



Raised Voices

Do looked after children with communication impairments need an advocacy service?



A research report for
Save the Children
by Mark Priestley

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What this report is about

This report is about the choices and rights of children with communication impairments who spend time away from home. It is based on research with local parents of disabled children and asks the question: Do looked after children with communication impairments need an advocacy service?

Concerns from previous research

Previous research with disabled children, young people and their families has highlighted the value of independent advocacy. In particular, concerns have been raised about the rights of children with communication difficulties.

In response to these concerns, there have been numerous recommendations that advocacy provides an appropriate model for promoting the rights and participation of children who have complex communication impairments, many of whom are not adequately included in consultation and decision making about the services they receive. This is particularly true for children who spend time away from home (for example, in respite care units, residential schools, hospitals, foster families, or with shared carers).

‘Disabled children, even those with the most severe impairments, are able to communicate their feelings about their lives and the treatment which they receive’ (Watson *et al.* 2000).

There is a growing body of research detailing successful approaches to involving children with complex communication impairments in decision-making (for example, see Morris 1998, or Noyes 1999). However, there is considerable evidence that the wishes and feelings of such children are frequently overlooked in day-to-day service provision, and in planning support for children and their families.

As a consequence, there is considerable concern that this particular group of children are failing to benefit equally from recent advances in children’s rights (such as the Children Act 1989 and the United Nations Convention on the Rights of the Child).

Concerns from government

The use of children's advocacy as a response to this problem is supported by central government policy. For example, within the framework of *Quality Protects*:

'Advocacy ensures that children in care have trusted people to whom they can speak and who will speak on their behalf to local authorities and others'.

Similarly the Social Services Inspectorate report, *Services to Disabled Children and their Families* argues that:

'Social Services Departments should consider the introduction of an advocacy scheme for disabled children to enable them to express their wishes and feelings'.

Numerous local authorities have responded to these calls by introducing new advocacy schemes to support the participation of disabled children, particularly those who spend time away from home. (a list of examples is included on page 22).

Leeds was initially at the forefront of developing advocacy with disabled children, specifically with children with learning difficulties, through the Children's Project in the mid 1990s (funded by BBC Children in Need). However, there is now some concern that provision in Leeds may be lagging behind developments in other parts of the country.

Local concerns

Specific concerns, raised by parents, young people and service providers in Leeds, have resulted in questions being asked about the possibility of an advocacy service to support the rights and choices of children with communication impairments who are also 'looked after' (i.e. spend time away from home under the responsibility of the local authority).

This report provides an initial response to these concerns.

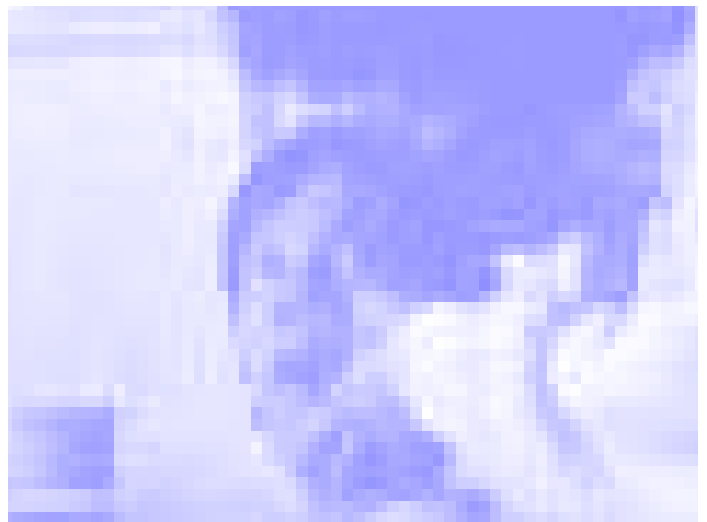
Background and limits to the research

This report arises from a short piece of research, commissioned by Save the Children Fund. The research and analysis were carried out by the Centre for Disability Studies at the University of Leeds, in partnership with the Leeds Children's Rights Service and staff from Leeds Social Services. The research itself was limited to 20 days work over a four-month period, and focussed on consultation with parents of looked after children with communication impairments.

Prior to commissioning the research, a questionnaire was sent to 415 parents of disabled children who used looked after services (or who were in the process of considering this option). The questionnaire was designed by the Development Officer for Disabled Children, in collaboration with the Children's Rights Office. The questionnaire was sent with a covering letter, explaining the background; it included questions about children's communication needs and the potential demand for a targeted advocacy service.

This report is based on the analysis of responses to that questionnaire, and on follow up interviews with a small sample of parents. In addition, it draws on previous research and on a national review of advocacy provision for disabled children within the framework of Quality Protects.

It is important to note that, due to constraints of time and resources, it was not possible to adequately involve looked after children with communication impairments in the preparation of this report. This is a significant issue and illustrates the very need that this report seeks to highlight. However, the report has been informed by more extensive research at the Centre for Disability Studies, involving disabled children and young people in Leeds and Bradford (which provided a great deal of in-depth information about children's views and choices, including the specific experience of looked after children with communication impairments).



Statistical analysis of questionnaires

The first part of this report deals with a statistical analysis the parental questionnaires. The purpose of this section is to identify something about the characteristics of the target population, and the potential demand for an advocacy service. Subsequent sections of the report provide more detail about particular issues, concerns and development options.

SUMMARY: Completed questionnaires were received from 56 parents or guardians, relating to 58 children, covering a range of ages. Approximately half were female and half male. Of these, at least 50 were identified as having some form of communication impairment. It was not possible to establish from the questionnaires alone which of these children currently use 'looked after' services, although it should be assumed that the large majority do.

Gender

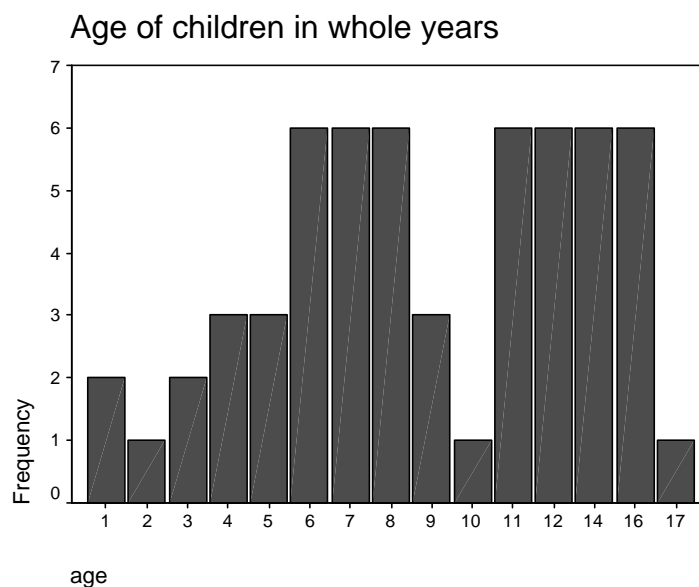
The questionnaires did not include any specific question on sex or gender. However, it was possible to positively identify the gender of all but two of those identified, using children's given names and parents' responses to other questions. This information suggested that the proportion of girls and boys identified was roughly equal, with a slight bias towards boys.

This would be consistent with the general population of disabled children and young people under 18, which includes a larger proportion of males than females (about 60% and 40% respectively). The gender balance amongst the general population of young people who are 'looked after' is also weighted in favour of young men. However, there is some evidence that the proportion of disabled girls and young women who are 'looked after' may be slightly higher than these figures suggest, and the questionnaire returns support this view.

	Frequency	Percent
Unknown	2	3.6
Female	27	46.6
Male	29	49.8
Total	58	100.00

Age

The questionnaire returns identified children across a wide age range. The youngest was less than two years old; the eldest was more than 17 years old. There was a fairly even spread of ages amongst those of compulsory school age, with fewer returns from younger children. This reflects the lower usage of looked after services by parents of very young children, and is supported by parental comments later in the report. The mean average age of those identified from the questionnaires was just over 9 years (although in practice this particular age group was under-represented in the questionnaires).



Race and ethnicity

No question on ethnicity was included in the questionnaire design. However, initial observation of family names suggests that the number of responses received from parents of South and East Asian origin was very low (possibly 3-4%). Existing research evidence suggests that children of South Asian families are less likely to use 'looked after' services than their peers of white, African, Caribbean, or mixed parentage, particularly as children reach their teenage years. It is worth noting that advocacy services may be particularly relevant to children with complex communication impairments from South Asian families who do not currently make much use of respite services. There may be considerable barriers of trust and cultural appropriateness to address in this respect.

Communication impairments

Although we anticipated a higher overall response rate (in the region of 100 questionnaires) we also anticipated that only a minority would identify their child as having communication impairments. We hoped to receive between 30-80 questionnaires relating to children who might be eligible for the targeted service.

Amongst children labelled as having ‘special needs’ we would estimate that around one third might be identified as having a communication impairment (although this proportion is likely to be higher for those using social services and overnight stays).

Despite the lower than expected return rate, the proportion of parents identifying children with communication impairments was very high indeed. Out of the 58 children identified in the questionnaires, more than 86% were considered by parents to have a communication impairment (in answer to Question 1).

Q1 ‘Does your child have a communication impairment?’

	Frequency	Percent	The number of children identified as having communication impairments was therefore well within our anticipated range (50) and the questionnaire seems to
No response	1	1.7	
No	7	12.1	
Yes	50	86.2	
Total	58	100.0	

have been well targeted at the most relevant group of parents - those who perceived their children to have communication impairments. Such parents were evidently highly motivated to respond (perhaps because they also perceived an opportunity for additional resources to help their child).

Use of ‘looked after’ services

The questionnaire did not include a question about children’s current use of ‘looked after’ services, and it is difficult to confirm exactly how many of the 50 (or 51) children with communication impairments would be considered as ‘looked after’. Parent responses to other questions provide some clues and it would be possible to establish the use of such services from the local authority if this was required. However, as the questionnaire was sent only to parents of looked after children (and those considering that option) we might assume the views expressed to reflect the needs of that particular population.

Initial analysis of need

This section of the report provides information about the likely need and constituency for a specific advocacy service with looked after children who have communication impairments. The data is drawn from the parental questionnaires and is subject to the limitations of that process (as described).

SUMMARY: An initial analysis of the questionnaires suggests that there is a demand for advocacy services targeted at this group of children. However, parental uncertainty about the role of advocacy makes it difficult to predict clearly the initial uptake. Experience of similar schemes suggests that development work on the role of advocacy would increase demand over time.

Initial interest in an advocacy service

The questionnaire responses suggest that the demand for a specialist advocacy service may be hard to predict, without more information and communication with parents and children. Significantly, only a minority of parents indicated that an advocacy service would definitely help their child (a larger minority indicated that it would not). However, many parents were unsure or did not answer the question. A few did not want a service because their children did not have communication impairments.

Q5: 'Do you think your child would benefit from an advocate to help them communicate how they feel about their needs and their placement?'

	Frequency	Percent
No	24	41.4
Unsure	14	24.1
Yes	20	34.5
Total	58	100.0

These initial figures are also complicated by the kind of comments parents wrote on the questionnaires. These are discussed in more detail later in the report.

Unless otherwise stated, the following analysis is based on the 51 children who we believe were identified as having communication impairments (rather than the 58 children identified overall).

Looking only at these children, the immediate positive interest in an advocacy service is still uncertain. Exactly equal numbers of parents answered ‘yes’ and ‘no’ in identifying a potential benefit from such a service for their child (37.3%). Again, the number of parents who were uncertain about the benefits remained high (at 25.5%).

Numbers of children identified as having a communication impairment and potentially benefiting from an advocacy service

	Frequency	Percent
No	19	37.3
Unsure	13	25.5
Yes	19	37.3
Total	51	100.0

If these figures are indicative of those parents who did not return questionnaires, then we might expect there to be around 90 children with communication impairments whose parents might

see the immediate benefit of an advocacy service.

Such an estimate must be treated with considerable caution at this stage – and the actual number might well be lower, assuming that those who recognised a benefit may have been more likely to return the questionnaire in the first place.

It is important also to focus on those parents who were unsure about the potential benefits of advocacy. This needs more investigation. The main reasons given relate to concerns that:

- (a) their child would be too young to benefit at the present time, or
- (b) they doubted that an advocate could easily learn to understand and convey their child’s communication to a third person (see later).

It is worth noting that if these concerns were to be allayed then the proportion of parents expressing an interest in the service would rise dramatically (potentially as high as 63.8%, or as many as 150 children in the local authority area). Again, such an estimate should be treated with considerable caution.

At this initial stage, we might realistically expect the initial positive interest in an advocacy scheme to be in the range of 20-50 children with communication impairments, but with the potential to rise upwards of 100 children as parents learn more about the role and support offered.

Children's communication needs

This section of the report uses data from the questionnaires and subsequent interviews with parents, as well as previous research with children who have communication impairments.

SUMMARY: The large majority of children identified do not generally use speech, text or formal sign systems to communicate with those around them. Very few children in this group use technological solutions for their everyday communication. Most rely on informal communication (such as body movement, vocalisation, facial expression, etc.). Communication is a two-way process and requires others to learn how a child expresses her/himself. Parents and carers often hold a wealth of detailed information about their children's communication preferences and skills.

Communication style and repertoire

The questionnaire returns provided very detailed information about children's communication needs and preferences. This information supports the findings of other relevant research, indicating that children's preferences and skills are highly individual, and that the needs of many disabled children are not adequately met by standard technical responses to communication (e.g. speech therapy, sign language, technical aids). The following selection of parental responses gives a flavour of children's preferred communication style and repertoire at home.

- *[my daughter] has different moans and cries to let me know what she needs. Some body language is used.*
- *Facial expression, body language (leaping for joy, hairpulling, running away, for example). Waking very early in the morning because of anxiety. Unwilling to get out of car. Non compliance. Tantrum etc.*
- *[our son]'s ability to make himself understood is very limited. We have to routinely feed, change his nappy and give him drinks as he is unable to indicate any of these needs to us.*
- *Facial expressions, behaviour and gesture. Makaton - uses one gesture – 'please'.*
- *[my son] communicates by changing behaviours and gestures. He can usually reach a cup and carry it around until it is noticed and he obviously wants a drink. If unhappy or bored he throws himself about (and anything in his way) and makes loud shouting noises.*

Techniques and technology

The questionnaire included a number of questions about children's use of specific communication aids, suggesting an assumption that this might be a significant factor in facilitating children's participation and involvement. However, the responses indicated that very few children in this group use formal communication aids. Of the 51 children identified as having communication impairments, more than 70% did not use a communication aid.

Question 3: Does your child use a communication aid?

	Frequency	Percent
?	3	5.9
No	37	72.5
Yes	11	21.6
Total	51	100.0

Subsequent discussions with a small selection of parents seemed to confirm these findings, suggesting that where communication aids are available and useful to this

group of children, they are predominantly of a low-tech and ad hoc nature (such as home made picture boards and objects of reference).

Of the 11 children who were said to use such an aid, only four used technological solutions to communicate directly with others (plus one who identified a hearing aid in this category and one who identified British Sign Language).

The following table summarises these responses.

Question 3a: Please describe your child's communication aid:

- 1 *picture boards, Makaton*
- 2 *hearing aid*
- 3 *pictures of reference (just beginning)*
- 4 *Chameleon Alphatalker*
- 5 *British Sign Language*
- 6 *unspecified*
- 7 *objects and pictures of reference*
- 8 *BSL, communication book, boards, Chameleon*
- 9 *Alphatalker*
- 10 *a few objects of reference*
- 11 *picture board*

Communicating away from home

Although the majority of children (63%) used similar methods of communication at school, a significant minority (32%) did not. Generally, this did not seem to create a disadvantage for children when they were at school. Indeed, for a few children it meant that they had access to specific communication techniques and aids at school that were not available at home. The following table shows the options available to children who had different communication choices at school and at home.

Additional comments provided in response to Question 2 (Does your child use a different communication method at school?)

- *Very little sign language, points with his hands to what he requires.*
- *A special computer program enables him to translate speech into 'writing'.*
- *unspecified*
- *Makaton*
- *He has some Makaton signs, more at nursery than at home.*
- *Beginning to use picture cards for choices.*
- *When at school he uses a Cameleon - Alphatalker. He does this using a head switch.*
- *School communicate with symbols and some sign language. [My child] has unfortunately not taken to signing.*
- *Signing (I do not understand sign). They use British Sign Language at school.*
- *unspecified*
- *Sign language, communication aids (Pecs, Spell).*
- *Sign language adapted for the blind*
- *At school the teachers use very basic Makaton signs i.e. please, thankyou and drink.*
- *Only to illustrate appropriate activity eg. Signing/PE/Playtime/hometime (picture board)*
- *Speech mediated by support worker*
- *Sign language and gestures and facial expressions*

For the small number of children who did rely on technological solutions, there were some significant issues. Of 11 children, 7 were identified as not always having their communication with them, and only one positively identified that the aid was available when the child stayed away from home with foster carers or in a children's unit.

Clearly this is a significant issue for this minority of children. However, it is important to note that the majority (who do not use technical communication aids) will face similar barriers to participation away from home, unless there is someone present who has learned their individual communication repertoire.

Taken as a whole, the analysis above suggests that the target population of looked after children with communication impairments have a very wide repertoire of communication style and preference. Most of them face barriers to participation and involvement that could not easily be met by the provision of 'off the shelf' technical or technological solutions.

Intervention to promote the involvement of children within this group would require the development of individual relationships with children and their carers over time, and detailed knowledge about individual circumstances.



Parental concerns

This section of the report draws on the questionnaires and interviews to highlight the kind of concerns raised by parents about their children's experience of using services and being away from home. Since parents (quite rightly) are less likely than professionals to articulate their concerns within the boundaries of individual services, they often talked about issues beyond their experience of looked after services. However, many of these examples add weight to the arguments made within that limited service context.

SUMMARY: Parents found it difficult to convey their children's needs and preferences to a variety of people in different service contexts. They often found it difficult to advocate on their child's behalf for resources and support. Parents held concerns about respect for their children's choices and rights while they were away from home.

Dealing with complex services

The children identified in this research are often referred to as having 'complex' needs. Although no question on additional impairments was included in the parental questionnaire, it is clear that a large proportion of children who have 'communication difficulties', and who spend time away from home, also have additional physical, sensory, or cognitive impairments and/or health conditions that require ongoing intervention.

It is perhaps wrong to define such children as having particularly 'complex' needs (since they also have the same needs and rights as other children). Consequently, it might be more accurate to note that their ordinary needs are met through a very complex array of services.

Many of the children concerned draw on support from multiple agencies and professions, sometimes with competing interests and priorities. Unsurprisingly then, parents articulated concerns about dealing with multiple and complex services – as the following extracts from parental interviews illustrate:

- *It's hard, you don't know which department to go to, to push.*
- *Sometimes you go to this department and they tell you to wait or go see other department. It's very complicated.*
- *People come into your home...you try desperately to hang on to some privacy, some dignity. Many people who I wouldn't choose to have in my home, and I'm expected to build up a relationship with them.*
- *Over the years there are loads and loads of people becoming involved, some of them are much more helpful than others...*
- *We must expect these people to move on, go on courses, get married, go on maternity leave. They're never going to be with us all the time and that break in continuity is difficult to deal with when you've built up a relationship.*

Moreover, the exposure of children to intervention from a variety of different people, for a variety of different reasons, in a variety of settings, compounds the sort of communication barriers that those children face in asserting their choices and rights.

This raises questions of consistency, as well as vulnerability to lack of involvement and to potential abuse. For this reason, action to assert the rights of children with 'complex' communication needs is particularly important. **Parents were supportive of advocacy that might bring with it some consistency of individual relationship.**

Access to resources

Some parents held particular concerns about their child's access to specific services and resources. In particular, parents sometimes felt very frustrated by bureaucratic delays and obstacles to obtaining support for their child when they needed it. For example:

- *The worst part of it is equipment. Getting equipment is horrendous... The length of time you have to wait is awful, it really is.*
- *That respite care, that's just a farce quite honestly.*
- *Social services said, once you get a respite carer, give us a ring and we'll arrange for someone to go with us... They'd had the papers for six months and now I need it they still haven't sorted it.*
- *Everything takes so long. It's a nightmare.*
- *The only people who are really and truly on [my child]'s side is me, my family and my friends.*
- *If you've got a disabled child, everything you need you've got to fight for – unless you're willing to pay for it.*
- *People say 'You're the expert' and I know I am, but I'd really like somebody else, you know, to wave the placard on [my child]'s behalf.*
- *Even me as an articulate person, I find it difficult to get the information*

that I want to get across, and how much more difficult is it for [my child]?

Such examples are by no means unique to the situation of looked after children with communication impairments. However, in combination with the child's need for communication and access to complex services, this effect seemed to be compounded. **Parents were therefore supportive of advocacy arrangements that might provide a stronger voice for their child in gaining access to resources.**

Getting the message across

Parents expressed specific concerns about the difficulty of explaining their children's communication style, vocabulary and preferences to service providers (particularly when leaving them in the care of respite or residential service providers). Some parents had put a great deal of effort into developing their own strategies to deal with this problem.

- *He's a very expressive child but it's hard to get that over to people.*
- *I could spend a whole day telling you how [my child] communicates.*
- *[My child] does have very definite preferences and is able to make very definite choices, has very advanced skills. That it is quite difficult for other people to begin to appreciate. Once they get to know her then they realise, and begin to follow what she's saying.*
- *She went for the first time last week...and along with everything else she took her booklet, which includes some of the things I think are important. And it's come back and I don't know if anyone's even read it.*
- *I've started to do a dictionary for her that has like just ten points in it, of her communicating with me...and how I communicate with her. An advocate could do something like that. Every child could have their own little dictionary, like some children have their communication boards... An advocate could work with me [on that]...And the next step could be that other people had that dictionary.*
- *They get a run-down, you know, like a form that you have to fill in, but to be honest most of it's just common sense. Once you've had him a few times you sort of get used to his ways. It's just a case of spending time with him.*

Trust in service providers

Parental responses also indicated a natural desire to safeguard children's welfare at the hands of service providers. Some found it particularly hard to 'let go' of their children to respite services because of their concerns about the capability, or attitudes, of staff .

For example:

- *A lot of people think that all nurses and social workers are naturally kind and caring people but...sadly...there are some people out there who don't particularly care and are in the job for the wrong reasons... which is why I think advocacy is such an important thing for children like [my daughter], who people from the outside would say doesn't communicate at all, because she doesn't speak.*
- *I believe they care about [my child] but in a professional way. We cannot expect professional people who are getting paid to do a job to love my [child].*
- *I'm big enough and ugly enough to fight for my rights...[my child doesn't have that].*
- *When I send her out from my care then she cannot come back and tell me what's happened. She has got no way, because she would not understand to cry before she went to these places...and her crying could mean a thousand and one things...We don't get to many respite care places for that very reason, because I am extremely worried about what happens when she is there.*
- *She's so much at the mercy of anyone who wants to do anything to her, and also to come back to me and tell me anything to keep me happy.*
- *I wish she could talk, I wish she could say 'Don't ever do that again to me', 'She's really rough with me' or, 'She ignored me'.*
- *There's a lot of emotional stuff when you're leaving [your child] there. It's difficult then. Until you leave they can't develop their own ways of relating to [your child]...It would be easier if you knew there was someone else who was beginning to take over some of that.*

Clearly, such concerns need to be taken very seriously (not only from the perspective of parental concern but also from the perspective of children's rights). **Parents were generally supportive of any advocacy initiative that might allay their concerns about respect for children's preferences and rights while away from home.**

Recognition of competing interests

Advocacy and children's rights work is fundamentally about the rights of the child, which may sometimes be in conflict with the interests of the adults who have responsibility for them. However, parents and carers will usually be the main point of initial contact, especially in work with children who have communication impairments.

Parents often know more about their child's communication skills and routines than anyone else, and parental co-operation and involvement will be particularly important in ensuring the success of advocacy for this group of children. Moreover, it is parents and guardians who are most likely to decide whether

their child would benefit from an independent advocacy service.

Despite the obvious concerns and worries outlined earlier in this section, parents were also aware that they might not always be the best guardians of their children's interests while away from home, and that children sometimes needed to assert their own choices too (especially as they grew older). For example:

- *You've always got to realise that there may be certain things that we do as carers that [my child] wouldn't necessarily agree with.*
- *It's not for me, it's for [my child]. The advocate is for [my child]. Unless you make it a family advocate, in which case that's the key worker.*
- *I have to step away. If they got to know [my child] and her communication...they might have to come to me and say 'It's you, she needs to go away from you. She's happy, she's communicating well with her respite carers'.*
- *There's a danger that that one person, if they're not trained properly in the idea of advocacy will become my advocate.*

Consequently, there was some considerable support from parents for a model of advocacy based on the rights of the child (rather than a model based on existing family support services such as social work or the key worker scheme).



Advocacy and children's rights

The evidence reviewed from existing research, from parental questionnaires and interviews suggests that there is considerable scope for rights based advocacy work with looked after children who have communication impairments. This section of the report examines what such an advocacy service might look like.

The role of the advocate

The data from questionnaires and interviews provided a useful insight into some of the reasons why parents thought that their children might benefit, or not benefit, from an advocate (although many did not add specific comments or concerns). An initial analysis of this data suggests a number of themes that would need to be addressed in the development of a successful service. In particular, the role of advocacy would need to be clearly explained to parents.

The data suggests that many parents view an advocate's role as dependent upon direct and effective communication skills with their child. This may suggest an underlying assumption that an advocate would function only as 'interpreter' for children – based on technical knowledge of communication skills and aids. Many do not believe that someone outside the family could ever do this as well as they do. **It would therefore be important for any advocacy service to demonstrate a respect for the communication skills of those close to the child, while also respecting the child's needs for opportunities to communicate without that person present.**

Some parents feel that very young children would be ineligible for such a service, or that their child would not need an advocate in settings where they are well known and can make themselves understood. Again, this may suggest a slight misunderstanding about the role of an advocate

The following extracts from parental questionnaires illustrate these reservations and suggest that the role of children's advocacy would need to be more clearly explained:

- *Not sure about this as [my child] has not had family/respite care before, but I think he would be able to communicate his needs.*
- *At the moment he is either at home or at school where he is well known and I think understood.*

- *I don't think he could communicate his feelings but someone more skilled than me may get results, and I think he should have the opportunity.*
- *Not applicable to my son at the moment.*
- *If that advocate could get to know her communication techniques and interpret her behaviour*
- *But how would she communicate with the advocate - I've had 11 years experience and still find it difficult.*
- *I think I'm the only one that understands my daughter.*
- *The person would really need to be able to relate or understand his ways/needs*
- *Too young, but maybe in the future*
- *Not at this stage as too young and too many other people involved at this stage. When he gets older YES. It would be a good idea.*
- *He would make it very obvious if he didn't like his placement or what they were providing.*
- *The people who are with her at home, school and placement know her very well and can understand her ways of communicating*

What kind of person?

Parents expressed views about the kind of person who might be most appropriate to fulfil the role of children's advocate and about how this might work in practice.

- *The role of someone like that would be great. I can see how that would be very helpful.*
- *You'd have to know my child really well to know how [my child] communicates.*
- *I have found that people tend to be a little bit protective of their own organisation. They [the advocate] would need that independence.*
- *It has to be somebody who's got the human element.*
- *They should have experience of children with communication problems, people who've had experience, people who've had children with disabilities.*
- *They may have extended families who can help.*
- *A team of people, maybe with advisers, maybe part timers.*
- *There will be some families who don't want to be involved in this.*

Models of advocacy

- *A lot of people won't know what advocacy means.*
- *The self-advocacy movement should be encouraged but we musn't forget the children like [my child]. Because they've got that same right to be heard, but it's just in a different way.*
- *There's a danger of introducing more and more people into a service, and parents say 'Is it a key worker or an advocate? Is it for me or for them?' And you think, 'Oh no, forget it'.*

Some Examples of Advocacy and Rights Work with Disabled Children

Locally, Leeds have demonstrated some commitment to developing services to disabled children, including welcome initiatives, such as:

- *Specialist Children's Rights Officer for disabled children*
- *parents forum*
- *new consultation forms for disabled children using short-breaks*
- *monitoring child protection processes for disabled children*

In addition, the social services department identified plans to involve an additional Children's Rights Officer for disabled children and children in foster care, and to identify 'a range of methods for eliciting the views of non-verbal and severely disabled children, to enable them to make an active contribution to their reviewing and planning processes'. Clearly, there is considerable scope to address these needs through independent advocacy arrangements.

The following examples from other authorities are drawn from a secondary analysis of data collected by the Council for Disabled Children (from Local Authority Management Action Plans in the first year of the Quality Protects initiative). Additional examples and updates are included from our own research, and from communication with a number of existing advocacy schemes.

The emphasis here is to identify concern about, and support for, children with communication impairments (a fuller list is available on the project web site).

Barking

A befriending scheme for parents of disabled children. Plans for a more systematic consultation with disabled children and a more pro-active approach to overcoming communication difficulties.

Barnsley

Independent Visitor Scheme to disabled children placed 'long-term' in Children's Resource Centres. Communication issues have been identified as significant for those with no verbal communication, or for whom English is a second language.

Bolton

Buying in sessional advocates to provide greater choice for disabled children (especially non verbal children and those whose first language is not English).

Bradford

Appointed a half time staff member to develop procedures and practice to enable children, and particularly non-verbal children, to contribute to, and influence the planning and review of their care.

Camden

Identified a need to communicate with disabled children and their families, including an advocacy scheme for non-verbal children.

Croydon

Working with the recently established Children's Rights Officer to ensure that disabled children/young people have a voice in service planning and delivery. Identified a need to develop means and capacity to communicate with children who have specific communication difficulties.

Dorset

Jigsaw Advocacy provide an independent advocacy service for children over the age of 10 who are looked after. They are developing a more specific service for disabled children.

Hackney

A part time advocate and visitor for disabled children living away from home will promote advocacy and independent visiting to children looked after who have learning, communication and specialist needs.

Hammersmith and Fulham

Formed a partnership with Save the Children Fund to develop consultation/communication strategies with disabled children and young people.

Havering

Children With Disabilities Team have identified ways to improve communication with children with language/communication difficulties, with implications for staff training.

Hounslow

Communications project for disabled children (including a communication profile for each child, aimed at promoting involvement in the review process). Aiming to provide advocacy for children with 'profound' impairments, including those who are non-verbal.

Knowsley

Half-time children's rights worker post with disabled children (jointly managed with Barnardos). Special project to develop advocacy services for disabled children.

Lambeth

Particular attention to the information and communication needs of children looked after, including disabled children and those for whom English is not their first language. Jigsaw Advocacy work with disabled children, young people and adults to develop opportunities for equal participation.

Manchester

Manchester Coalition of Disabled People operate an advocacy scheme for disabled children living away from home in residential schools.

North East Lincolnshire

Task group on Listening to Children examined the potential for an advocacy service for children and young people, including the particular needs of disabled children.

North Yorkshire

Children's rights and advocacy scheme run by the Children's Society (for health, education and social services) with children and young people who are placed away from home, including a large number of disabled children.

Nottingham City

Post of Children's Participation Officer, located in the voluntary sector, to develop the ways in which children and young people can have a voice in planning and delivering services, with a particular focus on working with disabled children.

Sutton

Advocacy Service for looked after children includes disabled children who use regular over-night respite care.

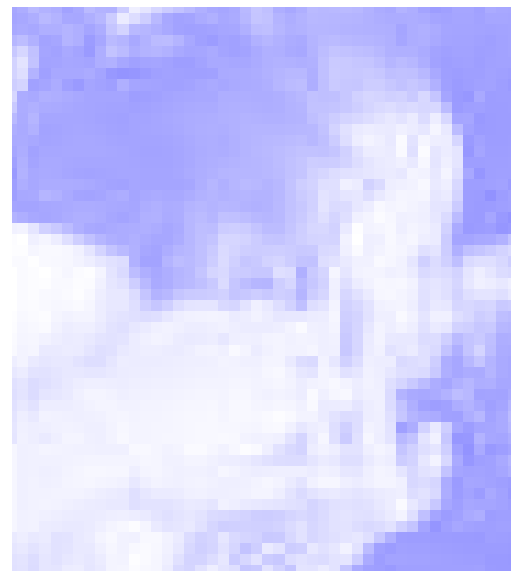
Tower Hamlets

Cross Borough feasibility study with the Children's Society for the establishment of an advocacy scheme for disabled children, to promote the rights and participation of these children, including those with communication difficulties, within the care planning and review process.

Worcester

Voice for the Child in Care have a small group of independent visitors working within a residential school for children and young people with learning difficulties, providing advocacy when requested by young people.

As these examples show, there is considerable and widespread interest in models of independent advocacy to support the choices, rights and participation of looked after children with communication impairments.



Do looked after children with communication impairments need an advocacy service in Leeds?

This report is about the choices and rights of children with communication impairments who spend time away from home. It is based on research with local parents of disabled children.

Previous research has raised concerns about the rights of children with communication difficulties, and has highlighted the value of independent advocacy in supporting them.

The use of children's advocacy as a response to this problem is strongly supported (but not funded) by central government policy, through the Quality Protects programme and the Social Services Inspectorate.

The concerns of local parents, young people and staff suggest that an advocacy service would help to support the rights of 'looked after' children with communication impairments.

Parents' views suggest that there is demand for such a service, and that it might ultimately be used to upwards of 100 children, as parents began to understand its role more clearly.

Most children with communication impairments do not use speech or formal sign systems, and rely on informal communication (such as body movement, vocalisation, facial expression, etc.). Parents and carers hold a wealth of detailed information about their children's communication preferences and skills.

For the small number of children who rely on communication aids, very few have that aid available away from home (when they are with respite carers or at a children's unit).

Parents favoured an independent children's advocate: to help convey their children's needs and preferences in different service contexts, and to allay concerns about respect for their children's choices and rights while away from home.

Numerous other authorities are already piloting innovative independent advocacy schemes with looked after children who have communication impairments (often in partnership with voluntary sector disability groups or children's organisations).

Points for action and service development

The recommendation of this research is that looked after children with communication impairments would benefit from additional advocacy support in Leeds, to strengthen and uphold their choices and rights (especially while away from home).

1. The local authority should consider the establishment of an independent advocacy service for this group of children, within the framework of Quality Protects.
2. Independent advocacy should be for the child (rather than duplicating existing family support). Consequently, the most appropriate model would be one based on disability rights and children's rights.
3. Intervention to promote the rights of children within this group would require the development of individual relationships with children over time.
4. Parents and carers should be encouraged to play an active role in providing knowledge about communication. Advocacy should find innovative ways of doing this, focussed on the child's preferences.
5. Children who do not speak and who use complex services may be more vulnerable to abuse of their rights. Advocacy should monitor and confront this concern.
6. Advocacy should address issues of trust and cultural appropriateness in looked after services for children of minority ethnic families.
7. Children described as having 'complex needs' have the same needs and rights as other children, but their needs are often met through very complex services. Advocacy should ensure that children's rights and choices are respected across services.
8. In the first instance, the above recommendations might be achieved by the appointment of a local advocacy worker (possibly on a part-time basis) with a view to potential future expansion of this role.
9. Such an appointment should be independent of service purchasers and providers, and might be best located within an independent organisation committed to disability rights and children's rights.
10. More research should be carried out with disabled children themselves, to explore their experiences and views.

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Do looked after children with communication impairments need an advocacy service?

This report is about the choices and rights of children with communication impairments who spend time away from home, based on research with local parents of disabled children in Leeds.

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This report is available online at:

www.leeds.ac.uk/disability-studies/projects/scfadvocacy.htm