaffee, Caspi, Moffitt, Polo-Tomas, & Taylor 2007; Prilleltensky 2012). Disabled children and young people are not one homogenous group and the breadth of their additional comments below, warn us against a one size fits all approach to an effective information service. Their responses also demonstrate the individuality of their needs and personal preferences and suggest a call for a skilled workforce able to elicit young people's trust and confidence and be responsive to this range.

What stops you from doing the things you like?

- The confidence to do things on my own
- Get worried and confused easily, worry about passport control and security, don't think I could deal with them
- Hard to get a job, too busy in the job market to find one
- Depends on my mood and if I can do it
- Confidence and courage
- Sometimes people make me jump, a bit nervous
- Very nervous of new things which holds me back and I worry about my condition
- Nothing stops me at the moment
- Money a burglar took it
- Nothing stops me doing what I want to do
- Would like to sleep more, need to take Melatonin 3 times a day
- Asthma and dyslexia
- Other clubs have people who don't get me and I don't like the attitude. I would do more things e.g. cinema. Clubs, concerts but don't have the money and friends don't live near me.
- Many amateur dramatic groups are in inaccessible buildings and there aren't many parts for wheelchair users anyway.
- have sore joints.
- Teacher
- Have a baby, myself and partner are both disabled so transport, access and getting around as a family is difficult
- Finding it difficult to communicate
- Managing money, struggle to find information, get lost and disoriented
- Always been held back, lack self confidence. Something inside stops me or I forget
- No time
- Because I have cystic fibrosis, can't go horse riding often because the dust makes my CF worse and I cough
- Accessibility
- If I had money it would help me do what I want to do
- No time
- Can't keep warm
- Anxiety, can't feel I can attend, get scared
- Recovering from and operation at the moment
- Lack of stimulation. Mood dependent, may choose not to go sometimes even if enjoys it
- Nothing, my family supports me
- Can't go out alone, people annoy me and I get upset
- Nothing in my area, seeing friends is difficult
- Homework stops me from going on the computer
- Nothing, mum and my support worker helps me
- Can't go alone x 2
- Bad weather
- Nothing
- Lack of provision for disabled people to take part in activities
- Tube in tummy means harnesses can be awkward
- Not enough time
- Weather
- I can't go on a proper holiday because I'm in care

When the same group of young people were asked **“Who helps you?”**

75% said family

41% said a teacher, support worker or keyworker

13% said a friend or someone else

And then when asked **“Who do you want to go with you when you are being assessed?”**

72% said family

15% said a teacher or support worker

11% said a friend

Parents are typically the child’s main advocates (Stalker and Moscardini 2012) and accessing good information and advice underpins their ability to do this with and for their children. Disabled children identify their parents, especially their mothers, as very important and usually their main source of support.

When asked **“What is the best way to find out what you want?”**

64% said meet and talk with me

26% said ask me questions or give me a survey to fill in

12% said via computers and technology

It is clearly important to capture the views, needs and experiences of disabled children and young people to ensure the relevance of support provided by the IS service. When answering the above question, tellingly one young person commented:

‘As long as I actually get a choice in the matter, then yes. If there isn’t a choice, then don’t bother asking’.

Parents too comment that they need to understand eligibility to services as there is point them trying to access these resources if they would never fit the criteria. The Local Offer should be able to help spell out thresholds for service and support (Clarke 2013).

Parents have reported their concerns that some disabled children and young people, particularly those with complex needs, may not be best placed to provide information about the protective systems or adversity present in their lives. One parent pointed out that, although it is good that the voices of children are being increasingly heard, these children are not in isolation and it is important to also ‘speak to carers and the whole family as we are the ones that have to bear the brunt of the decision making’. She said that this was particularly the case for families with children with neurodisability, where some children cannot always vocalise their needs or make informed choices (CMO 2013 p.103).

3.4 Education Health and Care Plan

The SEND reforms mean that requests for statutory assessment from September 2014 onwards will no longer result in Statements of Special Educational needs. Instead children and young people with SEN who have the greatest level of need will have an Education, Health and Care Plan (EHCP). These plans will look at all the child's needs and will bring together co-ordinated support services form education, health and social care to achieve agreed outcomes. The new statutory process is being reduced from 26 weeks to 20 weeks. EHCPs will also replace learning Disability Assessments (S139a) for young people remaining in education after the age of 16 years (except if in Higher Education). The eligibility for an EHCP should remain the same as currently exists for SEN statements. Academies, free schools and local authority maintained schools will all be covered by the Children and Families Act and have the same requirements placed on them.

The essential feature of this new process is that it involves a personalisation and an outcomes focus, and that the process is carried out in a co-productive way with the family and relevant workers, similar to Team around the Child approach (See Appendix 4 for a Model of a Pathway to Develop an EHCP). It is not intended to be a re-labelling of the old process or that varied assessments will merely be summarised into a single précis page. Instead, the fundamental difference is the collective definition of the outcomes and agreement about the plan to achieve these outcomes across different service providers.

With resourcing, it appears likely that the new process can work as families involved in the pilots to trial EHCPs have reported greater understanding of the process, feeling more involved and listened to, improved joint working across services, and having better information. A key finding is that when the process was conducted in a personalised way, families felt more satisfied with the service that they were receiving. They also appear to prefer the new process to the old SEN statementing approach, finding it broader based with a more long term focus. The families who were part of the pilot were compared with a control group who received the former statementing approach. When their experiences were compared, those families trialling the new EHCPs were less likely to report that they did not have enough choice or enough information about the choice.

The SQW national impact evaluation of the Pathfinders found that in general, between 8 -17% more Pathfinder families 'strongly agreed' with positive statements about the process than comparison families – however the overall level of change appears modest. This evaluation was only possible with families at an early stage of the process, and well before a robust comparison of the outcomes for the children would be compared to children who had experienced the existing statementing process. In view of the early stage the survey was undertaken it is perhaps not surprising that it ***found no consistent evidence to illustrate an improvement in outcomes had occurred***. If this finding was repeated in later years it would prove a very disappointing finding.

So while the new system is going ahead without the benefit of a more longitudinal test sample, the message from the evaluation was a need to try harder. Key factors thought important were:

- The involvement of a 'key worker' or 'group of individuals' that had delivered the new process – the approach, knowledge and skills of this group going forward will be crucial.
- There are still issues around the information available to families, emphasising the importance of getting the Local Offer right.
- While parents feel much more involved, this has not transferred to disabled children and young people – which might be a workforce issue for new keyworkers as they are expected to be jacks and jills of all trades.
- Joint working is getting better but the flows of information between services could be better.

What local parent carers say?

Local examples

We were able to collect nine cameos from parent carers who were involved in creating an EHCP. Overall we see again how it is the way things are done that matters, as well as the timeliness and impartiality of the information. The full accounts are in Appendix 2, and here are some themes about what works and does not work for parents and families.

They said:

- ***"There seems to be a lot of advice out there, but you get a slightly different slant depending where it comes from"***
- ***" As a family we need information to help us plan and make decisions and although the school has been trying to help us they don't seem to understand what we need to be doing either!"***
- ***" My son is 18 and has one year left at school. We have had very little advice about the reforms. I do know that he will have a new plan, but I don't know what that means and my main concern is that there is actually somewhere for my son to go"***
- ***"I believe there should have been some support with completing the form. For me, it was more about confirmation that the example I was providing was sufficient".***

What works well?

- ***"The reports that have been put together have made it clear what sort of support our son needed. The Team Around the Child meeting was excellent. Very positive, very good for my sons transition. Clear and focused on what was going to happen"***
- ***"That all professionals work from the same paperwork. They meet each other at the meetings and can discuss together how to progress my son. Our caseworker supported our older child's application to secondary school (out of area)"***
- ***"Very happy (and visibly proud) of EHCP and all assessment reporting that went into drawing it up. Very good relationship with all professionals involved with their child including the Planning Co-ordinator who was very supportive. Felt it captured their child, reading it gave a good sound description of what worked well, what was important to and important for them."***
- ***"The home visits gave the schools staff the opportunity to see the girls in a different context where they behaved very differently to how they behaved at school"***
- ***"We both felt very involved while writing the plan and that their opinions mattered. We felt respected and listened to".***

What does not work well?

- ***"I have two other children who don't have special needs and spending all my time worrying about my son is affecting my younger children too"***
- ***"Parent did not feel that the Outcomes where very clearly defined. Not clear WHO and HOW Outcomes would be reached and supported. Felt confident because a Special School Placement had been secured but if child was going to mainstream setting then they would not be confident how and by whom the Outcomes would be met"***
- ***"Did not know about Personal Budgets and their entitlement to one"***
- ***"(Age 15)We are only just starting to do our EHCP but school really don't seem to know what they should be doing with it"***
- ***"When people argue over who should be doing what and I don't know what is correct"***
- ***"When the 'Our Story' form came through I felt a lot pressure to get it right, even though the pamphlet on how to complete the form was very good"***
- ***"We're not really given any information. We know that something will be different and we've heard about our plan but I don't know anything else".***

What disabled children and young people say?

Disabled children and young people will need support to participate in EHCP – and those support needs will need to be assessed, for example:

- Suitably qualified and experienced practitioners will need to be part of the pool of IS
- Training will need to be provided in order to sensitively and appropriately support ccildren and young people
- Information and review and evaluation tools will need to be adapted, not only in terms of presentation in a suitable accessible format (e.g., short sentences, easy read or pictorial), but also in terms of concepts that are meaningful and relevant to children and young people (e.g., not asking about activities that they are unable to do), and not making assumptions (e.g., that having lots of friendships is necessarily beneficial or desirable to someone with autism);
- Extra time will need to be built into the role to support participation, which may also need co-operation and co-ordination of parent, carer or trusted adult attendance at sessions
- Arrangement of appropriate transport and/or travel expenses

3.5 Personal Budgets

Everyone with an EHCP will have the right to ask for a Personal Budget for some parts of the plan, if they want one. However, only a small proportion of families are expected to receive personal budgets as they will not be suitable or available to all and will depend on the individual's needs (for example whether the child or young person receive continuing health care or have an existing social care package) and what the school already provides as part of their Local Offer.

So far, the take up of personal budgets by families appears to be quite small. When the SQW conducted their first evaluation of Pathfinders in 2013, their report surmised that this was driven by the complexities of developing a robust process, the challenges of gathering information on the unit costs and a low take up of SEN direct payments by parent carers (Craston et al. 2013). Interestingly, more than half of the families invited to take part in Pathfinder personal budget pilots declined to do so. So what's going on?

When the National Deaf Children's Society asked parents for their views on personal budgets, many supported the option and could identify several potential benefits such as buying in support that matches their child's needs, knowing that the money is being spent on their child and is benefitting them, being in charge of the choice. Other parents, however, were less keen on having the responsibility and could identify a range of potential concerns such as inadequate budgets to cover all the services needed, spending part of the budget on administration like insurance and payroll services, feeling they had enough responsibility without having to deal with budgets and accounts, needing to be a specialist in areas that were not about parenting, not knowing if there would be enough services out there to hire or if they were any good and a lack of independent advice (NDCS 2013).

In theory, personal budgets ought to give disabled young people and families greater control over how money is spent on their support. It puts them more in the driving seat so that they can decide with workers on personalised outcomes. For example, when a school in West Sussex set out to explore the possibilities of using personal SEN budgets with five young people, parents commented that what worked well was being actively listened to by the school with the intent to understand, being frank and honest with the Head teacher and Senco in a respectful way, offering practical sensible suggestions and possible solutions and seeing those solutions put into practice and working well (Angmering QE2 school WSPCF 2011) .

However, self directed support appears to come with some considerable challenges.

In East Sussex, a report reviewing the first phase of the introduction of personal budgets originally with 18 families, concludes five general learning points (Dawes 2013):

1. The resource allocation process needs to be accurate and transparent and link to social care assessments.
2. Support planning is very useful for families and for workers, and the pilot noted that fewer specialist services were chosen by families in favour of recruiting personal assistants to support and take children out.
3. Workforce development was critical to the process and needs the allocation of time and resources including regular and frequent training to engage the work force and keep them on board with this new way of working.
4. Support is needed specifically for children and young people to engage and participate in the process of developing their plans.
5. Guidance and communication needs to be produced and be clear, up to date and able to be understood by both workers and parent carers.

In Brighton and Hove, a small group of 12 parents volunteered to take part in the Independent Budget pilot which set out to test how to deliver personal budgets. The findings include parent carer views and offer some useful insights into the infrastructure, flexibility and transparency needed to make personal budgets effective.

For example, parents said that the Resource Allocation Assessments (RAS) needed to be completed by someone who knew the child, the outcome of the assessments needed to be communicated quickly and that a carer's assessment should happen as part of the process. They also provided feedback on the Support Plan and said there needed to be a blue print for a good plan and that they should have help to complete the plan by someone who knows the child, so that they could think inspirationally and creatively about what they wanted for their child. They wanted more clarification about how much choice they have over the budget and they wanted accurate and transparent information. They suggested that older children should be included in the writing of their support plan and focus on what the child really wanted to do. Their experience of the Independent Budgets was that it definitely gave them more choice and control over short break care rather than fitting their lives into the services available. However they wanted support organisations to help them find Personal Assistants as many ended up recruiting PAs from people they knew and contacts that already existed and they were concerned to avoid transient and sort term contacts. Plus they said they needed good quality support and training on how to manage the budgets, contracts, payroll, employer's responsibilities and to help them feel more confident.

Like other aspects of the SEND reforms, personal budgets need to be properly resourced if they are to encourage and facilitate young people and parent carers to participate in decisions and determine the services and support that affect them. Helping parents and young people to develop the skills to commission services for themselves has been as essential as having a skilled workforce, and some local authorities and their partners have even arranged for joint training programmes to address issues such as safeguarding. In a recent evaluation of Personal Budget Pilots, the experience of the pathfinders has shown that the workforce development and culture change needed to implement the reforms takes time – building a robust resource allocation system, stimulating the provider market and integrating budgets across services to enable a single payment to families are posing challenges (Mott Macdonald 2013).

4 School based support

The most important factor in supporting the best outcomes for pupils with SEN and disability is not the type but the quality of the provision (Lewes et al. 2010).

In some areas, there has been very recent efforts to work with SENCOs and support groups of parents at whose children attend the same school. We are expecting that as Year groups of children and young people transfer from a Statement of SEN to the EHCP process, that there will be far more opportunities to maximise the impact of the IS team by assigning them to school clusters to work with those Year groups, SENCOs and support staff and groups of parents. As in the local examples cited below, these opportunities enable information to be shared at the same time across the group, facilitate sharing wide range of written material about the reforms and approach in the particular schools, and enable Question and Answers sessions that meet most families queries, and signpost further queries to named staff and advisers and helps to dispel myths and miss information. Local Offer advisers or computer points could also be available and a demonstration to the whole group of how to use the Local Offer.

This approach would aid empowering whose who could search their own family needs outside school and free up more time for work with families of children and young people with more complex issues or more significant support needs. As well as being more cost effective, it reaches more people more quickly and this is especially important at the pace of change is rapid and the timeframe very short. This approach also enables families to gain the information at the same time, and could increase a sense of a community problem solving within the schools, rather than families feeling they have to cope alone with all that is involved.

The difficulty in evaluating this work is that it is only months old and so few examples exist and there is very little concrete data to draw on. For this project, we collected two case study examples of where this has been tried. The West Sussex example shows the impact feedback by one SENCO from one parent group meeting facilitated by the parent carer forum. The second example is again written from a SENCO's perspective about how the parent group focus and dialogue has helped the school make a number of adjustments.

Case study 1 (West Sussex)

a) Feedback from SENCO from group held in school facilitated by local parent carer forum

What did you hope to achieve by holding a SEND parent group?

Establish the idea of the group; get parents to spread the word to widen participation; get to know the parents better; hear their perspective on what is working well/ideas for improvements and next steps.

Were there any unexpected outcomes, either positive or negative?

The range of ideas that they came up with for future projects.

What would you do differently if anything?

Try to meet more parents to invite them face to face to increase participation – I didn't manage this as much as I would have liked to.

Was it useful having a West Sussex Parent Carers Forum representative at the meeting and why?

Invaluable – kept conversation flowing so that many different issues were discussed. Lovely manner – engaging, put people at ease. It was good that it didn't seem driven by the school – it changed the dynamic and felt more natural, more like it was the parents' time to talk and share, with the school there to listen and support.

What are your future plans as a result of the initial group meeting?

To look into ways of information sharing for parents; to explore the idea of a parent event to celebrate individuality and promote understanding for all of every child's needs; to put a piece in the school newsletter about the event

How could WSPCF assist or support you in the future?

For a whole school parent event as above, WSPCF may be able to help us find speakers to share their stories.

B) Feedback from parent carer facilitator about school based parent group

- Families wanted accurate legal information, information about the local systems and want to know how to use it for their family.
- However, they also wanted more practical knowledge on how to help themselves and not just more knowledge and information.
- Practical advice and how to use tools that could help their whole family.
- 1/3 requesting information on Understanding Outcomes and using Person Centered Planning Tools.
- We talked openly about no more funding or resources but a change in culture where there are raised aspirations and acknowledgement for parent carers as experts in their own children/ young people.

Case study 2 Brighton & Hove

In Brighton & Hove the focus of one piece of work during the SEND pathfinder pilot was to look at the existing relationship between schools and the parents of children with SEN who attended those schools. There is a case study produced by a SENCO based at a primary school in appendix 7, which formed part of this work.

Seven schools, including five primary, one secondary and one special school, opted to take part in the pilot. We measured the current level of confidence by surveying all the parents of children with SEN at each school and identifying areas where both the school and parents could work together to form more of a partnership which would be mutually beneficial and potentially reduce the level of conflict between the two.

Outcomes from across the schools:

- Six out of the seven schools involved set up parent groups that gave them the opportunity to meet, network and undertake some training together
- The questionnaire indicated aspects where change was needed, and. Many reported different priorities to parents.
- In two of the primary schools, parents of children with SEN transitioning to secondary school met some parents whose children had already settled into the receiving secondary school. The event was considered very successful and resolved some anxieties for parents.
- In one school joint training for parents and staff about speech and language and raising resilient children facilitated greater understanding and consistency of routines for children at home and at school.

5 Transition to adult services

We know from the growing literature in this field that making the transition to adulthood can be an extremely difficult process for disabled young people and their families (refs). It's a time that ought to be full of promise and yet for many disabled young people, it's the most stressful and the most negative period of their lives (Williams 2003, Heslop et al. 2002).

Moving from children's to adult services is a critical time that the SEND Reforms are designed to support. Hence, the Preparing for Adulthood programme (PfA), funded by the Department for Education, has been charged with supporting the introduction of the SEND reforms with a focus on transition to adulthood. Over the last two years, the program team has worked with the Pathfinders to refine and promote the following 5 key elements considered essential to improving life chances for disabled young people:

1. Develop a shared vision of improving life chances with young people, families and all key partners.
2. Raise aspirations for a fulfilling adult life, by sharing clear information about what has already worked for others.
3. Develop a personalised approach to all aspects of support using person centred practices, personal budgets and building communities.
4. Develop post-16 options and support that lead to employment, independent living, good health, friends, relationships and community inclusion.
5. Develop outcome focused multi-agency commissioning strategies that are informed by the voice of young people and families. (PfA 2012)

Whilst rightfully optimistic, these aspirations need to be understood in the context of the challenges consistently reported by young people and families, to fully appreciate the task ahead for the IS service. The evidence provides a clear picture of the experiences and challenges encountered when transferring from one service system to another (children's to adult services). And there are umpteen documented accounts of the barriers and hurdles encountered when adopting a lifespan perspective that takes into account the ordinary things that young people want and should expect, like work related opportunities, education, ongoing learning, daily living support, friends, socialisation and community connections (refs www.valuingpeople.gov.uk).

The IS workforce will need to go the extra mile if interested in assisting young people and families to navigate the terrain of changing or disappearing services, diminished support, tightly defined and frequently excluding service criteria, new personnel, weaker entitlements to support and curbed opportunities. Providing information and simply pointing young people and their parent carers in the right direction won't cut the mustard because most young people and their parent carers will have little idea of what they up against.

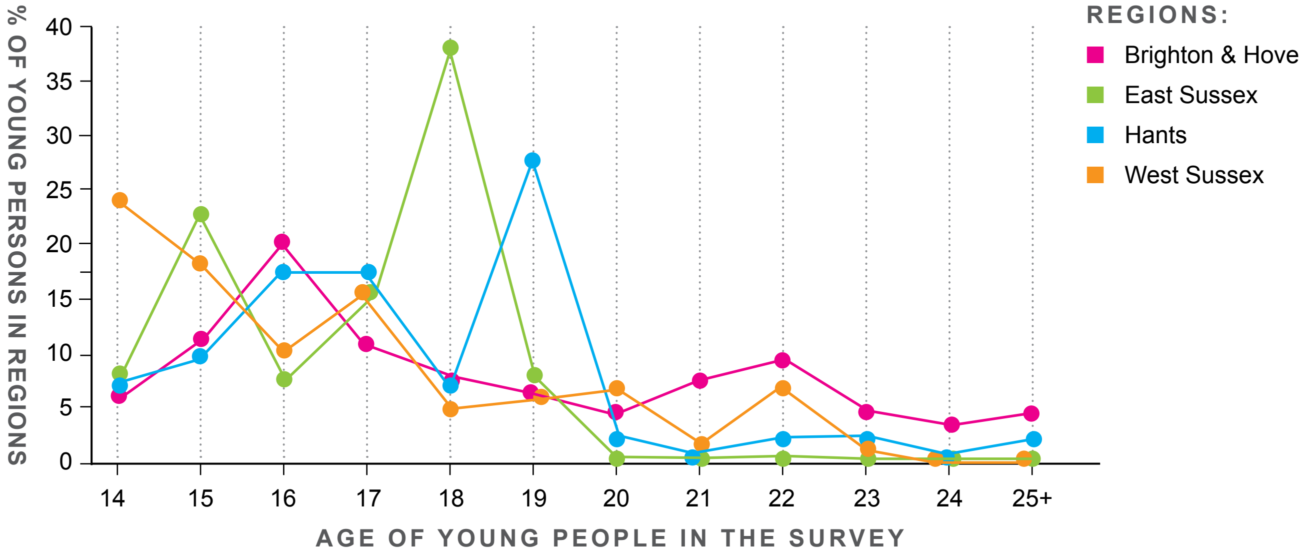
This is a crucial time for parent carers. Accessing information and advocating on behalf of their children comes at a time when many are exhausted from the persistent and draining parenting challenges they been managing so far (Moen et al. 2001, Seltzer et al. 2004) and facing the future with their children can feel overwhelmingly worrying.

The SEND reforms include the expectation that disabled children and young people are provided with information and support. When the Council for Disabled Children (CDC) carried out and commissioned 19 focus groups with disabled young people aged 5-25 years, across England, about the new Code of Practice, they highlighted their need for information at this time of their lives. They wanted the information to include:

- Education and career options, with clear explanations of what support they would be page 21 entitled to
- Information about benefits and funding, and where to access help to explain and complete forms
- Moving to adult health services: what will change and how can disruption to their treatments be minimalised
- Transport entitlements
- How will their social care needs be met under adult services
- How to develop independent living skills
- Information of their rights and access to advocates

Regional Transition Survey with 244 families represented

We were able to adapt a transition survey regarding young people aged 14 years plus that had just been compiled by a multidisciplinary group, including parents, in Brighton and Hove and use survey monkey and make this accessible to families across the region. In all, 244 respondents completed the survey despite the tight timescales and the results are shown in Appendix 5. During the three weeks the survey was available, 111 responses were from Brighton & Hove, 13 from East Sussex, 29 from Hampshire and 91 from West Sussex. Between 80% and 93% of the young people have a current Statement of Educational Need. For most of the issues the distribution of answers were broadly similar despite the wide range in sample size in each area. The table below shows the age distribution across the region.



Between 31% and 59 % of parents did not know about the Special Education needs planning process for preparing for a young person's future. Where some planning happened, parents were involved to a varied degree but young people always far less so. A key finding is the proportion of older young people living at home where the young person remains living with the family (see the table below), and the current poor experiences around information in general, but especially the relevant Post 16 reforms.

Only between 8% and 24% of these parents had had a Carers Assessment, and in one area 13% did not know if they had had such an assessment. The feedback about how useful different services are showed a range of experiences. The results illustrate the family based nature of these young peoples' lives and the involvement of parents. The fuller analysis of these results will be available after this report has to be submitted.

Where is your young person living now?

	Brighton & Hove	East Sussex	Hants	West Sussex
Still at home with family	81%	100%	83%	87%
In their own home/flat	1%	0%	0%	3%
In supported housing	8%	0%	0%	4.5%
In residential care	7%	0%	7%	2%
Other	3%	0%	10%	8%

Local example

Focus group with parents of young people aged 19 +

This focus group of only 4 parents provided invaluable qualitative family insights and examples to enrich the quantitative data. Parents described what has worked well for them but also gave examples of what had not worked for their very disabled young people.

What parents said about what works or does not work

Parent 1: *"I had a really good Transition Worker to start with from the Adult Social Care team. He sorted out good quality respite/short break provision for our daughter. He really followed things through and made a case for us to get this expensive provision. Unfortunately he left."*

Parent 3: *"I was signposted to short breaks by Social Care and he got a Personalised Budget to meet his assessed needs…*

More recently we've had really good support from Adult Social Care when my son had a mental health crisis. They acted respectfully and quickly. Without that intervention my son might have died. They found an appropriate, high quality provision. The transition from the therapeutic environment to his supported living arrangement has been excellent. We've been fully involved in this and so has my son. The Transition Social Worker was brilliant. She always did what she said she would. She's always been respectful of my son and communicated with everyone. She has found very innovative provision for him that really meets his needs."

About providing information for professionals

Parent 1: *"The number of meetings you have to attend, repeating the same thing over and over again. It takes a huge effort providing information to professionals and it begins to feel pointless. If the information provided doesn't lead anywhere, result in something positive happening, if it's not looked at properly or used. You feel 'what's the point'?"*

About post 19 provision

Parent 2: *"When I first asked about post 19 education options, she denied knowing about the local independent specialist college. No-one at the FE mainstream college could help. When I asked the Transition Worker about the local Independent Specialist provision that I happened to know about, she sucked in her breath and said 'that would be complicated', like 'you're not going to get that' I was told it was 'virtually impossible'. I feel there was no transparency. I was in tears afterwards, I was livid. I think there's a wall of denial or the information isn't forthcoming."*

A BME parent reported

"I didn't want to explain the weakest aspects of my son's needs. I didn't understand what the assessment process meant. So at first I didn't get the support I needed.

No-one told me about Personal Budgets… They didn't explain why they weren't giving it to us. They keep you in the dark. It was a really bad, horrible experience. I think because I'm not from this country they don't take me seriously."

Conclusion from this small group was that the Independent Supporter role would need to

- have a dedicated Transition Worker who draws up a plan, not just about education but about all aspects of young person's life.
- More transparency and an impartial approach.
- Clear information about eligibility criteria.

Their feelings were encapsulated by this parent's comments:

"Having someone to support us and our son with a proper planned transition after college. We worry he'll just end up sitting in his room all day. You need to know that there are 'gates', where they are and how to get through them to access support."

There is a hope that the SEND reforms will offer models that work and help to produce outcomes that matter. As transition from children's to adults' services too frequently causes disruption and stress, and results in unmet needs, appropriate transition arrangements should be a priority for all services (CMO 2013). Only time will tell whether or not EHCPs and arrangements for transition to adulthood will be sufficiently resourced to meet the needs of the many young disabled people who wish to live outside of the family home, especially when finding affordable and accessible housing is difficult and it is even more complex when the young person has significant daily living needs and few if any employment opportunities. Lack of services and good enough support could hold families back from promoting independence and may well hold young disabled people back from aspiring for the same. There can also be a tension between the contentedness for young people to be at home with parents managing closely managing daily life, and as outlined in the Beresford study (2013), parental unhappiness with scenario and wanting more help to develop the young person's independence. Failing to shape the system to meet the needs of disabled people leaves families carrying the burden of care and young people dependent on them for that care. While some might argue that this reduces the budget needed for services, the cost to disabled people, their families and to society are unacceptable and contrary to human rights legislation.

6 Comment on similarities and differences

A key issue is recognising and addressing needs of both parent carers and young people, within a family context. Just as Michael Rutter's resilience work shows, both parties impact the lives of the other, and support for each makes a difference for each party, and therefore contributes to the whole family. Sometimes, the interests and wishes of disabled young people may not be the same as those of their families and carers. But neither is more or less important than the other – disabled people need to be heard separately and just as loudly as those of their parent carers and families.

Similarities

Golden gateway opportunity that empowers parents and young people

Parents are asking for empathic personable help that assists them to be actively involved in decision making, offers options and choices and signposts to practical help. We note that the initial contacts parents have with supporters who ever they are, these early encounters can be golden gateways to other resources, and support. The IS programme is especially well placed to be a gateway as long as the workers are well linked into and knowledgeable about local resources and experienced enough to build parental and young peoples' skills and knowledge rather than reinforcing dependency.

We also offer evidence that when parent carers are helped to develop their skills and confidence this can positively impact other areas of the life, and build their resilience. Skills based courses like Insiders' Guide can be especially powerful in helping parent carers process what has happened to them and in equipping them for the next chapter of being parent cares. Face to Face and a few other courses are available but not widely across the region.

Lack of support and alternatives to living at home, relying on parental input

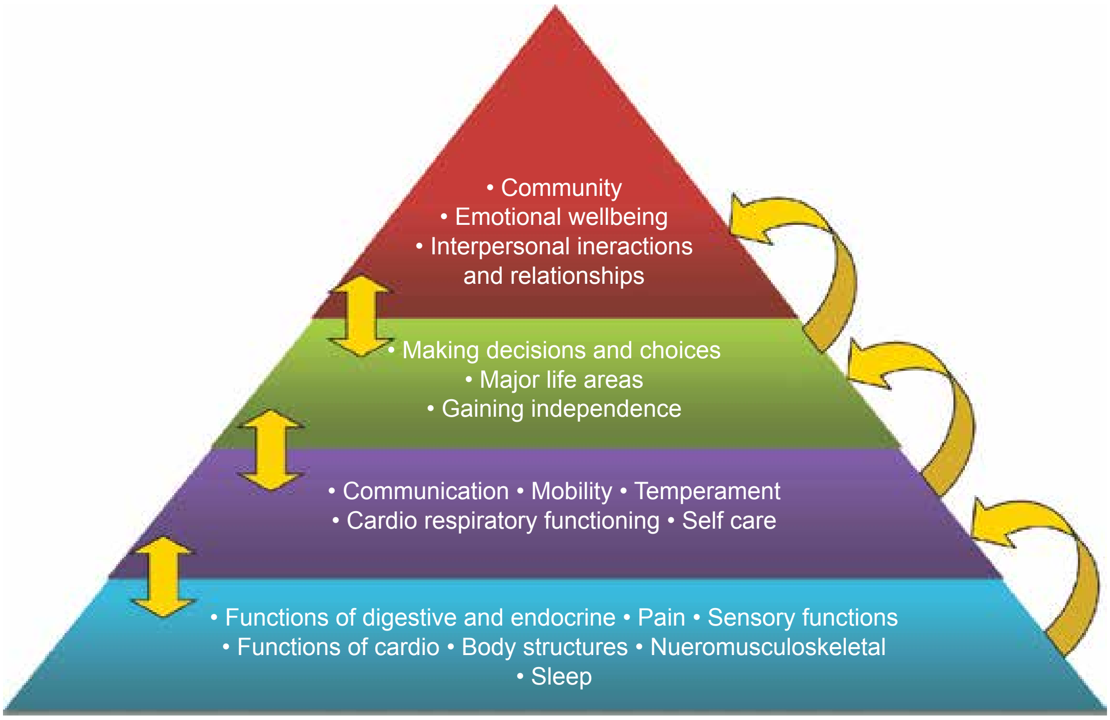
A recurrent theme emerging in the Beresford study (2013) was that parents appeared to be very much involved in supporting their son or daughters lives, and yet struggled with knowing how best to support and maximise their son or daughter's independent living skills. The accounts from the young people interviewed in this study suggest the high levels of parental involvement in their lives were not, typically, unwanted. However, this was not a role parents usually wanted to assume but happening in the absence of effective support and other safe accommodation options. Parental anxiety is likely to have been raised in out of home accommodation and group living by the shocking abuses documented in the Winterbourne Enquiry and shown frequently on television. So the combined development of support for both parents and young people to maximise daily living skills in addition to investing in safe supportive housing options may meet both parental and young people's needs.

In addition there is currently, once school ends, a lack of opportunities for meaningful daytime occupation and suitable social options so that these young people can continue to learn new skills, mix with peers and the wider community , and have fulfilling lives. Part of the task needs to be to develop these opportunities so that the young people can make choices where today there seem to be none for them or their parents.

Differences

The IS service might also wish to consider the appropriate language to use and this might be different for parent carers and for young people. A survey of families carried out in 2001 (Grewal et al. 2002) which defined the disabled population as being those covered by the Disability Discrimination Act asked these people if they saw themselves as 'disabled'. They found that only 48% actually considered themselves disabled and younger people (aged 16-44 years) were less likely than older people to see themselves as disabled.

In work by a team exploring the connectedness of health outcomes, there was evidence both of similarities and differences in what parent carers and young people sought. The tables below show their findings where there is a sense of building on basic priorities at the base of the pyramid, like Maslows (REF) Hierarchy of Needs, with more aspirational outcomes at the apex.



.Figure 1. Illustrative hierarchy of inter-relationships between aspects of health as perceived by children/young people.

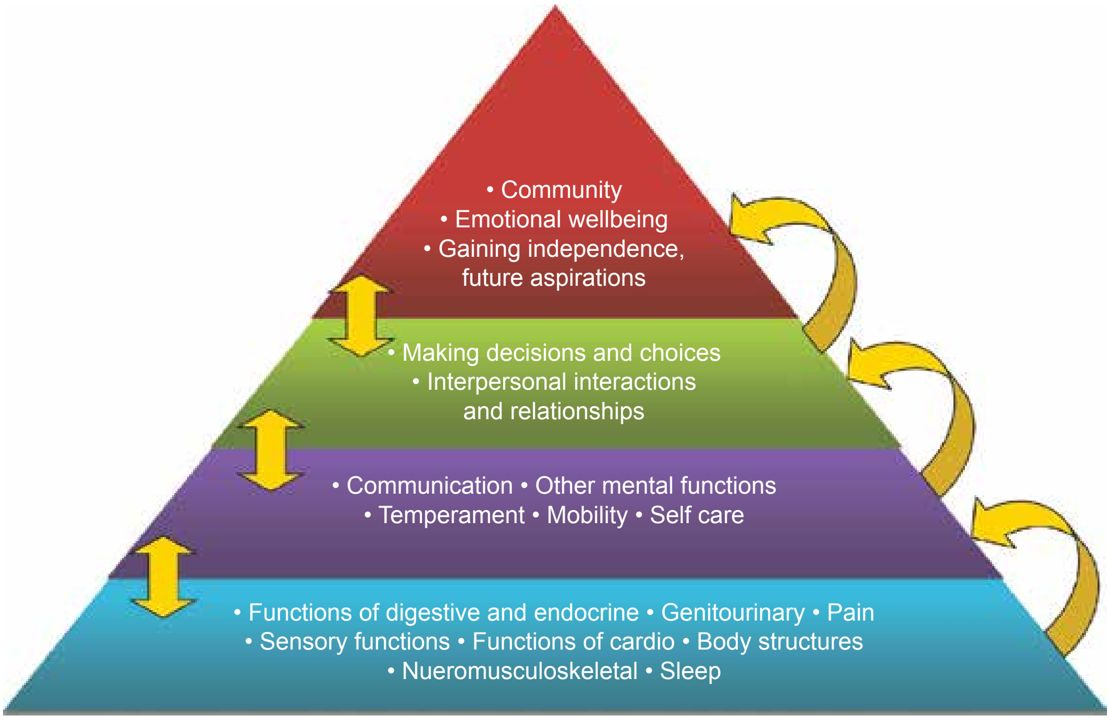


Figure 2. Illustrative hierarchy of inter-relationships between aspects of health as perceived by parents.

These two figures show similarities and differences, but also the interdependencies between the outcomes and further research would be useful to explore these further.

Parents, as shown in 2.1, are asking for empathic personable help that assists them to be involved in decision making, offers options and choices and signposts to practical help. Children and young people with additional needs are asking for information that helps them to know their options and supports them with the barriers to social inclusion.

7 Recommendations

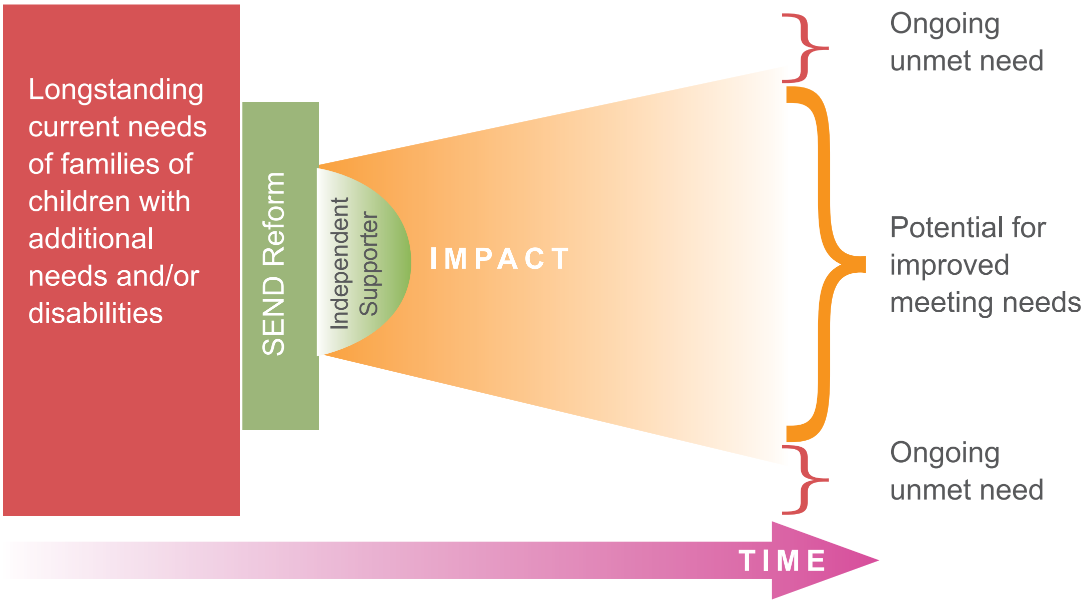
7.1 Recognising and tackling unmet need

The research evidence tells us that there remains significant areas of unmet need which the IS programme may not reach. The evidence suggests these include;

- Workforce development across sectors that makes co-production 'business as usual', and understanding the evidence base about families of children with additional needs
- Workforce development (including parent carers) that specifically focusses on understanding outcomes and effective outcomes planning. To move away from the need to fight for provision instead of the right outcomes and appropriate support to meet the outcomes
- Improving transition to adult services
- Investing in local meaningful occupation options, supported housing and social participation opportunities that enable young adults and make having a choice a reality for them and their families in the longer term.
- Helping parents support and promote the independent learning skills of children and young people
- Investing in therapeutic parental support that builds resilience and family opportunities for an ordinary life.

We recognise that much more work is needed to reach and respond to seldom heard communities. However we do believe that meaningful independent support is possible and where the design (see model opposite) includes the elements discussed in the next section, there could be extended reach so that more needs are resolved than just the 20 week EHCP process.

Model: Enhanced IS version with greater potential impact on families



7.2 About the IS programme

In order to shape a regional response we held an additional regional meeting including colleagues from across SE7. A separate report from the event is in Appendix 5. The recommendations are discussed in the following Report C.

What does the evidence tell us?

Themes within the national, regional and local evidence have been repetitive and consistent across local areas, families, service types and across the decades. For most children and young people and families there is not enough support and provision to assist them to have ordinary lives. How support is offered can often be as important as what is offered and can actively promote independence, confidence and resilience. However, if there are no services or few choices and options, then it doesn't really matter how they are offered! Parents say it is really hard to find good provision, the right Personal Assistants and current services are being shrunk by local authorities. The evidence from the regional workshop highlights many of the values and recommendations already stated in this report, and where the higher skill level and local expertise of the IS team are priorities for families and workers.

So having services operating there that can be accessed despite pressures to ration even further is the priority. Assuming relevant services exist, we see that it's not what you do but how you do it that then makes a difference – does the support grow or diminish dependency, confidence or resilience?

Our recommendations are in five areas; what children and young people say matters, what parent say works, family focussed information, advice and support, outcomes and effective strategies and resources to achieve them, and building a legacy of resilience.

Recommendations *continued*

1. Children and young people have said what matters is:

- Communicating with them about their wishes and feelings
- Communicating their rights and choices to them
- Supporting children and young people to join in and feel included
- Supporting children and young people with their futures and independence
- Being treated the same as other children and young people.
- Sharing information in small chunks and going at my pace

2. Parent carers have said that what works is:

- **Information and advice:** that tells it how it is rather than how it ought to be
- **With me – not about or for me:** because it's our lives, and we know something about what helps
- **Co-ordinated support:** is always important especially at transition times
- **Choice and range:** because we need different things at different times and some of us need more
- **The way support is given:** can be as important as what is given
- **Meeting other parents:** in the same situation can reduce isolation and provide us with the best source of tips
- **Champion our corner:** because getting the right support and promoting inclusive communities would turn our lives around

3. Family focussed information, advice and support

Yet the above are not just two sectors to be accommodated separately. The vast majority of children and young people with additional needs and/or disabilities grow up in a family context, and outcomes for both the child/young person and their family are influenced by a wide range of internal and external factors, including the support they are able to access. So a family based focus is essential, in additional to meeting the needs and wishes of individual members.

There remains strong evidence that information and advice about different aspects of the reforms is still sparse and not reaching families, even those engaged in the processes. This information needs to include legal rights and processes, as well as some skills training and support so that families are better able to express their needs and negotiate appropriate support in daily situations into the medium and longer term. At present we know from the SE7 pathfinder that working co-productively enables families to valued, informed and part of the solution.

4. Outcomes and effective strategies and resources to achieve them

Investment in appropriate social participation opportunities, occupation and housing options for young adults is essential offering choice, and to achieving independent supported living that is not parent dependent. However it is too early to have an evaluation about whether the outcomes were achieved and what difference the new processes made.

What we **can** say is that it is that the Children and Families Act 2014 states that the needs, wishes and aspirations of both children and their families should shape services at national, regional and a local services (CMO 2013). Together with other legal measures in health and social care it means that all services for children with additional needs and/or disabilities should be underpinned by legal rights and aim to maximise their health, wellbeing and life chances. Therefore to achieve the outcomes we seek, services should promote opportunities for social participation, lifelong learning, and the chance to lead an ordinary life.

5. Building a legacy of resilience

The IS service is a short term programme which could, as seen in Report A, be deployed in a way that enhances independence, builds confidence and grows resilience through the encouragement and promotion of new skills and opportunities. The evidence shows that building resilience is about the set up around the child and young person, around the family, not just an internal process responding to adversity. The challenge is shared by all of us, young people, parents, workers and the wider community too.

It is just as much about the way an individual's social environment or ecology opens new opportunities to overcome problems, or helps them to avoid exposure to risk in the first place. Our assumptions of vulnerability and frailty overlook what individuals are capable of achieving when the people and institutions in their lives (their social ecologies) provide them with opportunities to excel' (Cyrulnik, 2011).

Tangible outcomes include increased household income, a new volunteering opportunity, a job even, or support with independent living skills. Herein lies the hope – that the nudge comes in the form of top quality information and support from an Independent Supporter so that practical and tangible outcomes happen.

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Appendix 1

Table 1. Percentage of children and young people with specific neurodevelopmental impairments, conditions or needs

Impairment/condition	Disabled children %
Any neurodevelopmental disorder[2]	3.0–4.0
ADHD:[17]	
DSM IV	3.0–9.0
ICD10	1.0–2.0
Cerebral palsy[18]	0.2
Epilepsy[19]	0.3
Autism:	
All children[3]	1.0
School-aged children[20]	0.9
Specific learning difficulties[20]	1.0
Moderate learning difficulties[20]	2.0
Severe learning difficulties[20]	0.4
Profound learning difficulties[20]	0.1
Speech, language and communication needs[20]	1.7
Hearing impairment[20]	0.2
Visual impairment[20]	0.1
Multi-sensory impairment[20]	0.01
Physical disability[20]	0.4
Other (unspecified)[20]	0.4

In addition to information on children's impairments and conditions, information on functional difficulties is also important. **The most commonly reported functional difficulties are with memory/concentration/learning, communication, mobility and physical co-ordination** (see Table 2).

Table 2. Functional impairments experienced by disabled children and young people aged 0–18 years

Functional impairment type	All disabled children %	Boys %	Girls %
Mobility	18	17	20
Lifting, carrying	8	7	9
Manual dexterity	10 1	1	8
Continence	12	12	12
Communication	22	25	19
Memory/ concentration/ learning	24	29	17
Recognising when in danger	18	22	13
Physical coordination	15	17	12
Other	28	29	27

Source: Family Resources Survey 2010/11

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Appendix 2

Case studies about families experience of the existing system

1. Summary

- Fighting for Services – lack of working together – lack of emotional understanding or support (21 years old – diagnosed with Down Syndrome and ASD. Attended mainstream school, special school from age 8, and now at college. Living in accommodation with other adults with learning disabilities – 24 hours support)
- Information is hidden – parents find things out by speaking to other parents
- Struggled to find information and support over the years. Professionals not open and forthcoming with options and information and seemed to take opposing positions rather than a partnership approach.
- Lack of (or badly delivered) information at key points (birth, diagnosis, school transitions) led to parent feeling unsupported meaning increased stress.
- Generally good early years support but poor advice and information on school choice led to the child being incorrectly placed for a year. Some frustration with waiting times and lack of info in some areas.

2. What information and advice or support so far

- Booklet on Down Syndrome from the hospital at birth, Telephone conversation with consultant about heart surgery, Red book about normal developmental milestones, signposting to continence service, OT advice re housing, signposted to overnight respite unit, told no social workers available to assess
- 14 years old – diagnosis of quadriplegic athetoid cerebral palsy. Non-verbal and requires support with all daily living tasks. Lives with parents and younger and older siblings
- Information at birth about potential issues, diagnosis at 10 months – information patchy. Key information, advice and support in early years came from a US online parent support group, limited information about statementing process, little information about school choices at start and on transition to secondary.
- Support and signposting from Health Visitor. Diagnosis from paediatrician when aged 3, with a pack given about autism. Advice and information about school choice from educational psychologist. Hearing assessment. Information on continence supplies/services.

3. What went well

- Telephone call from consultant in London about oesophagus and trachea surgery. Happy that consultant took the time (1 hour) to explain fully and answer questions.
- Signposting to continence service at the appropriate time – parent wouldn't have known to ask
- Information from OT on housing issues was useful
- Social worker visited possible residential settings with parent – happy the SW was trying to help
- Excellent support and information from online support group (from other parents) about potential drugs and therapies. Good information from pre-school and school about what child had been working on and how his day had been (particularly important as non verbal). Second social work assessment and information on direct payments was very useful.

- Excellent support and information from Health Visitor. Good information from Portage about the service and eligibility on referral, then clear information about waiting times after assessment. Private hearing assessment – excellent information about what would happen etc, and clear information given at appointment. Clear information and explanation on diagnosis when child was 3 – pack of information was useful but poorly photocopied. Information given about DLA. Leaflet about statementing in preparation for school – appreciated a printed copy. Transition session for mainstream infants was well attended by everyone involved with the child.

4. What did not go well

- Diagnosis was badly communicated at birth – parent was given a booklet and left alone – felt upset and afraid as the baby had significant health issues.
- Felt unprepared about what to expect when she visited the baby in hospital after surgery
- Felt really upset when given the “red book” giving all the milestones her child wouldn’t achieve – unhelpful and insensitive
- Border issues over supply of home oxygen – all professionals involved said it wasn’t their responsibility – parent had to rent privately
- Information at birth was overwhelming. All verbal, after a difficult birth could not take it in. Left hospital believing child would be OK. No indication, even during follow up and subsequent testing, about potential disability, so diagnosis at 10 mths came as a huge shock. Diagnosis by telephone call and follow up letter enclosing details of scope and a list of services being referred to but no information about what the different therapies did. Child received therapies but no information on how he was benefitting or progressing. Didn’t appreciate the importance of statementing – parent actually told it wasn’t important – didn’t feel involved in the process. Went to tribunal over secondary school because options weren’t given or explained. Found the process stressful and intimidating. First social work assessment was poorly done – didn’t feel listened to.
- NHS hearing assessment had to be done to “tick a box” even though private one already done. Given incorrect information about the location of the clinic. Educational Psychologist interview meant we had to repeat our story. Also gave poor advice and information on choice of school and no-one was subsequently available to answer questions. Not told about Parent Partnership when applying for statement or when having a difficult time in mainstream school. Lack of information about continence supplies available – everything done over the phone.

5. Ideas to improve things in the future

- More delicacy and warning when delivering initial diagnosis at birth.
- To have been better prepared about seeing the baby after surgery.
- To be able to make informed choices about schooling not being presented with what would happen.
- To receive emotional as well as practical support.
- To have had access to a social worker when requested, without having to threaten legal action.
- To have been more involved in decisions over adult services.
- To have been informed earlier about banking/court of protection.
- Professionals being open and honest.
- Written information in the early days.
- A partnership approach rather than gatekeeping resources.
- Accurate information about hearing assessment and info on what to expect. Someone to go through the statementing forms with (or to have been told about Parent Partnership). Better information, prospectuses etc on school choices. Continence services – an online flow chart and a service level agreement.

Appendix 3

Parent carer cameos

What parents said independently about their experience of Education Health and Care Planning process so far…

1. Summary of experience

- There seems to be a lot of advice out there, but you get a slightly different slant depending where it comes from.
- I went to the events run by the parent forum and they were very useful, where I was given a leaflet and some other flyers, but I haven't been given any other advice or support. I am hoping that there will be some more events this term, because I still don't understand what I should be doing for my son.
- As a family we need information to help us plan and make decisions and although the school has been trying to help us they don't seem to understand what we need to be doing either!(ES1)
- I am still going through the process for an EHCP. The school & the EP have been a great support & have engaged with us throughout. They started the ball rolling & have completed the relevant forms from there end. So far, the process has been good one. I haven't had to obtain the information for myself or chase up anyone.
- Did not get signposted, sometimes felt information was not clear. We had a caseworker who came to our house and nursery to fill in the EHCP.
- We are a family of 4, my son has a younger sibling, who encourages his older brother to play along with other children.
- Initially paediatrician. Then XX (EP who was assigned caseworker). SALT and Theraplay were able to give us advice
- My son is 15 and in a special school and wants to go to college next year. I have two other children who don't have special needs and spending all my time worrying about my son is affecting my younger children too.
- My son is 18 and has one year left at school. We have had very little advice about the reforms. I do know that he will have a new plan, but I don't know what that means and my main concern is that there is actually somewhere for my son to go.

2. What information advice and support have we experienced (where possible, related to the new reforms (Education Health Care Plans, Local Offer, personal budget)

- Reforms events and leaflet from a Parent group, and I also went to a legal information day.
- I believe there should have been some support with completing the form. For me, it was more about confirmation that the examples I was providing was sufficient. I did e-mail my form to the parent group for them to give it the once over. A couple of days later I received a telephone call from one of the parent group to advise me about my form as I wasn't quite sure what to put in the final box. It was nice to actually speak to someone. That support would have been nice prior to completing the form, so that I would have felt happy to seek the support earlier on rather than worrying myself

- ESCC also send out newsletters, but they are not very frequent.
- I have been trying to find out, but just get told not to worry, there's plenty of time. There seems to be a bit of buck passing going on between adult and children's services.
- I know nothing about a local offer, but I'm guessing it might be something to do with what's available locally. Is that what will tell me what's available for my son?
- The plan will be instead of a statement, so I'm assuming it does the same thing, and I know we are starting it but I haven't been asked to do anything about it.
- Personal Budget was mentioned but my caseworker did not have a great deal of knowledge. Outside support was mentioned (ie. Leapfrog, Short Breaks). Local Offer was not mentioned.
- No knowledge of PB/Local Offer. Not really been told how the new reforms will affect us except that all the professionals helping us will be stopping as we go into the school system.
- The girls both have an EHCP and have also been part of the pilot to trial social care Personal Budgets.
- Information, advice and support to complete the EHCP came from the school (Both girls had their plans initiated when they were still at special schools before going to college). A member of staff from the school who knew the girls well came to visit the family at home to start this process. The process was explained and they were given an understanding of the new plan. The Social care pilot was supported by the girls' social worker who also knew them well.

3. What's been good for you / worked really well?

- For us as a family having a personal budget has worked really well. We were part of the pilot, and everyone worked together to meet our needs. It's made a huge difference to us as a family.
- School has worked really well. They did some info sessions about transition and invited people from adult services. At school everyone works together so I hope this will continue into adults.
- The reports that have been put together have made it clear what sort of support our son needed. The Team Around the Child meeting was excellent. Very positive, very good for my sons transition. Clear and focused on what was going to happen.
- That all professionals work from the same paperwork. They meet each other at the meetings and can discuss together how to progress my son. Our caseworker supported our older child's application to secondary school (out of area).
- Very happy (and visibly proud) of EHCP and all assessment reporting that went into drawing it up. Very good relationship with all professionals involved with their child including the Planning Co-ordinator who was very supportive. Felt it captured their child, reading it gave a good sound description of what worked well, what was important to and important for them.
- Happy to hear about Independent Supporters. Early Support worker was invaluable and they could see the value more people to carry out this role.
- The Educational Psychologist informed me that there was a new process & that the parents had more involvement with it. I was a little concerned at this stage as I am not an expert, but at least I would be able to put forward our thoughts what for our child to obtain an EHCP.

- Ordinary Lives Project (West Sussex)The project booklet is most useful and learning from WSx families features heavily (as well as all the photographs which is nice! Mums are so proud of their children so that small recognition is fantastic) There are also lots of associated papers free to download. http://www.learningdisabilities.org.uk/our-work/changing-service-delivery/an-ordinary-life/ The booklet highlights some amazing ideas all grounded in a person/family centred approaches and using very solution focused tools to help move forward (sometimes in small steps).
- The home visits gave the schools staff the opportunity to see the girls in a different context where they behaved very differently to how they behaved at school.
- We both felt very involved while writing the plan and that their opinions mattered. We felt respected and listened to.
- The plan was much more outcome focused and had a positive outlook on the girls' difficulties. We felt it was forward looking.

4 What's not gone well for you?

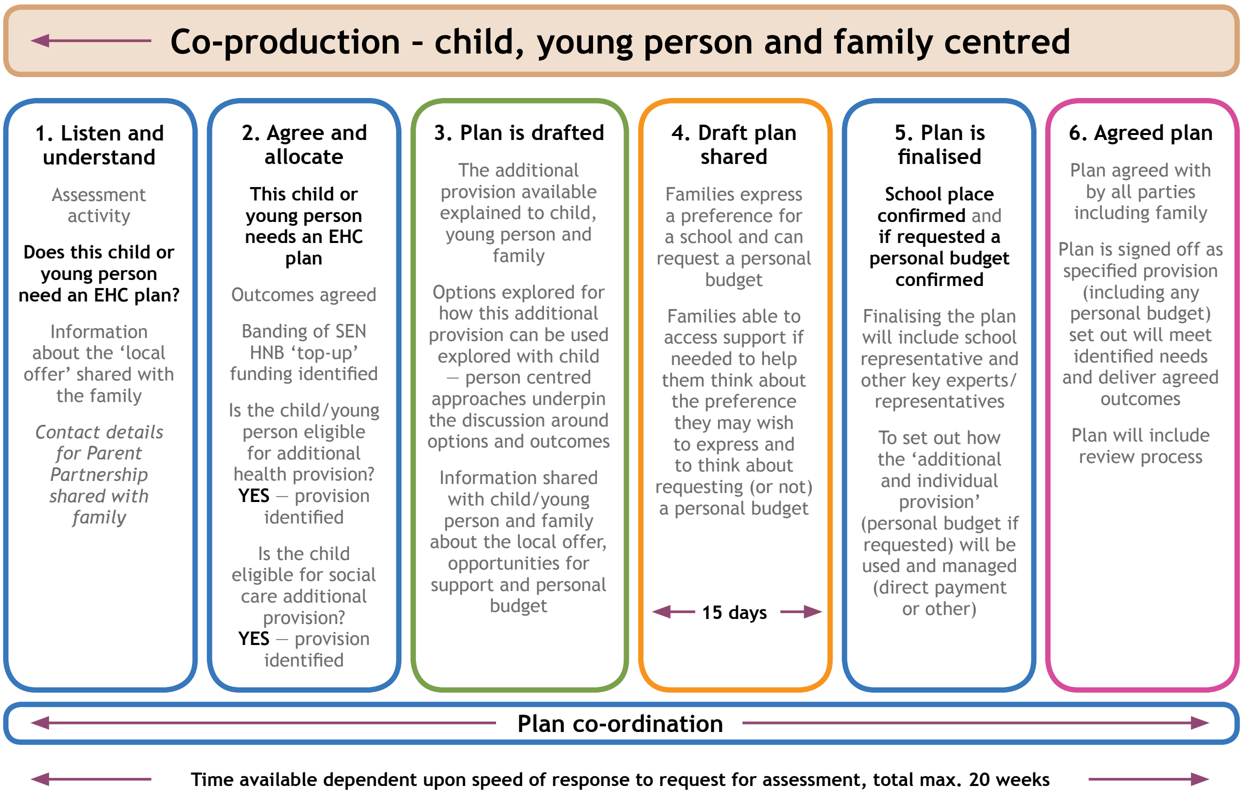
- Parent did not feel that the Outcomes where very clearly defined. Not clear WHO and HOW Outcomes would be reached and supported. Felt confident because a Special School Placement had been secured but if child was going to mainstream setting then they would not be confident how and by whom the Outcomes would be met.
- Did not know about Personal Budgets and their entitlement to one.
- (Age 15)We are only just starting to do our EHCP but school really don't seem to know what they should be doing with it
- When people argue over who should be doing what and I don't know what is correct.
- When the 'Our Story' form came through I felt a lot pressure to get it right, even though the pamphlet on how to complete the form was very good.
- We're not really given any information. We know that something will be different and we've heard about our plan but I don't know anything else.
- Someone to help me understand what I am meant to be doing. It's all very well to be told it will all be ok, but how do I know that if I don't know what should be happening. I could do with a personal adviser at the moment!
- Not been told about 'Inclusion Funding'. Early on. Being told at panel meeting a decision was going to be made and was not. Having to push for help all the time.
- Professionals persistently not doing what they agreed to at TAC meetings. Professionals not turning up at meetings. Professionals not talking to each other in between meetings. Unhelpful people/unsuitable people coming to meetings. Having to push for what we want more than we felt we should have to.

- Although the girls were taking part in both plans there was no communication between the school and the social care team. Much of the information was very similar in both plans and they felt that if the two had been pulled together then it would have given a much more holistic view of the girls' needs.
- The annual review to review the plan had not happened at the time of speaking and dad felt that the plan was becoming out of date as the girls has since then transferred to college.
- Health professionals did not really contribute to the plan.

4. What would have helped to make this better?

- (FH) Someone to help us who could work with all the people that we need to be involved with our plan. Somewhere we could easily find out information which was easy to understand, and somewhere we could find out our rights.
- I'm quite happy to look for information myself, but it can be difficult to find. Everything in one place or held by one person like a keyworker would make things easier for us.
- A clear step by step guide to what the process was. From the very start of the process.
- Caseworker took original notes from our 1st nursery where we only attended 6-8 weeks. They would not come and see our child at his new 'special needs' nursery which would have given her a better picture. Having more contact with caseworker in between TAC meetings.
- It would have been really helpful if all the professionals could have communicated throughout the process and pulled both plans together.

Appendix 4



Co-production - child, young person and family centred

1. Listen and understand

Assessment activity

Does this child or young person need an EHC plan?

Information about the 'local offer' shared with the family

Contact details for Parent Partnership shared with family

2. Agree and allocate

This child or young person needs an EHC plan

Outcomes agreed

Banding of SEN HNB 'top-up' funding identified

Is the child/young person eligible for additional health provision? **YES** – provision identified

Is the child eligible for social care additional provision? **YES** – provision identified

3. Plan is drafted

The additional provision available explained to child, young person and family

Options explored for how this additional provision can be used explored with child – person centred approaches underpin the discussion around options and outcomes

Information shared with child/young person and family about the local offer, opportunities for support and personal budget

4. Draft plan shared

Families express a preference for a school and can request a personal budget

Families able to access support if needed to help them think about the preference they may wish to express and to think about requesting (or not) a personal budget

15 days

5. Plan is finalised

School place confirmed and **if requested a personal budget confirmed**

Finalising the plan will include school representative and other key experts/ representatives

To set out how the 'additional and individual provision' (personal budget if requested) will be used and managed (direct payment or other)

6. Agreed plan

Plan agreed with by all parties including family

Plan is signed off as specified provision (including any personal budget) set out will meet identified needs and deliver agreed outcomes

Plan will include review process

Plan co-ordination

Time available dependent upon speed of response to request for assessment, total max. 20 weeks

From agreement to offer of an EHC plan to agreement of the plan

14 Developed by InControl, Preparation for Adulthood (DfE SEND Support programme) with SEND Pathfinders (July 2013)

Appendix 5

Regional Transition Survey Results

Tina Brownsbill, Amaze

	Brighton	East Sussex	Hants	West Sussex
Total number of surveys received for parents of young people aged 14+	111	13	29	91
How old is your young person now?				
14 years	6.3%	7.7%	6.9%	24.2%
15 years	12.6%	23.1%	10.3%	17.6%
16 years	19.8%	7.7%	17.2%	11.0%
17 years	11.7%	15.4%	17.2%	16.5%
18 years	7.2%	38.5%	6.9%	4.4%
19 years	6.3%	7.7%	27.6%	6.6%
20 years	5.4%	0.0%	3.4%	7.7%
21 years	7.2%	0.0%	0.0%	2.2%
22 years	9.0%	0.0%	3.4%	7.7%
23 years	5.4%	0.0%	3.4%	2.2%
24 years	3.6%	0.0%	0.0%	0.0%
25 years +	4.5%	0.0%	3.4%	0.0%
Didn't answer	0.9%	0.0%	0.0%	0.0%
Does/did your young person have a Statement of Educational Needs?				
Yes	82.0%	92.3%	86.2%	76.9%
No	16.2%	7.7%	13.8%	20.9%
Don't know	1.8%	0.0%	0.0%	1.1%
Didn't answer	0.0%	0.0%	0.0%	1.1%
Is/was your young person on School Action?				
Yes	7.2%	7.7%	10.3%	13.2%
No	49.5%	61.5%	51.7%	40.7%
Don't know	28.8%	23.1%	27.6%	34.1%
Didn't answer	14.4%	7.7%	10.3%	12.1%
Is/was your young person on School Action Plus?				
Yes	13.5%	15.4%	10.3%	22.0%
No	42.3%	53.8%	44.8%	35.2%
Don't know	28.8%	23.1%	24.1%	37.4%
Didn't answer	15.3%	7.7%	20.7%	5.5%
What is your young person's main area of need?				
Learning disability	38.7%	53.8%	51.7%	47.3%
Physical disability	7.2%	23.1%	17.2%	13.2%
Sensory disability	11.7%	0.0%	3.4%	2.2%
Autistic spectrum condition	33.3%	7.7%	27.6%	36.3%
Behavioural or emotional difficulty/mental health difficulty	15.3%	15.4%	13.8%	25.3%
Other condition	4.5%	7.7%	31.0%	3.3%
Didn't answer	9.0%	0.0%	0.0%	12.1%

Regional Transition Survey Results continued

What is your young person doing now? (in areas other than Brighton parents could choose more than one answer)

Still at school	33.3%	69.2%	62.1%	57.1%
At college	41.4%	23.1%	20.7%	28.6%
Working	5.4%	0.0%	0.0%	3.3%
Volunteering	5.4%	0.0%	0.0%	4.4%
None of these	10.8%	0.0%	6.9%	14.3%
Other	3.6%	7.7%	13.8%	8.8%
Where is your young person living now? (in areas other than Brighton parents could choose more than one answer)				
Still at home with family	81.1%	100.0%	82.8%	86.8%
In their own home/flat	0.9%	0.0%	0.0%	3.3%
In supported housing	8.1%	0.0%	0.0%	4.4%
In residential care	7.2%	0.0%	6.9%	2.2%
Other	2.7%	0.0%	10.3%	7.7%
How much have you been involved in planning for your young person's future?				
0	4.5%	0.0%	6.9%	5.5%
1	1.8%	0.0%	3.4%	4.4%
2	1.8%	0.0%	0.0%	3.3%
3	7.2%	15.4%	13.8%	8.8%
4	25.2%	30.8%	13.8%	12.1%
5	59.5%	46.2%	62.1%	57.1%
Didn't answer	0.0%	7.7%	0.0%	8.8%
How much has your young person been involved in planning their future? (0-5)				
0	13.5%	7.7%	27.6%	17.6%
1	8.1%	7.7%	0.0%	12.1%
2	10.8%	7.7%	17.2%	8.8%
3	13.5%	15.4%	13.8%	15.4%
4	16.2%	30.8%	17.2%	16.5%
5	37.8%	23.1%	20.7%	19.8%
Didn't answer	0.0%	7.7%	3.4%	9.9%
Have/did you have any support planning for your young person's future from…and how helpful was it (0-5)				
Your young person's school/college (number of those saying yes)	79.3%	84.6%	69.0%	60.4%
0	6.8%	0.0%	5.0%	17.1%
1	6.8%	8.3%	5.0%	5.3%
2	12.5%	8.3%	15.0%	5.3%
3	19.3%	25.0%	15.0%	13.2%
4	15.9%	16.7%	35.0%	23.7%
5	34.1%	41.7%	25.0%	35.5%
Transitions team/Transition social worker (number of those saying yes)	66.7%	46.2%	34.5%	35.2%
0	0.0%	0.0%	0.0%	0.0%
1	5.4%	0.0%	10.0%	6.1%
2	8.1%	16.7%	30.0%	21.2%
3	16.2%	0.0%	40.0%	21.2%
4	20.3%	66.7%	20.0%	21.2%
5	10.8%	16.7%	0.0%	30.3%

Regional Transition Survey Results continued

Have/did you have any support planning for your young person's future from…and how helpful was it (0-5)

Youth Employability Service etc (number of those saying yes)		71.2%	46.2%	37.9%	33.0%
	0	7.6%	0.0%	18.2%	0.0%
	1	5.1%	0.0%	18.2%	10.0%
	2	7.6%	16.7%	18.2%	6.7%
	3	19.0%	50.0%	0.0%	30.0%
	4	7.6%	16.7%	36.4%	30.0%
	5	21.5%	16.7%	9.1%	23.3%
Parent Partnership Service (number of those saying yes)		83.8%	7.7%	10.3%	6.6%
	0	1.1%	0.0%	33.3%	0.0%
	1	1.1%	0.0%	0.0%	0.0%
	2	4.5%	0.0%	0.0%	12.5%
	3	7.5%	0.0%	0.0%	50.0%
	4	14.0%	100.0%	33.3%	12.5%
	5	11.8%	0.0%	33.3%	25.0%
Parent and Carer Forum (number of those saying yes)		Not	7.7%	3.4%	7.7%
	0	applicable	0.0%	0.0%	0.0%
	1	in	0.0%	100.0%	30.0%
	2	this	0.0%	0.0%	40.0%
	3	area	100.0%	0.0%	10.0%
	4		0.0%	0.0%	0.0%
	5		0.0%	0.0%	20.0%

Do/did you know what the SEN planning process is/was for preparing for your young person's future as an adult?

Yes	39.6%	46.2%	34.5%	24.2%
No	38.7%	30.8%	58.6%	54.9%
Don't know	18.0%	15.4%	3.4%	12.1%
Didn't answer	3.6%	7.7%	3.4%	8.8%

When did planning for your young person's future start?

Year 9	21.6%	46.2%	37.9%	19.8%
Year 10	29.7%	7.7%	10.3%	18.7%
Year 11	20.7%	15.4%	31.0%	18.7%
Don't know	20.7%	7.7%	10.3%	14.3%
Didn't answer	7.2%	23.1%	10.3%	28.6%

Did you feel starting at this point was …

Just right	41.4%	46.2%	31.0%	35.2%
Too early	2.7%	7.7%	13.8%	4.4%
Too late	17.1%	23.1%	37.9%	23.1%
Didn't answer	38.7%	23.1%	17.2%	37.4%

Regional Transition Survey Results continued

Did you and your young person have help identifying their strengths and skills/what needed to be worked on?				
Yes	44.1%	53.8%	34.5%	24.2%
No	36.9%	15.4%	51.7%	39.6%
Don't know	16.2%	7.7%	0.0%	6.6%
Didn't answer	2.7%	15.4%	13.8%	29.7%
Has/did your young person have a Moving On Plan?				
Yes	31.5%	30.8%	48.3%	23.1%
No	22.5%	23.1%	24.1%	24.2%
Don't know	23.4%	7.7%	6.9%	11.0%
Didn't answer	22.5%	38.5%	20.7%	41.8%
If yes, how helpful has their Moving On Plan been? (0-5)				
0	11.4%	25.0%	35.7%	34.6%
1	14.3%	0.0%	21.4%	11.8%
2	2.9%	0.0%	7.1%	29.4%
3	20.0%	50.0%	28.6%	23.5%
4	22.9%	25.0%	14.3%	5.9%
5	22.9%	0.0%	7.1%	29.4%
If yes, how much input have/did you have into your young person's Moving On Plan? (0-5)				
0	5.7%	0.0%	35.7%	30.8%
1	8.6%	0.0%	7.1%	3.8%
2	11.4%	0.0%	21.4%	3.8%
3	14.3%	50.0%	28.6%	11.5%
4	11.4%	25.0%	0.0%	19.2%
5	28.6%	0.0%	28.6%	30.8%
Do you/did you know about the various local Further Ed Colleges and training providers?				
Yes	63.1%	46.2%	72.4%	42.9%
No	11.7%	7.7%	13.8%	16.5%
Didn't answer	25.2%	46.2%	13.8%	40.7%
If yes, do/did any of the courses they offer suit your young person?				
Yes	52.9%	66.7%	28.6%	54.8%
No	27.1%	33.3%	71.4%	28.6%
Don't know	4.3%	0.0%	0.0%	16.7%
Has your young person had/did your young person have a social care assessment of their needs for adult social care support?				
Yes	23.4%	15.4%	44.8%	18.7%
No	49.5%	46.2%	34.5%	35.2%
Don't know	20.7%	7.7%	6.9%	14.3%
Didn't answer	6.3%	30.8%	13.8%	31.9%
If yes did you feel the assessment was done at the right time?				
Just right	57.7%	50.0%	46.2%	36.8%
Too early	7.7%	0.0%	0.0%	5.3%
Too late	23.1%	0.0%	61.5%	57.9%

Regional Transition Survey Results continued

If yes, how did you rate this assessment? (0-5)				
0	0.0%	0.0%	15.4%	15.8%
1	11.5%	0.0%	30.8%	15.8%
2	3.8%	50.0%	0.0%	10.5%
3	11.5%	50.0%	38.5%	15.8%
4	34.6%	0.0%	15.4%	26.3%
5	23.1%	0.0%	7.7%	15.8%
no rating	15.4%	0.0%	0.0%	0.0%
Do you/did you have a clear understanding of the resources that will/may be available to your young person through adult social care, e.g. personal budget?				
Yes	18.9%	15.4%	72.4%	6.6%
No	65.8%	61.5%	13.8%	58.2%
Didn’t answer	15.3%	23.1%	13.8%	35.2%
If a Paediatrician has been looking after your young person’s health care, are you aware of how their health care needs will be met as an adult?				
Yes	27.9%	7.7%	10.3%	9.9%
No	31.5%	61.5%	62.1%	36.3%
Don’t know	11.7%	0.0%	6.9%	7.7%
Didn’t answer	28.8%	30.8%	20.7%	46.2%
When you first started to think about your young person’s future as an adult, how did you feel (0-5)				
0	28.8%	23.1%	48.3%	38.5%
1	10.8%	15.4%	17.2%	16.5%
2	19.8%	7.7%	10.3%	5.5%
3	21.6%	7.7%	13.8%	6.6%
4	9.0%	15.4%	0.0%	1.1%
5	4.5%	7.7%	0.0%	1.1%
Didn’t answer	5.4%	23.1%	10.3%	30.8%
What do you feel about your young person’s future now? (0-5)				
0	14.4%	23.1%	31.0%	24.2%
1	11.7%	7.7%	27.6%	10.9%
2	18.0%	7.7%	17.2%	9.9%
3	24.3%	15.4%	13.8%	13.2%
4	18.0%	15.4%	0.0%	9.9%
5	8.1%	7.7%	0.0%	1.1%
Didn’t answer	5.4%	23.1%	10.3%	30.8%
Have you had a Carers Assessment?				
Yes	23.4%	7.7%	20.7%	18.7%
No	52.3%	69.2%	65.5%	49.5%
Don’t know	12.6%	0.0%	3.4%	2.2%
Didn’t answer	11.7%	23.1%	10.3%	29.7%

Appendix 6

Thinking about Independent Support for Young People and for Parent Carers

Background

SE7 is a partnership of 7 LAs, our NHS partners, our Parent Carer Forums, our national and local voluntary and community sector partners and most importantly our children and young people and their families. SE7 was the largest pathfinder area covering 10% of children nationally and includes unitary authorities and large mixed shire counties.

The underpinning principle for the SE7 Pathfinder activity was coproduction meaning working together from the start to design things jointly. To support successful coproduction with our parent carers we have supported the 7 parent carer forums within our area to work together and to be an integral part of our work. We also support our young people to contribute through the SE7 Young People's Engagement Group. All partners in SE7, professionals, parent carers, young people, the voluntary and community sector are fully involved at all stages and everyone contributes and works together on an equal footing.

In January 2014 Edward Timpson announced £30 million to be used to recruit and train a pool of 'independent supporters' - champions drawn from independent voluntary, community and private organisations to help the families of children and young people with special educational needs (SEN) through the SEND reforms.

From within SE7 a partnership of Amaze, a parent carer led charity based in Brighton and the parent carer forums from Brighton and Hove, East Sussex, Hampshire and West Sussex (the 'What Works for Us' partnership) submitted a successful application to be part of the evidence and build phase of the programme from April to June 2014.

So in our own inimitable fashion more than 50 people including young people, parent carers, voluntary organisations, SEND reforms leads, commissioners and others from across SE7 came together on 21st May 2014 to think about how we would want our Independent Support service to work and what are the values and principles we would want to underpin this work. The key objectives of the workshop were:

- To remind us of what works well and not so well for families during the Pathfinder
- To shape/influence how we'd like to see the government's investment in IS role is used to the best effect
- To identify how this role can best complement the other good work going on in your area and who could do it
- How can it be made sustainable when the funding only goes to 2016

This document is a summary of our thoughts, views and expectations.

What we have learned from our Pathfinder about what works and does not work

Young people want …

- To know what the expectations are and to contribute to them beforehand
- Understanding what is happening prior to a meeting or event
- Support or keyworker available for consistency and act as an advocate if I don’t want my parents present
- Having an incentive to attend
- Big meetings are broken down into ‘bite sized pieces’
- Being asked if we can cope with one big meeting or have smaller meetings

They like it when the people who help them …

- Are friendly
- Are kind
- Are patient
- Are positive
- tell us when we’re doing well
- are happy
- are polite
- are fun and can have a laugh
- have clear boundaries
- are good at listening,
- are understanding,
- explain things clearly and take time to get to know us
- sort things out

Young People do not want …

- Meetings about us when we cannot attend
- Being patronised
- Inaccessible environments
- Meetings set up for adults only
- Communication needs not recognised or met
- Being let down by actions not being completed

They don’t like it when people …

- Are angry
- Are bossy
- swear
- are lazy
- don’t listen to us
- don’t help when I am being bullied
- have favourites

- are not around much
- tell us what to do over and over again
- too many people at meetings who we don't know

What works well for parent carers?

- Having a single point of contact or someone to talk things through with
- Having information prior to appointments knowing who's who, what they do and what they can expect
- Effective signposting – particularly when not eligible for a service
- Having options and choices (shared decision making)
- Being listened to

When things work well parents feel …

- relieved,
- involved,
- that they matter,
- supported,
- kept in the loop.
- empowered and less stressed

What does not work for parent carers?

- Some parents feel that they are 'left to their own devices' that professionals assume that they know everything and therefore don't signpost to other services
- Find a lot of information by accident and find a lot of Information too late
- Feel that some information is 'hidden' particularly around statementing and social care assessments
- Lack of clarity and responsibility for families living on the authority borders

When things don't work well parents feel …

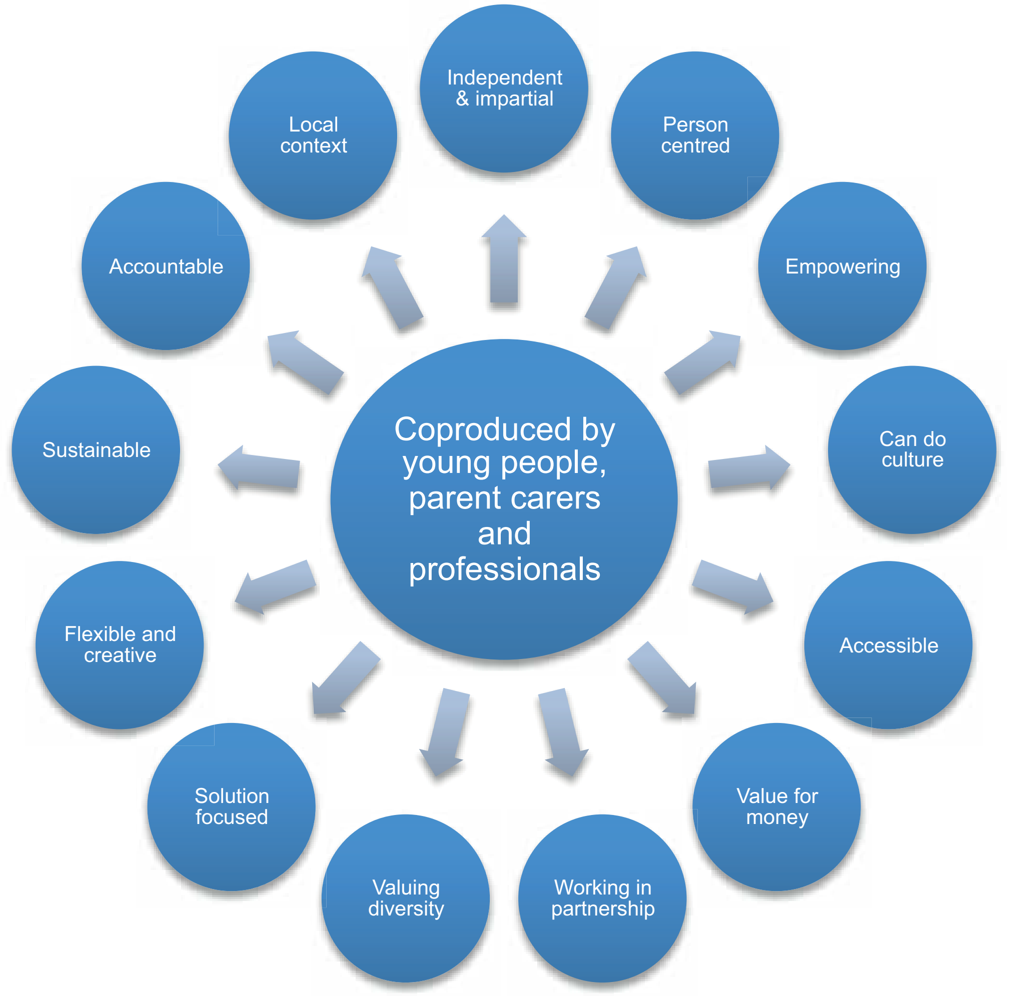
- Guilty
- Angry
- Isolated
- Farmed out
- Let down
- Bewildered
- Inadequate
- Overwhelmed
- Lost

All of this has a direct impact on young people's and parent carers' ability to cope

Implications for Independent Support of what young people and parent carers have told us …

The potential negative impact of poor quality Independent Support is significant and likely to be long lasting. It will be imperative to ensure that the Independent Supporters have the right knowledge, skills and personal qualities to fulfil this challenging role well and it is clear that this will not be an 'amateur' role and it will not be for the faint hearted. Recruiting people with the right personal qualities will be the first step. These can then be supplemented by relevant training and development which will then need to be supported by regular and high quality supervision, advice and guidance.

Our principles for our Independent Support Service



What these principles mean to us

Coproduced – this means working together on planning and implementing the service from the start

Independent and impartial – this means that the service should not be provided by nor answerable to statutory agencies nor should it adopt a 'party line', express preferences or seek to influence young people or parent carers

Person centred – we want the service to support the SE7 approach and principles. It should recognise and understand the family context and also focus on the child or young person who is going through the assessment and planning process

Empowering – the service should provide high quality information and support so that young people and parent carers are to make informed decisions for themselves. It will also be essential for the service to promote family resilience and actively strive to avoid creating a dependency culture

Can do culture – being able to support as and when necessary, being proactive and seeking out information and contacts, happy to work with young people and parent carers rather than providing a one size fits all service

Accessible – recognition that the service may need to be offered outside of normal office hours and at appropriate venues, well publicised and easy to contact. Ready to respond with no or short waiting times. Able to support a variety of young people and parents with differing disabilities, differing styles of communication, from different cultural backgrounds, living in rural areas, looked after young people, those with English as an additional language.

Value for money – supporting the best outcomes for the child or young person with high aspirations for a fulfilled adult life. Seeking to reduce conflict and adversarial approaches including reducing the necessity for mediation and formal appeals to the tribunal.

Working in partnership – with a wide variety of organisations and individuals including local VCS partners, educational settings, health providers and other sources of information, advice and support. It will be essential that the service works in close partnership with the local authority to ensure that those young people and families who are most in need of support receive it.

Valuing diversity – offering equality of opportunity in the context of a welcoming and accepting approach across the full range of diversity

Solution focused – seeking to find creative solutions and recognising constraints for both the family and the local statutory agencies through a positive and non-confrontational approach

Flexible and creative – not stuck in one frame of mind and are able to adapt their approach to the circumstance.

Sustainable – the service must be based on sound financial models and able to be sustained over the contract period and beyond

Accountable – accountable to the local stakeholders and able to evidence impact, responsive to feedback and need

Local context – fully integrated with but not overlapping the local pattern of support, fully familiar with the area's local offer and with contacts within the area

Some potential challenges and barriers – things we will need to address

Service users:

- Meeting the needs of the young person and their parents when there could be the potential for conflict – need to provide different IS for parent and for the young person
- Communication needs will mean that IS worker will have to tap into lots of different skills
- The different needs of those families new to the process and those converting statements to an EHCP

The timeframe:

- The need of the IS to be supporting a family in a very tight time frame and build up a trusting relationship with them. Some families may take all that time to build up their trust

The right support:

- There will be a challenge for IS workers to work across a whole range of ages from pre-schoolers to those who are entering the adult world. The needs of each will differ widely.
- Particular issues will arise when a family has a low-incidence need - need to have access to regional 'experts' to turn to if not sure
- Families who are 'harder' to reach
- Challenges of families living across borders and possible moving during the process
- Challenges of working with children in care.
- IS workers may have to work with very different and challenging families who have a high level of need. It may be challenging for the IS worker to manage their own emotions
- Deciding who is most in need of an IS – will need a jointly agreed process for identifying/referring in
- Lack of input/knowledge across health and social care in some areas esp. re. EHCPs

The range of stakeholders:

- IS workers will have to manage the differing expectations of the LA and the family
- IS workers will have to manage their role alongside others who are already doing the role. There will need to be very good boundaries set as to the role of each person in the process.
- Managing expectations with limited funding
- Having effective partnership working with the statutory agencies but retaining independence

Recruitment:

- Recruiting very quickly – possibly existing experienced people – other teams lose vital skills at such an important time of change
- Recruitment will be a challenge as the project is for a short term. It will take some time to recruit people to do the role
- Getting a good cross section of IS workers in terms of gender and age
- At the same time areas will need to be developing their IAS service – so lots of change at the same time

How we want our Independent Support Service to work

We need our IS service be actively supportive of the SE7 agreed regional principles and approaches. We also want it to have ‘sizzling hot’ local knowledge especially of our local offers. It is important that it builds on and involves the range of community sector partners already working in SE7 areas to support young people and parent carers. We need our service to work in partnership with our statutory agencies, our Parent Carer Forums and our Young People’s Engagement Group as we do. This will support it to be an influential, trusted, valued and complementary service in our region. We do not wish to see a service ‘imposed’ upon us.

Effective relationships with our local authority SEN Teams and SEND reforms leads will be essential to ensure that the service meets its intended aims to support those parent carers and young people who would most benefit from it. We want to work together with the service to develop fair and transparent eligibility criteria and access routes. These would be an important part of our local offers.

We want our service to be managed by a voluntary sector organisation which has credibility and which is able to promote partnership working regionally and locally to achieve the best outcomes but also retain independence and impartiality.

We want it to be flexible and responsive with a range of specialist skills in the workforce that could be deployed where needed in across the region as needed. Staff will need high quality support and supervision which is consistent across SE7. There will need to be a range of methods of providing the support including through groups as well as to individuals. This will support the aim of promoting family resilience.

In order to support the drive to improve outcomes for children and young people with SEND and their families the service will need to work closely with the commissioners and strategic leaders in our statutory partners. They should be able to add value to commissioning decisions and the review of the implementation of the reforms in all areas of SE7 by drawing on information collated through the service and knowledge of how things are working in each local area. This intelligence will need to be fed into the local strategic decision making processes in a sensitive and non judgemental way. It is therefore essential that the service has wide credibility within the region.

We would like to see the service grow from strength to strength delivering on its objectives and transparent in its operation. We believe this is the most likely approach to achieving continued commitment from the seven local areas within SE7 when the grant funding finishes. SE7 is a strong partnership and the local authorities are used to working together. A successful regional IS service would be much more likely to retain commitment from the SE7 partners in the future.

The knowledge, skills and qualities do the Independent Supporters need

There will need to be a range of roles within the service with frontline workers being supported by highly skilled and expert supervision. The management of the service will need to be able to promote and develop effective relationships with a wide range of partners and be credible in the full range of contexts.

The IS team will need a range of knowledge, experience, skills and qualities across its workforce. It is not a one size fits all approach. This will enable young people and families to be appropriately supported according to their individual situations. We felt that as a core the IS workers would need broadly the same knowledge, skills and qualities as we want for our assessment and planning coordinators set out in our ‘The Role of the Assessment and Planning Coordinator’ booklet.

How the Independent Supporters will need to be developed and supported

IS workers will need ready access to skilled and solution focused supervisors, coaching and mentoring. The supervisors will also need to be supported through an effective and knowledgeable management system. All training and development activities should be co-designed and delivered with parent carers and young people.

All IS workers will need a core of training and further on going development in:

- The SEND reforms and the legislation
- Working with families and valuing their diversity – building trust and good working relationships quickly and effectively)
- Outcomes focused and person centred approaches
- Effective communication with and to a range of people
- Lone working
- Solution focused approaches
- Understanding the roles of the various statutory agencies and their contexts
- Key working approaches
- Disability awareness
- Advocacy
- Confidentiality and data protection
- Safeguarding and child protection/working with vulnerable adults
- The SE7 approach and principles
- The assessment and planning processes within their local area
- The structure within the agencies in their local area and getting to know key people
- The local offer within the area(s) in which they are working

It is likely that there will need to be some IS workers who specialise in supporting young people and others who specialise in supporting parent carers whilst ensuring that the child (whatever age or disability) or young person has an independent voice. There will need to be considerable development activity in relation to managing possible disagreements between young people and parents as well as the implications of the Mental Capacity Act.

There will need to be ongoing development activities supported both by the IS service provider and the SE7 partners including our parent carers and young people.

Appendix 7

What works for you?

Case study drawn from the partnership working in schools in Brighton & Hove

Background

In Brighton & Hove the focus of one piece of work during the SEND pathfinder pilot was to look at the existing relationship between schools and the parents of children with SEN who attended those schools. We measured the current level of confidence by surveying all the parents of children with SEN at each school and identifying areas where both the school and parents could work together to form more of a partnership which wold be mutually beneficial and potentially reduce the level of conflict between the two.

One school that took part was a primary school with 50 children on the SEN register. It was a middle class school with a varying range of children attending but had traditionally been quite closed to parent involvement. This was something which the new SENCO was keen to address and wanted to take part in the pilot to identify areas where the school could become more open to parents.

What worked well?

1. The questionnaire was great to inform us of areas we needed to address.
2. We have held special evenings for different parental groups. We have done an evening for parents of adopted children.
3. Parents of children with SEN transitioning to secondary school met some parents whose children had already made the move to secondary. The evening was very successful and allayed a lot of worries.
4. We have held joint training for parents and staff on speech and language and raising resilient children.
5. Parents conference about planned changes to the Statementing process and SEN new policy.

The whole pilot was very successful for the school, who began do develop much more of an open door approach, letting parents know that they could contact the school at any time if necessary. Support was given by Amaze and the LA who visited the school on several occasions to help draw up an action plan and gave advice about partnership working.

Case Studies – Independent information, advice and support

Case study 1

Alli Farrell, LDD Adviser, Youth Employability Service

1. a) Information young person/people

As yet I am still to write an EHCP – I am due to convert a range of Moving On Plans to EHCPs and will start to write EHCPs for next year's leavers too. I have drafted some EHCPs and have started to collect young people's contributions but as the work is incomplete at this stage I am only able to broadly discuss issues rather than provide a specific case study.

b) Where relevant, has there been engagement with the SEND reforms?

The parents that have been involved with the draft EHCP have attended some SEND reform meetings and have an awareness of the basic ideas behind the reforms, some are aware of the local offer too.

2. Information about your service

At present we work with statemented young people and their parents/carers offering impartial careers information, advice and guidance regarding education, employment and training opportunities. We also currently write the Moving On Plans for further education and training. These will be rerplaced by EHCPs under the legislative changes and we await the Code of Practice which will inform our role in the future.

In terms of information, advice and support functions…

3. What has worked well?

- Starting to explore options preferably two years prior to transition to ensure that there is enough time to arrange visits to education/training providers and consider a variety of ideas before the application deadline
- Support for parents/carers who are unable/unwilling to visit providers by themselves
- Access to IAG materials and tools e.g. Pathfinder/KUDOS careers questionnaires, EClips careers leaflets, prospectuses that can help options be realistically identified
- Having good working relationships with schools and colleges that the young person attends to ensure that a client centred approach is made to coming up with solutions to any concerns/barriers that are presented in the transition process
- Having all of the staff that are involved with a family co-ordinate and liaise with regards to transition planning so that the family feel that everyone is working to the same set of objectives

E.G. In one case the young person had a strong relationship with their social worker and did not want to engage with anyone else – therefore we worked together – the young person knew who I was but was happier with me informing the social worker who then sat down with the young person direct. Without that link the young person would not have engaged with our service at the right time and would not have ended up going to college.

4. What did not work well and why?

- Occasionally planning happens later than hoped for a variety of reasons and this can make the process more stressful and time critical
- As I have not actually completed the EHCPs yet I cannot add more at this stage

5. Do you have any ideas about how Independent Support could be delivered to make a difference as the reforms are implemented locally?

- Early discussions re support and how to access it
- Support to visit providers and to have providers deliver talks on their options/services
- Ability to engage with students in a setting/or settings that are most appropriate for them (home, school etc).

6. (Where relevant):, when differences occur between what the young person wants or needs, and what the parents want or need; what intervention is good practice?

- Discussion with both parents and young person to clarify concerns, liaising with advocacy agencies for young people and parents and mediation with an appropriate impartial agency.

7. What do you think are the 3 key training needs essential to good practice in delivering information, advice and support to young people with additional needs?

- IAG qualification e.g. Diploma in Careers guidance or equivalence
- SEN awareness
- Child/Vulnerable Adult Protection

Case study 2

Kate Beecham, LDD Adviser, Youth Employability Service

1. a) Information young person/people

- Student in Chailey Heritage post 16 Department.
- Physical Disability and Communication Difficulties.
- Student is keen to continue with their education in a post 19 college. Parents support these plans.

b) Where relevant, has there been engagement with the SEND reforms?

- Participated in the SEND pathfinder in Brighton and Hove to have an Education, Health and Care Plan (EHCP) completed.

2. Information about your service

The Youth Employability Service is available to support young people aged 13-25 years who have a Statement of SEN. Our role is to provide information, advice and careers guidance to young people on the education and training options available to them when they leave school. We work closely with young people, their parents/carers, the school and other agencies to support young people with this transition.

In terms of information, advice and support functions…

3. What has worked well?

In your experience, generally what are the key things that work well

- Young person and parents fed back that they liked the format of the EHCP, they said it allowed them to have more input into the process and that their views and opinions were represented. It gave them a voice rather than decisions being made on their behalf.
- The family commented that it was a smooth process.
- Multi-agency working to support this young person with their transition and ensuring a suitable further education placement.
- Early planning with the transition process.

4. What did not work well and why?

In your experience, generally what are the key things that have been tried but do not work?

- Parents said that there was a lot of paperwork that had to be completed – the EHCP was completed alongside a Learning Disability Assessment (Moving on Plan) as this was part of the pathfinder project. However with the new code of practice a young person would only need to have the EHCP so this would eliminate the need for two assessments and reduce the amount of paperwork.

5. Do you have any ideas about how Independent Support could be delivered to make a difference as the reforms are implemented locally?

- Information to be easily available on how families can access Independent Support.
- Early engagement with families.

- Flexible approach to working and supporting families where they most need it – meetings, annual reviews, visits to providers.

6. (Where relevant):, when differences occur between what the young person wants or needs, and what the parents want or need; what intervention is good practice?

- Discussions with both the young person and parents to get a clear outline of their views and opinions, working closely with other agencies supporting the young person and parents, referrals for specialist advocacy support where appropriate.

8. What do you think are the 3 key training needs essential to good practice in delivering information, advice and support to young people with additional needs?

- Training on SEN (Disability Awareness, changes in SEN and new code of practice)
- Information, advice and guidance qualification
- Up to date information on available options and opportunities

Case study 3

Gerry Rowan, LDD Adviser Youth Employability Service, SEN – Children and Families Brighton and Hove City Council

1. a) Information young person/people

Age, interests, abilities, challenges

Primary additional needs their child/young person/people has?

Which school/college/other does their young person attend?

To collate this information I did a home visit to see Client A. At this meeting both Client A and Dad were present. Client A is doing a Level 3 ICT Advanced course (equivalent to 2 A levels,) course at City College. He is in his first year of this course – Client A is 17 Years.

Client A had a Statement of SEN which lapsed on his entering FE and was replaced with a Section 139A - Moving On Plan, which was written collaboratively with my client and parent(s).

Prior to Client A starting the course – whilst in year 11 an appointment was arranged with SEN personnel at City College – I attended with client A and parents, also in attendance were my clients, physiotherapist, and occupational therapist.

At this meeting issues around access to the classroom were discussed (originally the parent was told at an open evening that Client A would not be able to do the course as he could not access the classroom due to steps). However, adjustments were made and this was reported back at this meeting.

My client is a very able student who achieved several A – C grades at GCSE. He is a motivated student who is ambitious and keen to do well.

Client A has Cerebral Palsy which affects his lower limbs. He is a wheelchair user and uses the wheel chair much of the time. At college he tries not to use his wheelchair and has walked with the aid of crutches. He can be unsteady on his feet. Long distance walking is very tiring. Client A physical mobility difficulties will deteriorate over time. Busy environments can be challenging. Client A has a weakness in his hands and arms – which impact on his ability to complete lots of written work. Client A tires easily and needs breaks and desk / chair appropriate to his needs. He needs access to classrooms and around the college.

b) Where relevant, has there been engagement with the SEND reforms?

Have they heard of, contributed to or used the Local Offer?

About their Education Health Care Plan process…

Do they have a personal budget?

This client and family have not been involved in SEND reforms. Client A was a year 11 leaver from last year – when the reforms were not in place, nor being activily implemented. However, he may well request support through an

EHCP up to 25 years due to his SEN. They are at this stage unaware of the local offer, the EHCP replacing Moving On Plans and do not use a personal budget.

2. Information about your service

Organisational arrangements, CVS or statutory provision and source of funding

(e.g. full time supervisor, 3 part time case workers)

We are a team of LDD Advisers, providing support to Young People who have a Statement of Special Educational Needs attending mainstream secondary school (some with special facilities), and Special Schools covering Brighton and Hove mainly – with some out of county placements. We work with students to provide Careers Information and Guidance and support clients with planning, applications and support with transition post 16, into further education, training or employment. We provide young people with a Statement of SEN a Moving on Plan / EHCP which provides information that students and parents / guardians wish to share with colleges to support their continued learning.

In terms of information, advice and support functions…

3. What has worked well?

I met with my client and parents in school, on several occasions to discuss options at the end of year 11. My client wanted to do CAD graphics but the course at Northbrook was no longer available. We looked at a full range of courses.

Client A was given information about college open days and best times to visit.

Client A was seen in year 10 and Year 11 both individually and with his parent(s.) Client A's parents were involved in discussion about his progress and career options. I was able to attend his Annual Reviews in Year 10 and Year 11 to help gather information about Client A's Support needs.

The Careers Guidance and information given was impartial – and client centered and looked at the options that would best suit the needs and goals of my client.

I also liaised with my clients Physiotherapist, SENCO in School and his Occupational Therapist. I arranged a meeting with SEN Team at College to discuss my clients support needs and resources prior to my client starting his courses. At this meeting my client, parents, OT and Physiotherapist attended. Assessments were carried out by OT and Physiotherapist and advice given to the college regarding adjustments that might be required.

I also contacted transport and completed relevant information to access taxi to and from college – prior to Client A starting the course.

A Moving On Plan was completed with relevant information and reports and sent to the SENCO at the college. Parents and Client A report that they felt planning and Careers Information and Guidance were good, and support with transition was good.

My client reports that the physical environment at college is good. He has had good access to classrooms and that seating and tables are appropriate – and comfortable. The classrooms my student uses are accessible and all in one area so that he does not have to walk long distances. He is able to access areas of the college that he needs to include canteen and toilets.

He has the use of a Taxi to and from college – this is good – arriving and leaving at the set times, which have been pre-arranged and have been very reliable on the whole.

He had a key tutor at the start of the course and regular meetings were offered.

Client A reports that he had a good induction to the college.

4. What did not work well and why?

In your experience, generally what are the key things that have been tried but do not work?

Client A and his parent report that Client A was almost three quarters of his way through his course when a key tutor raised concerns that Client A had not completed relevant course work.

The College did not contact Client A or parents about their concerns. Client A and Parents, were called to a meeting where this was raised, "out of the blue" and they report that this could have been highlighted much earlier – by contacting parents.

It transpired that Client A had completed all the allocated work he was required to do. The problem was with the tutor who had not marked and recorded the work completed.

Client A and Parent describe tutors – as giving the impression that Client A should be "able to cope" with a higher level course – and not much thought was given to what support they were able to offer Client A.

Client A was very stressed by learning this – as were the parents. Client A described feeling like he was not "good enough" to do the course and he was made at this meeting to feel pressured into leaving the course. He was offered lower level course instead. It was only challenging by parent and Client A that tutors relented and accepted that the college had not recorded his work adequately.

Parent reported that his confidence was really crushed as a result - and it has taken a while for my client to feel comfortable – but having had these meeting issues around this has been largely resolved. Parent and client A are concerned with this as the outcome could easily have been Client A dropping out of the course, or being put on a lower level course which would not have reflected his capabilities..

The other key issue has been that my client is required as part of his course to complete software programming. However, frequently in these classes he is placed with a Teaching Assistant who has little understanding of programming. As he relies on information to be written on his behalf and sometimes conveyed verbally by TA's, who do not understand programming – this can lead to confusion – and to the curriculum not being accessible to Client A.

Client A and Parent Summary of what could / should have been in place:

- Client A should have had Review and Progress Report soon after starting the course so that any issues would have been highlighted from– both from Client and Tutors.
- Lack of communication between college and home – need for this was highlighted in Moving On Plan
- The Moving On Plan highlighted a range of support needs – Client A is a quiet student who does not like feeling as if he is demanding attention or is a burden – this information was in the Moving On Plan – therefore it is important that Tutors / key staff check the college is meeting his key support needs.
- Tutors did not appear to have got to know Client well. Teachers may have made assumptions about his abilities.
- Teaching Assistants who support Client A in Software Programming classes need to have expertise in this area in order to take notes and explain information – in the classroom – so Client A can access this.
- Parent suggested an outside agency / impartial professional attending a review meeting to ensure the right resources had been put in place.
- The Moving On Plan should be monitored by SENCO/Key tutors.

5. Do you have any ideas about how Independent Support could be delivered to make a difference as the reforms are implemented locally?

Client A and Parent to have more say in the expertise of the TA – so that they are able to adequately support students.

Moving On Plan to be monitored by and external agency with formal review process. Parent and Client report that raising issues at Parent Evening was not appropriate due to how busy this was and that appointments were generally for 5-10 minutes at most.

6. (Where relevant):, when differences occur between what the young person wants or needs, and what the parents want or need; what intervention is good practice?

Parents and Client A are in agreement about support needed – there is no conflict on this.

You can add a particular example here to illustrate this

7. What do you think are the 3 key training needs essential to good practice in delivering information, advice and support to young people with additional needs?

- Tutors use the Moving On Plan / EHCP and reports to have a clear picture of client and their Support Needs
- Formal Review arrangements to discuss progress early on in the first term
- Teaching Assistants have the expertise in Subject areas to support clients
- Better home / college liaison.

Glossary of Terms

Parent carer: This is an inclusive term used nationally and incorporates people who have parental or carer responsibilities for children or young people with additional needs and/or disabilities. Therefore it includes adoptive and foster parents, step parents and grandparents or others who have significant roles with these young people. The key aspect of this term is to include the additional aspects to parenting required to raise these children and young people.

SEND: special educational needs and disability.

SEN: special educational needs.

Health condition: disease, disorder, injury or trauma.

Impairment: moderate, severe or complex difficulty with physical or mental functioning which limits day-to-day activities as a result.

Disability: the dynamic interaction between impairment and attitudinal and environmental barriers that hinders a person's full and effective participation in society on an equal basis with others (UN Convention on the Rights of Disabled People).

Environmental barriers: physical and social aspects of the environment that may affect a person's experience.

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