

You tell me what we can do after this: Findings and recommendations for the participation of young people with learning disabilities

Charlotte Wilson

Abstract

In recent years the participation of children has been highlighted with ever increasing importance, due to a raft of inquiry reports and legislation. In spite of this, and the increasing number of **children defined as 'disabled'**, the participation of children with learning disabilities has been marginalised and is **often described as 'tokenistic'**. This article reports on a research project which explored the factors which impact on levels of participation, for children and young people with learning disabilities in a residential short breaks setting.

Keywords

Participation, learning disabilities, short breaks, communication

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Introduction

'About 16,000 school aged children and young people... in Scotland have learning disabilities and require support' (Scottish Government, 2013, p. 7). Legislation such as the Children (Scotland) Act (1995) has influenced the support provided to children with disabilities (SCIE, 2004), by requiring local authorities to provide **assessment and services to 'children in need'** (Read and Clements, 2001) such as short breaks. In spite of this it would appear that less than 1% of young people are accessing short breaks services in general (NEF Consulting, 2009); in

2009-2010 less than 58,000 overnight short breaks were provided to young people aged 0-17 years in Scotland (fSDC, 2010). This paper will report on a research study carried out as part of the MSc in Advanced Residential Child Care. The aim of this study was to explore the barriers to participation for children and young people with learning disabilities in a residential short breaks setting; the intention being to increase understanding and improve practice in this area.

Participation is commonly understood as the act of taking part or being involved, however, the meaning of participation seems unclear in much of the childcare literature (Watson, 2006) and in practice 'is often used simply to mean being 'listened to' or 'consulted' ' (Sinclair, 2004, p. 110). For the purpose of this study, understandings of participation were based on Shier's (2001) Model of Participation which has five levels of participation which range from children being listened to, being supported in expressing their views, and having their views taken into account, through to being involved in decision making processes, and sharing power and responsibility for decision making. This model is useful as it allows for consideration of staff's commitment to participation (openings), the resources required to facilitate it (opportunities), and the reflection of this in the organisation's policy (obligations) (Shier, 2001).

In recent years participation has become a popular area of concern, following the introduction of the children's rights agenda (Smith, 2009) brought about by the UN Convention on the Rights of the Child (UNCRC, 1989), and the government participatory initiatives this has influenced (Tisdall and Liebel, 2008). In addition to this many inquiry reports have made recommendations about the consultation of young people (McNeish and Newman, 2002), for example the Skinner Report (The Scottish Office, 1992). However, children with learning disabilities' options for making daily choices are limited; they are less likely to be involved in assessments, and more likely to be excluded from consultations (Dickins, 2008).

Methodology

Contact was made with the manager of a residential short breaks service for young people with learning disabilities where the researcher used to work; asking for permission to carry out the research. Due to the size of this research study it was felt that one service would provide sufficient data, but it is recognised that the findings may not be generalisable across other settings (Bryman, 2008), and that the findings may have been influenced by the researcher being an 'insider' (Bell, 1999). A common issue for researchers is the need to negotiate with gatekeepers (Blaxter et al, 2001), and so it was ensured that the benefits of the research for the unit were highlighted to the manager. Once organisational permission was granted all thirty six families (parents and children), and eleven permanent day staff were written to, with an invitation to take part in the research.

The decision to include all three groups of participants was influenced by notions of participation, in order to be inclusive of a wide variety of views, and to triangulate and strengthen the findings (Hardwick and Worsley, 2011). From the letters sent out replies were received from two parents (on behalf of themselves and their two children), and two staff interested in taking part; a low response rate had been anticipated due to the time commitment asked for from participants. A key issue that was highlighted at this stage was the role parents **play as gatekeepers to their children's lives (The Research Ethics Guidebook, n.d.)**, meaning that some young people were potentially inadvertently excluded from taking part. Because of the small sample size there was an unequal distribution in the data set with regards to gender (both staff members were female), age (both young people were mid-teens), ethnicity (both families were British and both staff members were European), and class (all participants would commonly be described as middle class).

Consideration was given to ethical issues for participants such as confidentiality and informed consent, and ethical approval was sought from the University of **Strathclyde's Ethics Committee before commencing with the research. Clear information appropriate to the participants' level of understanding was provided**, in order for them to make an informed decision about being involved (Kendrick et al, 2008). For the young people this required using simple language and short sentences, reinforced with photographs and pictures (Darlington and Scott, 2002). Due to the age and developmental range of the group of young people invited to participate, capacity of the children was assessed on the basis of their diagnosis and level of impairment, and a three pronged approach to seeking consent was planned:

1. Parental consent would be sought for children under the age of 12 to participate in the study.
2. For children aged 12-16 who were deemed to have the capacity to give consent, parental assent (i.e. agreement) would be sought.
3. For children aged 12-16 who were not deemed to have the capacity to give consent, parental consent would be sought.

In addition, the notion of on-going consent was followed (i.e. that the child was accepting the interview and could end the interview if they choose to do so) (Beresford et al, 2007; Dickins, 2008), for example by screaming or walking away (Morris, 1998). The young people involved were both able to stop and start **the interviews as they saw fit, using phrases such as 'You can go' or 'I'm finished now' to end the interviews, and 'What do I like?' or 'What else?' to re-engage.**

Following completion of the research appropriate summaries of the findings were made available to the three different groups of participants, along with a letter of thanks for their participation in the research. The summaries were adapted **according to individuals' levels** of understanding of the findings, and supported

with visuals for young people. The organisation also received a full, anonymised copy of the final report.

Due to the nature of the research that was undertaken, a qualitative method of data collection was employed, using semi structured interviews (Gubrium and Holstein, 1997). The interviews with young people were of a flexible nature to suit their cognitive level and communication needs, in order to be as inclusive as possible (Darlington and Scott, 2002; Murray, 2002). A variety of ways of **engaging children in the 'interview' process were used; including games, symbols, sign-a-long, scenarios, observations, 'showing'**, drawing, and the use of an iPad. The questions used were as follows:

For young people:

- How could someone find out what you like best?
- Do you think that adults listen to your ideas?
- How does this feel?
- Do staff let you make choices at the residential unit?
- What kind of things do they ask you about?
- What else would you like to be involved with?

For parents:

- Can you tell me about how your child came to receive short breaks?
- How do you think they were involved with this?
- How would you feel about your child attending their review?
- What would your reaction be if your child expressed a dislike in their short breaks provision?
- How much of a say do you think your child will have about their future?
- Can you talk about what helps or hinders this?

For staff:

- What does participation mean to you?
- How do you support children with the initial referral process to the short breaks service?
- How do you think you encourage participation at the short breaks service?
- What makes it easier for children to participate?
- What makes it more difficult?
- How do you support children to contribute to their reviews?

The interviews were recorded and transcribed in full. As a conceptual framework had been gained from existing knowledge and understanding of the literature it was possible to create a map of the themes, and this led to the development of

a thematic framework. Once the analytic coding framework was created NVivo (a Computer Assisted Qualitative Data Analysis software package) was used to identify the data corresponding to the themes by coding or indexing, ensuring the viewpoints of all three groups of participants were incorporated. The resulting data was then charted by taking it out of context (i.e. the transcriptions) and arranging it into a chart of the themes identified. Finally, mapping and interpretation were used to analyse the findings. A schematic diagram of the associations between the themes was created, and this guided the identification of concepts and developing explanations for these. Through analysis of the data, four main themes developed: the construction and rhetoric of learning disabilities; adults and their appropriate use of power; involvement through experience; and the impact of diagnosis and communication preferences. The findings within these four themes will be presented here.

Findings

Construction and rhetoric of learning disabilities

Perspectives of participation are not clear cut and from the interviews carried out can be seen as: participation as essential knowledge; participation as a helping tool; participation as a bureaucratic process; and participation as tokenism. For example, **participants felt that it was 'very important for them to able to express what they like and don't like' (parent), that 'participation is where we involve the person in their lives' (staff), that 'everybody's obsessed with this word recently' (staff), and that there was 'involvement of children of an inappropriate sort' (parent).** The last two comments are in keeping with the idea that participation has become a recent trend (Smith, 2009) which we pay lip-service to (McLeod, 2008).

It is likely the understanding of participation is linked to the way that childhood is constructed. Smith (2010) identifies the dominant constructions of childhood as being disempowering to children due to themes of vulnerability (which implies **a lack of competency**), **work being 'future-oriented,' being separate from** adulthood (which makes ideas less valued), and the political influences over this. There are parallels between the ideologies of childhood studies and disability studies (Tisdall, 2012), however, children with disabilities may be seen as being more dependant due to perceptions of their physical status which reinforce underlying assumptions about their vulnerability (Smith, 2010), and where children are not given opportunities to participate it can be seen how this idea translates into practice.

Participants acknowledged that young people have 'very different diverse levels of learning disabilities' (parent) seen through lenses of cognitive capacities, IQ levels, stages of development, levels of understanding, needs, abilities, skills, behaviours and communication styles. They expressed that there was a

'biological foundation' (parent) or 'physiological distinction' (parent) to this, which 'limits' (parents and staff) and 'can damage you physically' (staff). They felt that this is ignored by the social model, in keeping with authors such as **Morris (1991), Chappell (1998), and Shakespeare and Watson (2002).** The **'level'** was seen to influence expectations of what children could achieve, and while it was important to have high expectations it was also difficult to see past both **your own and others' limitations of what was possible. There was a feeling that the disability was something that 'they have to overcome' (staff),** in the same way that Adams (2003) spoke of.

Participants **felt that this 'diversity of levels' influenced children's social, educational, and ultimately employment access.** As other writers have acknowledged, people with disabilities are more likely to be denied access to mainstream opportunities (Beresford, 2002) and socially excluded (Shakespeare, 2000), especially people with more profound impairments (Whittles, 1998). Participants expressed anger at the social exclusion of children with learning disabilities, **describing it as unhealthy, and asking why it was 'justifiable' (parent).** They felt that there was a need for inclusion, and that it was **'good to mix' (parent and staff),** even within the variety of children accessing disability services.

Participants thought that the education system reinforced the **'diversity of levels'** by segregating young people with learning disabilities in special schools. Clements and Read (2003) have also commented on this. The impact of this was **expressed as young people with learning disabilities developing little 'experiential familiarity with mainstream society' (parent) which de-socialises them,** and decreases their levels of participation (YETRU, 1992). Additionally mainstream society has little experience or understanding of learning disabilities, leading to bullying and prejudice. **It was expressed that 'if you don't meet people who have any kind of special needs you don't realise that, because you don't know' (staff),** and that at best society offers pity or protection. Writers such as Goodley (2000) have also noted that society views people with disabilities as tragic and helpless.

This is further reinforced by the structure of employment **as 'our economic system and our bureaucratic system' (parent) are the 'main avenue of social inclusion in our society' (parent)** where people with learning disabilities are further excluded from society, as noted by Barnes et al (1999), Shakespeare (2000), and Oliver and Sapey (2006). One participant noted that disability is the only quality that is excluded in this way, as class, gender, race, and sexuality are not limited by capacity or skills. Aull Davies (1998) and Watson et al (1999) also noted the strength of the influence of the social identity of learning disabilities.

Adults and their appropriate use of power

Parents felt that catering to their child's needs (e.g. a need for structure) was **demanding and tiring, and that respite was required in order for them to 'get a break'**. This is recognised by Mencap (2003). Parents had been made to feel guilty or uncaring for wanting residential overnight breaks for their child; there seemed to be an idea that this would create a dependency for support, possibly influenced by a concern that the child would become accommodated full-time. **All participants referred to short breaks as 'respite'**.

The idea of attending a short breaks unit was not discussed with the children prior to them accessing the service; they did not meet with staff who were gathering information on them, and were excluded from the process of decision making (Beresford, 2002). However they were included in the process through **'preparation' (staff), 'doing some familiarising' (parent), 'an initial visit, and tea visits' (staff), 'a gradual introduction' (parent), and 'by seeing the place and seeing what we do' (staff)**. It was important that children saw the place, experienced it, and got to know the staff. In general the parents visited first to ensure that the placement was appropriate for their child. In this way it can be seen that they provide a filtering mechanism for their child and this idea will be revisited later.

Parents constructed the short break service as 'a holiday' for their child. Beresford (2002) attributes this to the lack of access to mainstream **opportunities (e.g. sleepovers at friends' houses)**. They expressed the importance of short breaks as benefitting the family, illustrative of the need to balance interests of individual family members against the interests of the family unit (Bainham, 1998). However the young people involved in the research were happy at the short breaks unit: **'young person drew a smiley face on the iPad and said this was a picture of their mood'** and this was also important to their parents. They felt that short breaks needed to benefit the child as well as the rest of the family, and that they **should be free to 'achieve their full potential'**. It was expressed that if the child was not happy this would impact on their behaviour and ultimately their parents emotions, thereby outweighing any benefit.

Parents were keen for their child to be involved in decision making, and **described it as 'worthwhile' and 'important'**. However, as parents, they often chose to advocate on behalf of their children, by guiding or overriding their **child's decisions if they felt it was important for their wellbeing, health** or development. Without this it was assumed that children would limit their experiences due to anxieties that they would not like or could not do something. In this respect it is important for parents to understand their responsibilities, which are regulated by the state for the benefit of children and society (Herring, 2011). **A respect for children's rights is not the same as a requirement for them**

to decision make (Flekkoy and Kaufman, 1997): **parents hold rights 'in trust' for the child and state, and parental responsibility can be seen as having decision making power (Herring, 2011). Rights and responsibilities are individual to each parent-child relationship and change depending on age and maturity (Herring, 2011).**

It was recognised that while the short breaks unit provided experiences the children liked - **'I like playing with (another young person) best... I like to play with... the Wii... I like playing with... marbles' (young person)** – it should do more than just this. Functions of respite were expressed as providing structure and calm; challenging and encouraging children to do more and try more; and being part of group processes. It was felt that the short breaks unit could create **new and different opportunities and experiences, such as 'play with messy things, or maybe just going for longer walks, or maybe cooking something... you know when they are doing something for the first time... like for example baking their own little cake, or cutting with a knife,... or recently a young person went to the cinema with us; first time ever in their life' (staff). Staff felt it was important for them to plan and share information as a team, so that they could provide experiences that would be best for that child. In essence, they replace the advocate filtering mechanism that the child's parents provide for them.**

The peer group at the short breaks unit was very important, to the point that it influenced whether or not children were willing to attend. The benefits of group relationships have been commented on by others, e.g. Doel (2010), and similarly staff relationships were important. Competent staff were able to boost **parents' confidence in the service, children named specific members of staff who they liked, and were keen to know who would be working with them. In order to engage skilfully with the children it was felt that staff needed a combination of experience and training.**

Staff's skills and abilities at involving or encouraging children influenced the quality of the interactions and the child's participation. This has been recognised previously by McNeish and Newman (2002), and Wright et al (2006). The staff that were met with felt that they should seek children's views more, and in a better way, and that it should be an ongoing process (as advised by Pinkney, 2011) similar to opportunity-led work (Ward, 2007). Staff's attitudes and values also had a big impact on the participation of young people, as noted by writers such as Shenton (2004), Sabo Flores (2008), and Dickins (2008). It was expressed that where staff behaved as though they did not have the time or resources, or were inconvenienced by seeking young people's views, this could be off putting for young people.

Staff's attitudes and values are formed from the way that they conceptualise care (Milligan and Stevens, 2006), and construct ideas of choice, rights, protection, and responsibility. Where interventions are framed by rights this is

seen as an ethic of justice, where they are based on relationships this is seen as an ethic of care (Banks, 1995). It was clear from the interviews carried out that in order for participation processes to be successful they must be based on an ethic of care, and the importance of relationships in this arena have been recognised by authors such as Sinclair (2004) and Emond (2008). Knowing people was seen as one way of making it easier for children to participate. It was important for staff to have prior knowledge and experience of young people so **that they could interpret meaning from children's body language and vocalisations**. Where staff did not have the suitable amount of knowledge they **were required to 'communicate with parent[s], you know, you actually talk to other people and professionals'** in order to gain this.

Involvement through experience

Adult participants felt that it was important for children to have involvement in **their own life, 'in the sense that 'It's your life' ' (staff)**. This reflects an ethic of justice as the right to be consulted is now recognised as a fundamental human right (Dickins, 2008). **Staff felt that children should 'take part' 'as much as possible' 'in any way that's appropriate for them'**. At the short breaks unit children were observed being involved in activities (e.g. what to draw), choosing activities (e.g. choice of walk or garden), and household tasks (e.g. setting the table). One of the children who was met with expressed that they felt happy when staff respected their ideas and bad when they did not. Participants thought that it was easier for more able children to give feedback. They recognised that children with learning disabilities have difficulty with self-reflection, and the verbalising or expression of this. Beresford (2012) also commented on the limited ability to self-reflect. Participants believed that children can reflect on experiences they have had, but the consistency of these responses varied, so **there was a need to 'check' the responses** by asking again at different times.

Participants expressed that the forms used for reviews can be too formal and inaccessible for young people, making them meaningless. The extent to which **this was true depended on the level of the child's ability**. Other writers have noted an over-dependence on formal methods (Martin and Franklin, 2010), an assumption that children can express their views on paper (Carpenter and McConkey, 2012), and some continue to perpetuate a focus on attending meetings (Murray, 2012). Different ways of gaining feedback were identified by **staff as 'observing' (which requires a relational aspect to ensure true representation), 'art work and videos, and taking photos of the young people's activities, and you can do a scrap book', 'computer', 'we've done Talking Mats as well', 'yes' and 'no' choices', and 'a more informal chat'**. These can be likened to **the 'participatory techniques' proposed by Kendrick et al (2008), or the more informal approaches advocated for by Martin and Franklin (2010)**. The importance of using appropriate communication tools was identified (as advised by Morris, 1998), and the use of symbols was given as one example of this.

The children who were met with did not attend their respite reviews, but they did attend their schools' reviews for a short time. This correlates to the findings of Whittles (1998) and Hawthorn (2010). Participants felt that it was possible for children to attend their review for a short time, but that they were restricted in their understanding of the process, and so this may be deemed tokenistic if the child is not fully aware of the procedure (Flekkoy and Kaufman, 1997). It was identified that the children did not always want to participate, the reasons for this being related to the nature of **the child's disability**. **For example:** they were seen to have restricted capacity; be limited by their behaviour; have limited expectations of themselves as competent to make decisions (sometimes projected by staff); or an anxiety around choice and change (often associated with autism, Beresford et al, 2007). Choice, and the associated autonomy and freedom are commonly posited as positive options, however, it is clear that for some people this is not the case.

There were a number of other areas identified **which limited the children's** participation: power, protection, reality, attitudes, and wellbeing. The effect of power on participation has been previously identified, for example by Martin and Franklin (2010), and Pinkney (2011). Staff held a belief that children were **limited by the fact that 'they expect a lot from staff to decide for them'**; based on their experience of adults who **'protect this child more from the beginning' they had become passive**. As Hyder (2002) expressed **'If children are not used to being consulted or expressing an opinion it may take some time for them to participate fully, if at all'** (p. 321). The effect of protection on participation has been previously identified, for example by Lansdown (2001), McNeish and Newman (2002), and Cross (2011).

Children's decision making was limited to safe, realistic, and appropriate choices. It was identified that the choices needed to be 'meaningful' (parent and staff), and so 'concrete' (parent and staff) and 'limited' (parent) choices (e.g. 'yes or no', a choice of two, or only offering available options) were used, and supported through the use of visual aids like symbols. This is in keeping with the recommendations of Ward (1997), McNeish and Newman (2002), and Stokoe (2003). Often, for this to happen the adult would choose first, again illustrating the filtering mechanism presented earlier. It was acknowledged by all participants that some things were a free choice (e.g. some activities, the order of activities, some food choices, where to sit, which bedroom to use, and which DVD to watch) and some things were not (e.g. going to school and respite, doing homework, some outings, some food choices, brushing teeth, and who was available to play with). This was true for neurotypical children (i.e. siblings) as well as those with learning disabilities.

Staff attitudes were capable of limiting a child's level of participation, as discussed earlier. Similarly the child may have had bad experiences of their views being sought. This is illustrative of the tokenism described by Tisdall and

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Liebel (2008). Finally, participation was limited for the child's wellbeing. As described earlier adults may choose first to 'narrow down' the choice, or guide and shape choices to promote new and different experiences. As Anglin (2002) identified, what is in children's best interests is often not what they want.

Impact of diagnosis and communication preferences

Participants recognised that the 'diversity of levels' presented earlier required different means of interacting, as advised by Simons (1998) and Adams (2003). The ASDAN Award Programmes (ASDAN, n.d.) also recognise the diversity of levels of children with learning disabilities. ASDAN provides an extensive choice of flexible education activities to develop and accredit skills in young people with learning disabilities. To reflect this there are a range of levels of support to differentiate between how each child has achieved each activity: 'No Help', 'Spoken/Signed Help', 'Gestural Help', 'Physical Help', 'Sensory Experience' and 'Experience Recorded'. Participants expressed that disability creates difficulties with expressive and receptive communication, and that this made it more **difficult to seek children's views. It has been well recognised that children with communication impairments are less likely to be included, have their opinions sought, or make choices (e.g. Whittles (1998); Scott and Larcher (2002); Sinclair (2004); Martin and Franklin (2010)).** Because of this staff felt it was **important to 'increase communication', 'to find a tool, or find a way to find out what they really want to do, or make this meaningful for them'.**

One of the ways presented by staff as increasing children's possibility of understanding was to 'blend all together' by using the 'Total Communication' approach. Total communication is a multi-sensory approach using tactile, auditory and visual information in which 'all means of communication are valued and promoted as appropriate' (Thurman, 2009, p. 9). However, staff identified difficulties with this such as 'you are just forgetting, and this is the most annoying thing, coz we could do so much more'. It was felt that school settings were more advanced in this area. Augmentative or Alternative forms of Communication (AAC) in use were British Sign Language (BSL), sign-a-long, on-body signing, visual choices, object representation, pictures, photographs, an iPad, symbols, Boardmaker, PECS, visual timetables, Talking Mats, Social Stories, object signifiers, and song signifiers. A number of other authors have commented on the use of AAC, such as Townsley (1998); Marchant and Gordon (2001); Scott and Larcher (2002); Cameron and Murphy (2002); Beresford et al (2007); and Dickins (2008).

The importance of recognising behaviours as a form of communication was highlighted by participants, but it was noted that this required a knowledge and experience of the variety of common attributes of people with learning disabilities, as well as of individuals. This again highlights the importance and significance of relationships (Ruch, 2010) in a residential child care setting

(Smith, 2009). **One way of gaining a child's feedback in relation to their** behaviour required observation and assessment of the behaviour. This required key staff to work directly with the child, and to know the individual. Ways of expressing distress or anxiety were described as hitting, pushing, screaming, **being 'upset'**, scratching, self-harming, **'acting out'**, hyperventilating, or refusing to engage. Pleasure was expressed as the child being calm, talking in a positive way about their experience, singing, or dancing. These examples correlate to the ideas of Whittles (1998) and Morris (1998).

Staff felt that children with more challenging behaviours 'usually have more attention, they usually have more, usually even better staff to work with them, **they usually have more outings'**, so in this way the behaviours were effective in ensuring the child received a better quality service, and shaped what worked for them. For children with complex needs it was felt to be more difficult to gain their feedback. However, the importance of understanding facial expressions and body language (including positioning in a wheelchair) was recognised, along with an understanding of their vocalisations and noises. This is illustrative of the **'creative conversation' approach presented by Caldwell and Stevens (2005)**.

The staff that were met with recognised that communication with children **'doesn't have to be words' and described talking as 'for any kind of young person kind of boring and doesn't make sense'**. However, there was a tendency for **them to focus on verbal communication, as 'it's so easy for us to just go back to talking...I think it is something which comforts us'**. **The fixation with children's** verbal skills can be seen historically, e.g. through the focus on oralism in deaf education (Marschark et al, 2002), and has been highlighted in the participation literature e.g. Mitchell and Sloper (2001); Lansdown (2001); and Dickins (2008). Tisdall (2012) **stressed that the focus on promoting children's 'voice' prioritises** their verbal skills, and McMahon (2010) identified that by only listening to **children's expressed choices we may be ignoring their unconscious voices (i.e.** what they say may not be what they mean). In a similar way to which BSL is **now recognised as Deaf people's first language (Sutton-Spence and Woll, 2011)**, consideration needs to be given to what the first language of each individual young person with learning disabilities is.

As discussed previously participants expressed that where children are making choices adults should ensure this is meaningful. The best way of achieving this **was expressed as basing the choices on the child's experience. Concrete** experiences create meaning, which provides the child with an informed opinion. Similarly, Smith (2010) proposed that children should be given opportunities to **draw on their 'lived experience', and in Beresford's (2012) study she used 'real life' concrete examples to support the children to reflect on their lives.**

Participants felt that children could only choose within their experience, similar to the way in which Flekkoy and Kaufman (1997) identified the ability to make choices as being dependant on experience and access to information. Children

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needed the experience first in order to reflect on it. Examples of where the child was able to reflect on aspects of their experience were holidays, respite provision, college, games, activities, food, and the reasons for limits imposed by adults (e.g. safety).

It was difficult for children to imagine outwith their own reality, for example staying overnight at a new short breaks unit, going to college instead of school, or living somewhere else other than home. This means that experiences create boundaries for **the development of the child's ability: 'the extent of their ability is the extent of their experience. So it has to be experientially based' (parent)**. Frames of reference construct the way we see the world (Mezirow, 1997) and exposure to experience is the basis of the formation of these. Without an experience on which to base their choice the child may avoid unknown choices or make an uninformed choice, which would be deemed tokenistic. They may also agree or disagree with the adult without understanding the choice they are making.

A more meaningful way of gaining their feedback was to observe their experience of the situation, as explored earlier. Murray (2012) describes the **need to enhance the ability to participate. Where children's participation is based** on their experience the most successful way to do this is to provide a variety of experiences, as the short breaks unit does. If your communication style means you are informed through experience rather than language, then you need to experience first in order to be informed. In this way participation becomes **'opportunity-led' by ensuring it is naturalistic and relevant (as advised by UNCRC (1989); Badham (2004); and Pinkney (2011))**.

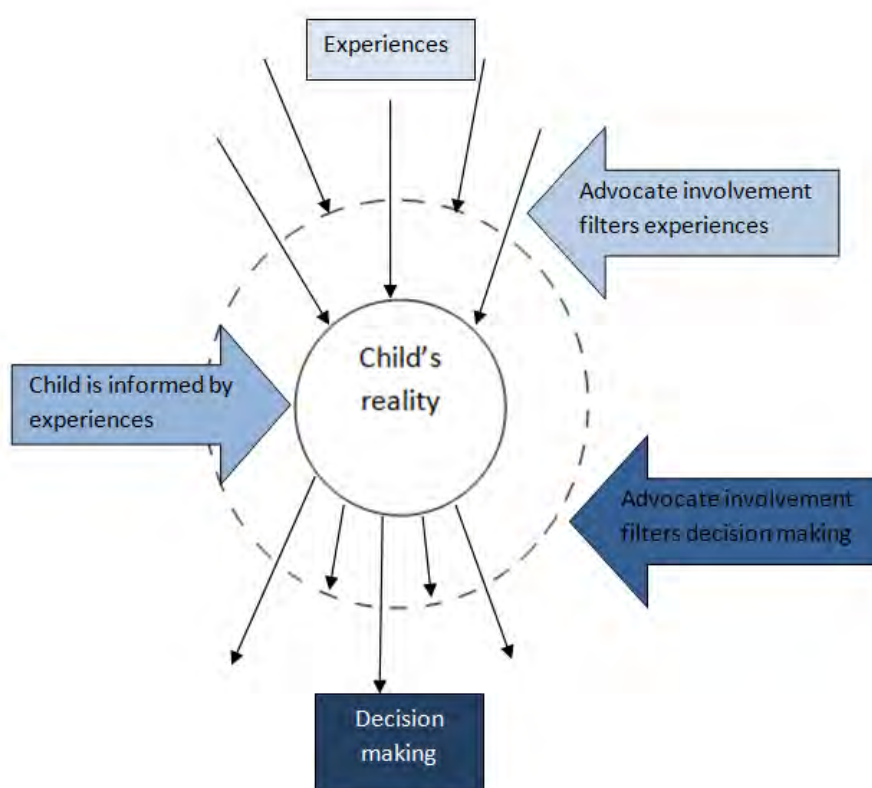
Conclusions and Recommendations for Practice

Recognition is given to the fact that this was a small study carried out in one setting, and that this will have limitations on the findings discussed above. If the study was to be repeated, it should be done so on a larger scale, across a variety of settings. From the findings presented here, it can be seen that the social construction of people with learning disabilities has a direct impact on their levels of participation. It has been shown that the social exclusion of children with learning disabilities decreases their level of participation, and therefore inclusive practice should continue to be the aim of all settings. When devising inclusion and participation strategies it is important that this is considered in the life context ensuring that adults with accountability for children with learning disabilities (i.e. parents or staff) understand their responsibilities **and use their power appropriately to provide a 'filtering mechanism', which ensures children's protection, wellbeing, and adherence to reality.**

It is likely that the exclusion of an understanding of learning disabilities from the most influential models of participation (Hart, 1992; Treseder, 1997; Shier,

2001) has in some way influenced children with learning disabilities from being excluded from meaningful participation in practice. Therefore, the need for the **development of a new 'experiential model of participation' has been identified** (see below) which takes account of the different abilities and communication preferences of people with learning disabilities, in a similar way in which ASDAN (ASDAN, n.d.) does. This model recognises that to participate in a meaningful way children first require to be informed by experience. Adults must take **responsibility for shaping these experiences by 'choosing first' and guiding** or limiting decision making on the other side to ensure appropriateness.

The Experiential Model of Participation (Wilson, 2012)



It has been demonstrated that children's ability to participate is increased through exposure to experiences as this provides them with meaningful and concrete information. If we appreciate that it is difficult for children with learning disabilities to imagine a truth outside of their own experience, then we must show dedication towards expanding the frames of their reality as much as is feasible. It is proposed that if one of the main functions of short breaks services is to provide children with new and different experiences then an increased ability to participate is a natural outcome of this. If this is understood to be true, then it can be assumed that participation should be embedded in the practice of residential short breaks units.

The focus on linguistic based interpretations discussed earlier can be seen in government guidance documents such as the National Care Standards (Scottish Executive, 2005) which are written as though they are talking directly to young people, but are not available in a variety of accessible formats. If the values which underpin them are truly meaningful then they must be accessible to all children. Therefore there is a need to produce versions of the National Care Standards which would be truly accessible to all young people (including children with a variety of communication differences). In addition, if the Social Care (Self Directed Support) (Scotland) Act 2013 is going to make a genuine commitment to including groups of people with learning disabilities, autism, and alternative communication styles, professionals will need to consider how their participation styles can be catered **for in the 'thinking process' phase of assessment. The way that the government constructs policy guidance influences policy and practice more locally, and ultimately young people's reality.**

It has been shown here the importance of recognising a variety of forms of communication, and it is recommended that the Total Communication approach (Thurman, 2009) be universally adopted by all services. In addition the significance of behaviours as communication must continue to be recognised and expanded to ensure that the reality of children with complex needs is also included (i.e. an understanding of facial expressions, vocalisations and positioning as both behaviour and communication). The importance of a relational approach as being central to this must not be underestimated. Where children communicate first and foremost through their experience and behaviour, this should be recognised as their first language.

About the author

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