Sixth Sense: The Disabled Children and Young People's Participation Project

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The Disabled Children and Young Peoples Participation Project (DCYPPP) was established by Barnardos (Northern Ireland) in 2002 to explore ways of involving children and young people with disabilities in decision-making processes within Children’s Services Planning of the Health and Social Services Board. Over 200 young people have participated in its 10 years of existence. This article describes how the DCYPPP practice has evolved in support of the young people and the factors that contribute to its successes. Policy-makers and professionals at all levels need to recognise the valuable contribution children and young people with disabilities can make and actively seek their engagement. © 2012 The Author(s). Children & Society © 2012 National Children’s Bureau and Blackwell Publishing Limited.

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Introduction

Article 12 of the United Nations Convention on the Rights of the Child (UNCRC) asserted the right of the child to have their say and Article 13, their right to receive and impart information in a format that suits them. Moreover, Article 23 states that children with disabilities have the same rights as any other child or young person (UNICEF, 2007). This article provides an example from practice as to how children’s participation can be supported and their voices heard. The factors that contributed to its success are identified along with the difficulties that arose. These insights should assist researchers and practitioners in forming similar partnerships.

As in other parts of the UK, the Children (Northern Ireland) Order 1995 introduced requirements for public authorities to work in partnership with children and families and for them to be consulted on matters that affect them. More recently, the Health and Social Care Reform Act (2009) Sections 19 and 20 reinforce the accountability of certain health and social care bodies including Trusts to seek the views of service users. The value of doing so has been endorsed nationally:

Social care organisations have begun to acknowledge that, when listened to, children and young people can play a vital role in the planning and delivery of services, (Wright and others 2006).

The Disabled Children and Young People's Participation Project (DCYPPP) was established as a User Involvement Project in 2002 as part of a new ‘Wraparound’ initiative in one Health and Social Services Board area. The initiative was funded by the Board, which has responsibility for commissioning services and by the Southern Health and Social Care Trust whose remit was the delivery of services either directly or by contracting with the non-statutory
sector. These developments, although unique to Northern Ireland, were in line with evolving developments in the UK and accorded with European legislation, which promotes partnership, consultation with service users and patients’ rights.

The 6th Sense project

The project aims to facilitate the involvement of disabled children and young people aged 5–25 years with a range of physical, learning and sensory impairments in high level, strategic Children’s Services Planning, underpinned by the promotion of advocacy for individuals. The young people chose to call the group ’6th Sense’. ‘We see ourselves as the eyes and ears of Children’s Services Planning and the voice of children and young people with disabilities’ (6th Sense meeting 2003). This is also indicative of how committed the young people are to the participation process.

It was recognised from the outset that the involvement of children and young people with disabilities would be time-consuming and required knowledge of disability issues and skills in engaging with individuals who had learning and communication difficulties. Arguably, the nature of the project dictated the need for voluntary sector management, and it is managed by Barnardos with a full-time project manager. However, the project is located in a Children and Young Persons Centre in Armagh, which is a health and social care facility.

Young people can be referred to the project by either a professional or family member or they can self-refer. A member of DCYPPP staff meets with the young person and their family/carer to inform them about the project and critical information is gathered. Young people have the choice to participate in peer groups through workshops or through one-to-one activities. In the past nine years, over 200 young people have been facilitated to participate in decision-making processes.

There are 27 members in the project’s advocacy group ‘6th Sense’. This group meets on a monthly basis to take forward issues that young people identify as having an impact on their daily living. A further nine young people attend the project on a weekly basis to develop skills in IT and advocacy. It is often necessary to facilitate evening meetings to participate in government consultations. The young people are involved in all decision making about the management and progress of the project. Six members sit on a project reference group.

The project seeks to identify and break down the barriers children and young people with learning and physical disabilities and sensory impairments may encounter, preventing them from having their say on issues that impact their lives. Young people are involved in every element of decision making within the project with an emphasis on ensuring that their participation in the project is fun. The project strives to be user-led and enables young people to make their own choices about issues such as what information they wish to share, at what level they wish to participate, when they wish to participate, in which format they wish to be involved and what support they need to enable them to participate.

Meaningful participation for young people with disabilities is a core principle in DCYPPP practice. Therefore, creative ways of working have been necessary to ensure that the young people can make choices, be informed and inform and essentially communicate their views. This is made more enjoyable by the various media of engagement used, including specialist IT, music, drama and the digital media provided by the project and supported by Barnardos.
As a number of young people rely on IT to help them express their views, an assistive technology suite was established. Currently, a young people’s Blog and video conferencing are being set up in the Centre to facilitate the exchange of views by young people with disabilities across NI.

Our experience has highlighted that group advocacy by disabled young people must be built on a strategic and structured process such as regular meetings with one another and shared activities that develop their confidence and skills. While the method and level of participation is person-centred, the individual has the benefit of trusting relationships with their peers, facilitators and the professionals with whom they come into contact.

Young people can remain with the group until they are 25 years. Two young people who were members have since become paid staff employed by Barnardos to work as advocacy and participation workers part-time (20 h/week).

Advocacy by the group

From an early stage in the project, it was important to create partnerships with Children’s Services Planning and with other statutory and voluntary agencies. This encourages policymakers and service providers to be accountable for listening to and acting on the recommendations of the young people. As facilitator I had to negotiate opportunities for young people to share their views with professionals who were willing to accept a power balance.

Hart’s (1992) Ladder of Participation has been the theoretical basis on which the young people have based meaningful participation (see Figure 1). This provided a graphical representation of young people’s involvement, enabling the young people to ascertain at what level they are being asked to get involved. As the project promotes outcome-based participation, a decision whether they should participate or reject an invitation to be involved would be made prior to the young people getting involved. Experience shows that any lower than rung 5 often does not secure accountability on behalf of the professionals to either feed back to the young people or to progress the issue. The young people’s use of this tool as a measurement of their involvement prevents individuals or the group from being involved in tokenistic participation.

DCYP PPP activities to date suggest that partnership in decision making, as in rung 8, is achievable and is an integral part of engaging with children and young people with disabilities.

The young people have influenced decision making locally, regionally and internationally on issues such as wheelchair service provision in Northern Ireland, hate crime legislation to include offences against disabled people, research on emotional wellbeing and mental health support needs of young people with disabilities and tackling the transitions from children’s to adult services. In 2005, three young people travelled to Geneva to participate in the UNC-RC day of general discussion on Article 12. They addressed a large convention to promote the right of children and young people with disabilities to have their say.

Four young people are currently being facilitated to be peer reviewers with the Northern Ireland Regulation and Improvement Authority. One young person sits on an advisory group with the BBC Children In Need and a number of young people are involved in high level
strategic children’s services planning processes within the Health and Social Care Board and the Southern Health and Social Care Trust.

Nonetheless, the young people are acutely aware when professionals, government officials and ministers alike listen but are not fully committed to engaging with them. ‘They were listening but they did not hear’ (6th Sense, 2005). Equally much has been learnt from the meaningful engagement of professionals committed to hearing the views of the young people and forging for outcomes. The young people have named these people ‘Champions’: ‘It is our experience that without the Champions we as young people would be powerless’ (6th Sense member).

Contributing factors to successful participation

The relationships between the Project Manager and young people, and between the young people and their peers, have over time resulted in an avalanche of thoughts, experiences and feelings, which has created a resounding insight into the needs of children and young people with disabilities. These insights might not otherwise have happened without the opportunity...
to build relationships and the young people having access to opportunities that help them gain the confidence that enables young people to express their views.

The experience of young people in DCYPPP suggests that, while their personal experience makes them experts in their own needs, there is also a need to learn about the needs of others so that they can be representative of the diverse needs of children with disabilities.

Good facilitation is perhaps one of the most important factors enabling the decision makers to engage with the young people and vice versa. It was necessary to enhance the young people's ability to participate and communicate while encouraging a change in behaviours of those professionals such as respecting the young people's views and not being overly sensitive to their criticisms. Moreover, the young people need to be informed about the structures of statutory policy-making and key aspects of service delivery such as budgeting. This must be done using a medium best suited to the individual’s learning, sensory and communication needs.

As already noted, the Project is based in a health care facility, which allows group members to have contact with service providers in a community-based setting and enhances relationships between young people and service providers. The Project’s IT suite creates opportunities, especially for children and young people with communication difficulties, to be informed and express their views using a range of assistive aided computers.

For the young people to feel that they are equal partners in the participation process, they are also now being facilitated to train staff in the agencies who wish to consult with them. This encourages a power balance between professionals and young people. The involvement of young people with sensory and physical impairments, and learning disabilities not only helps them to offer mutual supports to one another, but interestingly, it encourages professionals to adopt a flexible approach in how they engage with young people.

Advocates in 6th Sense believe that while local advocacy is vital, the difficulties often lie in regional policies. They recognise the need to research issues, attend the project to learn skills and maintain transparent partnerships with professionals at all levels. They need to be informed and to inform policy-makers at regional and national levels about what works well and to gain an understanding of government structures as well as prioritising within health and social care structures. The involvement of disabled children and young people in high level strategic planning can only happen if there is commitment to funding, which can create such environments as is DCYPPP.

Perhaps most importantly young people need to know that they have earned respect for their ability and that they have been supported to develop their own lives. ‘I feel empowered because I am with young people my own age, I have been encouraged to speak up for myself and other young people and I talk to people who want to listen’ (member of 6th Sense).

However, it would be foolish not to acknowledge that there is risk associated with involving children and young people in planning services. For the service provider and policy-maker, it might be that they will not hear what they want; and for the young person, they may not receive the outcome they wished for. However, this does not mean that their efforts have been wasted. As Alison Jarvis noted: ‘Don’t be afraid to chance your arm and take a risk. If you assume failure, you may well get it. If you assume success, you might just strike lucky’
The DCYPPP experiences suggest that without risks, there would be no progress either for service providers and policy-makers or for the young people and their families.

References


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Contributor’s details

Rosemary Murray, mother of five children, reconvened her education as a mature student and graduated from QUB in 2000 with a BA Hons Degree in Social Sciences. Prior to this, Rosemary volunteered her spare time to work with young people in her local community. Disability was always a feature in her and her family’s life and in fact this led her to pursue a career in disability advocacy work. In 1998, Rosemary took up her first post in the field of disability with Mencap as a Support and Development Worker. In 2002, she became Children’s Services Manager with Barnardos Disabled Children and Young People’s Participation Project. In 2009, Rosemary received an MBE for this work. Rosemary’s passion to make a difference to the lives of children and young people with disabilities and their families is driven by the commitment of the young people she has the pleasure to work with.