Research in Practice aims to support the children’s sector to use research in the design and delivery of services, to help secure better outcomes for children and families. We make reliable research more accessible – summarised and interpreted with the particular needs of those working with children and families in mind.

Our series of evidence reviews address key issues identified by strategic planners, policy-makers and practitioners. The reviews are intended to shape systems, services, approaches and practice in ways that will promote the well-being of children and families.

This review examines, in the context of recent reforms and innovation, the latest practice, policy and emerging evidence on supporting families with disabled children and young people. It brings together contributions from a number of experts, from different backgrounds and professions, to consider how to lead, effect and sustain systemic change that will make a lasting difference to the lives of disabled children and young people, now and into adulthood.

This review will be of particular interest to strategic leaders in the field of children’s services and disability, as well as managers and practitioners in social care, and their colleagues in health and education, who are working to support children and young people with special educational needs and disabilities and their families.
21st century social work with families with disabled children and young people
Quality mark

This review has been peer-reviewed by a range of academics, practitioners and staff working in this field who are committed to the development of evidence-informed practice. Research in Practice is extremely grateful to Sarah Ainsworth, Katy Evans, Colin Green, Ashley Hinson, Sam Laurie Blackman, Drew Llewellyn, David Miller, Barbara Newton, Karl Podmore and Phil Snell for their help and assistance.

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Introduction

Helen Wheatley

The purpose of this evidence review is to examine the latest practice, policy and evidence – social work in the 21st century – in the context of reforms to support families with disabled children and young people. The authors are experts, from a range of backgrounds and professions, who share a passion and abiding commitment to working with and for disabled children, young people and their families.

This evidence review is timely in that it gives us a point to pause and consider how all of the current change to the social work role, the drive towards innovation, ‘doing more for less’ and the focus on special educational needs and disability (SEND) will work to improve outcomes. The issues covered here are not new. Nor are they easy to solve with one Act of Parliament, one way of working or one local programme. They require a considered, flexible and collaborative approach. Underpinning this are some essential elements, which are not exclusive to social work or to supporting disabled children and young people. They are common themes that seem to be needed to support any degree of change to make it work and make it stick.

> Leadership and a skilled workforce with capacity
> Co-production and shared decision-making
> Partnership both inside and beyond organisations.

Leadership

Leaders who are confident, willing to champion change and actively seek and work with partners are essential in pushing forward practice in local areas. Leadership is a recurring theme in many documents about social work and in this publication also. In particular, leaders are needed who can take advantage of the reform process, support teams to work with families to identify issues and take the time to design and test different and creative approaches. The move to the Education, Health and Care (EHC) plan and partnership-working model to review and improve support brings an opportunity to do this. This of course means leadership across organisations too. The requirements for health, education and social care to work with each other and with a much wider set of partners – and, of course, with children, young people and their families – has never been clearer. This includes adult social care and other adult services taking a proactive approach to providing assessment and support. This is welcome if somewhat daunting to local teams.

Chapter 1 examines the mammoth project of social work innovation and looks in particular at innovative working with children and young people with SEND and their families. It describes the work and early findings, which centre on the importance of the workforce, leadership, working together and the participation of families.
Co-production

Each of the following chapters includes comments on participation and gives us evidence of the slow but sure shift towards the genuine participation, if not full co-production, of disabled young people and families in service planning. The wider reform of social work and the focus on improving support for disabled children, young people and their families presents an opportunity to move to a social model of support that is needs-led and person-centred and to test out these approaches in an open and solution-focused way.

As the authors describe, it is widely thought that embracing the participation of children, young people and families and co-producing support with them can make these tasks both easier (in the long run) and more effective.

The voice of children, young people and families is at the heart of SEND reform led by the requirements of the Children and Families Act 2014. It is seen as essential both to the planning and provision of support to individuals and to strategic planning also, so that the views of those experiencing services and support inform future service design.

In practice, achieving sustainable and meaningful input on any level from children, young people and families who use social care remains the exception rather than the rule in local areas. Chapter 2 looks at the many reasons for this and sets out how local areas, and young people themselves, think this can change.

Partnership

All social work teams have a role to play in the support of families with disabled children. Chapter 4 examines the safeguarding context for disabled children and young people and sets out how the shift towards children and young people being heard within services, and the move to provide a more holistic and family-centred approach to social work support, means we can start to see how things might change for the better over the coming years. The authors writing here strive, from their different points of focus, to look at how we can collectively use the reforms to push these entrenched issues forward and find ways locally, through partnership working, co-production, leadership and staff development, to take a more effective approach.

In Chapter 5 we have a detailed account from a large local authority of how they went from an entrenched problem, which was having a hugely negative impact on the children and families affected, to finding a way to work across a wide range of agencies and identify a workable and sustainable solution. This example brings together the elements of good leadership and management, willingness of staff to try new approaches, and an understanding of the need to record progress and evidence impact.
Alongside the need for leadership, co-production and partnerships is a need for well-constructed research and evidence to inform planning and practice. This remains a challenge. Practice-based evidence is building but remains scarce and reliant on a few sources. The authors here make the most of available research and the emerging findings from the local work on testing innovative approaches, developing a Local Offer and working with families and partners on EHC plans.

The notion that we live in a world of too much information does not hold true here. Historically, with a few notable exceptions, research, government programmes, local initiatives, the testing of social work reform in children and family services have all, at best, included disabled children and young people as a separate project, or an add-on at some stage in the process. This means many key studies that provide useful information and learning for practice fall short of considering the needs and outcomes for these families.

An area with some of the best evidence to date on what can work to improve local services and support is the point of ‘transition’ for disabled young people as they grow up and make plans for their future. The changes to support they receive can be significant. This often becomes the main focus of their time and efforts rather than their aspirations. This process of transition also brings together all the key issues – personalisation, multi-agency working, leadership, and innovation – into one period of a young person’s life. For young people, their families and the staff supporting them, it can be overwhelming to navigate and coordinate plans and actions. Chapter 3 examines the latest work in local areas to embed decent support for young people planning their futures.

The authors all agree that time and effort is required to make and sustain change. The wide-reaching social work reforms and the current focus on disabled children (and on all children and young people) being well supported to live their lives could offer us the opportunity to make the time to work with others to change practice for the better.

**About the editor**

Helen worked for a number of years in local and national voluntary organisations deciphering national policy and making it work in local practice to support children and young people with special educational needs and disabilities and their families.

She founded the Transition Information Network and has a particular interest in support for young people growing up into adulthood and reaching their potential.
Chapter One

Social work innovation and policy into practice

Authors: Caroline Bennett and Amanda Harvey

Introduction

This chapter will explore the current drivers for change and innovation in the social care system. It will consider the current national context alongside learning so far from the Department for Education’s Children’s Social Care Innovation Programme, to understand the potential impact of innovations on social work practice for disabled children, young people and their families.

The current climate of increasing demand for services and support, reducing budgets and changing legislation has created a need for new ways of working across the entire social care system. Increasingly there are reports of dissatisfaction not only among families but also among social workers who are feeling under immense pressure, with limited capacity to respond to the complex needs of children and families.

Innovation in social work

In attempting to address these issues, there is a natural fit between the social work ethos and the principles of innovation. Innovation is already at the heart of social work practice. It requires the ability to step back and evaluate how things work, engage all parties, understand the difficulties and be open to testing possible solutions. These are all things that social workers are skilled and experienced in, as reflected in the international definition of social work:

Social work in its various forms addresses the multiple, complex transactions between people and their environments. Its mission is to enable all people to develop their full potential, enrich their lives, and prevent dysfunction. Professional social work is focused on problem solving and change. As such, social workers are change agents in society and in the lives of the individuals, families and communities they serve. (The British Association of Social Workers, 2012: 6)

Innovation can be categorised into two broad types: evolution and revolution (Kline and Rosenberg, 1986). Evolution is where gradual, incremental changes over time lead to progressively new and more effective ways of working. An example of this is developments in assistive technology that have enhanced independence for disabled people in many different ways or have enabled young people with complex communication needs to express their views.
Revolution, on the other hand, is when a new idea is developed and tested with a view to creating change on a larger scale and over a shorter time period in order to address an ongoing problem. This revolutionary approach can be seen day-to-day as providers develop and test new and creative service initiatives. Person-centred planning and approaches are being implemented in order to deliver effective, individualised care and support.

When we start to look at innovation in the context of systemic change, however, our approach needs to be structured, collaborative and replicable at scale in order to generate value for the system as a whole and improve outcomes for disabled children and their families.

Drivers for change and innovation

The social work profession and social care itself is under reform. In 2013, the introduction of the role of Chief Social Worker for Children and Families (alongside the appointment of a Chief Social Worker for Adults) demonstrated a commitment from government to improving social work. The remit of this role is to drive the profession forward by providing support and challenge to the profession, expert advice to ministers, and leadership to a network of Principal Social Workers across each local authority in England. Knowledge and Skills Statements (KSS) for the profession were introduced in 2014 and 2015 and form the basis of a new national accreditation system for child and family social workers (Department for Education, 2014; 2015). The KSS is applicable to practitioners, as well as supervisors and practice leaders, and there is a clear drive to ensure a high standard across all parts of the system.

In 2016 Children’s social care reform: A vision for change (Department for Education, 2016a) set out the government’s programme for reform across three key areas: people and leadership; practice and systems; and governance and accountability. In order for transformation to happen, change is required in all of these areas. To support that change the Department for Education set up its Children’s Social Care Innovation Programme, which is testing a range of approaches and services to identify effective improvements in the way children’s social care is developed, implemented, reviewed and funded.¹

So change is happening in the social care system. In order for it to be both effective and sustainable, however, it needs to build on what works and involve all those affected by the challenges as equal partners in developing solutions that improve outcomes for children, young people and families. Change needs to be supported by a shared vision and clear leadership that links policy to practice, creates capacity and motivates the workforce (Templeton, 2016).

¹ See: http://springconsortium.com/about-the-programme
Systemic challenges to innovation in practice

Despite government policy recognising that effective innovation requires flexibility of regulation and taking risks, there is still a disconnect between the level of practical and financial commitment from government to enable local strategic leaders to support the level of flexibility and capacity development required. For example, standard performance measures can hinder local authorities’ ability to be innovative, as they may not reflect the outcomes being achieved by disabled children and young people or be set up to measure activity which supports outcomes important to disabled children (Department for Education, 2016b).

In addition, a central focus on the needs of children and families may not be the only motivating factor in the drive for innovation, with cost savings often being key in engaging leadership support. Austerity is impacting on statutory social care services, which are persistently expected to do more with less (Hastings et al, 2015).

Another key challenge for spreading innovation is that arrangements for developing, identifying and sharing good practice are sporadic. Many local authorities demonstrate good practice in particular cases, highlighted in recent Ofsted reports. Evidence of this impact is rarely collected or analysed, however, and social workers and their managers do not find it easy to find out what works.

Even where evidence exists, finding the space to review and implement effective changes to practice while continuing with the ‘day job’ is extremely problematic. It is intended that local authorities judged as ‘Good’ or ‘Outstanding’ by Ofsted should provide support to those judged as ‘Inadequate’. However, since only 42 out of 143 local authorities inspected so far were judged to be ‘Good’ (and two ‘Outstanding’) spreading effective practice has been difficult.

Innovation in practice is difficult within the current social care system. It requires strong leadership in order to take measured risks in a risk-averse system (Brown, 2010). It requires all stakeholders to be ready to challenge their own assumptions and really listen to and value the perspectives of others in order to do things differently and creatively at a time when practice is heavily prescribed, regulated and subject to wide-ranging policies and procedures. But it can be done.
Opportunities for innovation in practice

Experience has shown that effective innovation requires those leading it to engage with all those affected, learn about the problem the innovation is trying to address, analyse the evidence and build solutions together (Council for Disabled Children, 2015a). This means that the complexities of the changing landscape of support for disabled children offers the perfect opportunity for innovation that addresses wants and needs, or solves a problem in a better way.

The Children and Families Act 2014 introduced Education, Health and Care (EHC) plans for children and young people with special educational needs and disabilities (SEND). EHC plans require effective multi-agency working and this creates opportunities for multi-disciplinary working, allowing for a blurring of traditional roles and scope for flexible approaches. For example, local areas will have to establish:

> Which agency should provide the lead professional in assessment processes for children and young people with special educational needs who may need an EHC plan.
> Where a child has been or is being assessed for other reasons, how can the various assessments be better aligned or co-ordinated? (This could include EHC plans, personal educational plans, looked after children’s review plans and child protection plans.)
> How integrated personal budgets can be used to support young people to achieve their aspirations and specific agreed outcomes.

Embedding the Act in social work practice is a challenge but it has offered a chance for reflective practice and opportunities to create space in which practitioners at all levels can consider new ways of working.

Examples of innovation in practice

Case study: Innovation in developing new roles – social worker PAs

As part of the Children’s Social Care Innovation Programme, one project in Hampshire and the Isle of Wight explored the impact on social worker capacity of implementing a social worker personal assistant (PA) role. The approach involved one PA supporting three social workers by scheduling their visits and meetings, carrying out admin tasks, responding to emails and telephone calls, writing up aspects of assessments and helping to request information from other agencies. The evaluation found that this approach cut levels of social workers’ stress, gave social workers more time for direct work with families, and saved services money (Burch et al, 2017).
Case study: Transforming culture and practice in children’s social care assessment

With the support of the Children’s Social Care Innovation Programme, the Council for Disabled Children worked with five local authorities – West Sussex County Council, London Borough of Bromley, London Borough of Enfield, City of York and Cornwall Council – and their local partners to co-design and test a range of new approaches to social care assessment for disabled children and their families (Bennett et al, 2016; Bennett, 2016).

In order to ensure parent carers’ perspectives were at the heart of their innovation, two of the local authorities employed parent carers as project managers. Their roles included leading and facilitating co-production with all local partners, including parent carers and disabled children, in addition to their wider project management responsibilities.

A structured, facilitated learning model was used as a method of driving innovation and supporting the local authorities to fully understand the challenges in the current social care system from the perspective of all those who interact with it, including disabled children and young people, parent carers, families, and professionals across education, health, social care and the voluntary and community sector.

The learning model involved a four-phase approach:

1. **Discover**: Learn as much as possible about the current system and how it works.
2. **Define**: Analyse the learning from the ‘discover’ phase to clearly define challenges and barriers to achieving the aims of the programme in practice and to identify the key opportunities for change.
3. **Co-design**: Work in partnership with children, young people, their families and professionals to generate ideas and develop new approaches to test.
4. **Test**: Trial the co-produced ideas with children, young people, families and professionals.

Throughout the ‘discover’ and ‘define’ phases, each area worked to understand the existing challenges in the system from the perspectives of all stakeholders by using techniques such as emotive journey mapping.

![Graph showing journey mapping results](image)
Benefits of co-production

In order to develop a system that will work for and with disabled children, young people and their families it is vital to begin by working alongside them (and other partners) to understand what challenges and strengths are present in the system (from their perspectives) and to engage them in developing new ways of working. Due to countless interdependencies, this cannot consider only one aspect of the system but must consider whole system transformation (Selwyn, 2016).

Co-production can be an effective element to support innovation, generating new ideas and testing approaches. It involves a genuine shift in attitudes to ensure all those who are affected by a change are treated as equal partners and work together to solve problems by designing and testing practical solutions. This is easier with some groups of stakeholders than others.

The five local authorities who worked with the Council for Disabled Children on their ‘Transforming culture and practice in children’s social care assessment’ project worked to develop approaches that enabled co-production with disabled children and young people as well as families and practitioners across a wide range of agencies, including the voluntary and community sector (Bennett et al, 2016; Bennett, 2016). Evaluation found that children and young people were clear they want to be involved in any decisions about their lives. Parent carers reported seeing shifts in the approach and attitudes of practitioners and in their relationships with families and young people.

Emotive journey mapping involves asking different groups of stakeholders engaged in a process to rate their experience of different stages of that process from ‘negative’ to ‘positive’. This enables the identification of key priorities for change (where a majority of stakeholders find a certain element ‘negative’) or areas for transferable learning (where a majority find a particular element ‘positive’). This approach highlighted the varying experience that families, practitioners and children and young people have at different times in the process.

Some parts of the system were very negative for families but very positive for social workers within the Children’s Disability Teams (CDT). For example, the single assessment was perceived by professionals as one of the best parts of the process where they get to meet the family and the child and start to build relationships. For families this was the point where they felt unprepared, unclear on what to expect and anxious about being judged by a stranger (Bennett, 2016: 6).

Social workers viewed the overall process more positively than any other group of stakeholders. Further discussion suggested this may be because the social workers were able to feed their views on how the system could be influenced or changed directly to decision-makers, whereas other stakeholders had limited opportunity to share their experiences. Where professional-led changes were implemented, it was often without broader consideration of the impact on the wider experience of families.
‘I have not really experienced that kind of team working before … we are actually pulling all this together rather than just talking … it’s nice to be able to feel you’ve got something to contribute … that feeling of parity …’
(Council for Disabled Children learning seminar, 2016)

Many parents involved in co-designing and testing proposed solutions said that their experiences of problem solving together, in one room, with practitioners across education, health and social care also led to:

> improved understanding of the role of the social worker and other key roles
> a feeling that their views were valued and their contributions considered equally with those of professionals
> a sense of shared ownership of the approaches tested (Bennett et al, 2016: 9).

Despite concerns from professionals that co-designing solutions alongside parent carers, children and young people is costly, current findings from the Council for Disabled Children’s innovation programme indicate that a return on investment can be achieved within one to three years. Effectively co-produced systems and approaches result in:

> improved outcomes for children, young people and families
> improved satisfaction for the workforce, including increased resilience
> a sense of ownership of the outputs by families and key stakeholders
> and the development of ongoing, trusting relationships between children and young people, parent carers and services.

Embedding a culture of co-production and learning is vital to creating the space and capacity to think in a different way. Engaging with different perspectives and developing the skills to really hear and understand the experience of others are fundamentally part of social work practice.

Co-production creates a real opportunity for innovation in this sector as many of the individuals engaged in frontline practice have these transferable skills and need minimal support to apply them to a new and different process. But for innovation to work those individuals need leaders who create space and support for professionals and families to work together to build solutions and to reflect on what they have learned. Professionals need to build, develop and sustain these skills over time.
Leadership, values and vision

Strong and flexible leadership is also vital in creating the capacity to innovate in any sector. However, the recent backdrop of changing legislation and reducing resources has led to conflicting priorities within social care (Brookes et al, 2015). Those in strategic roles are often overwhelmed with management tasks such as planning and budgeting, staffing and, in some cases, crisis management. This leaves limited time for leadership functions such as promoting a shared vision, aligning people, motivating and inspiring, and producing positive change (National Development Team for Inclusion, 2017).

Yet this leadership element of strategic roles is crucial in both driving the innovation and in ensuring the sustainability of the approaches developed.

Coaching models are known to facilitate innovation and help embed new ways of working at both a strategic and operational level (Health and Social Care Board, 2014). Within the context of supervision, coaching and mentoring are valuable skills for social work supervisors to be able to implement (Perrault and Coleman, 2004) and might bring particular benefits when faced with difficult or traumatic cases (McBride, 2010).

Co-production to support system change

Local authorities in the Council for Disabled Children’s innovation programme identified key priorities for change across the assessment process. These included providing more information and better preparation for families and young people, developing consistency and proportionality of approach, and establishing a clear focus on outcomes. All the authorities went on to co-design and test varying approaches to address these priorities:

> West Sussex worked with young people to develop a video and toolkit which explain the role of the social worker, what to expect from an assessment and how to prepare, including questions that might be asked and information that might be requested, for both parent carers and disabled children and young people.2

> Bromley developed their ‘Time for Me’ brand, which shares experiences of other local families through videos and information posters promoting access to the Local Offer. They have also devised an online assessment system that has the potential to reduce the amount of social worker time in cases where low-level need is identified and to speed up the decision-making process. This enables families to access the social care support they need without the perceived stigma of an allocated social worker. It also frees up social worker time to focus on children and young people with more complex needs who may be at risk of family breakdown.

> York have developed new approaches to support families through the assessment process using a small team of trained peer and community volunteers, early help workers and community library staff.

> Cornwall have developed a ‘Let’s Talk’ introductory conversation as a preventative intervention to support families and reduce the need for statutory assessments. The approach builds on Motivational Interviewing models. It seeks to build resilience in families by focusing on a small number of specific and achievable goals that will improve outcomes for disabled children, and signposts families to community resources through the Local Offer (Bennett, 2016: 17).

2 To watch the video go to: www.youtube.com/watch?v=hZGw5Rn7LaM
What can be achieved when stakeholders are working together?

All of the local authorities involved in the Council for Disabled Children’s innovation project reported a number of benefits from working together in the early phases of the project:

> Problem solving together with parent carers, professionals and children and young people led to more creative and innovative solutions.

> The process of co-production developed a range of approaches to engaging with stakeholders and led to the professionals involved developing a number of key transferable skills and approaches. These can be used to ensure meaningful involvement at an individual level in assessment, as well as strategic level involvement in process development and service design.

> Having parent carers and professionals (including special educational needs co-ordinators, inclusion managers, health visitors, health professionals, social workers and local authority education teams, and voluntary and community sector organisations) in the same room discussing the same challenges and sharing their views in a solution-focused way led to a much greater understanding of roles and responsibilities.

> Parent carers developed a better understanding of the challenges and constraints that professionals are working with, but they also felt they were listened to and that their views informed the solutions that were being tested.

> Co-production gave more credibility to the outputs developed for the test phase, as it was clear that all of the stakeholders’ views were taken into account.

> Trusting relationships were developed between parent carers and professionals. This enabled open conversations about difficult topics leading to unexpected learning, which supported innovation. (Bennett, 2016)
Conclusion

The recent focus on increased local control and innovation has led to the development of new and innovative ways of delivering services (Forrester et al, 2013). Despite programmes and initiatives of innovation within social care often leading to improved outcomes for individuals or small groups, there is a risk that these improvements can be short lived. Long-term change and sustainability are difficult to achieve, particularly in an environment of reducing budgets, high staff turnover and limited capacity. Social work practitioners find themselves reacting to families in crisis rather than having the capacity to focus on direct, preventative interventions with families.

Parent carers, children and young people have a vital role in individual planning and in the development of services. Integrated working across agencies and a greater understanding of the roles and responsibilities of all practitioners are key to delivering a system that is flexible and can innovate to respond to the varied needs of families.

Evaluation of innovative approaches and evidence of the impact of innovation are central to sustaining effective practice across the system and crucial in enabling us to respond effectively to the needs of children, young people and their families now and in the future. It is about time these innovative approaches are accorded the priority they deserve by policy makers, local leaders and practitioners.
About the authors

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Caroline is Assistant Director for Social Care at the Council for Disabled Children (CDC). She is a key player in ensuring the success of CDC’s social care training programmes, which look at the links across recent changes in SEND legislation. She has a particular interest in supporting young people and their families as they prepare for adulthood.

For several years Caroline was the Director of a community interest company that she set up to support young people with autism to engage in outdoor adventure activities. She was previously the CQC registered manager of a short break outreach service in a local authority. Her experience of supporting families to navigate existing support systems has allowed her to see how challenging this system can be both for families and the professionals working within it. Caroline is committed to using her wealth of experience to change and improve outcomes for children and young people.

Amanda Harvey

Amanda is passionate about improving systems to better meet the needs of vulnerable children and families and has a particular interest in leadership development. Amanda’s most recent role was within the senior management team at CDC, prior to which she was at the helm of a Local Safeguarding Children Board in London where she focused on partnership working, multi-agency training and development, and improving local systems.

For many years Amanda worked as a frontline social worker within the field of child protection and safeguarding children as well as in an Adult Learning Disability Team. She has also held specialist roles providing therapeutic support to survivors of sexual assault, domestic violence and abuse.

Amanda has a Master’s Degree in Social Work as well as a postgraduate diploma in Advanced Social Work Practice Education. Amanda is passionate about making the biggest impact on the lives of disabled children and families.
Chapter Two

Voice, participation and co-production with disabled children and young people

Anita Franklin and Kate Martin

‘Tell a young person what to think and you lose their trust, ask a young person what they think and empower them for life.’ Megan, FLARE member (Council for Disabled Children and KIDS, 2017)

Introduction

Across the UK, there are rising numbers of disabled children and young people with complex needs who will most likely need health, education and social care support. Pinney (2017) estimates that this population has increased by 50 per cent in the last decade. This is due to a number of factors including:

- increased survival of preterm babies
- increased survival of children after severe trauma and/or illness, and

Government statistics estimate that in 2016 there were 237,000 children in England with special educational needs requiring specialist support and an individual plan for their care – an Education, Health and Care (EHC) plan (Pinney, 2017: 11). However, this figure is thought to be an under-estimate because of inconsistencies in how data are recorded nationally. In March 2015, there are approximately 50,800 disabled children defined as children in need. Nearly one in five (18 per cent) of these were in need due to abuse or neglect, and a further 13 per cent because of family stress or dysfunction (Pinney, 2017: 13). It is also estimated that over 1 million children and young people in the UK have some form of communication need.

Yet nearly 30 years after a child’s right to involvement in decision-making was established within the Children Act 1989 and 25 years after the United Nations Convention on the Rights of the Child (UNCRC, 1989) came into force in the UK, disabled children and young people continue to report that they do not feel listened to and are not involved in key decisions being made about them. This chapter attempts to understand what seem to be entrenched barriers to involving this group of children in decision-making and sets out the evidence indicating what needs to change in policy and practice.

3 FLARE is a young people’s advisory group formed as part of Making Participation Work, a participation programme run jointly by the Council for Disabled Children and KIDS. See: https://councilfordisabledchildren.org.uk/our-work/participation/practice/flare

4 The Communication Trust estimate that over 1 million children and young people in the UK have some form of long-term and persistent speech, language and communication difficulty: www.thecommunicationtrust.org.uk/about-the-trust/importance-of-communication
Chapter Two  Voice, participation and co-production with disabled children and young people

Policy background

‘It doesn’t matter if you’re disabled or non-disabled, you have a right to have an opinion and you bring with that a lot of experience and knowledge about what your impairment means.’ Dame Tanni Grey-Thompson

Domestic and international laws, as well as a wealth of practice guidance, advocate the right to involvement in decision-making. Social workers are subject to many of these legal and policy requirements, and should communicate directly with all children to ensure that assessments are informed by the wishes of the child, alongside the views of their family (Children Act 1989; Children Act 2004). Engagement with children in decision-making is a firmly established principle in the government’s statutory guidance on safeguarding (Working Together to Safeguard Children, HM Government, 2015; Department for Education, 2017) and, most recently, within the special educational needs and disability (SEND) reforms introduced by the Children and Families Act 2014.

All children and young people, regardless of how they communicate, have rights. These include the right to:

- have their views taken seriously
- freedom of expression
- access to appropriate information
- dignity, independence and active participation in their community.

These rights are enshrined under the United Nations Convention on the Rights of Persons with Disabilities (2006) and the UNCRC. Statutory guidance for Directors of Children’s Services (Department for Education, 2013) requires them to have regard to the UNCRC’s general principles and to ensure that children and young people are involved in the development and delivery of services.

Disabled children and young people have the right to be involved in decisions that affect them both as individuals and collectively as a group. For example, as part of the government’s SEND reforms introduced by the Children and Families Act 2014, there is an expectation that all children and young people will be involved in the development and review of their individual EHC plan. The Act also places a duty on all local authorities to develop and publish a Local Offer detailing all the support and facilities that families can expect to find in their area for children and young people with SEND. There is also a duty to involve disabled children and young people in the development of the Local Offer, thereby facilitating their involvement at a strategic level within a local authority.

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5 This quote is taken from an interview undertaken by the VIPER disabled young people’s research group as part of their research into disabled children and young people’s participation: www.allfie.org.uk/docs/Viper%20Guide%20Hear%20Us%20Out.pdf
Definitions and concepts of decision-making

‘Participation is a great way to help us learn how to make decisions and understand the choices we may face in the future.’ 6

‘Participation’, ‘involvement’, ‘co-design’ and ‘co-production’ are all terms that are used, often interchangeably, to describe what is in essence a shared decision-making process. For shared decision-making to be meaningful, however, it is important to be explicit about the level or degree of shared power the child or young person has in that process. This is to ensure that children and young people’s involvement is more than merely ‘being present’ (i.e., tokenistic) and actually enables them actively to influence decision-making or to be the main decider (Cavet and Sloper, 2004; Franklin and Sloper, 2006).

‘There’s no I in EHCP, there should be, it should be me!’ Megan, FLARE member (Council for Disabled Children and KIDS, 2017)

The level of power shared with children should be determined by circumstances and the wishes of the children taking part (Kirby et al, 2003). Good practice should mean that practitioners ascertain from each individual the level of involvement they want, and then continue to check this as time goes on (as the child’s wishes may change) (Alderson, 2002). A simple framework by Alderson and Montgomery (1996) defines four levels at which children can participate:

1. being informed
2. expressing an informed view
3. influencing the decision-making process
4. being the main decider.

However, evidence suggests that disabled children and young people are often denied even levels 1 and 2, so opportunities to reach the level of actually influencing decision-making are limited. Franklin and Sloper (2009) argue that a prerequisite for an effective framework is that access to communication and information is assured for disabled children and young people. Thus access to a communication system/method, and access to people who understand a young person’s preferred communication method, should be the first consideration in planning any participation activity. Communication takes many forms and involvement in decision-making can be facilitated via a variety of creative techniques – these can range from multimedia to simple arts and craft activities, observation and critical analysis of evidence from the people around a child who uses a complex non-verbal communication method.

Over-reliance on parents or carers

Social workers often lack confidence when communicating with disabled children and might be tempted to seek the views of parent carers rather than engage with the child directly. It is important not to use parents as proxies, however. Evidence shows that parent carers and their children can view things very differently and may prioritise different aspects of a service and the outcomes they want to achieve (Mitchell and Sloper, 2001). Parent carers are often best placed to understand the nuances of a child’s individual communication and the vast majority of parents will be supportive in this. However, caution must be exercised in terms of whether they present an unbiased view. Evidence from research in child protection procedures also indicates it is important for professionals not to over-empathise with parents and/or rely entirely on them to facilitate communication, thereby losing sight of the child (Taylor et al, 2014; Taylor et al, 2015).

What disabled children and young people say they want and need for successful shared decision-making

There is remarkable consistency in what disabled children and young people say they want from the professionals involved in their lives. They want:

> Positive relationships with professionals who are interested in them as people and who listen to them and provide them with accessible information.

> Professionals who are receptive to all forms of communication, who are proactive, who adapt their own verbal language and who build trust and a relationship with them. Children and young people advocate that workers should ‘give it a go’.

> A dialogue and feedback about what has happened when they have been involved in decisions, even if this might seem like ‘bad news’ or cause them to be disappointed. (Franklin and Sloper, 2007; Martin, 2008; Making Ourselves Heard, 2009)

Many ‘top tips’ have been developed by disabled young people to support professionals to involve children and young people in decision-making. Although the policy or assessment focus of the top tips may vary, the messages themselves are consistent and concern practice that is child-centred, aspirational and based on respectful listening and engagement. (See the examples set out at the end of the chapter.)
How can shared decision-making practice be facilitated?

A concerted effort is needed for shared decision-making with children and young people to become embedded and routine practice. There needs to be a focus on challenging current practice and improving the culture and attitudes within organisations. In particular, there needs to be a clear focus on supporting practitioners to change their practice and remove the barriers that may prevent them from doing so.

Changing cultures and attitudes and challenging current practice

The barriers to shared decision-making are well documented. These include the complexity of interaction between individuals and groups; the characteristics of the young person, their family and professionals; the culture of practice within services; limited resources and infrastructure of the organisation; and having to balance multiple agendas.

Although there is little systematic evaluation of disabled children and young people’s shared decision-making, it is reported that what is required are strong leadership and an adaptive organisational culture that allows and embraces, for example, the extra time for decision-making and rebalancing of power dynamics. For this to happen, all agencies at a strategic level need to understand why shared decision-making is important and to recognise disabled children and young people’s competency and right to be involved in decisions that affect them.

Integrating this into practice requires strategic level support and engagement across commissioning, strategic partnerships and within the design of pathway plans and commissioning cycles, for example. Although there is little evaluated practice in this area, anecdotal evidence suggests that some local authorities have embraced this way of working, and have developed partnerships with disabled children and young people at a number of strategic levels. This suggests that embedding shared decision-making is not impossible, but requires working in creative and child-centred ways. Facilitating such a change in culture requires critical reflection, and evaluation in partnership with disabled children and young people so that practice improves and becomes embedded.

Halton local authority provides one example of some of the ways that the involvement of disabled children and young people has influenced change and has begun to become embedded within the culture of an organisation.
Case study: Halton’s Bright Sparks

Bright Sparks supports young people to be involved in decision-making in Halton and helps children and young people with disabilities have a say in the services provided for them.

Bright Sparks gathers children and young people’s ideas and views and feeds them directly to the Halton Children’s Trust Board through the chair of the Bright Sparks Group.

Bright Sparks groups have recently been involved in areas as diverse as:

- Changes to urgent health care
- Developing the new Halton transitions booklet
- Improving the Cheshire Police website
- A sexual health consultation
- The quality of short breaks.

A group of Bright Sparks ‘kitemarkers’ also check out local venues, services and facilities to see if a young person with disabilities would have a good experience when visiting or using them. A Bright Sparks Quality Kitemark is awarded to those that meet the criteria the young people have developed. Not only is this helping to improve services, it is enabling young people to work alongside service managers who welcome the kitemarker’s feedback.

For more information on Bright Sparks see: www.haltonspeakout.co.uk/bright-sparks

Workforce implications

The need for improved communication skills to enable social workers to engage in more effective direct work with disabled children is widely recognised (Franklin and Sloper, 2006; Taylor et al, 2015). This is not new. The Munro Review of Child Protection reported a lack of meaningful relationships between social workers and children per se, and a system that can significantly hinder the work of social care professionals to develop such relationships (Munro, 2010; 2011).

As disabled young people identify, to facilitate this there needs to be:

- Training and upskilling of social workers in communicating with disabled young people.
- Opportunities for professionals to experience shared decision-making with disabled children and young people to overcome any lack of confidence or anxiety around either the process and/or the outcome of involving disabled children in decision-making.
- Challenging the barriers faced by disabled children and young people to their involvement in decision-making.
In particular, professionals need support to bridge the gap between principles and practice to develop the knowledge, skills and confidence to engage disabled children and young people in decisions about their care. In a qualitative study of implementing shared decision-making in child and adolescent mental health services (CAMHS), professionals (including social workers, psychiatrists and family therapists) reported that when trying to change their practice to involve children and young people in decisions about their care, they felt apprehensive about the consequences. They worried that new approaches may not work and were apprehensive about risk and ethical concerns about the capacity of young people to be involved in certain decisions (Abrines-Jaume et al, 2014). These concerns can lead to professionals procrastinating and avoiding making changes to their practice.

Professionals also reported that when they tried out new approaches to involving children and young people in decisions, this could sometimes feel awkward or ‘clunky’ and could leave them feeling deskilled. In order to integrate shared decision-making into their practice, professionals need time, practice, perseverance and reflection to develop their confidence and skills (Abrines-Jaume et al, 2014). They might also need reassurance that feeling ‘clunky’ or ‘clumsy’ may be a necessary part of the process of learning a new skill. Professionals are more likely to make these changes if they feel supported and encouraged to risk trying out new approaches. This suggests that to ensure shared decision-making becomes a reality for disabled children and young people, there needs to be a concerted effort to give social work professionals the time, space, training, tools and support to develop their knowledge, skills and confidence. Social workers need clear frameworks to understand what shared decision-making is and support to reflect on how they make this explicit within their practice through the use of quality improvement techniques and supervision.

Overcoming barriers also requires challenging the attitudes and assumptions that exist around disabled children – in particular, concerning children who have a learning disability, communication needs, mental health needs or behaviour that is seen as challenging. Barriers include an over-reliance on speech to communicate, low expectations and an assumption that children lack the capacity to be involved. Evidence and practice exist which refute these claims. Evidence has also shown that a lack of previous involvement in decision-making and not being given choices in life means children may lack confidence and skills at first; however, this lack of confidence is not necessarily linked to their abilities, but rather is simply a symptom of their lack of experience (Council for Disabled Children, 2017a: 5).

‘The more young people get involved they will learn gradually to make decisions. Young people need to be encouraged or it will be scary when they turn 16.’ Young person, EPIC (Council for Disabled Children, 2017a: 5)

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7 Between 2012 and 2016, EPIC (Equality, Participation, Influencing, Change) was the Department for Education’s young people’s advisory group on the SEND reforms
Multi-agency working to facilitate participation

If there is a change in attitude, expectation and preparedness to accept creative and alternative ways of ‘hearing’ the child’s views, then practitioners will be better equipped and more able to work in partnership with others such as the child’s school or key worker who will have a better understanding of the child’s communication.

The evidence suggests that multi-agency working and a commitment to involvement (from a strategic level down) can, when accountability mechanisms are in place, alter cultures of exclusion and create the time and space that workers need to develop shared decision-making with disabled children and young people. Changing attitudes, confidence and skill in workers, however, has to go hand in hand with addressing what is described as the biggest barrier – the limited amount of time available to conduct assessments and gain a thorough insight into children’s views. This is especially true when practitioners hold large and complex caseloads, which are not always conducive to building relationships with children or gaining an adequate awareness of their full needs and aspirations.

Prynallt-Jones et al (2017) report on the importance that social workers place on being able to visit children in a variety of settings, including the school, home and wider ‘community’, and how this facilitates an opportunity to build trust and potentially offer more coherent support for the child. This can enable the social worker to network directly with the wider multi-agency teams who support a child, learn a variety of communication methods and draw on those teams’ expertise when communicating with the child. Addressing the problem of limited time is particularly challenging in the current financial climate and requires creative thinking and working with multiple agencies. The introduction of single EHC plans provides an opportunity to tackle this barrier and evidence is now emerging of how local authorities are addressing these challenges (see Chapter 1).
Ensuring shared decision-making becomes more than an aspiration

There are a number of ways to ensure shared decision-making becomes more than an aspiration. These include:

1. Tools and resources to maintain a child-centred focus in direct practice
2. Independent advocacy to support children and young people to express their views
3. Empowering children and young people to enable them to develop the skills and confidence to be involved in decision-making.

1 Direct practice: Keeping the child at the centre and meeting individual needs

As mentioned above, there are a number of toolkits, guides and ‘top tips’ available online that describe both high and low-tech/low-cost ways of involving disabled children and young people in shared decision-making, both at an individual level and a strategic level.

These resources enable disabled children and young people to indicate their preferred method of communication, to communicate their likes and dislikes, what makes them happy or distressed, and what they would like to change. They are used within person-centred planning for children and young people and within the development of EHC plans and transition plans. Some examples include:

- Guidance on how to make participation mechanisms/groups such as Children in Care councils inclusive: [www.participationworks.org.uk](http://www.participationworks.org.uk)
- PowerPoint presentations or Facebook-type pages can facilitate expression of needs, wishes and aspirations.
- Choice books are easily developed at low cost and simply contain photos, objects, symbols of different activities or choices on offer so that children and young people can look through and communicate, be that through pointing, eye pointing or gesturing their preferred choice.
- Talking Mats uses three sets of picture communication symbols showing topics (the subject being explored) options (the different choices available) and visual scales (to enable the child to show how they feel about each choice using pictures of different emotions). These are now widely used within research and practice to facilitate involvement ([www.talkingmats.com](http://www.talkingmats.com)) (Murphy, 1998; Cameron and Murphy, 2002; Germain, 2004; Rabiee et al, 2005; Macleman, 2010; Mitchell, 2010; Mitchell and Sloper, 2011).
Fairly simple ideas such as these help children to develop the skills and experiences of choice-making, being involved in decisions and learning that they will be listened to. Many disabled children and young people will use these methods within school and/or within a residential setting and will have key workers who will know their preferred method of communication and who might be a valuable source of expertise in facilitating communication – although their impartiality must also be taken into consideration on occasion.

2 Access to independent advocacy

Access to an independent advocate for disabled children and young people has been shown to be a useful way to facilitate participation and shared decision-making, especially if a child has little experience of expressing their views and being involved in decision-making processes. There is a specific obligation for a local authority to provide independent advocacy under the Care Act 2014 if a young disabled person has substantial difficulties in understanding or retaining or processing information or communicating their views, wishes or feelings AND there is no one appropriate to represent them (this is particularly relevant to transition planning).

Advocacy is commonly described as enabling someone to have a ‘voice’ (Oliver and Dalrymple, 2008). An advocate does not necessarily agree with the child or think that the child’s views are in the child’s best interests – advocates act on the permission and instructions of children and young people. Acting on a child’s instruction can pose problems for children with complex communication needs who cannot instruct the advocate directly. Acting for someone who cannot tell you directly what they think or feel is called non-instructed advocacy or non-directed advocacy. Typically this involves observation, questioning and information gathering from those around the child and across multiple settings, clarifying the rights of the child and presenting this information on behalf of the child or young person.

Case study: An example of non-instructed advocacy

An advocate used a rights-based approach to advocate for a young person’s right to an education. Through observation, the advocate noted how much a young person loved school and his peers at school. However, the young person was missing considerable amounts of time at school because the sling on his wheelchair, which was used to hoist him when he required personal care, needed replacing. This could not be used at school so he had to be taken home when he needed changing and then he didn’t return to school for the rest of the day. Arguing for the young man’s right to an education ensured that the issue was resolved and the young person could enjoy a full day at school alongside his peers.

Taken from Franklin and Knight (2011: p60)
Disabled children and young people in care face particular challenges in accessing advocacy services, however. In a report on advocacy for children in care, the Children's Commissioner found that nearly a third of local authorities provide no access to non-instructed advocacy and advocacy is often issue-based rather than a generic service. The Commissioner expressed ‘considerable concern’ at the low number of disabled children, children with communication needs and younger children using advocates – ‘all of whom may need non-instructed advocacy’ (Children’s Commissioner, 2016: 6). The Commissioner has also called on the government to ensure that local authorities monitor the availability and take up of advocacy services by disabled children (Children’s Commissioner, 2017: 7). In medium secure in-patient CAMHS settings provision of advocacy is variable, with few children and young people accessing it. In one of the few studies which asks disabled children about their experiences of having an advocate, positive experiences were expressed:

‘I’m just sat there and like they’re all talking about things but he [the advocate] doesn’t talk about me, he talks to me. All others are sat at the table talking about me.’ Young person (Franklin and Knight, 2011: 32)

3 Empowering disabled children and young people

One of the main barriers to the participation of disabled children and young people is the lack of accessible information. This manifests itself day to day, but also specifically in a failure to inform children on how they can get involved in making decisions about their own lives and care plans. Many disabled young people will have experienced social exclusion throughout their lives and will assume they won’t be given opportunities to be involved in decision-making. So providing disabled children and young people with the right information is a critical first step to empowering and enabling them to make informed decisions. It is important that practitioners highlight that decision-making processes will be made accessible and that children’s needs will be met. In order to be inclusive, information needs to be available in different formats, including easy-read versions, photographs, pictures and audio. Advice on how to develop such information is included in some of the ‘how to’ guides listed at the end of the chapter.
Supporting practice

Despite the numerous barriers, there are examples of good practice across the country. Many local authorities and individual social workers and social work teams are working to secure the full involvement of disabled children and young people in decision-making. The Me first case study provides one such example.

Case study: The Me first communication model

Me first is designed to improve communication and shared decision-making between children, young people and professionals in health and social care. Me first is an education and training resource that helps professionals develop their knowledge, skills and confidence in communicating with children and young people by encouraging a ‘child-centric mentality’ and providing tools and advice to support this.

A common question from professionals when asked about shared decision-making is ‘Don’t we do that already?’. Me first, however, is co-designed with disabled and non-disabled children and young people and aims to help professionals bridge the gap between principles and practice.

> The Me first communication model provides a practical framework to support shared decision-making.
> A suite of practical tips provides advice on how to communicate with specific ages of children and young people as well as those with communication impairments or learning disabilities.
> Me first masterclasses, which are co-delivered with young people, support professionals to apply the Me first shared decision-making model to their practice. Training builds on the professional’s existing skills and expertise, and uses quality improvement techniques to enable them to embed the learning in their practice.
> The Me first website contains
  - An interactive communication model to enable professionals to build their own conversations and apply the model to their own practice
  - A resource hub that enables professionals to share tools, projects and ideas from across the UK
  - Practical advice and tips from children, young people and other professionals on how to put the model into practice.

For more information go to: www.mefirst.org.uk
Conclusion

Participation and shared decision-making are core elements of effective rights-respecting support and services for disabled children and young people. Many barriers to shared decision-making for disabled children still exist. However, there has also been a significant shift in attitudes and concerted attempts to find ways of understanding how we can overcome these barriers and meaningfully involve disabled children in decisions that affect their lives. Crucially, these efforts need to recognise that all disabled children can influence decision-making. We need to focus on changing the culture of services so participation becomes embedded. We need to support social care and other staff to develop the skills and confidence to involve disabled children meaningfully. And we need to empower disabled children and young people themselves to develop the confidence and experience to influence decisions that affect them.

Tools and resources for supporting disabled children’s participation and share decision-making

**VIPER - Ingredients of High Quality Participation**

This framework for participation has been designed by disabled young researchers. Based on their research evidence, it describes ten key ‘ingredients’ for ensuring good quality in the participation of disabled children and young people in strategic decision-making.


**Hear Us Out: A VIPER guide to participation in decision–making** (published by ALLFIE and Coventry University)

This guide, produced by disabled young people, provides practical advice on setting up or running participation opportunities for groups of disabled young people. Areas covered include meeting young people’s access needs, providing feedback and rewards, keeping young people engaged and 15 stages to successful participation.


**Top Tips for professionals who support children and young people to participate in their Education, Health and Care plan** (published by the Making Participation Work programme, a joint partnership between the Council for Disabled Children and KIDS)

This Top Tips guide is for all professionals who are involved in supporting disabled children and young people and those with special educational needs, to fully participate in their Education, Health and Care (EHC) plan. The guide aims to raise awareness of the barriers children and young people face when participating in their EHC plan and offer advice and ideas to help eliminate those barriers. The guide was co-developed with disabled children and young people and those with special educational needs.

[https://councilfordisabledchildren.org.uk/sites/default/files/field/attachment/Top%20Tips%20for%20Professionals%20who%20support%20CYP%20to%20participate%20in%20their%20EHC%20plan.pdf](https://councilfordisabledchildren.org.uk/sites/default/files/field/attachment/Top%20Tips%20for%20Professionals%20who%20support%20CYP%20to%20participate%20in%20their%20EHC%20plan.pdf)
**Decision Making Toolkit (Council for Disabled Children)**

This decision-making toolkit is a practical guide to support social workers, health practitioners, school and college staff, parent carers, families and anyone working directly with children and young people with special educational needs or disabilities (SEND).

The toolkit is designed to be used in partnership with a young person to support them to make their own decisions and to participate as fully as possible in decisions made on their behalf.

It includes a best interests template which practitioners can use to support a young person who lacks capacity to go through a best interests decision-making process (based on the best interests checklist in the *Mental Capacity Act 2005 Code of Practice*).

[https://councilfordisabledchildren.org.uk/help-resources/resources/decision-making-toolkit-0](https://councilfordisabledchildren.org.uk/help-resources/resources/decision-making-toolkit-0)

**Your Rights, Your Future Toolkit (Council for Disabled Children)**

Your Rights, Your Future, which has been developed by the Council for Disabled Children in partnership with disabled young people and Making Ourselves Heard, is a toolkit of interactive training materials aimed at disabled young people.

The toolkit will help practitioners to enable children and young people to understand the changes to SEND law and their right to be involved in decisions about their support. The training focuses on four key areas, as prioritised by young people:

> Education, Health and Care (EHC) plans
> Post-16 decision-making
> The Local Offer
> Personal budgets.

[https://councilfordisabledchildren.org.uk/making-ourselves-heard/resources/your-rights-your-future-toolkit](https://councilfordisabledchildren.org.uk/making-ourselves-heard/resources/your-rights-your-future-toolkit)
About the authors

Kate Martin

Kate Martin is Director of Common Room. Common Room is an independent organisation led by lived experience that connects the expertise of young people, practitioners, researchers and policy-makers across disability, health and mental health. Kate has worked for many national charities in the past and is also Director of the Child Outcomes Research Consortium and Chair of London Friend, England’s oldest LGBT charity.

Kate’s work focuses on empowerment and finding the best ways of involving young people who are disabled or experiencing mental health problems in decisions about their lives, services and support; co-production, co-design and participation; consent and decision-making; child and young person-centred communication and difficult conversations about safeguarding or mental health; and preventing bullying for children who are disabled, LGBT or experiencing mental health difficulties. Kate is also a PhD researcher at UCL, undertaking a critical analysis of decision-making in young people’s mental health inpatient units.

Anita Franklin

Anita Franklin is a Reader in Children and Families Research at Coventry University. Anita has over 20 years’ experience of undertaking research within the field of children and young people’s social care, where she has combined an academic career with leading research programmes within large children’s voluntary organisations.

Anita’s work has mainly focused on disabled children and their right to agency and empowerment. Most recently she has undertaken research on safeguarding issues for disabled children, ensuring the voices of disabled children and young people are heard within studies on child sexual exploitation and the child protection system. She co-authored the first UK study to explore the sexual exploitation of young people with learning disabilities: *Unprotected, Overprotected.*
Chapter 3
Transition to adulthood
Caroline Bennett

Social workers have a key role in supporting young people and their families as they navigate the transition to adulthood. By exploring how the changing policy framework is being implemented in practice and by reviewing evidence and research of social care practice, we will be able to identify the clear opportunities for social workers to support effective transition for disabled young people. This will ensure they achieve better outcomes and fulfilling adult lives.

What is transition?

‘Like falling off a cliff into the abyss.’ That was my feelings about the transition from children’s to adults’ services at sixteen years old. I remember it being a scary and confusing time for me and my family.’

Young person, FLARE (CDC blog, 2017)

Transition describes a process or period of change from one state or condition to another. It is a word often used to describe the period of time during which a disabled young person is preparing to move from Children’s Services to Adults’ Services and, more broadly, from childhood to adulthood.

Research has shown that when disabled young people and families do not feel adequately supported to deal with the challenges which transition to adulthood poses, they are left very vulnerable to emotional and physical distress (Townsley, 2004: 48).

A number of changes in legislation and policy in recent years have created opportunities to look at new ways of working to support young people as they transition to adulthood, but they have also created some confusion. As young people prepare for adulthood, they are supported by legislative priorities within the Children and Families Act 2014 and the Care Act 2014. These two pieces of legislation overlap for young people between the ages of 18 and 25 (Preparing for Adulthood, 2016)

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8 FLARE is a young people’s advisory group formed as part of Making Participation Work, a participation programme run jointly by the Council for Disabled Children and KIDS. See: https://councilfordisabledchildren.org.uk/our-work/participation/practice/flare
There are a number of positive requirements in the legislation that aim to avoid the potential ‘cliff edge’ that families (and the young blogger above) have referred to as young people reach 18 (Broach et al, 2016):

> Education, Health and Care (EHC) plans have the potential to continue to age 25.
> The Care Act 2014 introduces a suite of transition assessments that should be aligned to the EHC planning process and inform a holistic understanding of the young person’s needs.
> Children’s Services are required to continue providing services until an adult’s needs assessment has been carried out. The aim is to reduce the number of young people who experience a gap in provision while they await the outcome of an adult’s assessment.
> A focus on outcomes and aspirations from an early age should mean that provision is identified that best prepares the young person for independence well in advance of their 18th birthday.
> Person-centred planning is embedded in the legislation.

What does good transition look like?

When we think about a good transition to adulthood for a disabled young person, we should start by thinking about what a good adulthood looks like for all young people.

A good adulthood means choice and control over their future. It means further education, training or paid employment in a job the young person is interested in and skilled at, and it means being able to live independently in their community and being able to enjoy friendships and relationships.

Young people develop their skills in making choices by engaging in new experiences and, very often, making mistakes and learning from the consequences. The experience of taking risks and developing coping strategies to deal with these consequences builds resilience that is vital to enable young people to have fulfilling, independent adulthoods (Wijedasa and Selwyn, 2011). For most young people, many of these things take time and planning; for disabled young people, the barriers to achieving them can be more complex and require the support of a team of multi-agency professionals to overcome.

For disabled young people many of the things that other young people do come with a range of challenges (Townsley, 2004). This could be something seemingly as simple as being able to gain access to a certain building or area that hosts a particular opportunity, or a lack of confidence (or lack of support) that limits the opportunity to develop the skills the young person needs to get involved.

The social model of disability describes the way society is structured and organised as being the cause of disability rather than a condition or impairment (Oliver and Sapey, 1998). Barriers can be the attitudes of others or physical barriers to space and buildings. The important thing the social model tells us is that with some creative, person-centred thinking these barriers can be overcome.
Common challenges for both young people and their families surrounding transition include:

- A lack of information about relevant services and professionals, or communication with them.
- Disabled young people often feel left out of the decision-making process; those who have significant communication impairments are further excluded through a lack of support to help them engage.
- Limited availability of appropriate housing and employment options make it more difficult for disabled young people to make key steps towards the adulthood they want (Morris, 2002: 3).

The Preparing for Adulthood (PfA) programme, which is funded by the Department for Education and delivered by the National Development Team for Inclusion (NDTi), provides advice, guidance and support to local authorities and their partners in implementing the PIA elements of the Children and Families Act 2014. It is designed to provide expertise in embedding preparing for adulthood from the earliest years. The programme identifies four clear outcomes (employment, independent living, community participation, and good health) that lead to fulfilling adult lives for disabled young people, as shown in Figure 3.1.

Figure 3.1: Preparing for Adulthood Outcomes Tool (© Preparing for Adulthood, NDTi and Department for Education)⁹

Research with young people has reinforced the importance of these outcomes. Disabled young people most often want ordinary experiences and outcomes at transition, goals that are – with the right support – realistic, such as receiving paid employment, or achieving independent living (Townsley, 2004).

Disabled young people often have a large number of people, including professionals, involved in their lives. It is therefore extremely important that disabled young people’s care and support is viewed holistically and planned in a person-centred way. When this happens we see disabled young people thrive, moving into adulthood with paid employment, living independently in their communities with friends and enjoying making choices and being in control of their care and support.

The role of social workers and social care practitioners is integral to this holistic approach and to supporting families to accompany the young person on their journey into adulthood, building parental confidence at the same time as supporting disabled young people to develop the skills they need to be proud and resilient adults. Social work values are directly linked to human rights and social justice. Social workers endeavour to empower others to reach their full potential, which is integral when looking at transition for young people (The British Association of Social Workers, 2012).

Parental and familial support and confidence is especially important in supporting disabled young people:

*Those that make a successful transition to independence in adulthood usually do so because of the material, emotional and cultural support they can draw on from parents and the wider family.* (Morris, 2002: 6)

Social workers and other professionals therefore play a key role in facilitating and enabling families to provide ongoing advice and support to young people, as they have a duty to seek and support the voice of the disabled young person throughout the assessment, planning and review process.

*I just want to be proud of who I am and professionals supporting me can help me achieve that.*

Young person (*’Thriving, not just surviving’, Council for Disabled Children workshop, 2017*)
What are the challenges and how do we overcome them?

For families the process of assessment and planning can feel long and drawn out. Many feel as though they are engaged in a lifelong battle to achieve the best outcomes for their young person.

‘I’m still asking to be told or shown my options and I have been since [he was] 16 ... when I am given choices, my choices are disregarded!’ ‘We go around in circles, nobody is really doing anything to give me any clarity.’ ‘I’ve fought for him for the last 18 years, I’m lost and no-one will help me.’ ... ‘We have never been given any choices. Before she was 18 we were told that a lot of thought would go into a tailor made package, but it never happened.’ (Care Quality Commission, 2014: 37)

Many parent carers and young people have also spoken about how little they know of what happens during the transition process:

‘This [transition] is a major milestone and the impact of this was not properly shared. We had to learn about the process from another parent; that is sad. Our best source of information is other parents – things should not be like this. It falls on us as parents to instigate all that happens. We have been on tenterhooks for the past four years; nothing has happened, but the process is supposed to be going on.’ (Care Quality Commission, 2014: 14)

‘I am too scared to think about what will happen. It will probably mean he has to go into residential care. Nobody has talked to me about what happens next.’ (Care Quality Commission, 2014: 59)

Staff may share these views:

‘It all feels rushed and last minute. Some services transition at 16, some at 18 and if they are at school then it’s 19. It’s disjointed and confusing for me as a professional, let alone for the family.’ Social worker (Care Quality Commission, 2014: 31)

There is a concern that the recent legislative changes will simply move the feeling of being at a cliff edge to a later point in a young person’s life. It is not enough merely to extend the age of transition and expect that preparation for adulthood will somehow be improved. Rather, the focus must be on joined-up assessment, planning and reviews from an early age to ensure the young person is best prepared for adulthood.

If a disabled young person does not have people proactively finding ways to support them to overcome the challenges they face, then the impact on that young person’s and their family can be significant – in some cases leading even to mental health crisis for the young person and potential family breakdown. This can result in disabled young people starting on a potentially one-way path into long-term residential care away from their families at huge cost to the local authority with poor outcomes for the young person and their family (Lenehan, 2017).
These challenges – the length of the assessment and review processes, the lack of information about choices and the process itself, and knowing who to ask for help – are at the heart of the work in local areas who are finding ways forward in partnership with young people and families.

Challenges are also likely to manifest themselves in different ways for different young people – just because somewhere is accessible for one disabled young person does not mean it will be accessible for all disabled young people with similar needs.

This is why personalisation is so important (Sowerby, 2010). Although, broadly speaking, the PFA outcomes described earlier are relevant to all young people, the way that individuals will achieve them will vary greatly depending on their goals and aspirations, strengths and skills. The following sections explore the ways in which we can overcome these challenges through:

> Information and advice
> Outcomes and aspirations
> Preparation, assessment, planning and review
> Decision-making
> Support, provision and commissioning
> Workforce development.

Information and advice

Research tells us that young people need a wide range of information to support their transition. This includes information about everyday things, as well as the big decisions such as employment or where to live. Relationships and socialising are high on young people’s priorities when it comes to information that will enable them to achieve their goals. This evident desire for information also emphasises the significance for young people of feeling in control of their lives and the choices being made about their future (Townsley, 2004).

The Children and Families Act 2014 has sought to address the lack of accessible information and advice by placing a clear duty on local authorities to publish an accessible Local Offer of information on the support young people and their families can expect to find in their area. Improving the quality and accessibility of Local Offers has recently been the focus of a number of Preparing for Adulthood local authority demonstration sites. The emerging learning indicates it is vital for young people to be working with local authorities to co-produce the young people’s aspects of the Local Offer (Preparing for Adulthood, 2017).

Social workers play a vital role in distributing information and advice on services in the community. Early intervention through existing community services can prevent situations reaching crisis point or requiring statutory social care intervention.

Learning examples from the demonstration sites covering a range of topics can be found at: www.preparingforadulthood.org.uk/downloads

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10 Learning examples from the demonstration sites covering a range of topics can be found at: www.preparingforadulthood.org.uk/downloads
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As described in Chapter 1, West Sussex have developed toolkits which prepare parent carers and young people who are going to have a social work assessment. They have also co-produced a video with young people to help other young people understand the role of the social worker.\textsuperscript{11}

Ensuring that disabled young people and their families have access to relevant and appropriate information and advice is crucial in ensuring that they receive the right support to successfully manage their transition. This applies both to the general advice and information supplied by the local authority, but also to the specific and targeted information social workers and other professionals can help to provide (Sloper et al, 2010).

Young people, children and their parents also have a right to impartial information, advice and support on education, health and social care from their local SEND Information, Advice and Support (IAS) Service.\textsuperscript{12}

Outcomes and aspirations

The \textit{Children and Families Act 2014} puts a focus on children being able to achieve the best possible educational and other outcomes. This means children and young people (along with their parent carers and families) need to be supported to think about their future so that the plans and support put in place are tailored to promoting their strengths.

For most young people, any early aspiration to be a ballerina or train driver is likely to change as they grow older and move through education, where they will be exposed to a range of role models and different types of training and work experience. Disabled young people may need formal intervention to access these opportunities and social workers are well placed to support young people in exploring their aspirations.

The Transition Information Network produces the My Future Choices magazine, which shares a range of articles written by disabled young people on their experiences of transition and their achievements into adulthood.\textsuperscript{13} The magazine provides an excellent opportunity for disabled young people to develop their skills in writing articles, but also for readers to get a sense of the variety of different options that might be open to them, including supported internships.\textsuperscript{14}

It is important to be ambitious for young people when thinking about their aspirations and to share experiences and achievements of other disabled young people who have, with the right support, been able to achieve their goals. The Lenehan review clearly identified poor identification of, and support for, ambitious outcomes as a core systemic problem that continues to cause significant challenges for disabled children and young people (Lenehan, 2017).

\textsuperscript{11} You can view the video at: www.youtube.com/watch?v=hZGw5Rn7LaM
\textsuperscript{12} To find your local IAS Service go to: https://councilfordisabledchildren.org.uk/information-advice-and-support-services-network/find-your-local-ias-service
\textsuperscript{13} See: https://councilfordisabledchildren.org.uk/transition-information-network/my-future-choices-magazine
\textsuperscript{14} Supported internships are personalised study programmes (based at an employer’s premises) designed to enable disabled young people to achieve sustainable paid employment by giving them the skills they need for the workplace.
Disabled young people’s aspirations and desired outcomes should be central to all planning and support and practitioners should strive to support them to achieve the best possible transition to adulthood. However, young people tell us that the aspirations they identify in section A of their EHC plan (section A covers the young person’s views, interests and aspirations) are often not reflected in the outcomes in the rest of their plan. The Council for Disabled Children (2017b) have developed good practice guidance and case examples to help practitioners ensure that children and young people’s views, wishes and feelings are central to their EHC plans.

Preparation, assessment, planning and review

It is vital that assessment and planning is coordinated. The Care Act 2014 introduces a suite of transition assessments and places a duty on local authorities to assess where two conditions are met:

- It is likely that the young person will need care and support after becoming 18
- There will be ‘significant benefit’ to the young person for the transition assessment to take place.

This is an important part of the planning process for all young people. It encourages the early engagement of Adults’ Services, creating the opportunity to develop a clear understanding of whether a young person is likely to be eligible for support post-18. Where a young person is not eligible for post-18 support, then it creates an opportunity to support planning for skills development and support pre-18 to ensure they are able to build effective support in their communities.
**Case study: Circles of Support**

Circles of Support is an approach that has been found to have empowering effects for disabled young adults and their families. The concept is to create a supportive network around an individual, focusing on their strengths and abilities and creating a team approach to planning and support that is focused entirely on the aspirations of the person at the centre. The approach is based on a set of principles that include:

- Enabling the person to achieve their full potential.
- Linking them to their community through a network of individuals in their circle such as friends, family, support workers and members of the wider community.
- Creating capacity to think, plan and learn together while focusing on inclusion.
- Building a shared vision and understanding of roles and responsibilities that support the promotion of power to and for the individual at the heart of the circle.

Ultimately these elements must lead to action that those within the circle commit to deliver in order to achieve the person's aspirations and outcomes (Neill and Sanderson, 2012). In a recent study the impact was described as 'massive' for one person with complex needs who now felt confident that people were ‘looking out for her’ (Wistow et al, 2016). Although there is currently limited evidence available, case studies demonstrate a clear potential for improved experiences of families and young people.

For information on Circles of Support go to: www.circlesnetwork.org.uk/index.asp?slevel=021282142&parent_id=142
The Council for Disabled Children has worked with five local authorities on social care assessment as part of the Department for Education’s Children’s Social Care Innovation Programme. This includes work with disabled children and young people on their understanding of the role of the social worker. Young people came up with five top tips for how they think social workers should involve them in assessments (Table 3.1).

Table 3.1: Disabled children’s top tips for how to involve them in their social care assessment (Bennett, 2016: 11)

These top tips are a really useful quick guide to some of the key things young people see as barriers that need to be overcome in order for them to be able to engage effectively with the social care system and get the right support at the right time. Further examples of ‘top tips’ and engagement tools can be found in Chapter Two.

In 2016, the National Institute for Health and Care Excellence (NICE) published a guideline on ‘Transition from children’s to adults’ services for young people using health or social care services’. It focuses in particular on a number of recommendations related to planning, as do the Preparing for Adulthood programme self-evaluation tools for Children’s Social Care and Adults’ Social Care (Preparing for Adulthood, 2015a, 2015b).
Both the Preparing for Adulthood tools and the NICE guidance are clear that person-centred, strengths-based approaches to planning – where young people’s views, wishes and feelings are central – are vital to achieving positive outcomes. Young people should be fully involved in the assessment and planning process and should be supported and encouraged to make decisions for themselves wherever possible, and from age 16 onwards in line with the Mental Capacity Act 2005.

The focus on preparing for adulthood outcomes (employment, independent living, health, friends and relationships, and community participation) from Year 9 onwards as part of EHC plan reviews creates a formal opportunity to consider directly young people’s emerging views, wishes and feelings in relation to these outcomes, and to plan specific support for making progress towards them. In order to be effective, reviews need to engage the key professionals involved in supporting young people to share information and facilitate meaningful discussions. Social workers from Children’s Services and Adults’ Services are central to this process.

In 2015, the Preparing for Adulthood programme published a good practice review toolkit, which sets out a clear process for delivering a person-centred planning meeting focused on the views, wishes and feelings of the young person and the outcomes they want to achieve (Preparing for Adulthood, 2015c).

The Preparing for Adulthood Review

![Figure 3.2: The Preparing for Adulthood Review](© Preparing for Adulthood, NDTi and Department of Education, 2015c: 15)
Decision-making

The young people’s research project VIPER (Voice. Inclusion. Participation. Empowerment. Research.) found that assumptions are often made about young people’s supposed inability to engage in decision-making, both at an individual and strategic level. Such assumptions are at odds with the Mental Capacity Act 2005, which requires a presumption that young people have capacity. VIPER also found that when young people are involved in making decisions, this is often intended as a way to improve their skills rather than because they are perceived as having a valuable contribution to make to the decision at hand (VIPER, 2013). Social workers are integral to supporting young people to be involved in decisions about their lives and are responsible for ensuring information about opportunities to participate is accessible.

The introduction of a number of new decision-making responsibilities in relation to EHC plans for young people post-16 has refocused practitioners on the requirements of the Mental Capacity Act. For many young people, particularly those with learning disabilities or those aged 16 or 17, the principles of the Act are being overlooked. Often decisions are made by parent carers without consideration of the principles of the Act or a formal capacity assessment. This leads to young people feeling disempowered and lacking the skills and confidence they will need in order to make more complex decisions in adult life.

‘The more young people get involved they will learn gradually to make decisions. Young people need to be encouraged or it will be scary when they turn 16.’
Young person, EPIC
(Council for Disabled Children, 2017a: 5)

The NICE transition guidance highlights the importance of children and young people having the opportunity to be involved in their transition planning. It recommends that practitioners ensure young people have access to a range of support in order to achieve this, including peer support, coaching and mentoring, advocacy, and the use of mobile technology (NICE, 2016: 9-10).

The Council for Disabled Children (2017a) has also produced a Decision Making Toolkit to help social workers and other professionals support disabled children and young people in decision-making.

Support, provision and commissioning

Once young people and families arrive at the end of the assessment process and a plan is finally in place, the challenge of implementing that plan with limited resources remains. Often personal budgets and direct payments are seen as a ‘go to’ option to provide choice and control. However, where the provision that is needed is limited or doesn’t exist, the likely result is unmet need and poor outcomes (Slasberg et al, 2012: 170).

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15 Between 2012 and 2016, EPIC (Equality, Participation, Influencing, Change) was the Department for Education’s young people’s advisory group on the SEND reforms
The focus on preparing for adulthood outcomes requires corresponding provision to be available that will support young people to progress towards those goals. One example of this is the development of supported internships as an employment pathway for young people with EHC plans. Evidence shows that in some areas up to 65 per cent of young people engaged in a supported internship have progressed into paid employment (Allott and Hicks, 2016).

The Children and Families Act 2014 places a duty on local authorities and their health partners to jointly commission services not only across education, health and care, but also across Children’s Services and Adults’ Services.

The Preparing for Adulthood programme worked with a number of local authorities, colleges and health professionals to develop their joint commissioning in action guidance, which offers a range of options and approaches to commissioning (Preparing for Adulthood, 2015d). Given the lack of evidence on a ‘right’ approach, they suggest it is more useful to focus on ‘local agreement about clear boundaries around joint commissioning – what is in, what is out’ and (if appropriate) to start by working together on small-scale rather than whole system, big-bang change.

From their work supporting networks looking at joint commissioning the Preparing for Adulthood programme has identified some common emerging themes, which they cover in the commissioning guidance. These include:

> Personalising planning and support to achieve Preparing for Adulthood outcomes
> Developing commissioning processes and practice to support new aspirations and new ways of working, such as more flexible supports, recognition of ‘natural’ supports, increased choice and control
> Linking individual and strategic commissioning, so that individual plans and outcomes inform strategy and the strategic framework enables personalised responses. (Preparing for Adulthood, 2015d: 6)

The key activities for joint commissioning are the same as for commissioning – understand, plan, do and review – but undertaken in collaboration with relevant partners and underpinned by:

> capacity to lead/develop joint commissioning
> governance that keeps partners focused on outcomes, ensures accountability and resolves disputes.
Case study: Moving On, London Borough of Enfield

In the London Borough of Enfield the changes in the legal framework for SEND and adult social care, alongside the focus on preparing for adulthood outcomes, are acting as a clear driver for change.

Enfield’s existing approach to transition, which is known as Moving On, is clearly set out on their Local Offer with links to accessible information for parent carers and young people. However, there is still more to do. They are in the process of co-producing new approaches, in partnership with Adults’ Services, to look at how they can create a more ‘seamless’ experience of transition for young people.

As part of this work, Enfield will be focusing on joint commissioning across Children’s and Adults’ Services for young people who have had a child’s needs assessment/Moving On assessment under the Care Act 2014 and found likely to be eligible for an adult care and support plan when they reach age 18.

Enfield have also identified a gap for young people with SEND who are likely to need the support of being eligible for adult social care, but who may have achieved their educational outcomes and so no longer require an EHC plan, or who may be able to continue to meet their preparing for adulthood outcomes in a non-traditional educational setting.

Over the coming year, Enfield are planning to develop their SEND transition pathways for this group of young people. This will look at how the focus on preparing for adulthood outcomes is maintained and prioritised as young people move into the adult social care system with or without an EHC plan.

Workforce implications

In order for any of these elements of planning, commissioning and delivery to take place consistently, there are a number of things need to happen in relation to the workforce:

> Planning and designing the workforce to ensure the right mix and numbers of workers, with the right skills and knowledge, to meet the needs of the young people and families they are supporting.

> Developing and supporting staff, throughout their employment, to ensure they deliver a service that is person centred, outcome focused and that is right for the young people and families that they are supporting. This involves recruiting and selecting the right workers, ensuring they have effective inductions, supporting and supervising them, appraising their performance and focusing on their continual professional development.

> Offering a range of training and development options including formal or accredited training courses, informal training such as mentoring, shadowing, practical toolkits and learning from and sharing best practice – including through the involvement of young people in designing and delivering such training and development.

(Preparing for Adulthood, 2015e: 7)

16 To see more about Moving On, including a three-minute video, go to: https://new.enfield.gov.uk/services/children-and-education/local-offer/young-people/young-people-over-14/
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Systems and frameworks that are misaligned need to be better integrated and to focus on the experience of young people and families rather than the experience of professionals.

People working in the system want to support young people and their families to achieve positive outcomes and have fulfilling adult lives. They want to work together in partnership but the systems and structures within which they work continue to be in conflict with the ethos of integrated working. For many practitioners in frontline social work, there is also a feeling that transition is not a priority at a strategic level.

The NICE guidance recommends that:

*Health and social care service managers in children’s and adults’ services should work together in an integrated way to ensure a smooth and gradual transition for young people. This work could involve, for example, developing:

  > a joint mission statement or vision for transition
  > jointly agreed and shared transition protocols, information-sharing protocols and approaches to practice.*

*Service managers in both adults’ and children’s services, across health, social care and education, should proactively identify and plan for young people in their locality with transition support needs. (NICE, 2016: 6-7)*
Conclusion

Despite the array of guidance in this area, transition continues to be a challenge for many young people and their families, particularly where there are several agencies involved in a young person’s care. The relationships between children’s and adults’ social work teams can be variable, with different teams holding responsibility for transition in different authorities and some confusion over the accountability for young people achieving their goals into adulthood.

However, the drive for change is apparent and there is a renewed sense of priority in this area, with real aspiration and ambition emerging for disabled young people. Although new legislation has put pressure on areas to develop new approaches quickly, it has also highlighted the importance of young people’s involvement in decision-making at both a strategic and individual level. As this starts to become the ‘norm’ young people’s motivation and creativity will continue to have a positive impact on the system and the practitioners working within it, ultimately leading to better outcomes for young people and their families.

The role of social workers as aspirational and committed champions for young people going through transition is vital in engaging all of those multi-agency professionals involved in an individual’s care and support in order to develop joined-up, effective and person-centred plans that lead to positive outcomes.
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About the author

Caroline Bennett

Caroline is Assistant Director for Social Care at the Council for Disabled Children (CDC). She is a key player in ensuring the success of CDC’s social care training programmes, which look at the links across recent changes in SEND legislation. She has a particular interest in supporting young people and their families as they prepare for adulthood.

For several years Caroline was the Director of a community interest company that she set up to support young people with autism to engage in outdoor adventure activities. She was previously the CQC registered manager of a short break outreach service in a local authority. Her experience of supporting families to navigate existing support systems has allowed her to see how challenging this system can be both for families and the professionals working within it. Caroline is passionate about using her wealth of experience to change and improve outcomes for children and young people.
Chapter Four

Safeguarding and promoting the wellbeing of disabled children and young people

Amanda Harvey, Caroline Bennett and Hannah Warwick

Introduction

Disabled children and young people and those with special educational needs have a right to live full and happy childhoods, to fulfil their potential and to be active within their community. Social work with disabled children provides the unique opportunity to work with children, young people and families with a diverse range of needs and to offer varied support, often focused on promoting wellbeing. At the same time, safeguarding disabled children and young people is fundamental to good social work practice.

The safeguarding context for disabled children and young people

There are a variety of factors which increase concern in relation to safeguarding disabled children.

- There is a lack of specialist social work knowledge and confidence around working with disabled children.
- Research consistently highlights that disabled children and young people are at increased risk of abuse and neglect. Professionals working with disabled children, carers and their families must recognise and be alert to these vulnerabilities (Sidebotham et al, 2016; Schooling, 2017).
- Disabled children are over-represented in serious case reviews yet under-represented in child protection plans (Miller and Brown, 2014).
- There can be a lack of clarity within local services about where responsibility should be held for safeguarding disabled children and ensuring effective safeguarding responses are occurring (Stalker et al, 2010).

Children who live with a physical, sensory, intellectual or mental health disability are among the most stigmatized and marginalized of all the world’s children. While all children are at risk of being victims of violence, disabled children find themselves at significantly increased risk because of stigma, negative traditional beliefs and ignorance. (Groce, 2005: 4)

A sensible balance needs to be struck between managing risk and limiting freedoms as some types of risk-averse approach can limit children’s inclusion in mainstream activities (Gleave, 2008), which in turn may create pressure on families and potentially contribute to family breakdown (Contact a Family, 2011). In practice, there is significant variation in the application of law and policy across local authorities. Statistics suggest widely different approaches to early intervention, identification of children in need and rates of children taken into care.
Evidence indicates these differences are not simply due to local demographics or available resourcing, but that local policy has a direct impact on children and young people’s outcomes (All Party Parliamentary Group for Children, 2017).

This chapter will explore the evidence on effective practice for safeguarding and promoting the wellbeing of disabled children and young people in the context of the changing nature of assessments and direct practice.

The challenges for practice

Analysing the safeguarding of disabled children is challenging for a number of reasons. A recent report for The True Colours Trust and the Council for Disabled Children (Pinney, 2017) highlighted the limitations in data sets that record a single, primary category of need. Where the primary need is neglect, for example, a child’s disability may not be evident (Pinney, 2017: 19). Pinney also noted different definitions of disability are in use, with each sector using a different set of definitions tailored to reflect their own priorities.

Thresholds for social services support for disabled children and their families are high and vary widely from area to area. Across the UK, the number of disabled children and young people with complex needs who are likely to need health, education and social care support is increasing. Pinney (2017: 12) estimates that this population has increased by 50 per cent in the last decade. This is due to a number of factors including: increased survival of preterm babies; increased survival of children after severe trauma and/or illness; and increased life expectancy of children with life limiting conditions (Pinney, 2017: 4). Yet the proportion of children with a disability who are supported by Children’s Services is steadily falling and now stands at 0.4 per cent of all 0 to 17-year-olds; this suggests that qualifying for local authority help may be increasingly difficult for disabled children and their families (Pinney, 2017: 13).

The ‘Warwickshire judgment’ has implications for the assessment of disabled children. It arose from the processes by which Warwickshire County Council sought to reorganise its social care services for disabled children and achieve financial savings while also implementing the new scheme for special educational needs and disabilities introduced by the Children and Families Act 2014. Following the judgment, a duty to assess remains where a child is defined as ‘in need’ under the Children Act 1989, but it is up to each local authority to decide on the type of assessment that is appropriate in order to identify the needs of a disabled child (eg, via an ‘early help’ assessment or a section 17 assessment where a child’s needs are more complex) (Broach, 2015). This reflects the current context of increased local control and varied service provision. Whatever the assessment, it should be aligned with and informed by other assessments or plans in place, including Education, Health and Care (EHC) needs assessments and plans (Council for Disabled Children, 2015b).

While research indicates that disabled children are more at risk of being abused than non-disabled children, they are also less likely than other children in need to become the subject of child protection plans (Ofsted, 2012; Cooke and Standen, 2002; Schooling, 2017). In its thematic inspection *Protecting Disabled Children*, Ofsted found that although clearly identified child protection concerns were investigated promptly, delays were evident in relation to less clear-cut issues such as neglect (Ofsted, 2012: 32).

Stalker et al (2010) discuss qualitative findings on the under-reporting of abuse of disabled children. One of the challenges they identify is a ‘disinclination to register formal child protection concerns’ where a practitioner has a close working relationship with parents and may over-identify with the demands associated with caring for a disabled child.

*Other professionals were described as unwilling to believe that disabled children could be abused and consequently not ‘seeing’ it.* (Stalker et al, 2010: 18)

An increased focus on the safeguarding needs of disabled children and young people over recent years has undoubtedly led to improvements in practice across the UK (Miller and Brown, 2014; Ofsted, 2012). Ofsted’s thematic inspection found effective multi-agency support was being provided at an early point; a wide range of professionals made timely referrals when they had concerns about disabled children; and when children were placed on child protection plans, this led to an improvement in their outcomes (Ofsted, 2012: 5-6).

The introduction of the *Children and Families Act 2014* has brought a number of measures to improve the support system for disabled children and young people and those with special educational needs. The nature of access and provision of support and services for disabled children, young people and their families is changing. For example, personal budgets are increasingly being used to support and promote independence for children, young people and their families, including those with EHC plans (Crosby et al, 2015). Personal budgets afford young people and their families the freedom to determine the most effective support arrangements. However, they also carry risks (of financial abuse, for example), although involving young people in their own assessments and planning can help to mitigate this (Crosby et al, 2015). In addition, young people face multiple assessments to determine their education, health, social care and financial needs and there is a need for these to be coordinated.

The Council for Disabled Children’s experience from work with local authorities suggests that thresholds and eligibility criteria are often difficult for families to access and understand. This leads to confusion and anxiety about how to get the sort of support that could promote wellbeing and prevent family breakdown, such as short breaks (Bennett et al, 2016). Where thresholds are high, families are often only provided with support once their situation has reached a crisis point, which can have a significant negative impact on outcomes.
Concerns about inconsistent thresholds exist across all aspects of children’s social care. In their triennial analysis of serious case reviews, Sidebotham et al (2016) state that higher thresholds are connected to an increase in child protection cases from 2009, which has coincided with cuts to services and increased workloads. As a result, agencies tend to adopt short-term solutions that may not adequately take into account the long-term needs of children and families (Sidebotham et al, 2016).

Where specialist services are provided for disabled children and young people, it is unclear if needs are adequately met and coordinated through short break services, early help and universal provision, all of which are increasingly under pressure. However, where this does happen in a person-centred and coordinated way with a focus on outcomes, we know that the impact on disabled children, young people and their families is positive.

Research tells us that short breaks can have a positive impact on:

- carers’ health and wellbeing
- carers’ ability to continue caring effectively
- carers’ resilience in the face of other stressors
- children’s confidence and maturity (where short break services are high quality, consistent and sufficient to meet needs) (Hatton et al, 2011).

There is evidence that for some disabled children at a child in need level, work is poorly coordinated, with many plans lacking detail and a focus on outcomes. This lack of rigour in the child in need processes increases the risk of child protection concerns not being identified early enough (Ofsted, 2012). What is clear is that increasing thresholds for these services leads to a process where children and young people with high levels of need are escalated through tiers of service as gaps occur and the result is significant pressure on specialist services (Lenehan, 2017).

There remain concerns that findings from Ofsted’s (2012) thematic report on safeguarding disabled children are still relevant (Schooling, 2017). A survey conducted in 2015 suggests that Local Safeguarding Children Boards (LSCBs) have not made sufficient progress against Ofsted’s 2012 recommendations, which included prioritising disabled children, gathering and evaluating local information and practice on disabled children, ensuring that thresholds for child protection are understood and applied, as well as putting in place strategic, preventative approaches to safeguarding disabled children (National Working Group on Safeguarding Disabled Children, 2016). Schooling (2017) points out that only a minority of LSCBs’ annual reports include any analysis of why there are low numbers of disabled children on child protection plans. She also highlights the lack of preventative strategies to protect disabled children.
Very little research has been undertaken in which disabled children and young people have been asked about their experiences of abuse and/or the child protection system. A small-scale study into the experiences of deaf and disabled children by the University of Edinburgh and NSPCC (Taylor et al, 2015) heard from survivors of abuse that their disclosures of abuse were often not acted upon. Professional responses left children feeling as though they were not listened to, were blamed for the abuse or often were not believed. A recurring theme was the poor levels of awareness of what constitutes abuse among the children themselves, their family, the wider community and even the professionals they came into contact with. Children often felt let down by services or that some form of intervention from services had been needed at an earlier point than given:

‘... they should’ve recognised me when I was more littler ... That I wasn’t getting looked after.’ Jessica (Taylor et al, 2015: 30)

Parent carers have similar experiences of the system. They report a lack of understanding about how to seek help and the purpose and process of assessments. Parent carers also report anxiety and stigma related to having a social worker involved with their family and highlight a lack of transparency in decision-making processes, which can lead to confusion and disappointment. They felt the process took too long, was intrusive and often required them to duplicate information and chase progress (Bennett et al, 2016: 16). Parent carers want accessible and honest information about what services are available, the eligibility criteria for support and how to access services in a timely way.

Through the Council for Disabled Children’s work on transforming culture and practice in social care assessments (which is discussed in Chapter 1), families have consistently identified that they are ‘subject to an over intrusive, resource intensive approach to access basic requirements’ (Bennett, 2016; Bennett et al, 2016). Conversely, however, there is also ‘a tendency to under assess disabled children who need safeguarding support’ (Bennett et al, 2016: 6). Evidence highlights barriers to both the identification of concerns and an effective child protection response, such as a lack of holistic, child-focused assessments (Miller and Brown, 2014). Without robust, holistic assessments, social work interventions can become too focused on the child’s disability and on supporting parent carers in caring for their child without addressing broader issues within the family and how these might be impacting on the child (Miller and Brown, 2014).

Research has shown that good relationship-based social work practice will always make a difference in overcoming challenges. Sidebotham et al (2016) argue that children are safeguarded from abuse through trusting, nurturing relationships which lay foundations for good development. Practitioners play a key role in fostering better relationships between children and their parents and are successful in this when a good relationship with a family is established (Wilson et al, 2008).
What does good social work practice look like for disabled children and young people?

Sidebotham et al (2016) highlight that professionals working with disabled children and their families must recognise the heightened vulnerability of these children and, through the use of comprehensive assessments, the potential interaction with other risks or vulnerabilities within the family.

Leaders, managers and practitioners also need to ensure that the culture of their organisation values and prioritises work with this group of families and that the approaches taken are evidenced-based and effective. In their triennial analysis of serious case reviews, Sidebotham et al (2016) came across some cultures that worked against, and were a barrier to, effective safeguarding. Challenging and changing cultures requires strong and creative approaches which involve practitioners and management working together (Sidebotham et al, 2016: 229).

Early intervention

In our current system, an assessment is a key access tool for services and is often a family’s first point of contact with a social worker. This is the opportunity to develop a relationship with the child, young person, parents and carers; understand their unique strengths and needs; support joining up multi-agency information and plans; and develop a coordinated approach to planning and intervention.
Case study: Cornwall’s Supporting Change in Partnership (SCIP) approach

The Supporting Change in Partnership (SCIP) programme in Cornwall is a strengths-based, solution-focused, early intervention model to support disabled children, young people and families, originally developed through the Social Care Innovation Programme. It includes an introductory solution-focused conversation as a preventative intervention to support families early on and reduce the need for statutory assessment. The conversation is led by volunteer parent carers or early help staff, depending on the level of presenting need.

The approach was co-developed by bringing together a wide range of practitioners, including social workers and early help teams, and working with parent carers to create a shared vision and project plan.

The approach seeks to build resilience in families by:

> Focusing on setting a maximum of three specific and achievable goals that will improve outcomes for disabled children and young people.
> Celebrating success when goals are achieved, thereby improving families’ capacity for problem solving and reducing dependency.
> Signposting, sharing information and linking families to community resources through the Local Offer.

Key features of the SCIP approach are:

> It offers families a proportionate response.
> It is part of a systemic approach to working with disabled children, young people and their families; consequently it promotes the safeguarding and welfare of disabled children and young people.
> The approach is a time-limited intervention with a clear focus on improving outcomes.

To date, 100 families who would have previously had a social work assessment have received support through this early intervention.

A widely used approach for assessment is Signs of Safety (Turnell and Edwards, 1999) which incorporates a number of tools intended to involve children and young people in assessments and safeguarding, including ‘Words and Pictures’ storyboards (Turnell and Essex, 2006; Turnell, 2012). These tools are able to give children an understanding of what’s happened to them and why child protection services are involved with their family (Bunn, 2013). A Department for Education evaluation of Signs of Safety in ten pilot local authorities in England found that its use can lead to a strengthened partnership between social workers and families (Baginsky et al, 2017). Although the study found that significant improvement was required in the quality of assessments, it also found that where Signs of Safety mapping was done well ‘it provided the basis for informed, evidence-based analysis on which good assessments were based and then regularly reviewed’ (Baginsky et al, 2017: 103). While there is no specific evidence available on the impact on disabled children and their families, the accessibility of the approach makes it an attractive and potentially effective support tool.

Improving practice

We work in a system where we often learn from those cases that have gone wrong. In an online briefing the NSPCC (2016) has summarised findings from serious case reviews involving disabled children. The briefing includes recommendations for best practice (NSPCC, 2016):

> **Professionals should take a holistic, child-centred approach** which includes assessing all the needs of the child and their family, not just those related to the disability, as well as ensuring that parents understand and are supported to meet the additional needs of their child.

In addition, Sidebotham et al found that effective case management is fundamental to enabling good social work and is supported by good documentation, supervision and reflection. These can be promoted through appropriate training and their implementation monitored through effective audit and governance arrangements (Sidebotham et al, 2016: 226).

> **Hearing the child** means children should be spoken to alone when there are safeguarding concerns and parents not used as interpreters. Where a child’s disability limits or precludes verbal communication, then efforts must be made to facilitate communication by appropriate means. Professionals should also consider how a child may be communicating through their actions and ensure personal safety information and advice is tailored to the child’s needs and fully understood.

Even more important is understanding that children and young people, whatever their level of impairment, communicate and have a right to be heard. At a strategic level this understanding is vital for ensuring that those planning services and opportunities for disabled young people are informed by disabled young people themselves and develop services that are fit for purpose. At a societal level it is critical to challenging disablism and low expectations.
Awareness and training – professionals across all agencies should be aware of safeguarding issues for disabled children and aware of the range of services available to disabled children and their families.

Taylor et al (2014) propose that safeguarding training and guidance that is specific to disabled children is necessary for all social workers, not only those working in disabled children social work teams. Schooling (2017) emphasises that a lack of understanding and training about safeguarding disabled children can lead to professionals not recognising signs of abuse or neglect.

This is important because research indicates that identifying abuse of disabled children is most likely to come from observations of physical signs, behaviour or changes in mood. Research shows that disabled children are less likely to disclose abuse and more likely to delay disclosure. (Schooling, 2017)

Information sharing – professionals should have a shared understanding of the nature of disabilities, the services the family are receiving and the risk of harm. This information should be used by all agencies to distinguish between disability and child protection issues.

Sidebotham et al (2016) emphasise the importance of information sharing in relation to every serious case review. (Of 66 reports reviewed in depth, there was only one where information sharing was not specifically mentioned.) Effective communication requires a culture that promotes information sharing and clear systems and guidance that enable information to be used to guide decision-making and planning.

Interagency cooperation includes agencies working together to create a multi-agency safeguarding plan, having a designated lead professional to coordinate work across services and provide a single point of contact, and having specialist disabled children services embedded within wider support services for children and families.

Sidebotham et al (2016) highlight the role that schools are able to play in monitoring a child’s welfare. Schools hold important safeguarding responsibilities although, as with social care teams, variation was found among schools in terms of how they track and respond to safeguarding concerns. These key elements all point to the need for practice that is inclusive, person-centered and joined up across agencies, and focused on early identification and the provision of appropriate support.
What the evidence suggests needs to be done to enable excellent social work practice

Research suggests that new and innovative services, or new processes within existing services, are needed to help improve the lives of vulnerable people, including disabled people, to allow them to make more informed choices, give them control and enable them to participate equally in society (New Economics Foundation, 2012). The key challenge services face is how to develop and introduce these changes within the current resources and demands of the system.

Clear thresholds and pathways

Local thresholds and pathways must be set out in a way that ensures services provide appropriate support at the right stage and at the right level in order to help disabled children and young people access a full community life (Lenehan, 2017). Thresholds must be understood and applied at every stage in work with disabled children and young people (Sidebotham et al, 2016).

A major learning point from the Council for Disabled Children’s role in supporting social care workforce development activities across the country has been that local threshold documents are written within a child protection framework and do not make it clear how disabled children and young people’s broad range of needs will be met by the local area. Some areas have developed standalone threshold documents for disabled children but these are not adequately joined up with the child protection framework and, as a result, can lead to more confusion for families and practitioners alike.

The access points and pathways for disabled children and young people where there are not child protection concerns are in need of clarification. A shift of focus to early intervention and provision of specialist preventative services where needed would help to ensure all children and families who are likely to need a service in the future, receive help now. Recent research into repeated referrals to Children’s Services in England found that disabled children are at an increased likelihood of re-referral when their primary need is not their disability (Troncoso, 2017). We need to plan ahead to meet their needs so that ‘early help services become predominantly proactive rather than reactive’ (Selwyn, 2016: 2) and children and families are supported before they reach crisis point, when costly child protection proceedings, residential placement or admission to a mental health inpatient unit may become the only option (Pinney, 2017: 7).

The development of services and structures that support disabled children and young people to ‘step down’ safely from higher levels of services in a planned and person-centred way also needs to be prioritised to ensure disabled children and young people with complex needs can be supported in their communities.
Informed commissioning

Without appropriate services in place, the needs of disabled children and young people will not be met. Commissioning must be based on local need rather than on what provision is already available and must be able to respond to needs at all levels, including prevention, early intervention, targeted and specialist. The commissioning of services for disabled children and their families must take account of safeguarding and promoting the welfare of disabled children. Schooling (2017) highlights that accessible programmes to explore sex and healthy relationships and understand what abuse is are not always available to disabled children. Commissioners should ensure that services are available and accessible and are focused on developing resilience, reducing isolation and developing skills, including sex and relationships education and safety skills training (Taylor et al, 2015).

Multi-agency leadership and accountability

Disabled children and young people are often engaged with numerous professionals and services, yet there continues to be a lack of joined-up approaches to understanding and meeting their needs, both at an individual and collective level. Sidebotham et al (2016) recommend that children’s plans are reviewed at multi-agency meetings, with clear and focused actions as an outcome. This clearly echoes the Working Together (HM Government, 2015; Department for Education, 2017) and Safeguarding Disabled Children (Department for Children, Schools and Families, 2009) guidance, which emphasise professionals sharing responsibility for safeguarding.

Implications for workforce development

There is a need to support local areas to consider how to use resources effectively so that staff work to their skills and strengths and families get the right type of intervention when they need it. This includes developing the capacity of universal staff – for example in schools, early years settings, general practices, pharmacies, nurseries and fire services – so that they can move into a more impactful role, including dealing with issues at the point of identification rather than referring to more expensive statutory services that do not have an established relationship (Selwyn, 2016).

A vital part of meeting the needs of disabled children and young people effectively and in a proportionate way while tackling increased risks of abuse is about having the professional knowledge, skills and awareness to recognise need and signs of harm. This includes:

- The ability to communicate with the child
- Being able to undertake holistic child-focused assessments
- An ability to challenge (appropriately) parent carers and professional colleagues
- Having the skills and knowledge to recognise and act appropriately on the signs of abuse or neglect
- Having access to resources and specialist services to meet needs. (Taylor et al, 2014)
It is clear that more training and guidance in the area of child protection and disability is needed, including disability training for child protection professionals, child protection training for children’s disability teams and communication training for all staff whose job brings them into contact with children with communication impairments.

In order to support consistently good practice and identify when further development is needed, support and challenge from skilled managers at all stages is essential. Ofsted (2015) found this ensured that good assessments focused on the needs of the children and were completed within appropriate timescales for individual children.

Conclusion

Safeguarding disabled children and young people needs to be prioritised and professionals need to be supported to do this effectively. It is clear that legislative changes that promote the need and wellbeing of disabled children and young people are having a positive impact on raising awareness about the vulnerabilities disabled children and young people face.

Trying to meet the needs of disabled children, young people and their families in a timely and proportionate way while resources are reducing and demand increasing is a daunting challenge. However, key underlying principles in social work practice and opportunities in the system to create change provide us with the chance to review existing provision and to develop creative solutions to best meet these needs.

Understanding a child’s needs, building on their strengths, overcoming the barriers and developing innovative solutions for meeting the challenges will not only enhance the child’s wellbeing and protection from abuse, but will provide learning that may also be of benefit to non-disabled children. Ensuring that the many professionals who come into contact with disabled children and young people work together is fundamental to effective safeguarding. A system that is effective for disabled children will be one that is effective for all children. We need to do more to consider how best to adapt practice, assessment and intervention for children with a range of needs at an individual, local and national level. Despite the challenges for practice, the evidence points to the importance of holistic and rigorous child-focused assessments by highly skilled professionals.
The legal framework

The Children Act 1989 provides local authorities with a duty to ‘promote and safeguard the welfare of children in their area’ (HM Government, 2015: 96) and specifically includes disabled children within the definition of ‘children in need’ under section 17.

The Chronically Sick and Disabled Persons Act 1970 includes a specifically enforceable duty to provide any of a list of specified services where these are ‘necessary’ to meet the needs of the disabled child or young person, at a level that is sufficient to meet those needs.

The Children and Social Work Act 2017 enshrines in law a series of changes to the social work profession including: the creation of a new organisation, Social Work England, to take over as the profession’s regulator; a requirement for the Education Secretary’s approval for professional standards; and new powers for the Education Secretary to set improvement standards and introduce assessments for practitioners.

The Children and Families Act 2014 (Part 3) sets out core principles to which local authorities must have regard when supporting disabled children and young people and those with special educational needs (SEN) and their families. These include: obtaining their views; ensuring participation; and ensuring educational and other outcomes are promoted through appropriate education, health and social care provision. The act also places a duty on local authorities to identify all disabled children and young people and those who have or may have SEN within the local area.

The Equality Act 2010 incorporated previous anti-discrimination laws into a single Act. It provides protection from discrimination in the workplace, in receiving services and in wider society for people with ‘protected characteristics’. This legislation is the basis for all agencies having to ensure that their practice offers the same level of safeguarding to disabled as to non-disabled children.

Article 16 of the United Nations Convention on the Rights of Persons with Disabilities mandates policymakers to ‘take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse’ (UN, 2006: Article 16).
Chapter Four  
Safeguarding and promoting the wellbeing of disabled children and young people

The government’s **Working Together** (HM Government, 2015) statutory guidance sets out how organisations and individuals should work together to safeguard and promote the welfare of children and young people. (Revised Working Together guidance is due to be published during 2018 to take account of changes introduced by the *Children and Social Work Act 2017* – see Department for Education, 2017; 2018.)

The **Safeguarding Disabled Children** (Department for Children, Schools and Families, 2009) practice guidance recognises that disabled children have additional needs caused by barriers, impairments and heightened vulnerability and sets out possible indicators of abuse and neglect.

More information on the legal and policy framework is available in *Disabled children: A legal handbook* (Broach et al, 2016) published by Legal Action Group, the access to justice charity. A full version of the handbook is available to download free of charge from the Council for Disabled Children’s website.\(^{18}\)

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About the authors

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Caroline is Assistant Director for Social Care at the Council for Disabled Children (CDC). She is a key player in ensuring the success of CDC’s social care training programmes, which look at the links across recent changes in SEND legislation. She has a particular interest in supporting young people and their families as they prepare for adulthood.

For several years Caroline was the Director of a community interest company that she set up to support young people with autism to engage in outdoor adventure activities. She was previously the CQC registered manager of a short break outreach service in a local authority. Her experience of supporting families to navigate existing support systems has allowed her to see how challenging this system can be both for families and the professionals working within it. Caroline is committed to using her wealth of experience to change and improve outcomes for children and young people.

Amanda Harvey

Amanda is passionate about improving systems to better meet the needs of vulnerable children and families and has a particular interest in leadership development. Amanda’s most recent role was within the senior management team at CDC, prior to which she was at the helm of a Local Safeguarding Children Board in London where she focused on partnership working, multi-agency training and development, and improving local systems.

For many years Amanda worked as a frontline social worker within the field of child protection and safeguarding children as well as in an Adult Learning Disability Team. She has also held specialist roles providing therapeutic support to survivors of sexual assault, domestic violence and abuse.

Amanda has a Master’s Degree in Social Work as well as a postgraduate diploma in Advanced Social Work Practice Education. Amanda is passionate about making the biggest impact on the lives of disabled children and families.

Hannah Warwick

Hannah is Principal Officer for Social Care at the Council for Disabled Children where she works on a range of policy and practice programmes focusing on the social care needs of vulnerable children, including disabled children and those with special educational needs.

Hannah holds an MSc in Social Work and is a Systemic Practitioner, having also obtained a Graduate Diploma from the Institute of Family Therapy. Hannah’s practice experience is in child protection and family support social work. She is passionate about strengths-based practice with families and sharing innovative practice with other professionals.
Chapter Five

Working together for disabled children in Birmingham

Chris Bush

Introduction

Partnership is at the heart of what social workers do – both working with those whose lives we endeavour to support and working in partnership with other agencies and practitioners across a range of professional disciplines.

Working together was explicitly recognised as an integral part of practice by the Children Act 1989. For social workers working with disabled children, young people and their families, the Children and Families Act 2014 and Care Act 2014 extended the expectation of partnership working to promote personalised support for young disabled adults and those with special educational needs up to age 25.

This chapter is about how Disabled Children’s Social Care and a range of partners in Birmingham have worked together to identify improved ways of working to support disabled children, young people and their families. Specifically, it highlights three projects:

1. Bringing plans together for children, young people and families, in education, health and care
2. The Disability Network Forum: A solution-focused approach to supporting disabled children and their families
3. The Children Who Wait project: Working together to ensure a positive discharge from hospital for children with complex needs.

Implementing the government’s reforms for children and young people with special educational needs and disabilities (SEND) in our large and diverse city has been challenging, as it has for many other local authorities and their partners around the country. In Birmingham, the whole system has been under great strain to try and meet deadlines to deliver within the allocated budget.

In highlighting these three projects, we are not seeking to suggest we have been exceptionally successful or to advocate any particular methodology for partnership working. But by sharing our partnership experience, and in particular our efforts to overcome some entrenched problems, we hope we might be able to contribute to positive developments and debate elsewhere.
The chapter concludes with a summary of some of the lessons we have learnt and which we are taking forward as we seek to build on and consolidate our partnership working for the benefit of disabled children, young people and their families.

**Birmingham in context**

> Birmingham has a total population of 1.1 million people, of whom 270,000 are aged 0 to 18.

> Around 47,000 children and young people (aged 0 to 18) have some form of special educational need or disability (SEND) in its broadest sense. This includes children with complex health needs, as well as those known to the disabled children’s service.

> Around 8,300 children and young people (aged 0 to 25) have an EHC plan or SEN statement.

> At any one time, the city has around 1,800 children in care, 1,000 children with a child protection plan and 2,200 children with a child in need plan.

> Within the child in need statistics are children who are disabled and meet the threshold for support from the Disabled Children’s Social Care team.

> In 2016, Birmingham had the largest volume of school pupils (more than 6,500) with a Statement or EHC plan of all major cities in England - more than 2.5 times the next highest, which was Manchester.

> More than 1,000 new EHC plans were made in Birmingham during 2016 - a 13 per cent increase on 2015 levels.

> Young people aged 16 to 25 account for more than one in four EHC plans in Birmingham.

**Working together across education, health and care**

**1 Bringing plans together for children, young people and families**

In Birmingham, as elsewhere in the country, developing Education, Health and Care (EHC) plans with children, young people and families has been a major component of the implementation of the SEND reforms introduced by the *Children and Families Act 2014*.

We benefited from close links with a number of SEND Pathfinders in the region, especially Solihull and Nottinghamshire; we also learnt some valuable lessons from the work of Wolverhampton, who had developed innovative practice. These contacts, in part, helped us to develop an effective Local Offer website, and a programme of work (where most EHC plans are delivered within the timescale required) and models for co-production of services and pathways.
Our planning for the introduction of EHC plans was developed over a couple of years. In the early stages, we held a range of initial low-key consultations with families. This enabled us to identify young people and parent carers with whom we could co-produce a new approach to meeting the needs of disabled children, young people and their families.

Over a two-year period, we also ran three large-scale strategic consultation events for young people and parent carers. These were attended by councillors and directors, as well as practitioners. Each event was informed by the work we had already done with families and so we were able to include a 'you said, we did' element. During this time, we were also drawing up our Local Offer, which was developed entirely with young people and parent carers.

Our close work with local families had led us to see the introduction of EHC plans as an opportunity to develop a new approach – in particular, to use the Local Offer, Early Support and Early Help as an opportunity to overcome some long-standing problems and develop a coordinated response to bring a team around the child and family to meet needs with one assessment and plan. Across education, health and social care, we wanted to use the new process as a framework to provide the right support at the right time, allowing for an escalated response wherever needed.

Much of the learning from this work was about communication and supporting families to tell their story once with good coordination where necessary. The difference was that of expectation – establishing an expectation of working together and an expectation that social care and Early Years would be aware of children at an early stage. This approach allowed professionals who historically had often worked in isolation, or in 'silos', to begin to appreciate the benefits of working together across services from partner agencies.

The SEND and Inclusion Strategy

Our efforts to bring about substantive and sustainable change were supported by the City Council’s decision to appoint an independently chaired Inclusion Commission to undertake a wholesale review of provision for children and young people with SEND and to take a lead role in developing a new SEND and inclusion strategy for the city (see box).

A draft strategy was published in the summer of 2017. It envisages a strengthened approach to co-production and a step-change in personalisation and potential for individual budgets (including offering a Personal Budget to all families or young people with an EHC plan). The strategy also includes a commitment to supporting children and families as close to their home as possible, in line with what parents and children say they want (see next page).

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19 Parents and young people made it clear that they wanted to be actively involved in the development of the programme. As well as co-production of the Local Offer, for example, we ran a number of family days (with a ‘graffiti wall’ consultation), in-school lesson plan consultations, and included young people in our pilots steering group (and in the pilots themselves).
Birmingham’s Inclusion Commission and SEND Strategy

In 2016, Birmingham City Council appointed an independently chaired Inclusion Commission to lead a comprehensive review of the city’s approach to providing support for children and young people with SEND.

While the city already had many strengths – including high-quality special schools with a good working relationship with health and social care, good outcomes at age 16 and 19 for most young people with SEND, and a multi-agency Complex Cases Panel to co-ordinate provision where commissioning involves education, health and social care – councillors and officers had identified the need for a root and branch review for a number of reasons. These included:

- There was a lack of clarity about the package of SEND support families should expect in mainstream schools and other settings from age 0 to 25.
- Many families were not satisfied with the level of support and there were too many complaints and appeals to the SEN and Disability Tribunal.
- Compared to its statistical neighbours20 and other large metropolitan boroughs, Birmingham had a high number of EHC plans, and there was a perception among families that this was the only way to guarantee needs being met. When EHC plans were needed, the contribution from health and social care was sometimes limited.
- Most high-needs funding was being spent on specialist provision, which was under huge demand. In particular, many young people were placed in costly independent placements, which was unsustainable in the long term.

The review was informed by six work streams, each chaired by a senior leader from a local school or the council. Parent carers were fully involved throughout, either as members of an individual work stream or through a separate consultation facilitated by the Parent Carer Forum. This helped ensure their views would be embedded in the final strategy.

A joint vision was developed by the Inclusion Commission and the council for every child and young person aged 0 to 25 with SEND to have the opportunity to be happy, healthy and achieve their fullest potential, enabling them to participate in all aspects of life.

A draft Strategy for SEND and Inclusion 2017-2020 was published for consultation in summer 2017. A key aspect of its mission is a commitment to developing an inclusive system where practitioners work with families, children and young people to build genuine and good quality partnerships to achieve the best possible outcomes for children and young people.

The new strategy sets out actions across three key priorities: assessment, service provision and funding.

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20 Statistical neighbours are local authorities that have similar characteristics. Since 2007, every local authority has been assigned to a group of authorities with similar socio-economic characteristics. This enables an authority to compare its performance in a range of children’s services and outcomes (eg, pupil attainment, child protection, children in care, as well as SEND) against similar authorities and so provide a guide as to whether performance is above or below the level that might be expected.
How has this approach strengthened practice?

Our step-by-step approach to consultation and our commitment to co-producing new policies and procedures with families has enabled us to develop an effective EHC planning process that meets our statutory obligations and is well on the way to reflecting fully the voice, aspirations and lived experiences of disabled children, young people and their families.

As practitioners and service leaders, we now recognise explicitly the need to work together to have one plan that addresses the needs of each child or young person and in a way that is recognised and owned by the family. Families in Birmingham have made clear to us that this is what they want and expect, so that has become the driving force for all frontline practice.

For practitioners, another key change has been a growing appreciation of each other’s roles. Professionals recognise that each agency has specific responsibilities and there is increasing recognition and respect about whose role it is to make a ‘call’ in terms of resources. (It is now less likely, for example, that a doctor will tell a parent what school or social care resource they need; rather, they will recognise this as the responsibility of education and social care.)

As the Strategy for SEND and Inclusion is implemented over the next three years, we also intend to carry out an Appreciative Inquiry\(^2\)\(^{1,2}\) review that will help us build on what we have achieved so far.

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21 Appreciative Inquiry (AI) is a strengths-based (rather than deficit-based) approach to organisational change. It is a way of reviewing organisational and collaborative working by focusing on an organisation’s intentions and aspirations through an approach that encourages thought about how an issue may be addressed differently. AI makes a conscious choice to study the best of an organisation and what is working well (rather than seeking to overcome weaknesses); it focuses on core strengths and using those strengths to bring about change and create a more effective and sustainable future. See: [www.davidcooperrider.com/ai-process](http://www.davidcooperrider.com/ai-process).

22 See also Kessler (2013): [http://dx.doi.org/10.4135/9781452276090.n14](http://dx.doi.org/10.4135/9781452276090.n14).
The Disability Network Forum: A solution-focused approach to planning support

Birmingham’s Disability Network Forum is a solution-focused network of professionals who first came together in 2014 to address a gap in provision for disabled children and their families. The initiative was developed as a direct response to three problems:

> There was a commonly held belief among a range of local community professionals that it was ‘almost impossible’ to gain access to Disabled Children’s Social Care. This was compounded by a mistaken view that only safeguarding concerns, rather than requests for early help, could be referred to children’s social care.

> At the same time, there was a growing belief within Disabled Children’s Social Care that the service was not getting to see some disabled children with specialist social care needs who would benefit from our service. In particular, we were concerned that very young children and children with very complex needs were not being referred to the service early enough.

> Disabled Children’s Social Care had received a number of complaints about a lack of response to referrals of which the service was completely unaware; this was because the referrals had been passed to another team for resolution. These referrals had been directed to the wider children’s social care team correctly; however, the referring agencies were not aware that the DCSC team does not deal with every request from a family with a disabled child.

The initiative

As a first step, we held a series of small-scale consultation events with parent carers and professionals. Groups met to consider whether there was a need to establish a new type of referral pathway or discussion forum at which frontline community practitioners could receive advice, information and specialist guidance on individual cases as part of a solution-focused approach. (It’s worth pointing out that one anxiety expressed within the Disabled Children’s Social Care team at this time was a perceived risk that any new process might substantially increase demand to the team.)

Following the consultations, it was agreed to trial a new forum-based scheme in the East of Birmingham. This area was chosen because we knew many families there felt excluded and because it had the highest discrepancy between potential and actual demand. Language issues and cultural expectations meant some families struggled or were unable to navigate the existing systems effectively. The pilot forum was set up in a local Family Centre.
The original forum members were:

- Health visitor
- Early help advisor
- Educational psychologist
- Social worker
- Occupational therapist
- Teacher (from Early Years Inclusion Support)
- Nursery special educational needs co-ordinator (deputy manager)
- Health visiting service manager
- Nurse (from the local Child Development Centre)
- Special Educational Needs Assessment and Review representative
- Social care senior manager (Chair).

Membership of the forum is kept under review. The majority of members have remained the same, but the forum now includes a housing adviser (from Shelter) and a school nurse (from the Special School Nursing team). There is now also an active link with the housing needs service to help resolve potential housing issues for children with very complex needs.

Members of the forum agreed their purpose was to:

- Improve access to services for disabled children and their families
- Build on the early support and early help approach and implementation of EHC plans
- Improve understanding among all professionals about what other local services do and can offer, and how those services can support children and their families
- Consider cases where discharge from hospital is an issue (see the Children Who Wait project described below).

The Disability Network Forum and how it works

Birmingham has five Early Help Panels, which operate across the city’s Areas, and we have developed a model of working whereby up to three members from the panels have also become members of the Disability Network Forum. This enables them to seek advice from the forum when the local panel does not possess sufficient specialist knowledge to advise practitioners on the best way forward.

Panels can identify disabled children and young people whose support is being managed through the Common Assessment Framework or an Early Help plan, but for whom that process appears to have become ‘stuck’ or for whom services appear not to be meeting their needs effectively. The panel member can then refer the case to the forum once the relevant practitioner has secured the family’s agreement to the case being discussed within a wider multi-professional group.
The forum does not take operational responsibility for individual cases, but it does offer to address any barriers to the child and family receiving the support they need. This restorative practice\(^{23,24}\) approach ensures that the range of professional 'contacts' on the forum, and the breadth of expertise they represent, are used to facilitate the family getting access to the right support at the right time. In practical terms, we have found that we can jointly identify solutions to difficulties and ensure agencies are working in a coordinated and effective manner, and this in turn can provide more constructive and focused support to families.

An important additional benefit of the multi-agency forum has been the opportunity it has provided for all professionals involved to provide information about their service to other forum members (and so for onward wider dissemination). All members of the Disability Network Forum were asked to provide a ten-minute talk with information and leaflets. Similar invitations are regularly extended to other local agencies, such as voluntary sector agencies providing different kinds of specialist support.

**How has this approach strengthened practice?**

The Disability Network Forum meets twice a month and now covers the whole city. Since it was first set up in the spring of 2014, the forum has provided advice and guidance in relation to more than 75 children. Feedback has been very positive from both professionals and families. The forum has proven to be an effective model for responding to children’s needs, as well as reducing demand on services for more complex children. As the forum establishes itself, we are seeing a ‘tipping point’ where practitioners are actively choosing to use this resource before escalating an issue.

Only a handful of cases have been allocated on to Disabled Children’s Social Care, dispelling earlier fears of creating increased additional demand. In fact, more professionals have been helped to support families within the community by using universal or targeted services. For most of the children and families whose cases have been discussed by the forum, issues have been resolved by the support given following the forum’s advice. For a smaller number of children, it is clear that the forum has enabled their cases to be escalated (appropriately) to Disabled Children’s Social Care, and at an earlier stage than would have happened previously. Other benefits resulting from the project are: a better understanding among other agencies of the role of Disabled Children’s Social Care; closer links with Early Years Inclusion Support and Child Care; and changes to the commissioning of Early Help and Health Visiting based on learning from this work.

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\(^{23}\) Restorative practice describes a way of working that focuses on building and maintaining healthy relationships, finding solutions to difficulties, and repairing harm where there has been conflict. Rather than one specific approach, it covers a range of formal and informal processes to encourage more effective communication and understanding, and a sense of shared responsibility. Leeds City Council have published a helpful ‘one minute guide’ to restorative practice; see: [www.leeds.gov.uk/docs/Restorative%20Practice.pdf](http://www.leeds.gov.uk/docs/Restorative%20Practice.pdf)

\(^{24}\) The fundamental unifying hypothesis of restorative practices is that ‘human beings are happier, more cooperative and productive, and more likely to make positive changes in their behavior when those in positions of authority do things with them, rather than to them or for them’ (Wachtel, 2005). See: [www.iirp.edu/what-we-do/what-is-restorative-practices/defining-restorative](http://www.iirp.edu/what-we-do/what-is-restorative-practices/defining-restorative)
All members of the forum (and, through dissemination, the wider professional teams from which those members are drawn) have become much better informed about the roles and responsibilities of partners and what services are available locally. Forum members who attend Early Help Panels are now more widely skilled in offering information, advice and guidance, which has helped improve the panels’ response to disabled children and their families.

A further development of the Disability Network Forum has been their support and involvement in the Children Who Wait project with Birmingham Children’s Hospital. Details of this project are set out below as our third example of working together.

3 The Children Who Wait project: Working together to discharge children in hospital with complex care needs into the community

The Children Who Wait project was set up to help ensure a positive discharge from a long-term hospital stay within Birmingham Children’s Hospital (BCH) for children and young people with complex health needs. It was initiated to address the situation of children routinely staying in hospital longer than necessary and receiving inconsistent support on discharge. Not only was this protracting the child’s return home, it was placing additional stress on families.

NHS commissioners and senior managers of Birmingham Children’s Hospital NHS Foundation Trust25 had identified this as a significant problem in the autumn of 2014.

At that time, Birmingham City Council had no children in BCH who had been identified for discharge and were delayed. However, we knew there were children in the city with continuing healthcare or complex needs for whom the process of discharge had not always gone well. This was our driver for change; all professionals must be ready to support a positive discharge for children and their families.

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25 In February 2017, Birmingham Children’s Hospital and Birmingham Women’s Hospital merged to form Birmingham Women’s and Children’s NHS Foundation Trust
On reviewing our practice within Disabled Children’s Social Care and with BCH, we identified a number of shared problems and issues. Using a restorative practice approach (see above) we carried out a process mapping exercise with the direct involvement of children, young people and families. This identified these key issues:

- Communication between BCH and the services involved in supporting children and families was often poor or lacking.
- BCH’s planning for discharge was often starting too late, which was compounded by long lead-in times for assessments from other teams.
- Engagement with other agencies (eg, housing, fostering) was not always completed or carried out early enough.
- A need for all concerned to understand and appreciate the different roles, expectations and timescales for other professionals – and to appreciate the expectations of and timescales for children and families themselves.
- The service response must recognise that admission to hospital can signify a major – and often completely unexpected – change in the life of a child and their family (eg, a major accident with lifelong consequences); in these circumstances, support to families is likely to be significant but each family will have different needs.

How the project works

Our aim was to develop a simple process and pathway. We identified the following groups of children as those who would come within the project’s scope:

- Children who have been in hospital for more than 30 days.
- Children with medical complexity who require care from more than two specialist departments (eg, oncology, neurology, audiology) within BCH and who will need to be discharged with support.
- Children with life-limiting conditions or who have other complex needs, including psychosocial or physical health needs.
- Children whose families are under significant stress and are likely to need intensive support.

The project involves an innovative partnership working together to support the local delivery of services and of children’s return to the community. As well as Disabled Children’s Social Care the partnership includes: consultant paediatricians; hospital discharge sister; discharge co-ordinators (including housing needs); hospital and community occupational therapists; community complex care nurses and commissioners; physiotherapists; health commissioners; and BCH’s Young Persons’ Advisory Group (YPAG).

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Process mapping helps professionals understand the care experience from a service user’s perspective. A process map can capture how many times (and for how long) a child and family has to wait, for example, and how many different people and services they have to see. It can be especially helpful when care involves a number of clinical and social care pathways. Like a road map, it shows the child’s journey through a particular service or range of services. The map is usually drawn up by bringing together young people and families with those involved in their care and support.
The project group worked together to review processes and identify children to return to the community. Individual meetings were held with families using a ‘child in need’ approach that brought all agencies together. These multi-agency meetings helped identify and overcome the barriers to a positive discharge and helped speed up the process. For example, it was important that all involved recognised that social care need up to 35 days to complete an assessment and that ‘early alerts’ from hospital staff are required to enable the assessment process to begin, even when a discharge date is not imminent. This helped ensure there was no delay in discharge.

The project worked through the Disability Network Forum (see above) to promote early case discussion and offer advice. This has included forum members identifying a number of recommended actions to complete prior to discharge. Individual examples include a referral to Early Years Inclusion Support to request home teaching, and applications for housing which have enabled families to move to a more appropriate or adapted home to meet children’s needs.

Some practical adjustments have also been made to accommodate a multi-agency approach:

- Disabled Children’s Social Care have agreed that all social work assessments for children on this pathway will be completed by a senior social worker who has sufficient experience to appreciate the complexity of the child and family’s needs.
- Meetings now take place within BCH as well as the local community (in recognition of the difficulties health professionals face in attending meetings away from their work base).

**How has this approach strengthened practice?**

Partnership working through the project has helped improve outcomes for some very ill children with complex needs, including those with life-limiting conditions, and their families. Advice from the Disability Network Forum has helped bring about a number of changes with significant practical benefits for the children and families receiving services. For example:

- Support is now coordinated at a universal and early help level for young disabled children, when none may have been provided previously.
- Children with complex health needs are returned home safely in a coordinated and more timely manner than previously achieved.
- Children and families with very particular needs are being identified and prioritised for appropriate housing. (Previously, we were quite unable to effectively identify and act on housing issues.)

BCH staff also now report (and demonstrate) greater awareness and understanding of the universal provision and support available for families within local communities. This aspect of the project – striving to support a ‘seamless’ transition from hospital care to community care – has proven to be highly effective, and strong working relationships continue to develop between health, social care and education.
The project has created partnerships among professionals who now know each other well and are able to have ‘difficult’ conversations if need be. The group is also able to provide knowledge and skills to parents to help prevent the re-occurrence of crises. Feedback from parents has been positive. Since May 2015 (from when our most recent data is available) we have supported 21 families and received positive feedback of children returning home safely with adequate support and help.

Although it is clear that discharge into the community is now more positive and engaged, with a better level of shared understanding about the issues and risks involved, formal data is limited at this stage. Our perception is that work to speed up a move out of hospital is better for the child and family, but also saves money. Our intention is now to gather data on these issues. We are also considering implementing a qualitative assessment of change for the child and family using a quality of life questionnaire.

Postscript: A merger

In June 2016, professionals on the citywide Disability Network Forum and those working to improve hospital discharge as part of the Children Who Wait project reflected on what they had learnt. A decision was taken to merge the Children Who Wait project and the Disability Network Forum in order to create a strong and effective group to support disabled children, young people and their families.
Conclusion – learning the lessons

What overall lessons have we have learnt from our experience of seeking to innovate in our partnerships for disabled children and their families in Birmingham? A number of key learning points have emerged from our working together.

> **Systems must focus on the child and family:** A key ingredient of each initiative has been an attempt to focus on the needs of the child and family and the context of their lives – in other words, to hear their views *in a meaningful way*. Professionals must have full regard to the child and family’s aspirations and identify the needs that can be met. This is not the same as ‘doing what people want’; rather, it means facilitating a conversation about actual needs and realistic solutions. Time after time, in each of these projects, solutions were found when professionals worked together to focus on the needs of both child and family.

> **Partnership means recognising everyone’s role, including parents and young people:** Aims are better achieved through a partnership model that recognises and respects the roles and responsibilities of professionals and parent carers alike. Any approach that fully involves parent carers and young people as genuine partners is more likely to support change and ensure effective services. All our projects adopted an approach that explicitly supports each professional role, including the voices of children, young people and parent carers. A crucial part of this has been requiring professionals not to speak for other agencies, but instead to refer back to professional colleagues. Examples of getting this wrong are well known – a doctor who suggests a child needs a children’s home, or a social worker recommending a special school. We have had to learn to express our views and respect the decision of the responsible authority.

> **A restorative approach helps ensure a focus on solutions:** Restorative practices (see footnote on page 77) are an important part of the way we endeavour to support families and partner professionals to become better equipped to address challenges and find solutions. The Disability Network Forum and the Children Who Wait initiatives were both set up with this particular approach.

Our model has been always to be ‘solution focused’ as professionals and to facilitate working together with a view to improving the lives of the child or young person and their family. Although situations have sometimes been challenging for the professionals involved – when a child’s situation has become ‘stuck’ in some way and practitioners disagree about how to move forward – feedback from those who have turned to the Disability Network Forum for help (and feedback from the families themselves) has been that the guidance and support have enabled them to resolve issues almost entirely without escalation.

A more recent element of our approach has been to use Appreciative Inquiry (see footnote on page 74), whereby we have engaged with stakeholders and partners to determine change and to avoid, wherever possible, a deficit model. The approach has involved utilising a high-challenge and high-support model where evidence of actions and inactions are addressed at all levels.

Both approaches have been a practical way to support local provision and buttress early help while reminding staff that our overriding commitment is to provide the right service, at the right time, and locally to meet the child and family’s needs.
Champions are crucial to success: Although developing the right systems and pathways are a part of effective community provision for families, it also became increasingly clear during the course of our projects that having engaged ‘champions’ to promote a new approach is essential to its success. Each of our three projects has had key professionals who have been willing and able to lead, communicate, train and promote the approach to a range of professional groups.

Co-production matters: What is becoming increasingly apparent is that even good partnership working with parent carers, children and young people is not the equivalent of effective co-production. Co-production, using the latest co-production standards, is now becoming integral to service development. During the development of each of our projects, there have been events and activities that have helped us to co-produce policies, standards, procedures and pathways. Our intention in Birmingham is now to review our approach to co-production and engage parent carers and young people using a new set of standards.

Celebrating success is important: In developing these complex partnerships and collaborative approaches, we found it became important to share our challenges together. By the same token, it has also been essential to celebrate and share our successes together. For example, both the Children Who Wait project and the Disability Network Forum were recognised as initiatives that demonstrate good partnership working in the 2016 Chamberlain Awards, Birmingham City Council’s staff recognition scheme. We hope that sharing our partnership experience in Birmingham will contribute to future developments elsewhere.

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27 See for example the development of the Rotherham Charter: https://rotherhamcharter.co.uk/

28 90 per cent of local authorities who responded to the December 2015 SEND reforms implementation survey said parent carers were either fully or largely engaged in strategic planning and co-production of SEND services; 34 per cent said young people were involved; and 17 per cent had involved children. See Annex A of the SEND Newsletter (February 2016) at: https://councilfordisabledchildren.org.uk/sites/default/files/uploads/resources/images/dfe-send-2016-february-newsletter.pdf
About the author

Chris Bush

Chris Bush is the Head of Disabled Children’s Social Care, which will be part of the Birmingham Children’s Trust from April 2018. Chris has worked in a number of authorities throughout the midlands and has over 35 years’ experience as a social worker in practice in a variety of roles within the field of children and young people’s social care. This has led to a developing interest in the needs of disabled young people and their families’ needs.

Chris’s work in recent years has mainly focused on disabled children, preparation for adulthood, commissioning and developing services for disabled children in partnership with agencies, as well as developing opportunities for disabled young people and their siblings. As the operational lead Chris has led on partnership developments and systemic approaches which have included employment opportunities for disabled young people and systemic and solution-focused models identifying support through a single system approach.
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Our series of evidence reviews address key issues identified by strategic planners, policy-makers and practitioners. The reviews are intended to shape systems, services, approaches and practice in ways that will promote the well-being of children and families.

This review examines, in the context of recent reforms and innovation, the latest practice, policy and emerging evidence on supporting families with disabled children and young people. It brings together contributions from a number of experts, from different backgrounds and professions, to consider how to lead, effect and sustain systemic change that will make a lasting difference to the lives of disabled children and young people, now and into adulthood.

This review will be of particular interest to strategic leaders in the field of children’s services and disability, as well as managers and practitioners in social care, and their colleagues in health and education, who are working to support children and young people with special educational needs and disabilities and their families.