

Report



Someone on our side:

Advocacy for disabled children and young people

2011

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Foreword from Dr Roger Morgan, Children's Rights Director

I am pleased to write a foreword to this important report from The Children's Society on advocacy for disabled children. As the researchers say, there has been very little research on advocacy for children in general and little either research upon, or widespread access to, advocacy specifically for disabled children.

While small scale in terms of involvement of children themselves, a fact that illustrates the very difficulties in enabling disabled children to participate that the researchers at the end recommend ways of addressing, this report has three big attributes.

Firstly, it is an informative and professional contribution in an as yet under-researched area of great importance to children themselves. Secondly, it gives the reader an informative mix of previous research and writing, new views from its own respondents, and commentary combining both. Thirdly, it deals head-on with the tricky issues in providing advocacy in this field: issues of awareness and access to advocacy, the substantial challenge of how to advocate where the child is not able to give instructions on the views to be advocated, and the complex minefields of relationships and boundaries between advocates and the other people involved in cases.

As well as providing illuminating case examples and quotations on advocacy work and its outcomes for disabled children, the report does something often not widely available, in giving voice to the views and dilemmas of the advocates themselves. I commend this report to readers as an important advocacy issues-raiser.

Roger Morgan

Children's Rights Director for England

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The views expressed in this report are those of the authors and do not necessarily reflect those of The Children's Society.

1.Introduction

Policy background

The last two decades have witnessed a significant increase in the number of advocacy services for children and young people, with over a hundred advocacy services in England now being run by voluntary organisations and local authorities (Oliver et al, 2006; Brady, 2011). This increase in advocacy services has been influenced by several policy initiatives. These have occurred hand-in-hand with a growing recognition of children's rights and legislation, which has given children and young people the right to be consulted about all decisions affecting their lives. The Children Act 1989, for example, emphasised the need to 'ascertain the child's wishes and feelings' in all matters affecting him or her.

The right of children and young people to participate in decision-making is enshrined in the UN Convention on the Rights of the Child 1989 (Article 12), which was ratified by the UK in 1991. More recently, both the Human Rights Act 1998 and the Convention on the Rights of Persons with Disabilities 2006 have embodied the participation of disabled children and young people.

The Adoption and Children Act 2002 established a statutory obligation for local authorities to provide advocacy services for children making formal complaints under the 1989 Children Act, and the same year saw the publication of national standards for the provision of children's advocacy services (DH, 2002). The Children (Leaving Care) Act 2000 and its accompanying guidance emphasised the role of advocacy in supporting young people through complaints procedures.

Most recently the Care Planning Placement and Review Guidance (DCSF, 2010a), which came into force in April 2011, states that "where a child or young person has difficulty in expressing their wishes and feelings about any decisions being made about them, consideration must be given to securing the support of an advocate". Similarly, the statutory guidance for Independent Reviewing Officers (IROs), which came into force in April 2011, makes clear that every child has the right to be supported by an advocate. It also clarifies that if a child is reasonably regarded as not having sufficient understanding to express a consistent view, the child's current feelings, as far as they can be ascertained, must be given due weight as part of the review and care planning process. Furthermore, the IRO handbook makes clear that where an IRO team does not have the knowledge and experience of a child's specific communication method, a presumption should be made that the child will be supported by an independent advocate. Thus creating a mandate that all children,

regardless of any communication need, should be involved in the planning and reviewing of their care (The IRO Handbook, DCSF, 2010b).

The Mental Capacity Act 2005 includes specific mention of support for those aged 16 years and over that lack capacity. The Act makes it a legal requirement for people lacking mental capacity to have independent advocacy when there are no known relatives or close friends to speak for them. Advocacy must be provided in specified circumstances including when decisions are being made regarding serious medical treatment and/or a move in accommodation. The Act refers to Independent Mental Capacity Advocates (IMCA) making representations about the person's wishes, feelings, beliefs and values to inform the decision-making process. The IMCA can also challenge any decision on behalf of the person lacking capacity if necessary.

The statutory guidance on The Roles and Responsibilities of the Lead Member for Children's Services and the Director of Children's Services (DCSF, 2009) makes clear that systems must be in place to enable the voices of children and young people to be heard and to help inform the authorities strategy for corporate parenting. The guidance notes that particular attention should be given to those who are especially vulnerable, including disabled children and those living in placements at a distance.

The right of disabled children to participate in decision-making, whatever their abilities or communication skills, has been emphasised in a range of policy developments. As the Children Act 1989 Guidance and Regulations pointed out:

"Even children with severe learning disabilities or very limited expressive language can communicate preferences if they are asked in the right way by people who can understand their needs and have the relevant skills to listen"

(DH 1991, p.14)

Similarly, the SEN Code of Practice, 2001, emphasised the importance of enabling all children, including those with communication needs, to be consulted about their views. In addition, the National Service Framework for Children, Young People and Maternity Services in England, emphasised the need to consult children and to take into account communication needs:

"Professionals should ensure that disabled children, especially children with high communication needs, are not excluded from decision-making processes. In particular, professionals should

consider the needs of children who rely on communication equipment or who use non-verbal communication such as sign language.” (DH/DfES 2004, p.29)

In 1994, the Social Services Inspectorate recommended that social services departments should aim to provide advocacy schemes for disabled children to enable them to express their views (SSI, 1994), and in 1997, Utting’s report concluded:

“The review believes that children wishing to use the formal complaints procedure should be entitled to the services of an advocate. This is particularly important for disabled children with communication or mobility difficulties.” (10.12)

The Quality Protects initiative (Department of Health, 1998) influenced the growth of advocacy, particularly for looked after children. Guidance from the Department of Education and Skills for providing effective advocacy services placed advocacy in the context of a “culture of openness where listening and responding to children and young people’s concerns becomes an integral part of everyday practice” (DfES, 2004, page 1). The White Paper *Valuing People* (2001) specified that one of the ways that public services can give learning disabled people more control over their lives is through the development and expansion of advocacy services. The report *Improving the Life Chances of Disabled People* (Strategy Unit, 2005) stated that disabled young people will require increased access to advocacy in the future.

More recently, the Aiming High for Disabled Children programme, which aimed to improve outcomes for disabled children and their families, had a central theme of empowerment. Specifically, it stated that disabled children and young people should, through a core offer, expect the following:

- Tailor-made opportunities using a range of creative methods to ensure disabled children and young people can meaningfully participate in service planning and development.
- Choice over the support provided to them through full involvement in the assessment and design of their packages of care.
- Support to be available to enable disabled children and young people to provide feedback, for example, advocacy (HM Treasury and DfES, 2007).

Despite a plethora of policy and guidance supporting the participation of disabled children and young people in decision-making processes, the evidence suggests that their participation lags behind that of their non-

disabled peers (Morris 1998a, 1999; Sinclair and Franklin, 2000; Sinclair, 2004; Cavet and Sloper, 2004; Franklin and Sloper, 2007, 2008). There is limited systematic gathering of evidence of good practice and disabled children with complex needs, including complex communication needs, and those from black and minority ethnic backgrounds are even less likely to participate (Marchant and Jones, 2003; Knight et al, 2006). This is despite the fact that disabled children are more likely to become looked after in the care system and are generally more vulnerable to abuse and neglect, both at home and in care (Marchant and Page, 1993; Morris, 1995; Russell, 1995). For all these reasons, it is even more crucial that disabled children and young people have access to independent advocacy, which helps safeguard the rights and well-being of disabled children, at home or in care (Sherwood, 2004).

It is the combination of greater vulnerability and traditionally less participation of disabled children and young people that produces a paradox. On the one hand, independent advocacy is even more important for disabled children, but on the other, because disabled children have traditionally been excluded from participating in decision-making, advocates working with disabled children face greater challenges (Knight and Oliver, 2007). Many disabled children and young people are not used to being asked for their views and some may think that what they say is unimportant (Lewis and Porter, 2004). Other disabled children may just say yes to things as they are used to being controlled or remaining passive (Stalker, 1998).

The research evidence highlights that a combination of practical and attitudinal barriers exist that adversely affect the involvement of disabled children and those with complex communication needs. For some children their involvement is hampered by a lack of availability of the communication aids on which they rely (Morris, 1998b; Rabiee et al, 2001; Stone, 2001) or a lack of access to advocacy services (Oliver et al, 2006; Knight and Oliver, 2008). Whilst a study by Franklin and Sloper (2007, 2008) highlighted the following: a lack of commitment to valuing participation at whatever level is appropriate for a child, a lack of a culture of participation for disabled children and a reliance on a few individuals to facilitate involvement, a lack of understanding of how to facilitate involvement of children with complex needs, few resources and limited time dedicated to participation, a lack of shared information about a child's communication method and little joint working to facilitate a child's involvement in decision-making.

Defining advocacy

Advocacy has been defined as a way of facilitating a child or young person's participation in decision-making (Oliver, 2003). As the guidance for local authorities, *Get it Sorted*, stated:

"Advocacy is about speaking up for children and young people and ensuring their views and wishes are heard and acted upon by decision-makers."

(DfES, 2004)

Advocacy is also commonly described as enabling someone to have a 'voice' (Dalrymple and Hough, 1995; Dalrymple, 2005; Oliver and Dalrymple, 2008). For disabled children and young people who do not use speech to communicate, this definition is clearly problematic, yet at the same time makes the provision of advocacy even more important for a group who may not have a 'voice'. As Garner and Sandow (1995) point out, the significance of advocacy lies in the recognition that a person may not have the ability to speak for him or herself. Therefore, the provision of advocacy should be placed within the context of human rights.

There are several different kinds of advocacy, including citizen advocacy, self-advocacy, short-term or crisis advocacy and visiting advocacy. Citizen advocacy most commonly consists of a paid co-ordinator who recruits, matches and supports a volunteer advocate who builds a friendly, trusting relationship to empower a young person. Self-advocacy, often facilitated in a group, involves helping young people to speak up for themselves, building up their confidence and helping them learn to make choices. Short-term or crisis advocacy, which is the focus of this study, consists of dealing with individual issues/crises as they arise. Usually this involves a paid advocacy worker who supports the child for a period of time until the issue has been resolved (Caldwell et al, 2006). Visiting advocacy services aim to empower children and young people living in residential care by providing regular visits to their homes. Visiting advocates can get to know the children and young people over time, learn how they communicate and engender the trust needed for the child to raise issues of concern.

In its study on advocacy in 2007, The Children's Society used the following definition and this was also used within this current research:

"Advocacy that is provided on a one-to-one basis to assist a child or young person to express their views, wishes or feelings to inform decisions about their lives. It may be to increase their involvement in small as well as big decisions, and it may occur in an informal or a formal context."

(Mitchell, 2007)

Levels of need for advocacy for disabled children and young people

The research evidence suggests that there is limited involvement of disabled children and young people in decision-making arenas. No national data is collated on the numbers of disabled children making complaints (and thus entitled to advocacy), being referred to advocacy services and receiving such support. Using the few statistics that are available indicates that there must be high levels of unmet need. New duties within statutory guidance for Independent Reviewing Officers and local authorities on their functions in relation to case management and review for looked after children may create an increase in demand that advocacy services will need to address (DCSF, 2010b).

Based on the broad Disability Discrimination Act definition of disability¹ it was estimated that there are 770,000 disabled children in the UK. *Aiming High for Disabled Children: Better Support for Families* (HM Treasury and DfES, 2007) suggested this equates to 570,000 disabled children in England - 7% of the child population. For the purposes of the Aiming High for Disabled Children Programme, the numbers of severely disabled children in England were estimated at around 100,000 - about 17% of the total disabled children population and 1.2% of the whole child population (HM Treasury and DfES, 2007). It might be expected that the vast majority of these children will have a speech, language or communication impairment, or will require support with their communication, and thus possibly be in need of some form of advocacy to enable them to express their views, although data of this nature is not collected.

In 2007, it was estimated that there were 2,300 looked after children whose principal category of need was disability - 4% of the looked after population (DCSF and ONS, 2007)². However, a significantly higher number of looked after children have communication needs, but their principle category of need would not necessarily be a disability. In addition, the figure of 4% does not include children who are looked after as a result of having a series of short breaks. This same year research by The Children's Society estimated a figure of 877 disabled children and young people receiving advocacy services over a six-month period in

¹ The Equality Act 2010 replaced the Disability Discrimination Act 1995 and Disability Discrimination Act 2005. Disability is defined as a physical or mental impairment that has a substantial and long-term adverse effect on the person's ability to carry out normal day-to-day activities.

² The latest DfE statistics shows that at the end of March 2010 there were 2,200 looked after children whose principle category of need was disability - 3.5 % of the looked after population (DfE's First Statistical Release on 'Children looked after in England [including adoption and care leavers] year ending 31 March 2010).

England. This represents a very small minority, even when the recognised limitations of this research have been considered (Mitchell, 2007). In addition, it should also be noted here that this is despite the fact that looked after children have a right to advocacy under legislation. It appears that few are enabled to exercise this right.

Townsley et al's study of independent advocacy support during transition of disabled young people also highlighted the lack of information on levels of need for advocacy within this group of young people (2009). They could only conclude that for specific impairment groups, such as young men with Duchenne Muscular Dystrophy, and young people with autism, they were less likely than other disabled young people to be able to access advocacy at transition (see also Abbot and Carpenter, 2009). Likewise, disabled young people who are looked after, or who are living in out of area placements at residential schools or colleges are often disadvantaged in accessing information and making choices at transition (Morris, 2002; Heslop and Abbott, 2007).

Non-instructed advocacy

Advocacy can include expressing the child's view on their behalf to help their participation in decision-making. This may be even if the advocate does not agree with what the child or young person is saying or does not think that these views are in the child's best interests - advocates act on the permission and instructions of children and young people. In a survey of children's views about advocacy they report that advocates should focus on putting forward the child's views rather than their own opinions (Ofsted, 2008). As some authors have pointed out, it is this difference that distinguishes advocacy from social work (e.g. Dalrymple, 1995). However, for advocates working with disabled young people who have complex communication needs defining advocacy in this way poses major problems.

Acting for someone who cannot tell you directly what they think or feel has been called 'non-instructed' or 'non-directed' advocacy and most advocates working with severely disabled young people find themselves practising this type of advocacy. Typically non-instructed advocacy involves observation, questioning, information-gathering, clarifying the rights of the child or young person and presenting this information on behalf of the child or young person. Yet practising non-instructed advocacy could also be described as acting in someone's best interests rather than advocating for them in the truest sense and this is a dilemma many advocates working with disabled children experience.

In order to ensure that, as far as possible, advocates are working with a young person's informed consent and are sure of their views and feelings,

it is crucial that advocacy services devote both time and resources to working with a child with complex communication needs. As Caldwell et al (2006) have shown, advocacy projects should be familiar with a wide range of approaches, tools and techniques to aid communication. As the authors point out, simple aids like Talking Mats™ (Murphy, 1998; Cameron and Murphy, 2002; Germain, 2004; Rabiee et al, 2005; Macleman, 2010), objects of reference, photographs and drawings can all help.

There is now a wide range of creative communication techniques and methods for working with severely disabled young people known as augmentative and alternative communication. There are also a large number of resources available to those working with young people with communication needs including work carried out by Triangle (e.g. 2001, 2002; Marchant et al, 1999) and The Children's Society (e.g. Kirkbride, 1999; Badham, 2005). The Children's Society's *Disability Toolkit* website showcases hundreds of resources available to support practitioners to involve disabled children and young people (www.disabilitytoolkit.org.uk). Methods for consulting and communicating with severely disabled children and young people, including some of the ethical and practical considerations that need to be applied, have also been outlined and reviewed in some detail (see for example, Beresford, 1997; Ward, 1997; Morris 1998b, 2002; Knight et al, 2006; Mitchell et al, 2009).

Despite the many resources and guidance now on offer for consulting with disabled children and young people, there is no substitute for allocating enough time, over possibly many months, to establish a relationship with a young person who requires advocacy. Regular visits with the young person in different settings in order to find out about their communication methods, and how their behaviour, gestures and noises may indicate likes and dislikes is a crucial step towards ensuring that advocacy is as effective as possible (Knight and Oliver, 2007). Sherwood et al (2006) go further when they recommend that before any attempt to introduce the subject of advocacy to children with learning disabilities is made, they should first be introduced to the concept of rights, self-expression and participation. Priestley's research (2001), which asked the parents of disabled children for their views about advocacy, recommended independent advocacy for children with communication needs to strengthen and uphold their choices and rights, especially while living away from home.

The question remains whether non-instructed advocacy is indeed advocacy.

The need for more guidance for the practice of non-instructed advocacy was highlighted by research carried out by The Children's Society

(Mitchell, 2007). Like other research findings (Knight and Oliver, 2007, 2008) some respondents in this 2007 Children's Society research reported that they had experienced ethical dilemmas about the practice of non-instructed advocacy. One respondent said that the commissioning local authority had excluded children and young people who could not instruct the advocate, because non-instructed advocacy was not considered to be advocacy. This policy potentially excludes a large group of disabled young people who may benefit from an advocacy service, even if this is not advocacy of the purest kind. As one social services officer said, as reported in research by Knight and Oliver (2007, 2008) advocates are doing the best they can in the circumstances. In this view, it is better to offer an advocacy service than not to a severely disabled young person who cannot communicate his or her wishes clearly.

The Children's Society agrees with the above statement and thus uses non-instructed advocacy, where appropriate, across its advocacy services. To support this work strict guidance and a good practice guide has been developed by the organisation. To provide example, this states that non-instructed advocacy must be seen as a last resort and that an assumption should be made that a child will be able to communicate their views or preferences on a subject, and the advocate must take all reasonable steps to establish a method of communication using whatever method works best for the individual. Likewise, non-instructed advocacy should be assessed on an issue-by-issue basis, and assumptions should not be made that if a child cannot communicate a view on one subject they cannot do so on another. Methods of communication should also be reviewed regularly, as a child might develop new communication skills or the relationship between the advocate and child might develop further. This will give a better understanding of the child's communication. Safeguards to ensure that on no occasion does the advocate give their own view (apart from reiterating a child's rights) and only expresses what the young person seems to be communicating through their observed behaviour are put in place through supervision and careful self-reflection on observations. However, there has been little examination of this in practice and much is to be learned about the process and outcomes of using this form of advocacy with disabled children and young people.

Advocacy services for disabled children and young people

There is limited data on the accessibility, use of and benefits of advocacy for disabled children and young people and there is little systematic data on the reasons why children and young people approach advocacy services (Oliver et al, 2006). Atkinson (1999) noted that children and young people with learning or literacy difficulties and those with communication needs had limited or no access to advocacy. In a more recent study, Oliver et al (2006) reported on the accessibility difficulties

for disabled children and those with communication needs. It still remains the case that the views and opinions of disabled children and young people about advocacy services remain largely unheard. Most recently, Brady concluded that there remains a postcode lottery for children attempting to access advocacy, in terms of availability, independence and accessibility (2011).

In 2007, The Children's Society undertook a survey of advocacy services in England (Mitchell, 2007). This report illustrated that the vast majority of advocacy services have strict service criteria set by local authorities that, in the main, funded them. This criteria was often age-related or restricted to those 'at risk', who wanted to make a complaint or those children and young people in, or leaving care. The results of this survey suggest that the number of disabled children and young people receiving advocacy was small. Approximately 877 disabled children and young people across England received advocacy during a nine-month period (April 2006-December 2006). The survey also found that a quarter of advocacy services were unable to accept a referral or provide an advocacy service for disabled children and young people either because the referral did not meet the criteria for the service, because of a lack of capacity to meet the child's needs, particularly if the child had a communication need, or because the service could only provide advocacy to those who could instruct. Two-fifths of survey respondents specifically stated that they could not provide advocacy for children and young people with complex communication needs and over a third could not meet the needs of children with autism. Provision of advocacy for those placed away from home varied: under three-quarters (47/64) of services worked with those living in foster care; a similar number worked with those living in residential care (44/63), under three-fifths worked with those in residential schools (36/63) and just over a quarter worked with those living in health settings (17/62). The numbers of children and young people receiving advocacy in these settings remains unknown, but given the overall numbers it can be expected to be low.

Advocacy services in this 2007-published research reported on a lack of awareness of advocacy and its potential by professionals, parents and disabled children and young people, a lack of commitment amongst some professionals to ensure that children's views are heard, and a lack of understanding that children with communication needs can communicate. Barriers were also reported to be limited or restricted access to children and young people to raise awareness of advocacy and their rights. The need to raise awareness about the principles and practices of advocacy among practitioners and policymakers has also been identified by Oliver et al, (2006).

Previous research, however, has demonstrated that advocacy has benefited disabled children and young people in many ways. Although many of these studies are small-scale, they have illustrated benefits in terms of improved transition to adult services (Caldwell et al, 2005, 2006), being represented in reviews and child protection meetings and ensuring that their needs are being met in foster and residential care placements (Knight and Oliver, 2007, 2008). Knight and Oliver drew on data collected from 12 disabled young people using advocacy services to illustrate that disabled children and young people placed importance on the informality and the caring and relational aspects of the advocacy role. The young people were generally positive about the advocacy services, expressing that they valued being listened to and having their views being taken seriously. Positive outcomes for these young people were identified as being able to speak out more, having their views taken into account in reviews and changes in issues around personal care in residential units. Advocates identify perceived practical and psychological benefits for individuals including enhanced self-esteem and confidence, improved communication skills, improved care packages, increased involvement in reviews and reversal of decisions perceived as contrary to young people's views or welfare. Little is known about the extent to which advocacy makes a positive difference to developments in children's services more generally. Although advocates report that as a result of advocacy interventions policy changes had been made to children's services, a fifth of advocates in the Oliver et al survey reported being frustrated by local authorities' resistance to apply learning from individual advocacy to children's services at a strategic level (Oliver et al, 2006).

Despite these benefits, advocates working with disabled children face many challenges. Knight and Oliver (2008) report on the lack of time, skills and knowledge to communicate effectively with young people with severe learning disabilities and/or those with communication needs, in addition to the following: limited or restricted access to children and young people to raise their awareness of advocacy and their rights, a lack of awareness or consensus about a child's right to express their views, in some instances particularly a lack of awareness that disabled children can communicate and express a view, a lack of consensus on the practice of non-instructed advocacy and lack of access to appropriate training. Methods adopted by those undertaking advocacy with children with complex communication needs include: using simple words or a specialist communication method such as Makaton, sad and happy faces, drawing and games and adopting an experiential, creative and flexible approach. Spending time with the young person and observing their non-verbal methods of communicating were also identified as important.

Enabling factors for disabled children and young people's advocacy were identified by the research to be: using a rights-based approach, using a creative, flexible and child-centred approach, the commitment of key professionals (e.g. IROs) to ensure the views of young people were heard, having skilled advocates, having access to specialist support, flexible, realistic funding and having sufficient time to carry out work with groups of children and young people with complex communication needs.

Children and young people's views on involvement and advocacy

Although there is an increasing amount of literature detailing from children's perspectives the benefits of participation and suggested methods, the views of disabled children and young people do not feature highly within this, and those children with complex communication needs remain almost invisible. Much can be learnt from the evidence gathered from the general population of children and young people: however, it is important to not treat all children homogeneously. Disabled children and young people may have very different experiences and opinions than those of their non-disabled peers.

Knight and Oliver (2007, 2008) gathered data from 12 disabled young people who had an advocate. These young people were positive about the service and expressed value at being listened to and having their views taken seriously. Other positive outcomes of advocacy and of participation in general, as reported by disabled children are: feeling included, valued and empowered, increased confidence and skills, and services changing to better meet their needs, including for example, personal care in residential settings (Franklin and Sloper, 2007, 2008; The Children's Society, 2001).

The Children's Rights Director in England undertook a consultation on advocacy with a group of young people in care (n=138) and almost 20% defined themselves as having a disability. Half of those consulted had not heard of advocacy despite the fact that all children in care have the right to help from an advocate if they want to make a complaint. Participants reported that:

"advocates need to be good listeners and speakers, understand children's issues, have the right personal qualities and be reliable."
(p10)

Personal qualities included honesty, reliability, respectfulness, a sense of humour, confidence and being non-judgemental. Although the sample was small, 6 out of 10 young people stated that advocacy had made a difference to their lives (Morgan, 2008).

Rationale for this research

Despite extensive policy and guidance highlighting the need for advocacy, there is some evidence to suggest that children do not have access to this service, and access is very limited for disabled children and young people. However, there is little published research in this area. This research aimed to contribute to the small body of literature by illustrating advocacy in practice for disabled children and young people, and exploring the processes and outcomes of advocacy.

2. Research aims and objectives

Specifically the aims and objectives of the research were to:

- Explore the nature, processes and outcomes of advocacy services for disabled children and young people in England,
- Identify and explore the issues that impact upon the provision of advocacy for disabled children and young people,
- Provide case study examples of advocacy in practice for disabled children and young people, particularly where possible, those with complex communication needs,
- Identify policy and practice recommendations in relation to advocacy for disabled children and young people.

3. Research methods

Stage one: Screening letter to Directors of Children's Services

In the absence of a central database of information on advocacy services for disabled children and young people across England, all local authorities were sent a short

one-sided screening questionnaire addressed to Directors of Children's Services in spring 2009. This questionnaire simply asked two questions: are there advocacy services for disabled children and young people in your authority and, if so, what is the name of the person to whom a more detailed questionnaire about the service should be sent. This strategy has been used effectively in other studies and has yielded good response rates (see for example, Greco et al, 2005; Franklin and Sloper, 2007).

107 out of 150 local authorities replied to the screening questionnaire (a response rate of 71%). Of these, 75 (70%) stated that they had advocacy services for disabled children and young people and supplied a contact name. Following this a detailed questionnaire was sent to the named contact (n=75).

Stage Two: Survey of advocacy services and advocates

In addition to the above, the questionnaire was also kindly circulated via the CROA (Children's Rights Officers and Advocates) newsletter. CROA's membership database is considered to be one of the few sources of information on advocacy services for children and young people. This database contains contact details for individuals and organisations involved in the field of advocacy. Membership is considered to be comprehensive and includes almost all services providing advocacy. Membership at the time of the survey distribution in summer 2009 was 99 projects, 11 individuals and six large organisations.

The 2007 Children's Society survey, distributed via this route, yielded a response rate of 68 advocacy services, 64 of which provided advocacy for disabled children and young people (Mitchell, 2007). Other research studies have also identified similar numbers of advocacy services operating in England. For example, Oliver et al (2006) identified 75 advocacy services by supplementing a survey of CROA members with contacts made to those local authorities not represented among CROA members, although these were not all necessarily providing services for disabled children and young people.

The survey explored the following areas:

- Accessibility and availability of information about advocacy services for disabled children and their families, and practitioners and professionals
- Accessibility of advocacy services for disabled children and young people
- Main avenues of referral to the advocacy service
- The nature of the advocacy provision provided to disabled children and young people
- Outcomes of advocacy
- Barriers and facilitators for the provision of advocacy services for disabled children and young people.

Sample

45 survey responses were received in total, of which 42 provided advocacy for disabled children and young people. These 42 respondents came from 35 different advocacy services (in some instances more than one advocate from a service completed a questionnaire), of which four provided advocacy solely for disabled children and young people. Of the 35 advocacy services, 20 were provided by voluntary agencies, 14 were part of statutory services and there was one private advocacy agency. The 35 services were reported to provide advocacy across at least 60 local authorities within England, although it should be noted that there were a couple of services that provided advocacy across a large number of authorities. Three services (national voluntary agencies) also described how they supplied advocacy services in other settings such as CAMHS (Child and Adolescent Mental Health Services) wards in hospitals, YOTs (Youth Offending Teams), open and secure children's homes and within the local health authority and PCT (Primary Care Trust).

Given that in 2007 a previous Children's Society survey identified 64 services providing advocacy to disabled children, this does suggest that our sample is under-representative; however, whether this is the case is difficult to ascertain. Anecdotal evidence also suggests that there are fewer services

now than in 2006. It is known that the Quality Protects initiative funded the expansion of advocacy services; this ring-fenced funding ceased to exist in 2004, and therefore may have adversely affected the number of services currently being funded.³

Stage three: Case studies

Case studies were also conducted to illustrate in detail the nature, processes and outcomes of advocacy in practice both on an individual level and, where possible, within service development generally. The original methodological design consisted of eight case studies. In order to ensure multiple perspectives were gathered for each case study, the young person, their advocate, parent/carer and significant other person (their social worker, key worker or independent reviewing officer) were to be interviewed (n= 32). However, due to difficulties described below, modifications to the research methods had to be made. Fewer disabled young people took part in the research than desired and it was not possible to place the child/young person at the centre of the case study as originally designed.

Identification of case studies

Through the survey, advocacy services were asked whether they had in the last six months provided advocacy services to disabled children and young people and whether they would be willing to send research information packs to families. A six-month time frame was considered to be important as the ability to recall details will diminish with time. All willing advocacy services were asked to send out research information packs to young people and families on our behalf. The information packs explained the research but at this stage did not commit the respondent, asking them instead to contact the research team if they were interested in the research. Such an approach enables the respondent and researchers to clarify any details and particularly enables both sides to explore suitable, accessible methods to engage the young person.

It was anticipated that the numbers of disabled young people receiving advocacy services in the last six months would be small. Initially it was hoped that a purposive sampling frame could be used in order to identify case studies reflecting a desired range of advocacy situations (e.g. advocacy in reviews, advocacy for those young people placed away from home) and a target group of young people who have complex communication needs and autism. Evidence suggests that these groups of young people are most likely to not be participating in decision-making processes (Franklin and Sloper, 2007, 2008). However, given the small

³ It should also be noted that this research was undertaken before the election of the coalition government and the announcement of major public sector financial cuts; data is not available on the extent to which this has affected advocacy services.

numbers of disabled young people receiving advocacy and the difficulties in recruitment, it was not possible to be so selective. The sample thus reflects those young people whom we could access. Fortunately, however, the sample does reflect a wide range of diversity.

The case studies explored the following areas:

- Understanding and awareness of advocacy
- The distinctiveness of advocacy as compared with other roles
- Referral processes for advocacy
- Information given to parents and young people
- The circumstances surrounding the need for advocacy
- The methods used to provide advocacy
- The skills and resources required
- The training and support available for advocates
- The advantages and disadvantages of advocacy
- What worked and what could have been improved upon
- Outcomes of advocacy.

To minimise costs a combination of telephone and face-to-face interviews were undertaken. An individual approach was undertaken with each young person in order to ensure accessibility of the interview schedule; however, similar questions were asked across the sample wherever possible. Because of limitations in terms of cost and time, it was not possible to undertake observations of advocacy in practice. This method would be most suited to gathering data for those disabled children and young people receiving non-instructed advocacy. This is a limitation of this short piece of research and should be taken into consideration for any future research work in this area.

Case study sample

After considerable negotiation, nine advocates were interviewed and they spoke in depth about 12 case studies of young people they had advocated for. Access was granted to interview four of the young people; in addition two mothers of these young people and two teachers were also interviewed. A total of 20 interviews were conducted. Across the 12 case studies, seven young people were male and five were female. The age range was 14 to 20 years old. Three of the young people came from black and minority ethnic backgrounds, eight of the young people were looked after, four had a physical disability, two had autism, two had health conditions, four had complex communication needs, while eight were reported to have a learning disability - predominately reported to be a severe learning disability. Three of these young people received non-instructed advocacy. In the twelve case studies, referrals to advocacy had been made by PALS (Patient Advice Liaison Service), children's rights officers, social workers, clinical psychologists, foster carers and siblings.

Difficulties in gaining access to participants

One of the main challenges faced by this research was accessing disabled children and young people to participate in the study. The first challenge consisted of finding advocacy services willing to be considered for the case study element of the research. Many services, although keen to assist, felt that they could not spare the time especially as they were often over stretched and their advocates working with disabled children often worked part-time. Once services were onboard a second challenge emerged, whereby advocates having identified potential young people for the researchers to approach subsequently decided that it was inappropriate to invite the young person to take part. Reasons given included that the young person would find it stressful, or that the case was too complex or at a critical point so they did not want to potentially disrupt proceedings. Interestingly, the young people had not been asked whether they had wanted to take part and had not been given the short information leaflet about the research, so they had not had any input into this decision. This provides a useful illustration of why advocacy is so important for this group of young people for whom decisions are often taken without their involvement or, in this case, knowledge. In fairness to the advocates, they were often dealing with very complex cases and had spent a considerable amount of time building relationships with the young person, their family and with the professionals supporting the family. They possibly saw the research as adding more complexity to often challenging circumstances.

Analysis

The survey responses were analysed using SPSS and descriptive statistics. Qualitative data from the survey responses and interviews with advocates, young people, teachers and mothers were collated and analysed thematically. Particular care has been taken to anonymise data: the relatively small numbers of disabled children receiving advocacy and of advocates for disabled children might make identification easier than in other circumstances.

Although there was a desire to print the case studies in their entirety to illustrate fully the often distressing situations faced by some of these young people, we will not compromise on our promise to hide their identities. All names and identifiable details have been changed. The findings are thus organised to report on current advocacy practice for disabled children and young people, barriers faced by advocates, solutions to barriers and outcomes of advocacy for disabled children, their families and wider service provision.

4. Advocacy provision for disabled young people

Key findings:

- There is little evidence to suggest that advocacy services for disabled children and young people have developed vastly in number in the last five years, despite its increased emphasis in policy guidance.
- Only small numbers of disabled children and young people receive advocacy services. Across 30 advocacy services in a six-month period (August 2008-January 2009) only 529 referrals were accepted (88 per month).
- The vast majority of services were providing advocacy according to strict predefined parameters set within their contract with a local authority.
- Advocacy services for disabled children and young people living away from home could not always be provided.
- Disabled children and young people had very little, or no choice over who advocated for them. A lack of skilled advocates, small numbers of advocates and workload pressures prevented choice.
- Nearly a third of advocacy services, that completed the survey, only had one advocate available to work with disabled children and young people.
- 80% of advocacy services provided non-instructed advocacy, although the numbers of disabled children and young people receiving this service were very small. Some advocacy contracts did not allow this form of advocacy.
- There is a clear need for more accessible information about advocacy for professionals, parents/carers and disabled children and young people. Advocacy was reported to be little understood and none of the young people interviewed had heard of advocacy before being referred for the service.
- Only a half of advocacy services reported providing accessible information to inform disabled children and young people about their right to advocacy.

Availability of advocacy services

Oliver et al (2006) and Brady (2011) reported that there were over 100 advocacy services in England being run by local authorities and voluntary organisations; how many of them supported disabled children and young people is unknown. Through contact with local authorities via our screening letter, 75 out of the 107 who responded (70%) stated that they had advocacy services for disabled children and young people. It also became apparent that many services funded by local authorities are only for looked after children (including those who are disabled). Advocacy

does not appear to be available to the wider group of disabled children and young people accessing services.

Advocacy services were in the main working within geographical boundaries, with looked after children and responding to referrals made by the commissioning local authority. However, they also had other specified criteria that determined whether they could provide a service to a child. For some they mentioned parental consent (if the child was unable to give consent), a very small minority could also provide services to children and young people using short breaks, making a complaint or going through transition to adult services, one service specifically provided advocacy related to education, and another could provide advocacy to any young person with a statement of special educational needs.

Such limited access to advocacy services for disabled children and young people was also reported within a DCSF investigation into the involvement of children with complex communication needs within the reviewing process of their care (Franklin and Osborne, 2009). Many of the IROs who took part in this investigation reported that they had limited access to specialist advocacy support. IROs reported that they particularly faced challenges to involving children on the autistic spectrum and those with severe learning disabilities and/or sensory impairments, and they reported that there was a clear need for advocacy to assist them to fulfil their new duties under The Children and Young Person's Act 2008. Specifically, IRO respondents from 22 local authorities (from a sample across 44 local authorities) indicated that they had access to advocacy for disabled children, but only 12 felt that they had sufficient services to meet demand. In addition, access to advocacy was often limited to certain age bands or only for specific issues, and access to advocates with specific training, skills and experience of working with children with complex needs was lacking. This is particularly important to note as under Section 1.10 of the 2010 Care Planning, Placement and Case Review statutory guidance, children are required to be *"active participants and engaged in the process when adults are trying to solve problems and make decisions about them."* (p4)

Specifically the guidance states that *"where a child has difficulty in expressing his/her wishes and feelings about any decisions being made about him/her, consideration must be given to securing the support of an advocate"* (p4). In addition, Section 4.7 of the 2010 Independent Reviewing Officers Handbook states that *"Where specialist expertise is not available within the IRO team a presumption should be made that a child with communication needs will be supported by an independent advocate who has the appropriate expertise"* (p34). Thus the commissioning and provision of advocacy services needs to take into account these

requirements if IROs are to fulfil their duties under the guidance and fully involve disabled children and young people within their care.

As already described, The Children's Society's survey of advocacy services (Mitchell, 2007) found that a quarter of them were unable to accept a referral or provide advocates for disabled children and young people because the referral did not meet the criteria for a service (the criteria was often set by the local authorities funding contract). In addition, there was also not enough capacity to meet the needs of some children, particularly if the child had a communication need or because the child could not instruct. Under half of these services could not meet the needs of the following groups: children and young people with autism, those who do not communicate verbally and those with moderate to severe learning disabilities.

In this current research, the vast majority of services also reported they were providing advocacy according to predefined parameters set by their contract with a local authority. Predominantly this defined the age range of those young people whom they could support and mostly this included up to 21 or 25 years old to incorporate care leavers.

When asked whether the service could provide advocacy to a disabled child/young person placed outside of their geographical boundary, 11 out of 35 (31%) reported that they could always provide an advocate, three stated no, whilst the remainder (21) could sometimes. Strict criteria applied to them being able to offer a service, however. Predominately this was that the child was looked after or in one case had used the service previously whilst living locally. In three cases, the availability of spot purchasing advocacy was a factor taken into consideration, presumably meaning that the authority required advocacy to be commissioned from a local service near to where the child was placed (although it should also be noted that spot purchasing advocacy is sometimes used as an add-on to a contract if the advocacy service has reached its target numbers for the year and a local authority wants to purchase additional advocacy). The lack of access to advocacy for disabled children living away from home is particularly concerning. A significant number of children are placed away from home for 52 weeks of the year without looked after status. Research by Gordon et al (2000) found that over a third of these children were isolated from parents and other family members and thus in a potentially vulnerable situation.

Referral routes to advocacy services

Advocacy services were asked to name their main routes of referral for disabled children and young people. Table 1 illustrates that, in the main, social workers and IROs were referring most frequently, although

interestingly, children and young people themselves were reported to be proactively seeking advocacy.

Table 1: Main routes of referral to advocacy services for disabled children and young people (n= 34)

Referral route	Number
Social workers	29
Independent reviewing officers	24
Children and young people	17
Schools	13
Parents	12
Voluntary sector	6
Hospitals	5
Foster carers	4
Hospices	2
Connexions	2
Residential homes	2
Other*	5

*Only one service mentioned each of the following: young people’s officer, family group conference workers, disabled children panel meetings, community health care teams, children’s rights officer.

Choice of advocate

The majority of survey respondents reported that where possible they try to give disabled children and young people a choice about who they would like to be their advocate. Given the importance young people place on the relationship with their advocate, the ability to choose someone in whom they can trust and with whom they can form a positive relationship, must be crucial. However, in reality, this choice was very limited and, from further comments describing this matching process, choice was often non-existent. The lack of skilled advocates who can work with disabled children, the small numbers of advocates and pressures of workload prevented real choice. Comments included *“Only one person available”* and *“They are asked their preferences and we try to meet their ideal requirement but this depends on the availability of advocates in our pool of sessional workers.”*

Numbers of advocates who work with disabled children and young people

Across the 31 advocacy services that provided information, the total number of advocates who worked with disabled children was 247. Ten

services (32%) reported that they only had one advocate available to work with this group of children, 22 out of the 31 services (71%) had five or less advocates available to undertake this work.

Numbers of disabled children and young people receiving advocacy

Through the survey responses it is possible to estimate that across 30 advocacy services in the six-month period August 2008 – January 2009, 529 referrals of disabled children and young people were accepted (88 per month). The Children's Society undertook a similar survey exercise and identified that across 59 advocacy services, 877 disabled children and young people had received advocacy during a nine-month period (April 2006 – December 2006) (97 per month). Although it is not possible to directly compare these figures, what they indicate is the very small number of disabled children and young people receiving advocacy, even accounting for some missing advocacy services that may not be represented in these surveys.

More positively, the survey data collected for this study illustrated that few disabled children and young people referred for advocacy were turned away. This, however, gives no indication of how many disabled children need advocacy but do not get referred. As we will illustrate, information on advocacy services for disabled children and young people is not readily available or accessible, making it incredibly difficult for disabled children and young people to know about services and thus self-refer or enquire about the service.

The need for independent advocacy

The importance of independent representation of the views of children and young people with communication needs was raised as an issue throughout the DCSF investigation into the involvement of this group of children within the reviewing process. The general lack of skilled workers with the training, time, resources and sometimes commitment often limits opportunities for disabled children to participate independently. Often they are dependent on carers, parents or others to translate or communicate on their behalf. This is not necessarily a problem if the translator can be objective and interpret without bias, but this is not always the case: some people can promote (deliberately or subconsciously) their own agendas (see for example, Beresford, 1997; Mitchell and Sloper, 2001). As Mitchell and Sloper's research indicated, disabled children and their parents/carers often want different things from services and define quality of services in different ways (2001). Thus it becomes important not to treat all parents/carers or others as proxies for children. In some cases it is imperative that some independent validation is sought. (Some of the difficulties of parental involvement in disabled children and young people's

participation are explored in more detail later). IROs identified that advocacy was vital in these situations, and many stated that access to advocacy should be seen as a right for disabled children and young people (Franklin and Osborne, 2009). In addition, advocates can provide a safeguarding role, particularly for children with complex communication needs who might only have a handful of people who understand their communication method. Advocates within this study reported that they had raised safeguarding concerns and that disabled children had disclosed issues that required immediate investigation.

A teacher in this research described how she felt a pupil could talk to school staff but also said:

"It's having that independent person who is not actually affiliated to anything else is the important thing and I know that he tells [advocate] things which are very confidential between the two of them." Teacher

Throughout this research, the independence and the distinctiveness of an advocate's role were identified by all participants as being of crucial importance. The basis for the relationship between advocate and young person, as well as the more equal power balance between them, created a dynamic which was seen as empowering and vital. Advocates worked to the young people's agenda:

"I come in when he wants me... I'm there quite specifically when they want me to be there... and when we've finished with the issues that they want me to address with them I'm not involved." Advocate

"He's [advocate] more jolly, he's friendly and he's like down to earth and he explains what he's going to do before he does it and if Paul [young person] agrees about it he does it; if Paul doesn't agree about it then they do it in a different way." Parent

Use of non-instructed advocacy

Survey respondents were asked whether they undertook non-instructed advocacy. This was defined within the questionnaire as "a form of advocacy that sets out to support children who are not able to instruct an advocate or to say what they want for reasons of communication impairment or severe learning disability." Of the 35 services that responded, 28 (80%) provided non-instructed advocacy. However, the percentage of advocacy cases that took this form varied diversely across the services. In 13 services, non-instructed advocacy made up less than

5% of their cases, whilst the proportion in the remainder varied from 20% to 80%.

Those who did not provide non-instructed advocacy were asked for the reasons why they did not provide this service. One advocate wrote:

"I would feel anxious to represent them effectively, but I have advised professionals of the rights of children for whom I have not strictly acted in an advocacy capacity." Advocate

Another advocate wrote that they *"did not feel it is appropriate."* Clearly some authorities also did not feel it was appropriate as respondents reported that this was not allowed under their contract, stating that this was because they were providing services for children wishing to make a complaint or representation under The Children Act 1989. Children and young people with such complex or high levels of need are clearly not able to access the complaints procedures as it stands without support, and thus would require someone to make a complaint on their behalf. It would appear that some authorities did not expect complaints to be made by these children, or if they did, did not expect them to be involved in the procedure and thus require the support of advocacy.

Availability and accessibility of information about advocacy services

Oliver and Dalrymple (2008) state that *"advocacy is not widely understood as a concept or as a practice"* (p9). Advocates within this study had also encountered confusion from others about their role and none of the young people interviewed knew what an advocate did before they had been referred to a service. Boylan and Ing also report on young people's limited knowledge of advocacy (2005):

"It's not an understood role so it's really important when you meet people for the first time or you start working on the referral of an agency that you are clear about what you are as an advocate and what the rules of confidentiality are. This is really important".
Advocate

The survey explored whether advocacy services produced information materials for practitioners, parents/carers and disabled children and young people. Table 2 illustrates that there is scope for further development of information.

Table 2: Number of advocacy services providing information materials (n= 34)

	Practitioners	Parents/carers	Children and young people
Information about the advocacy service	29	19	32

Positively, nearly all services stated that they produced information for disabled children and young people, but interestingly, when probed further only just over half of the advocacy services (18 out of 34 (53%)) stated that they produced materials for disabled children and young people in accessible formats. Of these 18 services, most produced materials using *Widgit* or other symbols such as *Boardmaker*. Some had innovatively produced materials such as a DVD on the right to complain about a short breaks service, and one produced a young person-friendly magazine. Two respondents, however, shared the difficulty of producing information accessible to all, stating that children often prefer face-to-face contact and explanations rather than written information:

"I did create a symbolised leaflet. I took this to a meeting at a respite unit where I discussed with the children and young people how to make our service more accessible – they felt the symbolised materials were too difficult to understand, too many symbols and felt verbal explanation, relationship-building through regular drop-ins and a leaflet for parents would be better." Advocate.

"There's an expectation that we make our presence known to all looked after young people. To expect disabled young people to interact with posters and to understand the concepts in the poster. A lot of our young people would find that very difficult." Advocate.

Pithouse and Crowley also highlighted that children and young people felt advocacy needed to be more accessible and visible. Leaflets and written information were often not read or retained by young people and they suggested more innovative multi-media approaches (2006).

Within a DCSF investigation into the involvement of children with complex communication needs within the reviewing process of their care, a number of IROs reported that they did not know about advocacy services in their authority or the referral criteria being adopted (Franklin and Osborne, 2009). In addition, they called for there to be a national register and referral system to assist in identifying advocates with specialist skills across the country. Clearly there is a need for improved information about advocacy to be made available to disabled children and young people, their parents/carers and for those professionals supporting them.

5. Disabled young people's experiences of advocacy

Key findings:

- Disabled children and young people highly value advocacy services, and the relationship they develop with their advocate. They also welcome the independence and distinctiveness of the role.
- Disabled children and young people report feeling confident, supported, listened to, respected and empowered.
- Disabled children and young people do not, however, want advocates to work with them on a single issue (as many are currently commissioned to do so). They expressed a need for longer-term engagement.

In other studies, disabled young people have explained advocacy as:

"Someone you can talk to... it stays in the room and [she] won't tell other people. When you tell, it matters, she'll do something about it... Just because you're disabled or fostered doesn't matter, she treats us as special."

(Knight and Oliver, 2007, p421)

Other words used by disabled children and young people to describe their advocate have included *"a second mum"* and *"people who look after me"* (Knight and Oliver, 2007). One young man in this study stated that all disabled young people should be told about advocacy and should get an advocate when *"they're not listening and they're all making excuses."*

Throughout the published literature on young people's participation in decision-making a clear message emerges: one of young people's powerlessness, feelings of not being listened to and not being included in decisions being made about them (see for example, Boylan and Ing, 2005; Knight and Oliver, 2007). One young man in a study by Boylan and Braye (2006) spoke of advocacy in these terms:

"I think somebody else being there would make a difference, help our voices get heard, somebody that was on our side, someone who can say it for us, because they won't listen to us." Young person, (p238)

The looked after young people in this study expressed similar feelings:

"Michael is brilliant. He is a big support for me. He's always been there for me, he listens to me, talks about it and then does it all for me. It's brilliant... I'd be gutted if Michael goes because he's been

helping and everything, and supporting me and everything. It's amazing." Young person

"There's no point keeping it in; keeping it in is stupid. It's not easy but I can talk to Neil. He's been there for me and helping me. He's a good listener and works hard." Young person

Young people within this study expressed the importance that advocacy had made to their lives. As one young man, who has a learning disability, stated:

"I wanted to tell someone what happened in the past. If I didn't have one [an advocate], I wouldn't be here now." Young person

He went on to describe:

"I am more confident. When I first saw him [advocate], I got butterflies inside me. He asked me what happened. I said I was fed up moving from carer to carer – it's not healthy. I am happier that Jay helped me." Young person

One young man stated that:

"I'm just sat there and like they're all talking about things but he [the advocate] doesn't talk about me, he talks to me. All others are sat at the table talking about me." Young person

Clearly from the quotes of young people it can be seen that they highly value the relationships they develop with their advocate and they respect the work they do for them. Young people want to be respected and thus welcomed that advocates were trustworthy, reliable, responsive and, above all else, listened to them.

However, what the quotes also illustrate is that some young people do not want advocates just to be reactive and work with them on an issue basis. The importance placed on relationships indicates the need for longer-term engagement. The need for, and the value of talking to, someone who listens and cares is a reoccurring theme throughout research on children and young people's views, especially those in care.

When asked how it feels to have an advocate, one young man simply stated:

"It's absolutely brilliant. Brilliant." Young Person

6. The advocacy process: what works best when advocating for disabled children and young people?

Key findings:

- Advocacy is being provided across many complex decision-making processes such as reviews of care, safeguarding meetings, and planning for transition to adult services.
- Disabled children and young people often do not know what advocacy is, and what it can offer them. The role of visiting advocacy services, which visit schools and specialist provision, to inform children of advocacy appears to provide a vital source of information.
- Advocates report using a wide variety of methods to support and empower disabled children and young people to express their views.
- The quality of the relationship between a young person and their advocate is significant in facilitating their participation in decision-making; a relationship built on mutual respect, and more equality of power.
- Enabling factors for disabled children and young people's advocacy were identified to be;
 - A creative, flexible approach to working with the child.
 - A shared commitment across services and across key professionals such as Independent Reviewing Officers (IROs) and social workers to ensuring that disabled children and young people's views are sought and considered.
 - Training and skills development to support advocates working with disabled children and young people particularly those with communication needs.
 - Increased funding that is realistic and ensures that advocates have the necessary time to spend with the child, in order to facilitate them expressing their views.

Across the survey and case study data, advocates reported advocating for disabled children and young people across a multitude of issues and within many complex decision-making processes. These included representing young people's views in: review and safeguarding meetings, planning for transition to adult services, ensuring that the child's needs are met in residential and foster care, moving from mainstream to special school, housing adaptations, personal care needs, lack of privacy, waiting for suitable mobility and other equipment, wheelchair safety in taxis, suitable transport to and from school, contact with parents, suitable placements and making sure that a child's cultural needs are met in residential settings.

Explaining advocacy to disabled young people

Often children and young people do not know what an advocate is and what advocacy can offer them. Therefore, being offered an advocate or being referred for advocacy without full information severely disadvantages disabled young people and does not enable them to make an informed choice. A lack of information, especially in accessible formats, also renders disabled children at a further disadvantage. Without such information it would be difficult to recognise their own need for an advocate, know such services exist or know how to self-refer (although self-referral is not always possible given the tight criteria imposed by local authorities funding advocacy services). Although not part of this study, the role of visiting advocacy services who visit schools and specialist provision for disabled children, to inform them of advocacy, of their rights and to empower them, appears to provide a vital source of information particularly given the lack of accessible alternatives.

Advocacy was described by advocates to disabled children and young people as: *"Supporting you to have your voice heard"; "You are my boss, you tell me what you want to say" and "I am here to listen to you and I will do my best to help you."*

Another advocate stated:

"I don't work for your foster carer, I don't work for your parents, I don't work for college; I only work for you. I am there to try and make sure that people listen to you and what you want though I can't guarantee you'll get what you want." Advocate

One advocate explained in detail how they operate an initial agreement process with young people they provide services to. This agreement lists the issues that the young person would like to be addressed, what outcomes they would like to achieve, and what the advocate needs to do (e.g. keep the young person informed of every action). The agreement also describes the confidentiality policy. Although this is produced in written form it is kept short and simplified. Young people and advocates sign the agreement when they are both satisfied.

Explaining advocacy to a child or young person with complex communication needs was particularly challenging for advocates. Assessing how much the young person consented to the advocate visiting was also difficult for the advocate at the beginning of their involvement. The following example shows one advocate's approach:

Case study example: Amir, age 17

This young man had autism and used a few single words to communicate. He had presented with some challenging behaviour in the past and as a result had a one-to-one in his residential unit. The advocate explained his approach to obtaining Amir's consent for his visits:

"After visits he was always happy to come up close to you and want to shake hands and say 'shake hands'. He was never aggressive so I would take that as consent; that's all I could do. At least he was accepting of me being there. If he was aggressive two times in a row, I would have taken it as him not wanting someone hanging around and watching him, which is what I was doing really. So that's all I could do for consent." Advocate

A few advocates spoke of the difficulties of trying to explain to young people what their rights were. This was a concept that few young people had heard of. In most cases advocates broach the subject by explaining that young people had a right to have their voice/opinion heard. Despite trying to keep the concepts of rights and advocacy easy to understand, for some young people these needed to be explained on a number of occasions and revisited during the course of advocacy work. A few accessible resources have recently been produced to explain rights in decision-making to disabled children and young people. These are available from www.disabilitytoolkit.org.uk.

Finding suitable methods to facilitate participation

For some advocates, challenges centred on the specific demands of advocating for children with complex communication needs and/or who have challenging behaviour. Some reported lacking the skills, experience and training to undertake this work, whilst others mentioned that with time and a variety of methods such challenges could be overcome. The following case study examples illustrate the wide range of communication methods we found advocates using to facilitate the advocacy process:

Case study examples: Communication methods**Mary, age 8**

One advocate described how she used a mixture of observation and Makaton signs to communicate with an eight-year-old child with autism who used basic Makaton and spitting to communicate. The advocate met the child at school and at home and observed that, following a move to a residential school her behaviour was settled and calm as she developed relationships with the staff at her new school.

Jonathan, young person

Within a non-instructed advocacy case, the advocate was tasked with trying to establish a looked after young person's views about contact with their family. The young person had a complex communication need.

Through using photographs of the young person's friends, teachers, parents and others, and watching his reaction, the advocate was able to report to social workers that the young man consistently smiled when shown photos of his family.

Hamid, age 17

The advocate needed to assess the young man's views about where he lived. The advocate visited Hamid on several occasions so he would become more familiar to Hamid and so that he could observe the young person's behaviour and non-verbal communication methods. The advocate then showed Hamid photographs of where he was living and of another home, gauging consistent reactions over a period of time. This process and the single words Hamid used to communicate enabled the advocate to build up a picture of Hamid's views that could then inform decisions made about his future.

Another advocate described using a storyboard to aid a child with autism who found it difficult to articulate his situation in words. Some advocates reported difficulties when disabled children articulate what they think the adults in their lives want to hear, thus reinforcing the argument that participation, involvement and empowerment needs to start from an early age before such patterns develop.

The advocacy process

As the examples above illustrate, advocates working with disabled children work hard at finding appropriate methods to facilitate communication with disabled children and young people and to build up a picture of the young person's likes, dislikes, behaviours and non-verbal communication. This process is time-consuming and often necessitates weeks or months of regular visits, depending on the severity of the young person's communication impairment. Once the advocate has established a relationship with the young person, he or she can start to advocate for the young person more effectively. One advocate spoke in terms of a process of obtaining 'shared' understanding between himself and the young person in order for the young person to be able to start making choices. The advocate was then able to be clear about 'what does he want to do?', then breaking that down into 'what does he want me to do to help him do things?'

Many of the advocates and young people we spoke to identified the important role advocates play in putting forward young people's views in meetings, such as review meetings at school or with their social workers. Preparation for such meetings was seen as vital and often involved meeting one or two weeks before to discuss what might be said and then

again just before the meeting took place. The following case example, in the young person's own words, illustrates this important process:

Case study example: Kate, age 20

"Me and the advocate arrange to meet about two weeks before [the meeting with social services]. She jots down what I want to say and checks what I want said in meetings about 10 minutes before. She asks what I want to happen. [In meetings] the advocate normally speaks for me. This makes me feel a bit more comfortable. The meetings prior to the social services meetings are really useful. They made me aware of writing down notes before meetings and being clearer in my mind."

Another common way of advocating for a young person's views was by composing a letter to the person or service concerned. Advocates spoke about how they would draft a letter after discussing the issues with the young person and then ask the young person to check it or they would write the letter together. The following example shows how one advocate used the process of letter writing as a way of involving the young person in decision-making.

Case study example: Peter, age 15

Peter, who has learning disabilities, decided he wanted to write a letter to his social worker. He asked the advocate to type and prepare the letter for him after which he would look at the draft and decide if it was OK to send. Peter and the advocate worked on questions he wanted to ask and then the advocate wrote the letter. The advocate said that this would then feed into the process of reviewing and planning with the young person. The advocate put the letter together by, wherever possible, using the language the young person would use. He took it to show Peter and only posted it when Peter was happy to sign it. The young person explained this process in his own words:

"He [the advocate] writes a letter, then comes and brings it to do and I change it. He likes writes a rough copy while I'm sat there and then he goes back and writes it. And then he'll check it's all okay with me before he sends it off, in case there's something that I don't want, what I want to put in it."

Both advocates and young people also reported keeping in contact, however briefly, between more formal visits and meetings, by phone, texts and email. As Kate explained:

"I can ring her anytime or drop her a text message. We have regular contact – I speak to her every couple of months. She sometimes drops me an email to see if I am OK."

Advocates reported that they helped to make sure that the child's perspective was considered particularly when professionals and parents/carers were at loggerheads. Support was given to prepare a young person for decision-making by, for example, making lists of possible questions and answers, providing feedback after the meeting and checking the child's views.

"I talked to him about what has happened and how it has affected him." Advocate

What works?

Previous research has identified the following enabling factors for disabled children and young people's advocacy: ethos and a rights-based approach, a creative, flexible and child-centred approach, awareness of advocacy's potential and accessible information, commitment of key professionals (e.g. social workers and IROs) to ensuring that a child's view is heard; skilled advocates, flexible and realistic funding and time to carry out the role with children with complex needs (Knight and Oliver 2008; Mitchell 2007).

Previous research evidence about the effective involvement of disabled children and young people in decision-making concludes that there needs to be a wide understanding that disabled children's participation has to be facilitated in multiple and flexible ways. Franklin and Sloper (2007, 2008) present a continuum of participation, whereby children's involvement can be at whatever level is appropriate to their ability and wishes. Advocacy embraces this and advocates adopted a vast range of methods to enable disabled children to express their views, as well as multiple levels of involvement in decision-making arenas. To aid communication, advocates reported using white boards, symbol cards, stickers and drawing, the creation of picture books, a Talking Mat™, photography or letter writing. Those advocates using non-instructed advocacy spoke of undertaking observations over time and in multiple settings so that they could better understand a child.

Advocates spoke of the need to adopt a staged approach to empowering the young people, particularly as they often had little experience of being involved in decision-making processes and of expressing their views. Advocates described how they would present a child's view on their behalf at first, then work towards the child presenting their views with the advocate present, and finally hoping to reach a position where the child could present alone or with a friend. All advocates hoped to achieve this position; however, most advocacy is issue-based and time-limited, thus not always allowing the time necessary to build up the skills and confidence a child might need to reach this position.

As evidenced in many reports on participation, respondents within this study also frequently mentioned the difficulty of trying to empower children to express their views within an adult meeting structure. Although anecdotal evidence suggests some developments have been made to make, for instance, reviews more child-friendly and less formal, there still appears to be some way to go. Pressure of time and the need to complete bureaucratic processes appears to create barriers to being more creative and open to different forms of communication. There needs to be less rigid structures and more evidence of how this can be achieved to convince those with less experience, expertise, or willingness to adapt. As one advocate explained:

"He needs to be able to think about his answers and it is better for him if one chats to him alongside an activity or using pictures, symbols or writing." Advocate

Such activity would not necessarily be acceptable to all professionals attending bureaucratic meetings. Although one advocate described how he successfully integrated one young person into the reviewing process by simply holding up a flipchart which listed what the young person wanted to talk about and what they would like to happen, the advocate would start the discussion with the young person joining in when they felt comfortable. A young person described how they prepared for meetings with their advocate:

"I will talk to James before and he will write it down on a piece of paper for me. In the meeting he let me talk and he talks about it as well. If I forget something he will do it because he's got the piece of paper there. He works very hard, James. I'm glad I've got him as well. I'm glad I've got him". Young person

Importance of trusting relationships between advocate and child

Knight and Oliver's study concluded that the quality of the relationship between a young person and their advocate is the most significant component in facilitating their participation in decision-making (2008). A finding echoed in this study.

One advocate described how a young person asked her to tell his school that he did not want any homework. The advocate (knowing what the school would say), however, asked the school who refused, but this helped to illustrate to the young person who had a learning disability what advocacy meant, what the process was and that it might not always result in them getting everything they might want. However, by following up the young person's request the advocate was able to build trust between

them and move on to tackle the more complex situations and main need for advocacy:

"I made sure that I visited him at least every two weeks as I wanted to keep up that relationship. Sometimes there wasn't much that came out of them but it kept up that relationship and meant that when he did want to talk about things, he would be OK to talk." Advocate

The importance of building trust and a relationship was reported to be vital; it took time, skill and patience but once established the advocate was able to get to the heart of issues with the young person. In some instances this had led to disclosure of safeguarding issues:

"This came out after a certain time and it was clear it wasn't something she was comfortable talking about. When she was talking about it you could tell she was angry about it but she wasn't sure whether other people would find it bad that this was happening, whether it was a normal thing." Advocate

One young person, Peter, age 15, who took part in the study, spoke about the importance of the advocate talking to him and taking an interest in his life in general rather than just focusing on his complaint, and as a result he felt more listened to:

"He [the advocate] don't just ask questions about letters and complaining and stuff, he asks what happened at school and what I'm gonna be doing at the weekend or something. He doesn't wanna do that - just come to your house cos of his job - he just comes cos he likes to come and talk to us. He's funny...and he listens to me." Peter, age 15

His teacher also commented about the trust she thought there was between Peter and the advocate and that this independent trusting relationship had facilitated levels of trust between Peter and other professionals:

"Obviously the advocate has built up a long-term relationship with Peter and Peter trusts him an awful lot. I think because of the sort of school that Peter comes to he's now got to a point where he does trust staff and can talk to staff, but it's having that independent person who's not actually affiliated to anything else that is the important thing and I know that he does tell the advocate things which are very confidential between the two of them." Teacher

Another young person said that what was really important about his relationship with the advocate and what made it different from his relationship with other professionals was how the advocate treated and respected him as a person, reflected in the way he spoke *to* him and not *about* him:

"It's like other people we meet and I'm just sat there and like they're all talking about things but he [the advocate] doesn't talk about me, he talks to me. All the others are sat at table talking about me. But now he's started coming to meetings they listen to me." Peter, age 15

Such accounts of the advocacy relationship by young people are not uncommon. Dalrymple identifies from her interviews with young people that independence of the advocate, friendship, and therefore more equality of power and respect are important characteristics of the relationship (2005). Pithouse and Crowley report from their study that young people view the advocacy relationship as almost one of friendship and this is quite different from their relationship with other professionals (2006).

7. Challenges faced by advocates

Key findings:

- Advocacy was often commissioned when cases were extremely complex and/or had reached serious levels of concern, conflict or distress.
- Although most advocates worked on a single issue, in reality once assigned a case many more issues emerged, issues did not get resolved and cases often lasted a long time.
- The complexity of the parent/carer role in the advocacy situation should not be under-estimated.
- There still exist negative attitudes amongst some professionals towards, and a lack of understanding about, the participation of disabled children and young people in decision-making.
- Although highly regarded by most people, there also existed some lack of respect for the advocacy role amongst a few professionals.
- The isolation and lack of friendship opportunities for disabled children and young people meant advocates had to establish clear boundaries with children as to the purpose of the relationship: advocate not friend.
- Advocates reported that on numerous occasions, disabled children and young people's confidentiality was broken by professionals working with the child. Disabled young people placed high importance the confidentiality that existed between them and their advocate.
- Challenges facing advocacy for disabled children and young people included:
 - Levels of awareness of advocacy appear to remain low amongst professionals, parents/carers and disabled children and young people.
 - Inappropriate timescales in which to undertake advocacy.
 - Limited and restricted access to disabled children and young people to raise awareness of their rights and of advocacy services.
 - A lack of consensus on the practice of non-instructed advocacy.
 - A lack of resources and limited funding.
 - Lack of training opportunities and skills development

Resources required for advocacy

Advocates reported that they, more often than not, needed more time with the child than that which was available to them. Some were contracted to only work with the child for a certain number of hours. However, time was needed to maintain continuity, get to know the child

and their method of communication, and to build up a relationship of trust. Advocates reported that each visit to a child could last from one and a half to three hours depending on circumstances such as a child's abilities and communication needs, or that very frequent shorter visits might be required. As one advocate explained:

"I worked with a young person for nine months on a weekly basis to provide advocacy surrounding transition issues; this was particularly challenging due to the nature of his disability, his behaviour problems and the fact that he was non-verbal. We started out working for 10 minutes and then having to finish because that was as much as he could cope with. During the process this was extended to about 40 minutes." Advocate

Another advocate stated:

"I made sure I did a lot of visits. Although Adam has a lot of capabilities to speak on the phone unless you have got his attention he won't take much in." Advocate

It is difficult to quantify the amount of time required by advocates working with disabled children as this will be dependent on a host of factors, such as the issues being dealt with, the child's abilities to communicate and/or the skills of the advocate. To provide illustration, one advocate working with a young person with reportedly good communication skills spent a total of 45 hours face-to-face with the child over an 18-month period and also attended meetings concerning the case. This did not include any travel time. The advocate estimated that this time allocation could have doubled if the child had more severe disabilities. Similarly, another advocate supporting a child with a physical disability and very good verbal communication reported that this case was open for 19 months and still issues had not been resolved.

As one advocate reported:

"I think that I've had positive impacts but I remain frustrated that this work should have been finished in the last six months. All of it. I feel that I have done the right things but I don't think Harry has had the response [from service providers] that his representations deserve or as quickly as they deserve". Advocate

Advocates reported that as part of the empowering process for the young person it was important that they were given choice and control over their advocacy; for example, where and when to meet (a lot of young people did not want to meet their advocate in their home). Again this could take

extra time to plan and facilitate. Similarly it was reported that building a young person's capacity takes time and this could be a slow process. As one advocate described:

"I also went to meetings with him at school or with social services and to assist him and try and promote him advocating for himself. So making sure he can speak up for himself has been a big part of it. He would have a proportion of time when he could speak about what he was happy with, what was going well and what wasn't going well." Advocate

It can thus be seen that advocates need to be commissioned early and be given the time to develop trust and understanding between themselves and the child. This is particularly important to note, for example, in relation to new duties placed on IROs, who are required to access advocates as part of the reviewing process. Such arrangements will need to be planned in advance if children are to be fully involved in the process.

Training and skills of advocates

A survey question explored whether advocates felt that they required any further training/skills development in order to undertake their role. 26 out of the 35 advocates who responded stated that they did need further training (nearly three in four), particularly training concerning communicating with children with complex communication needs and autism, and training in non-instructed advocacy. Other elements of required training included keeping abreast of new legislation and policy, the Mental Capacity Act and safeguarding, commissioning of advocacy and generally continued professional development through the sharing and learning of advocacy practice.

Relationship with parents/carers and foster carers

Knight and Oliver (2007) highlighted issues around the challenges faced by advocates of disabled children and young people of sometimes deciphering who is the actual client in advocacy – the disabled child or their parent/carer. Similarly, advocates in this study reported that they faced difficult situations where there could be potential conflicts of interest. Parents were reported to sometimes see advocates as potential allies in battles with service providers and thus could (intentionally and unintentionally) apply pressure to the advocate. Additionally, challenges were presented by too much parental/carer involvement in the relationship between the advocate and young person (See also Caldwell et al, 2006). In some cases, parents/carers pushed for the advocate to present their own rather than their child's views, whilst some parents found it difficult to 'let go' and consider an advocate working with their child, and their child beginning to represent themselves. Often, parents

who had been advocating for their child for many years thought that they were the child's best advocate, and thus found it difficult to relinquish power and control. In one case study, the advocate reported that it took eight to nine months before the parent would allow her to meet her child alone. Negativity to advocacy by parents/carers is particularly problematic as it was reported that they often have to give consent for their child to receive advocacy. As one survey respondent wrote: *"if a parent feels it will disadvantage them then the consent will not be given."*

The following quotation from an advocate illustrates the challenges he faced when there was a clear conflict of interests between the young person and parent:

"I advocated for a young man with complex physical needs and learning difficulties. He was referred by a teacher and was moving into adult services. His parents received his benefits and were very reluctant to spend money on anything they felt was unnecessary, stating they wanted to save for his funeral, although the opinion was that the benefits were being spent across the family. I advocated for his equipment needs to help him enjoy day-to-day life, for him to have outings and holidays. His parents disagreed and decided that he should no longer have an advocate. Legally there was nothing we could do because he could not speak for himself and they were his next of kin." Advocate

Another advocate reported that:

"Mum was insistent that she wanted to attend the meetings as well. Part of the reason for referral [for advocacy] was that the young person's voice wasn't being heard, as mum was so forceful in her responses. It took a lot of work to get to the point where the young person was happy to meet me on his own." Advocate

Another advocate reported:

"It was challenging at first as B's mother wanted me to put her views forward. At first she wouldn't let me see her without being there. So it was a challenge not to get the two people's views tangled up." Advocate

Sometimes foster carers were reported to be domineering, and in one case it was reported that they made a young person write a letter stating they did not want an advocate.

The complexity of these relationships means the relinquishing of parental power and allowing another person into the relationship could be challenging to all involved. A few advocates spoke of how they overcame such difficulty by encouraging the parent to get their own advocate. However, creating space for a child to express their views and then ensuring that these views are not overshadowed by the dominant voice remains a challenge. Equally, it does raise issues about a child's right to express their views (as represented under Article 12 of the United Nations Convention on the Rights of the Child); for these young people this right is dependent upon the willingness and permission of their parents/carers – disabled children and young people appear to have little power to redress this.

However, other parents/carers saw the advocate as an ally for them and/or saw how advocacy was supporting their child. As one parent voiced:

"I think everyone should have one of these for disabled people... If every child has one of these I think there's gonna be a lot of positive sides." Parent

In some cases foster carers had referred children to advocacy and saw that advocacy could provide potential benefits for the child they cared for.

Attitudes of other professionals

Advocates working within health settings and with health professionals frequently stated that they encountered negative attitudes towards, and a lack of understanding about, the participation of disabled children and young people. Assumptions were made that disabled children cannot be involved in decision-making and would not understand the situation. It was reported by advocates that there was little understanding amongst some professionals about how participation might be possible. When a disabled child did express their views, it was also reported that their views were not always taken seriously by the professional involved. In particular, a case study that used non-instructed advocacy in a health setting faced considerable challenges. As the advocate described:

"I'd be in meetings with [NHS Assessment] staff, nurses, clinical nurses and the team managers from social services – there'd be so many people there all giving their views, and I think to try and put across the view of a young person that everyone in the room knows doesn't communicate, and would have no comprehension of communicating anything on the level of where he wants to live or how he's feeling at the moment...nobody will say it because no

one's allowed to say it but you get the sense that 'OK that's nice' but we know that this is what is best." Advocate

The examples of advocacy within health settings shared for the purposes of this study centred on situations where parents/carers and the health professionals were in dispute over the child's care, and the child was described as being *"lost in the middle without a voice or understanding of the dispute or what is going on around them."* One advocate reported that a child they were advocating for felt that their parents were being bullied by the health professionals. On a more positive note, advocates supported young people in health settings by helping them to prepare for medical appointments through, for example, creating lists of questions to ask, spending extra time with the child so that their understanding of the situation could be assessed and seeking any further information the child might require.

Within social care some similar attitudes did exist. For example, some advocates reported that they had encountered social workers who assumed that the young person would not understand or could not communicate even though the advocate was able to facilitate this. One advocate supporting a physically disabled young man described how the young man felt that because he used a wheelchair social care staff did not treat him as a 'full-shilling'.

However, this was not always the case as some advocates reported very good working relationships with social workers. Supportive, responsive social workers obviously made the task much easier for advocates and this could create a positive, mutually beneficial relationship. As described later, advocacy can help social workers through, for example, highlighting safeguarding issues, or improving the stability and appropriateness of placements. An advocate, when describing a child's social worker and other care staff, stated:

"I think they felt that they got somebody who was accepted as objective, is outside the organisation helping Chanelle say things, so I think the other professionals felt supported." Advocate

In the main, schools were reported to be supportive of the advocacy role and helped facilitate this by enabling advocates to visit children on school premises. Such receptiveness meant visits could be easily arranged and facilitated. One advocate felt that schools were supportive of advocacy as they could see it helping their pupils to develop their abilities to speak for themselves.

However, support for advocacy appeared to often be reliant on education staff understanding the role of the advocate and therefore not feeling challenged or undermined, as illustrated in the next example:

"A young man was referred to me who had no verbal communication. He was referred by his social worker who had concerns that he was not developing any system of communication in school... when I approached the school to discuss the referral they were not very welcoming and wanted to know on whose authority I was acting, as if I was inspecting them... they were more accommodating once they were clear what my role was and how I could help." Advocate

Overall, advocates reported that there still needed to be a change in attitudes across the workforce towards the participation of disabled young people, thus echoing earlier research (see for example, Franklin and Sloper, 2008; Franklin and Osborne, 2009).

A lack of a culture of involvement and little prioritisation of children's views and opinions is a common theme within the literature, although there does appear to be some progress. Franklin and Osborne (2009) highlighted that involvement is often seen as a luxury and reported on how advocates and IROs faced challenges *"when those around [a child] do not believe they can have a view"* (p21). Dalrymple talks about the need for a *"culture of advocacy"*, but also points out that to achieve this involves a struggle to promote and justify the need for advocacy, and requires that *"all adults involved in the lives of young people need an understanding and commitment to the ideas, beliefs, values and knowledge which constitute the basis of advocacy"* (p12, 2005).

As Dalrymple argues, disabled children's access to advocacy is very much dependent on people around them believing in their right to be heard and that they have a valid view and contribution to make to the decision-making process, and thus make a referral. However, as demonstrated in this report, even when disabled young people have overcome this hurdle and have accessed advocacy, this does not guarantee that their views will be considered. Advocates report continued challenges, including an example of a local authority holding their reviews of disabled children and young people in an inaccessible building, thus making it impossible for physically disabled young people to attend their own reviews.

Across this study it is evident that advocacy for disabled children and young people came late in the day, responding reactively to a crisis or complex specific issue (most services were funded by a local authority to provide only issue based advocacy). Such an approach fails to ensure

disabled children and young people's voices are included earlier when, for example, stress or upset might have been avoided (see also Boylan and Braye (2006) who identify this issue with looked after children):

"At the time I became involved David ...hadn't been upstairs to bed or had a shower for two-and-a-half years and I was invited to join David to help him make representations to the district council housing department about his need and his own right to be able to bathe and shower and sleep in his own home." Advocate

In addition, as will be described later, the lack of participation in decision-making in general and involvement at early stages of issues often meant that young people divulged a multitude of issues as the advocacy relationship developed. This meant that advocacy often lasted longer and tackled more issues than was originally intended.

Respect for the advocacy role

It can be seen throughout this report that advocates were highly regarded by those young people, parents and professionals interviewed. Some advocates reported, however, that they were sometimes not seen as credible or respected, or taken seriously by some professionals and that this affected whether they could successfully perform their role. As one advocate explained:

"It is quite difficult to fight on behalf of a young person if you're not taken seriously" Advocate

We cannot dismiss that this may be due in part to individual personalities, skills or experience [not just those of the advocates]; however, if a culture prevails where disabled children and young people's participation is not viewed as a priority, or indeed as desirable or achievable, then the role of the advocate will be given little respect or status. As one advocate reported:

"You can put forward as much information as you get from the young person but a lot of the local authorities can put this down to your interpretation or they might not take it as the whole truth." Advocate

Even in a case in which an advocate describes their relationship with the social worker as very positive, the information the advocate presented was always treated as 'second-hand'. In this situation questions need to be asked: would this be the same if the child were not disabled? Would this information be treated differently if the child did not have a learning disability or did not communicate using non-verbal means of

communication? Is there still an underlying culture that does not value disabled children's participation? Or is it simply as young people in other studies have perceptively noted:

"The social workers and advocate sometimes don't see eye to eye, cos they [advocate] are telling social workers that they are doing their job wrong. The staff hate [the advocate]." (Young person quoted in Boylan and Braye, 2006, p239)

Thus is it easier to dismiss the advocate and the information presented on behalf of disabled children and young people than to tackle the issue at hand?

However, the complexity of this issue should not be underestimated. The following example provides an illustration of how the way in which a young person expresses their view can serve to undermine the authority of an advocate inadvertently:

"We wrote out a complaint for Alfie about wanting to stay at the respite foster carer. It had to be carefully thought out as it was written by me on behalf of Alfie, but at the last minute he changed his mind about doing this... It was a difficult one because although Alfie agreed with all the points at the time, if you asked him 15 minutes later, he wouldn't remember what was in the complaint."
Advocate

In contrast, however, others used/saw advocacy as a tool to achieve outcomes that they were finding difficult to achieve. For example, Knight and Oliver (2007) reported that some social care staff in residential units viewed advocates as a bridge between them and local authority social workers, because advocates could sometimes be relied on for support to challenge decisions made by social workers. Advocates in this study reported that they felt some social workers saw advocacy as a way to achieve changes in services that they were not empowered enough to facilitate. However, this could lead to difficulties around boundaries of roles and professional duties and confidentiality:

"His social worker had got frustrated and couldn't see any more progress and therefore asked for an advocate. If you want me to speak candidly I would say that sometimes social services departments find it easier to involve people from outside to fight the battles with other departments." Advocate

"I was referred by his social worker and because they referred me into the family they also see me as an ally. Whatever I say, they

see me as an ally, and I have to be very careful that I keep telling them that I'm there as Sara's advocate and that I keep telling them that my rules of confidentiality are the confidence of Sara and anything that they tell me that's in Sara's interest they should expect me to use in Sara's interest. They find that quite strange given that they were the referrers and the fact that I am a registered social worker and a professional person... every now and then they'll ring me up and they'll ask me to give them information which is effectively monitoring what's going on in the house."

Advocate

Complexity of cases

Case studies and survey findings illustrated that advocacy often appears to be commissioned when cases are extremely complex and reached serious levels of concern and/or conflict and/or distress. For example:

- Hospital complaints procedures,
- Concerns over care placements including safeguarding issues, ensuring the child's needs are met in residential and foster care and loss of belongings,
- Transition issues,
- Decisions over complex medical operations and 'do not resuscitate' status,
- Disputes over funding between social care, health and education,
- Housing adaptations, mobility aids and equipment,
- Personal care needs and privacy,
- Concerns over provision within school and moving from mainstream to special school,
- Wheelchair safety in taxis', and pain-free transport to and from school,
- Contact with family,
- Mental capacity assessments.

In addition, although most advocates worked on an issue basis, many reported that in reality once assigned a case, many more issues emerged and cases lasted for long periods. This was described by one advocate as "*the smaller advocacy issues within the bigger issues*":

"There have been a couple of times when I've gone to see Keeley to actually say: we've got as far as we're going to go with this so we've done all the things that we wanted to do and now I am going to shake your hand and walk away and each time I've gone something else has suddenly occurred which has meant that I've needed to be involved further." Advocate

Across both the survey and case studies respondents were asked to identify cases that were particularly challenging. The range and complexity of these, even within this small sample, illustrates the difficulties facing advocates and advocacy services. Some advocates faced issues such as; *"a looked after child who has had ten social workers in the three years I have worked with him"* and *"there were problems with the local authority accepting his diagnosis (a common challenge) thus the situation remains unresolved and the child remains out of education."*

Unresolved issues still requiring advocacy

As already illustrated, although disabled children and young people were generally referred to advocacy for a few specific issues, in reality advocates reported that advocacy involvement lasted much longer than originally expected because issues continued to emerge, and issues did not get resolved. Of course, it cannot be expected that all disabled children and young people, once having their views listened to, will achieve fully what they desire. However, on numerous occasions advocates reported that the child's rights continued to be denied and promises made by service providers were broken. For example, an advocate reported on one young man with a physical disability who wanted to be able to go upstairs in his house, sleep in his bed and be able to take a shower after waiting two and half years for a lift to be installed. As the advocate described:

"As part of the second phase of this work there was to be a ceiling hoist from his bedroom to a refurbished bathroom. We were told that this would have to be done in the following year because they couldn't afford it. I said to Danny we could push this one and he was actually grateful for what they had done and felt that he would accept their word that it would be built in the next year. Well the end of the year is next week and it hasn't been built yet." Advocate

An advocate described the following as her greatest challenge:

"People not taking responsibility for their decisions, passing the buck, especially as Lucy is going through the transition from children's to adult services. There are so many people involved, so many people can say it's someone else's problem. There has been no lead professional co-ordinating everything, this would have helped." Advocate

Similarly, another advocate described:

"The barriers are the pressures trying to get this a priority in an authority who already had a heavy workload and it was seen as something which could be done at a later stage." Advocate

Establishing boundaries with disabled children and young people

There is a lot of research evidence to illustrate the social isolation and lack of friendship opportunities for disabled children and young people (see for example, Petrie et al, 2000; Morris, 2001; Knight et al, 2009). A few of the advocates interviewed spoke of how they had to be mindful of the need to establish boundaries and reinforce the purpose of their relationship – they were not there to be a friend. Because of either the complexity of the cases or because of the need to spend a lot of time with a young person to establish their views, advocates were in some instances visiting the young people for a considerable period of months, or even years. If a young person has few other visitors or a limited social network then it could be possible for boundaries and the basis for the relationship to become blurred. A number of advocates explained that they had to spend time explaining and preparing a young person at the beginning and when they were going to close the case.

Confidentiality

As reported in the study by Knight and Oliver (2008), confidentiality can be a very contentious issue when working with disabled children and young people, especially for children with complex communication needs or severe disabilities. This study supports this finding. Knight and Oliver illustrated that parents and professionals expressed doubts about the significance of confidentiality as a result of what they perceived to be a lack of understanding on the part of the young person or a perceived need for enhanced protection of the child.

Within this study, on a number of occasions advocates reported that a young person's confidentiality had been compromised because other professionals shared information with the advocate without a child's prior consent. One advocate reported being emailed a child's confidential health information without the child's permission.

Yet disabled children and young people view confidentiality as vital and place a high value on this aspect of advocacy (Knight and Oliver, 2008). Young people in this study highlighted the importance of confidentiality to them:

"Trust? I trust Carla. It's very important because advocates they don't tell your mum and dad at all what you feel. It's very, very important. With the social workers they tell your mum things; Carla doesn't at all." Young person

Advocates reported that it was vitally important for the child that they took confidentiality seriously so that trust could be built between them. Yet the issue is complex: advocates reported that they could not assure complete confidentiality because they were required to report safeguarding issues. Other studies have reported on the difficulties of this (see for example, Boylan and Braye, 2006).

An advocate in this study who was required to report on safeguarding concerns stated that he explained to the child that what was happening was wrong and therefore he would have to tell the social worker. The advocate reported that the child seemed to accept this, possibly because this was a validation that what was happening was wrong and the child had been unsure of the boundaries between appropriate and inappropriate behaviour by adults. This was confirmed in a subsequent interview undertaken with the child concerned, who stated:

"When X [advocate] told the social worker about what I had said about being bullied, she cried her eyes out. I cried, I was pleased to tell someone." Young person

8. Outcomes of advocacy

Key findings:

- Disabled children and young people, including those with complex communication needs, can express a view and contribute to complex decision-making processes, if supported and enabled to do so through advocacy.
- Advocacy, including non-instructed advocacy, can lead to improvements in disabled children and young people, and their families' lives through improved services. For example, more appropriate placements in care, improved stability at home, reduction in pain and improved safeguarding.
- The advocacy process itself can bring significant benefits to the individual child, through improved confidence, self-esteem, independence and communication and increased trust in adults.
- It appeared that lessons learnt from individual advocacy cases were not replicated to improve services generally for the wider population of disabled children and young people.
- There were also reported changes in professionals' attitudes and approaches towards a child following advocacy: a more open and honest relationship, improved understanding of how a child communicates and higher expectations about the child's capabilities.

Despite the numerous challenges facing advocates working with disabled children and young people, when given the time to establish a close and trusting relationship with a child and time to understand any communication method they may have, the reported outcomes can be very positive and bring many benefits to disabled young people, their families and to services in general. Disabled young people report positively about having an advocate, feeling nurtured, being taken seriously and having someone to talk to in confidence (Knight and Oliver, 2007). Townsley et al (2009) report that sometimes the outcomes of advocacy are not always those desired by the disabled person, yet the support provided by the advocate is still regarded as a positive experience. This study supports this conclusion.

However, there have been few studies that examine the outcomes of advocacy for disabled children and young people, possibly because of the difficulty in measuring these, but also because of the individualistic nature of advocacy. Townsley et al also raise the question of measuring the effectiveness of advocacy when there are no obvious positive outcomes, but where the process has been supportive and enjoyable for those involved. This has been the case for a number of young people within this

study who report on the positive benefits of advocacy for them but who have not achieved their desired outcomes.

Townsley et al's study examined independent advocacy for disabled young people during transition to adulthood and found the following outcomes of advocacy: increased and better quality involvement of disabled young people, a positive impact on the behaviour and knowledge of professionals and better quality service provision post-transition. In terms of personal development for the young person, advocacy led to increased confidence and self-esteem, raised expectations and a more positive self-identity as a disabled person.

It is important to establish the distinction between benefits related to the process of advocacy (e.g. personal development) and the benefits resulting from the outcomes of advocacy (e.g. changes in services) (Townsley et al, 2009). However, measuring the effectiveness of independent advocacy is complicated and Townsley et al's review did not find any research to indicate that a framework for measuring and comparing outcomes for advocacy for young people had been developed. The Scottish Executive (2000) suggested that it should involve the following methods of data analysis: listening to people's stories about the difference it has made to their lives; valuing relationships as well as results; balancing the visible successes with the invisible work of preventing worse things from occurring; and assessing the impact of advocacy on policies and practice in the service system both in relation to individuals and more generally. Although this study is small-scale, it can be seen that advocacy achieved outcomes both in terms of process (personal development) and services.

Process (personal development) outcomes

As with the small number of previous studies, this research supports the findings that advocacy can produce a number of personal development outcomes for individual children and young people: empowerment, confidence and improved self-esteem and well-being.

"Advocacy has greatly improved Jamie's self-confidence. He is a lot more confident and is more empowered. He is able to stand up and say things now. He seems a lot happier." Advocate

The young person when interviewed confirmed this. When asked what difference has having an advocate made to you, they emphatically stated:

"Confident and happy. Really, really confident and happy. Absolutely confident and happy. I feel confident talking to Matthew." Young person

When asked about dealing with other people or meetings, the young person confirmed again: *"really happy"*.

Across the board, confidence and empowerment was considered to be a major benefit from the advocacy process:

"I think Jack can talk to people now having experienced it and done a bit of rehearsal with me. He can talk to officials in a way that he didn't used to be able to, so he's got confidence through having impact." Advocate

One teacher when interviewed spoke about the benefits of advocacy to her pupil:

"It's given him confidence... I think Harry has got a lot of personal challenges in his life because of the disability he's got and a lot of coming to terms with things, and I do think that it's probably helped him with that in some ways." Teacher

And another teacher commented on a young person's increase in confidence as a result of having an advocate:

"I have seen a huge difference in Simon since the advocate got involved – he is much happier, more confident." Teacher

It can also be seen that the advocacy process can lead to an increased level of trust in adults by disabled young people. The evidence provided in this study illustrates that disabled young people, once comfortable, or maybe after their expectations of being heard are raised, reveal other issues of importance to them, and in some cases disclose safeguarding issues.

In addition, the advocacy process enables disabled young people to become more informed about, and increases their understanding of, decisions being made about them. Advocacy can ensure that the child is not just seen as part of a family, and thus the child's needs are considered and not just those of the parents/family.

Another outcome of the process of advocacy can be identified as the increased personal independence of disabled young people. A few advocacy cases illustrated within this report highlighted difficulties with parents/carers preventing their child accessing advocacy independently, and/or presenting their views independently. Through skilful advocacy practice, it was reported that these barriers can be overcome and that

parents/carers can see the benefits that advocacy can bring to their child and family.

One advocate reported that a parent had learnt new ideas from them about different ways of communicating with her son, and was now using more creative methods that appeared to have improved their communication and relationship.

Some advocates reported witnessing changes in the professionals' and practitioners' attitudes and approach towards a child following advocacy, including the development of a more open and honest relationship between the child and the professionals in their life and improved understanding of how a child communicates. A teacher explained how advocacy had helped in review meetings:

" I think both James and [advocate] in meetings have got a lot of respect from other people, and people will stand back and give them time and listen to them and I think it's maybe in some ways helped towards making some meetings which could be quite difficult a lot easier and a lot more light-hearted. More informal." Teacher

Other reports suggest that limitations and assumptions made about a child are challenged by advocacy. A case study reported in Caldwell et al (2006) provides an example of this:

"A recent case involved a young man who said repeatedly that he wanted to be a mechanic. However, he was fed up because he kept being told that he could not be a mechanic because of his learning difficulties. They explained to him that he could not read, write or do maths to the level that was needed to be a mechanic, so this was not a possible job prospect for him. His advocate talked to him about what exactly he would like about being a mechanic. He said he would like to clean the cars inside and out to make them look good. So the advocate established that the young person had just been using the wrong word in meetings. This was resolved successfully by offering the young person a place with a car valeting firm." (p77)

One young person when asked during an interview 'what would you say to other young people thinking of getting an advocate?' emphatically stated:

"Get one now! Get one and look back at what happens – leave the past. Take all the rubbish out of your head." Young person

Service outcomes - individual level

Advocacy led to many changes in services for disabled children and young people, with the provision of more appropriate services, and in some cases the provision of a service that the child had a right to, for example, an education or privacy. These outcomes led to considerably improved lives for individual children, young people and their families. Examples included: more appropriate placements leading to improved stability at home and at school; reduction in pain following improved transport arrangements; and feeling safe and being protected. On a simpler level, for children with more complex needs advocates were able to establish their likes and dislikes, which were used to plan more appropriate services and increase their quality of life on a daily basis:

Case study example: Simon, age 17

An advocate shared how they had supported a disabled young person to negotiate a more appropriate care placement. Through building a positive and trusting relationship with the young person, the advocate was able to establish that the young person did not want to be placed with his sister in future, but wished to maintain regular contact. The sister had greater needs than him, and they had both been looked after for many years during which time the sister had become very dependent on him. He had found the relationship too intense and felt responsible for her care. Following such a move, the young person appeared much happier and more settled.

Similarly, another advocate described how they advocated for a young person who wanted to leave foster care and go home. Although this did not work out long-term, the young person felt satisfied that, after two years of wanting this, he had been listened to and had the right to change his mind.

A young person described when interviewed how his advocate had helped him with his anti-social behaviour:

"I don't get into trouble no more with the police and everything. Ben had been there for me. If I didn't have Ben I would still get into trouble. I went to a shop and I stole beers and that was bad. I don't do that no more." Young person

Service level outcomes

To truly empower a larger number of disabled children and have a longer-lasting impact on their lives requires that the lessons learnt from, and outcomes achieved through, advocacy make a wider impact on decision-making processes, structural procedures and service provision across the board. Advocacy from individual cases provides the data needed to

promote changes in legislation, policy and practice (Oliver and Dalrymple, 2008). Yet there is very little evidence to suggest that this is occurring. A few survey respondents were able to describe how they had applied learning from individual advocacy to improve their advocacy services; however, only a couple could identify how learning had been applied to services for disabled children and young people. The two examples shared were the development of communication passports for children and the need for contact plans and schedules for all children in care.

Outcomes from non-instructed advocacy

Despite opposition that this is not pure advocacy, the few examples illustrated here have demonstrated that non-instructed advocacy can lead to positive outcomes for the child or young person involved. As already described, one advocate used photos of family members to help a young person inform a decision about contact arrangements with his family.

Case study example: Martin

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

Case study example: Thomas

A further case study illustrated how an advocate, through non-instructed advocacy, observed a young person's unhappiness and discomfort in a residential placement. Initially the placement had meant to be a temporary arrangement; however, the young person had remained there for a considerable time. The advocate was asked to establish whether the young person, who had severe autism, wanted to return to their home. Although the young person could not instruct the advocate, the young person would always consistently say "mum" to the advocate and grab his hand and walk away, as if he were saying, "take me to mum".

The advocate was also able to establish from the young person that he remembered and knew his siblings' names, his address, his old school, his old teacher, and was familiar with the old life he had before the placement. At the placement the advocate observed him walking around with nothing to do and his frustration. This information was fed into the decision-making process and the young person returned home to his

family and back to school after an absence from education of nearly two years. The young person is reported to be very settled and happy.

Franklin and Osborne (2009) reported in their investigation into the involvement of children with complex communication needs within the reviewing process that reviewing officers saw benefits to using non-instructed advocacy. Information collated independently on day-to-day issues of importance, such as a child's likes and dislikes and what makes them happy or sad helped to inform decisions made about the child's care plan. However, the need for wider recognition of non-instructed advocacy as a legitimate form of advocacy is needed, as is more research into its practice and outcomes.

9. Conclusions and recommendations

The following draws together the main findings from the research and concludes with recommendations for the future development of policy and practice. In addition, the need for further research in this under-explored area is presented.

As Oliver and Dalrymple argue, "*advocacy offers a potentially important mechanism for translating children's rights to participation in decision-making into practice*" (2008, p12). This study has illustrated that advocacy for disabled children and young people is important and can sometimes make considerable improvements to the lives of disabled children and young people. The process itself can bring significant benefits to the individual child. Despite evidence of some negative attitudes toward the involvement of disabled children and young people in decision-making, the evidence shows that they have a view, can express a view and can contribute to complex decision-making processes if supported and enabled to do so through advocacy.

Although advocacy practice for disabled children and young people does not necessarily differ from non-disabled children and young people, advocates working with children with complex health needs, communication needs, and severe learning disabilities face particular challenges and barriers. Yet these advocates are arguably working with some of those young people most in need of having their views and concerns considered. There is little evidence to suggest that advocacy services for disabled children and young people have developed vastly in number since 2007, and it appears that they are still facing the same challenges identified by Knight and Oliver in 2006, despite the increased emphasis within policy guidance on the importance of advocacy. There clearly is a need for more awareness of advocacy and its potential contribution to empowering disabled children and young people to express their views and be involved in decisions which impact on their lives.

In summary:

Challenges facing advocacy/advocates for disabled children and young people

- Levels of awareness of advocacy appear to remain low amongst professionals, parents/carers and disabled children and young people.
- Continued professional attitudes that disabled children and young people cannot express their view, and a lack of awareness of their right to do so.
- Inappropriate timescales in which to undertake advocacy.

- Limited and restricted access to disabled children and young people to raise awareness of their rights and of advocacy services.
- A lack of consensus on the practice of non-instructed advocacy and some lack of respect towards the advocacy role by professionals.
- A lack of resources and limited funding.
- A lack of training opportunities and skills development.

Enabling factors for the provision of advocacy for disabled children and young people

- A creative, flexible approach to working with the child.
- A shared commitment across services and across key professionals, such as IROs, to ensuring that disabled children and young people's views are sought and considered.
- Training and skills development across advocates to working with disabled children and young people particularly those with communication needs.
- Increased funding that is realistic and enables advocates the necessary time to spend with the child.

Outcomes for disabled children and young people accessing advocacy

The study has illustrated that advocacy can bring positive outcomes to disabled children and young people in terms of their personal development, for example, improved confidence, self-esteem and well-being and increased independence. On a service level, advocacy can bring about improvements to the services that these children and their families access. Advocacy was reported to also change attitudes in professionals and practitioners, improve communication and raise expectations. However, not all outcomes were achieved for the young people despite there being a very real need for change. In a number of cases, achieving an outcome took a very long time and required a long hard battle.

From the case studies it is also important to note that, although advocacy was mostly meant to be on a single issue basis, young people often raised multiple issues once their relationship with the advocate developed. Thus advocacy unmasked many hidden problems. This underlines the need for more sustained advocacy involvement, wider access to advocacy and a need for there to be more of a participatory, listening culture developed amongst professionals for disabled children and young people.

Specific policy recommendations include:

To ensure that all disabled children and young people can benefit from the positive outcomes that independent advocacy offers central and local government should work towards:

1. Increasing the availability of specialist advocacy provision for disabled children and young people

- Specifications for the provision of advocacy services should take into account the full range of legislation, regulation and guidance that relate to independent advocacy.
- Greater consistency and equity should be achieved in disabled children's access to advocacy through the commissioning of an independent advocacy service in every local authority, and ensuring that both generic and specialist advocacy services are able to deliver advocacy for all disabled children who need this service in relation to social care, health or education.
- There should be increased access to, and use of, training to assist advocates to develop their skills in working with disabled children, particularly those with complex needs.
- Specialist advocacy services for children with additional needs should be commissioned to support them in accessing NHS services [as recommended in 'Achieving Excellence and Equity for Children' Department of Health, 2010]

2. Improving the awareness of advocacy services for disabled children and young people

- Information on advocacy services in a range of accessible formats should be provided by local authorities for all disabled children and young people as soon as they enter the care system or move into a long-term residential placement and before every review. Care should be taken to ensure that the information provided is understood by the child and that, if they wish to, they have the means to make contact with the advocacy service.
- Information on advocacy services for disabled children, including the use of non-instructed advocacy should be provided by local authorities in initial and in-service training for foster carers and residential care staff. In addition, IROs should have information on where they can access advocacy services in order to ensure that disabled children and young people's views inform the care planning and review process.
- Information should also be made available by local authorities to parents/carers so that they can more fully understand the role of advocacy.

3. Monitoring the availability and accessibility of advocacy services and ensuring that learning from individual advocacy cases leads to improvements in services for all disabled children and young people

- Section 1.10 of the 2010 Care Planning, Placement and Case Review statutory guidance should be implemented in full and rigorously monitored by Ofsted to ensure that all children who have difficulty expressing their wishes and feelings are secured the opportunity to have the support of an advocate.
- Section 4.7 of the 2010 Independent Reviewing Officers Handbook should be implemented in full by local authorities and IROs and rigorously monitored to ensure that where specialist communication expertise is not available in an IRO team, children with communication support needs are supported by an independent advocate.
- The new Principal Child and Family Social Worker role, which local authorities are expected to have in place by July 2012, should act as a guarantor of high quality advocacy provision in each area, monitoring and reporting on services each year.
- Local authorities should compile and publish information about the operation of their complaints procedure (The Children Act 1989 Representations Procedure (England) Regulations 2006 Section 13(3)). As set out in section 5.6.2 of the guidance 'Getting the Best from Complaints', the complaints annual report should include information about learning and service improvement.
- Local authorities should incorporate in their commissioning arrangements a requirement for advocacy services to produce an annual report, to be published alongside the annual complaints report.

4. Ensuring access to advocacy for disabled children and young people placed away from home

- A right to advocacy for all disabled children placed away from home should be embodied in legislation.
- The guidance supporting implementation of the Visits to Children in Long-term Residential Care regulations, that came into force in April 2011, should make clear that all children with communication support needs in long term residential placements, regardless of whether they have looked after status, should have the support of an independent advocate skilled in methods of non verbal communication.

Further areas of research

The paucity of research on advocacy for disabled children and young people leaves many questions unanswered and there is a need for more funded research and evaluation in this area. The following presents a few

suggested ideas based on what appears to be the most pressing areas requiring evidence:

- Access to, and outcomes of advocacy for disabled children and young people placed away from home, and who may often be very isolated.
- Use of advocacy in the planning and reviewing process for looked after disabled children and young people, particularly in light of new duties placed on IROs to facilitate this.
- Research into the use and possible benefits of non-instructed advocacy.
- Research into the processes and outcomes of group advocacy.
- Evaluations of advocacy practice to further understand, improve and develop practice and to understand factors determining effectiveness.
- Research into unmet need for advocacy, and the extent and nature of the need for independent advocacy.
- Longitudinal research examining longer-term outcomes of advocacy.

It is important that any further research ensures that disabled children and young people's views are included – this research has shown the difficulties of doing this but has also demonstrated that it is important.

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'Michael [advocate] is brilliant. His is a big support for me. He's always been there for me, he listens to me, talks about it and then does it all for me, it's brilliant' Young person

Further information

This full report and the summary *Someone on our side: Advocacy services for disabled children and young people* by Anita Franklin and Abigail Knight is available at www.childrensociety.org.uk/research

To download a copy of *Advocacy services for children and young people: A guide for commissioners*, please visit www.childrensociety.org.uk/policy

For further information about The Children's Society's Research Unit, or to join our mailing list, please email research@childrensociety.org.uk