

Submission to the Journal of Intellectual Disabilities:

Social pedagogy as a model to provide support for siblings of children with intellectual disabilities:
A report of the views of the children and young people using a sibling support group.

Sid Carter*
Faculty of Health and Social Sciences, Bournemouth University

James Cook
Plymouth Child Development Centre, Plymouth Hospitals NHS Trust

Gary Sutton-Boulton
Children's Learning Disability Service, Dorset HealthCare University NHS Foundation Trust

Vicki Ward
Children's Learning Disability Service, Dorset HealthCare University NHS Foundation Trust

Steve Clarke
Children's Learning Disability Service, Dorset HealthCare University NHS Foundation Trust

* Corresponding author:
Dr Sid Carter
Faculty of Health and Social Sciences
Bournemouth University
Room 204
Royal London House
Christchurch Road
Bournemouth
BH1 3LT
Tel. 01202 968118
Email: scarter@bournemouth.ac.uk

Abstract

The experiences of non-disabled children growing up with a sibling with an intellectual disability vary considerably, with reported impact ranging from increased mental health problems through to evaluations of life-enhancement. However, there is evidence that the net impact is neutral to positive, which was supported by the findings of this report of a service evaluation survey. The value of providing support to those young siblings is however clear. An established method of support is within a group of peers who also have a sibling with an intellectual disability, though no specific method for running this type of group has yet been fully explored. This paper reports the views of 39 children taking part in such a group, analysing their perspective through a proposed model for the operation of sibling groups: social pedagogy. It was found that the closer the group's activities were to social pedagogy, the more supported the children and young people felt.

Key words:

intellectual disability, non-disabled sibling, children, social pedagogy, support group.

Introduction

The psychological and emotional impact that a child with intellectual disabilities has on their non-disabled siblings has been widely studied, but the collective results are equivocal. It remains open to question whether growing up in a family with a brother or sister with an intellectual disability harms, benefits or has no overall effect on their non-disabled siblings, as all three outcomes have been reported (Bayat, 2007; Giallo et al., 2012; Giallo et al., 2014; Moyson and Royers, 2012; Petalas et al., 2009a; Petalas et al., 2012; Williams et al., 2010). It is important to gain a better understanding of this relationship, at least to ensure that appropriate help is provided.

One potential explanation for this lack of clarity in the findings of sibling studies is that any child, disabled or not, on becoming part of a family is joining a system that is universally complex and multifactorial. Schuntermann (2007) proposed that this complexity could be captured within six domains. The first domain contained the panoply of family system theory, including sibling birth order, gender order, and shifts in mother-child relationship following the arrival of a new sibling. The next four domains related specifically to the sibling experience: triadic parent-child interactions, sibling relationships, intergenerational setting (grandparents), and social setting (friends, peers). The sixth domain focused on siblings' perspectives on how to give meaning to living with a developmentally-challenged brother or sister, now and in the future. Schuntermann's model is comprehensive, but Orsmond and Seltzer (2007) added the dimension of changes that may occur over the child's lifespan. They further contributed to an already complex picture by suggesting that variability in findings may indicate that there are factors at work that have not been measured or taken account of yet.

Part of the variability in findings may arise from the use of either parental observation or data directly from the children themselves. Cuskelly and Gunn (2006) investigated siblings of children with Down's syndrome, comparing data from mothers, fathers and their non-disabled children. The Child Behaviour Checklist (CBC) was completed by both parents to measure the "adjustment" of the target sibling. Agreement between fathers and mothers on the CBC was statistically significant,

but the correlations were low, placing doubt on the accuracy of any parental assessment of their child's status. When parents' scores were compared with their child's self assessment, mothers were marginally better predictors than fathers. There were statistically significant correlations between parent and child scores for some elements of the test, but not all, and the greatest correlation was 0.36. Sharpe and Rossiter's (2002) meta-analysis found that parent reports were more negative than children's self reports. Guite et al. (2004) carried out a study to specifically test the level of agreement between parental (particularly mothers) evaluations of the responses of siblings to having a brother or sister with chronic illness (CI) or intellectual disability, and the sibling's self reports. Fifty one non-disabled siblings aged 8-13 completed the Sibling Perception Questionnaire, and their scores were compared with their parent's (98% mothers). Discordance was common (18 concordant dyads and 33 discordant dyads, of which 22 siblings reported having less problems than their parents did, and 11 reported more problems than their parents had). Siblings who reported more problems than parents tended to be younger and male. There was a trend for parents who reported that their non-disabled children had more problems than the children themselves did to also report higher negative consequences on family functioning of CI or intellectual disability than other parents. These results clearly indicate that for a rounded picture of adjustment, multiple viewpoints are essential, particularly the viewpoint of the non-disabled child themselves.

Studies of the impact of having a sibling with intellectual disability also demonstrate a complex array of methodologies: they often have small numbers of participants, and vary widely in the number and range of variables being investigated. Thus direct comparisons between studies are made more difficult, and this adds to the variability of results. However, a number of researchers have attempted to eliminate as many confounding variables as possible, to isolate the independent variable of having a sibling with an intellectual disability. Such studies have produced interesting results.

Pilowsky et al. (2004) studied three groups of siblings (autism (30), intellectual disability of unknown genetic aetiology (28), and developmental language disorders (DLD) (30). The groups

were compared on measures of social-emotional adjustment, behaviour problems, socialisation skills, and sibling relationship. The participants and their families were rigorously matched on several parameters to attempt to reduce the effect of confounding variables. It was hypothesised that siblings of children with autism would exhibit more mental health difficulties than the other sibling groups, due to genetic vulnerability and factors in the environment. This includes the important point that genetic elements of autism may be present to some extent in siblings without fully 'expressed' autism. It also presumes that living in the same family as someone with autism will be extraordinarily stressful. However, results revealed that there were no differences in the family daily stress levels between the three groups.

The siblings were extensively clinically tested, and 14 siblings received clinical mental health diagnoses: 4 siblings in four families in the autism group, 3 siblings in two families in the intellectual disability group, and 7 siblings in five families in the DLD group. These differences were not statistically significant, indicating that there were no clinical differences between the three groups of siblings. There was equal prevalence of autism among the siblings of all three groups, despite the prediction that the autism group siblings should have been higher.

The study found that siblings of children with autism coped remarkably well, "...we would venture to suggest that siblings' adjustment is not necessarily affected by having a sibling with autism, if anything, it is positively modulated revealing, as siblings grow older, an enhanced empathic ability towards their sibling" (Pilowsky et al. 2004: 862).

Roeyers and Mycke (1995) studied 60 siblings (aged 8-15): 20 had a sibling with autism, 20 had a sibling with intellectual disabilities, and 20 a non-disabled sibling. They were matched for factors such as gender, age, and birth order. The study was based on an interpretation of Lazarus and Folkman's stress theory, including coping mechanisms. A questionnaire method was used, but the young people completed them themselves, there were no second hand parental reports. The three groups were broadly similar in their ratings of stressors involving their siblings, plus there was a trend for the siblings of children with disabilities to rate their relationship with their brother or sister

more positively. The group with siblings with autism were tested for their knowledge of the condition, and this was correlated positively with the quality of their relationship. The theoretical model chosen focused on anger, there were no significant differences between the three groups. There were no significant differences between the groups in the range and use of coping mechanisms either, leading the authors to conclude that "having a disabled sibling does not necessarily lead to a problematic sibling relationship" (Roeyers and Mycke 1995: 315).

An Australian study attempted to eliminate some of the potential 'family structure' confounding variables by focusing on Down's syndrome, and matching these families with corresponding ones without any disabled children, but whose structure was much the same by gender, age, and position in the family (Cuskelly and Gunn, 2006). Families were also matched by family size and father's occupation. Thus there were 53 families with a child with Down's syndrome, and the same number of families with the same overall structure, but with only non-disabled children. The study also made sure to include the views of the siblings alongside the reports from both parents (but not the child with a disability). Ultimately the study aimed to find out the impact of a child with Down's syndrome on the "adjustment" of the non-disabled sibling.

The Child Behaviour Checklist (CBC) was completed by both parents to measure the "adjustment" of the target sibling. The Self Perception Profile for Children (SPPC) was completed by the target siblings to measure self esteem and satisfaction. Parents and non-disabled siblings completed the Sibling Inventory of Behaviour (SIB). Caregiving and chores completed by the non-disabled sibling were also measured. Overall, the study found no meaningful relationship between having a sibling with Down's syndrome and poor "adjustment". The study concluded that any risk to a non-disabled sibling emerges from the complex array of intra family factors rather than simply belonging to the group of children who have a sister or brother with an intellectual disability.

Neely-Barnes and Graff (2011) used large scale US survey data to find children with and without siblings with disabilities. The type of disability was not specified, but the questions used to isolate

the cases were to do with development, so probably found mainly cognitive impairment-related disability. The initial bivariate analysis between siblings with and without a brother/sister with disability revealed the common higher occurrence of mental health problems, behavioural difficulties and so on in the children with disabled siblings, though the effect sizes were small. Following the initial analysis, a statistical technique called Propensity Score Matching (PSM) was applied to the data. PSM was claimed as a robust method to eliminate confounding variables in quasi experimental or observational data. This procedure isolated 369.4 matches out of the original set of thousands of families. Once these matches were made, the bivariate differences between the two groups of siblings, already low, diminished to non-significance. Predictors of negative mental health outcomes for children with or without siblings with disabilities were factors such as lower socioeconomic status and being part of a single parent family, irrespective of the presence or not of a child with a disability in the family.

There were several potential flaws in the study, fully acknowledged by the researchers. It could be that having a sibling with a disability does have specific effects on a child, but that these are both positive and negative and so may achieve some kind of balance. There were also some widespread demographic differences between families with or without a child with a disability. So the exact process is still open to investigation, but these findings strongly suggest that having a brother or sister with a disability has no net effect on the mental health and behavioural consequences of a child's development (see also review by Families Special Interest Research Group of IASSID, 2014). The study also makes a strong case for the use of PSM in quantitative studies of this type.

This set of findings could be interpreted by suggesting that dispositional and demographic factors are primary in producing negative outcomes for siblings. The presence of a child with intellectual disability in a family simply triggers difficulties within a flawed family system. Peverley's (2011) poignant personal reflection on what it was like growing up in a family with a challenging elder sister with autism offers an illustration of this possibility. The main coping strategy of the whole family was to pretend that everything was OK, leading Peverley to lead a fantasy life about being

an international ballet dancer. The effects in later life were more pernicious though, leaving her with a fear of confrontation, constantly scanning the needs of others, and low self esteem. This family "culture" led to her difficulties, the fact that her sister had autism was in that sense irrelevant. "Pretending becomes a way of life. It is pretence that creates areas of personal dysfunction, not parents or other family members" (Peverley, 2011: 11). Peverley's recollections are thought provoking - the family member with intellectual disabilities simply triggers some family-specific coping method that may or may not be harmful to that family's members.

To augment this view, there is evidence that non-disabled siblings appreciate support, presumably this would contribute to existing positive elements of their family life, helping towards a net overall positive outcome. The next section reviews what types of support are available, along with what is known about the effectiveness of these approaches.

Supporting non-disabled siblings

The primary approach reported in the literature to proactively help siblings is the use of support groups. Research on the structure and process of sibling support groups, and the relative efficacy of the different approaches, is limited, but several common themes emerge. There is evidence that the majority of siblings value this mode of support (Pit-ten Cate and Lools, 2000; Roeyers and Mycke, 1995). The siblings studied by Naylor and Prescott (2004) valued the separate time offered by a support group, as did the young participants in studies by Smith and Perry (2004) and Kramer-Roy (2012). The value attributed to support groups by siblings was partly because of the opportunity to share experiences with other children in a similar situation (Smith and Perry 2004), but also because they gained the chance to express their unique perspective, perhaps for the first time. For example, Naylor and Prescott (2004) carried out a questionnaire (parents and children) and a series of semistructured interviews (children only) with seven non-disabled siblings. A fascinating outcome was that the children queued up to be interviewed by the researcher; they were so keen to be listened to in their own right by an independent adult. A further example was provided by Kramer-Roy (2012), who studied the experiences of Pakistani families with a child with

disabilities. She found that a common experience for all participants, including the siblings, was that no one had asked them about their perspective before.

However, a preeminent theme in the evaluations of sibling support groups was the primacy given by the siblings to fun, playing, and games-based activities over discussion-based activities (Petalas et al., 2009). Lock and Finstein (2009) studied the expectations of the value of a sibling support group amongst parents and siblings of children with autism in rural Texas. Questionnaires were completed by parents and siblings; 82% of parents agreed that separate support groups for siblings were needed, compared to 45% of the siblings agreeing that they would like to take part in such a group. The researchers found that sibling enthusiasm for support groups increased when they discovered that they were focused on relationship building through fun and child centred games rather than onerous sharing of feelings. Evans, Jones and Mansell (2001) ran three sets of time limited support groups; the aim was intentionally educational and had a "problem solving focus". "Leisure" activities were incidental to the planned programme, but in their evaluation, the children highlighted them as a very positive element of their experience, including outdoor activities, being part of a group, and craft activities. Staff also evaluated that the activity groups were more effective than discussion groups. Smith and Perry (2004) studied 26 non-disabled siblings aged 6-16 who took part in a support group that met weekly for eight weeks. The group was primarily educational in focus, but deliberately incorporated activities that were fun and promoted "group cohesion". Several children completed the programme more than once because they simply enjoyed it and had fun.

It is apparent from the evidence that siblings find support groups beneficial, particularly when they are based on fun and creative activities as part of a group. These findings would come as no surprise to practitioners of social pedagogy, as these are foundational precepts of their philosophy. Social pedagogy is a primary and ubiquitous approach to working with children and young people right across mainland Europe. The following sections describe the foundational principles of this approach and profession, illustrating how adopting it provides a ready-made, coherent, and tried and trusted method of emancipatory practice with children.

Social Pedagogy

Social pedagogy is a well established philosophy, practice and profession in working with children in mainland Europe (Cameron et al., 2009), which has evolved and developed over centuries. In many countries in mainland Europe (for example, Germany, Denmark and Norway) social pedagogy is the primary profession working with children in the space between formal education and social work, such as the care of looked after children (Cameron et al., 2007). Europe-wide, social pedagogues are typically prepared for professional practice through three or four year bachelor degree programmes (Stephens, 2009). Social pedagogy has its roots in philosophies and educational activism reaching back to the eighteenth century and beyond, for example Comenius (1592-1670) promoted the pedagogue as 'gardener' rather than 'sculptor' (Comenius, 1631/1967). Another significant figure in the development of social pedagogy was Johan Pestalozzi (1746-1827) (1801/1894). As well as promoting a spontaneous and child-led approach in direct encounters, he emphasised that work with children always has a sociopolitical context. Thus social pedagogy as an approach and as professional practice actively aims to be part of the fight for social justice; social pedagogy overtly promotes the political rights of children and young people. A more recent and familiar name in the pantheon of social pedagogy's influences is Maria Montessori. Amongst Montessori's many contributions was the principle of 'following the child' and the importance of joy (Montessori, 1949).

The rich, diverse, yet essentially pragmatic, heritage of social pedagogy has led to an approach that has a very holistic view of the child, with the inclusion of 'head, heart and hands' as a central precept (Petrie et al., 2006). Social pedagogy prizes the benefits of working primarily as part of a group, the use of creative arts and crafts, and active, preferably outdoor, activities (Cameron et al., 2007). It is a fluid approach, and Hämäläinen (2003) noted that each nation practising social pedagogy lends to it its own particular slant. However, Petrie et al. (2009) produced a nine point

summary of the key principles of social pedagogy, which is widely accepted and is reproduced in the first column of table 3.

Until the beginning of the current century, social pedagogy was little known in the UK. With a changing philosophy towards children and families emerging in UK social policy, namely a greater emphasis on children's rights and more integrated services, a fresh approach was needed (Cameron et al., 2009). Attention turned to our European neighbours' use of social pedagogy, which has been interpreted as 'education in its broadest sense' (Petrie et al., 2009), or a collective and collaborative effort in the 'bringing up' of children (Eichsteller and Holthoff, 2012). This led to a strategy of investigating the processes of social pedagogy in its European homelands (Cameron, 2004), and its introduction into a variety of children's services across the UK (Cameron et al., 2011).

Enlightened UK practitioners 'recognise' social pedagogy straight away when introduced to it, perceive it as the way they always wanted to work with children (Bengtsson et al., 2008:12), that is, to engage with children with authentic emotion. However, social pedagogy is in stark contrast to the risk averse neoliberal philosophy currently dominant in health and social care. This may at least partially account for the mixed success of a major pilot project to more formally introduce social pedagogy to looked after children's services across the UK (Berridge et al., 2011; Cameron et al., 2011).

Social pedagogy continues to be applied in the UK, including work to involve children and young people with intellectual disabilities in their services (Carter et al., 2013). It has tremendous potential, but as predicted by European social pedagogues, presents a direct challenge to powerful neoliberal ideologies in UK education, health, and social care (Coussee et al., 2010; Lorenz, 2008). However, social pedagogy is a non-pathologising, well-established, empowering, and emancipatory way of working with children and young people. It has a longer history than most methods, and fully integrates a vital sociopolitical critique that is commonly omitted when working with children.

Survey of children and young peoples' views on their support group

Ethical issues

The survey reported here was a service monitoring and improvement activity and thus did not need approval from a research ethics committee. This was checked and confirmed by the Trust's research Lead. The parents of the children and young people taking part in the survey gave written consent for their children to complete the survey, and also consented for the findings to be disseminated. The subsequent comparison of the children's views with the principles of social pedagogy emerged later, and represents the reflections of the practitioners involved.

Process

The findings presented in this paper represent two separate, but interconnected, processes. The first is a questionnaire based survey of the views of the children and young people attending a sibling support group (known as SIBS). The survey was carried out as part of a continual process to involve the young service users, and to ensure service improvement. The second emerged from the practitioners running the group reflecting on their practice, and seeking an evidence base for the intervention. Thus, the second process is a critical analysis and interpretation of the findings of this survey through the perspective of social pedagogy, to determine to what extent the success of the SIBS group could be attributed to applying social pedagogy principles. SIBS is a group for young people who have a sibling with an intellectual disability, which has been established for over 10 years, and is run by NHS community intellectual disability nurses. Each SIBS session lasts 6 hours and sessions take place once or twice a week over most school holidays. Families pay a nominal fee for each session, which contributes to the materials used for the group's activities.

1. Survey of lived experience of being a sibling

Thirty nine children who attended the SIBS group (81% of the total 48 attending the group) completed a questionnaire containing closed and open questions, thus providing individual qualitative data as well as quantitative. Questionnaires were completed as part of information-gathering and quality assurance for the service; participation was with full parental and the child's own consent. Support was available to the children for completion of the questionnaire, but the intention was very much to capture the perspective of the young group members as closely as possible.

The questionnaire had two main areas of enquiry, the first called 'All about SIBS', which focused on the experience of being part of the support group. The second was 'Being a sibling', which explored the child's life with a brother or sister with an intellectual disability.

2. Evaluation of the SIBS group through the social pedagogy perspective

The findings of the survey, qualitative and quantitative, were mapped onto a grid created from Petrie et al.'s (2009) nine point summation of the principles of social pedagogy. This process was part of the practitioners' reflections on facilitating the group. Social pedagogy is a fluid and dynamic concept, but is well captured in this format, which has been used previously to investigate the application of the approach to interventions (Carter et al., 2013). The use of a grid is by no means intended to suggest an empirical analysis; it is more akin to a thematic, qualitative approach. The tabular configuration does, however, have the purpose of expressing the synergies between the children's' experiences of the group and the principles of social pedagogy in a readily accessible visual format.

The two processes described above combine to add to understanding about the experience of being a sibling of a child with intellectual disability, but also to use that insight to shed light on the type of support that the children themselves find most useful.

Survey findings

Being a sibling

Table 1 contains the findings related to the 'Being a sibling' closed question section of the questionnaire, revealing information about the everyday lives of the children. The questionnaire also included an open question section for the children to add more of their own perspective on being a sibling. Open questions included asking what is good and what they would change about having a brother or sister with a disability. Responses from the girls of all ages were fuller than the boys. Boys under 10 reported that what they liked about their disabled brother or sister included "everything", "nothing", "she is calm sometimes", "because its different", and "they are kind". The contributions from boys over 10 made several references to going to SIBS and special treatment at theme parks as being good, but also "you look after them". Girls under 10 made several mentions of liking that their brother or sister was "funny" or "cute", but also some "don't knows". Several of the girls over 10 mentioned that attending SIBS was good, and also that their brother or sister were "funny", "sweet", and "friendly". Fuller answers from the older girls included "all my friends like her and that's really nice", and "it gives you another view of the world we live in, and makes you appreciate things more".

Boys under 10 who responded to what they would change about their brother or sister stated several times that it would be "nothing", though some said they would prefer them to be "gentle", "make her more kind", and to stop the "hitting". Some of the older boys over 10 said they would not change anything, but there was another theme from other older boys wanting change in the form

of: "not having a disability", "be normal", and that "he could talk". Girls under 10 primarily would have changed nothing, though there were shared wishes to change "her shouting and getting her own way", "stop screaming and pulling", and "I would like him to be nicer". Some of the girls in the over 10 group shared the boys' desire that their brother or sister could talk, in one case "to be able to talk and tell us what is wrong". Other things the older girls would change about their brother or sister with a disability were "being naughty", "their OCD because he is obsessive", "I'd like to be able to spend more time as a family", and a poignant "I wish she behaved better, but I think I am a better person now so I wouldn't change her".

Being part of a sibling support group

Table 2 presents the children's views on their experience of SIBS as a group to support them ('All about SIBS'), providing the closed question responses of the entire group, plus the same responses further categorised by age and gender.

This section of the survey also presented some open questions, giving more insight into the children and young peoples' experience of the group. When asked what they enjoyed most about SIBS there was a remarkable consensus across age and gender. Frequent responses were "everything", "playing", "games and fun", "the activities", "water fights and cooking", "going outside", and "having time off and just relaxing and resting and having fun". There was a similar level of agreement in response to asking what the children liked least about SIBS. Most of the responses were "nothing", though some boys objected to the "rules", and some older boys did not like "little kid activities". Responses to a question regarding how the group could be better also received a fairly universal answer. Some of the responses included specific suggestions, but the overall theme was clear, "play more". One of the older girls expressed it as "just more of the same - I really enjoy coming to SIBS". A revealing open question asked the children how they would describe SIBS to a stranger. A fair proportion of the responses across the range mentioned that it was for the siblings of a disabled child, but some of the older girls expanded on this: "its a group

where kids with disabled brothers or sisters can have fun together", "it is a group for children with disabled brothers or sisters to come and meet other people with the same problems and to get away from them. Its important to understand ways of coping with various problems", and "SIBS is where you talk and understand how you deal with a disabled sibling". However, the overwhelming response across age and gender was summed up by one of the older boys, "to just have fun".

Application of social pedagogy to survey findings

Findings of the evaluation of the SIBS group through the perspective of social pedagogy are presented in Table 3. Evidence from the quantitative and qualitative elements of the survey are aligned with Petrie et al.'s analysis of the primary features of social pedagogy. Reflections concerning the effectiveness of the SIBS group, and how that effectiveness was closely related to adhering to the principles of social pedagogy, emerged from transposing Petrie et al's analysis on the children's reports of their experiences. This comparison showed that SIBS aligns closely with social pedagogy, providing evidence that this may be a factor in its success.

Discussion

Much of the study of non-disabled siblings relies on parental reports. Thus the findings of the quantitative and qualitative elements of this report represent a relatively rare and valuable insight into the views of the children themselves. The contributions from the children and young people reported here supported existing findings about the experiences of the non-disabled siblings of children with intellectual disability, namely, that there is a wide variety of experience, and much of it is positive. It was also found, as in previous reports, that siblings highly value the support of their peers, and that they see real benefits from that support. In addition, this paper addressed the issue of what kind of approach to providing a sibling support group is most effective, finding that the success of the group matched closely with the precepts and practice of social pedagogy. This

complements the body of evidence that social pedagogy contains the essential elements for effective work with children and young people across a wide variety of settings, and indeed across different nations and cultures.

A theme from the literature was a critique of the "pathologising" of the presence of a family member who has an intellectual disability, particularly in terms of mental health. A compelling hypothesis emerged from previous evidence that any pathology experienced by young siblings arose from fault lines already firmly established within some families. Schunterman's (2007) analysis made clear the myriad of factors that may influence relationships inside any family. The appearance of a child with an intellectual disability may exacerbate already existing pernicious patterns. Added to this was the evidence from studies whose methodologies allowed for better control of confounding variables (see Cuskelly and Gunn, 2006; Pilowsky et al., 2004; Roeyers and Mycke, 1995), that having a sibling with an intellectual disability did not have a significant negative impact. In addition, Neely-Barnes and Graff (2011) found that generic demographic factors such as being part of a lone parent family and low socioeconomic resources were better predictors of negative mental health outcomes than having a sibling with a disability. In contrast to the pathologising tone of some of the literature, there is also evidence that being the sibling of a child with an intellectual disability may be protective of good mental health (Pilowsky et al. 2004).

The results of this survey were congruent with these previous findings of neutral or positive net gain to the mental health of young non-disabled siblings. The qualitative self-reports of the children indicated an understandable negative response to "shouting", "hitting", and other stressful stimuli, but much of their perception was overall positive. As a corollary to these specific findings, they also further emphasise the importance of giving at least equal status to the self-reports of the children and young people themselves. Many of the studies in the literature do not convey their voice at all.

An important feature of this study was the analysis of the philosophy and activities of SIBS using the principles of social pedagogy. Social pedagogy is highly respected in mainland Europe, being based on the accumulated wisdom of centuries of practice and the development of benevolent

philosophies. Petrie (2013) analyses the historical and current barriers to full scale UK uptake of social pedagogy, despite its impressive heritage. However, even given these barriers, UK workers share some of this heritage, as professionals working with children and young people were taught complementary approaches up until the 1970s (Fielding 2011).

The results of the comparison of SIBS with the principles of social pedagogy reveal that when the burden of neoliberal policy is lifted, even if temporarily, the children and young people benefit enormously. The hard-won social pedagogy principles of being child-centred, non-hierarchical, group-focused, and emphasising non-instrumental creative play provided a safe and supportive experience for the siblings. Nearly 90% of the young participants felt that the adults listened to them, which combined with the exclusive use of child self report for evaluating SIBS, indicates the relative lack of hierarchy and 'inhabiting the same life space'. This social pedagogical feature of SIBS relates to findings that being able to express the experience of being a sibling to peers and/or adults may be a singular benefit of sibling support groups (Smith and Perry 2004; Kramer-Roy 2012).

Social pedagogues emphasise being practical and creative, which is matched by SIBS being overwhelmingly about activities. The results indicate that it is this aspect of the time spent at SIBS that is most appreciated by the children and young people. One of the few areas of SIBS that received more negative responses from the young participants paradoxically demonstrated the efficacy of social pedagogy. It is fundamentally about working with and through the group, using the collective activities to benefit each individual. The survey reveals that not all the participants felt fully integrated, and so adhering more closely to this principle would enhance SIBS even more, demonstrating the value of social pedagogy as an underpinning guide.

Another element of SIBS that is reflective of social pedagogy is expressed in Petrie's analysis as a "combined effort in the 'bringing up' of children". SIBS is facilitated by a wide range of professionals, who take part in addition to their everyday work because they want to contribute. Many of the professionals know the child with a disability as well, and know the family. There is a

strong sense within SIBS of all working for the common good, in partnership with the families, for the well being of all the children.

A primary theme from the findings was that the children greatly valued informal fun over formal 'lessons'. This supports findings from other studies (Lock and Finstein 2009; Petalas et al. 2009b). There is a place for imparting information, for example evidence for a positive correlation between knowledge of a sibling's condition and positive self-concept (Smith and Perry 2004). However, evidence from the young respondents was overwhelmingly in favour of social pedagogy's emphasis on creative, fun, active, and preferably outdoor activities. For example, there are few formal lessons that could convey challenges to hierarchy and encourage adult-child bonding more effectively than a free play outdoor water fight (one of the favourite SIBS activities). Fun is an element that is neglected in Petrie's and other published analyses. Though alluded to, it is not explicitly named, perhaps because it would appear too frivolous. However, fun is what the children and young people call it, which gives the term legitimacy.

The views of the children and young people represented here were a valuable addition to the accumulating 'voice' of siblings, but there were limitations in the approach taken, including the questionnaire approach itself. The survey's questions and areas of enquiry were chosen sensitively, but by adults. A positive development would be to seek the views of the children on what questions are important to ask. This relates to another limitation, which is the relatively high responses of 'unsure', which may indicate not understanding the question, or not appreciating its relevance.

The findings point to several future areas of study or development. One area that needs rigorous further exploration from both the empirical and interpretative traditions is to challenge the prevalent default assumption that having a brother or sister with an intellectual disability is developmentally harmful to their siblings. Another area of development is to further explore the evidence base for methods of providing support to siblings. Although having a brother or sister with an intellectual disability may or may not cause net harm to their non-disabled siblings, they deserve our best

possible support. They are, after all, the close family of some of the most vulnerable members of our society.

References

Bayat M (2007) Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research* 51(9): 702-714.

Bengtsson E, Chamberlain C, Crimmens D and Stanley J (2008) *Introducing social pedagogy into residential child care in England*. London: Social Education Trust.

Berridge D, Biehal N, Lutman E, Henry L and Palomares M (2011) *Raising the bar? Evaluation of the Social Pedagogy Pilot Programme in residential children's homes*. London: Department for Children, Schools and Families.

Cameron C (2004) Social pedagogy and care: Danish and German practice in young people's residential care. *Journal of Social Work* 4(2): 133-151.

Cameron C, McQuail S and Petrie P (2007) *Implementing the social pedagogic approach for workforce training and education: A preliminary study*. London: Thomas Coram Research Unit.

Cameron C, Petrie P, Wigfall V, Kleipoedszus S and Jasper A (2011) *Final report of the social pedagogy pilot programme: development and implementation*. London: Thomas Coram Research Unit.

Carter S, Cameron F, Houghton J and Walton M (2013) Never mind what I like, it's who I am that matters: An investigation into social pedagogy as a method to enhance the involvement of young people with learning difficulties. *British Journal of Learning Disabilities* 41(4): 312-319.

Comenius J A (1631/1967) *The great didactic* (Didactica Magna). Translated by M.W. Keatinge. New York: Russell and Russell.

Coussée F, Bradt L, Roose R and Bouverne-De Bie M (2010) The emerging social pedagogical paradigm in UK child and youth care: Deus ex machina or walking the beaten path? *British Journal of Social Work* 40: 789-805.

Cuskelly M and Gunn P (2006) Adjustment of children who have a sibling with Down syndrome: perspectives of mothers, fathers and children. *Journal of Intellectual Disability Research* 50(12): 917-925.

Eichsteller G and Holthoff S (2012) The art of being a social pedagogue: Developing cultural change in children's homes in Essex. *International Journal of Social Pedagogy* 1(1): 30-46.

Evans J, Jones J and Mansell I (2001) Supporting siblings: Evaluation of support groups for brothers and sisters of children with learning disabilities and challenging behaviour. *Journal of Learning Disabilities* 5(1): 69-78.

Families Special Interest Research Group of IASSIDD (2014) Families supporting a child with intellectual or developmental disabilities: The current state of knowledge. *Journal of Applied Research in Intellectual Disabilities* 27(5): 420-430.

Fielding M (2011) Radical democratic education and emancipatory social pedagogy: Prolegomena to a dialogue. In: Cameron C and Moss P (eds) *Social pedagogy and working with children and young people: Where care and education meet*. London: Jessica Kingsley Publishers, pp177-194.

Giallo R, Gavidia-Payne S, Minett B and Kapoor A (2012) Sibling voices: The self-reported mental health of siblings of children with a disability. *Clinical Psychologist* 16: 36-43.

Giallo R, Roberts R, Emerson E, Wood C and Gavidia-Payne S (2014) The emotional and behavioural functioning of siblings of children with special health care needs across childhood. *Research in Developmental Disabilities* 35(4): 814-825.

Guite J, Lobato D, Kao B and Plante W (2004) Discordance between sibling and parent reports of the impact of chronic illness and disability on siblings. *Children's Health Care* 33(1): 77-92.

Hämäläinen J (2003) The concept of social pedagogy in the field of social work. *Journal of Social Work* 3(1): 69-80.

Kramer-Roy D (2012) Supporting ethnic minority families with disabled children: learning from Pakistani families. *British Journal of Occupational Therapy* 75(10): 442-448.

Lock R H and Finstein R (2009) Examining the need for autism sibling support groups in rural areas. *Rural Special Education Quarterly* 28(4): 21-30.

Lorenz W (2008) Paradigms and politics: Understanding methods paradigms in an historical context: the case of social pedagogy. *British Journal of Social Work* 38: 625-644.

Montessori M (1949) *The absorbent mind*. Madras: Theosophical Publishing House.

Moyson T and Roeyers H (2012) 'The overall quality of my life as a sibling is alright, but of course, it could always be better'. Quality of life of siblings of children with intellectual disability: the siblings' perspectives. *Journal of Intellectual Disability Research* 56(1): 87-101.

Naylor A and Prescott P (2004) Invisible children? The need for support groups for siblings of disabled children. *British Journal of Special Education* 31(4): 199-206.

Neely-Barnes S L and Graff J C (2011) Are there adverse consequences to being a sibling of a person with a disability? A propensity score analysis. *Family Relations* 60: 331-341.

Orsmond G I and Seltzer M M (2007) Siblings of individuals with autism or Down syndrome: effects on adult lives. *Journal of Intellectual Disability Research* 51(9): 682-696.

Pestalozzi, JH (1894) *How Gertrude teaches her children*. Translated by L. E. Holland and F. C. Turner. London: Swan Sonnenschein.

Petalas M A, Hastings R P, Nash S, Lloyd T and Dowey A (2009a) Emotional and behavioural adjustment in siblings of children with intellectual disability with and without autism. *Autism* 13(5): 471-483.

Petalas M A, Hastings R P, Nash S, Dowey A and Reilly D (2009b) "I like that he always shows who he is": The perceptions and experiences of siblings with a brother with autism spectrum disorder. *International Journal of Disability, Development and Education* 56(4): 381-399.

Petalas M A, Hastings R P, Nash S, Hall LM, Joannidi H and Dowey A (2012) Psychological adjustment and sibling relationships in siblings of children with Autism Spectrum Disorders: Environmental stressors and the Broad Autism Phenotype. *Research in Autism Spectrum Disorders* 6(1): 546-555.

Petrie P (2013) Social Pedagogy in the UK: Gaining a firm foothold? *Education Policy Analysis Archives*, 21(37): 1-12.

Petrie P, Boddy J, Cameron C, Simon A and Wigfall V (2006) *Working with Children in Residential Care: European Perspectives*. Buckingham: Open University Press.

Petrie P, Boddy J, Cameron C, Heptinstall E, McQuail S, Simon A and Wigfall V (2009) *Pedagogy - a holistic, personal approach to work with children and young people, across services: European models for practice, training, education and qualification*. London: Thomas Coram Research Unit.

Peverley L (2011) Just make believe. *Learning Disability Practice* 14(8): 11.

Pilowsky T, Yirmiya N, Doppelt O, Gross-Tsur V and Shalev R S (2004) Social and emotional adjustment of siblings of children with autism. *Journal of Child Psychology and Psychiatry* 45(4): 855-865.

Pit-Ten Cate I M and Loots G M P (2000) Experiences of siblings of children with physical disabilities: an empirical investigation. *Disability and Rehabilitation* 22(9): 399-408.

Roeyers H and Mycke K (1995) Siblings of a child with autism, with mental retardation and with a normal development. *Child: Care, Health and Development* 21(5): 305-319.

Schuntermann P (2007) The sibling experience: Growing up with a child who has pervasive developmental disorder or mental retardation. *Harvard Review of Psychiatry* 15(3): 93-108.

Sharpe D and Rossiter L (2002) Siblings of children with a chronic illness: a meta-analysis. *Journal of Pediatric Psychology* 27(8): 699-710.

Smith T and Perry A (2004) A sibling support group for brothers and sisters of children with autism. *Journal on Developmental Disabilities* 11(1): 77-88.

Stephens P (2009) The nature of social pedagogy: an excursion in Norwegian territory. *Child and Family Social Work* 14: 343-351.

Williams PD, Piamjariyakul U, Graff JC, Stanton A, Guthrie AC, Hafeman C and Williams AR (2010) Developmental disabilities: Effects on well siblings. *Issues in Comprehensive Pediatric Nursing* 33: 39-55.

Table caption

Table 1. Responses of siblings to the "Being a sibling" questions.

Questions/categories of respondents	Responses as percentages		
	Unsure	No	Yes
Do you understand your sibling's diagnosis?	Unsure	No	Yes
All	19	22	59
Girls under 10	27	46	27
Girls 10 and over	37	0	63
Boys under 10	11	33	56
Boys 10 and over	0	0	100
Do you help look after your sibling?	Unsure	No	Yes
All	22	3	75
Girls under 10	18	9	73
Girls 10 and over	25	0	75
Boys under 10	22	0	78
Boys 10 and over	22	0	78
Do your friends know you have a brother or sister with a disability?	Unsure	No	Yes
All	17	11	72
Girls under 10	30	20	50
Girls 10 and over	37	0	63
Boys under 10	0	25	75
Boys 10 and over	0	0	100
Do you think your school understands what it is like having a brother or sister with a disability?	Unsure	No	Yes
All	31	33	36
Girls under 10	30	20	50
Girls 10 and over	43	43	14
Boys under 10	22	33	45
Boys 10 and over	30	40	30
Are you bullied because of your brother or sister?	Unsure	No	Yes
All	11	76	13
Girls under 10	0	70	30
Girls 10 and over	25	75	0
Boys under 10	22	78	0
Boys 10 and over	0	80	20
Do you get help or support from anywhere other than SIBS?	Unsure	No	Yes
All	30	19	51
Girls under 10	40	10	50
Girls 10 and over	37	0	63
Boys under 10	11	22	67
Boys 10 and over	30	40	30

Table caption

Table 2. Responses of siblings to the "All about SIBS" questions.

Questions/categories of respondents	Responses as percentages		
	Unsure	No	Yes
Do you feel safe when you come to SIBS?	Unsure	No	Yes
All	5	0	95
Girls under 10	8	0	92
Girls 10 and over	0	0	100
Boys under 10	12	0	88
Boys 10 and over	0	0	100
Do the adults at SIBS listen to you?	Unsure	No	Yes
All	10	3	87
Girls under 10	17	8	75
Girls 10 and over	12	0	88
Boys under 10	12	0	88
Boys 10 and over	0	0	100
Do you know who to talk to if you are worried at SIBS?	Unsure	No	Yes
All	5	5	90
Girls under 10	8	17	75
Girls 10 and over	0	0	100
Boys under 10	0	0	100
Boys 10 and over	10	0	90
Do you enjoy coming to SIBS?	Unsure	No	Yes
All	3	0	97
Girls under 10	8	0	92
Girls 10 and over	0	0	100
Boys under 10	0	0	100
Boys 10 and over	0	0	100
Does everyone at SIBS listen to each other?	Unsure	No	Yes
All	30	27	43
Girls under 10	27	18	55
Girls 10 and over	50	50	0
Boys under 10	12	12	76
Boys 10 and over	30	30	40
Would you like SIBS to happen more often?	Unsure	No	Yes
All	19	0	81
Girls under 10	18	0	82
Girls 10 and over	25	0	75
Boys under 10	12	0	88
Boys 10 and over	20	0	80
Does SIBS help you with having a brother or sister with a disability?	Unsure	No	Yes
All	24	10	66
Girls under 10	18	27	55
Girls 10 and over	37	0	63
Boys under 10	22	11	67
Boys 10 and over	20	0	80
Do you think there are clear rules at SIBS?	Unsure	No	Yes
All	11	5	84
Girls under 10	18	0	82
Girls 10 and over	12	0	88
Boys under 10	11	0	89
Boys 10 and over	0	20	80
Would you like SIBS more if everyone there was the same age as you?	Unsure	No	Yes
All	37	39	24
Girls under 10	28	36	36

Girls 10 and over	63	37	0
Boys under 10	11	89	0
Boys 10 and over	50	0	50

Table caption

Table 3. Matching the findings of the survey with Petrie et al's analysis of the features of social pedagogy.

Petrie et al social pedagogy feature	Quantitative survey findings	Qualitative survey findings
A focus on the child as a whole person, and support for the child's overall development	<p>95% of the children in total said they felt safe at SIBS.</p> <p>Overall, 87% of the children responded that adults listen to them at SIBS.</p> <p>In total, 90% of the children stated that they knew who to talk to if they were worried at SIBS.</p> <p>97% of the children reported that they enjoyed coming to SIBS.</p>	<p>What do you enjoy most about SIBS?</p> <p>Activities, playing, fun, making friends (this included the children over 10, who still valued 'playing').</p>
The practitioner seeing themselves as a person, in relationship with the young person	<p>Overall, 87% of the children responded that adults listen to them at SIBS.</p>	<p>Not directly alluded to in the survey results, but adults contributed mainly in addition to their usual activities and were there to "join in" and get to know the children and young people.</p>
While they are together, children and staff are seen as inhabiting the same life space, not as existing in separate, hierarchical domains	<p>Overall, 87% of the children responded that adults listen to them at SIBS.</p> <p>In total, 90% of the children stated that they knew who to talk to if they were worried at SIBS.</p>	<p>"All the adults are really nice and supportive, and I know I can talk and just chat with them or play" (girl, 10 or over).</p>
As professionals, pedagogues are encouraged to constantly reflect on their practice and to apply both theoretical understandings and self-knowledge to their work and to the sometimes challenging demands with which they are confronted	<p>The survey itself is evidence of reflecting.</p> <p>Overall responses to question of whether SIBS helps with having a brother or sister with a disability of 66% especially shows reflection.</p>	<p>Individual practitioners may well reflect privately and informally amongst themselves in small groups. Arguably, building in time to reflect as a team would be beneficial.</p>
Pedagogues should be both practical and creative; their training prepares them to share in many aspects of the children's lives, such as preparing meals and snacks, or making music and building kites	<p>81% of the participants expressed they would like SIBS to happen more often (19% balance of responses were Unsure, there were no negative responses). Each SIBS day consists primarily of practical and creative activities.</p>	<p>Individual responses indicated clearly that it was the "activities" that the children enjoyed.</p>

<p>In group settings, children's associative life is seen as an important resource: workers should foster and make use of the group</p>	<p>One aspect that was not so good for this feature of SP: reports that the children did not always listen to each other, older girls feeling this particularly (50% responded negatively).</p> <p>50% of boys aged 10 and over expressed that they would prefer SIBS more if everyone was the same age, that is, without the younger children. This suggested that work was needed for everyone to feel part of the whole group.</p> <p>Clear rules question elicited an 84% positive response. These are generated by the group and for the benefit of the group.</p>	<p>Some older boys expressed not liking "little kid activities", showing a need to be more integrative.</p>
<p>Pedagogy builds on an understanding of children's rights that is not limited to procedural matters or legislative requirements</p>	<p>95% of the children in total said they felt safe at SIBS. Overall, 87% of the children responded that adults listen to them at SIBS. In total, 90% of the children stated that they knew who to talk to if they were worried at SIBS.</p>	
<p>There is an emphasis on team work and valuing the contribution of others - family members, other professionals, and members of the local community - in the task of 'bringing up' children</p>	<p>A wide range of professional volunteers help to run the group.</p> <p>Works in partnership with families, who know most of the helpers well.</p>	
<p>The centrality of relationship and allied to this, the importance of listening and communicating.</p>	<p>Overall, 87% of the children responded that adults listen to them at SIBS.</p>	<p>"I would run away (if I was not receiving support)" (boy, 10 or over).</p> <p>"SIBS is where you talk and understand how you deal with a disabled sibling. You also play and do activities" (girl, 10 or over).</p>