Life to the Full

CARE AND SUPPORT IN THE UK FOR DISABLED CHILDREN AND CHILDREN WITH LIFE-LIMITING AND LIFE-THREATENING CONDITIONS

2015

AN INDEPENDENT REPORT
BY DEMOS COMMISSIONED
BY THE TRUE COLOURS TRUST

Front cover image: © Robert Spigel

Contents

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- Amanda Batten, chief executive, Contact a Family
- Professor Myra Bluebond-Langner, True Colours chair in palliative care for children and young people, Institute of Child Health, University College London
- Professor Bernie Carter, professor of children's nursing; director, Children's Nursing Research Unit, Alder Hey Children's NHS Foundation Trust
- Nic Crosby, Director Children's Programme, In Control
- Anna Gill, parent expert; trustee, Together for Short Lives
- Beth Grossman, head of policy and research, Scope
- Dr Lisa Kaufmann, chair, Paediatricians in Medical Management Committee, Royal College of Paediatrics and Child Health
- Christine Lenehan, director, Council for Disabled Children
- Katrina McNamara, director of practice and service development, Together for Short Lives
- Alex Mancini, pan-London lead nurse in neonatal palliative care, Chelsea and Westminster NHS Foundation Trust
- Dr Sally Robinson, principal lecturer, School of Public Health, Midwifery and Social Work, Canterbury Christ Church University
- Robert Spigel, parent expert
- Cheryl Ward, chief executive, The Family Fund

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All errors and omissions remain, as ever, the authors' own.

Ally Paget

Charlie Cadywould

June 2015

Foreword

In the UK there are an estimated 800,000 disabled children and 49,000 children and young people living with a life-limiting and/or life-threatening illness. The True Colours Trust has always been committed to making a difference to the lives of these babies, children, young people and their families and to ensuring that they can live their lives to the full.

Ten years ago, we commissioned some research on these groups of children and young people to help better understand their needs, and the landscape of the organisations that supported them. Two reports were produced, one covering disabled children and their families, and the other focusing on children with life-limiting and/or life-threatening conditions, and they clearly showed the challenges that these families face daily.

A decade later there have been many changes in policy and service provision, and we wanted to see what the impact of these changes has been on families and what the current provision looks like. The original reports highlighted that these two groups of children face many of the same challenges, and that many children fall into both groups. Since the number of disabled children with life-limiting and/or life-threatening conditions has increased significantly in the last ten years we felt it would now be more effective and beneficial to produce one report which covers both populations.

We commissioned Demos to produce this report, in order to get an independent assessment and a fresh perspective on the care and support being offered to these families. Demos' report gives details of the changing landscape, the gaps in service provision, examples of best practice across the sector, the current policy framework, and opportunities for strategic funding in the future.

Much has been achieved since 2005 but there continue to be significant and ongoing challenges at national and local level for disabled children and their families, as well as for children with life-limiting and life-threatening conditions. This report identifies a number of good practice case studies which show how some of these challenges can be overcome, especially when organisations work together and place families at the centre of their care.

We are grateful to Demos, and Ally Paget and Charlie Cadywould in particular, for their work on this important piece of research. They have produced a number of recommendations for policy-makers and the charitable sector which they believe would help improve these families' experience. Demos' recommendations will be a useful starting point for our discussions with those in the sector as we all work together to develop approaches to meet the challenges posed in the report. We look forward to discussing these issues with families and experts from within the sector to ascertain how we might best use the trust's resources for maximum impact.

I passionately believe that disabled children and their families, and children with life-limiting and/or life-threatening conditions, deserve to receive better support than they are currently getting and that everyone – professionals, policy-makers, funders and the families themselves – needs to work together to enable these children and families to live their lives to the full.

Lucy Sainsbury
Chair of Trustees, The True Colours Trust

Executive summary

In 2005, the True Colours Trust commissioned two reports on the state of care and support for two groups of children and young people. **Ordinary Lives** examined the support available for disabled children and young people, while **Valuing Short Lives** focused on those with life-limiting and life-threatening conditions.[1] This report looks at the situation ten years on. It explores how the landscape of support for these children and families has changed, how progress can be built on, and the areas where challenges remain.

Rather than looking (as Ordinary Lives did) at the larger group of disabled children and young people, this report considers only those with the most complex needs. Its focus is on the age range 0–21, though in practice we have considered the needs and experiences of young people aged up to 26. This is to reflect the span of the recent reforms to special educational needs and disability in England, which apply from ages 0 to 25, and the importance of raising the question: 'What happens after that?'

Different datasets give slightly different figures, but prevalence estimates from 2011/12 put the number of disabled children aged 0–16 in Great Britain at around 800,000.[2] Disabled children with complex needs, whom this report concerns, are a subgroup within that larger figure. There are an estimated 49,000 children and young people aged 0–19 with life-threatening and life-limiting conditions across the UK who may require palliative care services. Overall, the prevalence of these terminal conditions has risen, and an increasing number of serious conditions are classified as 'rare'.[3]

As a proportion of the general population, then, the number of children whom this report concerns is small. Yet they are a group with significant, diverse and complex needs for support. Furthermore, advances in medical treatments have contributed to children with the most complex health and care needs living longer than in past decades. Expectations about the lives these young people will be able to lead have risen considerably, but the structure, design and capacity of the services that should enable them to do this are struggling to keep pace.

Findings

OVER THE LAST TEN YEARS, SUCCESSIVE GOVERNMENT AND CHARITABLE INITIATIVES HAVE ATTEMPTED TO IMPROVE THE LIVES OF DISABLED CHILDREN AND YOUNG PEOPLE WITH COMPLEX NEEDS AND THOSE WITH LIFE-LIMITING AND LIFE-THREATENING CONDITIONS, AND THEIR FAMILIES.

This has taken place within a context of important changes to the way education, welfare and health care are delivered, and in some areas progress has not been sustained, or has been rendered less impactful by cuts to wider services.

This report identifies some areas of real and sustained improvement. These include a shift towards person-centred care, increased choice and control (personalisation), and widespread, formal channels for patient and service user involvement and 'voice'. Our research indicates that more families are listened to, and more feel able to find a school where their child is valued and supported.

The disabled children's sector and the children's palliative care sector have each benefited from a stronger, united voice, from the Council for Disabled Children and Together for Short Lives. These umbrella bodies represent a much larger number of campaigning organisations, grant-makers and voluntary service providers of all sizes. The sector as a whole has led the way in innovation and improvement, and continues to fund and deliver innovative support that addresses unmet need. The report contains examples of good practice which provide just a small snapshot of this activity – of help provided (like dedicated sibling support, and bereavement counselling that surmounts cultural barriers), and ways of providing it (multi-agency care coordination at the end of life, a specialist transition service to prepare young disabled people for independence).

Such improvements demonstrate that progress can be made – and thousands of lives improved – when statutory and voluntary services form the right kinds of relationships with children and their families.

However, significant challenges remain. Time and again, families describe the 'battle' they have to engage in to understand what support is available and what they are entitled to, and to have their basic needs met. Although satisfaction with many services (especially health and palliative care) is very high, such support is often hard-won, while geographical variation in the quantity and quality of what is available is a source of frustration for families and service providers alike. Families too often fall foul of poor communication and coordination between different agencies – a problem that becomes especially critical for the young people making the transition to adult services.

In addition, there have been setbacks in important areas. Much of the progress of the last ten years has been – or is in danger of being – lost because of the recent and imminent cuts to local authority budgets. Cuts to services that help families prevent, mitigate or manage challenges are resulting in more acute problems in the longer term. Fewer families find themselves able to take short breaks with the help of government schemes, while access to highly valued universal support such as childcare, play and leisure has been restricted at a time of budget constraints. These changes affect not only the quality of life of children and their families, but can also have knock-on effects for other services, if families find themselves unable to cope on their own.

The challenge is therefore threefold:

- to clarify what support children and families can expect from statutory services
- to finance forms of support that help families cope with the pressures they face and ease demand on services in the long run
- to ensure that services are designed so that they adapt to the needs of children and their families, not vice versa

Recommendations

THE PRIMARY AIM OF THIS RESEARCH IS TO GENERATE RECOMMENDATIONS ABOUT WHERE THE VOLUNTARY SECTOR CAN ADD THE GREATEST VALUE, AND CONTRIBUTE TO THE GREATEST IMPACT, FOR THESE CHILDREN AND FAMILIES.

In practice, however, what the voluntary sector can add is to a very large extent dependent on the environment that policy creates for it. Therefore, the first four recommendations are to government and policy-makers. They focus on creating the optimum environment: stability, structure, fair resourcing and collaboration.

There are innumerable small changes and specific services that could improve the experience of the children, young people and families whom this report concerns. Recommendation 5 lists just a few. Taken together, though, this report's recommendations focus on bigger changes that will support providers to make those smaller changes happen. They are designed to meet the three key challenges identified, and are not exhaustive. Their overarching aim is to increase the visibility of these children and families – in policy and in their communities – and to address the uneven distribution of knowledge and support which has resulted from their relative invisibility until now. Priorities for funding and funders should be to spread best practice, build capacity in under-served areas, and sponsor innovation. New thinking and new commitments are needed to enable these children and their families to 'live life to the full'.

For government and policy-makers

1 The Government should commit to the development of a children's social care framework for England, clearly setting out minimum standards for what should be provided by local authorities, to replicate the equivalent clarity for adults that has been created by the Care Act.

2 The Government should ensure that the infrastructure exists for the needs of disabled children with complex needs, and those with life-threatening and life-limiting conditions to be met locally, and that this is communicated clearly to families.

3 Bodies responsible for the education, training and professional development of health practitioners in each of the four nations should work closely with the children's palliative care sector and those parts of the disabled children's sector which support children with the most complex needs to develop a formal model for 'cascading' knowledge and expertise from specialist to generalist practitioners.

4 The Government should work with the new models of care approach, reflected in the NHS Five Year Forward View, to explore innovative approaches to commissioning, including regional models and social impact bonds.

For charities and charitable funders

5 Where they choose to fund specific services, charitable (and statutory) funders should focus on:

- 24/7 end-of-life care
- transition from neonatal services and from child to adult services
- community nursing
- practical, social and emotional support for the wider family
- bereavement support
- sibling support
- short breaks.

6 Charitable funders should provide grants for 'twinning' or 'secondment' arrangements between palliative care networks in different areas of the UK, to promote the sharing of knowledge, expertise and ideas.

7 Charitable funders should set up a challenge fund to encourage joint working between children's palliative care services (both hospice- and community-based).

8 The charitable sector should establish a programme of work to ensure that the voices and views of children with the most complex needs are heard, communicated to key decision-makers, and acted upon.

9 Sector leaders should continue to pursue every opportunity to partner with government to champion visibility, inclusion and aspirations for children with the most complex needs, focusing particularly on supporting transitions to adulthood. This should be a priority for the new complex needs team within NHS England.

Introduction

This report tells a story of both change and continuity.

In 2005, the True Colours Trust commissioned two reports on the state of care and support for two groups of children and young people. **Ordinary Lives** examined the landscape for disabled children and young people, while **Valuing Short Lives** focused on those with life-limiting and life-threatening conditions.[4] This report looks at the situation ten years on. Because of the significant overlap in the challenges these two groups experience and the support they require, the True Colours Trust has commissioned a single report covering both groups for 2015.

Around
800
thousand

DATA SUGGESTS THAT THERE WERE AROUND 800,000 DISABLED CHILDREN AGED 0-16 IN GREAT BRITAIN IN 2011/12[5]

We explore how the landscape of support for these children, young people and families has changed, how progress can be built on, and the areas where challenges remain. Rather than looking (as *Ordinary Lives* did) at the larger group of disabled children and young people, our report considers only those with the most complex needs. (For more information on the terminology used in this report, including 'complex needs', 'life-threatening' and 'life-limiting', and a glossary of terms, please see Appendix A.) Our focus is on the age range 0–21, though in practice we have considered the needs and experiences of young people aged up to 26. This is to reflect the span of the recent reforms to special educational needs and disability in England, which apply from ages 0 to 25, and the importance of raising the question: 'What happens after that?'

Different datasets give slightly different figures for the numbers of disabled children in the UK. Disability prevalence data from 2011/12 (based on the Family Resources Survey) suggest that there were then around 800,000 disabled children aged 0–16 in Great Britain.[5] The 2011 Census, counting disabled children or those with a long-term condition aged 0–19, suggests that in 2011 there was a lower total of just over 621,000.[6] These figures include *all* disabled children; those with complex needs, whom this report concerns, are a subgroup within that larger 600,000–800,000, but it is not straightforward reliably to quantify how large a subgroup they might be. (Appendix B contains further explanation, and a breakdown by nation.)

Across the UK, there are an estimated 49,000 children and young people aged 0–19 with life-threatening and life-limiting conditions who may require palliative care services. In England, the prevalence of these terminal conditions has risen, and an increasing number are classified as 'rare' – affecting fewer than five in every

10,000 people.[7] There are approximately 8,000 identified rare conditions, and around 20 new ones are described every month; 75 per cent of rare conditions affect children, and 30 per cent of children affected die before their 5th birthday.[8]

The lives of these children and their families are complicated. Simple things like going shopping, eating dinner together – the ordinary business of being a family – are made harder, even before the additional challenges of dealing with doctors' appointments, special equipment, forms and assessments. On top of that, the children and young people face challenges that do not fit comfortably under the label of the things that the state provides ('health', 'social care', 'education') – but have no less impact, including realising their right to friendship, play and participation, and equal opportunities.

The contribution of unpaid carers to society (which includes that of family carers of ill and disabled children) has been valued at £87 billion per year.[9] The Government has committed to doing more to recognise this contribution, which though indispensable (in 2010, it was almost equal to total spending on the NHS) is often made at significant social, financial and emotional cost to those providing care.[10] A recent survey of parents of disabled children by the charity Scope found that nearly half (47 per cent) had been to see their GP because of stress and worry, and the vast majority said they felt frustrated (80 per cent), stressed (78 per cent) or exhausted (70 per cent) as a result of the struggle to access local services for their children.[11]

The impact on families is compounded by the extra costs associated with raising a disabled child, which are estimated to be up to three times as much as for a non-disabled child.[12] As a result, disabled children and their families are disproportionately likely to experience economic disadvantage: 4 in 10 disabled children live in poverty, compared with 3 in 10 in the general population.[13] Evidence suggests that between 2010 and 2015 these families experienced a bigger drop in their household income (4.7 per cent) than all families with children (3.3 per cent).[14] Contact a Family's 2014 survey 'Counting the costs' found that a third of families with disabled children were regularly going without basics like food and heating.[15]

Reforms and challenges

OVER THE LAST TEN YEARS SUCCESSIVE GOVERNMENT AND CHARITABLE INITIATIVES HAVE ATTEMPTED TO IMPROVE THE LIVES OF DISABLED CHILDREN AND YOUNG PEOPLE AND THOSE WITH LIFE-LIMITING AND LIFE-THREATENING CONDITIONS, AND OF THEIR FAMILIES.

This has taken place within a context of important changes to how services – childcare and education, health and social care, and social security – are delivered.

In some areas there have been significant improvements. These include a shift towards person-centred care, increased choice and control (personalisation), and widespread, formal channels for patient and service user involvement and 'voice'. The disabled children's sector and the children's palliative care sector have each benefited from a stronger, united voice, from the Council for Disabled Children and Together for Short Lives. The voluntary sector, which

49
thousand

THERE ARE AN ESTIMATED 49,000 CHILDREN AND YOUNG PEOPLE AGED 0-19 WITH LIFE-THREATENING AND LIFE-LIMITING CONDITIONS WHO MAY REQUIRE PALLIATIVE CARE[7] includes these sector umbrella bodies and campaigning organisations, as well as voluntary service providers and grant-makers, has led the way in innovation and improvement. Such improvements demonstrate that progress can be made – and thousands of lives improved – when statutory and voluntary services form the right kinds of relationships with children and their families.

However, accessing care and support undeniably remains a continuous challenge for many families. This is partly a question of resources. Much of the progress of the last ten years has been – or is in danger of being – lost because of the recent and imminent cuts to local authority budgets. Cuts to services that help families prevent, mitigate or manage challenges are resulting in more acute problems in the longer term. But also at issue is the way the system relates to those it is there to support. Despite recent reforms, bureaucratic rules and structures often struggle to adapt to the needs of individual children and their families.

47%

A RECENT SURVEY OF PARENTS OF DISABLED CHILDREN BY THE CHARITY SCOPE FOUND THAT NEARLY HALF HAD BEEN TO SEE THEIR GP BECAUSE OF STRESS AND WORRY.[11]

The challenge is therefore threefold:

- to clarify what support children and families can expect from statutory services
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- to ensure that services are designed so that they adapt to the needs of children and their families, not vice versa

Methodology

RESEARCH FOR THIS PROJECT TOOK PLACE BETWEEN OCTOBER 2014 AND APRIL 2015.

It comprised the following elements:

- We reviewed evidence related to the needs of children and their families, and the services available to them in the voluntary and statutory sectors. We also looked closely at key policy and funding changes over the last ten years in all four nations of the UK.
- We held 16 semi-structured interviews (face to face and by telephone) with professional experts drawn from the voluntary and statutory sectors, including senior practitioners and representatives from campaigning and representative bodies.
- We held two expert workshops (of 12 people each) with similar audiences to the interviews, one focusing on practice and the other on policy; both included 'experts by experience' – young people and family carers with first-hand experience of living with these conditions.
- There was a focus group with 13 family carers, hosted jointly by Contact a Family and the National Network of Parent Carer Forums. Although held in London, participants came from across England and Wales.
- We held six interviews with children and young people (aged 12 and over) with complex disabilities and life-threatening and life-limiting conditions. Four were held at a hospice, and two in the young person's home or place of study.

- We made an online call for evidence consisting of three surveys: one for family carers, one for children and young people, and one for practitioners and formal service providers. These were shared and publicised through a variety of networks, charities and services by email and social media, promoted on the Demos website, and advertised through the hospice news website. We received responses from 434 family carers, 128 practitioners and service providers, and 17 children and young people.

- We undertook six 'good practice' case studies, two of which involved a visit to a service, with structured observation of services (where applicable), and semi-structured interviews with a range of staff and stakeholders. We conducted a further four case studies remotely, through semi-structured interviews with staff and reading published promotional literature, evaluations, and so on. These visits and interviews formed the basis of the case studies contained within this report, illustrating the challenges services are facing and the innovative solutions being employed.

- The project benefited from an expert advisory board (see list of names and positions in the acknowledgements), which met three times during the course of the research to discuss and provide feedback on methodology and interim findings. The board's expertise proved invaluable in sourcing relevant documents, making contacts at various organisations, and distributing our call for evidence.

Report structure

THIS REPORT IS DIVIDED INTO FOUR PARTS.

CHAPTER 1:
POLICY BACKGROUND

Introduces the key changes to policy, funding and practice that have taken place in the UK in the last ten years. This is drawn from desk research, expert interviews and workshops.

CHAPTER 2:
THE EXPERIENCE OF FAMILY CARERS, CHILDREN AND YOUNG PEOPLE

Focuses on the needs, experiences and priorities of children and young people with complex disabilities, life-limiting and life-threatening conditions, as well as their families. It is based largely on our qualitative research with children, young people and parents, while taking the insights of practitioners into account.

CHAPTER 3:
OPPORTUNITIES AND CHALLENGES

Examines the main challenges that still exist in funding, structuring and delivering support. It also considers how these problems are being addressed, with a particular focus on the voluntary sector. Interspersed throughout chapters 2 and 3 are boxes summarising our seven good practice case studies.

CHAPTER 4:
CONCLUSIONS AND RECOMMENDATIONS

Draws out key conclusions from our findings. It makes a number of recommendations for policy-makers, service providers and charitable funders.

1/3

OF FAMILIES WITH DISABLED CHILDREN WERE REGULARLY GOING WITHOUT BASICS LIKE FOOD AND HEATING.[15]

1

Policy background

Since the publication in 2005 of **Valuing Short Lives** and **Ordinary Lives**, successive governments have attempted to grapple with many of the problems identified in those and many subsequent reports. The ten years to 2015 have seen periodic announcements of new pots of funding from central government, new guidance and regulations, and top-down reorganisations. This represents a considerable shift from the previous decade, when very little policy was directed at improving care and support for disabled children and young people with complex needs, and those with life-limiting and life-threatening conditions.

Family carers, and children and young people themselves, have high aspirations for living their lives to the full, and it is to be applauded that policy is moving in the right direction to realise these. However, join-up across these initiatives has often been lacking. Gaps in services have remained and effective coordination between service providers has proved elusive. Increased expectations have not necessarily been matched with improvements in provision. Exceptions, where communication and coordination work smoothly, are still extraordinary 'best practice' rather than the norm.

It has not been possible to provide an exhaustive review of every policy change affecting the children, young people and families in question in all four nations. Needless to say, changes to many universal services and entitlements driven by austerity have impacted on these groups alongside (and in many cases more than) others. Disabled children's charities have been active in documenting these effects, and they featured heavily in our conversations with families and practitioners. They are covered in subsequent chapters. More limited in scope, this chapter provides an overview of recent changes to policy in five key areas: palliative care funding, short breaks provision, personalisation, joint working and transition. A summary table of the policy changes covered can be found in Appendix C at the end of this report.

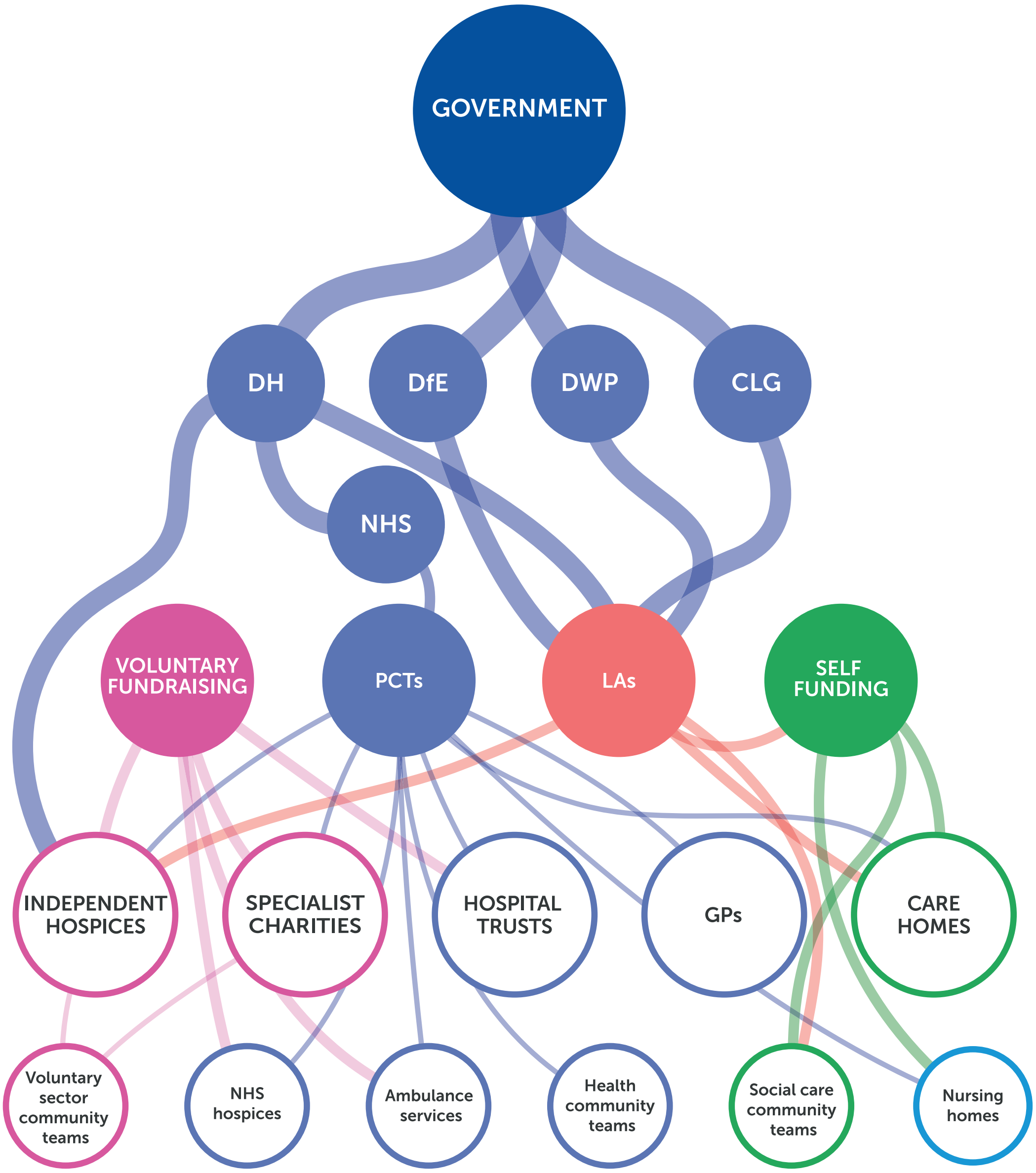
Palliative care funding

England

In 2006 the Government pledged £27 million over three years to support hospices and hospice at home services as an interim measure on the route to developing a long-term palliative care funding strategy.[16] In 2008, this was increased by a further £20 million to cover the period up to 2010/11.[17] Under the terms of the Coalition Agreement, the Coalition Government pledged £10 million annual revenue funding to children's hospices, increasing their overall level of statutory funding.[18] Data collected in that year showed that children's hospices earned on average 24 per cent of their expenditure from government and other statutory bodies, though the proportion received by different hospices varied greatly, some receiving much less and others as much as 50 per cent.[19]

In 2010, the incoming Coalition Government committed to establishing a per-patient funding system for children's and adult palliative care, leading to the launch of the independent Palliative Care Funding Review.[20] The impetus for the review was the recognition – cemented by a 2008 National Audit Office report – that palliative and end-of-life care (for both children and adults) is extremely complex, and an overhaul of the system crucial if future demand were to be equitably met.

FIGURE 1: THE MAIN FUNDING FLOWS FOR END-OF-LIFE AND PALLIATIVE CARE



Source: Hughes-Hallett et al, *Funding the Right Care and Support for Everyone*[21]

The reviewers were tasked with the creation of a per-patient funding mechanism or tariff to ensure that 'funding follows the patient in a fair and transparent way, as the level of funding provided to a service would be determined by the complexity and level of need of the patients'.[22]

The review recommended that the tariff should cover:

- a regular assessment of the needs of the patient
- all the clinically assessed palliative care needs of the patient, irrespective of setting
- a coordinator for the patient and their family
- the social care needs of the patient[23]

As a first step, NHS England has developed a draft palliative care 'currency'. This involves 'units' of care based on similar levels of resource and clinical need, which form the basis for payment between commissioners and providers.[24] However, full implementation of the tariff remains some way off. NHS England hopes to pilot the currency during 2015, with the aim of finalising it and mandating its adoption the following year.[25]

Figure 1, which is taken from the published review, illustrates the complex funding flows within children's and adult palliative care services. The boxes and arrows in pink demonstrate the contribution of the voluntary sector. Hospices, specialist charities (eg condition-specific charities) and some community teams are voluntary-run. Local primary care trusts (PCTs) – which, since the writing of the report, have been replaced by clinical commissioning groups (CCGs) – may commission the voluntary sector to provide services, and likewise health services like ambulance services and hospital trusts may benefit from charitable funding.[26]

Wales

Following a £10 million contribution in 2003, from 2004, £2 million of Welsh Government funding was ring-fenced for all voluntary sector hospices through a bidding process, where hospices effectively competed against each other over the same pot of money.[27] This was followed, in 2007, by the announcement of a 50 per cent rise in direct funding to Wales' children's hospices.[28] For example the funding of Hope House, which runs the Ty Gobaith Hospice in Conwy, increased from £99,375 to £149,062.[29]

In 2008, the Palliative Care Implementation Board was created to improve palliative care services in Wales. It agreed with Independent Hospices Cymru, the Welsh umbrella hospice organisation, that the bidding process did not provide stability for hospices, had proved inequitable across regions, and was not the most efficient use of funding.[30] In 2008/09, funding decisions for the voluntary sector were instead based on the cost of the core clinical service that would need to be provided in the absence of the charity.[31] By 2012/13, total funding for palliative care in Wales had increased to £6.4 million, and a further £6.4 million funding package is in place for 2014/15.[32]

Scotland

In 2008, the Scottish Government published its plan for palliative care, *Living and Dying Well*.[33] Many of the key proposals informed the Palliative Care (Scotland) Bill 2010. The bill, which applies to both children's and adult services, aims to address variable provision in

Scotland by mandatory annual reporting on the state of palliative care, and by placing a duty on Scottish ministers to

> *provide, or secure the provision of, palliative care to – a) every person diagnosed as having a life-limiting condition; and b) family members of persons so diagnosed, according to the reasonable needs of such person or persons.*[34]

In 2011, Nicola Sturgeon – then cabinet secretary for health, wellbeing and cities strategy – set up the Managed Service Network for Children and Young People with Cancer for Scotland. It aims to ensure that cancer services for children and young people are delivered as a single and sustainable service across Scotland, to create outcome measures for service evaluation, and to develop age-appropriate services for teenagers and young adults.[35] This is funded through the £3.2 million of additional investment made in cancer services for children and young people through the Scottish Government's National Delivery Plan for Specialist Services.[36]

The Children's Hospice Association Scotland (CHAS) is the only children's hospice service in Scotland; it has two sites – Rachel House and Robin House – and a hospice at home service. In the year up to March 2014, CHAS provided care to over 370 children and young people in Scotland.[37] The service received just over £1.5 million in statutory funding and grants in 2013/14, compared with over £6 million from donations, legacies and shop sales.[38] This included £38,000 for Diana Children's nurses.[39]

Northern Ireland

In 2008, Northern Ireland Children's Hospice (the country's only children's hospice) was given a recurrent grant of £210,000 by the Northern Ireland Executive, raised to £245,000 in 2010. This was in addition to funding from the health and social care trusts, responsible for providing care services, and the Health and Social Care Board, responsible for commissioning services, bringing total public funding to almost £600,000. A further £1 million of funding was announced in November 2014 under the Delivering Social Change Programme to undertake a targeted programme for children and young people with life-limiting and life-threatening conditions and their families, and enabling the hospice to develop services.[40]

Short breaks

England

The 2005–10 Coalition Government published *Aiming High for Disabled Children* as part of the comprehensive spending review in 2007, committing to the provision of £340 million revenue funding to local authorities and PCTs from 2008 to 2011 to transform services for disabled children.[41] Of this, £280 million was allocated to expand short breaks services. This was augmented in 2008 by an additional £90 million of capital funding, as a result of the Government's Children's Plan.[42]

Instrumental to the publication of *Aiming High for Disabled Children* was the successful campaigning of EDCM. Set up in 2006, EDCM aimed to make the Labour Government's aspirations for all children set out in *Every Child Matters* a reality for disabled children.[43]

A statutory duty to provide short breaks was introduced in the Children and Young Persons Act 2008, which applies to England and Wales.[44] This was expanded in the Breaks for Carers of Disabled Children Regulations 2011 (England only), which make clear that local authorities must not only consider the needs of parent carers at crisis point, but also 'have regard to the needs of those carers who would be able to provide care for their disabled children more effectively if breaks from caring were given'.[45] These regulations require local authorities to prepare and publish a short breaks duty statement, giving details of the local range of services and their eligibility criteria. They set out the kinds of short breaks services that must be offered, including day-time care, overnight care, education or leisure activities outside the home, and services to assist carers in the evenings, weekends and during school holidays.[46]

In 2010, the incoming Coalition Government introduced a new approach to short breaks funding that has been the subject of some controversy. In December of that year, it announced that local authorities in England would be given £800 million over the next four years to fund short breaks for disabled children, made available through the £2 billion Early Intervention Grant. This grant is not ring-fenced, so local authorities do not have to spend a specific proportion of it on short breaks, and are not held to account over their short breaks funding.[47] According to the Department for Education, the total funding provided by the Early Intervention Grant was 11 per cent less than the funding streams it replaced, although the Local Government Association puts this figure at 32 per cent.[48] Therefore when councils came under financial pressures from overall cuts to local authority funding, short breaks services may have ended up being cut to safeguard other services.

On the other hand, local authorities that did want to prioritise short breaks in the face of financial pressure would have found their efforts more difficult when the Government announced in 2012 that the Early Intervention Grant was being abolished, with funding instead redirected to the ring-fenced Dedicated Schools Grant to expand nursery provision, and £150 million retained centrally by the Department for Education. The remainder would be rolled into the new business rates retention scheme, which allows councils to keep a proportion of business rates revenue.[49] This ultimately reduced the amount of non-ring-fenced funding that could be spent on children's services, including short breaks.

Research from Mencap published in 2013 confirms that children's short breaks provision has declined since its peak in 2010/11. It found that 63 per cent of local authorities reduced their children's short breaks expenditure in 2011/12, and 43 per cent projected reductions in 2012/13. Six in ten local authorities reported a reduction in the percentage of children with a learning disability in their area accessing short breaks in 2012/13 compared with 2009/10.[50]

Of particular concern was the recent announcement that the Short Breaks Network would be closing at the end of March 2015 because of financial challenges. It was the national coordinating body for the short break sector, and in 2013 had secured a two-year contract from the Department for Education to deliver training, policy support and good practice guidance in the short breaks sector across England Wales and Northern Ireland, and with its sister organisation Shared Care Scotland. This funding was not renewed at the end of the two years.[51] However, in March 2015, Department for Education funding was awarded through the Voluntary and Community Sector National Prospectus Programme to support the delivery of the special educational needs and disabilities (SEND) reforms, and provide information and advice to short break stakeholders. This funding has been provided to the Short Breaks Partnership, a consortium made up of Contact a Family, the Council for Disabled Children, Action for Children and KIDS.[52]

Related to the question of short breaks is that of childcare for disabled children. In July 2014, the report of a parliamentary inquiry into the issue was published, looking at affordability, availability, quality, and access and information. The report found that 86 per cent of parent carers were charged higher than average fees for childcare, and that many were not accessing their full entitlement of 15 hours of free childcare per week because of the failure of the market to provide childcare for disabled children. The report recommended the introduction of a requirement for local authorities to publish information on childcare as part of their local offer for SEND children and their families, and clarifying the arrangements for redress for parents unable to access their full 15 hours of free early education.[53]

Wales

In Wales, the Government provided £1.5 million annually for four years in grant funding to local authorities between 2007 and 2010 to promote short breaks for disabled children, young people and their families.[54] Since then, funding for short breaks has been provided through the central grant to Welsh local authorities, the Revenue Support Grant, which is entirely unrestricted and is allocated at local authorities' discretion.[55]

The Welsh Government introduced its own regulations in 2012 to ensure that breaks were not just offered as an emergency intervention but as part of the general support provided by local authorities, setting out the range of breaks that should be offered, and requiring them to publish information about the range of services offered locally.[56]

Scotland

In 2011, the Scottish Government announced that £2 million would be made available to improve short breaks opportunities for disabled children, young people and their families through Short Breaks Fund programmes. Of this, £100,000 was used to support the exchange of learning and good practice, while £700,000 was allocated to the Family Fund to administer grants directly to families in Scotland.[57]

In December 2013, the Scottish Government announced it was investing a further £250,000 through the Short Breaks Fund. Of the £250,000 allocated, £100,000 was ring-fenced through the Better Breaks Programme, which aims to help those under the age of 30 with disabilities and their families.[58] Additionally, in 2014 and early 2015, individual carers were able to apply for a grant of up to £500 to pay for a break of their choice through the Take a Break Programme. In total, almost £14 million has been invested in short breaks through the Scottish voluntary sector between 2010 and 2015.[59]

Local authorities do not currently have a statutory duty to provide short breaks in Scotland. This is consistent with the 2007 Concordat between the Scottish Government and the Convention of Scottish Local Authorities (COSLA), which reduced ring-fencing of funding, and increased autonomy for councils.[60]

A year earlier, Shared Care Scotland published a position paper on behalf of all the national carer organisations in Scotland setting out the case for a statutory short breaks duty to be included in the bill.[61] In its current form, this duty has not been included, although Shared Care Scotland has given its support for the inclusion of a duty on local authorities to prepare and publish a short breaks statement.[62]

£87bn

THE CONTRIBUTION OF UNPAID CARERS TO SOCIETY HAS BEEN VALUED AT £87 BILLION PER YEAR.[9]

Northern Ireland

The Carers and Direct Payments Act (Northern Ireland) 2002 gives carers the right to request an assessment of their needs, and places an obligation on health and social care trusts to meet those needs, although at the time no extra funding was provided to meet these requirements.[63] While those needs could include respite care, there is no specific duty, as in England and Wales, to provide a range of short breaks services. However, guidance in 2010 from the Department of Health, Social Services and Public Safety details minimum standards for respite services that Northern Ireland's health and social care trusts should provide.[64]

In 2008, Northern Ireland's Department for Health, Social Services and Public Safety made £3.2 million available to invest in an additional 200 new or enhanced learning disability 'respite [short breaks] packages' in Northern Ireland over the period of 2008–2011, although this was later revised down to 125 packages.[65] A survey conducted in 2011 by the Patient Client Council in Northern Ireland found that most people thought short breaks provision had 'stayed the same' over the previous five years, and recommended that the Department for Health, Social Services and Public Safety further develop and expand the provision of flexible short breaks services.[66]

Personalisation and control

PERSONALISATION IN HEALTH, AND PARTICULARLY IN SOCIAL CARE, HAS INCREASED CONSIDERABLY OVER THE LAST TEN YEARS.

While first conceived as a means to give working age and older people greater choice and control over the services they receive, this has now been extended to children and their families, albeit in a piecemeal manner. The Department for Education undertook a major review of the work for children and families between 2008 and 2011, including a formally evaluated review of a pilot developing individual budgets for disabled children.[67] An individual budget involves placing a monetary figure on the services being delivered to each disabled child. The equivalent amount is then given (either in cash, known as a direct payment, or virtually) to families to spend on a range of support services as they see fit.

The evaluation showed the wide variation in the use of social care budgets of both kinds – direct payments and virtual – in England. A main conclusion was that the quality of the process for engaging families was often a more important factor in improving outcomes for families than the financial payment itself. Some families found the flexibility associated with the approach made a significant difference to their everyday life, but this experience was not universal. Indeed, a small number of

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families of disabled children with complex needs chose to drop out of the pilot; they reported that the quantification of the high financial costs of their children to the state made them feel uncomfortable, and they felt it reinforced the perception of their children as burdens rather than citizens with reasonable expectations of support.

Personalisation in health services, in the form of personal health budgets, has been slower to come to fruition. Initially only children and adults with continuing care needs were eligible for a personal health budget, but in October 2014 budgets were extended to include children and young people with long-term conditions. However, the Children and Families Act 2014 has prompted a radical shift in scope, by broadening the right to request a personal budget in education. The act requires that a family should be able to request a personal budget as part of their EHC plan assessment. It is too early to say how many families will take up this right, and how well local authorities and other services will cope with the consequences for planning and delivery if they do. Like other areas of the Children and Families Act reforms, this remains an area of confusion and fragmentation for many families. However, it is clear that there is real potential – felt by families and services alike – for combined budgets for children and their families across care, health and education to be used effectively and create significantly better outcomes.

England

Individual social care budgets were initially piloted in England in 2005–2007, and subsequently rolled out for adult social care.[68] The right to what is now known as a personal budget was extended to disabled children and those with special educational needs in 2014. A personal budget is a pot of money allocated to an individual or family from a local authority or NHS commissioner to spend on support.[69] A young person, or a child's parent, may request that some or all of this money is taken in the form of a direct payment. It can also be held by the local authority, school or college, which then commissions the support, or a third party individual or organisation.[70]

The drive from Whitehall to roll out personal budgets to all disabled children and those with special educational needs has not been matched in Wales and Northern Ireland. However, direct payments have been available in some form for certain aspects of social care since before devolution, and since the late 1990s[71] the devolved nations have taken different paths towards giving families more direct control over the care and support they receive.

Wales

The Social Services and Well-being (Wales) Act 2014 will come into force in April 2016, and consultation on the first tranche of draft regulations, which includes direct payments, ended on 2 February 2015. Under these draft regulations, direct payments will be available in all cases where an individual, or their representative expresses a wish to receive one. They will bring Wales in line with Scotland to allow individuals to use direct payments to purchase care and support directly from their local authority if they wish.[72]

Scotland

In Scotland, the framework for giving families more control over their support is known as self-directed support. The legislative underpinning for this is the Social Care (Self-Directed Support) (Scotland) Act, passed by the Scottish Parliament in 2013, which applies to children as well as adults and carers.[73] Very similarly to English personal budgets, the act requires councils to offer four choices on how people receive their social care: in the form of direct payments; allowing the individual to direct the available support; leaving the local authority to arrange the support; or a mix of these three options.[74] All four options must also be offered to carers if the local authority decides they too are entitled to paid support.[75]

For children under age 16, parents make the decisions about the form support takes, while those aged 16–18 can choose for themselves. Unlike in the rest of the UK, in Scotland, direct payments can be used to purchase services from one's local authority.[76]

Northern Ireland

The Northern Ireland Executive is currently consulting on the introduction of self-directed support for children and adults, within which sits an option for direct payments in a similar framework to that introduced in England and Scotland.[77]

Commissioning and joint working

JOINT WORKING AND COORDINATED COMMISSIONING HAVE BEEN LONG-TERM GOALS FOR SUCCESSIVE GOVERNMENTS IN PROVIDING CARE AND SUPPORT FOR CHILDREN AND YOUNG PEOPLE.

England

In England, the government-funded Early Support Programme ran from 2002 to 2015, aiming to improve the way services worked for the families of disabled children. Towards the end of the programme, it worked towards improving coordination between professionals in education, health and care, and supporting the implementation of the SEND reforms.[78]

More recently, the Government has announced support for developing key working through training and resources.[79]

Many of the provisions in Every Child Matters, the Government's 2003 programme for children and children's services, were enacted in the Children Act (2004).[80] The act required each local authority to appoint a director of children's services and designate a lead member for children's services to have responsibility for education and children's social services. It required local authorities to cooperate with partners, and to produce a single children and young people's plan. Guidance issued in 2005 explained that the duty to cooperate with partners implied the creation of children's trusts.[81]

In 2009, the Apprenticeships, Skills, Children and Learning Act brought schools, colleges and Jobcentre Plus under the duty to cooperate, and required all local areas to have a children's trust board. These boards were given the responsibility to publish joint children and young people's plans. This duty was removed in 2010 when the Coalition Government came to power.[82]

However, in his 2010 report *Getting it Right for Children, Young People and Families*, Professor Sir Ian Kennedy highlighted how parents and carers remained frustrated at the lack of coordination between services, between NHS services and between the NHS and other providers. The report places school nurses in a leading role coordinating support, education and training for families, carers and school staff.[83]

The Health and Social Care Act 2012 placed a duty on health and wellbeing boards to encourage integrated working between commissioners of NHS, public health and social care services. The act states they must 'provide such advice, assistance or other support as it thinks appropriate'. Similarly, CCGs must promote the integration of health services where it considers it would improve the quality of services or reduce inequalities.

The 2014 Children and Families Act – and the subsequent SEND statutory guidance – place a duty on CCGs and local authorities to jointly commission care for disabled children and young people and those with special educational needs between the ages of 0 and 25, and to cooperate in ensuring that education, health and care plans (henceforth 'EHC plans') are put in place. The SEND statutory guidance makes clear that local authorities should publish a local offer, which sets out information in one place about services across education, health and social care for SEND children and young people in the area, including those who do not have an EHC plan.[84]

Wales

In Wales, the National Service Framework for children, young people and their families was published in 2005. It sets out the support that should be available for this group, including disabled children. It gives local health boards, NHS trusts and local authorities joint responsibilities in a number of key areas. Each local health board or local authority area should have a child development team to 'facilitate multi-agency assessments and holistic care for disabled children and their families'.[85] It gives local health boards, NHS trusts, local authorities and the Ambulance Service joint responsibility to produce a individual multi-agency care plan for disabled children with complex needs, including arrangements for dealing with emergency situations.[86] Local health boards, NHS trusts and local authorities should also offer an assessment to parents and carers of disabled children, and provide a key worker service for families with disabled children with complex needs.[87]

In March 2009, the Welsh Government announced the new Early Support Programme for families with young disabled children to be run by the umbrella group Children in Wales. It targets the quality, consistency and coordination of services for disabled children under the age of 5 and their families.[88]

The Children and Families (Wales) Measure 2010 places a statutory duty of cooperation on health and local government, leading to the creation of integrated family support teams.[89] In 2011, the Welsh Government published the Framework for Action for Social Services, which prioritised integration of delivery for families with complex needs and transition to adulthood for disabled children. This included an expectation on partners to deliver pooled budgets, and consultations on extending the entitlements of disabled children to the age of 21, and requiring local authorities to appoint transition workers to 17 and 18-year-olds to help coordination between services.[90]

Scotland

In Scotland, local authorities have been under an obligation since 1995 to prepare children's services plans including services for disabled children. These required consultation with health boards, voluntary organisations and others, but have been replaced by full joint planning requirements for local authorities and NHS boards under the Children and Young People (Scotland) Act 2014.[91] This is supplemented by the Public Bodies (Joint Working) (Scotland) Act 2014, which requires local authorities and NHS boards to integrate health and social care, including their respective budgets. While the minimum requirement is for this to be implemented within adult services, local authorities can also integrate children's services. This can be achieved either through one party taking the lead role for planning, resourcing and delivering integrated services, or this responsibility can be delegated from both parties to an integration joint board. In the Highland area, for example, the NHS has taken responsibility for all adult health and social care, while the Council has taken responsibility for children.[92]

Northern Ireland

In Northern Ireland, health and social care are provided as an integrated service by five regionally based health and social care trusts, and a single health and social care board has responsibility for commissioning services, resource and performance management, and service improvement. The board commissions through five local commissioning groups, which cover the same geographical areas as the health and social care trusts.[93]

Transition

England

Improving the transition to adult services was one of the main goals of *Aiming High for Disabled Children*.[94] The 2005–10 Coalition Government published a framework on transition planning for young people with long-term health conditions and disabilities in 2006, followed by guidance on transition for health professionals and partners in 2008.[95] This led to the creation of the Transition Support Programme, which ran from 2008 to 2011 with £19 million government funding, aiming to improve and coordinate young people's transition.[96] It consisted of two main elements: the National Transition Support Team, which coordinated work between local authorities, PCTs and others, and support for changes at local level through direct grants and regional adviser activity.[97]

Since 2011, the Preparing for Adulthood Programme has supported local authorities, families and other stakeholders to improve the transition to adulthood for disabled children and those with special educational needs. It is funded by the Department for Education and delivered by a partnership between the National Development Team for inclusion and the Council for Disabled Children.[98]

Wales

In Wales, statutory guidance requires schools to draw up a transition plan when children reach 14 if they have a statement of special education needs. During this process the views of the pupils should be sought and recorded where possible, and the views and advice of careers advisers, social services and health services should be provided.[99]

In Wales, the children's National Service Framework 2005 states that a key transition worker should be appointed to all disabled young people at the age of 14, coordinating the planning and delivery of services, and monitoring the young person until the age of 25.[100] The framework requires that one joint organisation transition plan be produced for each disabled young person to form the basis of the unified assessment within adult services.[101]

In 2009, the Welsh Government published *We Are On the Way*, setting out the progress made on the framework, and its plans to improve the life chances of disabled children and young people, including through early years support, training for professionals, safeguarding, short breaks and transition.[102]

Scotland

Education authorities have certain obligations under the Education (Additional Support for Learning) (Scotland) Act 2004, amended in 2009. They must request information from local authorities, NHS boards and others to begin planning for the child at least 12 months before they are due to leave school, and must pass on information to other agencies at least six months in advance. Once they reach age 16, young people obtain person rights under the Additional Support for Learning Act: education authorities must seek and take account of their views, and young people have the right to advocacy and the help of a supporter.[103]

In the most recent financial year CHAS received £720,000 from the Big Lottery Fund to support a new Transition Team, to help 17–21-year-olds move to age-appropriate adult care provision. The team consists of a transition manager with responsibility for the service as a whole, a transition worker at Rachel House and another at Robin House, as well as a part-time admin support assistant.[104]

Northern Ireland

Article 4 of the Education (Northern Ireland) Order 1996 requires the Education & Library Board to produce a transition plan at the first annual review after a young person's 14th birthday. The plan should aim to reflect the young person's needs and wishes, with a named teacher coordinating the process. Information should be drawn from a range of professionals, such as health and social services and careers teachers, who should coordinate to produce effective and coherent plans. Annual reviews of the plan should take place up to the age of 19.[105]

The contribution of the UK voluntary sector

THE VOLUNTARY SECTOR PLAYS A KEY ROLE IN DELIVERING SERVICES FOR THE CHILDREN AND FAMILIES CONCERNED, ACROSS ALL FOUR NATIONS.

In fact, charities supporting ill and disabled children have a particularly intricate relationship with the statutory sector. While they rely extensively on donations and grants, they also receive statutory funding from local authorities, CCGs, or occasionally central government, to run services or provide training. They may also administer public consultations on behalf of the government (see PAMIS case study on pp 49).

Analysis of 2008/09 Charity Commission data (covering England only) counted 64,000 charities – half of all those in England – working with children and young people. Around half of these had children and young people as their main beneficiaries; these are referred to as 'core' children and young people's charities. More than one-quarter (28 per cent) of all charities providing services registered with the Charity Commission catered for disabled children and young people and their families.[106]

'Core' children's and young people's charities were found to be more reliant on the statutory sector for funding, and less reliant on private or corporate funding, than all charities. They received more than half their income (52 per cent, or £1.7 billion) from the statutory sector, predominantly (79 per cent) from contracts. Only 1 per cent of their funding came from private or corporate sources, compared with 4 per cent for all charities.[107] They have therefore been vulnerable to recent public spending cuts. A follow-up report in 2012 found that children and young people's charities faced public funding cuts of almost £405 million.[108]

Conclusion

IN SUMMARY, THE POLICY LANDSCAPE OF THE LAST TEN YEARS HAS BEEN MARKED BY FRAGMENTATION AND LITTLE STABILITY.

In many ways, the children and young people concerned have moved up the agenda; in 2015, there are more strategies concerning their support, more consideration of how wider policy developments, like personalisation, can be made to work for them, and more recognition (though perhaps not yet enough) of the need to involve them and the best ways of doing so. In other respects, they still lack a clear place at the table. Even considered as a single group – albeit with diverse needs – they are relatively small in number, and run the risk of being hidden. Health and social care support is increasingly planned and delivered at the local level. This sort of localism has the potential to work extremely well for families, providing them with care tailored to their specific needs. What instead too often happens is that this already small group becomes even less visible at a local level, leading to gaps that families can fall through too easily.

The next two chapters consider the effect of this policy environment and the changes to it – first on children, young people and families themselves, and then on the services (statutory and voluntary) which support them.

The experience of family carers, children and young people

2

The previous chapter gave an overview of policy and legislation over the last ten years. This chapter examines how those changes have played out, directly or indirectly, in the lives of the families themselves. Of course, much of the day-to-day lived experience of being, or supporting, a child or young person with the most complex health and care needs will remain unchanged regardless of what bills are passed in Westminster, Holyrood, the Senedd or Stormont – and this chapter reflects that experience, too.

In the course of our research, we heard directly from nearly 450 family carers, and 25 children and young people through interviews, focus groups, expert workshops and a call for evidence. Charities and service providers also told us about the feedback they received from families, and we drew on the extensive wider literature that exists exploring the impacts on families and capturing their voice.

The chapter identifies:

- positive news about schools as valued sources of support
- the value of short breaks in helping take the pressure off families, even though funding for such support is under pressure
- the success of innovations, such as parent carer forums, which have given a stronger voice to service users

However, the chapter also notes:

- a lack of clarity among families about entitlements to care
- contrasting experiences of health and care services, with the former more reliable than the latter
- negative as well as positive experiences of personal budgets, including nervousness about families becoming employers

Family carer call for evidence: about our respondents

THERE WERE 434 FAMILY CARERS WHO RESPONDED TO OUR ONLINE CALL FOR EVIDENCE.

The vast majority (94 per cent) were parents, but respondents also included 15 grandparents, six foster carers, two brothers or sisters, and three people with another relationship to the ill or disabled child. Most respondents (84 per cent) had more than one child, and a significant minority (13 per cent) reported caring for more than one disabled child with complex needs, or life-threatening or life-limiting illness.

As figure 2 illustrates, we heard from family carers looking after children of all ages, from under 1 year to 26, though most fell into the early years and primary school age bands. Notably, only four respondents had babies aged under 1, reflecting the importance of dedicated research with parents of neonates and babies (see p 48).

We asked, too, about the age at which the child's needs were first identified or a diagnosis first received (figure 3). The most common age of identification was between 0 and 5 (57 per cent), though 14 per cent had been identified between ages 6 and 11, and 5 per cent at over age 12. A small minority (3 per cent) had known about their child's condition prior to their birth.

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FIGURE 2: AGES OF DISABLED CHILDREN AND YOUNG PEOPLE WITH COMPLEX NEEDS OR THOSE WITH LIFE-THREATENING OR LIFE-LIMITING CONDITIONS, AS REPORTED BY FAMILY CARER RESPONDENTS TO OUR SURVEY

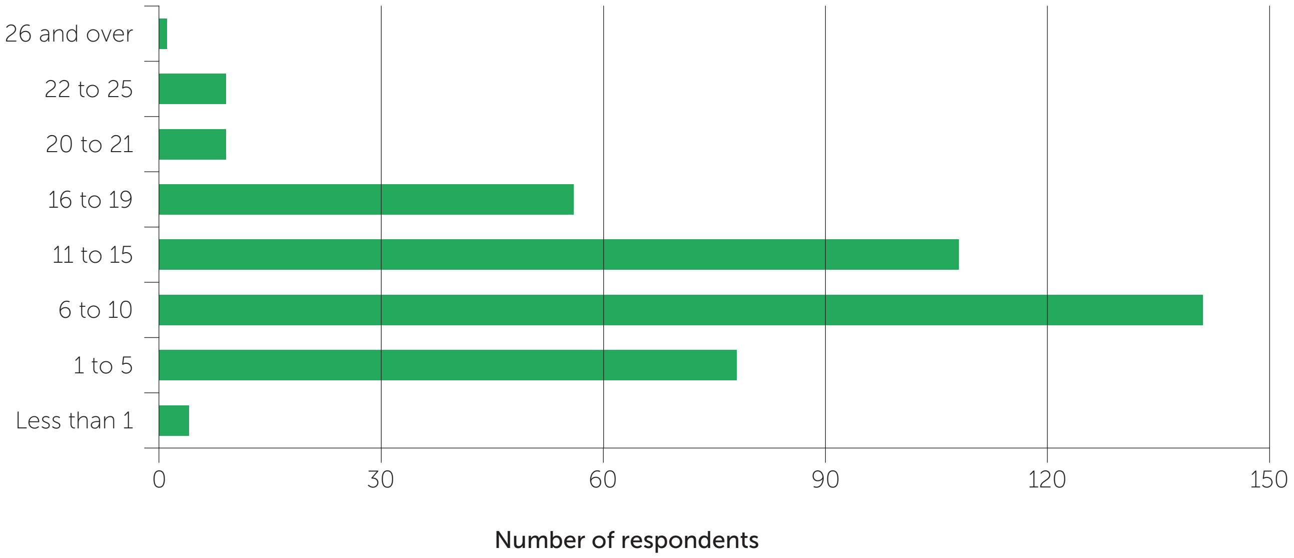
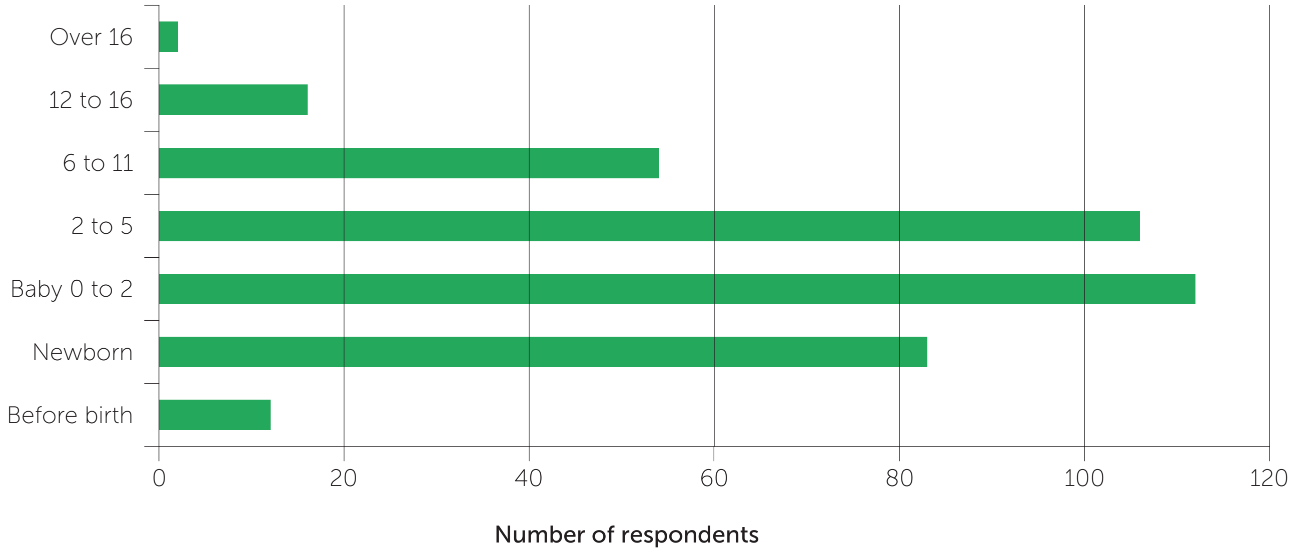


FIGURE 3: AGE AT WHICH THE CHILD OR YOUNG PERSON'S DISABILITY OR CONDITION WAS FIRST IDENTIFIED OR DIAGNOSED, AS REPORTED BY FAMILY CARER RESPONDENTS TO OUR SURVEY



Respondents came from all regions, and were from a mix of urban, suburban and rural areas. A large majority of respondents (almost 90 per cent) were White British, while those from black and minority ethnic (BME) backgrounds (in which we include those identifying as being from 'any other White background') made up just over 7 per cent.

Although monitoring data are not routinely collected, evidence suggests that life-limiting and life-threatening conditions are significantly more prevalent in the Black (70.8 per 10,000) and South Asian (31.5 per 10,000) populations, than in the White (25.7 per 10,000) or Chinese and Other (24.4 per 10,000).[109] The prevalence of disability among those from ethnic minority backgrounds appears to be the same as, or slightly lower than, the overall prevalence, for all four nations.[110] The views of BME families were therefore under-represented in our survey. This is likely because of our reliance on charitable and statutory service providers to distribute the survey, as BME families with a disabled child or a child with complex health needs are less likely to access various forms of support, from Disability Living Allowance (DLA) to short breaks and palliative care services.[111]

BME families were better represented elsewhere in this research; 5 of the 13 family carers who attended our focus group, and 1 of the 6 young experts by experience whom we interviewed, were from ethnic minority backgrounds.

The survey was distributed through newsletters, mailouts and social media by a number of charities within the sector, and some statutory service providers. The sample of respondents is unlikely to be representative of the population as a whole; family carers not in touch with the organisations distributing the survey, those without internet access or those with (for example) visual impairment, for whom the survey was not accessible, were not included. This is reflected in the low numbers of responses from non-white family carers, and from those with a baby under 1 year. For that reason, what we report here is not intended to be representative of *all* family carers in the UK; it reflects the trends in responses within our particular sample.

At the survey design stage, much consideration was given to the best way of ensuring that respondents reflected the remit of the research: complex disabilities and life-limiting or life-threatening conditions. Our approach was to provide on the cover page a brief description of what we meant by these terms, and to allow respondents to self-identify.

Respondents were asked whether they would describe their child as having:

- a complex disability (63 per cent)
- a diagnosed life-limiting or life-threatening condition (16 per cent)
- both (14 per cent)
- an undiagnosed condition (6 per cent)

The remainder responded that they did not know or would rather not say. We included an optional question inviting respondents to give some information about the child or young person's diagnosis, or a brief description of their condition. We were able to use this data (which most respondents supplied) as an additional check for relevance. While the responses indicate that the large majority of those responding to the survey did clearly fall into the intended category, around 50 of the responses from the family carers fell outside the scope of the research. Most were parents of children with autism spectrum disorder or autism spectrum condition, learning or behavioural difficulties.

Analysing this group separately, we found, unsurprisingly, differences in the kinds of services used. These 50 families were less likely to report receiving specialist care, a paid carer, community nursing or specialist equipment, but more likely to say their child attended a mainstream day school. They were more likely than the larger group to report concerns about a shortage of leisure activities, although the same issues of a lack of short breaks, the need to 'fight' to access services, and communication and coordination all featured heavily. Although bearing these differences in mind, the rest of this chapter represents the views of the whole sample, as well as other family carers we spoke to (in focus groups and interviews), and practitioners supporting them.

Support that is most valued

WE ASKED FAMILY CARERS AND CHILDREN AND YOUNG PEOPLE THEMSELVES ABOUT THE TYPES OF SUPPORT, OR THE WAYS OF PROVIDING SUPPORT, THAT THEY VALUED THE MOST.

Specific services

Of those who provided answers, nearly a third (31 per cent) mentioned the support their child got from school. Comments centred on the attitude of the school (see p 34) and particular forms of support (eg therapies) delivered in the school setting. The young people we spoke to highlighted school as one of their most valued sources of support, though for slightly different reasons; they spoke about their friends, how the school accommodated their needs, and the way support was coordinated (manifested by, for example, problems being sorted out quickly).

Susan

Susan, a young woman with a very complex health condition, described how staff at her local college had done everything in their power to support her to attend classes for as long as possible. Susan was unable to sit upright for more than a couple of hours at a time, but the college worked with her and her mother to ensure she could go home to lie down and return in the afternoon. When she became unable to do this, the college made arrangements for her to attend classes virtually, via Skype.

Short breaks, where available, were also valued highly – as were weekly and holiday play schemes, and small grants.

A few family carers singled out personal budgets or direct payments and the support (including personal assistants and holiday clubs) they had been able to purchase with them. However, this was balanced by the number who, elsewhere in the survey, reported that (for example) they could not pay for support with the amount of money the local authority had allocated, or did not want to have to employ someone.

Ways of providing support

NOT SURPRISINGLY, GIVEN THAT POOR COMMUNICATION BETWEEN SERVICES WAS CONSISTENTLY NAMED AS A BARRIER TO A GOOD EXPERIENCE OF CARE, GOOD COMMUNICATION AND COORDINATION WERE HIGHLY VALUED:

'NHS services are well-integrated and there is good liaison between professionals. Also *good* liaison between NHS and social care OT [occupational therapist].'

By the same token, families appreciated services that took it upon themselves to 'check in' rather than being chased:

> "What we found is that they're proactive; [the] hospice, they contacted us for services, and they tell us to use the service – not us chasing them up, which is different to any other thing."

Young people placed a high premium on consistency. Two young adults spoke to us at length about practitioners (a paediatrician and a nurse) who had supported them throughout their lives, including with matters beyond their professional remit, and who had gone on supporting them informally when they reached adulthood.

Several families spoke about particular professionals who – irrespective of the nature of the support provided – had gone 'above and beyond' to accommodate their needs:

> "My son has complex needs and his brother is also on the autistic spectrum as well. Two of them are seen by the CAMHS [Child and Adolescent Mental Health Services] specialist, but he said he would see my other son because he's part of our family and that's made such a difference to us… we don't have to coordinate appointments, we go at the same time. He still treats them as individuals, but just the practicalities around that… The fact that he was willing to say, you know, 'I'll look outside the box, not this tick-box criteria, I'm going to look at what you need, rather than what the system said' – it really made a difference."

> "Yes, I went to a doctor and he said to me, 'Why do you have to make separate appointments for two different things to see me?' and he said, 'It has to stop.' From now, on… he takes responsibility for doing the appointments all together and they see the same doctor – we see the neurologist, respiratory doctor everything. He arranged that we could come to respiratory in the morning, otology in the afternoon, so it was all in one day. That was really helpful because sometimes I was away in London every single day… sometimes some of the doctors go the extra, they look outside of the box and look beyond the tick-boxes."

These examples of the most valued support are in many ways cause for concern as much as for celebration. For professionals to provide support beyond their remit, or to take on a key working role, are things that the system militates against. They are the exception rather than the rule, and the fact that (for example) paediatricians are going out of their way to support young people well beyond their 18th birthday only serves to highlight their lack of faith in what formal systems exist to facilitate transition. Finally, while each individual case of practitioners going 'above and beyond' is welcome to the family who benefit, once it becomes systemic it can be positively counterproductive – causing staff burnout on the one hand and, on the other, hiding from view some gaps that urgently need attention.

Finding out about and accessing services and support

ONE THEME IN OUR CONVERSATIONS WITH AND SUBMISSIONS FROM FAMILY CARERS WAS SO COMMON AS TO BE OVERWHELMING: THE NEED TO 'FIGHT' FOR SUPPORT.

The quotes here are a small selection of the many comments family carers made in this regard:

> "Everything is a fight, and what would make life much easier is if it wasn't."

> "Every appointment or department we have been to is done because I have fought for that person to see my child."

> "We don't get support of any services until we put in a complaint."

> "Have to fight for the services and healthcare that should automatically be available; life is difficult enough as it is without these barriers. This takes valuable time that I feel should be spent with my other children too."

> "Everything is a fight to get something that is an actual need for the disabled child; it's not like we ever ask for anything that is luxury."

> "You have to actually beg for many of these services – you have to demonstrate that you and your family are in crisis to get help."

The need to fight was the norm for many, as was an antagonistic relationship with (statutory) service providers. As the final quote shows, there was a perception that the 'burden of proof' rested squarely with the family. Related to this, the nature of needs assessments and eligibility criteria was also problematic for families in the two groups under consideration. We heard that assessments for social care and continuing care were often poorly suited to capture the complex and fluctuating needs of children with complex disabilities and complex health conditions. Furthermore, for families undergoing assessments, eligibility criteria can seem as though they have little to do with quality of life. We heard the example of a young man with very limited mobility – able to walk to his front gate, but no further – who was deemed ineligible for a wheelchair, leaving him effectively cut off from any activities outside home.

Once again, the best informed family carers knew how to maximise their chance of getting support. One mother reported: 'One of the best pieces of advice that somebody gave me was fill it in on his absolute worst day, because [if] you fill it in on his best day… he wouldn't get it.' That family carers feel pressure to fight for support in this way demonstrates that the system is in danger of being unfair and counterproductive; as the penultimate quote makes clear, families are not asking for luxuries, but for essentials.

Increasingly, families were having to resort to lodging complaints and even threats of legal action or actual legal action to get support. This sets a worrying precedent: if complaints become the gateway to support, then families who lack the resources (capacity, time, know-how or connections) to do so, which may well include the families in greatest need, are at risk of not getting that support. Moreover, such a trend risks disempowering young people themselves even further; young people who are *not* living with any disability perceive that a complaint from an adult is more likely to be heard than one made by a child,[112] and the odds against disabled young people with complex needs being listened to may be (or seem to be) impossibly high. Regulators have a role to play in ensuring complaints procedures are clear and accessible to all.

Above all, this ongoing battle (as it is so frequently described) is a drain on families' resources, including their emotional resources. Respondents to our call for evidence had first-hand experience of lost employment, marital or relationship breakup, and nervous breakdown.

While the thrust of changes to policy and practice has been to reduce the burden on families, certain developments may, conversely, have contributed to family pressures. One is the introduction of personal budgets, which will see family carers and young people over 18 effectively becoming employers, responsible for recruiting their own carers and personal assistants. Of course, many will embrace this, but others will require support with this significant change, and perhaps all would benefit from guidance. Professional experts we consulted cautioned that, although they remain optional, some families might be (or feel) 'pushed' into taking on a personal budget.

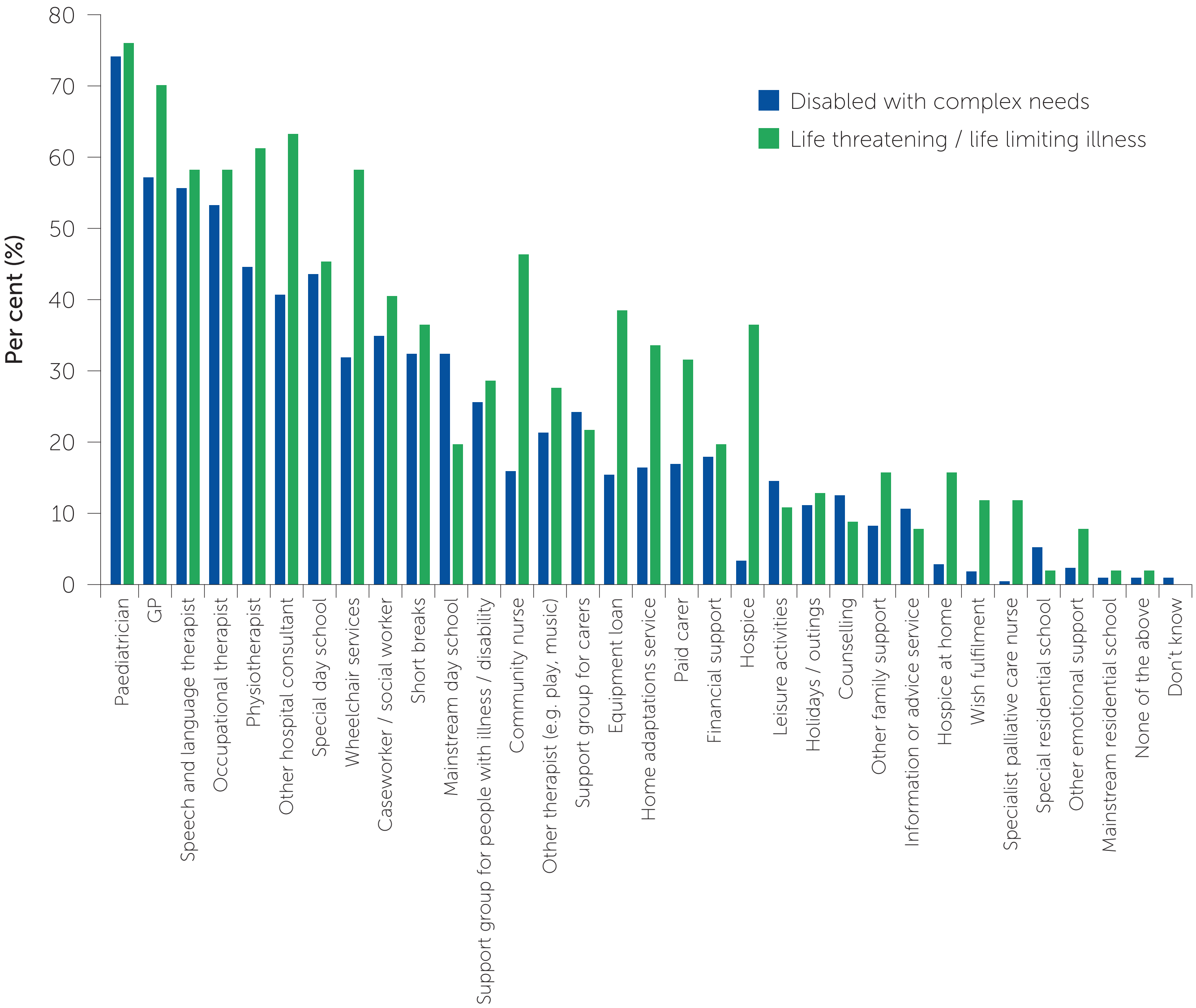
EHC plans are intended to reduce the need for families to fight. The requirement for local authorities and schools to publish a 'local offer' should enable families to find out what is available. The joint plan, reinforced by duties on education, health and care to work together, should ensure that coordination occurs more automatically. Finally, the right to a personal budget should ensure that families have choice and control over what they receive. However, attitudes towards EHC plans were mixed. Family carers' feelings are discussed alongside those of professional experts and service providers in chapter 3.

Services and support used

WE ASKED RESPONDENTS TO OUR CALL FOR EVIDENCE TO TELL US ABOUT THE DIFFERENT PROFESSIONALS AND SERVICES THEY WERE IN TOUCH WITH.

Figure 4 shows a breakdown of the support used by the two broad groups of families – those with children with life-threatening and life-limiting illnesses, and those with disabled children with complex needs.

FIGURE 4: REPORTED USE OF DIFFERENT FORMS OF SUPPORT BY RESPONDENTS TO OUR FAMILY CARER CALL FOR EVIDENCE



There are some clear differences in the services accessed by the two broad groups of children and young people demonstrated in figure 4. Families caring for a child with a life-threatening or life-limiting condition are, unsurprisingly, more likely to be in touch with palliative care and medical services. They appear to be slightly overrepresented as users of physiotherapy, occupational therapy and speech and language therapy, as well as wheelchair services and equipment loans. This might reflect higher levels of need for these forms of support within this group or that services for these children are better coordinated – perhaps mediated by health or palliative care.

Below are two brief case studies, based on anonymised survey responses, that illustrate the number and range of services that might be involved in the care of a child or young person.

Bella

Bella is a 4-year-old with cerebral palsy, epilepsy and cortical visual impairment. She is non-mobile, fed through a percutaneous endoscopic gastrostomy (PEG) tube, and sometimes relies on supplementary oxygen. Bella goes to a special (day) school. Involved in her care are a paediatrician, GP, occupational therapist, physiotherapist, speech and language therapist and music therapist.

Her family receive a direct payment, which they use to pay for a carer for four hours per week; they also use wheelchair services and equipment loans, and are in touch with the hospice.

Bella has two siblings, and her parents feel there is not enough support for them.

Francis

Francis is 17 and lives with a foster carer. He has a life-limiting genetic condition, which has resulted in profound and multiple learning difficulties and a number of health conditions. Francis uses a wheelchair, and attends a special (day) school.

Francis sees a paediatrician and at least one other consultant, as well as his GP, an occupational therapist, physiotherapist and other therapists. He and his foster carer are in touch with wheelchair services, equipment loans and a home adaptations service, and they also get financial support.

He is able to go on short breaks, holidays and outings, and he participates in a support group for disabled people and other leisure activities, though not all services are suitable for his needs, as many do not deal with PEG feeding or offer personal care.

Francis' foster carer attends a carers' support group and has accessed an information or advice service, but most information about the support they use has come either through their social worker or friends with disabled children. Support is also available from the family.

Services and support needed

Short breaks

We asked family carers and young people to tell us what further support they felt they needed that they were not currently getting. A quarter of them named respite care or short breaks – someone coming into the home to allow them to go out for a couple of hours, or the right to more overnight stays for their child in a hospice. Equally important were social and leisure activities, which were top of the agenda for the young people we spoke to. Respondents named a number of motivations for this: wanting their children to meet peers with similar disabilities (which was something young people themselves wanted) and to have the opportunity to get out of the house, local leisure services not being accessible, and transport difficulties.

Practical and emotional support for the wider family

Family carers reported a need for information, training and support that fitted in realistically with their commitments. In particular, they wanted counselling and bereavement counselling, and support (whether psychological or social) for their other children.

Brothers and sisters of ill or disabled children make up about half of all young carers, but they are often not recognised as carers (partly because parents are reticent to have them recorded as such).[113] Young carers in England (and parent carers) have a new right to a carers' assessment under the Care Act from 1 April this year, but there is a risk that without more targeted efforts siblings may not benefit fully from this.

Some we spoke to thought that siblings were doubly vulnerable to the retrenchment of resources. First, as a group in their own right, brothers and sisters seem to have slipped down commissioners' lists of priorities. Training providers reported seeing fewer health and social care professionals at sibling support training sessions than (perhaps) ten years ago, while dedicated support groups for young carers are less readily available or less widely accessible, for example, because of stricter eligibility criteria that require the young person to be delivering significant amounts of direct personal care.

Second, practitioners were aware of young people bearing the brunt of reduced services for their ill or disabled brothers and sisters, for example, being called on to deliver more personal or medical care. Parents may rely on their other children to check on a sick child during the night, particularly where they share a room. The resulting lack of sleep, along with a whole range of emotional and practical impacts, can have a lasting, detrimental effect on brothers' and sisters' own health and wellbeing, and their educational outcomes. Interviewees reported long waiting lists for the already extremely stretched Child and Adolescent Mental Health Service. Unless children are registered as young carers, there is no formal channel through which schools will be aware of their situation – even less so if the ill or disabled child is not at the same school.

Sibs: dedicated, UK-wide support for brothers and sisters of disabled children and adults

There are over 2 million adults and children in the UK who have a disabled or chronically ill brother or sister, and only one charity exists to support them. Sibs is an example of a charity that campaigns on behalf of, and provides direct support to, a group whose members are easily overlooked. It builds the capacity of the wider workforce who come into contact with children and families (eg education, health and social care) to recognise and meet the support needs of siblings. Sibs plays a role that is increasingly important as local budgets tighten and eligibility criteria for help become stricter.

As explained above, young siblings are often called on to help deliver care in the home. At the same time, parents of disabled children may struggle to find the time to give their non-disabled children the attention they would like to.

Sibs runs an online support service for young siblings, YoungSibs, and phone support and workshops for parents with advice on supporting their non-disabled children. Advisers have the time (which increasingly pressed statutory services may lack) to listen to parents' concerns about siblings, and are trained to offer practical advice to help improve siblings' family relationships and wellbeing. The organisation provides training and consultancy for professionals on how to support siblings and develop local services.

Sibs campaigns nationally for the recognition of the rights of siblings of disabled children and adults. The charity is concerned that young siblings are taking on more medical responsibilities, as the statutory support for families has become less available with reduced health and social care funding. Sibs calls for siblings of disabled children to be recognised as a vulnerable group within the education system, as they are at risk for problems with learning and wellbeing.

© Sibs

Staying on the theme of support for the wider family, some family carers thought there was too little acknowledgement (at least in a way that translated into support) of the strain that caring for a child with complex needs placed on couple relationships. One parent told us:

> "I don't think there's enough said about as a married couple, or as a couple, bringing up your family... and it does unfortunately happen where the relationships bust apart if you don't get pulled together... I just think there has got to be consideration of the fact that we should've had the right to just be a couple and try and support us to stay together and do this journey together. Because if they don't help us, they're putting obstacles in the way."

Getting a diagnosis

Family carers frequently felt that it had taken too long to receive a diagnosis (a problem because a diagnosis can act as a helpful trigger for other services on a care pathway, and because of the degree of emotional clarity it offers) and reported long waiting lists for therapies (especially things like speech and language therapy) but, as one interviewee put it: 'People are very complimentary about services when they receive them, but it's still difficult to get them and they're in too much short supply.'

Our own findings broadly confirmed those of the two-year study *The Big Study for Life-limited Children and their Families* (funded by the Big Lottery in collaboration with Together for Short Lives, looking at children's palliative care services in the West Midlands).[114] The researchers found a contrast between families' experiences of health and social care services – long waiting lists notwithstanding, once they were receiving health services, families reported good levels of satisfaction with these, but they reported much poorer experiences of services that came under a social care heading. In our own interviews we found that interviewees perceived that the problem was partly one of a lack of understanding on the part of local authorities of the importance of these services to families. For instance, families who had been put on a waiting list for home adaptations felt that the service simply did not understand the impact of the delay on their lives. This was the case for Jonathan (see below).

Jonathan

The wait for adaptations had left Jonathan's family in a Catch 22 situation. As Jonathan reached his mid-teens, his mother struggled to support him to use the bath, so they had to wait for his father to get home from work. But Jonathan's father was already working longer hours and night shifts so that they could afford to move to a more accessible home. Thus, they were faced with the choice of compromising either Jonathan's wellbeing or his mother's.

Outside drivers

Financial impacts, welfare reform and the 'scrounger' narrative

72%

OF PARENTS OF DISABLED CHILDREN REPORTED THAT THEY HAD HAD TO CUT BACK ON WORK OR GIVE UP ON CAREERS BECAUSE OF CHILDCARE PROBLEMS.[117]

The charity Contact a Family has been publishing its report 'Counting the costs' regularly since 2008, charting the financial impact on families of disabled children.[115] Many issues are consistent for all years (for example, the higher cost of heating, transport and childcare for disabled children, and so on), but in the most recent years the report has noted a rise in benefits sanctions, food poverty and problem debt among families of disabled children.

Changes to the economy and the political response to them have affected families directly and indirectly. The indirect impact is the shift in public attitudes towards disability, and especially the emergence of the so-called 'scrounger' narrative (a word used by many of our interviewees, but always in inverted commas). An academic study looking at reporting of disability in print media found an increased politicisation in portrayals of disability in 2010/11 compared with 2004/5, with a smaller proportion of articles describing disabled people in sympathetic or deserving terms, more coverage of disability benefit and fraud, and a concomitant increase in the use of pejorative language such as 'scrounger', 'cheat' and 'skiver' in relation to disabled people.[116]

Interviewees were acutely aware of the detrimental effect of public attitudes on families, who are now reticent about seeking (and being seen to seek) support, and may delay doing so until their circumstances are completely unmanageable. In addition, there was a sense among parents and the voluntary sector that some of the policies aimed at reducing the deficit 'targeted' them specifically. Notable such policies included the removal of the spare room subsidy (also called the 'underoccupancy penalty' or 'bedroom tax') – which, in regard to disabled children, was left to the discretion of local authorities; the introduction of Universal Credit; and the possibility (provided for in the Welfare Reform Act 2012, but not yet introduced) of reform to DLA for under-16s.

Families are experiencing a *triple* impact: the higher 'baseline' cost of raising a disabled child; the impact of higher cost of living (including welfare reforms – some of which remove what was originally intended as compensation for that higher baseline cost) which affects many families, not just those of disabled children; and reduced services.

The dynamics are further complicated by the fact that reduced access to services such as short breaks and childcare can have a compounding financial impact – they affect the ability of parents (usually in practice mothers) to remain in or take up employment, which can plunge them into poverty. According to Contact a Family, as many as 72 per cent of parents of disabled children reported that they had had to cut back on work or give up on careers because of childcare problems.[117]

Aside from the extra cost of caring for a very ill child or a disabled child with complex needs day to day, there are some financial penalties associated with particular circumstances. One is where families are coping with the death of a child. The so-called 'cost of dying' (which comprises more than the cost of the funeral) rose seven times faster than the cost of living during 2014[118] and, while help is available, almost half (47 per cent) of social fund applications are rejected.

Even where they are not, the average shortfall between the grant and the actual cost totals over £1,000.[119] Most bereaved families want and need time away from work to grieve, and to support any other children, but much is left to the discretion of employers. While guidance exists (for example, Child Bereavement UK[120] and Sands[121] have useful publications), many employers will not access it or be able to implement it, and the only formal 'tool' they have of supporting bereaved parent employees – compassionate leave – is inadequate to the task of addressing longer term impacts.

Frequent or lengthy hospital stays, or stays in emergency respite, also contribute to financial instability for parents. In a report published last year, the special care baby charity Bliss highlighted the costs of parking, accommodation, meals, and time off for parents of premature babies (and many of the same considerations apply for older children). Again, support from employers is often key, and Bliss publishes useful guidance on this.[122] Paternity leave, in particular, is an area that requires improvement. Fathers have to use their leave between the actual date of birth and 56 days after the expected date of birth. Very premature babies may well be in neonatal care for longer than that period, but couples do not have the option to split paternity leave (eg half when the baby is born, half when the baby comes home) or defer it until the baby comes home. This leads to additional strain for both parents in adjusting to life at home. The recent changes to paternity leave (introduced in April 2015) do not appear to have altered the position for parents of premature babies.

THE SO-CALLED 'COST OF DYING' (WHICH COMPRISES MORE THAN THE COST OF THE FUNERAL) ROSE SEVEN TIMES FASTER THAN THE COST OF LIVING DURING 2014.[118]

Helen House and John Radcliffe Hospital Neonatal Intensive Care Unit: Effective statutory and voluntary sector collaboration

Set up in 1982, Helen House in Oxford is the world's first children's hospice. Helen House has always offered support to neonates needing immediate end-of-life care, but the hospice and hospital are now working together to provide early support to families with babies likely to survive infancy.

Helen House promotes early referrals from the Neonatal Intensive Care Unit (NICU) at John Radcliffe Hospital, so that babies spend time as inpatients in the hospice as an interim measure before discharge home. Not only does this ease the pressure on hospital staff, it also allows parents to prepare for taking the baby home. Even taking a healthy new baby home can be a difficult adjustment for families, but for babies with complex health needs who may have been receiving inpatient care for several weeks or even months, the prospect of not having medical assistance on hand can be especially overwhelming.

At Helen House, parents can stay overnight with their baby and receive support from staff to build their confidence in caring for them at home. The family is introduced to local community teams; once the baby is discharged, they can use the hospice for respite and out-of-hours palliative care.

Helen House's approach to early support starts even before birth; the hospice is now working with local obstetricians to arrange antenatal referrals when an antenatal scan leads to diagnosis of a life-threatening or life-limiting condition.

© Helen & Douglas House Hospice

Attitudes

A common theme in our research was the need for services to follow through with positive aspirations for disabled young people with complex needs, and offer them 'positive opportunities'. Family carers and young people themselves praised schools and colleges in particular for this:

"We're actually at a school at the moment where we're in the best place that we've been and that's because the school really sees [my son] as an individual and recognises us as parents who have a role to play in his life and something to offer his school. They've also got a really good focus on the future; so what we've found is that for our son (who's got severe learning difficulties and will need life-long support) some schools aren't willing to think about the future."

"When [my daughter] was born, with two older sisters, I felt that she was equal. She was tiny, but she was a human, she was equal. I wanted her to have education like her sisters, to try the best I can – my husband and I – to parent her as we parented the other two. Additionally, with her complex needs, let her be part of the family, part of the local community, her rights to education and everything else that needs to come with it. Treat her with her individual needs, but have aspirations for her. We've actually had to say to people, 'Don't write her off', just because she has these diagnosed conditions."

There is of course a degree of interaction between the culture within services and the prevailing attitudes towards these children and young people in society at large. A case in point is the experience of one service whose representative we spoke to, which provided care for disabled young adults with complex needs. The service had been approached by a large local employer (an insurance company) with an offer of apprenticeships for some of the 16–24-year-olds. After further discussions, it transpired that the office toilets were not fully accessible. The only solution suggested by the prospective employer was that the young people could return home to use the facilities there during their lunch break. As one interviewee put it, 'Inclusion is more of an aspiration than a fact in the way that children and young people experience accessing universal services.'

Voice

One area was universally thought to have improved over the past decade: the opportunity for family carers to have their voice heard, and the willingness of policy-makers and service providers to hear it. This was attributed in large part to the establishment of parent carer forums (of which there is now one in almost every local authority in England – just under 150).

Services were felt to have taken on board the need to work in partnership with parents, and in a way that put the family at the centre of their care. Some of our interviewees saw this as a matter of cultural change – of organisations putting individuals' and families' needs before their own. They thought that organisations needed to be 'in a certain place' before they could contemplate this – a place that children's hospices were just beginning to reach, but one that, for stretched statutory organisations, would be hard to reach or to sustain. It was felt that the voluntary sector had been quickest to adopt this way of working. Indeed, some saw this as a case of the formalisation of the ethos the voluntary sector had been putting into practice informally for decades.

Our interviewees were keen to keep up the momentum of parent carer forums, speaking of a danger that the much-needed funding for their infrastructure might be taken away once they were seen as 'embedded'. They thought this would be short-sighted, as member parent carers are of course volunteers and participation is an enormous commitment in addition to caring responsibilities. In addition, health was felt to be somewhat of a missing partner in listening to parent voice. Contact a Family, supported by a grant from the Department of Health, has been working to improve links between parent carer forums and health commissioners and services.[123]

On the related matter of children and young people's voice(s) and involvement in decision-making, it was thought that although progress had been made here, too, there was further to go. Commitments have been made. For example, the pledge made in 'Better health outcomes for children and young people', launched in 2013 and signed by a range of statutory health and social care regulators and umbrella bodies, includes the promise that 'children, young people and their families will be at the heart of decision-making, with the health outcomes that matter most to them taking priority'.[124] However, the Children and Young People's Health Outcomes Forum (to whose first report the pledge was a response) has drawn attention to a serious gap in accountability here; it is not clear how health bodies can demonstrate that they have involved young people, and how they have incorporated their feedback. There is certainly scope for more formal channels, eg inclusion of children and young people in patient experience measures that apply to adults. This is true across all healthcare (for example, in the Friends and Family Test) but it becomes more important the smaller the sample and the less visible young people are – hence, finding a way to include children and young people in VOICES (the national bereavement survey) was named as a priority.

Routine data collection is important because it is equitable; the burden of participation is considerably less than with membership of a forum. It therefore provides a better opportunity to capture the many 'hidden' families, as opposed to those who are – as one interviewee put it – 'so used to talking they've almost become semi-professional'. The family carers from the families whose children are most sick, least stable, who have the fewest resources (practical, financial, emotional) to cope with their situation are unlikely to attend a forum. The same is true of parents who do not (or do not *yet*) identify as having children who belong in this group. Parents of very young babies with complex health needs, in particular, may not have had the time or 'headspace' to access support – indeed, they may not have understood or accepted their child's needs or likely future needs, and are unlikely to associate their child with the word 'disability' (which society tends not to apply to babies).

Young people we spoke to emphasised the need to be empowered at as young an age as possible. They were keen that we understand that parents' priorities are not always the same as their children's – there is a danger that, by listening only to one-half of the story, services may not act in the best interests of the child. Quite apart from the statutory rights of children and young people to be listened to,[125] doing so would help to address some of the problems that systems tend to create for them later on, particularly as they make the transition to adulthood. At present, as we shall see, the sudden transfer of decision-making responsibility on a young person's 18th birthday can be daunting – even distressing – for them and their family, who suddenly find themselves disempowered.

Conclusion

THE EVIDENCE RECEIVED FROM FAMILIES AND THEIR CARERS DEMONSTRATES THAT THERE ARE SOME IMPORTANT, POSITIVE STORIES TO TELL ABOUT THE LAST TEN YEARS.

In particular, children are positive about their experiences about schools, where they often feel well supported. Parents, meanwhile, have more opportunities to make their voices heard, largely through innovations such as parent carer forums. However, children's voices are yet to be embedded. Other ideas, such as personal budgets, have been introduced as part of the drive to put families in control, allowing them to commission the services and support they consider right for them. When they work well, personal budgets can be used to cover the costs of short breaks, which help take the pressure off families and may ease demand for public services in the long run.

However, these new ideas are not without their problems. Though the use of a personal budget is a choice, there are indications that some families may feel pressure to adopt them – with many reluctant to take on the responsibilities that they entail. Another source of strain on families is the lack of clarity over entitlements to care, with many suggesting that they have had to 'battle' to access the support they need. This is a particular problem in social care, which contrasts with a more positive story in health. This mixed picture shows how progress can be made in many areas, but that considerable challenges remain.

3

Opportunities and challenges

Few, if any, of the challenges outlined in this or the preceding chapter are new. Some have had a continuous impact on families for years. Others have had a more complicated trajectory – they have abated, during the last ten years, with an injection of resources, but efforts have lost momentum. This has occurred for several reasons: loss of investment (or a failure, in the first place, to ensure that improvements were sustainable); lack of leadership, framework or accountability to embed change; change in political priorities, and so on.

Most of those we consulted for this research – parents as well as practitioners – were keenly aware of further changes on the horizon. We encountered anxiety about further cuts, and a mixture of optimism and cynicism about new legislation and policies. In this chapter we present the challenges from the point of view of those providing services. We convey their views on what the barriers are to change, and the movements they feel are potential enablers.

This chapter identifies some major challenges:

- There is a lack of clarity over care entitlements which is a problem for local authorities and families, and unhelpful variation of services across the country.
- Coordination between health, social care and education remains a major challenge. Commissioners need to guard against discouraging collaboration between different service providers.
- There are also significant workforce challenges ahead, if children and families are going to receive the care and support that they need.

However, there are also good news stories:

- Medical advances are leading to more children with life-threatening or life-limiting conditions living beyond the age of 18. This brings new challenges around transitioning from care arrangements designed for children to those for adults.
- Hospices have become 'much more outward-looking' and collaborative with other institutions, to the benefit of patients.
- Services are beginning to liaise more with one another, and the EHC plan is seen as a cause for optimism.

We received responses to our online call for evidence from 128 formal service providers. Responding services operated in each of the UK regions, and some that operated nationally in the whole UK. Most respondents (60 per cent) were from well-established services (of more than 15 years' standing). A sixth of respondents (16 per cent) had been established for five years or less. Among the respondents, 55 per cent supported under 18s; 46 per cent supported disabled young adults over 18 with complex needs; 79 per cent supported under 18s; and 54 per cent supported young adults over 18 with life-threatening and life-limiting illnesses.

A lack of clarity

AS WE SAW IN CHAPTER 2, THE VAST MAJORITY OF FAMILY CARERS FIND THE EXPERIENCE OF INVESTIGATING AND ACCESSING SERVICES, PARTICULARLY SOCIAL CARE SERVICES, IS ONE OF 'STRUGGLE' AND 'FIGHT'.

Families tend to be thrown back on whatever resource they have – late nights spent on internet discussion forums, the goodwill of a particularly proactive social worker – to find out what is available and what they might be entitled to. In fact, this stems from a lack of clarity right at the top.

MEDICAL ADVANCES ARE LEADING TO MORE CHILDREN WITH LIFE-THREATENING OR LIFE-LIMITING CONDITIONS LIVING BEYOND THE AGE OF 18.

While there is some clarity about the definition of disability, the definition of 'disabled children' as a group is less clear cut – and even more so for the smaller group of disabled children with complex needs. The Equality Act 2010, which covers England, Wales and Scotland, introduced a broader definition of disability – that it is 'a physical or mental impairment that has a substantial and long-term adverse effect on the ability to carry out normal, day-to-day activities'.[126]

For a start, disabled children are not considered as a group in legislative terms; they are, as one professional expert described it, 'just sort of stuck under "children in need"'. 'Child in need' status is a definition used in the Children Act 1989; it applies to any disabled child, and any child unlikely to achieve or maintain a reasonable standard of health or development without the support of local authority services.[127] Hence, for legislative purposes, disabled children and their families are considered within a child protection framework. This contributes, first, to families' fears of how they are perceived by social care (and consequently their trust and willingness to engage with services). Second, it is very much at odds with the categorisation used in education, where disabled children are a subgroup within SEND. Within schools, SEND support and safeguarding are quite separate functions. The result is awkward and counter-intuitive funding arrangements such as a family support service for disabled children funded through a local authority's safeguarding budget.

The Care Act 2014, which followed the recommendations of a Law Commission report into the adequacy and fairness of adult social care in England, enshrines the duties of local authorities to provide people with support, based on an assessment of their needs. There is no equivalent framework for children's social care in England, and there are no plans at present to develop one. This contrasts sharply with the other nations of the UK: in Scotland, national care standards were published in the early 2000s and have been gradually revised since. Separate care standards documents exist for adult, children's and integrated services.[128] In Wales, the Social Services and Well-being (Wales) Act 2014 sets out the duties and functions of local authorities and partners in improving the well-being of children and young people.[129] In Northern Ireland, the Executive is currently developing a service framework for children and young people's health and wellbeing.[130]

In England, by contrast, there remain no one clear route to (or right to) assessment for children's social care, no clear eligibility criteria linked to an assessment of needs, and no national specification for the support that should be provided.

The needs assessment for adult social care has a defined set of outcomes, including the ability (assessed *without* the help of an informal carer, even if the person normally receives this) to move around safely, use the toilet, and participate in activities like volunteering and learning. In England, the needs assessment for disabled children is the same as that for other children in need; the focus is on safety and development, not on enjoyment, achievement or contribution (the Every Child Matters principles). The assessment is a particularly blunt tool for children with the most complex needs, as this parent explained:

> "What they are using for assessment are quite funny, because most of our children are very complicated and sometimes their needs are fluctuating as well. Those ones are just tick-boxes – nothing for the person who is actually there."

It should perhaps be little surprise, then, that local authorities themselves are unclear about what they should be providing and inconsistent about what they should provide. Disabled children's charities are increasingly having to advocate for families, drawing on the piecemeal and out of date legislation that does exist: the Chronically Sick and Disabled Persons Act 1970 (designed, in any case, for adults) and the Children's Act 1989 (see p 48). One person we interviewed commented:

> "It's all a muddle. You have to sort of pull different bits of policy and law from different places to try and build up the case for that assessment."

PAMIS: involving and empowering families amid changes to support in Scotland

The charity PAMIS (Profound and Multiple Impairment Service) provides support to people with profound and multiple learning disabilities and their carers across five areas of Scotland: Tayside, Grampian, South Lanarkshire, Fife, and Greater Glasgow and Clyde. As well as providing practical and emotional support to individual families through a regional family support service, and campaigning nationwide for inclusion and accessibility, PAMIS delivers consultations that give young people and their families the opportunity to significantly influence policy. PAMIS ensures the maximum benefit to families by making sure consultation and practical training are closely linked.

For example, PAMIS led consultations on the Scottish Government's ten-year strategy for people with learning disabilities, *The Keys to Life* (2013),[131] and the Self-Directed Support (Direct Payments) (Scotland) Regulations 2013. PAMIS has just received confirmation of its second successive round of funding (to last for three years) for the delivery of training and support for family carers with the implementation of self-directed support.

PAMIS does not describe what it does as advocacy. Rather, its training, called 'Empowering conversations', is about equipping family carers and young people with the information and skills to manage the changes and to practise self-advocacy. Topics covered include 'adult support and protection and risk enablement' and 'employment law' (equipping families to employ personal assistants).

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Up to

50%

THERE IS A NEED FOR LONG-TERM INVESTMENT IN COMMUNITY SERVICES AND AN INCREASE OF UP TO 50% IN THE NUMBER OF PAEDIATRICIAN.[137]

Workforce

ALL THE CHILDREN WHOM THIS REPORT CONCERNS WILL BE IN TOUCH WITH A LARGE NUMBER OF PROFESSIONALS.

As discussed, though, the makeup of these professionals may be slightly different depending on the child's needs (see pp 39-41); disabled children with complex needs tend to draw more on support from social care, while children with life-limiting and life-threatening conditions are more likely to be in contact with healthcare professionals and to access palliative care. We have also seen (see p 44) that, in the main, families report greater satisfaction with the quality of healthcare than with social support. This is reflected in the slightly different challenges associated with the workforce supporting each of these groups of children. Both groups are disadvantaged by a lack of access to universal services, and a lack of knowledge among the generalist workforce (including GPs, social workers, and so on). However, the most pressing issues for families with a child with palliative care needs are coverage, recruitment and retention of staff, while many families of disabled children (with any level of need) urgently require support with the transition to becoming employers (of personal carers, etc) themselves (already discussed on p 39).

Numbers of specialist staff

Particularly within children's palliative care, the recruitment and equitable distribution of specialists in is an historic challenge, and was identified in the New Philanthropy Capital (NPC) 2005 reports and the Craft–Killen review.[132] Since then, there has been limited progress – for example, there are now 16 paediatric palliative care consultants in the UK, compared with six a decade ago.[133] Nonetheless, 16 is a very small number when distributed throughout the UK; Scotland and Wales have only one level 4 consultant each, and there is not one for Northern Ireland.[134] Moreover, taking into account the disparity between child and adult need for palliative care, to put the two on a par, we would need between 10 and 20 more consultants for everyone who is currently registered.[135]

Expanding community nursing, and especially community specialist palliative care nurses, was something many of our interviewees wanted to see as a policy priority. Some earlier progress in this area – for example the Treasury-funded teams of specialist palliative care nurses ('Diana teams') in England and Wales – has not been fully sustained.[136] Judith Ellis, chief executive of the Royal College of Paediatrics and Child Health, has explicitly linked the UK's poor performance on child mortality (now the worst in Western Europe) with the underinvestment in paediatricians and child nurses. Referring to commissions for children's nursing as 'minute', she has called for long-term investment in community paediatric services as a matter of priority, and for as much as a 50 per cent increase in the number of paediatricians.[137]

Loss of specialist expertise

Among those we spoke to in the allied health professions (speech and language therapy, occupational therapy, physiotherapy), too, there was a perception that there were not enough people at the appropriate skill level in many areas. Some were concerned about a 'hollowing out' of these professions, as senior therapists were replaced by newly qualified therapists (who were expected, nonetheless, to take over the same caseload).

The Health and Social Care Act 2010 (which applies to England only) moved school nursing into the remit of Public Health England, and thereby under local authority control, cementing an emphasis on the promotion of health and wellbeing, reduction of health inequalities, and early identification of health needs. The service is commissioned and provided at four levels. The fourth, most specialist, level – 'universal partnership plus' – requires nurses 'to work in partnership with partner agencies in the provision of intensive and multi-agency targeted packages of support where additional health needs are identified',[138] and is thus the level which children with complex health needs will require. Local authority commissioners must ensure that there is sufficient coverage at all levels for all children in its schools. Our interviewees found that this arrangement has not worked well for special schools, which of course have a much higher level of nursing need than the general school population. Professional experts reported that special schools sometimes lacked (sufficient hours of) access to a nurse at the required level of specialisation, but were equally told that less specialist nurses were 'no longer allowed' to perform functions like tracheostomy care, replacing gastrostomy tubes, and so on.

Knowledge within the generalist workforce

The need to train the generalist workforce, and particularly to involve GPs was highlighted as a priority by a number of professional expert interviewees. When GP-led commissioning in England was first floated (eventually introduced, as 'clinical' commissioning, under the Health and Social Care Act 2010), there was a fear that GPs would wield too much power over services. Yet professional expert interviewees working in the health sector reported that their experience was the reverse; as GPs have taken on more responsibility for commissioning (non-specialised) services, and as children's palliative care has grown into a clear specialism, generalists have become 'disenfranchised'. There is a sense, in other words, that children's palliative care is 'not their job', and that they lack the specialist knowledge to provide support: 'Sometimes I think healthcare professionals either don't know enough about the condition, its implications, life expectancy and so on – or they are frightened of telling families the truth.'

To address this, interviewees wanted to see GP training and education in children's palliative care. They thought it was particularly important to include education about the distinction between adult end-of-life care (provided in the last months of life) and children's palliative care (provided throughout a child's life and, increasingly, to children likely to live to adulthood).

Past efforts at training were thought to have been hampered either by a lack of standardisation (delivered through optional courses, their availability varying from one area to another), or through resources becoming out of date. For example, a GP handbook produced by Together for Short Lives was named an excellent resource, but it had been removed from circulation because it contained technical guidance (on dosages and so on) that was no longer recommended practice. Several interviewees thought it was important to explore best practice in linking generalists to specialist expertise – particularly in community nursing. Likewise, the recent Carter Review of Initial Teacher Training in England notes that SEND is consistently one of the areas of training that primary teachers rate lowest, and recommends the inclusion of SEND in a national framework for Initial Teacher Training Content.[139]

Coordination

AFTER THE 'FIGHT' TO ACCESS SERVICES, LACK OF COORDINATION BETWEEN SERVICES IS ANOTHER MAJOR SOURCE OF IMPACT ON FAMILIES' LIVES.

It too often falls to family carers to plug gaps in communication, information-sharing, advocacy and record-keeping. One professional expert interviewee described 'that role that they have to take on – sort of go-betweens and administrators, facilitators of conversations between different agencies, different professionals'.

There are other reasons for making coordination a priority issue. Poor coordination leads to worse outcomes, and higher costs to services. It can lead, on the one hand, to waste and duplication of resources (for example, multiple assessments) or, on the other, to families falling through the gaps between services and settings (increasing the likelihood that families will need acute or crisis support). In the very worst cases, poor coordination can result in unwanted or unwarranted treatment.

The impact of poor coordination is perhaps easiest to discern at the end of life. In adult end-of-life care, coordination has received increased attention – it is recognised as key to truly delivering choice at the very end of life, most notably over place of death. A parallel conversation has been taking place within children's palliative care. Given this impetus, it is perhaps not surprising that there have been the greatest improvements in coordination in the area of end-of-life care. Representatives from children's palliative care cited an increase in successful discharges from hospital to hospice or home (supported by hospice staff), and – in some cases – from NICUs to hospice. As one professional expert interviewee noted, 'There's a lot more talking between people about death.'

East Anglia Children's Hospices: an innovative model of multi-agency support, care coordination, and 24/7 end-of-life care

East Anglia Children's Hospices (EACH) provides palliative care services for children, young people and their families in the large area of Cambridgeshire, Essex, Norfolk and Suffolk.

In April 2015, EACH was providing care for 328 children and young people and supporting a further 495 friends and family members, including those who had been bereaved.[140]

EACH provides an innovative 24/7 symptom management service through its Symptom Management Team. The team delivers care where required: in the hospice, the home, hospitals or schools across the region. It focuses on anticipatory planning, ensuring the child's needs are met as far as possible during normal day-time hours, to minimise the pressure on the out-of-hours service. The team is supported by the Managed Clinical Network, currently funded by a CCG, which brings together professionals and organisations to promote partnership working. It provides specialist telephone advice overnight and at weekends. This is delivered by paediatric consultants with additional children's palliative care expertise.

This model demonstrates the long-term impact that charitable grants can have on the voluntary and statutory sectors. EACH's 24-hour care service was initially introduced following a grant from the True Colours Trust. The scheme started with just four clinical nurse specialists in the Symptom Management Team, but as pressure on the service grew, new anticipatory planning practices and organisational models were introduced. The success of the model enabled EACH to make the case to the CCG that funding the programmes would be an efficient use of resources.

An internal 2012 evaluation of the True Colours Trust funded pilot programme demonstrated the success of anticipatory planning that allows for an affordable 24/7 service.

© Together for Short Lives

But getting coordination right at the end is just the beginning. Where a family has a child with a complex, life-threatening or life-limiting condition, it is inevitable that there will be several professionals involved. Add to that the likelihood, for many children and young people, of (repeated) emergency hospital admissions – where at least at the initial, triage stage the professionals will not know the family – and the picture is still more complex. One interviewee working in the community described families' 'dread' of hospital admissions, with the rigmarole of having to fight to be listened to, to have your superior knowledge of your child's condition acknowledged, and so on.

Most families with children over age 5 navigate three kinds of support: health, social care and education. The ideal, according to one professional expert interviewee, is 'that what the child experiences is there being no 'wrong door' through which you can go to get what you need'. In reality, we were told, the changes to commissioning may have created new gaps for families to fall through. Children with complex health conditions, in particular, tend to have a hospital focus for their plans, and there is an expectation that the GP will take over that plan during the time they are in the community. In practice, there is a risk that because plans have not been put together by the same agency as will own the budget for meeting them, they will be rejected by commissioners.

Integration

Integration can take several forms. In its broadest sense, 'integration' can be used synonymously with 'joint' or 'multi-agency working', 'person-centred' care, or 'designing services around people'.[141] In a stricter sense – and as a political buzzword – 'integration' refers to a formal arrangement between health and social care for the joint planning, delivery and sometimes funding of services. Health and social care integration in Scotland came into full force at the beginning of April 2015, but children's services have in practice been integrated for some time. In England, there has been clear commitment from government to move towards integration; the Care Act 2014 and the Children and Families Act 2014 include duties to promote integration. Simon Stevens, chief executive of NHS England, has pointed out the business case for integration, exhorting NHS commissioners to 'think like a patient, act like a taxpayer'.[142] This was a sentiment echoed by our professional expert interviewees (eg, 'these artificial divides between services are just wasting money'). The Children and Young People's Health Outcomes Forum has raised concern that children have been largely left out of discussions about integration. In particular, we do not have any success indicators to measure whether integration is 'working' for children as a distinct group.[143]

Integration of services is a separate issue from care coordination. In a non-integrated system, where there is no provision for automatic cooperation or information-sharing between distinct services, like health and social care, or social care and education, there is as much need (if not more) for a way of assisting families to navigate smoothly between the resources they draw on. In an integrated system, there will be some degree of automaticity to allow these things to happen. Nonetheless, it is important to recognise that the group of children we are concerned with will have a different pattern of needs at different times – families with babies born prematurely and/or with a complex condition are likely to get most of their support from health up until age 5, for example. The number and nature of services involved can still be complex, and will still require coordination. Moreover, interviewees we spoke to were mindful of the urgency of solving coordination regardless of whether integration came to fruition as policy. This was, in part, because integration was seen as 'a next generation thing', whereas the disabled children's sector rightly has its sights on improving the lives of children now.

Transition

PARTICULARLY AT THE LOCAL LEVEL (WHERE IT IS MOST NEEDED, TO ASSIST THE EQUITABLE DEVELOPMENT OF SERVICES) WE STILL HAVE RELATIVELY LITTLE DATA ABOUT THE NUMBERS OF CHILDREN AND YOUNG PEOPLE WITH COMPLEX DISABILITIES AND LIFE-THREATENING OR LIFE-LIMITING CONDITIONS, AND ON THE NATURE OF THEIR CONDITIONS AND SUPPORT NEEDS.

The 2005 reports by NPC highlighted the need for this, and there has been some valuable research since (for example the 2012 prevalence study by Leeds University[144]).

We do know, though, that the number of affected children and families is rising. The Leeds study estimated (on the basis of 2010 data) that there were some 40,000 children under 19 living with a life-limiting or life-threatening condition in England alone in 2012, and Together for Short Lives, the umbrella body for the children's palliative care sector, estimates there are 49,000 across the UK who require palliative care support. These figures are roughly double previous estimates. Without doubt, a large part of this jump is due to changes in the counting and interrogation of data. Nonetheless, another important factor is medical advances, which make it possible for more premature (and especially very premature) babies to survive into childhood, and more children to survive beyond age 18. Indeed, the Leeds researchers found that the biggest increase in those requiring palliative care support was in the 16–19 age group. At the same time, epidemiological research shows that the pattern of prevalence of different conditions is changing, with rare or undiagnosed conditions accounting for an ever greater proportion of children with complex health needs.[145]

'Transition' refers to any of the changes from one service or form of support to another that children and families undergo. Among these, there are some that all children make, but which are for various reasons more complicated for those who require a high level of support – starting nursery, primary school, secondary school, college or university, turning 18, and so on – and there are other changes in care that only those with medical needs experience: moves from hospital to home, and vice versa. All these are important, and most are moves that we heard could be improved by better coordination, but this section will focus on what is historically the most intractable: the move from child to adult services. This is how one professional expert interviewee characterised the transition to adulthood:

> "This age group is not just a time in your life at which you move into adult services, it's a time in your life when you have very specific developmental, physical, emotional, practical needs that it would be useful to address, specifically."

THE BIGGEST INCREASE IN CHILDREN REQUIRING PALLIATIVE CARE SUPPORT WAS IN THE 16-19 AGE GROUP.[145]

Time and again in compiling this research, we heard and read of poor experiences of transition:

- parents being in the dark about adult social care arrangements for their daughter until three or four weeks before her 18th birthday
- Sally, who spent her 18th birthday in hospital for a complicated procedure and went overnight from having her mother stay with her to being on an adult ward, where her mother could only be with her during visiting hours, and where she was expected to make decisions about her treatment alone
- Josh, who almost missed out on taking up his place at university because of the time it took his local authority to arrange for the personal assistant he would need

Although comprehensive records exist within children's services, adult social services are all too often unprepared for the incoming cohort of children with complex disabilities and health needs – particularly those with rare conditions. One contributing factor to the difficulty regarding transition is that disabled young people turning 18 is a small part of the adult social services caseload, which is primarily focused on older people and disabled adults more broadly.

The challenge of transition within health services is slightly different. The sharing of data is better, so adult health services can be expected to know that children are 'coming through' in a way that does not always happen within social care. However, the impact of the experience of the transition can be greater for young people, especially those with complex medical needs (a life-limiting or life-threatening condition) who have received most of their support in a hospital setting.

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Leonard Cheshire Disability, Number One Lavender Fields: supporting disabled young people with complex needs through transition to adulthood

Number One Lavender Fields in Hitchin, Hertfordshire, is a nursing and residential care facility run by Leonard Cheshire Disability, offering accommodation for ten disabled 16–24-year-olds with complex needs. Most referrals to the service are made by residential, specialist or mainstream schools and colleges. Whatever educational setting they come from, as they approach adulthood the young people are likely to have to manage with less intensive support, much of which they will have to arrange themselves, alongside all the challenges of financial independence, living in the community, and negotiating employment and further study.

Number One Lavender Fields is an example of the voluntary sector bridging that gap. It aims to equip residents for independent living, while providing a physically and socially supportive environment. All bedrooms are en suite and fully equipped with hoists and so on, and young residents have considerable choice and control over their environment, and how and where they spend their time. Almost all residents spend the day offsite at college, and they have the opportunity to go on days and evenings out. The service partners with the likes of Barclays to arrange 'study days' on how to manage finances, and so on.

Moving on from school can be isolating, particularly for disabled young people who may have fewer opportunities than others to socialise or participate in their community. Young residents particularly appreciate the social aspect of their care facility, as this quote shows:

> "It's cool at 1 Lavender Fields. It helps me live independently and I have lots of mates here."[146]

'Cliff edges'

A large cohort who qualify for support as children are ineligible for equivalent services as adults because there are different eligibility criteria for children's and adult services (and that contrast has become more stark with the cuts to adult services). Thresholds for adult care are primarily restricted to those assessed as having 'substantial or critical needs'.

Certain services are particularly susceptible to a 'cliff edge' – a sharp drop-off in availability before and after age 18. Child and Adolescent Mental Health Services (CAMHS), and the treatment of children and young people experiencing acute mental health needs, is under government scrutiny at the moment. The CAMHS system is far from perfect – professional experts and family carers highlighted the long waiting lists for such support – but nonetheless the eligibility criteria are more generous than those for adult services. As one professional expert interviewee told us, 'You could be receiving support from CAMHS but find that you need to [practically] have psychosis to get something from adult mental health.'

Often, it is not even a question of eligibility criteria, and there are simply no equivalent services for adults, whatever the level of need. One family carer's comment that 'the older they get, the harder it gets' was echoed by many. Moreover, it had been the experience of several family carers whose children had turned 18 that support was withdrawn at precisely the time it was most needed; as one person pointed out, 'The gap between [our children] and their mainstream peers gets greater as they get older. The need actually accelerates.'

This problem applies particularly to short breaks and leisure activities, although young adults for whom employment or further education are not options because of their very complex needs go from having something to occupy their time to nothing, placing strain on their mental health and on the family as a whole:

> "It is reasonable to assume that if adult services have been cut more severely than children's services, what is then available to a young person going into the adult service sector may be quite limited."

> "They come out of education now and… it's like they drop off a cliff."

Joint working

AMONG RESPONDENTS TO OUR CALL FOR EVIDENCE, 68 PER CENT REPORTED JOINT WORKING ARRANGEMENTS WITH OTHER AGENCIES, WHILE 19 PER CENT REPORTED NONE.

There were no significant differences in the existence of these arrangements for those with complex disabilities compared with those with life-threatening and life-limiting illnesses.

There was a perception that services were beginning to liaise more with one another, and some were optimistic that this would only increase with the advent of the EHC plan (see p 61). Equally, though, there were also fears that coordination and joint working were already difficult to maintain in the light of existing cuts, and that further cuts might render such efforts untenable; there was a fear that 'everybody will sort of… stick their heads back into their shells and… focus only on their own area':

> "We've got almost a dichotomy going on between central government on the one hand telling us all that we've got to work in partnership and we've got to respond to individual needs, we've got to listen to people… the reality of which, although [it] will lead to better outcomes in the long term, in the short term takes more time and is resource heavy… It's an almost impossible… juxtaposition of pressures."

Interviewees pointed out that resources were not the only barrier to coordination – just as important were services' different thresholds and priorities. Quite a few people thought that coordination came down to attitudes: 'Ultimately care coordination is almost as simple as that, it's a sort of different way of thinking outside of silos.'

Thus, mutual understanding between services – with one understanding the existence, purpose and remit of the other – was thought to be key. This was particularly the case for relations between the statutory and the voluntary sector, and palliative care providers such as children's hospices (see the section 'Workforce' p 50). Undoubtedly, there had been progress in the last ten years: but there was still room for improvement from both sides. One NHS interviewee spoke of the need for statutory services 'to identify what hospices can add, or what the third [voluntary] sector generally can add that [statutory services] can't provide'.

> "The joined-up approach on the whole between the statutory sector and the hospice sector is notably better, with much more mutual respect and understanding that we can work together."

It was increasingly the experience of service providers that reductions in some services had an impact on others. Hence, the cuts to low level, easy access services such as short breaks, Saturday play schemes and so on was recognised as a 'false economy'. Families rely on these services, and without them they risk a 'crash' (a crisis in mental or physical wellbeing that leaves them unable to cope), which aside from being extremely undesirable for the family is hugely expensive as it can result in the need for intervention for other family members, and/or out of area placements for children. It was striking that health services themselves were recognising this false economy – and experiencing its financial consequences. One NHS interviewee told us: 'If the families had access to more things that we can't provide like short breaks then that would actually help us to provide as well.'

This reinforces the need – which has been recognised in areas beyond disabled children's services and palliative care services – to look holistically at the impacts of cuts on services and budgets.

Joint working within the voluntary sector

Thus far we have looked at the shifting ground *between* the statutory and voluntary sectors, but there has also been considerable movement *within* the voluntary sector. Professional experts pointed to a 'huge change' in willingness to work together, at national and local level, as evidenced through (for example) joint bids for funding, and a noticeable reduction in what might be called 'proprietorial' attitudes ('This is our client group, that's your client group'.)

The children's palliative care sector enjoys a higher profile, and also – crucially – benefits from wider reach. The two umbrella organisations for the palliative care sector, the Association for Children with Life-Threatening or Terminal Conditions and the Association for Children's Hospices, merged in

October 2011 to become Together for Short Lives – 'a single, stronger voice for children's palliative care'. Together for Short Lives is increasingly making links with disabled children's (and indeed disabled adults') charities, and with stakeholders in the adult hospice and end-of-life care sector (eg Marie Curie, Hospice UK, National Council for Palliative Care). There are now more children's hospices: some 53, compared with 36 in 2005.[147] Across the wider sector, the growth in largely building-based hospice provision is seen as a mixed blessing; some see hospices as comparatively less efficient than community-based services (as they are resource intensive and reach fewer children), and it is sometimes a bone of contention that they find it easier to attract funding.

Notwithstanding their growth, and its associated pros and cons, many agreed that the hospice sector had become 'less dominant' and that hospices had become 'much more outward-looking' and 'much more engaged with the wider sector'. Examples of this that were brought to our attention included mergers between children's hospices (and, in London, the formation of a regional group), development of community services, and partnerships with hospitals in order to train and even share staff.

This was thought to be partly a function of their having 'come of age'; from a more secure position, they have been able to relax their focus on 'waving the flag' for themselves, and concentrate more on their patients. However, despite this general progress, many we spoke to thought that children's hospices were still resistant to joint working. There was a perception that this might stem from a concern on the part of hospices not to dilute their relative financial stability. At least one community care provider we spoke to had been rejected when it suggested a merger or partnership with a local hospice.

Yet further evidence appeared to show that there were obstacles to hospices working in partnership even when they wanted to. A case in point was one children's hospice we spoke to ('children's hospice A'). Over time, children's hospice A was seeing increasing numbers of children live beyond 19, the cut-off age for its services. It was aware that transition to adult hospice care had proved problematic in the past. Some young people would not meet the relatively stricter eligibility criteria for adult hospice services and the experience of transition itself was difficult for those who did: hospice care is designed primarily to meet the needs of older adults, and there are different expectations such as parents not being permitted to stay overnight. In response, children's hospice A approached local adult hospice B, with a view to establishing an initiative for hospice A's patients aged over 14 and hospice B's patients aged under 30. In the event, when the different catchment areas had been accounted for (as the area covered by hospice A was larger than that covered by hospice B), there were only two patients who met the age criteria. It was decided that this was not a large enough sample to build a viable programme, and the attempt at joint working was abandoned.

Education health and care plans

We encountered mixed attitudes to EHC plans. Some we spoke to acknowledged that the SEND reforms were 'the right thing to do... the principle is absolutely correct [and] full of hope and ambition and intention'. That they are a step in the right direction is hard to argue with, when the message from family carers is so clear:

> **"It's always difficult to access a new service, or find the right service. But mostly they don't talk to each other. When they do it's without me, and until they acknowledge I am the hub, mistakes will keep happening."**

Nonetheless, if that ambition is not achieved, the stakes are very high indeed. As some of our professional expert interviewees pointed out, in the context of an overall restriction of the services available, the SEND reforms are unlikely to be felt by families as a reduced struggle, or to improve goodwill between them and local authorities.

Others were wary of the strong education focus, which was seen by some as a narrowing of the wider (and widely welcomed) EDCM approach (seeing the whole life needs of children).

In part because of the education 'ownership' of the EHC plan, interviewees pointed out the difficulty of active involvement of health and social care partners. Furthermore, it was thought that this might pose a disadvantage to children whose primary needs fall under health (or social care) as opposed to education – life-limited children, as opposed to disabled children (with and without complex needs), for whom the Department for Education has a more explicit responsibility. Together for Short Lives has begun a stream of work which aims to involve health more in integration and transition.

Perhaps the majority view on EHC plans was that they had potential, but the proof would be in the implementation. Interviewees confronted us with much evidence to support the suspicion that implementation would not live up to the hopes for EHC plans – not least the limited success of the Pathfinder schemes, where miscommunication about simple matters had persisted. It was also pointed out that there were existing statutory requirements to enforce coordination, which had not been effective:

> **"There were requirements on adult social care being involved... at the 14+ review and yet... time after time in area after area we only ever hear that never happened and young people were left to the very last minute."**

Once again, therefore, concerns came down to the challenge of enforcement and accountability. Indeed, there were already indications that the reforms were not being – or could not be – properly implemented. Professional expert interviewees cast doubt on the idea that it was a realistic expectation to get representatives of health, social care and education together in the same room to draw up a plan for every child. Moreover, the speed with which the reforms had come into force (with a matter of weeks between the issuing of guidelines to schools and the start date for implementation) had already undermined faith in their potential for some. Family carers reported having had very little information about the changes themselves, and commented:

> "It's all been done on the back of a fag packet."

> "I just feel that everything has been done so fast: just as I begin to understand one part, something else arrives. Things have gone too fast."

Some thought that local authorities were no better equipped:

> "The new changes that have come into play, because they're so new, nobody seems to know – the left hand doesn't seem to know what the right hand is doing."

Inequality and variation

AN IMPORTANT FOCUS IN THIS REPORT WAS THE EXISTENCE OF VARIATION IN AVAILABILITY OF, ACCESS TO, AND EXPERIENCE OF, SERVICES.

Services mentioned in regard to variation in availability were:

- 24/7 end-of-life care
- community nursing
- hospice care (hospice at home, inpatient short breaks or 'respite', and inpatient care at end of life)
- short breaks

Services mentioned in regard to variation in quality were:

- bereavement support
- community nursing
- links between NICUs and children's palliative care
- early stage neonatal care

Geographical variation

Children's services are subject to wide geographical variation in availability and quality, largely because of the dominance of the voluntary sector; where services are charitably funded, they have often been developed without an assessment of need or geographic spread in mind. This explains for example the 'clustering' of children's hospices in some regions of the country, compared with others which are less well served. A related major contributing factor is the lack of a national specification for what services 'ought' to exist for disabled children or those with life-threatening and life-limiting conditions.

Some interviewees suggested there is a need for geographical regulation, as the line between voluntary and statutory provision becomes blurred. Charities may be not only delivering but even part-funding so-called 'core' components of care (eg care specified in guidance from the National Institute for Health and Care Excellence), particularly for children with complex health needs. Given the variable access to support provided by the charity sector, it is not straightforward to see how the NHS can rely so heavily on charities while still ensuring an equitable service.

Interviewees pointed out that geographical inequality need not be due to poor planning; sometimes, a particular expertise simply becomes developed around a particular area. Confirming this, numerous interviewees drew a clear association between distribution of palliative care expertise and the relative activity of palliative care networks. Although welcomed as a positive development across the board in the last ten years, some palliative care networks are more active than others – and this, in itself, depends on the quality of leadership and the presence of passionate individuals:

> **"Services are developed on the basis of people who have interests, as much as anything... Because so much of this world is down to individual leaders, whether that's individual champions in local authorities or individual paediatricians in health services or whatever."**

Demographic variation

In our interviews and call for evidence from service providers, we asked them to comment on whether they were aware of any demographic groups that tended to be under-represented among their service users, or in services within the sector generally. Some were very aware of – and refreshingly honest about – the way that they had to go in this regard. For example, an interviewee from one children's hospice was able to quote offhand the statistic for the local BME population and the statistic for BME families using the hospice's services. In the main, though, it was striking how many responses betrayed little consideration of this issue (eg, a typical answer was 'I imagine all the usual inequalities would apply').

Undoubtedly, the 'usual suspects' *do* apply – deprivation, inner city residence, English language ability, migration status, and so on. Perhaps the most widely recognised, but the most poorly researched with regard to these groups of families, is ethnicity. The incidence of life-limiting illness is greater in some BME communities, as are infant mortality rates (which are twice the national average in mothers born in Pakistan and the Caribbean).[148] At the same time, to deliver an equitable service, practitioners have to adapt to different cultural and religious beliefs and attitudes towards disability, caring, illness, death and dying. The Woolf Institute is currently conducting a research study (which will be published in November 2015) into access to adult and children's hospice care among UK Muslims.

Children of Jannah: specialist bereavement support for Muslim families

Children of Jannah is a specialist bereavement service for Muslim families who have lost a child. It provides counselling and face-to-face support, with separate groups available for men and women, as well as support online, by telephone and via published information packs.

Although set up to provide care with a Muslim ethos, the service does not turn anyone away, and has supported increasing numbers of people of other faiths and of none.

Children of Jannah also provides a unique telephone service that health and social care professionals can access, where staff offer information and advice on supporting bereaved Muslim parents – for example, explaining religious beliefs and practices surrounding the death of a child. The charity has now developed a training package for professionals working in health, social care and the Police, and friends and family of bereaved parents, mosques and other organisations.

As Muslim families (and those from other religious and ethnic minorities) are under-represented as users of palliative care, sharing this information has significant potential addressing this inequality. Chris Scott of Francis House children's Hospice in Manchester has commented:

> **"Having supported bereaved parents within the Muslim community, I have become very aware of my shortcomings in knowledge and understanding of the faith. This is why I feel there is a real need for Children of Jannah's work."[149]**

In 2012–2014, Children of Jannah took more than 1,000 support calls, responded to more than 800 emails, and distributed over 1,000 bereavement support packs. It has over 300 members on its online mothers' group.

The 'standard' health inequalities interact with geographical inequalities. Areas of greater deprivation have higher numbers of babies born prematurely, increasing local demand for neonatal intensive care, while different areas have been differently affected by welfare reform – the changes to housing benefit in London having a big impact, for example. Nor are wealth inequalities only to do with families' difficulties; they have just as much to do with the workforce. Parts of the UK where the cost of living is higher than average may find workforce recruitment and retention harder, as lower-waged healthcare workers may be priced out.

Access to services may also vary with diagnosis or (for social care) assessed level of need. Not having a diagnosis may preclude some children or young people from getting support (or timely support). Conversely, where there is a specific diagnosis there may or may not be a condition-specific charity to turn to. Where such exists, 'starting block support' is easier to obtain. Children with mental health needs and/or challenging behaviour are at risk of receiving a poorer experience of care. We heard, for example, that those in receipt of the higher component of the DLA tended to get 'a very good package' while those with 'mid-level' needs risk falling off the cliff edge of eligibility for social care.

Commissioning

MANY WE SPOKE TO WERE KEEN TO EMPHASISE THE LIMITATIONS OF THE 'OPEN MARKET' APPROACH TO CHILDREN'S SERVICES.

Particularly in this relatively early phase of its implementation, commissioning does not appear to be a level playing field. Several professional expert interviewees from the voluntary sector noted that the level and quality of services in an area was still largely dependent on the sector's ability to engage with local commissioners. This was felt to be resource intensive. We were also made aware of a differential impact on voluntary providers as commissioning embeds, and as larger contract awards become the norm. Larger, more generalist children's charities are having to deliver more disability-specific services. In theory, this should open doors to collaboration between larger (more generalist) and smaller (more specialist) providers. In practice, though, this is not always true; being a subcontractor is not always financially viable. At the same time, the smaller, specialist organisations often lack the resources to bid successfully on their own.

Opening up commissioning to more providers (what might be termed the 'marketisation' of services) risks creating or widening inequalities. This is particularly true where the service in question is a universal one, but where one of the intended groups of beneficiaries is very small (like children with complex disabilities and health conditions). In childcare – which we do now describe as a 'market' – there are many providers and (in theory) many options. Yet these options are not necessarily available to all parents and all children. Last year, a parliamentary inquiry into childcare for disabled children highlighted that only a quarter of local authorities report having sufficient, suitable childcare for disabled children, particularly those with complex needs (who are likely to require more support in adaptations and staffing) – and fewer still for disabled children over the age of 5.[150]

More generally, there was a feeling among respondents that increased competition militated against cooperation. This seemed particularly true within the children's palliative care sector. An interviewee from one community-based service we spoke to explained that the service had approached the local children's hospice to explore the possibility of a merger – a suggestion the hospice had strongly resisted. The same community service was now reluctantly exploring partnership with a private provider, though the interviewee made clear that this was not the organisation's preference.

Clinical commissioning vs national commissioning

The Health and Social Care Act 2010 made a distinction between local, clinical commissioning and national, specialist commissioning. Five years on, professional expert interviewees reported that the link between the two had not really been made. Too much specialist commissioning (it was felt) still takes place via block contracts, because national level commissioners are not in touch with local need. The breakdown in communication is two-way: children and young people with the most complex health needs can find themselves in limbo, as specialists may recommend a package of support that the local CCG refuses to fund.

Neonatal care furnishes a good illustration of the pros and cons of changes to commissioning. The introduction of national, specialised commissioning for neonatal care has been controversial. Practitioners have felt the benefit of national quality standards and guidelines, and in the main the more effective use of resources (with different ‘tiers’ of care delivered in the best suited setting) has been welcomed. On the other hand, the new system is not without its drawbacks for individual families. Where a baby is born very prematurely and/or in need of the most specialist (level 3) surgical care, families who would once have been catered for more locally may now find themselves having to travel some distance to the nearest large hospital for the appropriate service. This can have a sizeable impact on the parents’ resources (in time and money). Again, when the baby is discharged to a lower level of care (eg to an NICU), although now closer to home, families may find the transition to a new team difficult to cope with.

Conclusion

IT IS REASSURING THAT SERVICE PROVIDERS IDENTIFY SOME OF THE SAME CHALLENGES AS CHILDREN AND FAMILIES DO.

Service providers recognise the fundamental challenge of clarifying entitlements to statutory care, so that families are clear what support they can expect and unwarranted geographical variations in service provision can be addressed. More clarity in this point will also help make clear to all concerned where voluntary provision can add extra value, rather than filling in the gaps where statutory provision should be. Providers also recognise the urgency of making sure that services revolve around the needs of families – and are therefore coordinated effectively, rather than working to their own priorities and according to their own thresholds and bureaucratic boundaries.

However, the evidence from providers also reveals some positive stories. While it is vital that transitions from children’s care to adult care are effective, this challenge arises because more children with life-threatening and life-limiting conditions are living into adulthood. Service provision is also improving in some important ways. The advent of the EHC plan is a reason for optimism about services working together more effectively and the way in which the hospice movement has evolved is also positive. Hospices are seen as more outward-looking, collaborative and focused on the needs of their patients.

4

Conclusions and recommendations

This report has considered what has changed in the last ten years for disabled children with complex needs and children with life-threatening and life-limiting illnesses and their families. It has found that in some important areas sustained progress has been made.

Our research indicates that more families are listened to, more are placed at the centre of the care their child receives, and more feel able to find a school where their child is valued and supported. The voluntary sector has led the way in these developments, and continues to fund and deliver innovative support that addresses unmet need. The examples in this report provide just a small snapshot of this activity – of help provided (like dedicated sibling support, and bereavement counselling that surmounts cultural barriers), and ways of providing it (multi-agency care coordination at the end of life, a specialist transition service to prepare young disabled people for independence).

However, significant challenges remain. Time and again, families describe the 'battle' they have to engage in to understand what support is available and what they are entitled to, and to have their basic needs met. This report has detailed the frustrations of families and those who serve them at the enormous geographical variation in the quantity and quality of support. Voluntary services do their best to fill the gaps but it has never been their role to provide blanket provision. It is important that the government clarifies what support children and families can expect from statutory services, just as it has done with adult social care.

In addition, there have been setbacks in important areas. At a time of budget constraints, access to universal support like childcare and play schemes has been restricted. Fewer families find themselves able to take short breaks with the help of government schemes. These changes affect not only the quality of life of children and their families, but can also have knock-on effects for other services, if families find themselves unable to cope on their own.

Finally, there is the long-standing challenge of ensuring that support for families reflects their circumstances, needs and aspirations, not just the bureaucratic structures that services are organised around. In recent years, new approaches have been adopted to tackle these problems, such as personal budgets, which are designed so that families could put together packages of support that made most sense to them. However, this new approach has brought its own challenges: many families do not want to become employers themselves. Policy-makers must make sure that families do not take on more responsibility than they are ready for – and that other approaches, such as joint commissioning and partnership working, work better.

Recommendations

THE PRIMARY AIM OF THIS RESEARCH IS TO GENERATE RECOMMENDATIONS ABOUT WHERE THE VOLUNTARY SECTOR CAN ADD THE GREATEST VALUE, AND CONTRIBUTE TO THE GREATEST IMPACT, FOR THESE CHILDREN AND FAMILIES.

In practice, however, it is hard to divorce these from the case for action by policy-makers. As we have seen, the relationship between statutory and voluntary support for this group is particularly intricate: children's palliative care providers are waiting expectantly to see the impact that the per-person funding tariff will have; a charity providing family support workers for families of disabled children is funded from the local authority's safeguarding budget, because there is no dedicated budget for disabled children; NHS providers report that they are seeing the impact in their own budgets of the withdrawal of short breaks. What the voluntary sector can add is to a very large extent dependent on the environment that policy creates for it. Therefore, the first four recommendations are to government and policy-makers. They focus on creating the optimum environment: stability, structure, fair resourcing and collaboration. For funders, the priorities should be to spread best practice, build capacity in under-served areas, and sponsor innovation.

For government and policy-makers

1 The Government should commit to the development of a children's social care framework for England, clearly setting out minimum standards for what should be provided by local authorities, to replicate the clarity with which standards for adults have been set out by the Care Act.

The Care Act 2014, which followed the recommendations of a Law Commission report into the adequacy and fairness of adult social care in England, enshrines the duties of local authorities to provide people with support, based on an assessment of their needs. To date, there are no plans for an equivalent clarification of children's social care, despite the development of such standards in other parts of the UK. There is currently little clarity on what local authorities have to provide; confusion is widespread among families, the children's sector, and authorities themselves. Disabled children's charities are increasingly having to advocate for families, drawing on the piecemeal and out of date legislation that does exist: the Chronically Sick and Disabled Persons Act 1970 (designed, in any case, for adults) and the Children's Act 1989.

The result is that it is the default position for families of disabled children with complex needs to have to fight to get the support they need. This risks eroding good will between family carers and services, and it also creates inequalities, as family carers who are not equipped to 'fight' are more likely to lose out. Worse still, the absence of a framework contributes to a lack of accountability; in cases where local authorities are failing in their statutory duties, there is no clear recourse for families.

We recognise that this is a challenging time to develop a framework, as local authority budgets are further reduced, the changes to SEND legislation are still embedding, and England is moving towards greater integration of health and care. Nonetheless, the message from families and the services that support them is unanimous: the need for clarity is urgent. By making this commitment, the Government can signal that it has disabled children firmly on its agenda.

With that in mind:

- The framework should be developed in thorough consultation with children, young people and families, through the organisations that represent them (eg Contact a Family, the Council for Disabled Children) and the Association of Directors of Children's Social Services. We understand that a coalition of charities has already begun a draft framework, and it is important – to avoid wasting resources, and in order to establish goodwill between government and the sector – that any existing work is fully taken into account.
- The framework should incorporate any children's social care elements of the Palliative Care Funding Review, once this has been agreed.
- The recently elected Government should make it a matter of priority to agree on the new palliative care funding tariff.
- Within the new framework, disabled children and children with complex or serious long-term health conditions (which includes those whose conditions are life-limiting or life-threatening) should have a clear and distinct legal status with regard to social care, where they are removed from the current, vague label of being 'children in need'. They should be distinguished from children with (only) a safeguarding need, and from the overlapping but different group of children with SEND.
- The new framework should be accompanied by clear and well-publicised guidance about appeals and legal recourse for families who feel that their local authority is not meeting the minimum standard.

2 The Government should ensure that the infrastructure exists for the needs of disabled children with complex needs, and those with life-threatening and life-limiting conditions to be met locally, and that this is communicated clearly to families.

The aspirations behind the local offer, introduced by the Children and Families Act 2014 – to provide clear information about local services for families of children with SEND – are laudable. It is important, however, that all local offers fully embrace the needs of the groups of children whom this report concerns. The Government should require local authorities to address the needs of these children and young people, no matter how small they are in number, through their local joint commissioning arrangements. In addition, this information should be clearly communicated to families and voluntary organisations through the local offer. To date, the split between specialist (national) commissioning and local commissioning has not been well implemented; it has fostered a lack of clarity about what should be provided at a local level and contributed to the 'battle' that families so frequently experience. Central government guidance on this should be the first step in supporting local infrastructure.

3 Bodies responsible for the education, training and professional development of health practitioners in each of the four nations should work closely with the children's palliative care sector and those parts of the disabled children's sector which support children with the most complex needs to develop a formal model for 'cascading' knowledge and expertise from specialist to generalist practitioners.

Recruitment and equitable distribution of specialists in children's palliative care is an historic challenge, and was identified in the NPC 2005 reports and in the Craft–Killen review.[151] Since then, there has been limited progress – for example, there are now 12 level 4 palliative care consultants in England, compared with two or three a decade ago. Some initial progress, for example the establishment of specialist palliative care nursing teams and children's community nursing teams, has not been fully sustained. We heard, moreover, of some promising initiatives within the sector, such as more openness to student placements and rotational posts for newly qualified nurses, but these are not sufficient in themselves.

The uneven distribution of specialists is a major driver of unequal access to high-quality palliative care. While we do not wish to diminish the importance of improving recruitment of specialists, we believe that concentrating efforts on up-skilling the *generalist* workforce – GPs, paediatricians, hospital and community nurses – is the most efficient way to increase coverage. All families have access to a GP, so GPs are well placed to help plug the gap (estimated to be over 16,000 children and families) between those receiving and not receiving palliative care. Furthermore, at a time of increasing emphasis on choice and control as an indicator of good care, some children and young people are unable to fulfil a choice to live, and to die, at home, because of a shortage of expertise in the community workforce.

Again, training for generalists does exist – Health Education England is funding GP training in palliative care, for example – but unless this is standardised, inequalities will persist. What is needed is a formal framework for spreading specialist expertise equitably and sustainably. The children's palliative care sector should work with Health Education England, NHS Education for Scotland, Wales Deanery and the Medical and Dental Training Agency Northern Ireland and other stakeholders (eg the General Medical Council, the Nursing & Midwifery Council and royal colleges) to develop such a framework. Children's palliative care services should have a formal role in providing this training. Importantly, formalisation does not mean standardisation; it is important to maintain a balance between equitable coverage, and responsiveness to local need. Efforts should be supported as much as possible by data on local palliative care needs and usage – for example, the current Public Health England palliative care data collection initiative.

4 The Government should work with the new models of care approach, reflected in the NHS Five Year Forward View, to explore innovative approaches to commissioning, including regional models and social impact bonds.

As the Government and the NHS work together to find new ways of delivering, commissioning and financing care services, Demos would like to see these children given the consideration they deserve as high users of services.

This report evidences the challenges that families continue to face in accessing appropriate social care services, and the postcode lottery that too often exists in this regard. Government should make the most of the opportunity presented by regional health and social care integration pilots to address this. In addition, social impact bonds are a way of generating additional investment in early intervention, often involving expertise from the voluntary, community and social enterprise sector. Private or philanthropic investors are invited to fund government interventions and then share in the savings that accrue to the taxpayer.

There is an upfront investment in an initiative aimed at achieving a specific social outcome, with a clear associated cost saving, for example, a programme enabling children 'on the edge of care' to remain with their families, which saves the cost of a foster placement (or multiple placements). If the programme delivers outcomes at the required threshold, the investor begins to recoup their investment as half the cost savings go to them.

To date, there do not appear to have been any social impact bonds focusing on improving outcomes for disabled children with complex needs or children with life-threatening or life-limiting illnesses, and their families. (However, Sandwell and West Birmingham CCG is planning to use a social impact bond structure to fund a 24/7 coordination hub to improve patient and family experiences of care, enable people to die at home, and reduce emergency hospital admissions in the last month of life.[152]) According to research by the National Council of Voluntary Organisations, charities dedicated to supporting children and young people receive a smaller proportion of their funding from private or corporate sources than the voluntary sector as a whole – just 1 per cent, compared with 4 per cent.[153] Social impact bonds are designed to recognise, reward and upscale the voluntary and community sector's success in addressing long-term outcomes which the Government recognises as priorities. This being the case, charities operating in the disabled children's sector should surely be prime candidates for consideration.

It is important, however, that charities can demonstrate outcomes in the form of cost savings before they consider using social impact bonds. The priority areas should therefore be those that are most closely associated with quantifiable cost savings: 24/7 end-of-life care (saving unwanted hospital admissions), short breaks, and practical and emotional support for families (saving the costs associated with family carer 'crisis' – emergency hospital admissions, mental health treatment, and emergency and out of area placements for children). The proposed feasibility study should attempt to quantify the potential cost savings, basing these partly on existing evaluations (eg of the EACH 24/7 service, and of existing short breaks and practical help schemes).

For charities and charitable funders

5 Where they choose to fund specific services, charitable (and statutory) funders should focus on:

- 24/7 end-of-life care
- transition from neonatal services and from child to adult services
- community nursing
- practical, social and emotional support for the wider family
- bereavement support
- sibling support
- short breaks

All of the above emerged from this piece of research as forms of support which are highly valued by families where they exist, but where availability is highly variable (and has proven vulnerable to budgetary cuts).

6 Charitable funders should provide grants for 'twinning' or 'secondment' arrangements between palliative care networks in different areas of the UK, to promote the sharing of knowledge, expertise and ideas.

We know there is considerable variation in the availability and quality of children's palliative care, and the degree of coordination between palliative care and other services, in different areas. A clear theme to emerge from our research was that good practice is very often contingent on good leadership – on a particular professional, or a particular service (from either the voluntary or the statutory sector) committed to driving improvement across a whole area. In particular, well-functioning regional palliative care networks were a common denominator in areas with the best practice.

Giving networks the opportunity to learn in depth from one another may therefore result in sustained improvement in the quality of services in an entire area. This might be achieved by 'twinning' arrangements, with two networks given funding to shadow one another, hold joint learning events, or conduct joint research, or through 'secondment' arrangements, with a lead practitioner in one network spending a substantial period of time in another.

7 Charitable funders should set up a challenge fund to encourage joint working between children's palliative care services (both hospice- and community-based).

Many of those we consulted for this research saw children's palliative care as having 'come of age'. Public and professional awareness of the sector is growing. Children's hospices, recognised as the 'gold standard' of care, are well established in their local communities, and this has helped them to weather the financial crisis. The emphasis now needs to be on extending the reach of palliative care services, improving coordination (particularly around the time of transition to adult services) and addressing inequalities of access and experience.

Joint working will be key to achieving this. We heard that there had been progress on this front, but we were also made aware of a number of persistent barriers – practical and cultural, external and internal – inhibiting children's palliative care services from reaching out successfully to one another or to wider local services. (Of course, this does not apply to all children's hospices – they show the variability you would expect given their independence, geographical distribution and locally rooted nature, and there were some outstanding exceptions.) In chapter 3 we described a children's hospice and an adult hospice which had tried to work together to improve transition, only to be thwarted by practical considerations (incompatible catchment areas, too few patients). This example clearly demonstrates that partnerships require more than good will; there is a strong case for outside support and outside impetus to get them off the ground.

A challenge fund would allow children's palliative care to explore partnerships with a range of agencies such as adult hospices, university nursing departments, local authority children's services, special schools and residential care providers. Grant-makers might consider giving priority to the types of support detailed in recommendation 5. Demos proposes an arrangement whereby palliative care providers and potential partners make a joint bid, clearly and candidly identifying the existing barriers to working together. The role of the funder would be to help broker a match funding arrangement (the funder matching the combined contribution of the two partners) tailored to overcoming the identified barriers. On top of setup and running costs, the funder would supply additional resource for measuring outcomes and for producing a frank report from which others can learn.

8 The charitable sector should establish a programme of work to ensure that the voices and views of children with the most complex needs are heard, communicated to key decision-makers, and acted upon.

The last ten years have seen increased recognition by policy-makers and services of the importance of family carer voice and involvement. The establishment of parent carer forums across England is one example of what was widely cited as a welcome development. As discussed in chapter 2 (p 47), it is crucial that that momentum is not lost, and that local forums continue to receive the financial support they need to be effective.

At the same time, there is still some way to go, especially as regards children and young people themselves. The voices of these children and young people need to be heard, and their stories told. It is encouraging that emerging legislation and government policies (eg the Children and Families Act and revised SEND Code of Practice in England, provision for care and support plans within the social services, the Well-being Act in Wales, Self-Directed Support in Scotland and the Children and Young People's Plan in Northern Ireland) set clear expectations for continuous consultation. The priority now must be to ensure that the will and the infrastructure exist, in every service, for embedding children and young people's voice.

In addition, there is a difference between being 'listened to' and knowing you have been 'heard', so it is important that involvement is not allowed to become a tick-box exercise. Consultation that is meaningful has the potential to foster trust between families and service providers, to improve services' responsiveness to local and individual needs, and to prepare children and young people for the choice and control they will need to exercise over their care in adulthood. Consultation should involve a 'feedback loop', where services clearly communicate the changes they have made in response to children and young people's views.

This applies both to shaping services in general and, at the individual level, to person-centred care. Where the latter is concerned, insufficient consideration has been given to situations where the views of parents or carers and their children may be at odds.

This is an area where government and the charitable sector can play a role, as follows:

- The voluntary sector should receive support to gather and disseminate best practice in demonstrating how services have changed in response to disabled young people's feedback, and set a cross-sector standard in doing so. This should be done in collaboration with patient and service user involvement structures, children's and disability rights organisations, and regulators of education, health and social care, in all four nations.
- The Children and Young People's Health Outcomes Forum (CYPHOF) has called for all children to be included in routine patient experience measures such as the Friends and Family Test and VOICES (the national survey of bereaved people). Demos fully supports this.
- Further research should be conducted (with the full involvement of young disabled researchers) into situations where family carers' and young people's views might conflict. This should include elements of law, policy and best practice, and culminate in the creation of guidance for professionals across health, social care and education.

9 Sector leaders should continue to pursue every opportunity to partner with government to champion visibility, inclusion and aspirations for children with the most complex needs, focusing particularly on supporting transitions to adulthood. This should be a priority for the new complex needs team within NHS England.

Three interrelated themes came up repeatedly throughout our research with families and service providers alike: attitudes, access and visibility. The voluntary and community sector has long recognised that young people are denied access to what should be universal opportunities in their community (for leisure, employment, social activities, and so on) because of ignorance of their needs.

There have been a number of positive changes, which should not be ignored; in education, in particular, service providers with aspirational and inclusive attitudes towards children and young people have had an enormous impact on families.

As evidenced in this report, such efforts are perhaps most crucial where young people are making the transition into adulthood. In practice, this often involves a transition away from more specialist support (eg that provided through schools) into a wider sphere where housing, employment and social and leisure opportunities are not supportive. Again, significant progress is being made; the Transition Taskforce, spearheaded by Together for Short Lives, is reaching out to wider agencies like housing and employment, to discuss their role in supporting young people to navigate this change.

To stop children and young people with the most complex needs from falling foul of gaps between health and social care, specialist and universal services, children's and adult services, joined-up thinking needs to begin at the top. There are plans to establish a dedicated complex needs team within NHS England. It is hoped that government and sector leaders will capitalise on this opportunity to consider how to meet the needs of this distinct and diverse group.

There are innumerable small changes and specific services that could improve the experience of the children, young people and families whom this report concerns. Recommendation 5 lists just a few. Taken together, though, these recommendations focus on bigger changes that will support providers to make those smaller changes happen.

They are designed to meet the three key challenges identified in the report:

- to clarify what support children and families can expect from statutory services
- to finance forms of support that ease pressure on families and give them a role in shaping services that meet their needs
- to ensure that services are designed so that they adapt to the needs of children and their families, not vice versa

They are not exhaustive.

Their overarching aim is to increase the visibility of these children and families – in policy and in their communities – and to address the uneven distribution of knowledge and support which has resulted from their relative invisibility until now. New thinking and new commitments are needed to enable these children and their families to 'live 'life to the full'.

Appendices

Appendix A: Definitions and glossary

Many of the terms we use in this report (eg 'disabled', 'complex needs', 'life-limiting' and 'life-threatening') do not have a clear, agreed definition. Others, like 'family carer' and 'disabled child' are potentially sensitive and require some explanation at the outset. Here we explain our choice of terminology.

Children's and young people's palliative care

Together for Short Lives defines palliative care for children and young people as:

> *An active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of the quality of life for the child/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.*[154]

We occasionally refer to children and young people 'with palliative care needs', which we use interchangeably with children and young people with 'life-threatening and life-limiting illnesses'.

Complex needs

We distinguish between the larger group of disabled children and young people and the smaller group, which this report concerns, with the most complex needs. We recognise that this is to some extent a subjective description, but we operate with the parameters suggested by the North of England Specialised Commissioning Group, which states that 'complex' refers to 'the presence of sensory, physical or neurological problems'.[155]

'Disabled' child, young person or adult

We follow Scope and other disability organisations in avoiding 'person first' terminology with regard to the terms 'disabled' and 'disability', so we favour 'disabled child or young person' over 'child or young person with a disability'. According to the social model of disability, the term describes the experience (mediated by society) of a person with an impairment ('a long term limitation of a person's physical, mental or sensory function').[156]

Family carer

We use the term 'family carer' to denote any family member with the main (or shared main) caring responsibility for a child or young person. We recognise that not all family members who provide care would wish to be described as a 'carer'; they may feel, for instance, that they are simply, or first and foremost, 'a mother', 'a grandfather', and so on. We use the term as the clearest and most convenient way of distinguishing between family members and paid or 'formal' carers. While a family carer is most often a parent, we use the wider term 'family' so that others fulfilling this role (eg grandparents, foster carers) are not excluded. A family carer may or may not be a child or young person's registered carer. In the context of discussing parent carer forums, we use the term 'parent carer'.

Life-threatening or life-limiting condition

For the purpose of this report, we refer to children with 'life-threatening and life-limiting conditions' as a single broad group, though Together for Short Lives provides the following explanation of the difference between the two terms:

> *Children are usually said to have a 'life-limiting condition' where there is no reasonable hope of cure and a 'life-threatening condition' where the possibility of cure exists.*[157]

Wherever possible, we used these definitions shown here as the parameters of the research. However, it was impracticable (and arguably undesirable) in some aspects of the qualitative research rigidly to categorise every individual as definitively 'within' or 'outside' the project's scope. Rather, we sought to make clear the scope while allowing potential participants and respondents to judge its applicability to them. The introductory text to our public call for evidence glossed 'complex disability' and 'life-threatening or life-limiting condition' as follows:

> *If you care for a child or young person with a disability or health condition which means s/he needs help and support with everyday things – like washing and dressing, getting around, eating, learning or having a conversation – then we'd like to hear from you.*

The makeup of the respondents is discussed in further detail in chapter 2 (pp 32 ff).

Glossary

BME	Black and minority ethnic
CAMHS	Child and Adolescent Mental Health Services
CCGs	Clinical commissioning groups are groups of general practices that work together to plan and design local health service in England by 'commissioning' or buying health services
CHAS	Children's Hospice Association Scotland
CYPHOF	Children and Young People's Health Outcomes Forum
COSLA	Convention of Scottish Local Authorities
DLA	Disability Living Allowance
EACH	East Anglia Children's Hospices
EDCM	Every Disabled Child Matters
EHC plans	Education, health and care plans
MCN	The key function of the Managed Clinical Network is to support commissioning and delivery of sustainable and high-quality health services
NCVO	National Council of Voluntary Organisations
NICE	The National Institute for Health and Care Excellence provides national and advice to improve healthcare
NICU	Neonatal intensive care unit
NPC	The New Philanthropy Capital is the author of two reports commissioned by the True Colours Trust in 2005
PAMIS	The Profound and Multiple Impairment Service
PCTs	Primary care trusts were part of the NHS from 2001 to 2013, largely administrative bodies responsible for commissioning primary, community and secondary health services from providers
PEG	Percutaneous endoscopic gastronomy
SEND	Special educational needs and disabilities

Appendix B: Prevalence statistics

This appendix provides estimates from a variety of sources on the number and prevalence of disabled children, and those with life-limiting and life-threatening conditions. Data on disability are taken from the 2011 censuses, and estimates for life-limiting and life-threatening conditions are drawn from Fraser et al,[158] and based on 2009/10 hospital inpatient data.

Disability prevalence data are presented as percentages, while for life-limiting and life-threatening conditions prevalence is given per 10,000 of the population, owing to the smaller numbers involved.

Censuses in all four countries asked respondents an identical question about whether their day-to-day activities were limited because of a health problem or disability that had lasted, or was expected to last, at least 12 months. The possible responses are 'Yes, limited a lot', 'Yes, limited a little' and 'No'.[159]

For Scotland and Northern Ireland, it is possible to see the full breakdown of these responses for different age categories under 19. For England and Wales, the published data only allow for a detailed comparison by age for the combined 'Yes' responses ('limited a lot' and 'limited a little').

TABLE 1: THE NUMBER OF CHILDREN AGED 0–19 WHO ARE DISABLED OR HAVE A LONG-TERM HEALTH CONDITION, BY NATION, 2011

	England[160]	Wales[161]	Scotland[162]			Northern Ireland[163]		
Age	Total	Total	Limited a lot	Limited a little	Total	Limited a lot	Limited a little	Total
0–4 years	70,922	4,535	2,702	4,016	6,718	1,768	1,867	3,635
5–9 years	117,464	7,353	4,838	8,557	13,395	2,900	3,690	6,590
10–14 years	150,724	10,200	6,498	12,918	19,416	3,389	4,772	8,161
15–19 years	161,355	11,041	7,251	14,105	21,356	3,410	4,780	8,190
Total	**500,465**	**33,129**	**21,289**	**39,596**	**60,885**	**11,467**	**15,109**	**26,576**
Prevalence (%)	**3.94**	**4.61**	**1.80**	**3.34**	**5.14**	**2.38**	**3.14**	**5.53**

Source: Census 2011

TABLE 2: THE PREVALENCE OF LIFE-LIMITING AND LIFE-THREATENING CONDITIONS PER 10,000 OF THE POPULATION AMONG CHILDREN AGED 0–19, BY NATION (2009/10 ESTIMATES)

Age	England	Wales	Scotland	Northern Ireland
Under 1 year	125.7	140.3	88.0	148.1
1–5 years	34.1	55.4	45.7	28.9
6–10 years	24.8	38.0	35.0	19.3
11–15 years	24.0	32.0	32.6	16.7
16–19 years	23.6	30.6	29.9	19.2
Total	**32.2**	**44.6**	**38.6**	**27.8**
No of patients	**40,042**	**3,199**	**4,463**	**1,307**

Source: Fraser et al[164]

Appendix C: Policy changes by nation

TABLE 3: SUMMARY OF POLICY CHANGES BY NATION

	England	Wales	Scotland	Northern Ireland
Funding	£10m annual revenue funding to children's hospices under the 2010 Coalition Agreement Plans to introduce a per-patient funding system Key role for voluntary sector, relying extensively on donations and grants, alongside some commissioned work	£2m ring-fenced for all voluntary sector hospices through a bidding process from 2004 In 2008/09, bidding process abolished, and funding decisions based on the cost of the core clinical service needed in the absence of the charity £6.4m total funding for palliative care in Wales for 2014/15	CHAS received just over £1.5m in statutory funding and grants in 2013/14, compared with £6m from donations, legacies and shop sales Included £38,000 for Diana Children's nurses	NI Children's Hospice given a recurrent grant of £210,000 by the Northern Ireland Executive in 2008, raised to £245,000 in 2010 £1m further funding announced in November 2014 under the Delivering Social Change Programme to undertake a targeted programme for children and young people with life-limiting and life-threatening conditions
Short breaks	Provision expanded under *Aiming High for Disabled Children* between 2008 and 2011 Statutory duty to provide short breaks introduced in 2008 Short breaks funding no longer ring-fenced under 2010–15 Coalition Government, and overall grant funding cut	Welsh Government provided £1.5m to local authorities annually for short breaks provision between 2007 and 2010 No longer ring-fenced, with funding provided through the central Revenue Support Grant 2012 regulations ensure breaks offered as part of general support provided by local authorities, not just as an emergency intervention	£2m made available through Short Breaks Fund programmes in 2011 Almost £14m invested in short breaks through the Scottish voluntary sector between 2010 and 2015 2015 Carers Bill entitles carers to support plans, and places a duty on local authorities to prepare and publish a short breaks statement	Carers have the right to request an assessment of their needs, which could include respite care, but no specific duty on health and social care trusts to provide a range of short breaks services £3.2m provided in 2008 to invest in new or enhanced learning disability respite packages, later revised down to 125 packages Guidance published in 2010 details minimum standards for respite services that health and social care trusts should provide
Personalisation	Right to request a personal budget extended to SEND children in 2014	Draft regulations would make direct payments available in all cases where an individual or their representative wishes to receive one	Social Care (Self-Directed Support) (Scotland) Act 2013 requires councils to offer direct payments as part of a package of options	Currently consulting on the introduction of self-directed support for children and adults, within which sits an option for direct payments

	England	Wales	Scotland	Northern Ireland
Joint working	Early Support Programme ran from 2002 to 2015; particular focus on coordination towards the end Funding for developing key working announced to continue some the work of the Early Support Programme 2004 Children's Act placed duty on local authorities to cooperate with partners and produce a single Children and Young People's Plan 2014 Children and Families Act places a duty on CCGs and local authorities to jointly commission care for SEND children and young people	2005 National Service Framework for children, young people and their families gives local health boards, NHS trusts and local authorities joint responsibilities New Early Support Programme introduced in 2009, in part targeting coordination for disabled children under age 5 and their families Children and Families (Wales) Measure 2010 places a statutory duty of cooperation on health and local government on the establishment of integrated family support teams	Obligation to prepare children's services plans since 1995, requiring consultation with health boards, voluntary organisations and others Replaced by full joint planning requirements for local authorities and NHS boards under the Children and Young People (Scotland) Act 2014	Health and social care provided as an integrated service by five regionally based health and social care trusts A single health and social care board has responsibility for commissioning, resource and performance management and service improvement
Transition	Transition Support Programme ran from 2008 to 2011 aiming to improve and coordinate young people's transition to adulthood Since 2011, the Preparing for Adulthood Programme has supported local authorities, families and other stakeholders to improve the transition to adulthood	Statutory guidance requires schools to draw up a transition plan when children reach age 14 if they have a statement of special educational needs Children's National Service Framework 2005 states that a key transition worker should be appointed to all disabled young people at the age of 14	Education authorities must begin planning for the child at least 12 months before they are due to leave school CHAS received funding in 2014/15 to support a new Transition Team to help 17–21-year-olds move to age-appropriate adult care	The Education & Library Board must produce a transition plan at the first annual review after a young person's 14th birthday, aiming to reflect the young person's needs and wishes, with a named teacher coordinating the process

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Life to the full

Care and support in the UK for disabled children and children with life-limiting and life-threatening conditions

AN INDEPENDENT REPORT
BY DEMOS COMMISSIONED
BY THE TRUE COLOURS TRUST

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The True Colours Trust
The Peak
5 Wilton Road
London SW1V 1AP

Registered Charity number 1089893

Demos
Unit 1, Lloyds Wharf
2-3 Mill Street,
London SE1 2BD