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Advocacy for disabled children and young people: benefits and dilemmas

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ABSTRACT

Recent policy has emphasized the need for advocacy services for children and young people, developments that have gone hand-in-hand with greater levels of participation of young people in decision-making. Advocacy for disabled young people is especially important, as they are a particular vulnerable group and have, traditionally, been even more excluded from decisions about matters affecting their lives. This paper reports the findings, as they relate to disabled young people, from a study that investigated the role of advocacy for looked-after children and children in need. The paper highlights some of the benefits of advocacy for disabled children, the dilemmas facing advocates between advocating and acting in someone's 'best interests', identifying the client and the boundaries between advocacy and social work. It argues that time given to establish a close relationship with a disabled child or young person is crucial if advocacy is to be effective and participation in decisions affecting their lives a reality.

INTRODUCTION

The last couple of decades have seen a significant growth in advocacy services for children and young people, particularly for children who are looked after or are disabled (Oliver 2003, 2006; Dalrymple 2005). There are now over a hundred advocacy services in England being run by both local authorities and voluntary organizations (Oliver *et al.* 2006). Several policy developments, both in the UK and internationally, have played a major contribution to this growth. Children's rights in the UK, for example, have been increasingly recognized by the ratification by the UK government in 1991 of the United Nations (UN) Convention on the Rights of the Child and by the Human Rights Act 1998. The Children Act 1989 encouraged the participation of children in decision-making about their everyday lives in that it emphasized the need to 'ascertain the child's wishes and feelings' in all matters affecting him or her. The Quality Protects initiative (Department of Health 1998), which aimed to improve the outcomes for and participation of looked-after children, also contributed to the growth of advocacy services. More recently, the 2002 Adoption and Children Act has meant that local authorities are now obliged to provide advocacy services for children who want to make a complaint under the Children Act.

This paper discusses the role of advocacy for disabled children and young people, including young people with severe learning disabilities and/or communication impairments. It draws on findings from a study carried out by the Thomas Coram Research Unit, Institute of Education, University of London, between 2003 and 2004 and funded by the Department for Education and Skills in support of the Quality Protects research initiative (Oliver *et al.* 2006). Although the study examined the role of advocacy for looked-after children and children in need, this paper refers only to those findings of the study that relate to disabled young people.

The paper highlights a number of issues relating to the role of advocacy for disabled children and young people. These include some disabled young people's experiences of advocacy. Also included are some of the tensions and dilemmas practising advocacy for disabled children poses, such as the blurring of boundaries between advocacy and acting in someone's 'best

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interests' and identifying who is the client (disabled child or parent). The barriers to participation of disabled young people about decisions affecting their lives and how these impact on the practice of advocacy are explored. Finally, the relationship between the role of advocacy and social work is examined, illustrated by examples from the study. We will argue that despite the numerous challenges facing advocates working with disabled young people, when time is committed to the establishment of a close relationship between an advocate and a disabled young person, the practice of advocacy can bring many far-reaching benefits to this group.

ADVOCACY AND DISABLED CHILDREN

Advocacy has been defined as enabling someone to have a 'voice' (Dalrymple & Hough 1995; Dalrymple 2005). The emphasis on having one's 'voice' heard is clearly problematic for children and young people who are severely learning disabled and cannot effectively – through speech anyway – express their feelings and wishes. It is important that one interprets 'voice' therefore as a symbolic concept, which can be related to all children and young people using an advocacy service, i.e. that their views need to be put forward regardless of their communication methods (Oliver 2003). As the Children Act 1989: Guidance and Regulations points out:

> 'even children with severe learning disabilities or very limited expressive language can communicate preference if they are asked in the right way by people who understand their needs and have the relevant skills to listen' (Department of Health 1991, p. 14).

In addition, the National Framework for the Provision of Children's Advocacy Services (Department of Health 2002) states that no young person should be prevented from accessing services because of their communication difficulties.

Traditionally, children have been excluded from participating in decisions affecting their everyday lives, and this is even more the case with children who are non-verbal or who have other communication impairments. Disabled children are known to be more vulnerable to abuse and neglect (Marchant & Page 1993) and are more likely to end up in the care system, where some are still at risk of abuse and neglect (Morris 1995, 1998a; Russell 1995).

This vulnerability makes it even more important that disabled children and young people have access to independent advocacy (Sherwood 2004). Such advocacy has the potential to help in safeguarding the well-being and rights of disabled children, whether they live at home or in the care. In its report *Services to Disabled Children and Their Families*, the Social Services Inspectorate (1994) recommended that social services departments should aim to provide advocacy schemes for disabled children to enable them to express their wishes, a point echoed in *Valuing People* (Department of Health 2001). Furthermore, the report *Improving the Life Chances of Disabled People* (Strategy Unit 2005) states that disabled young people will require increased access to advocacy in the future.

Although many disabled children and young people have a greater need for advocacy, it is important for those working with disabled children to adopt a positive stance, which sees disabled children – like all children – less as passive victims and more as 'social actors' who have valuable perspectives to contribute. Arising from a relatively new discipline, the sociology of childhood or childhood studies (see, e.g. Prout & James 1997; Mayall 2002), this discourse raises the status of childhood. As children first and foremost, it is important that disabled children are included in this discourse and, as a result, are seen as active contributors to society rather than as passive objects. In this way, disabled children are more likely to feel consulted, empowered and valued in their everyday lives. There are indeed several innovative projects working with disabled children and young people that ensure that their 'voices' are heard. These include, for example, the work of Triangle (2001, 2002) and the Children's Society (e.g. Kirkbridge 1999; Badham 2005).

THE STUDY

The research is described in this paper is drawn from a study that was made up of three parts: first, a literature review (Oliver 2003); second, a telephone survey of advocacy services for children and young people in England; and third, a qualitative investigation of 10 advocacy services. The 10 advocacy services were selected for their diversity in terms of client group, geographical location and mode of delivery (i.e. whether provided directly by a local authority or by an external provider, such as a voluntary organization). Of these 10 advocacy services, one was a specialist service working with disabled children and young people. The examples used in this paper are derived only from the qualitative part of this study and relate mainly to this specialist service but also from the other advocacy services investigated.

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Research sample

Across the 10 advocacy services investigated as part of this study, 48 children and young people who had used the service within the previous 12 months were included in the research. Ten of these young people (across all 10 advocacy services) were disabled and aged between 10 and 17 years. Information obtained from interviews with an advocate about advocacy undertaken with two additional disabled young people, aged 17 and 19 years, was also used in this paper. We therefore drew on 12 examples of disabled young people using advocacy. The 10 young people mentioned earlier experienced a variety of disabilities, including moderate learning disabilities, severe physical and learning disabilities, communication impairments, and emotional and behavioural difficulties.

The study also included qualitative interviews carried out with 18 advocates, one of whom specialized in working with disabled children and young people and with 40 health and social care professionals. These professionals included social workers, five of whom specialized in working with disabled children; managers responsible for children's services and policy development; residential care staff; and complaints officers. In addition, 13 interviews were conducted with parents and carers, four of whom were of disabled children and young people. Because this paper discusses the research findings as they relate to disabled young people, only interview data obtained from a small number of advocates, social care professionals and parents who were working with or caring for a disabled child were used.

Methods

There is increasingly a wide range of creative communication techniques and methods for working with severely disabled young people, collectively known as augmentative and alternative communication. These include using symbols (Murphy & Scott 1995) and Talking Mats (Murphy 1998; Germain 2004). There is also a significant amount of research and guidance available detailing the approaches available to consult with children and young people with learning disabilities and the research ethics that need to be taken into account (e.g. see Beresford 1997; Ward 1997; Marchant *et al.* 1999; Morris 1998b, 2002; Knight *et al.* 2006).

Bearing these approaches in mind, the most overriding being the message that everyone can communicate in some way, the research methods utilized in the study took into account the communication needs and ages of the children and young people who participated. Although the topic guide that was used with children and young people asked children about their understandings of and access to advocacy, and their views of the advocacy service they received, not all these questions could be asked of children with learning disabilities. Instead, the topic guide was used flexibly according to the degree of learning disability of the child or young person and was used to guide a short conversation. This discussion was often accompanied by using simple play techniques, such as drawing and playing with a ball, allowing the child or young person to direct the discussion. Two observations of how the advocates worked and interacted with the children were also recorded. These were used to complement interviews and were particularly useful where the young person had little or no speech.

Analysis

The two observations of the advocates with disabled children that were carried out were analysed to identify the methods used to communicate with disabled children, i.e. how speech was used and the importance of non-verbal communication. They were also analysed to assess the quality of the relationship between the advocate and the child in terms of the warmth of the interactions. Was the child comfortable in the company of the advocate, for example, and pleased to see him or her? How did the advocate act with the child? Were they distant and business-like with the child or were they friendly and emotionally close in their manner? When interviews with disabled children were possible, they were audiotaped and transcribed. They were also analysed in a similar way to the interviews with adults. This was achieved by categorizing their responses to questions and then identifying key themes in relation to the research questions.

Ethical considerations

We were mindful of a number of ethical considerations that needed to be adhered to when carrying out research with children and young people, in particular those with learning disabilities. These considerations included being aware of the power relationship between the researcher and the young person, ensuring that informed consent was sought and giving the young person some control over the research 'interview' by allowing the young person to 'lead' it as much as possible. This meant obtaining knowledge of the

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young person before the 'interview' by talking to those who knew the young person well, such as the advocate, the social worker or the parent. It was important to understand their likes and dislikes and communication skills, i.e. what sort of behaviours might signal distress or a need to discontinue the meeting with the researcher, if they were unable to articulate this in spoken language.

Accessing disabled children and young people for the research: challenges and obstacles

One of the main challenges facing the researchers was accessing disabled children and young people to participate in the study. Like other similar studies, the researchers needed to rely on gatekeepers, such as social care professionals, to access potential participants. In one of the research sites, some social workers (both residential and field) working with disabled children using advocacy services refused access to two young people, on the grounds that the research was of no benefit to them and that it might be too stressful for them. However, the information (in the form of a short leaflet and a verbal explanation) about the research had not been passed onto them so that the young people did not themselves participate in this decision. Interestingly, these challenges mirrored the advocate's own difficulties in working with young people in the same residential establishment and are a useful illustration of why advocacy is so important for this group of children and young people. Facing these challenges, the researcher worked closely with the advocate, exploring her experience of working with disabled children and young people in some detail, two examples of which have been used in this paper.

The names of all interviewees have been changed in the text to ensure anonymity.

RESULTS

Disabled young people's experiences of advocacy

The advocates working with disabled young people in our study commonly dealt with a multitude of issues. These included representing young people's views in review and child protection meetings, working with young people in their transition to adult services and ensuring that disabled young people's needs are being met in residential and foster care. More specifically, one Asian young woman, who had a learning disability, became pregnant as a result of sexual abuse and was subsequently placed in foster care with an Asian family. Sunna wanted to keep her baby and remain in long-term foster care, but social services had other plans. With an advocate's help, the case went to court, which made the decision that the baby should stay with Sunna and the foster family. As Sunna explained in her own words:

> '[The advocate told social services that] Sunna doesn't want to be split up from her baby and she doesn't want to go back to her family . . . And they said I can't care about him (the baby), but I can. My aunty (foster carer) helps me . . . they said I have to go to court to see what the judge says. And then we went to court and the judge said that the mother and baby should stay together. The judge said, take a residence order for the baby, and they can stay in foster care long-term.' (Sunna, 17 years)

Several of the disabled children and young people we met during the study were receiving help from advocates for representation in reviews and other meetings with social services. For one young man, who had both learning disabilities and mental-health problems, the advocate was instrumental in getting key staff, such as the Independent Reviewing Officer, to see the young man after his review meeting. This was because he had been prevented from attending the meeting by his social worker, because, in her view, it would have been too stressful for him. Another learning disabled young person felt that she was both listened to more and able to speak up in meetings because of the involvement of the advocate:

> 'Researcher: Did people listen before Sarah [the advocate] came along?
> Young Person: I don't think so
> Researcher: Why do you think Sarah was able to make them listen to you?
> Young Person: Because she said that they have to listen.
> Researcher: Did you feel able to speak up in meetings?
> Young Person: I didn't before but now I can.'

Liaising with residential staff about issues of care and privacy was another common area of work undertaken by advocates working with disabled children and young people. One advocate explained, for example, how the bathroom door in one residential home had a window in it. Although it had a curtain, the curtain was outside the window, meaning that staff could still look in if they chose to. They argued that this was for health and safety issues but as the advocate said:

> 'We've got to balance the health and safety issues and risks against this humane need and desire for privacy. I talk to all the young people at children's meetings. One of the issues around privacy came upon the way to someone's room. I was

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> asking about the bathroom and the young person said that he prefers to use the shower because he can put a curtain around him. I said, surely you can lock the door on the bathroom. He said he couldn't because the laundry basket was kept in there.' (Advocate)

By talking to the staff about these issues of privacy and by simply asking them to move the laundry basket to another room, the disabled young people in this residential home were immediately given more respect and dignity when bathing.

Overall, the disabled children and young people who took part in the study were very positive about having an advocate. Feeling nurtured, being taken seriously and having someone to talk to in confidence emerged as important themes from the study.

One disabled young woman reported her understanding of advocacy as

> 'Someone you can talk to . . . it stays in this 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.' (Sally, 15 years)

One disabled young person described her advocate as like a 'second mum' and another defined advocacy as 'people who look after me'. Molly, age 10, who was being looked after in foster care, reported that she thought the advocate was 'fun' to be with and that she would feel able to talk to her if she was unhappy in her placement. She saw the role of the social worker as someone who 'takes her out and stuff' whereas the advocate 'sees how you are'.

Despite the small sample of disabled young people referred to in this paper, our research findings suggest that the benefits of advocacy for disabled young people can be great and far-reaching but also pose a number of challenges and dilemmas for its practice. It is to these issues that we now turn.

Advocacy or acting in 'best interests'?

Research interviews with the advocates showed that enabling young people to express their views, even if the advocate themselves did not agree with them, was, for them, an important part of the role. Yet for advocates working with children and young people with communication impairments, such a definition of advocacy poses major difficulties. In fact, the most challenging circumstance for advocates in our study was identified as exploring the wishes of young people without speech. Not *really* knowing what the young person with communication impairments wants can result in the tension between putting someone else's views across or acting in their 'best interests' ('non-directed' advocacy). The advocates we interviewed who were working with severely learning disabled young people expressed anxiety about this dilemma in their practice. Some emphasized the ethical importance of being careful that they 'did not take advantage of their role'. One advocate, for example, queried her own practice with a young disabled woman when she said,

> '. . . it's a thin line: are you saying what you think, or what they want?' (Volunteer advocate)

However, as one social care professional commented,

> '[Advocates are] doing the best they can in the circumstances, including in circumstances where they're not absolutely certain what the child's views are. (But it's) far better than doing nothing.' (Principal Officer, Children and Families)

And as one advocate explained:

> 'You've got to acknowledge that the disability will influence the way you work with the young person . . . He doesn't communicate verbally; I can tell he likes certain things and not others from experience, but even knowing his dislikes and likes and then being able to say to him 'where would you like to live' is implausible. That's absolutely no way that I can do that. What I can do is to look at what does work for him, what doesn't, making judgements after seeing him, talking to staff who know him, taking to parents, talking to anyone who knows him really. But at the end of the day, I still don't know whether he really thinks. That's always a dilemma for people like him. I can only base it on my experiences of him, what would be an average 18 years olds wishes and what kind of things would this sort of young man be looking for. For example, he likes his music on loud so he would need to be housed with people who wouldn't object to him having his music loud.' (Advocate)

In the example given above, the advocate can be seen to be taking a 'best interests' stance. Another example of this approach was summed up by one advocate who described working with a young woman with learning disabilities in transition to independent living. Although the young woman's social services department had planned to move her to hostel accommodation in a different county, the advocate argued that she needed the added protection of a semi-independent unit as the young woman had previously experienced sexual exploitation.

A 'rights' approach

Another approach used by some advocates particularly when working with severely learning disabled young people was the rights-model of advocacy, which

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emphasizes the rights of the child under legislation such as the Children Act 1989 and the UN Convention on the Rights of the Child (1989). This was perceived to be valuable in situations where advocates were involved in advocating for children when they were not present at a meeting, or when there were difficulties in obtaining their views because of communication impairments:

> 'So, even though we can't say directly on behalf of the young person, we can say any child would be entitled to this. That would be the case for a disabled young person too. When you don't have something directly from the young person . . . then we could say, any young person of this age in this situation would be entitled to this, so what is happening about it?' (Advocacy service manager)

One advocate, who worked mainly with disabled children and young people, was also very clear about taking a children's rights approach to her work:

> 'I come from a children's rights model and use legal documentation to provide the mandate to get people to provide services. I have used Article 12 of the UN Convention and Section 17 of the Children Act to argue that a disabled child is a child in need and is therefore entitled to a service that the social worker is saying they shouldn't have.' (Advocate)

The challenges facing advocates when taking a 'best interests' and a 'rights' approach to advocating for disabled young people are not specific to advocacy services. They are also very real challenges facing many professionals working with disabled children and young people, including social workers. We will now turn to the relationship between advocacy and social work, exploring some of the differences and similarities between the two roles.

Is there a blurring of roles between advocacy and social work?

Discussions with one advocate working solely with disabled young people revealed two examples where she appeared to be carrying out a social work role. One of these young people, Alan, was 19 at the time of the research, a wheelchair user with profound physical and learning disabilities and complex health-care needs. He communicated through high-pitched crying, rolling his head and hitting things out of the way when he did not want something. Alan was being looked after by social services in a residential unit when he was referred to the advocate. The main role of the advocate was to bridge Alan's transition to adult services, to support his move from the children's unit to appropriate adult care and to ensure that effective communication took place with the staff in his new unit about his likes and dislikes. For two other disabled young people, who were siblings, the advocate arranged after-school activities for them as their domestic situation restricted their access to leisure opportunities.

In both these examples, the advocate was using a 'best interests' approach to the work, as a social worker might. The young people had not instructed her to do these tasks; in this sense, the advocacy was 'non-directed' advocacy. Is this true advocacy? Does this type of advocacy blur the boundaries between the role of the advocate and that of social workers and other professionals who are concerned with the care of a child or young person and in this way 'muddy the waters' (Boylan *et al*. 2006)?

The view that there is a perceived blurring of boundaries between the roles of advocacy and social work was most evident in interviews with social care staff working with disabled children and young people. Contrasting views about the relationship between advocacy and social work were expressed. On the one hand, it was reported that advocacy was beneficial to social workers, as advocates could focus on the views and wishes of the child, thus freeing up the social worker to concentrate more on the family's needs. On the other hand, several social workers who were interviewed for the study questioned the need for advocacy. One social worker, for example, felt that her role overlapped with the advocate's because they both needed to focus on the young person as the client:

> 'I think I sometimes do the same job as the advocate does. I talk to the young person, get them to express their views, write down their views, then I think that the advocate has done the same. That to me is duplication. A couple of the young people I work with don't know what the advocate does – they think it's someone like me who goes to see them. The difference lies in what sort of relationship you have, as a social worker, with the young person. If you have a very active and positive relationship with the young person, then I don't think the role does differ.' (Social worker)

Having pointed out some of the negative aspects of the possible blurring of roles between advocacy and social work, however, our interviews also revealed instances of where the two roles did indeed differ and complement each other. For example, some social care staff, particularly those working in residential units for disabled children and young people, described the role of the advocate as a kind of bridge between themselves and local authority social work workers. This was because some advocates were perceived to have more influence in decision-making

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arenas than they, as residential staff, did and meant that they sometimes relied on the support of advocates to challenge decisions made by social workers.

Who is the client?

Another key theme to emerge from our study and which particularly affected advocates working with learning disabled young people was the possible confusion over who was the actual client, the parent or the young person, a situation leading to potential conflicts of interests. One parent of a disabled child, for instance, perceived her daughter's advocate to be an ally in battling with the local authority and another defined advocate as someone who could listen to her own needs.

The advocates we spoke to about this issue often described situations where parents tended to take a 'best interests' approach to their child and, as a result, were less likely to keep the child or young person fully informed and allow them to express their own views. One volunteer advocate, for example, described a case of a young woman in residential care who was in the process of moving on to supported living and how her parent repeatedly contacted the advocate to be updated on the situation:

> 'And the young person's parent had different needs and wants for the child, rather than what the child wanted. (The parent) was saying, what is happening? Why hasn't that happened? And I'm saying 'are you sure she wants that? Or are you just speaking as a parent, wanting the best for your child?' . . . You have to say, 'look, I'm an advocate for your child, not for you. I can only deal with what she wants to tell me, not what you want to tell me. I can take your views into consideration, but I'm only here for her.' (Volunteer advocate)

Some social care professionals working with disabled children and young people also highlighted the question of 'who is the client'? Some were rather critical of advocacy that may be more carer-led and felt that advocacy needed to be more assertive in supporting disabled children rather than their parents. As one social worker explained:

> 'For example, we have a respite care service downstairs and most of the time the young people don't want to come and it's about the parents' needs. I think this is what the advocate could get involved in as it's about negotiation and try and work out a compromise and be more child-led.' (Social worker)

Dealing with conflicting views between young people, their parents and sometimes professionals, especially social workers, was reported to be a complex area of advocacy practice. One advocate explained how important it was to be clear about her professional boundaries in dealing with this issue:

> 'I have to say to them [parents], I'm not here to represent your views, I represent the child's. I can refer them to the carers' advocate if necessary.' (Advocate)

Disabled children and barriers to participation

Early on in this paper, we stated how disabled children and young people have traditionally been excluded from participating in decision-making and how their vulnerability makes advocacy even more crucial for this group. Paradoxically, though, it is the traditional perception by society of disabled children as being passive, vulnerable and in need of protection that makes advocating for disabled children particularly challenging. One of the main difficulties of working with disabled young people reported by some of the advocates in our study was caused by disabled young people growing up in a culture that valued passivity, preventing them from participating in decision-making. Many disabled children and young people are not used to being asked for their views and may not think that what they have to say is important (Lewis & Porter 2004); others may acquiesce to the suggestions of others because they are so used to being controlled (Stalker 1998). As one advocate we spoke to explained,

> 'The other dilemma is working with people who are so unused to making choices and decisions and they are always going to say 'yes' to everything.' (Advocate)

The advocates we interviewed took the view that children and young people, regardless of age or disability, were entitled to express their views and have them taken into account as a matter of principle. For these advocates, then, the barriers to disabled young people participating in decision-making were about resources and attitudes. To ensure that disabled young people are fully informed and involved, it was acknowledged that resources in regard to skills, staffing and funding were key components that needed to be in place. As these two advocates explained,

> 'It has a bearing on our capacity to help them with it. You need more resources to work with a younger child or a child with disabilities.' (Advocate)
>
> 'I think (disabled children and young people) should always be given the opportunity to participate. They probably say it is not possible, because it makes life a lot more difficult. Meetings would probably go on a lot longer, but there are ways of managing it . . .' (Advocate)

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The importance of the relationship between advocates and young people

Perhaps above all, the quality of the relationship between advocates and young people was identified as the most significant component in enabling disabled young people to participate in decision-making. As this social worker explained,

> 'Three years ago, a young man, with no other sources of support – it was not clear what he wanted. (The advocate) attended meetings, struggled, because he was not verbalizing. (The advocate) knew him previously, and managed to ascertain that he didn't want the residential unit they wanted to put him into. It ended with him getting a better package of care . . .' (Social worker)

Interviews with parents and carers also emphasized the importance of positive relationships between advocates and disabled children and young people, something they acknowledged, could be resource-intensive. One parent reported that the advocate spent more than a year developing a relationship with her disabled daughter. The advocate met and observed her daughter in different social contexts, such as at home and at school, in order to establish rapport and a close relationship. This meant that in meetings, the advocate was able to make perceptive comments about the young person, illustrating how much she had learnt about her.

Establishing and maintaining a quality relationship with a disabled young person in this way therefore requires spending regular periods with the young person in different settings and over a period of months, if possible. It means getting to know their methods of communication, behaviour, gestures, likes and dislikes. It also means getting to know people in the disabled child's social network and using their expert knowledge. Only then is it possible to build up a comprehensive picture of a child's life and situation in order to advocate for them effectively.

CONCLUSIONS

The findings from this study showed that advocates working with disabled children and young people, particularly those with learning disabilities and communication impairments, face a multitude of dilemmas. Advocating for a group which has traditionally been undervalued by society is a challenge in itself. Advocates have to work hard at convincing those working with severely disabled young people as well as the young people and their families themselves that participation is not only useful but also bound by policy and legislation.

Advocating for severely learning disabled young people produces an additional layer of complex issues that advocates working in this area have to address. Advocates need to build up a coherent and comprehensive picture of a disabled young person's life to aid communication with that young person and advocate effectively. To this end, it is important for advocates to be able to establish rapport with the young person's parents, carers, key workers and social workers, a process that is almost, perhaps, as important as the establishment of a positive relationship with the young person him or herself. At the same time, however, advocates must be wary of becoming an advocate for the parent, carer or even professional.

Unlike advocates working with non-disabled young people who are 'instructed' by their clients, advocates working with severely learning disabled young people must tread a fine line between advocating for the young person and acting in their best interests. Sometimes advocates for disabled young people appear to be carrying out 'non-directed' advocacy and because their concern for the young person is based on what is in the young person's 'best interests', their role is sometimes no different from other professionals, such as social workers. For many advocates, taking a children's and/or human rights stance to the work is often what makes this boundary clearer. The fact that this may not be advocacy in its purest sense is a controversial and complex issue. The question remains whether it is better that the young person receives support from an advocate, even if this advocacy is 'non-directed', or does not receive a service at all. The answer lies in the quality of the relationship that the advocate is able to develop with the young person. Being able to spend time with a young person and establish rapport over time may mean that many severely disabled young people are able to 'instruct' the advocate after all.

Despite the dilemmas they face, our study showed the important and sometimes life-changing work that advocates are carrying out with disabled children and young people. Having the necessary communication skills to work with young people with learning disabilities and communication impairments requires not only skilled training but also time and resources, which are often in short supply for advocacy services. A commitment of resources in terms of specialist training and sufficient time for advocates to establish a close relationship with a severely disabled child or

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young person is crucial if such valuable and far-reaching work is to continue.

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