

Someone on our side: Advocacy for disabled children and young people

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Key messages

- Advocacy for disabled children and young people is important and can lead to considerable improvements, both in their and their families' lives. The advocacy process itself can bring significant benefits to the individual child, through improved confidence, self-esteem and independence.
- Despite 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.
- 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 increased emphasis in policy guidance. Only small numbers of disabled children and young people receive advocacy services.
- There is a clear need for more awareness of advocacy and its potential contribution to empowering disabled children and young people, and to improving the quality of local authority services.
- 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.
- Advocacy is, in the main, commissioned to address a single issue. However, young people often raise multiple issues once their relationship with the advocate develops, because advocacy can reveal many hidden problems. This underlines the need for more sustained advocacy involvement, wider access to advocacy and a more participatory, listening culture to be developed among professionals working with disabled children and young people.
- Not all issues requiring advocacy are resolved for the young people, despite there being a very real need for change. In a number of cases, achieving an acceptable outcome takes a very long time and requires a difficult battle.

This research focused on the under-explored area of advocacy for disabled children and young people across England.

"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



Aims

This study set out to explore the nature, processes and outcomes of advocacy services for disabled children and young people in England and to identify the issues that impact upon this service.

Background

Advocacy has been defined as a way of facilitating a child or young person's participation in decision-making. It is commonly described as enabling someone to have a 'voice'. Advocates act on the permission and instructions of children and young people, and express the child's views even if the advocate does not think that these views are in the child's best interests. This unique role makes advocates entirely different from other professionals in a child's life. For disabled children and young people who do not use speech to communicate, the provision of advocacy is a particularly important mechanism to enable them to express their views.

Although there are various kinds of advocacy, this study concentrated on advocacy that is provided on a one-to-one basis by adult independent advocates. Advocates working with children with complex communication needs, who are not able to directly tell them what they think or feel, undertake non-instructed advocacy and this was also examined in this study.

Non-instructed advocacy involves an advocate observing a child in various settings, and talking to people who know the child, to form a view about a child's likes and dislikes. The advocate then makes representations based on the evidence gathered.

Research evidence suggests that there is limited involvement of disabled children and young people in decision-making concerning their careⁱ. This is despite the fact that children have a right to be involved and the

introduction of a range of legislation and policy guidance requiring their involvementⁱⁱ. It was estimated in 2007 that only 877 disabled children and young people received advocacy services over a nine-month period in Englandⁱⁱⁱ. Yet disabled young people repeatedly report feeling powerless, not listened to and not involved in decisions being made about them.

In addition, these are children who are more likely to be looked after and more vulnerable to abuse and neglect. The need for an independent advocate is particularly acute for children with speech, language and communication needs, who are often dependent on parents/carers or a few other people who can understand them and help facilitate their communication. Evidence has shown that advocates provide a key safeguarding role.

The limited evidence available suggests that disabled children and young people face many barriers to accessing advocacy, advocates face challenges in supporting these young people, yet advocacy can bring many benefits to disabled children and their families.

Methods

The research consisted of:

- A survey of 35 advocacy services in England
- Interviews with a total of 20 disabled young people, advocates, parents/carers and other professionals.

Findings

Availability of advocacy services

This research supports early findings that there is limited access to advocacy for this group of children – it is estimated that during the period August 2008 – January 2009, only 529 referrals of disabled children were accepted across 30 advocacy services and nearly a third of services only had one advocate available to work with this group.

The numbers of children receiving non-instructed advocacy were very small. Advocates were advocating for disabled children across a multitude of issues and within many complex decision-making processes. These included reviews and safeguarding meetings, planning for transition to adult services, and moving from mainstream to special school.

Access to information about advocacy

Advocacy was reported to be little understood and none of the young people interviewed had heard of advocacy, before being offered the service. Only half of advocacy services were providing accessible information for disabled children. There was also a reported need for improved information about advocacy for parents/carers and other professionals.

Methods to facilitate participation

Advocates were using many different and creative methods to facilitate the advocacy process. One example involved Jonathan, who received non-instructed advocacy. The advocate was tasked with establishing Jonathan's views on contact with his family. Jonathan is looked-after and has complex communication needs. Through using photographs of his friends, teachers, parents and others and watching his reactions, the advocate was able to report to social workers that he consistently smiled when shown photos of his family.

"I can talk to Neil. He's been there for me and helping me. He is a good listener and works hard."

A young person describing their advocate.

Relationship between advocate and young person

Throughout the research, the independence and the distinctiveness of an advocate's role were identified by everyone to be of crucial importance. Advocacy empowered the young people.

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

Disabled young people spoke highly of their advocate. One stated that all disabled young people should be told about advocacy and should get an advocate when ***'they [other professionals] are not listening and they'll all making excuses.'*** Advocacy can be time-consuming and often necessitates weeks or months of regular visits to develop a relationship and understanding between child and advocate. However, the young people did not want advocates to work with them on a single issue, preferring longer-term engagement with their advocate. They spoke of the trust and respect that had developed between them.



Outcomes of advocacy

Research findings highlight how advocacy was often commissioned when cases are extremely complex or reach serious levels of concern. In addition, once assigned a case, many more issues emerged and cases lasted for long periods of time. This, coupled with the fact that issues did not get resolved, meant that the need for advocacy continued. On numerous occasions advocates reported that children's rights continued to be denied (eg the right to education or health care) and promises made by service providers were broken.

Despite these difficulties, advocacy was reported to bring many benefits to disabled children and young people, their families and services in general. The support provided by

advocates was regarded by young people as a positive experience, even if they did not achieve their desired outcomes. One young man reported that having an advocate had made him feel confident and happy. ***'Really, really confident and happy. Absolutely confident and happy. I feel confident talking to Matthew'.***

Other reported process outcomes for disabled young people included: increased trust in adults, more informed about, and increased understanding of, decisions being made about them, increased personal independence, and improved communication. In addition, it was reported that advocacy led to changes in professionals' attitudes and approach towards the child; more open and honest

relationships, improved understanding of how they communicated and higher expectations about the child's capabilities.

Advocacy, including non-instructed advocacy, led to many changes in services for disabled children and their families, and subsequent improvements in their lives. Examples included more appropriate placements (eg foster care which better suited a child's needs), improved stability at home and school, reduction in pain and feeling safe and protected. However, it appeared that the lessons learnt from, and outcomes achieved through, individual cases of advocacy were not replicated to improve services generally for the wider population of disabled children and young people.

Enabling factors for the provision of advocacy

- 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 which is realistic and ensures that advocates have the necessary time to spend with the child, in order to facilitate them expressing their views
- Local authorities identifying the children and young people who are eligible for advocacy, integrating the arrangements for their commissioning services and providing one point of contact and referral route.

Challenges facing advocacy/advocates for disabled children and young people

- Levels of awareness of advocacy appear to remain low among professionals, parents/carers and disabled children and young people
- Continued professional attitudes that disabled children and young people cannot express their views 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 a few professionals
- A lack of resources and limited funding
- Lack of training opportunities and skills development.

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 help 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 can contact the advocacy service through the means appropriate to them.
- 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 get 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.

Areas for further research

The lack 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 suggestions:

- Access to, and outcomes of, advocacy for disabled children and young people placed away from home, 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 explore how to improve and develop it, and to understand the factors determining its 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.



References

- i. Franklin, A. and Sloper, P. (2007) Participation of disabled children and young people in decision-making relating to social care. Social Policy Research Unit, University of York. www.york.ac.uk/spru
- ii. Advocacy services for children and young people: A guide for commissioners. The Children's Society, (2011) provides an overview of the range of legislation governing advocacy services. www.childrenssociety.org.uk
- iii. Mitchell, F. (2007) When will we be heard? Advocacy provision for disabled children and young people. The Children's Society. London. www.childrenssociety.org.uk/research

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

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

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