

Unlocking key working: information and transparency for families with disabled children

Every Disabled Child Matters (EDCM) is the national campaign to get rights and justice for every disabled child.

EDCM is a consortium campaign with four lead members: Contact a Family, the Council for Disabled Children, Mencap and the Special Education Consortium. Between them, the campaign partners work with and represent 770,000 disabled children and young people in the UK. EDCM has over 34,000 supporters and 200 'Friends in Parliament'.

The Every Disabled Child Matters Campaign wants central and local government to:

- Give disabled children and their families new rights to the services and support they need to lead ordinary lives.
- Invest resources to make sure these rights can become a reality.
- Give disabled children and their families a new level of priority, and work with them to improve the services they receive.

For more information and to sign up to support the campaign please visit **www.edcm.org.uk**

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Contents

Executive Summary	pp. 4-5
Introduction	pp. 6-7
Methodology	pp. 8-9
Overall Trends	pp. 10-11
Pervasive Themes	pp. 12-13
Provision of key working services	pp. 14-16
Availability of information on key working	pp. 17-18
Quality of information on key working	pp. 19-23
Eligibility criteria	pp. 24-25
Conclusion	pp. 26-27

Executive Summary

It has long been acknowledged that one of the major challenges for families of disabled children to access the services and support they need has been the lack of effective multi-agency working, placing the burden of gaining access to and coordinating multiple services across agencies on parent carers. The consequence of failing to deliver appropriate services at the right time is significant distress to disabled children and their families. Over a quarter (26%) of lone parents are caring for a sick or disabled child¹.

The 2006 Parliamentary hearings on services for disabled children found 'universal support' for key working among parents and recommended that 'Families caring for a disabled child needing support from multiple agencies should be entitled to a key worker'². However, despite being identified as vital for families, key working has not received the same priority in service improvement as short breaks has enjoyed in the intervening years.

Proposals put forward by the present Government in *'Support and Aspiration: a new approach to special educational needs and disability'*³, which will be introduced to Parliament as part of the Children and Families Bill, give a pivotal role to key working in a number of respects: the extension of Early Support resources to families with school aged children; the role of key working support in the delivery of the single assessment and planning process and 'Education, Health and Care Plans'; and practitioners trained in key working to advise families who have a personal budget. Significantly, proposals also include a Local Offer to clarify what support is available for children and young people with special educational needs (SEN) and disabilities aged 0-25 and from whom.

1 Lyon, N., personal communication based on data from the 2004 Families and Children Study (FACS)

2 Parliamentary hearings on services for disabled children: Full report (2006), p.51

3 Department for Education (2011), [Support and aspiration: A new approach to special educational needs and disability - A consultation](#)

EDCM wrote to all local authorities (LAs) in England with a Freedom of Information request for the following:

- The information LAs have available to families with children with SEN and disabilities on their key working services, including information on the process for parents to gain support from someone fulfilling a key-working function and any eligibility criteria that may apply;
- The LAs policy and/or strategy on key working;
- The number of key workers in the LA and the caseload they support, and how key working is funded in the local area.

EDCM then analysed the 124 responses that were received by the set deadline and examined the relevant areas of the LA websites. We found that:

- Only 65% of LAs stated that they provided key working. There was extensive confusion about what should be considered key working and specifically about the relationship between key working and the lead professional role, social workers, and Parent Partnership Services. Given that all LAs will need to provide key working after 2014 in order to deliver the ambitions of *Support and Aspiration*, it is vital that Government takes steps to ensure every LA does so.
- In many LAs key working was confined to Early Support. 33% of LAs that responded only provided key working to disabled children from the ages of 0-5, and only 19% provided key working up to age 17 or above. EDCM notes the positive impact of Early Support in developing key working across England, but also the limited extent of key working further up the age range. This will require a significant expansion of key working and this must be achieved without compromising standards.

- Only a third (33%) of LAs provided key working and made information about how to access it widely available to families with disabled children through leaflets or similar methods. Even fewer (25%) made information accessible on the internet. If children, young people and their families are not aware of the benefits of key working and the availability of key working in their and surrounding areas, they will not be in a position to ask for this kind of support for themselves or influence how these services are delivered in their local area.
- Only a quarter (25%) of LAs provided key working and produced information about their services that was user-focussed, meaning that families with disabled children knew how and where to get support. Materials produced by LAs using the Early Support approach accounted for much of the good practice found by EDCM. However, compared to the information available in short breaks services statements, even the best practice lacked the level of transparency about how services were designed to meet parent carers' needs, and how parent carers were involved in producing information and developing services. LAs should adopt an approach to information that is designed to empower local parent carers to access support that meets their needs.
- Of LAs that provided key working, only 40% made eligibility criteria to access key working widely available. EDCM considers it essential that all information on key working services includes eligibility criteria expressed in everyday language that all parent carers should be able to understand. Transparent eligibility criteria are essential for parent carers to be involved in negotiating with LAs about the local provision of services, and eligibility criteria designed in partnership with parent carers are more likely to take into account real levels of need.

Our findings demonstrate a significant gap between the ambitions expressed in *Support and Aspiration* and the current state of key working. It will require a step-change in culture for many LAs to produce an effective Local Offer that includes key working in 2014, and this is only likely to be achieved with concerted Government leadership.

EDCM Recommendations

1. **The Children and Families Bill must define key working support as an essential part of the Local Offer and require LAs to provide robust information on how key working is delivered.**
2. **Funding through the Early Intervention Grant should be provided to support the development and improvement of key working support across England.**
3. **Regulations and guidance under the SEN and disability provisions of the Children and Families Bill must provide LAs with a clear requirement to provide key working support for all disabled children from 0-25.**
4. **All LAs must publish transparent information on any eligibility criteria that they operate for their key working services as part of the Local Offer, so that all disabled children, young people and families are aware of them.**
5. **There should be a requirement to publish user-focussed information on key working developed in partnership with children, young people and families, so that they know where and how to access the support they need. The success of the Short Breaks Duties should be built on to develop the standards of information and transparency LAs are required to publish.**

Introduction

It has long been acknowledged that one of the major challenges for families of disabled children to access the services and support they need has been the lack of effective multi-agency working, placing the burden of gaining access to and coordinating multiple services across agencies on parent carers. The consequence of failing to deliver appropriate services at the right time is significant distress to disabled children and their families. Over a quarter (26%) of lone parents are caring for a sick or disabled child⁴.

In 2007, Every Disabled Child Matters (EDCM) asked parents and carers one question: 'If you could change one thing for disabled children and their families, what would it be?' The most common response was 'To not have to fight for support', or as one parent put it;

*"...to not have to fight for every little thing. To be treated as if we belong in this world, and when I say every little thing, I mean EVERY little thing."*⁵

Parents and carers repeatedly presented three practical solutions to the constant problem of having to fight for what they need: more information for parents; better joined-up working between services; key workers to co-ordinate care for families.

The 2006 Parliamentary hearings on services for disabled children echoed this demand for key working to co-ordinate services and appointments and avoid endless repetition of information. One parent told the hearings,

*"A key worker would be ideal. Someone to support the family and provide information as it was requested."*⁶

Key working has been widely advocated as the most effective means to ensure that families with disabled children can access integrated services across Health, Education and Social Care. Both the National Service Framework for Children Standard 8 (2004)⁷ and the Aiming High for Disabled Children (AHDC) National Core Offer (2007)⁸ promoted key working to manage the delivery of services from all agencies involved. The Parliamentary hearings in 2006 found 'universal support' for key working among parents and recommended that 'Families caring for a disabled child needing support from multiple agencies should be entitled to a key worker'⁹. Most recently, the Children and Young People's Health Outcomes Forum has recommended the Commissioning Outcomes Framework includes a composite indicator to measure integrated care including access to key working¹⁰.

However, this prominence has not been matched by comprehensive provision of key working to families that require it. The need for effective joined up delivery of services has persisted, as evidence given to the Children and Young People's Health Outcomes Forum attests¹¹. Key working was not given the same priority in service improvement under Aiming High for Disabled Children as short breaks for example, despite it being identified as a priority for families with disabled children.

7 Department of Health (2004), National Service Framework for Children Standard 8: [Supporting Parents, Strengthening Families](#), section 5.8

8 Department for Children, Schools and Families and the Department of Health(2007), [Aiming High for Disabled Children National Core Offer, Section 2: Assessment](#)

9 Parliamentary hearings on services for disabled children (2006), p.51

10 Report of the Children and Young People's Health Outcomes Forum (2012), p.28

11 Children and Young People's Health Outcomes Forum (2012), Report of the Long Term Conditions, Disability and Palliative Care Subgroup

4 Lyon, N., personal communication based on data from the 2004 Families and Children Study (FACS)

5 EDCM (2007), 'If I could change one thing...' – Parent's views, , p.4

6 Parliamentary hearings on services for disabled children: Full report (2006), p.51

Proposals put forward by the present Government in *'Support and Aspiration: a new approach to special educational needs and disability'*, which will be introduced to Parliament as part of the Children and Families Bill, give a pivotal role to key working in several respects: the Green Paper proposes that Early Support resources are extended to families with school aged children; the role of key working support in the delivery of the single assessment and planning process and 'Education, Health and Care Plans' is being tested by pathfinder areas; and practitioners trained in key working will advise families who have a personal budget, available to all families with children with a statement of SEN or a new 'Education, Health and Care Plan' by 2014. The Green Paper proposes that the Department for Education funds voluntary and community sector organisations to provide free training on key working for a range of professionals to achieve this.

Significantly, *Support and Aspiration* also proposes a Local Offer to clarify what support is available for children and young people with (SEN) educational needs and disabilities aged 0-25 and from whom. The Local Offer is intended to increase parental confidence by providing improved, clear information on the services available and how to access them. The Local Offer will also make it possible to see the differences between the services offered in neighbouring local areas.

This report examines the information on key working support provided by LAs that is currently available to families of disabled children. It aims to identify good practice and explore how far LAs are from being able to deliver a Local Offer that meets the needs of children with SEN and disabilities.

Early Support

Throughout this report, we refer to Early Support. This is a Government funded approach to delivering services for disabled children, young people and their families,

underpinned by 10 key principles. It enables services to coordinate their activity better and provides families with a single point of contact and continuity through key working if they require it. Early Support has been introduced by many local authorities and Primary Care Trusts across England. The Early Support Consortium is a core delivery partner for the implementation of the proposals set out in *Support and Aspiration*.

Short breaks

Following the Parliamentary hearings in 2006, AHDC led to unprecedented funding for short breaks and the rapid expansion of short break services. The coalition Government has matched this commitment with an additional £800million funding through the Early Intervention Grant (EIG) and the implementation of The Breaks for Carers of Disabled Children Regulations or the 'Short Breaks Duty', which requires LAs to publish a Short Breaks Services Statement. It has also funded Impact to help LAs deliver their legal obligations to provide short breaks.

Funding from AHDC and the EIG has led to the transformation of short breaks services since 2008, with over 105,000 more disabled children receiving short breaks¹². The Short Breaks Duty has maintained the focus on developing these services and requirements to publish Short Breaks Services Statements have provided unprecedented levels of transparency and accountability for decisions made on their provision. This report will compare the information available on key working with short breaks and draw conclusions about its effectiveness.

12 Together For Disabled Children (2011) Towards a more ordinary life...A report on the progress of parent carer participation and the development of short breaks: 2008 - 2011

Methodology

At the end of May 2011, EDCM wrote to all LAs in England with a Freedom of Information request for the following:

- The information LAs have available to families with children with SEN and disabilities on their key working services, including information on the process for parents to gain support from someone fulfilling a key-working function and any eligibility criteria that may apply;
- The LA's policy and/or strategy on key working;
- The number of key workers in the LA and the caseload they support, and how key working is funded in the local area.
- Accessible: using everyday language, alternative formats, the internet and community languages as necessary
- Available: "to hand" without delay in places where families with children routinely go, including schools and colleges, health centres and GP surgeries and Sure Start Children's Centres
- Joined-up: co-ordinated across local authorities, schools and colleges, PCTS, provider trusts and the voluntary and independent sector
- User-focussed: always focussing on the desired outcome i.e. families know where, and how, to get help and support.

EDCM then analysed the 124 responses that were received by the set deadline and examined the relevant areas of the LA websites if the response had not referred to it. Unlike for short breaks, there are no specific duties on LAs to publish information about key working and no guidance about what information should be provided. Therefore, we have compared the information available to families of disabled children against relevant standards in the National Core Offer, published as part of the previous Government's Aiming High for Disabled Children (AHDC) programme. We considered these standards to still be relevant benchmarks as AHDC was the context for the development of disabled children's services until relatively recently, including the expansion of short breaks provision and the national mainstreaming of the Early Support programme.

The Core Offer sets a number of relevant standards in regards to information and transparency "to empower families to find their own ways to meet the needs of their disabled child, their other children and themselves"¹³, including;

¹³ Department for Children, Schools and Families and the Department of Health (2007), [Aiming High for Disabled Children National Core Offer, Section 1: Information and Transparency](#)

EDCM analysed the responses from LAs to establish how many reported that they were delivering key working support, how many made information on their key working support available and accessible to families with disabled children, and how many produced information which was user-focussed, including how many published eligibility criteria to access key working. To ensure we received information from LAs who did not provide information to families on their key working services, we requested LAs strategies and/or policies on key working, the number of key workers supporting disabled children in the LA, and information about how key working was funded.

Defining key working

Definitions of key working and the terms used to describe key workers have varied considerably against a backdrop of local initiatives and variation in the way services have operated¹⁴. The Care Coordination Network UK (CCNUK) was an organisation that promoted and supported key working across the UK and their definitions and practice

¹⁴ Care Coordination Network UK: Judith Cavet (2007), Best Practice in Key Working: what do research and policy have to say? p.3

standards are widely accepted and virtually synonymous with Government definitions¹⁵.

CCNUK defined key working:

“Key working/care coordination is a service, involving two or more agencies, that provides disabled children and young people and their families with a system whereby services from different agencies are coordinated. It encompasses individual tailoring of services based on assessment of need, interagency collaboration at strategic and practice levels, and named key worker for the family and child.” (CCNUK, 2004)

Key worker:

“A key worker is both a source of support for disabled children and young people and their families and a link by which other services are accessed and used effectively. Key workers have responsibility for working together with the family and with professionals from services and for ensuring delivery of an interagency care plan for the child and family” (CCNUK, 2004)¹⁶

However, the understanding of key working has continued to develop. To overcome confusion around the terms used for key workers, key working is increasingly defined as a set of functions and an approach to support, rather than being restricted to a role or a separate key working service.

The main functions of key working are typically identified as: -

- Being a single point of regular and consistent contact for the child, young person and family
- Providing information and signposting to other services
- Identifying and addressing the needs of all family members
- Acting as an advocate on the child’s, young person’s and/or family’s behalf where appropriate
- Providing emotional and practical support when required
- Coordinating services and practitioners around the child, young person and family

Key working may involve performing all or some of these functions depending on the needs of the child and family. When this report refers to key working and key worker it means any services or individuals that fulfil the key working functions. When EDCM wrote to LAs, we asked them to provide information on all professionals or services that fulfilled key working functions and unless there were specific reasons not to which this report will discuss, we accepted their understanding of which services or professionals were engaged in key working.

Proposals in *Support and Aspiration* and the forthcoming Children and Families Bill also include specific functions that some key working practitioners will be expected to deliver. These include supporting a single planning and joint assessment process, and assisting disabled children, young people and their families to use a personal budget to meet their needs.

15 CCNUK (2009), Care Co-ordination Network UK Key Worker Standards

16 Care Coordination Network UK: Judith Cavet (2007), Best Practice in Key Working: what do research and policy have to say? p.3

Overall trends

The following table presents the findings from our analysis of 124 responses to our Freedom of Information request on the information available to families on key working services.

	Yes	No	Significant doubts *
Does the LA provide key working services?	65%	15%	20%

	Yes	No **
Does the LA make information on key working services widely available?	33%	67%
Does the LA make information about key working services accessible on its website?	25%	75%
Does the LA provide user-focussed information on key working services?	25%	75%
Where LAs provide key working, are eligibility criteria widely available?***	40%	60%

It is worrying that given the prominence of key working in *Support and Aspiration* and its fundamental role in delivering the Education, Health and Care Plan and personal budgets, that only two-thirds (65%) of LAs who responded to our FOI request reported that they currently provide key working services.

EDCM is also very concerned that:

- Only a third (33%) of LAs provided key working services and made information about them widely available, and only a

quarter (25%) of LAs provided key working services and made information about them accessible on the internet. If children, young people and their families are not aware of the benefits of key working and the availability of key working in their and surrounding areas, they will not be in a position to ask for this kind of support;

- Only a quarter (25%) of LAs offered key working and produced information

* These responses include those where it was unclear whether key working functions were delivered or not in the LA but there were significant doubts that they were, and those where the LA's responded that they were not sure. This will be discussed further in section 6.

**These figures include those LAs that told us they do not provide key working, except for the figure regarding eligibility criteria.

***This figure excludes LAs that told us they provide key working information but did not make it available to us by the deadline.

that we considered user-focussed¹⁷. This demonstrates a significant gap between the proposal for all LAs to provide a Local Offer with clear information about what services are available and how to access them and the quality of information currently available;

- Only 40% of LAs that provide key working make eligibility criteria for these services available through leaflets or on the internet. It essential that all information on key working services includes eligibility criteria expressed in everyday language that all parent carers should be able to understand.

These very low figures demonstrate a significant gap between the ambitions of *Support and Aspiration* and the current extent of provision of key working and information on these services.

¹⁷ As explained in the methodology, this term is used in the Core Offer to mean 'always focussing on the desired outcome i.e. families know where, and how, to get help and support'.

Pervasive themes

Quality and access to services

The scope of this report does not include the quality of key working services or how easy it is to access them, but restricts itself to the information LAs provide to families of disabled children. We asked LAs how many people delivered key working in their area and how many children they supported to get an impression of the variation in access to key working. Where LAs said they provided key working, the number of children receiving these services could vary from a few dozen to hundreds. Some LAs also told us that they had waiting lists for these services and that they were aiming to expand when they could secure funding. Therefore, it is important to emphasise that where an LA says that it provides key working to a group of disabled children, this does not mean that all disabled children that require key working necessarily receive it.

Key working strategies

Very few LAs sent us strategies on key working, but where LAs did this usually corresponded to higher quality information being made available to families. This suggests that developing key working services has not generally been a priority for most LAs. However, it was also noticeable that even outside the Pathfinder areas some LAs were developing strategies to implement the proposals of *Support and Aspiration*, including key working, and the Green Paper is providing an opportunity for key working to gain prominence.

Data

In some cases, LAs stated that they used a key working approach but were unable to tell us the number of professionals delivering key working in their area, or the number of children supported by key working because this information was not collected and they could not estimate these figures. This lack of

data raises questions about how key working is embedded in these areas. The CCNUK Practice Standards (2009) suggests that data on key worker services should be collected to inform strategic planning (1.16) and that practitioners delivering key working should have it written into their job descriptions (1.9)¹⁸.

Information on funding

In their responses, LAs told EDCM that key working in their areas was funded through a variety of streams but involved funding through the LA, Health and occasionally Education. Different arrangements reflected both the nature of the key working schemes in question and local variation. For example, in most areas Early Support was only funded by the LA but in others funding was split across other agencies, usually including Health. Funding typically came from general service budgets including children's services or social care rather than a dedicated funding stream, but LAs were able to disaggregate investment in key working in terms of key working coordinators or managers, and training costs. Many LAs identified funding for key working from the Early Intervention Grant.

However, a worrying number of LAs were unable to disaggregate any funding used to invest in key working services. These were typically the same LAs that did not provide any information on numbers of key workers. Once again, this raises questions about the extent that key working is really embedded in these areas.

18 CCNUK (2009), Care Co-ordination Network UK Key Worker Standards

EDCM response

This report focuses on the information on key working available to families with disabled children, not on the quality of those services. However, the information that we asked LAs to provide us to give some context to these enquiries revealed a lack of clarity among many LAs on their approach to key working. Despite key working being repeatedly identified as a priority for parent carers and having a hugely beneficial effect on their experience of services, too many LAs do not have strategies for delivering these services or were unable to provide the most basic data about them. This raises concerns that in some areas that say they provide key working, some practice standards are unlikely to be met.

It is also important to emphasise that the information provided did not include the capacity of those services to meet local need. EDCM is aware that even in some areas that provide key working, not all families with disabled children who require key working are able to access it.

Provision of key working services

65% of LAs that responded to EDCM's request for information said they provided key working services

However, only 15% stated definitively that they did not provide services that delivered key working functions. The remaining 20% provided responses where it was unclear whether key working functions were delivered or not in their area but there were significant doubts that they were. These responses included: LAs whose responses considered lead professionals and key working to be synonymous; LAs who stated they only had 'unofficial' key workers; LAs whose responses consider social workers and key working to be synonymous; LAs that stated that Parent Partnership Services provided key working support in the area; LAs that referred to key workers but describe their role in terms that do not fulfil key working functions.

Key working and lead professionals

A worrying number of responses demonstrated confusion over key working and its relationship to the lead professional role. CCNUK has explained the distinction, "Lead professionals will support families with children who do not meet the thresholds for statutory or specialist services but whose needs, when considered in combination, are significant. The lead professional may support a disabled child with some additional needs but not children whose impairments are complex or severe"¹⁹. There is overlap in some of the functions of the lead professional role and key working and some areas use the term lead professional for both. Many LAs made it clear that in their area lead professionals did provide key working functions and worked with children with complex needs, undertook key worker training or were identified as non-designated key workers.

However, others LAs were unclear on whether lead professionals in their area provided key working functions or not. EDCM has only categorised responses as uncertain where they did not recognise a distinction and considered the two terms synonymous or where the LA expressed doubts that their lead professional model provided key working.

Key working and social workers

Responses from some LAs also blurred the lines between social workers and key working. These LAs told us that children who met the threshold for a social worker received one and below this threshold children received support from a lead professional. Many social workers do deliver key working, however, it should not be assumed that they do so as part of their regular role or that they are always the best placed professional to do so.

Key working and Parent Partnership Services

Parent Partnership Services (PPS) provide impartial information, advice and support to parents and so part of their role corresponds to some of the key working functions. However, many families will need to access support providing key working functions which do not come under the remit of the PPS, in particular coordinating services and practitioners around the child, young person and family. In addition to the PPS, there is a need for a more formal approach to delivering all of the key working functions that PPS's do not cover.

19 CCNUK (2007), The Role of the Key Worker and the Lead Professional, p.2

Other meanings of key worker

Some LAs used the term key worker in a very different meaning from the general definition. These LAs referred to key workers who worked with children below the threshold to access a lead professional. The main function they fulfilled was as an information broker. The use of the term key worker in this context does not meet the Practice Standards of key working as explained by CCNUK²⁰.

Designated and non-designated key working

Key working services are commonly divided into 'designated' and 'non-designated' key workers. Designated key workers confine their professional role to key working whilst non-designated key workers provide key working in addition to their normal professional role. Both types of key workers provide the same functions and CCNUK's Practice Standards refer to both.

The majority (54%) of LAs that told us they offered key working, exclusively provide non-designated key working services. Over a third (38%) provide a mix of designated and non-designated key working services and only a small number (8%) exclusively provide designated key working services.

Where there is a mix of key working services, designated services generally provide key working to families at strategic points of a child's life such as when a child first receives a diagnosis, or in specific contexts.

In their responses, LAs often referred to the training that was offered to professionals before they would become non-designated key workers. This could be as little as a one-day training session. Many LAs reported that they support non-designated key workers with a key working manager or coordinator. However, this is often not the case particularly where key working functions were provided by professionals outside of a specific key working scheme.

Provision and age range

33% of LAs that responded provided key working only to disabled children from the ages of 0-5. Even fewer areas (19%) provided key working up the age range up to or beyond 17 (see table below). These findings demonstrate the important role played by Early Support in promoting a model of joint working incorporating key working throughout England, and also the more limited provision of key working to disabled children and young people beyond this age group. It appears that there may be a welcome focus by some LAs on providing key working to young disabled people at the time of transition to adult services however, it is disappointing that key working up to this age is not more prevalent.

	None	0-5	0-6	0-7	0-8	0-13	0-17+
What age range do LAs provide KW services for? *	42%	33%	2%	1%	2%	1%	19%

*These figures exclude LAs that responded but did not tell us the age range they provide key working for.

The changing picture

Much effort has been put into developing key working over the past decade and this has been reflected in the expansion of key working services from about 22% in December 2002²¹. Our research demonstrated the continued development of key working in England; 15 LAs told us they were developing or piloting new key working services, although many of these said they were at the very earliest stages of developing an understanding of what key working is; a further 12 LAs said they were adapting their key working services in light of the Green Paper; and 8 LAs said they were specifically looking at how to expand key working up the age range; 3 LAs said they were disestablishing their Early Support Programme to cascade its principles of joint working throughout their services. All of these groups except for the last one include LAs that are Pathfinder areas and those that are not.

EDCM response

EDCM welcomes the progress that has been made in expanding the availability of key working within England. In particular, EDCM notes the leading role played by Early Support in developing key working services aimed at early intervention and giving children the best start in life possible. However, it is still of major concern that in nearly a third of LAs, key working services either were not provided or there were significant doubts that they were provided, especially given the role that key working will play in delivering the reforms to SEN and disability provision proposed in Support and Aspiration.

EDCM is also very disappointed that the progress in provision of key working for children aged 0-5 has not been matched for disabled young people further up the age range, especially as the Parliamentary hearings had already identified this as a priority in 2006 and recommended key working to be extended up the age range into transition to adulthood²². It appears that progress made in this area has been slow and limited.

EDCM also has significant concerns regarding the ongoing confusion around what is understood by key working at a time when disabled children's services are anticipating widespread change. A key point of concern is that with the expansion of key working to meet the requirements of *Support and Aspiration*, expectations around practice standards and levels of training are maintained and quality of service is monitored.

21 Care Coordination Network UK: Judith Cavet (2007), Best Practice in Key Working: what do research and policy have to say? p.3

22 Parliamentary hearings on services for disabled children: Full report (2006), p.51

Availability of information on key working

33% of LAs provide key working services and make information about them widely available

LAs described a range of methods they might use to disseminate information on key working services including: through newsletters sent to families on local registers of disabled children, such as Bolton's On The Record; face-to-face via professionals working with families such as social workers; via Children's Centres; through organisations working as information hubs to signpost families to services, such as The Heathway Centre in Barking; through Family Information Services; through parent carer councils. All of these methods are valuable however the Core Offer refers specifically to 'having information to hand', because of the importance of making information as widely available as possible.

When we analysed how LAs made information available we looked specifically at whether they produced leaflets, posters or anything similar about their key working services or which referred to key working. These methods enable families of disabled children to obtain information directly and unmediated. It would also be expected that any organisation or professional that was signposting a family to key working services would rely on these materials as well.

It is concerning that only one third (33%) of LAs produce leaflets or similar materials on their key working services, especially given the value that families with disabled children place on these services. The majority of these materials were produced by LAs' Early Support provision and there were few examples of leaflets produced to promote key working further up the age range, except where there were integrated children's services that supported children from birth to adulthood.

Making information accessible on the internet

Only 25% of LAs published information about key working on the internet and only 22% did this as well as providing information on key working in a leaflet or equivalent. In most cases the LAs published information on their own website but some did so only through partner organisations. Examples included Family Information Services, separate websites designed as one-stop sites for information on local disability services, and links to voluntary sector organisations.

Good practice

- LAs produced leaflets to make information on key working services available widely, in addition to a range of other methods used to disseminate information.
- LAs published information about key working on their website and through partner organisations.

Poor practice

- In a small number of cases, links were broken or went to websites that no longer existed. In other examples, LAs signposted us to websites that did not provide any information on key working services. It is important that the LA ensures that information it signposts families to is available and up to date, and is aware of what information is provided.
- Some LAs were unable to provide any information on key working schemes that were led by the local NHS. It is worrying that in these cases, cooperation between the LA and NHS appeared to be poor as LAs will play the leading role in developing the Local Offer.
- Some LAs stated they only provided leaflets or other information on key working to families after a referral to the service had been received.

EDCM response

EDCM is particularly concerned that information on key working is made widely available by so few LAs who provide these services. If children, young people and their families are not aware of the benefits of key working and the availability of key working in their and surrounding areas, they will not be in a position to ask for this kind of support for themselves or influence how these services are delivered in their local area. Again, it is important to note the positive role that Early Support has played in making information on key working available as part of the Early Support approach.

Information and transparency is fundamental to parent carer involvement in commissioning services that meet their needs and improving outcomes for disabled children. This is of particular significance because of the proposed requirements in *Support and Aspiration* for LAs to develop a Local Offer. For many LAs this will represent a step-change in their culture of communicating information about the services they provide.

Quality of information on key working

25% of LAs provide key working services and publish information about them that is user-focussed

EDCM looked at both the information provided in leaflets and published on the internet. User-focussed information should tell families how and where to get the support that they need. The information EDCM found that achieved this typically consisted of three aspects: an explanation of how the service supports families with disabled children; an explanation of the referral process to access the service; information about who to contact to be referred to the service or for more information. Providing all of this information in a transparent and accessible format allows any parent carer to understand what services they can reasonably expect to access and take steps to do so.

Less than half (40%) of the LAs that do provide key working also provided user-focussed information (see table below). The majority of the good practice EDCM found in regard to the information provided on key working was produced by LAs' Early Support provision.

EDCM found that 11% of the information we were sent or signposted to by LAs was not user-focussed. This typically meant that EDCM was sent or signposted to information that did not refer at all to a key working or referred to key working without providing any of the information necessary to understand what it was or how the service could be accessed. EDCM had concerns with 9% of the information we were sent or signposted to because it omitted an important aspect of the required information.

	Yes	Concerns with information	No	Information not widely available to families
Is information provided to families on key working user-focussed?	40%	9%	11%	40%

Good practice

Explanation of key working:

- LAs provided a full explanation of key working and how it benefits families of disabled children. This was typically presented in a bullet point format that separated each aspect of the key worker role.
- Examples of best practice emphasised that key working included providing emotional support and advocacy to the family and used language about empowering families within the system. For example, one leaflet stated "The main job of the key worker is to empower parents by providing them with support, resources and information". Another stated that key workers would "provide a 'listening ear'" and "speak on behalf of your family".
- Many examples included quotes from parents on how they had benefited from key working, such as "I have to fit in four working days, endless appointments, daily physiotherapy as well as find time to enjoy my child and my family. Before our key worker came into our lives. I was struggling to achieve this". There were also examples that had

involved parents in creating the information. One guide to key working created by parents said, "Information is power... Care Co-ordination supports you in receiving the information you need, when you need it"

- The highest quality information put key working in context with a wider approach. This information often explained what the approach was designed to achieve, and how it should meet families' needs. For example, many of the leaflets provided by Early Support programmes explained the Early Support approach and detailed other available Early Support resources, as well as explaining the role of key working within it.
- High quality information often included details on who would become the key worker and how a key worker was chosen.
- Some examples explained which services were available for families with different levels of need, how families may access different services at different times, and where key working fitted in. One example was an eligibility matrix which showed how the number of specialists services that a family accessed and other factors such as housing issues, corresponded to a sliding scale of support from just providing Early Support resources, to combinations of lead professionals, a Team Around the Child, a Family Service Plan, and a key worker.

Explanation of the referral process:

- User-focussed information explained how a family could be referred to a key working service and provided full contact details for families or professionals to seek a referral or get more information.
- High quality information included how a referral would be reviewed, whether an assessment was necessary (for example via a Common Assessment Framework assessment), the timeframe that a referral would be considered in, and the next steps that would be followed, as well as what would happen if a family did not want a key worker. For example, one leaflet had a 'What can you expect?' section with three steps to accessing key working and a key worker starting to work with a family.
- User-focussed information about who to contact included: multiple methods for contacting the service including telephone, email and postal addresses; a named individual or the specific job title of the person to contact.

Poor practice

Information leaflets on CAF and integrated children's services:

- Some LAs provided information leaflets on the CAF process which referred to key working but gave no explanation of what it is or which families were eligible to receive key working. One example simply stated that “If a number of people are providing support to your child, one of these people may be appointed as a ‘lead professional’ or ‘key worker’” without explaining what these roles were. Other examples included leaflets for integrated children's services that made similar omissions.

Information on websites:

- Information available on LAs' websites was generally less user-focussed than information available elsewhere. Some LAs provided high quality information in leaflets but not consistent quality information on their website.
- Where information was of poor quality, an LA would usually only include one or two short web pages on all services for disabled children generally, with almost no information on specific services except short breaks. Other LAs avoided this by making information leaflets available for download in the relevant section of their website.
- Typically, a phone number or email address for a disabled children's services team or an equivalent was provided with little indication about what services a parent carer should be able to expect.
- Some LA websites referred to key working or lead professionals but made no effort to explain what they were or how to get a referral. In some cases EDCM was signposted to specific web areas that did not contain information on key working at all. Many LAs appeared not to be aware of what information was available on their website.

Family Information Services and service directories:

- A number of LAs referred EDCM to the local Family Information Service (FIS) to find information on key working. Research from the Daycare Trust has found that around 9 out of 10 FIS budgets are being cut and a third may no longer be fulfilling their legal duty to supply information to families²³.
- Some LAs also sent EDCM service directories as the only source of information on key working. The information that is readily available from both FIS and service directories was very limited in comparison to the good practice EDCM found. Typically, both just provided a brief description of a service and a telephone number or email address for more information. Relevant services were also harder to find without knowing what you were looking for.

Short Breaks Services Statements

Under the Short Breaks for Carers regulations, LAs are obliged to produce a Short Breaks Services Statement and publish this on their website²⁴. Short breaks statements must publish evidence that the full range of required services are provided. They must also provide evidence about how short breaks services meet local carers' needs, how they had regard for the views of carers when developing the statements, and publish eligibility criteria.

In the report 'Short Breaks Services Statements: Commitment and transparency', EDCM found examples of widespread good practice in fulfilling these duties²⁵. Information about how short breaks were designed to meet local carers' needs was often presented in a 'You said, we did' format that was explicit about how the LA was meeting local carers priorities. Information was provided about how services were being developed and LAs commonly presented data on the numbers of children accessing these services and how access was changing.

Evidence that LAs had regard for the views of carers when developing their statements meant that information was provided on how they consulted with parent carers, the range of methods they used, the regularity they sought views and parent carer involvement in local decision-making. Short Breaks statements sought feedback on the statement itself and the services they provide information on.

This information is important to provide transparency about what parent carers should expect from local provision and consultation in an area long identified as a priority issue. Similar information is not widely available on key working, even in LAs that provide high quality information on their key working services. EDCM did receive a handful of examples of this information being collected and published in annual reports, evaluations or internal strategies. However, it is unlikely that this information reaches many parent carers and it is unclear whether the parent carers have the same level of involvement in shaping the development of key working services as has been evidenced in the area of short breaks.

24 Department for Education (2011) The Breaks for Carers of Disabled Children Regulations 2011

25 EDCM (2011), Short Breaks Services Statements: Commitment and transparency.

EDCM response

EDCM is very worried that only 25% of LAs provide key working services and publish information about them that is user-focussed. This demonstrates a significant gap between the ambitions of the proposals in *Support and Aspiration*, with all LAs offering key working and a Local Offer providing clear information about what services are available in a local area and how to access them, and the current extent of provision of key working and information on these services.

The standards that EDCM used to assess information based on the Core Offer should not be difficult for LAs to meet and are far less stringent than duties placed on LAs in regard to short breaks. The fact that families with disabled children had high quality information on key working available to them in only 40% of LAs that did provide key working services indicates a lack of transparency. LAs should adopt an approach to information that is designed to empower local parent carers to access support that meets their needs.

Once again, it is important to note the positive role that Early Support has played in providing user-focussed information on key working. EDCM is concerned that outside of Early Support good practice is less prevalent.

It is notable that the information required from LAs by the short breaks duties has resulted in greater numbers of families having access to information on these services and a far greater level of transparency about how and why short breaks services have been commissioned. This can only help facilitate the involvement of parent carers and disabled children and young people in the design and commissioning of services and information materials that are used by them. Similar information regarding key working is not widely available to families of disabled children, despite key working being recognised as a priority.

Eligibility criteria

40% of LAs that provide key working services make eligibility criteria widely available

It is concerning that less than half (40%) of LAs that provide key working services make eligibility criteria to access these services available. Typically, eligibility criteria were not available where no information on key working was available, or where information was not user-focussed and made other significant omissions.

It should also be highlighted that in many cases eligibility criteria were available for Early Support but not for key working further up the age range where it was available. This again reflects the positive impact of the Early Support on promoting key working as part of its approach.

Quality of eligibility criteria

Eligibility criteria to access key working services was generally easy to understand and in everyday language. EDCM only had concerns with just under a quarter (23%) of the eligibility criteria we looked at.

Good practice

- LAs provided eligibility criteria based on the number of specialist services that are accessed by a child. These criteria are transparent and leave little room for confusion.
- Some LAs also provided helpful lists of services that might be accessed by a child.

Poor practice

- In some cases, eligibility criteria were included on information leaflets but not with information on the LA's website.
- Some examples of information stated only that access to key working services was through a CAF assessment without any further explanation. One example stated that a service was for "children and young people who have ongoing needs at level 3 or 4" without explaining what this meant.
- Eligibility criteria were generally omitted where the only information on key working was references to key working in leaflets with a more general focus on disability services.
- Some eligibility criteria used language that was overly medical without explanation such as "delayed development in multiple areas", "significant" or "complex needs".
- Some LAs stated that they had no set criteria for families to receive key working support.
- Some LAs stated that all children who were supported by an integrated service could receive key working, without explaining how to access the integrated service.

Access to key working

The range of eligibility criteria shows that key working is far more highly targeted in some local areas than others. Some LAs stated that all families with children with complex needs would have access to key working and that their entire workforce was trained to deliver key working functions. Many other LAs provided key working to children accessing 2 or more specialist services. However, eligibility criteria were set as high as accessing 5 or more specialist services in some cases which means that many children with very complex needs will not be considered. One LA stated that their eligibility criteria would be raised in the future to gain participation from the local NHS.

EDCM response

EDCM considers it essential that all information on key working services includes eligibility criteria expressed in everyday language that all parent carers should be able to understand. It is worrying that nearly two thirds (60%) of LAs that provide key working did not publish their eligibility criteria. Transparent eligibility criteria are essential for parent carers to be involved in negotiating with LAs about the local provision of services, and eligibility criteria designed in partnership with parent carers are more likely to take into account real levels of need.

EDCM is also extremely concerned that in some LAs key working support is restricted only to children with the most complex support needs, yet in others is available far more widely. Disabled children and young people should be able to access key working support if they require it across England and without this support many of the Green Paper proposals will not be deliverable. Making this information widely available makes it possible to compare provision across different local areas and empowers parent carers to hold their LAs to account.

Conclusion

Key working has been widely advocated as a vital solution to a fragmented system of support that leaves too many disabled children, young people and their families in distress and without the services they need, when they need them. Despite being recognised as a priority for families in the 2006 Parliamentary hearings, key working has not received the funding and focus that has helped transform short breaks services since 2008.

Proposals in *Support and Aspiration* and the forthcoming Children and Families Bill, give key working a pivotal role in achieving an ambitious new approach to integrated support for children with SEN and disabilities. However, the findings of our research reveal significant causes of concern about the gap between current practice and the Government's proposals.

Too many LAs still do not provide key working despite the many years it has been advocated and the evidence of its efficacy. Where key working is provided, it is often confined to Early Support and only rarely available for young people at transition, one of the crucial stages of a person's life. There remains significant confusion about what key working is and how it should be delivered. A committed focus on developing key working services across England is required to deliver the ambitions in the Green Paper.

The attitudes of too many LAs to information and transparency about their services remain insufficient for families of disabled children and young people to know where and how to get help and support. LAs frequently do not provide information at all or do not make it accessible on their website. Too much information is poor quality, and eligibility criteria for key working are often not available. It will require a huge change in culture for many LAs to publish Local Offers by 2014 that families of disabled children and young people are confident in and can rely on to access the services they need.

LAs have made significant progress with regards to short breaks, but it is concerning that the lessons about transparency, provision of information and partnership with local parents and young people does not appear to have been transferred to their approach to key working. The experience of short breaks should be learnt from. Short breaks enjoyed sustained funding and combined with the Short Breaks Regulations, which laid out clear expectations about the type of information that should be published by an LA and how it should be made accessible, unprecedented levels of information and transparency were achieved about how that funding has been used to meet the needs of local parent carers.

The current reforms to SEN and disability provision have refocused attention on to key working, so that it is once again a priority. Getting key working right is vital to delivering the Government's proposals, and promises to improve the lives of thousands of families with disabled children if it can be achieved.

EDCM Recommendations

- 1. The Children and Families Bill must define key working support as an essential part of the Local Offer and require LAs to provide robust information on how key working is delivered.**
- 2. Funding through the Early Intervention Grant should be provided to support the development and improvement of key working support across England.**
- 3. Regulations and guidance under the SEN and disability provisions of the Children and Families Bill must provide LAs with a clear requirement to provide key working support for all disabled children from 0-25.**
- 4. All LAs must publish transparent information on any eligibility criteria that they operate for their key working services as part of the Local Offer, so that all disabled children, young people and families are aware of them.**
- 5. There should be a requirement to publish user-focussed information on key working developed in partnership with children, young people and families, so that they know where and how to access the support they need. The success of the Short Breaks Duties should be built on to develop the standards of information and transparency LAs are required to publish.**



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