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Editorial

Charlotte Wilson and Chris Walter

We're delighted to have been asked to edit this special themed edition of the Scottish Journal of Residential Child Care, on perspectives and understandings of disability. It's been an inspiring experience to see the research and practice which is being carried out, and to consider the learning from this. This issue represents the great diversity of people with disabilities, and their experiences, from all over the world. We have a varied international collection of full-length articles and shorter pieces.

Following on from the critical findings of the UN report into people with disabilities in the UK (Butler, 2017) it is timely that this journal now has an issue dedicated to the policy context, lives and experiences of disabled people. Whilst it is undeniable that there have been huge developments in understanding and provision in recent years, many prejudices and misunderstandings remain.

As Runswick-Cole and Goodley (2018) argue, the continued marginalisation of disabled children indicates that they have benefitted less from recent developments in policy and practice than other looked after children. It could indeed be argued that this is even more the case for those children with developmental impairments whom it can be all too easy for researchers and policy makers to side-line due to the difficulties of engaging with them. In this period of welfare austerity their provision can be amongst the first to suffer from reduced resources, inadequate staffing and over-medicalised assessment processes.

This issue starts with a paper from Antonia Kenny and Martin Power, presenting the findings of a research study undertaken with social care workers in Ireland, on their perspectives of barriers and opportunities to social inclusion for people with intellectual disability. Karlis Laksevics, Arturs Poksans, and Kristians Zalans' article provides a different perspective on a similar theme, with a critical review of the deinstitutionalisation process for residential child care in Latvia. The social inclusion of people with learning disabilities in all contexts can be seen as a direct illustration of the rhetoric formed from constructions of disability.

As both these and other contributors to this issue attest, there remain many challenges to meaningful inclusion, chief amongst these being what Thomas (2007) described eleven years ago as psycho-emotional disablism: hurtful, hostile language and attitudes that have a huge impact on self-esteem and a sense of belonging. She argues that the cumulative impact of psycho-emotional disablism can result in 'barriers to being'; affecting what people with impairments feel they can be or become. Despite many positive developments, societal discourses regarding disability can often appear deeply contradictory; oscillating between a sometimes overly sentimental attitude, and an anxiety about 'challenging behaviour'. This ambivalence is evident in many of its' institutions, chief amongst them being the school system, and may be reflected in the number of school exclusions. Indeed, children in secondary schools with additional support needs are twice as likely as those without additional needs to be excluded (Goodwin, 2018).

Many of us working with children and young people with a range of developmental issues have faced the frustration of attempting to work within the school system and current educational priorities. As Runswick-Cole and Goodley (2018) argue, it is all too often the case that the main purpose of the educational system seems to be to create neat, tidy, conformist, hard working adults. Of course, disabled children don't fit into this picture and consequently are too often excluded and thus further marginalised. This is not the fault of individuals but rather our gaze needs to focus on the wider socio-political priorities that, they argue, too often see this population as problems to be solved that disrupt the smooth running of society. Consequently, the 'hidden curriculum' of many educational institutions can too often seem predicated on the need to move disabled individuals towards more socially acceptable ways of being, rather than valuing difference.

Goodley (2014) traces the way ableist concepts permeate the whole of our society, often in ways that we barely realise. As he says, ability starts off as a fairly benign concept: we all want to have and develop abilities. But when the measuring of ability is linked to how we are valued as people then it becomes a yardstick for how we measure up to a normative model of humanity. Kenny and Power's article cites the realisation of some respondents that our aspirations for people with disabilities (for example, to integrate with others in society rather than staying in their groups) may be based on our assumptions of what everyone should be like. There is a growing realisation that we need to understand the experience of children with disabilities from a much wider, holistic perspective that values all aspects of their lives, rather than a ‘monochrome’ version. In this context, it is refreshing to encounter Vanessa Wilson’s paper, and the article by Mary Morris which both explore the benefits of animal-assisted therapy with a focus on children with autism spectrum disorder. Mary’s article is based on a recent publication ‘Animal Magic,’ which she was heavily involved in. They provide two very different but fascinating perspectives on a previously less well-researched area.

Despite the encouraging development of disability legislation over the last twenty years and the rhetoric of inclusion, we are still in danger of adopting a binary view of such children with disabilities where they are either seen as ‘sick’ or ‘out of control’. Stalker’s (2014, p. 8) words in this journal still ring true: ‘There still appears to be a lingering view that disabled children are different from others in some undefined but negative way, while inclusion can be interpreted narrowly, minimising impairment effects and failing to make appropriate adjustments’.

One such appropriate adjustment is in relation to communication preferences. Ann Clark and Dermot Fitzsimmons’s article discusses the communication needs of disabled children within the Scottish Children’s Hearings system. While the majority of people with a learning disability have a communication impairment, difficulties with communication are not limited to children with disabilities. Many neurotypical children in residential care have communication impairments; possibly on a scale similar to children diagnosed with autism spectrum disorder. At the same time, many residential workers feel frustrated in their work with disabled children and young people due to a lack of knowledge and understanding of these ‘impairment effects’ and the ways in which these have been compounded due to negative life experiences. In this sense a label of Autism Spectrum Disorder, or ADHD, can limit our perspective as we fail to recognise the attachment difficulties and trauma a young person is dealing with. However, it is important to recognise the protective factors that residential environments have the potential to offer, in enhancing all young people’s resilience.

Finally, as usual, we conclude the issue with book reviews contributed by Moyra Hawthorne and Claire Cameron.

We’d like to take the opportunity here to say a special thanks to the practitioners and young people who’ve brought this issue to life, and to Dr Graham Connelly for his creative suggestions and astute guidance, in bringing it all together.

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Costs, benefits and mechanisms of animal-assisted therapy: adopting a change in perspective

Vanessa A. D. Wilson

Abstract

Animal-assisted therapy has progressed in recent years, helping a broad spectrum of people to tackle stress, loneliness and health problems, including those with life-long disabilities. For children with autism spectrum disorder (ASD), animal-assisted therapy helps with social functioning and communication. Whilst numerous articles document the human benefits, far fewer studies have addressed the benefits, or costs, to the therapists themselves —– the animals. Whilst some studies indicate that humans and animals may mutually benefit from positive social interactions, we are yet to fully understand the mechanisms that regulate the social and behavioural outcomes of human-animal interactions under animal-assisted therapy, or its effects on the therapy animal. In this article, I discuss the benefits of examining the physiological and endocrinological mechanisms that underlie such interactions, and why it is important to understand the effects on both nonhumans and humans alike, focusing on animal-assisted therapy for children with ASD. I address species suitability and animal handling experience, and discuss an individualised approach that suits both child and animal, by considering patient needs and animal temperament. Together, these points allow us to reduce the potential of stress in therapy animals, improve the impact of animal-assisted therapy on recipients, and move towards a human-animal interaction that is mutually beneficial.

Keywords

Autism spectrum disorder, wellbeing, individual differences, human-animal interactions

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Benefits of animal-assisted therapy in autism spectrum disorder

Records of pets used in human therapy date back over 200 years, with pet therapy and research into its benefits developing in earnest since the 1960s (Hooker, Freeman, & Stewart, 2002). Animal-assisted therapy helps people tackle stress, loneliness and health problems (Bert, Gualano, Camussi, Pieve, Voglino, & Siliquini, 2016; Souter & Miller, 2007), and the associated literature now spans a broad medical array, from people facing mental health problems and the elderly to those living with life-long disorders such as autism spectrum disorder (ASD) (Hoagwood, Acri, Morrissey, & Peth-Pierce, 2017; Nimer & Lundahl, 2007; Perkins, Bartlett, Travers, & Rand, 2008). In the following discussion, I will focus specifically on the role of animal-assisted therapy for children with autism spectrum disorder (ASD). Specifically, I will discuss the mechanisms that underlie human-animal interactions, and will consider how understanding more about these interactions could be beneficial to both parties.

Autism spectrum disorder is a challenging condition in which people struggle with social interactions, communication and restrictive or repetitive behaviour (American Psychiatric Association, 2013). The symptoms associated with ASD are diverse in nature, but may include difficulties such as lack of eye contact, verbal deficits, inability to process social information such as facial expressions or gestures, strong sensitivity to sensory stimuli, strict adherence to routines and potential cognitive deficits.

Animal-assisted therapy is demonstrated to help children with ASD with social functioning and communication. A meta-analysis, which found a positive role of animal-assisted therapy across four domains, found the strongest effect sizes[1] in studies assisting people with ASD, suggesting that animal-assisted therapy in

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[1] Effect size: defined as the quantitative measure of a relationship, for example, the extent to which two variables correlate. For more information see Lalongo (2016).

these cases produced beneficial outcomes (Nimer & Lundahl, 2007). The studies assessing ASD reviewed by Nimer and Lundahl (2007) all used dogs as their therapy animal. More recent research supports the role of dogs as beneficial in therapy for children with autism, such as reducing distraction and helping to engage them socially (Berry, Borgi, Francia, Alleva, & Cirulli, 2013; Solomon, 2010). Other research suggests that equine therapy may also benefit children with autism. A review paper revealed that of nine studies examining animal-assisted therapy in ASD, five studies indicated positive outcomes in social functioning, motor skills or communication; four of these five studies used horses as the therapy animal (Hoagwood et al., 2017).

Animal-assisted therapy sessions can take place in a variety of settings, from individual sessions to the classroom. Recently, the role of animals in the home has also been considered a form of therapy: amongst families living with ASD, the presence of a pet dog was associated with decreased family difficulties, in comparison to families without a dog (Hall, Wright, Hames, & Mills, 2016; Wright, Hall, Hames, Hardiman, Mills, & Mills, 2015). These findings however are criticised for their limited methodology, such as excluding from analyses participants who rehomed their dog, and relying on participant choice in taking on a pet rather than random assignment (Crossman & Kazdin, 2016). Given that the emotional and health benefits of pets have been well-documented (Amiot & Bastian, 2014; Friedmann, 1995; Julius, Beetz, Kotrschal, Turner, & Uvnäs-Moberg, 2013), it is highly probable that pets may provide an important role in families dealing with the difficulties of ASD. A family pet is not however a fix-all solution and acquiring one for the sole purpose of being a support-animal raises several ethical considerations. Whilst a growing literature continues to address the benefits of nonhuman animals (from here on referred to as simply animals) to people, we continue to neglect to address the other side of the coin: the benefits (or lack of) to the assisting animals. In the following section I address the effects of animal-assisted therapy on the therapy animal.

Animal benefits or costs of animal-assisted therapy

There are a number of possible concerns regarding the treatment and welfare of animals that assist in human therapy. Iannuzzi and Rowan (1991) are amongst the earliest authors to address the issue of animal ethics in animal-assisted therapy. Welfare concerns range from health problems that may develop from a lack of appropriate diet or exercise, as occurred in some cases where rescue dogs were housed with elderly people; to fatigue in residentially housed therapy-animals, who do not get enough time to rest; to stress and exhaustion as a result of visitation programmes. Whilst many animal-assisted therapy programmes use domesticated animals, captive undomesticated animals such as dolphins and monkeys have also been used, which raises additional questions about appropriate species selection for use in human interactions (Iannuzzi & Rowan, 1991; Nathanson, De Castro, Friend, & McMahon, 1997).

Appropriateness can be considered in two ways. Firstly, when examining animal type in the effectiveness of the therapy, species matters. Nimer et al (2007) found that when comparing the effectiveness of studies, the use of dogs generally resulted in high effect sizes, whereas the use of horses and aquatic animals did not. Secondly, we must consider whether using non-domesticated or only recently domesticated species is a form of exploitation (Zamir, 2006). Pets such as dogs and cats have been domesticated over thousands of years, a process that has shaped both the behaviour and physiology of these species (Clutton-Brock, 1995; Driscoll, Menotti-Raymond, Roca, Hupe, Johnson, Geffen et al., 2007). If an animal seeks out the company of a person, it may not be considered exploitative to use them for human benefits (Zamir, 2006). Captive animals on the other hand (i.e. animals taken from the wild or bred from their descendants) do not have this history of human interaction and by extension, did not ‘choose’ their living environment. They are also more prone to stress than their domesticated counterparts (Hemmer, 1990). Thus we must consider that whilst a human interaction with, for example, a dolphin may benefit us, it might prove stressful for the animal involved if they have no choice over the situation (Frohoff & Packard, 1995).

The same could also be said for domesticated animals in particular contexts. A survey addressing teacher attitudes to the use of animal-assisted therapy in classrooms with children with ASD revealed animal welfare concerns: a dog becoming overwhelmed by children unresponsive to its needs, or practical issues such as who will care for the dog outside of school hours, or what happens when the dog is ill or ready to retire (Smith & Dale, 2016). Concerns about welfare are thus valid to all animals used in therapy; however, the direct effects of animal-assisted therapy on animal stress have not been widely studied.

Haubenhofer and Kirchengast (2006) found that dogs tended to experience physiological arousal as a result of therapy sessions, as indicated by increased cortisol levels following these sessions. The results were particularly pronounced in shorter, more intense sessions where the dogs were unlikely to get a break. Cortisol is a glucocorticoid hormone produced by the adrenal cortex as part of the hypothalamic-pituitary-adrenal axis, a negative feedback cycle which regulates a number of mechanisms, including response to stress. In response to a stressful event, cortisol increases, which regulates the cardiovascular, metabolic and central nervous systems (Dedovic, Duchesne, Andrews, Engert, & Pruessner, 2009). However, continued exposure to high cortisol levels can have high physical costs such as negatively affecting brain development and the immune system (Elenkov, Webster, Torpy, & Chrousos, 1999; Lupien, McEwen, Gunnar, & Heim, 2009).

Whilst Haubenhofer and Kirchengast (2006) note that arousal does not necessarily indicate a negative effect of therapy sessions on the dogs, prolonged arousal can lead to chronic stress, suggesting that rest time between sessions is important for the dogs' wellbeing (Haubenhofer & Kirchengast, 2006). Serpell et al (2010) note that if a therapy animal is unduly stressed during an interaction, then the interaction should be suspended — an important observation, but one that requires a handler who knows the signs of stress in the animal and will intervene accordingly. One study in therapy dogs indicated an increase in cortisol levels during therapy sessions compared with baseline (King, Watters, & Mungre, 2011) but behavioural signs of stress varied with age and experience. It is thus unclear in this case if changes in cortisol were due to 'positive' stress, posed by a stimulating environment, or 'negative' stress, where an individual may experience negative emotions as a result of becoming overwhelmed. In contrast to these findings, a study of animal-assisted activity (in contrast to animal-assisted therapy this is giving opportunities of more informal animal-assisted activity outside a regulated therapeutic context) in dogs found neither cortisol levels nor stress-related behaviours showed any significant difference between an activity session and at-home baseline level (Zenithson, Pierce, Otto, Buechner-Maxwell, Siracusa, & Werre, 2014). Similarly, Palestrini et al. (2017) found no changes to heart rate in a canine subject used in post-operative therapy. They did observe the most frequent behaviour to be panting, a potential sign of stress, although this could also have been due to room temperature.

Taken together, these studies do not give a strong indication of particularly negative effects of animal-assisted therapy on the participating animals. But it is noteworthy to add that positive or negative effects to the animal depend largely on the circumstances in which they are required to work. For example, a dog that visits a hospital for a few hours a week experiences a completely different environment than one that works as a live-in therapy dog at someone’s home. Serpell et al (2010) note for example that an animal-assisted therapy animal housed in a residential setting is likely most at risk of becoming fatigued through lack of rest.

There are a number of additional things to consider here. Firstly, the studies reviewed above all considered dogs as therapy animals. Secondly, these studies all address stress of animals in therapy sessions, and do not account for animals that have more permanent roles in therapy, such as household pets (Hall et al., 2016). Thirdly, the findings present mixed evidence of negative or null effects of therapy sessions on the animals. All of these points highlight the need for further study of the stressful effects of animal-assisted therapy, both in varying contexts (considering not only environment but also considering patient type, number of people in a session, session length) and across a broader array of species.

Mutual benefits and underlying mechanisms of human-animal interactions

Whilst the benefit to working animals who provide human therapy may be under question, there is evidence that some human-animal interactions may benefit both parties. Here, I draw on the literature examining the neurochemical and physiological mechanisms underlying social interactions. In shelter dogs, positive contact with humans after arrival at a shelter was associated with decreased cortisol levels the following day, compared with dogs that did not receive positive contact (Coppola, Grandin, & Enns, 2006). Human contact has also been demonstrated to alleviate the effects of stress in the laboratory. When dogs were exposed to a conditioned tone-shock sequence, their heart rate in response to the tone was lower when the tone was accompanied by petting from a person (Lynch & McCarthy, 1967). Given the potentially negative effects of cortisol produced by prolonged stress (Elenkov et al., 1999; Lupien et al., 2009), these findings suggest possible beneficial effects of human-dog interactions on the dog. It is suggested, at least amongst primates (including humans), that social bonds provide a buffer against stress, which could be mediated by oxytocin, a neuropeptide that is released upon social contact with a bond partner (Crockford, Deschner, & Wittig, 2017; Doom, Doyle, & Gunnar, 2017; Dunbar, 2010). In turn, oxytocin stimulates social interactions such as increasing eye contact (Beetz, Uvnaes-Moberg, Julius, & Kotrschal, 2012). It is thought that oxytocin down regulates hypothalamic-pituitary-adrenal activity, thus reducing cortisol levels and associated feelings of stress (Beetz et al., 2012; Crockford et al., 2017). Associated benefits of oxytocin release can even include wound healing, as has been found in socially-housed hamsters, and when oxytocin is administered to socially isolated hamsters (Detillion, Craft, Glasper, Prendergast, & DeVries, 2004).

The majority of research examining the relationship between oxytocin and social interactions has focused on studies within-species, such as in groups of chimpanzees or macaques (Crockford et al., 2013; Young, Majolo, Heistermann, Schülke, & Ostner, 2014), however, there is also evidence that inter-species bonds can have similar effects. Dog owners were found to have an increase in urinary oxytocin levels after 30-minute interactions in which they made eye contact with their dogs (Nagasawa, Kikusui, Onaka, & Ohta, 2009). Moreover, dogs’ oxytocin levels increase following long-gaze-based interactions with their owners, indicating mutual attachment between bonded dogs and humans (Nagasawa, Mitsui, En, Ohtani, Ohta, Sakuma et al., 2015). Similarly, Odendaal (2000) found increases in, amongst other neurotransmitters, oxytocin and dopamine, in both dogs and humans following positive social interaction. Odendaal also found a significant decrease in cortisol levels in people following the interaction, but not in dogs. Lower morning cortisol levels have been found in dogs whose owners perceive them as social partners (Schöberl, Wedl, Bauer, Day, Möstl, & Kotrschal, 2012). Reduced cortisol awakening response was also found in children with ASD in the presence of a service dog, and was associated with decreased behavioural problems after the dog was introduced (Viau, Arsenault-Lapierre, Fecteau, Champagne, Walker, & Lupien, 2010).

Interspecific interactions may also depend on prior attitudes: in a study assessing stroking of horses, heart rate of people with negative attitudes towards horses was initially higher than those with positive attitudes or prior experience with horses, but heart rate of all participants decreased over a 40 second period (Hama, Yogo, & Matsuyama, 1996). Notably, the heart rate of horses being stroked by people with negative attitudes was also initially higher than when stroked by people without negative attitudes; these findings suggest that there may be a process such as emotional contagion (whereby emotion in one individual invokes that emotion in another) taking place between horse and human (Hama et al., 1996; Hatfield, Cacioppo, & Rapson, 1993). Similar to dogs, this could invoke feedback between underlying physiological mechanisms (Nagasawa et al., 2015).

To date, there are only a few studies examining the mutually beneficial effects of human-animal interactions, especially with regard to the underlying mechanism of these interactions. However, it is evident from the human literature that pets generally have a positive effect on humans, such as reduced heart rate, blood pressure and anxiety (Beetz et al., 2012; Julius et al., 2013) (although, not all studies find positive health effects of owning pets; see for example Amiot & Bastian, 2014). Given that measures of these physiological responses increase under stressful situations, it is feasible that human-pet interactions reduce effects of stress in humans through changes in cortisol and oxytocin levels (Beetz et al., 2012). It would therefore be worth addressing in more detail whether similar physiological outcomes are apparent in pets receiving positive contact from people.

Suitability of animals for animal-assisted therapy

The findings discussed above suggest the possibility that animals, like people, can benefit from positive human-animal interactions. It is unclear however as to what extent a social bond is required for such positive effects to take place. One should also be wary in extrapolating across species. Earlier I touched upon the issue of species suitability to animal-assisted therapy, noting that domesticated species may be more suitable to this role than non-domesticated species. However, suitability can vary also between domesticated species and even within species. Dogs for example are not only domesticated but tend to form strong bonds with their human owners; in contrast, horses, a prey animal who typically form their own within-species social groups, may not benefit from human interaction to the same extent as dogs (Payne, DeAraugo, Bennett, & McGreevy, 2016). An animal's response to a human may depend a lot on their prior experience with social interactions, and their familiarity with the person involved. For example, the early handling of rabbit pups leads to reduced fear of humans in adulthood, and is accompanied by bolder behaviour, increased weight gain and reduced mortality rate, compared to rabbits that do not receive regular handling (Jezierski & Konecka, 1996). Thus early-life experience with people can have a lasting impact on both behavioural and physiological outcomes, and should also be an important consideration when involving animals of all kinds in animal-assisted therapy. A rabbit with no handling experience that is put into a room full of children will likely experience more stress than a well-handled rabbit. However, given that rabbits are prey animals, they are still more likely to experience stress when placed in a new or overwhelming environment compared to a well-handled dog.

There are two additional considerations to handling suitability. Within historically domesticated species, breed plays an important role in behaviour (Serpell, McCune, Gee & Griffin, 2017; Svartberg, 2006). Dogs and horses especially are bred for a variety of roles — to run fast, pull heavy equipment, defend property, herd sheep — which of course dictate the temperament of that breed. A highly-strung horse or dog that is bred for aggressive purposes may not be the most suitable animal for therapy. It is additionally important to consider that temperament, which varies with breed, can also vary with an individual. A family that adopts a dog in the hope that it helps them to communicate with their child may find themselves struggling if the dog is easily scared or not well trained. Indeed, research on dog temperament, also referred to as personality (Jones &

Gosling, 2005), has revealed certain traits to be more suitable for particular behavioural roles. In guide dog puppy training, eight-month old puppies have a higher probability of qualifying as guide dogs if they exhibit traits of low distraction, low anxiety and low reactivity (Harvey, Craigon, Sommerville, McMillan, Green, England, & Asher, 2016). Temperament in young dogs has also been linked to maternal care, with puppies that experience less maternal care more likely to succeed on tests assessing suitability to becoming guide dogs (Bray, Sammel, Cheney, Serpell, & Seyfarth, 2017). This compounds an earlier point that early-life environment is important to predicting behavioural outcomes. Temperament should also be included as a variable of consideration in future research assessing the effects of stress on therapy animals.

In sum, species, breed, handling experience and temperament are all important considerations in addressing which animals are most suited to use in animal-assisted therapy. In turn, addressing suitability of therapy animals can help to not only reduce negative effects on the animal but also increase the positive effects for the human recipient. Increasing the suitability of an animal in animal-assisted therapy should therefore improve the chances that the therapy can provide mutual benefits to human and animal alike.

Animal-assisted therapy for children with ASD: taking an individualised approach

Earlier evidence indicates that animal-assisted therapy can help children with autism to engage socially (Berry et al., 2013; Hoagwood et al., 2017; Solomon, 2010). Implementation of animal-assisted therapy in a care setting could provide a relational approach, encouraging children to form bonds with animals and giving them the chance to feel valued and nurtured (Garfat, 2003). Given what we know about the endocrinological feedback mechanisms of social interaction, forming a bond with an animal may act as a buffer against stress (Beetz et al., 2012; Crockford et al., 2017; Julius et al., 2013). It could also form a feedback mechanism to stimulate further social engagement, such as eye contact, self-worth, and healthy attachment (Beetz et al., 2012; Fahlberg, 1991; Nagasawa et al., 2015). Thus, social interactions with animals could help to provide a ‘bridging experience’ to positive interactions with people (Anglin, 2004).

What additional considerations would be beneficial for children with ASD to get the most out of animal-assisted therapy? Animal-assisted therapy may not be suited to everyone (Smith & Dale, 2016). Whilst for example having a pet or classroom dog may help some children with ASD engage and interact, others may be fearful which can exacerbate problems. The goal of animal-assisted therapy in the case of children with ASD should be to find a good person-animal match, where it is both needed and wanted. For example, if one is unsure what type of therapy would be best for a child, a first step would be to let them try a riding or dog-petting session to gage how they respond. It might also be useful to consider which type of animal would be most suited to the child — a dog can provide social comfort and interaction; a horse can provide stimulation and engagement through motion; it is important to think also of how the animal would respond if a child has challenging behaviour — will they be calm, will they be scared, will they avoid or engage in the situation? If one wishes to use animal-assisted therapy on a more day-to-day basis, it might be worth considering what benefits a pet could bring. For a child with ASD, a well-adjusted pet dog may provide a more mutually beneficial relationship than attending intermittent therapy sessions where child and animal are strangers. However, this also brings with it the burden of ethical responsibility to the pet.

The relationship between child and pet can have a lasting impact on their social-cognitive abilities (Daly & Morton, 2009; Poresky, 1996). Given the potential importance of strong bond formation between child and pet, especially for a child with ASD, it is worth considering what variables may influence bond strength. For example, affection towards pets is related to personality traits; people who are more conscientious (constrained and organised) and more neurotic (anxious, tense) report higher affection for pets (Reevy & Delgado, 2015). Attachment to a pet is stronger in six to ten year-old children when the pet is more closely phylogenetically related, for example having a dog or cat over a pet fish or insect; in eleven to fourteen year old children, girls were also found to have higher attachment to pets than boys (Hirschenhauser, Meichel, Schmalzer, & Beetz, 2017). Thus, just as different animals may be differentially suited to work in therapy, different people will also likely respond varyingly to interaction with animals, depending on their age, sex, personality and prior experience with other species. These questions and considerations bring into play a number of the issues discussed earlier, and should be considered by carers and therapists alike in regard of getting the most out of animal-assisted therapy.

Can animal-assisted therapy be mutually beneficial?

It is clear that the relationship between patient and animal-therapist is not straight forward and that the effectiveness of animal-assisted therapy depends upon a number of factors. What is still not clear is to what extent being a therapy animal may affect the wellbeing of the animal in question, or how this in turn affects the effectiveness of animal-assisted therapy as a treatment. To understand this better the field needs to address the mechanisms underlying the behaviour of human-animal interactions during therapy sessions, through examining indicators of arousal, stress and positive emotional effects, such as changes to cortisol, oxytocin, heart rate and blood pressure in both animal therapists and human recipients. Of particular interest would be to assess the occurrence of emotional contagion, and determine if there are any positive or negative feedback processes occurring that mediate the interaction between person and animal. Such research would also benefit from further assessment of individual variables, such as personality, prior experience, age and sex of both parties, and motivation of the patient to interact with the therapy animal.

In particular, further research in residential settings is required. Many children with ASD receive residential care. If animal-assisted therapy can be implemented as a routine aspect of care systems, numerous children could benefit, as demonstrated by a recent report of equine-assisted therapy at Camphill school and care home (McArdle, 2016). As cautioned earlier however, a system first needs to be established to assess how the animals could be appropriately cared for, receive rest days, and avoid becoming overwhelmed. Care would equally have to be taken to ensure that the children involved could benefit. A potential starting point would be to introduce the animals to children in short one-on-one settings, thereby gauging potential risks and allowing relationships to develop.

It is no longer enough to note that an animal is not stressed or negatively affected by a human encounter. The best-case scenario should be that the animal can benefit from it, too. This is especially so for live-in animals, who have a constant relationship with one or several individuals. Regarding choice of animal, some key considerations in finding a suitable animal for therapy are: (1) is the species suitable for human handling, in other words, is this a domesticated species which is adapted to human interaction? (2) Does the animal have handling experience from an early age? (3) Does the animal have a suitable temperament for the job? The question as to whether animal-assisted therapy can be mutually beneficial depends a lot on these factors. If the animal is well suited to the task, then it already has a good chance to benefit from the human interaction, especially when it has a bond with that person. If the animal can benefit, there is a good chance that this improves the benefits for the human recipient, too.

The benefits of animal-assisted therapy to children living with ASD have been widely reported. ASD is a challenging condition, for both the people that live with it and for their families and carers. Animal-assisted therapy provides an approach that seems to help improve the lives of people living with ASD and in reducing the daily challenges that they face. It is therefore time that research began to address how we can improve the use of animal-assisted therapy for people with ASD by assessing simultaneous effects on both human and animal alike.

About the author

Vanessa Wilson received her PhD in Psychology in 2016 from The University of Edinburgh. She has ten years of research experience with a variety of different species, from cats to monkeys to humans, and currently works as a Postdoctoral researcher at the German Primate Centre, Goettingen. Her research interests include the study of personality, wellbeing, social interactions and communication, emotional expression and perception, social cognition and animal welfare.

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Falling through the cracks: critical review of the deinstitutionalization process in post-socialist state

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Abstract

Throughout Eastern Europe, the attempts to carry out successful deinstitutionalisation (DI) have been hampered by the legacy of Soviet-era practices of care. In Latvia, it is present in the form of residential schools for children with special needs which continue to host a large proportion of children with disabilities. In order to monitor the progress that has been made since ratifying the UN Convention on the Rights of Persons with Disabilities a nationwide evaluation of accessibility of employment and education was carried out. Using the data from this work, we argue that due to the fragmented implementation of DI and lack of a child centred approach throughout the education sector, despite educators firmly believing they are acting in the best interests of children, current practices of care contribute to the creation of 'inclusive exclusion'. Using the theoretical framework of Giorgio Agamben, we propose viewing the current approach to DI as one that sustains the exclusion of children with disabilities by increasingly marginalising children with severe disabilities by keeping them segregated in special forms of residential care. We show how this approach is primarily rooted in the specialist-based approach being seen as the most effective form of care for children with disabilities.

Keywords

Deinstitutionalisation, post-Soviet, exclusion, disability

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Introduction

Once it was announced that the deinstitutionalisation process had finally reached Latvia, the only question most people had was — how is it going to be subverted? It was clear that there would not be organised opposition to the process, but at the same time it was clear that it would never succeed. This article is dedicated to explore local idiosyncrasies and entrenched institutional perspectives that allow institutions to be preserved, transformed and maintained even as they are officially being shut down. By presenting three stories of how children with disabilities and their families experience the institutional framework and learn to survive in it, we hope to contribute to a better understanding of possible shortcomings of the deinstitutionalisation process where it is implemented in a way that procludes full awareness of all of the actors in their new roles and the kind of changing practices of care it involves.

If viewed from a top-down perspective, support for people with disabilities, efforts to promote deinstitutionalisation, and the inclusion agenda in Latvia is being administered by the Ministries of Welfare, Education and Health. In this model, each ministry is responsible for a fraction of the support at times making it difficult for their employees to coordinate particular policy initiatives. By way of example, there are two vocational schools that offer education for people with disabilities, yet one school is governed by the Ministry of Welfare while the other is under the responsibility of the Ministry of Education.

If viewed from a bottom-up perspective, people with disabilities will often come in contact with non-governmental organisations (NGOs). They work as information providers that also execute particular state funded initiatives and allow for sociality. Although people with disabilities generally appreciate the work of NGOs, it is implied that NGOs have to exist only to cover for the lack of an effective and easily understandable state system of support.

The existing model puts a lot of responsibility on the people working as career consultants, teachers within regular schools, and so on (either with or without special programmes). On the one hand, norms of inclusion have been written into existing laws (a child has a right to study in the nearest school; career consultants should have expertise on employment for people with disabilities; and so on). On the other hand, no comprehensive road map for allocating finances towards school infrastructure and personnel development exists. A school principal has to either deny a child with disability her rights by sending her away or deny her rights by admitting her and providing less than adequate services. We are not advocating such a perspective of two limited choices or arguing that this is the opinion of everyone involved. Instead, such a lose-lose scenario serves as an introduction to the challenges of the current deinstitutionalisation process in Latvia.

Current context

Giorgio Agamben’s philosophy of sovereign power and bare life serves as our main theoretical standpoint for analysing the effects of deinstitutionalisation on children with disabilities. Agamben argues that sovereign power produces a political order based on the exclusion of bare life (Agamben, 1995). This is done by enacting the exception in which normal legal processes are suspended, the human being is stripped of legal status, and transformed into a bare life without rights. In Agamben’s view, this means that an individual is forced to be a ‘good citizen’ or risk losing the state’s protection and therefore the rights that come with it.

We offer to expand the analysis of Agamben and similarly of Zigon (2011) and Zaviršek (2009) to explore how the ‘state of exception’ and ‘inclusive exclusion’ can be used to better explain the place of other marginalised groups in contemporary society.

Zigon (2011) in his work *HIV is God's Blessing: Rehabilitating Morality in Neoliberal Russia* emphasises the importance of spatially removing the addicted persons from society, therefore effectively forming non-places where they exist in a constant state of exception. Zaviršek (2009), in turn, argues that it is important to recognise that most people who require help from social services are included by exception – the very nature of social services as a system that serves only the neediest stipulates that the individual is in a state of exception which qualifies him/her for these services. This transforms the person from being an active political individual to a welfare consumer that in most extreme cases leads to exclusion by confining individuals to institutional care.

We combine these perspectives to argue that it is important to recognise institutions for children with disabilities, which exist in Latvia, as places of 'inclusive exclusion' due to a poorly implemented deinstitutionalisation process which leads these institutions not towards dismantling a state of exception, but rather to enforce it, thus ensuring their continued existence. Instead of arguing that an individual in state care exists in permanent state of exception, we would like to show how this state of exception comes to pass due to deinstitutionalisation process which makes their existence impossible both inside and outside of the institution.

Background

The deinstitutionalisation process has been an ongoing effort by countries around the world to decrease the number of people who for various reasons would be institutionalised. As noted by Kuuse and Toros (2017) it can be explained as stemming from several perspectives. Deinstitutionalisation can be seen as a concerted effort to decrease the costs of long-term care, to improve the level of care, or to improve the health outcomes for the former residents of the institutions. Kuuse and Toros (2017) point out that these approaches are promoted by international organisations such as the UN arguing for a human rights perspective on deinstitutionalisation.

In post-socialist countries, the deinstitutionalisation process has been met with considerable resistance from ground level workers in the childcare system and from the general public. As argued by Rasell and Iarskaia-Smirnova (2014) one of the possible reasons is that specialists that were employed in the welfare sector were taught to regard residential care as the best possible solution. At the same time, the high number of children in residential care stemmed from state policies such as deportations, famine, war and repressions. This led to an outlook where children in the institutions were perceived as problematic and connected to either the criminal underworld or their bourgeois/kulak parents (Zezina, 2001). Among other factors, this perception of children in institutions as morally reprehensible led to a hesitant implementation of deinstitutionalisation in post-socialist countries, including Latvia, where the process earnestly started only in 2015 with the creation of an ‘Action Plan for Implementation of Deinstitutionalisation 2015-2020’. Although the laws and regulations for the provision of social services since 2002 have stipulated that institution-based care should be an exception rather than the rule, it took 13 more years to address the fact that for most cases it was the other way around. This was so particularly for children with disabilities in care. Work by Iarskaia-Smirnova and Pavel Romanov (2007) showed that, although the officials and administrators may support deinstitutionalisation and integration for the most part, children with severe disabilities and orphans are still seen as groups that require institutionalisation.

Some research indicates the situation is even worse in Latvia (Legzdina, 2016) where interviews with childcare professionals revealed a lack of faith in deinstitutionalisation. Nevertheless, the situation has been changing in Latvia, as according to official statistics the numbers have been decreasing – in 2010 there were 469 children with disabilities in social care institutions while in 2017 the number has been reduced to 305 (Central Statistical Bureau of Latvia, 2017).

Methodology

Emerging from a broader debate on subjectivity and objectivity in ethnographic writing, fictional ethnography is generally understood as combining ethnographic observations with fictional people, places and events in a single narrative to better explain a particular research setting (Rinehart, 1998; Richardson, 2005; Rottenburg, 2009). We wish to highlight two reasons for using fictional ethnography. First, it enables us to write detailed descriptions of particular actors as persons with multifaceted motivations and concerns without compromising their anonymity and privacy. Second, fictional ethnography allows researchers to expose and explain systemic conditions through storytelling so that the reader can follow how these conditions are experienced by the person and how these encounters shape their further decisions. We will attempt to describe the system of Latvian residential childcare for children with disabilities by telling three stories which, although based on three separate research participants, incorporate details and insights obtained from multiple conversations with various stakeholders.

The stories are based on research we conducted during the winter of 2016/2017 for the Ministry of Welfare in Latvia. The aim of the research was to evaluate the available support mechanisms for people with disabilities in relation to education and employment. It included desk research as well as discussions and interviews with the relevant stakeholders — principals of schools, state officials, NGOs and people with disabilities. By carrying out interviews with both the relevant authorities and the people who themselves have had experience with these support systems we gained a multi-faceted view on how the support systems are created and experienced in Latvia. The research included 32 semi-structured interviews, 18 structured interviews and 2 focus group discussions that were complemented by secondary research of available information sources. This article draws on this wealth of information and is constructed both from the direct experience of interview participants and from broader trends and repeated stories we learned about. Through using the fictional ethnography approach, we are able to incorporate all of this information in the form of short stories instead of trying to reproduce it in form of numerous tables, arguments and explanations.

By following the trajectories of these children as they went through instances of Latvian education, healthcare and employment, different systemic practices of exclusion reveal themselves, thus allowing for a debate on how the process is experienced by children, and to what extent it was inclusive at the time of conducting this research.

Alice

Alice and her parents did not worry about institutionalised care until the fourth grade (age 10). Sometimes her anger outbursts in school about certain situations created tension, and certain classes had tasks she was not able to perform. While her parents were notified about these difficulties and suggested consulting a psychologist, they were afraid that this could result in them being asked to move her to another school. In fifth grade, the pressure increased as teachers started to pay more attention to students' performance. Alice was referred to the nearest Pedagogical Medical Commission (PMC) by the school's psychologist. The PMC serves to assess whether a person has special learning needs and to recommend an individual learning plan and one of nine special educational programmes. These programmes are taught and accredited only at certain schools and in most cases the PMC recommends the child changing the school to one with the special programme available. Furthermore, there is often pressure from other parents who see the child as potentially harming others' chances to learn.

The local specialists from the PMC determined that Alice needed a classroom assistant and had to be assessed by a psychiatrist for autism spectrum disorder (ASD). They recommended a special school that was located slightly out of town where Alice would need to be taken daily by car and stay after school until she could be picked up. After a few months of negotiation with a reluctant principal of the school who assured the PMC that the school could not support Alice in the way the other school would, they decided to conform.

In the new school, Alice had access to a classroom assistant, an individual plan, as well as rehabilitation, but the quality of learning was poorer as this was a programme for children with mental development disorders. Compared to her previous experience, the objectives in her individual plan seemed to be behind what she felt capable of doing.

Alice and her parents started to search for ways for her to get better education and develop the necessary social skills, as they were afraid that learning at a special school might affect her progress in the educational system. They contacted an NGO for children with ASD. If before they had seen special needs and disability as stigmatising and being a limitation, then consulting the NGO made them recognise how each of the statuses can grant certain benefits. They managed to get her recognised disability status because it fulfils a requirement outside of special schools in order to get an assistant granted by the school.

Children with ASD get different recommendations from PMCs meaning that you can be in various special programmes with the same diagnosis. Despite the school being very welcoming and providing assistance, visual aids and social training, after a year Alice's parents pushed for another evaluation at the state PMC which can make changes to the decisions of municipal PMCs.

This time with the help of her psychiatrist's description, it was recommended that Alice should be referred to a programme for children with learning difficulties available at a school closer to her home. The school, however, was not that well suited to a child with ASD, as only a few teachers were aware of certain intricacies of working with her. At least this time she had an assistant as a result of having disabled status. A few years later, after work with the NGO and other parents to support the staff who had previously little experience of children with ASD, the teachers and classes slowly adapted to her needs.

As can be seen, none of the three schools were perfect for Alice as each addressed a different issue and each excluded certain ways of learning, care and socialisation in their own way. Alice was pushed out of the first school, but the second time her parents decided to move her out themselves because of the stigma resulting from long-term institutionalisation and segregation of children with disability. Special education is seen by many parents as the best option as there are better possibilities to get an individual approach to learning, there are fewer children in class and there is more community involvement. At the same time, being at a special school does not solve the problem of being excluded and misunderstood in other contexts, which is particularly visible and important for people diagnosed with ASD, where social interaction is one of the major criteria.

Eventually Alice's parents changed their strategy from avoidance to working closely with the school staff, going through possible adjustments with the newfound knowledge gained from the help of the NGO. In many cases, parents do not communicate their child's potential special needs to the school; but without communication inclusion becomes complicated. While the aim of this strategy is to avoid institutionalisation, it comes with a high risk to facilitate it.

In this sense, Alice and her parents were contesting the claims of both special and general education to be inclusive. If the issues of inclusion are not taken as a right, but instead are mediated through approaches that medicalise the issue at hand, as in the PMC evaluations and applying for disability status, the possibility to make a change is decreased. As has been argued, inclusion demands that the politics of exclusion and representation are addressed (Slee, 2007; Hassanein, 2015), but in none of Alice's school experiences was the medical model of disability fully overcome by social considerations. Alice got an assistant because of her disability status and the place at a mainstream school through the recommendation for a special programme that the school had accredited. Therefore, in order for Alice to claim her right to be at a school, her issue had to be medicalised. Disability became an object of interest both when she was seen as not belonging where she was and when she wanted to belong somewhere else.

The few schools in Latvia that have moved towards a more inclusive organisation of their work have done so based on particular cases where a child provided cause to evaluate their practices. In most cases, the pressure comes from parents of relatively high socio-economic status who have been able to demand support at municipal level. The basis of such possibilities comes from Section 17 of the Education Law (Latvia, Saeima 1999), which makes the municipality responsible for granting every child the right to learn at a school that is closest to their home. In this sense, deinstitutionalisation starts with the law that can be used by parents to ask for change to the school closest to their place of residence. The scenario in such cases is usually that the parents convince the school management of the need for adjustments in infrastructure or staff training and the schools work this out with the municipality to get appropriate funding. In Alice's case, it granted the school to make adjustments based on her needs. At the same time, she was still part of a special programme where she was together with other children excluded from general education.

It is common for teachers and managers of schools to think that due to a shortage of resources and lack of training their schools cannot be inclusive for children with disabilities. They try to exclude these children from mainstream schools and move to special schools, an approach which creates an environment of mistrust and limits possibilities for inclusion that requires a lot of co-operation and exchange of information between doctors, parents, teachers and children. Schools that aim to be inclusive strive to organise more training for teachers and parents, hire assistants and provide assistive technologies. The same goes for schools which have accredited special programmes, as the teachers are required to go through training and resources are allocated to work on inclusion.

If deinstitutionalisation requires schools to introduce specific institutionally managed ways of care, the schools that are first in line to adjust slowly develop expertise as 'special' schools as they attract more children with disabilities and special needs. Including children with disability and special needs makes these schools an exception since their inclusion into special programmes attracts more resources to the school. Reforming the educational system to enable new teachers to give significant attention to inclusive education will take years to bear results in the classrooms. As deinstitutionalisation aims to close or transform boarding schools and decrease special schools, many such schools in Latvia are now working to become 'inclusive' schools, a change that is regarded as being essential. Special schools are reorganising to become resource centres for general schools, but their challenge is that the practices at special schools are different from how social life is organised in inclusive schools. For the time being, children like Alice exist somewhere in between.

Kristers

Kristers' hometown is located near a small river that during springtime gathers just enough water to allow for canoeing. When Kristers was 11, he went for a family trip during which his left eye was accidentally hit by a paddle. He underwent surgery which seemed successful, yet shortly after complications began. The surgery had caused an infection that now had spread to both of his eyes and caused irreparable damage. Kristers became unable to move around the town on his own, make sense of letters on the blackboard and read regular schoolbooks.

His school had no previous experience with students with visual impairments. For a few weeks while Kristers' parents held talks with his teachers and school principal, Kristers continued in the same class. His sister helped him walk to and from school, and his best friend helped him around. Although his education continued, the school staff made it clear that this was only a temporary solution and Kristers would eventually have to leave.

Historically the support for people with visual impairments in Latvia has been concentrated on the outskirts of the capital, Riga, at what was commonly referred to as ‘the village of the sightless’. Nowadays it contains a library, a boarding school from pre-school to secondary school level, a rehabilitation centre and an association devoted to vision related disabilities that also co-ordinates some social entrepreneurship incentives. The district is equipped with sidewalk rails, the local shopkeeper is aware of people's needs and the traffic lights have a signalling beep.

The only school suggested to Kristers was located within this district. The school had infrastructure adaptations, learning materials, trained staff and a special learning programme for learners with visual impairments. Kristers was still overwhelmed with trying to re-learn doing everyday things when he learned that due to his hometown being 110 kilometres away, he would have to reside in this institution during weekdays.

For a few years, Kristers learned the necessary skills to become as self-sufficient as possible, continued his education at the boarding school and learned Braille. There were periods when Kristers felt depressed and did not travel home during the weekends. Noticing these changes in Kristers, his parents decided he should leave care.

Since the accident, his parents had followed developments in the state, municipality and NGO support networks. During the last year of primary school, they actively consulted with NGO specialists and Kristers’ boarding school to learn pedagogical methodologies that could be used for Kristers and provided the teachers from Kristers’ hometown with examples of what he was capable of doing. For example, by consulting with the Latvian Academy of Sport Education Kristers’ parents were able to forward some information to the local sports coach. The previously reluctant principal was convinced when he learned that Kristers was the first student of his boarding school to attempt and pass the state examination (non-obligatory). Ultimately, Kristers’ parents found an apartment that was closer to school so that once Kristers got acquainted with the surroundings he was able to navigate the way to school on his own.

An analysis of Kristers' story shows that his educators did not believe institutionalisation was desirable, they believed it was necessary. The effects of this perspective can be seen throughout Kristers' story. For practical purposes, the state deemed specialist care sufficient, while the physical and social environment available to Kristers was limited. Boarding school students were expected to continue their education at the same place, and there was no precedent for students willing to face countless difficulties in striving for regular education. What Kristers' story shows vividly is that systemic circumstances made it reasonable for children with disabilities to accept being and remaining excluded. This begs the question: what reasoning makes it possible for a specialist care paradigm to co-exist with efforts to encourage inclusion?

Firstly, Kristers' boarding school was on the very outskirts of Riga. The physical environment was designed according to Kristers' needs but only so far as the district boundary went, which produced effects of exclusion. This has been recognised by authors unconcerned with the way exclusion through inclusion is theorised by Agamben (see Biehl, 2005 and Comarroff, 2007) and also authors attempting to develop his perspective (see Zigon, 2011 and Zaviršek, 2009). For example, Zigon was fascinated with how a site aimed at turning those with HIV into 'appropriate' citizens was located only 20km away from St Petersburg. Similarly, since this community is located on the outskirts of the city, children with disabilities were reminded of their qualitative difference from the 'real' citizens. Thus, spatial exclusion not only confines but also demarcates the possibilities and difference, easing the way into trajectories of marginalisation.

Secondly, effects of exclusion continue as children age and pursue careers. Our research found that career advisers in mainstream schools generally lacked the competencies required to consult children with disabilities. Also, being spatially confined, children learned of careers that are popular among other residents. For one of Kristers' acquaintances choosing to be a wicker weaver resulted in primarily interacting with the people from the district. For another, studying to be a masseuse in an EU-funded project resulted in studying and working together with some of his schoolmates. As the overall employment system is not inclusive, it is also reasonable for NGOs to seek out particular types of jobs that would require less preparation and extra effort from both people with disabilities and employers. Being in the boarding school would likely affect the career opportunities Kristers would be encouraged to consider.

Thirdly, the state incentives for inclusion contributed to this cycle of exclusion. NGOs temporarily hired their clients in state funded subsidised employment incentives, thus both providing their clients with job experience and confining them to the social circles of disabilities. Many of the people interviewed for this research voiced their critique of Section 109, Part 2 of the Labour Law (Latvia, Saeima 2002) which prohibits employers from discriminating against people with disabilities. The provisions of this section put employers at risk of being sued, which can prevent employment in the first place.

The arbitrary gain of state support for people with disabilities may best be understood with reference to funded assistant services. Assistants do not receive any prior training and the job is under-paid. In the case of municipality-funded assistants, regular accounting sheets must be completed in order for clients to continue receiving the service. The low pay often results in relatives serving as assistants, while excessive paperwork in some cases results in families refusing the service and paying an assistant from personal funds. All three of these examples serve as a bleak illustration of how ineffective inclusion incentives may further aggravate exclusion by reminding a person he or she is not able to function socially at times when assistance is unavailable.

Fourthly, exclusion through inclusion works by marginalising people with disabilities through welfare (Zaviršek, 2009). Our research participants told us that people with disabilities are often offered jobs that require low qualifications and offer little pay. If the support they could receive through welfare is similar to their potential salaries, they may choose not to work. The short-term effect of this is exclusion of people with disabilities from employment. In the long-term this normalises welfare as income, again reminding people with disabilities of their qualitative difference from others.

Zaviršek argues that political rights and equality (or citizenship, in Agamben's terms) may only arise from efforts of inclusion that are demanded by the excluded group itself (Zaviršek, 2009). At the time of our research, a few NGOs, but mostly parents of particular children, served as agents of change by consulting state and municipality representatives of children's needs and demanding fair treatment. The parents interviewed saw themselves as the true deinstitutionalisation movement, not only recognising the flaws in state deinstitutionalisation policy but, more importantly, their own political capacity and determination to demand inclusion. It is important to note that we do not argue that residential care in itself caused exclusion for Kristers. His example clearly shows that it is rather the specialist care paradigm which produces the state of exclusion instead of institutionalisation itself. By leaving the decision of what constitutes the disability and what are the appropriate tools for inclusion in the hands of experts the Latvian system fails to adequately implement deinstitutionalisation and rather contributes to the complexity of everyday life of people with disabilities.

Linda

Linda has lived in institutions almost all her life. As she reached the age of three, it became evident that she had cerebral palsy. As her parents did not feel they would be able to take care of her they decided to give her away to a state institution. Adoption rates in Latvia are low and at the time of her birth (Linda was born during the late 90s), they were even lower. Her situation was exacerbated by her disability which destined her to end up in one of the state’s children homes. As she reached school age, there were only a handful of options available to her – with disability as severe as hers there were few choices and all of them were a form of state care institution. The children’s home decided that she should study in one of the state’s boarding schools. This practice was seen as logical and very financially beneficial for the children’s home as it still received funding for caring for the child while the actual care was carried out by the boarding school. This is possible because boarding schools in Latvia are mainly recognised as educational institutions and not as a form of out-of-family-care.

Linda, despite her physical constraints, was a gifted child and was able to finish her assignments and follow the learning material without much difficulty. This helped her to finish compulsory education with relative ease. In the Latvian system, children attend compulsory nine-year basic education and then move on to three-year secondary education. Secondary education is not compulsory, so there was little incentive for the children's home to look for a place that would accept Linda. Her boarding school received money according to the number of students they were willing to board which led to Linda staying at the boarding school for the next three years and studying at the final grade of primary education.

After reaching the age of 18, Linda was forced to leave the boarding school as by this age students are legally required to leave basic education institutions. As she was one of the few students determined to continue her education, her only option was a specialised state institution for people with disabilities. This institution provided basic vocational training and had links with a college level institution for people with disabilities which she hoped would allow her to continue her studies. The institution provided different kinds of courses and programmes but due to her disability her options were limited. She was not able to take part in secondary education aside from separate vocational courses because her previous education was in a parallel special education system not integrated into the overall state education system. This meant that, although she had been going to school for 12 years, in the end she still did not receive a diploma that would grant her the right to enter secondary education, the lack of which prevents her from ever entering higher education.

Linda presents a complex case for education and social care systems in Latvia. Zaviršek (2009), basing her approach on Agamben's theoretical framework, argues that one of the ways a person with a disability gets excluded from being an active citizen is by effectively being a welfare consumer which allows a certain amount of basic rights to be denied to the person. In Linda's case, although she received specialised education as a form of state support, in order to receive it she had to give up a right enshrined in Latvian legislation (Latvia, Saeima, 1999), that it is a child's right to receive education as close to her home as possible. This right was taken away from Linda first when she was sent to a boarding school and second when to continue her education she was required to move again to another part of Latvia where there was another specialised institution that was willing to take her.

The case of Linda also shows the problematic space occupied by institutions that cohabit this space of exclusion together with the children. Due to the nature of her disability, Linda was unable to take part in most of the vocational courses that were provided for her by her educational facility which mainly consisted of teaching basic manual skills. At the same time, she was both capable and motivated to learn computer science as her physical impairments did not prevent her from being able to learn how to use and work with computers. However, she was prevented from doing so due to the fragmentation of the system that is even made worse by the irregular place of this institution within the Latvian education system. Linda received her education in an institution that is a part of a larger state agency. Its functions include both administrative (to keep and update registers of people who need support) and practical (offer training programmes, provide professional/social rehabilitation) arrangements to improve the life of people in need of social support. This includes the previously described school and college for people with disabilities. The institution is financed and overseen by the Ministry of Welfare which in itself already constitutes a very particular case in the Latvian system, as most educational institutions are regulated and financed by the Ministry of Education. This creates endless complications, both for the staff of the school and the overall system, regarding certifying the level of education, circulation of information and, as Linda’s case shows, also in relation to making the transition from one system to the other.

The state of exception here also harms the desire to use these educational institutions as a tool for progressing deinstitutionalisation – both of them are promoted as integrated learning institutions that welcome students with and without disabilities. But since the vocational school is part of the Ministry of Welfare, only students with disabilities can receive state funding and, therefore, study for free while everyone else must pay up to EUR 1,800 a year effectively barring any prospective students without disabilities. The current complicated space that this institution inhabits in the Latvian care system also means that most of its students are adults who are taking vocational courses as the complex education system prevents more students from joining this place and gaining skills that may result in their reintegration to society.

The experience of Linda also illustrates the urgent need for deinstitutionalisation while shedding some light on the current complications in the way it is carried out. The decision by the orphanage to send Linda away to the boarding school shows they do recognise their own lack of skills and resources to be able to care adequately for children with disabilities. In all three of the cases of Linda, Kristers and Alice the specialised institutions are recognised as places where there is available both the expertise and the equipment to ensure the best possible care for the child. Nevertheless, their flaws not only impact the quality of life and integration of children, but through continued removal of persons with disabilities from the public space it further strengthens the view that this is the only possible solution. Furthermore, the resistance of municipalities can also be seen as stemming from the financial perspective according to Kuuse and Toros (2017), where the main motivation for implementation of deinstitutionalisation is to reduce costs. This is seen as true at state level, as it is claimed to be less costly in the long term. It is possible to fund the transition using EU grants, while at the local level it is mostly seen as both economically and structurally complicated, due to the need to invest more funds into education and loss of funds from the state for the maintenance of special schools.

Concluding arguments

The stories of Alice, Kristers and Linda reveal the often-chaotic trajectories of children with disabilities in changing practices of care. As the ground is shifting from a medicalised understanding of disability to a social one, and from segregated education to rights-based approaches to deinstitutionalisation, children with disabilities are left to find their own directions in a perpetual state of exception. From the one side, there is a need for addressing the politics of representation that construct children with disabilities as destined for certain forms of institutionalised care. From the other, there are practices of families that actively construct their ‘neediness’ to facilitate DI.

We have highlighted stories where it is easy to identify the agency of children and families trying to make a change and communities willing to provide support. However, the stories are also of ‘good citizens’ that do relatively well in school and have resourceful parents of higher than average socio-economic status. Somewhat paradoxically, to show your neediness for DI, you have to be an agent that is particularly eager not to be a *welfare consumer*. Conversely, for persons without such resources, demanding their right to be included is harder to reach and their rights are subject to chance. Changing practices of care and certain initiatives of DI, therefore, can be seen as producing two classes of children and both can be put in situations where they are in high risk of becoming a part of new and potentially worse ways of institutionalised forms of care.

While we can see that top-down and bottom-up approaches have a large impact on changing practices of care, what is often missing is the middle ground: the coordination at municipal and public discourse levels. By this coordination we don’t mean only developing more effective resource management and effectively available ways of helping educational and social institutions to become more inclusive and open, but to engage the broader social issues directly. First, coordinating municipal and public discourse has to take the politics of representation seriously as social marginalization is also one of the factors that decreases the efforts to improve diagnostic practices. Second, it has to introduce community-based learning as a part of DI as it is not enough to train only the ‘specialists’, like social workers or teachers, but principals, fellow children, and parents must be included. And finally, it has to expand the understanding of care beyond residential and institutionalised mechanisms while at the same time removing the stigma. By addressing these issues, we can hope for the most marginalised child to also be recognised as the subject of deinstitutionalisation.

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Social inclusion and intellectual disability in Ireland: Social inclusion co-ordinators' perspectives on barriers and opportunities.

Antonia Kenny and Martin Power

Abstract

Social inclusion is a cornerstone of policy for individuals with disabilities. Yet, studies have shown that in spite of positive developments, meaningful social inclusion remains a challenge. In Ireland, a number of policies have been enacted in recent years to promote social inclusion. In 2011, 'Time to move from congregated settings – A strategy for community inclusion' (2011), was introduced and sought to move individuals from congregated settings into the community. This was quickly followed by 'New Directions' (2012), which promoted the use of community supports to expand choice and inclusion. Implementation however has confronted a number of challenges. Against this backdrop, this study explored social inclusion co-ordinators' perspectives of social inclusion, barriers and facilitators. Two semi-structured group interviews were conducted with eleven co-ordinators in two day services. These co-ordinators have a particular remit to promote social inclusion in the day service they work in. The interviews were analysed thematically and two key themes emerged: a disconnect between the policy goals and lived experience, and barriers to meaningful social inclusion.

Keywords

Intellectual disability, social inclusion, day service, community attitudes.

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Background

Social inclusion can be defined as 'the interaction between two major life domains: interpersonal relationships and community participation' (Simplican, Leader, Kosciulek & Leahy, 2015, p. 18). The term emerged from France in the 1970s (Silver, 1994), and has since expanded to include both an emphasis on tackling social exclusion and marginalisation, as well as efforts to promote inclusion through enhancing community safety, access and social participation (Azpitarte, 2013; Bates & Davis, 2004; Christie & Mensah-Coker, 1999). As such, social inclusion and social exclusion are very much two sides of the same coin and both have structural and attitudinal components. For example, addressing inflexible organisational structures, procedures and practices can reduce barriers to accessing resources and opportunities. While tackling prejudice and stereotyping helps to encourage participation, creates opportunities and allows individuals and communities to build upon and expand capabilities (Australian Social Inclusion Board, 2012).

More recently, social inclusion has been applied to services for individuals with intellectual disabilities, with a focus on the cultivation of meaningful inclusion through occupying valued social roles to enhance belonging in the community (Community Living British Columbia, 2009; Kendrick & Sullivan, 2009; Randt, 2011; Simplican et al., 2015). These developments have been informed by calls for greater recognition of individuals with disabilities. For example, in 2007, the United Nations Convention on the Right of Persons with Disabilities (CRPD) called on states to ensure the 'promotion of the full enjoyment by persons with disabilities of their human rights and fundamental freedoms' (United Nations, 2007, p.1).

Implementation has proven more challenging however. In the Netherlands for instance, initiatives resulted in higher levels of social participation by people with a mild or moderate intellectual disability within the domains of work, social contact and leisure activities. However, interactions were mostly with other individuals with disabilities, rather than with non-disabled individuals (Dusseljee, Rijken, Cardol, Curfs & Greonewegen, 2011).

Social inclusion in Ireland

In an Irish context, efforts toward social inclusion are best understood against both the historical and contemporary backdrop of disability services. Historically, the state took an arms-length approach to health and social services and ceded substantial control to the religious and voluntary sector (Adshead & Millar, 2003; Harvey, 2007). Today a mixed economy of provision operates and services for children and older people have seen a substantial shift toward private sector involvement, while the disability sector remains dominated by state funded voluntary providers (Mulkeen, 2016) which account for 90% of specialist intellectual disability services (National Disability Authority, 2010).

Nonetheless, commissioning is increasingly favoured as a framework for service provision and it is likely that market mechanisms and/or private sector involvement will soon feature within the disability sector (Power, 2017). Certainly, during the recent recessionary period where a moratorium on recruitment was imposed, agency staffing through private recruitment services became common within the disability sector (Cantwell & Power, 2016).

Moreover, in 2011, a major reform programme for disability services was initiated - *Time to move on from congregated settings - A strategy for community inclusion* (Health Service Executive (HSE), 2011). This sought to move individuals with disabilities from congregated settings into the community, with congregated settings those where ten or more individuals lived together. This policy also included a move away from sheltered employment to open employment and was quickly followed by the *Value for money and policy review of disability services in Ireland* (Department of Health, 2012) and *New Directions* (HSE, 2012). This latter strategy envisages the utilisation of community supports to facilitate choice and inclusion, and reflected the wishes of individuals with disabilities for more involvement with communities, to build circles of friends (Abbott & McConkey, 2006). At the same time however, 'overall funding for disability services was reduced by €159.4 million between 2008 and 2015' (Dolan, 2016).

Furthermore, the extent to which communities are receptive to such changes remains uncertain. The National Disability Authority (NDA) examines public attitudes to people with disabilities through regular surveys. Surveys in 2001 and 2006 showed improving public attitudes, though those with intellectual or learning disabilities were more likely to report negative attitudes than those with other types of disabilities (NDA, 2006). More worryingly, the 2011 survey found that attitudes had taken a negative turn (NDA, 2011).

Day services and the role of day service staff and co-ordinators

Underpinned by the *New Directions* strategy, over 25,000 adults are provided with interventions to promote social inclusion in day services and staff have a particular remit to promote and facilitate social inclusion (HSE, 2012). This entails accessing and drawing upon the supports available in the community and most often includes participation in educational opportunities, sport and recreational activities, social events and local partnership projects. Staff advocate and facilitate access, as well as planning, co-ordinating and supporting participation (HSE, 2012). Nonetheless, supports can be of varied quality and intensity, particularly amongst auxiliary staff who tend to prioritise direct care tasks (McConkey & Collins, 2010).

Many services have specific co-ordinators or facilitators, who have a particular responsibility to manage and oversee social inclusion initiatives (McConkey & Collins, 2010). The term 'co-ordinator' is a generic term used throughout this paper to avoid indirectly identifying individuals or organisations, as recent research found that care staff have a multitude of titles, many of which are specific to organisations (D'Arcy & Power, 2018).

Study aim, participants and methods

This study aimed to explore the perceptions of co-ordinators around social inclusion. In particular it sought to investigate co-ordinators' perceptions of facilitators, barriers and the experience of inclusion. Purposeful sampling from two day services in the midlands region of Ireland yielded eleven participants, through poster advertising on staff notice boards facilitated by the organisation's management team. Participants were required to have more than one year's experience in the co-ordinator role, ranged in age from 21 to 55 years, and there were ten females and one male. Two separate semi-structured group interviews were conducted — Group A with three females and one male; Group B with seven females. The group interviews lasted between 40 minutes and just over an hour. Ethical approval was granted by the Discipline of Health Promotion, National University of Ireland, Galway, and informed consent from all participants was confirmed in writing prior to the interviews starting. The interviews were transcribed verbatim and analysed thematically with the assistance of Nvivo software (Fereday & Muir-Cochrane, 2006).

Findings

Two major themes emerged — a disconnect between policy goals and lived experience and barriers to social inclusion. Each theme had a number of sub-themes.

Disconnect between policy goals and lived experience:

- Service rather than user driven approach;
- Group activities as the norm, limiting individual choice;
- Community attitudes and a lack of awareness and sensitivity.

Barriers to meaningful social inclusion:

- Lack of experience of control;
- Family and services fears;
- Need for integration and partnership approach.

Disconnect between policy goals and lived experience

Service rather than user driven approach

While it was suggested that the New Directions policy 'can be positive' there was a concern that it was challenging to apply in a tailored fashion (2 Group A). For example, it was noted that 'seniors might want to go for teas and coffees or a massage. For them that's being active, whereas the younger ones, active might be working' (3 Group B). The concern was that 'you can't put everybody in the same box' (2 Group A). Amongst some, New Directions was 'fascicle' and was 'just throwing it back to the community' without adequate supports (3 Group A). Across both groups a lack of staff was commonly cited as 'one thing that would really stop us, the amount of staffing' (1 Group A). Moreover, this was often compounded by medical need, which often meant that health and safety concerns dominated even where an individual was 'probably more able than most' (2 Group B). In a similar fashion, 'if there is something that someone with autism wants to access, two staff are needed' (1 Group A).

It was not just staffing but also a lack of available resources within communities, which often limited activity choices. This may help to explain the migration of individuals with disabilities to urban centres where a greater variety of services are often available (Fleming, McGilloway & Barry, 2016). Where limited options, staffing levels or demands on transport collided, it was often a case that 'even if they don't want to go that day, it's their choice, but there's still a pressure on them' (4 Group B). Moreover, it was felt that 'we don't ask people who would you like to go with when out in the community, it's decided for them by the service' (7 Group B). The focus on activities and being active was felt to override that 'sometimes it's okay to do nothing, or say nothing, with or without a disability' (5 Group B).

The shift from sheltered to open employment was felt by members of Group A to be a specific loss, as it had provided 'a link to people that used to collect deliveries...they'd get to know people, they'd be talking to them' (3 Group A). Moreover, 'they felt worthy as well' and some individuals with disabilities 'even want to go back to that model' (4 Group A). The wish to return to the previous model was often informed by employment opportunities, as although employers frequently offered work experience, this rarely translated to a job offer. As a consequence it was 'back to square one trying to get jobs' (2 Group A). While no doubt well-meaning, participants felt that work experience was counterproductive as 'they want a job where they get paid' (2 Group A) and the 'only way we will ever get proper links to the community, is for people to feel like they are contributing to it meaningfully' (3 Group A).

In a national context, sheltered workshops have been criticised and policy was informed by a concern with alleviating misgivings around the 'risk of exploitation by service providers' (Fleming, McGilloway & Barry, 2017, p. 387). Nonetheless, mapping of day services over a 15 year period found that service provision often did not reflect demand and that few new services had developed (Fleming et al., 2017). The conclusion was that policy had moved too rapidly, as there were no national systems to support the types of services envisaged (Fleming et al., 2017). More importantly perhaps, a reduction in sheltered workshops was matched by a similar level of increase in 'activation centres' leading to the suggestion that this 'was perhaps a rebranding exercise, whereby service providers were seen to make changes in line with policy goals, but with little changing in reality' (Fleming et al., 2017, p. 389). Certainly, within the interviews some participants felt the model of day service itself was outdated as 'programmes are put on. We should be going out to the people, not people coming to us' (2 Group A).

In spite of such concerns, participants in both groups were keen to acknowledge the benefits of day services, particularly as a supportive environment for building relationships and skills. Often the day service was the service users 'social life. The actual relationships that people have here are very important' (2 Group B). Similarly, skills for living more independently had been developed and 'they wouldn't have done that if they weren't in day service' (4 Group A).

Group activities as the norm, limiting individual choice

The sense that services most often dictated options was reinforced by the dominance of group over individual activities. In part because of the challenges of staffing to support individual needs, as 'there is not always one available, that's a barrier we face' (3 Group B). Participants also acknowledged that constraints meant that staff often grouped individuals consciously or unconsciously and 'you are not looking at the person, it's like what group can they go into...you are not seeing the person, you are seeing the group' (5 Group B).

The grouped nature of activities and its impact upon community participation drew contrasting views. It was seen as a positive as it was felt 'that's why they are such an effective part of the community, everyone knows their buses' (3 Group B). Yet, it was also suggested that 'if you look at our transport, it's like everyone get on the bus, you might has [sic] well have our colours' (1 Group A). Participants overall felt that this was a challenge for integration, as although service users were known to the community they were most often known as a group rather than as individuals. This was compounded by the tendency for activities to be separate to community activities as 'it's not like for the most part joining in a group of people from town, it's like a specific group is set up' (3 Group A).

At the same time, interaction with other service users was often what individuals with disabilities wanted and participants cautioned against considering 'social inclusion from our perspective', since for 'people with intellectual disabilities it's inclusion with their own peers' and 'no matter what, they stick together' (2 Group A). Routine and familiarity were important and service users 'go to the same place, where staff know them' (5 Group B) and they wanted to 'sit with people they know from the centre' (6 Group B). As such, participants cautioned that social inclusion needed to reflect the wishes of service users as they felt it 'helps some people, but for others it's not for them' (2 Group B) and that it 'can be positive in some ways, but it has to be individualised' (2 Group A). This is not an uncommon finding and there is undoubtedly a complex relationship between segregation and self-segregation (Hall, 2017; Robertson & Emerson, 2007).

Community attitudes and a lack of awareness and sensitivity

Amongst both groups a significant barrier was attitudes within communities and a general lack of understanding of intellectual disabilities, with one participant describing the community as 'uneducated' (4 Group A). It was highlighted that 'with autism people automatically think — challenging behaviour' (2 Group A) and that people 'don't understand disability; why someone might be repeating themselves, there is no tolerance for it' (3 Group A). It was felt that 'mainstream society is never going to bother trying to understand autism' (4 Group B) and 'there's a long way to go with understanding different groups' (3 Group B). There were situations when you would have to 'ask people if everything was alright, as they would be staring at the service users' (5 Group B) and the sense was that 'for real community inclusion I don't know if there is much of a change' (7 Group B).

There were different viewpoints however, and it was highlighted that 'some of the community are starting to come around and not be as fearful' (4 Group A). Indeed, in one instance a local supermarket had introduced an autism friendly hour one day a week and such examples helped to acknowledge that 'people in the community have been trying to minimise barriers' (2 Group A). Similarly, 'younger people are more accepting now, and understand a little more, and are sympathetic' (3 Group B). Nonetheless, a number of examples were given of where individuals or groups of service users were not welcomed and community groups had even 'sent people away' because of fears or experiences of behaviour that challenged (3 Group B).

Moreover, participants highlighted that communication around behaviours was most often directly with them rather than with the individual with a disability and that community groups commonly requested staff accompany a service user to an activity. This could create its own complications, especially where a service user met someone they knew in the community — 'he could not figure out how to tell them who I was. So confused and flustered in how to describe his relationship with me, awful position for him' (2 Group B). As such examples suggest public perceptions can present dilemmas for staff. Where there are behaviours that challenge for instance, staff must balance bringing 'a service user into the community on your own as a staff member, or with a second staff', while also being conscious of 'how that is going to look' (4 Group A).

Negative attitudes toward individuals with disabilities are well documented (Kiddle & Dagnan, 2011; Scior, 2011; Simpson, 2007). In an Irish context, the more recent reversal of the previous positive trend in public attitudes is therefore a particular cause for concern (NDA, 2011). As negative attitudes increase susceptibility to risks such as depression amongst individuals with intellectual disabilities (Kiddle & Dagnan, 2011). The experiencing of a negative climate may also help to explain self-excluding and the desire to 'stick together' (2 Group A).

Barriers to meaningful social inclusion

Lack of experience of control

If community attitudes and group activities contributed to structuring social inclusion, independence was often shaped by opportunities for autonomy over decision-making. Participants queried whether service users 'pick up their own mail' and are 'given the opportunity to explain what it is' (2 Group B). The general sense was that 'hardly any of them know they actually get bank statements' (2 Group B) and that for some 'pocket money' was controlled and 'she'd have to ask her mam for money' (3 Group B). As such, it was felt that 'a lot of things are controlled by money, which they haven't got control of themselves' (6 Group B). The situation was perceived similarly for more independent service users, though it was the amount of income rather than access to it that was the barrier, as the 'money from the disability allowance is not enough' (2 Group A) and 'it's so little' (1 Group A). Indeed, it was suggested that even going 'out for a pint Saturday night, they're not going to be able to do that on €188 a week' (4 Group B).

Of interest, amongst participants in group A there was a certain ambiguity here. On the one hand, financial concessions and subsidies around rent or household bills were felt to have a negative impact on public perceptions and social inclusion. Yet, it was acknowledged that service users did not 'have the money to access everything outside of the day centre' (4 Group A) and concessions are 'made for the right reasons...if they weren't in place a lot of people would not be able to do anything' (4 Group A). At the same time, participants raised concerns around concessions made where individuals with disabilities had struck members of the public, 'they would not be prosecuted due to their disability' (4 Group A) or caused physical damage, 'who had to pay for it, the sports centre because he had autism' (3 Group A).

In part, such ambiguity may be related to frustration. Participants in group A recalled situations where service users largely lived independent lives, yet when they accessed day services 'they can't walk to the shops on their own anymore, we actually create barriers and take away their independence' (3 Group A). Moreover, it was noted that some service users 'come here because they feel their wages are going to be docked' (2 Group A). As a consequence, there was a feeling that 'we are all complicit in the lies' (3 Group A).

Family and services fears

Fears around independence within services, such as going to the shop unaccompanied, were often shaped by the focus on risk assessments, regulatory compliance and responsibility. Risk assessments promoted much discussion and it was felt that while they were designed to protect staff and service users, they were often informed by a fear of being held accountable. Thus, they tended to restrict independence as for 'social inclusion you need spontaneity', but concerns over responsibility mean 'a lot of it is being cautious, being afraid to' (3 Group A). As such, it was felt that 'the service itself puts up barriers to going out into the community, risk assessing everything' (7 Group B). In cases where there were medical needs caution was even more likely, as it 'all comes down to their insurance, health and safety and risk assessments' (2 Group B). This was compounded by the 'mountain of paperwork that goes with it' (7 Group B). The litigious backdrop in Ireland, which has the 'dubious distinction of being the most litigious country in Europe' (Cusack, 2000, p. 1431) can only encourage a focus on defensive practice.

Understandably, families also often 'don't want to let the person go due to fear' (2 Group A). Certainly, it was felt that 'you need to start at home' (6 Group B) and that 'if you don't bring the family along, you're at nothing' (3 Group B). It was also acknowledged that the situation was complicated for families and that families could be reluctant to encourage independence, as they were concerned that 'if they get a job, they will lose so much' (2 Group A), as the disability allowance or place in the day service could be jeopardised and responsibility shifted solely to the family. Such concerns are likely part of wider anxieties about reforms to disability services, as the 'family perspective to reform is characterised by fear and suspicion of the motivation behind these reforms, with cost efficiencies being perceived as the main driver' (O'Doherty, Lineham, Tatlow-Golden, Craig, Kerr, Lyncy, & Staines, 2016, p. 138).

It was not just financial concerns that presented barriers and relationships were felt to be an especially awkward issue. Group B in particular suggested that the 'majority of service users wouldn't get an opportunity to experience relationships or dates' (3 Group B) and that there were 'even barriers to having a conversation...if they want to have a conversation and talk about boyfriends and girlfriends, they should be allowed' (5 Group B). The area of relationships and sexual education for individual with disabilities is generally controversial and nowhere more so than in Ireland (Healy, McGuire, Evans, & Carley, 2009). The Catholic Church's historical influence on social policy, health and education is well documented (Adshead & Millar, 2003; Moran, 2013) and has left an indelible mark on the Irish psyche. As a consequence, there is little, if any, sex education for individuals with disabilities and relationships are generally discouraged. Where there are relationships they are often kept secret (Healy et al., 2009; Kelly, Crowley & Hamilton, 2009). More worryingly, in the National Disability Authority's 2011 national survey, the public's support for the 'right to fulfilment through sexual relationships' for individuals with intellectual disability or autism not only reduced from the level in 2006, but fell below the level of support recorded in the 2001 survey (McConkey & Leavey, 2013).

Need for integration and partnership approach

The final sub-theme was the need for unity amongst all stakeholders for the promotion of social inclusion of people with intellectual disabilities, including family, services, the community and the person with intellectual disabilities. It was felt that services and staff 'need to work more closely with parents' (1 Group B) and that there 'has to be complete unity between parents and the service' (5 Group B). Family both needed to understand where staff were coming from and how they could contribute to supporting skills learned in services. Family status and standing in the community were viewed as an important 'influence on how active a person is in the community' (3 Group A) and facilitated access to work, leisure and inclusion. Amongst some, 'families need to step up a little bit more' (7 Group B). To promote social inclusion more generally it was felt that it 'has to start from a young age, from home, school' (2 Group A).

Integration between services was also highlighted as in need of improvement as often 'when we get referrals, we get wrong information' and 'you wouldn't recognise the person on the piece of paper' (2 Group B). It was felt that there needed to be integration and transparency between services 'across the board from a young age and that doesn't happen' (6 Group B) and a lack of timely and sufficient information exchange between services was only 'setting them up to fail' (3 Group B).

Discussion

It is clear from the group interviews that the promotion of social inclusion for individuals with disabilities is complex and challenging, with competing demands and aspirations that require balancing. Services for example, must grapple with striving to meet the needs and desires of each individual in the context of finite resources, while families have to negotiate a range of choices around autonomy, independence and caring. Social participation and quality of life are related to levels of self-determination (Wehmeyer & Palmer, 2003; Lachapelle, Wehmeyer, Haelewyck, Courbois, Keith, Schalock, Verdugo, & Walsh, 2005) and supported autonomy initiatives can nurture self-determination and improve satisfaction (Pellitier & Joussemet, 2016). Families however, are concerned that the drive toward community living is 'synonymous with a reduction in staff support' (p. 143) and requires relinquishing of current supports for 'a more individualized albeit unchartered arrangement' (p. 145), with sustainability a particular concern (O'Doherty et al., 2016).

While within the interviews the pivotal role that family can play was acknowledged and previous studies in Ireland have highlighted the need for strong family and natural supports (Fleming et al., 2016), it is equally obvious that community attitudes can be a significant facilitator or barrier. Here, it can be argued that a less than welcoming attitude within communities can in part be related to a lack of leadership at the political level. Ireland was the last of the 27 EU states to ratify the Convention on the Rights of Persons with Disabilities, only doing so in March 2018. This delay can be attributed in part to the recession, when other priorities were to the fore, and to a series of legislative changes that were required to bring laws into contemporary times. For example, the *Assisted Decision Making (Capacity) Act* (2015) repealed the *Marriage of Lunatics Act* (1811) and *Lunacy Regulation (Ireland) Act* (1871), which had governed capacity for over a century. The longevity of such legislation highlights the extent to which inertia, inequality and discrimination are structurally embedded. Indeed, key elements of the *Decision Making Act* (2015) have yet to be commenced.

A number of disability organisations also suffered significant reputational damage and a loss of public trust during the recession, as a series of high profile scandals emerged around pay and bonuses to senior staff (McInerney & Finn, 2015). When considering community attitudes it is interesting to note the findings of Fleming et al. (2017) who observed a migration to urban centres and those of McConkey and Leavey (2013), who found respondents to the National Disability Authority's 2011 survey 'were more likely to agree to the right to sexual relationships for people with intellectual disabilities if they: lived outside Dublin', Ireland's largest urban centre (p. 181).

Though a couple of studies do not provide sufficient information to make judgements about a relationship between migration to urban centres and community attitudes, they do provide food for thought. For example, it may be that in migrating to urban centres to access services, individuals with disabilities come into increasing competition for resources such as housing. Ireland is once again in the grip of a housing crisis and rents in many areas have now surpassed even the previously unprecedented levels seen at the height of the Celtic Tiger era (Lyons, 2018).

Moreover, negative attitudes may help to explain why individuals with disabilities self-segregate. This may be reinforced where family have concerns, as some individuals compromise to meet the wishes of their families (Fleming et al., 2016). Certainly, without appropriate supports to access mainstream recreational and leisure activities, individuals with disabilities tend to access segregated services because the supports are available there (Walsh-Allen, 2010). As group activities are the norm there may be something of a self-reinforcing circle, which limits the opportunities for engagement with communities (Overmars-Marx, Thomese, Verdonschot & Meininger, 2014). This can only be compounded by the reluctance to engage in positive risk taking and the concern with 'risk assessing everything' (7 Group B). It has been argued that until policy-makers and service providers accept that human services are essentially risky, then service provision is likely to be limited to safe options

(Sykes, 2005). As such, Fleming et al's (2017) argument that policy moved too rapidly as there were no national systems put in place to ensure or nurture the community supports envisaged, would therefore seem very plausible. Indeed, in many ways it reflects the historical ad hoc and localised evolution of disability services development in Ireland (Harvey, 2007).

Limitations

A small sample size and localisation to two services in the midlands region limit generalising from the findings. The limitations of group rather than individual interviews must also be considered, as individuals with more forward personalities have the potential to lead or sway discussion.

Conclusion

This research set out to explore how co-ordinators perceive social inclusion for individuals with intellectual disabilities. Though small scale, findings indicate that coordinators view numerous barriers to social inclusion. Barriers are often multifaceted and shaped by the nature of service delivery, levels of family involvement and the extent of welcome within communities. Social inclusion is generally defined in a two-fold manner, community participation and acquiring a broader social network. However, the first does not always lead to the second and when community participation is limited so too are the opportunities for fulfilling meaningful social roles. Nonetheless, co-ordinators felt that there were many positives to the promotion of social inclusion and that communities had made efforts to minimise barriers.

About the author

Antonia completed her BA in Social Care at Athlone Institute of Technology (AIT), where she developed a particular interest in working with individuals with disabilities. Antonia has worked in both residential and day services over the last 5 years. Antonia recently completed the MA in health promotion at National University of Ireland, Galway (NUIG), and this paper is based upon her MA dissertation research.

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Awareness of and support for speech, language and communication needs in Children’s Hearings

Ann Clark, Dermot Fitzsimons

Abstract

Looked-after children commonly experience speech, language and communication needs (SLCN) (McCool & Stevens, 2011; Department for Education, 2017). Unidentified and unmet SLCN have negative effects on children’s educational attainment as well as social, emotional and mental health (Law, Rush, Parsons & Schoon, 2009). In Scotland, the institutional body with primary responsibility to address the needs of looked-after children is Children’s Hearings Scotland (CHS). The focal means of decision-making is the Hearing. Previous FOI requests showed very few referrals from the Hearings to SLT services (Clark & Fitzsimons, 2016). Panel Members’ and Children’s Reporters’ views on children’s SLCN and on support for these needs in Hearings were gathered using an online questionnaire. 35 responses were received. Findings emphasised the importance of a child’s individual needs. Many respondents had concerns over a child’s communication during the Hearings process. SLTs rarely attend Hearings. Barriers to effective communication were seen to be intrinsic to the child, but also within the environment. The paper concludes that an increased role for SLTs within the Hearings System would be beneficial, both working directly with children to support their SLCN, and training and supporting decision makers in developing confidence to refer children to SLT services.

Keywords

Speech, language and communication needs, Children’s Hearings, participation, awareness

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Introduction

In Scotland, primary responsibility for addressing the needs of children who have come to the attention of authorities as a result of offending behaviour, care/protection needs or both, is held by the unique care and justice system for children and young people, the Children's Hearings System. The Children's Hearings System works with a number of agencies to provide care and support, including social work, education services, NHS providers, Police Scotland, the Scottish Children's Reporter Administration and Children's Hearings Scotland.

The focal point of the Children's Hearings System is the Children's Panel. Children's Reporters, facilitated by the Scottish Children's Reporter Administration, receive an initial referral of concern which may come from a variety of community sources e.g. police, schools, parents or in some cases, the child themselves. In 2016-17, 15,118 children and young people were referred to the Children's Reporter (1.7% of Scotland's children and young people) (Scottish Children's Reporter Administration, 2017), the majority of referrals (75%) being from the Police (Scottish Children's Reporter Administration, 2017).The Reporter then decides whether grounds exist on which a Panel might place a child on a Compulsory Supervision Order from information gathered from relevant sources named above and/or the child and family. The Reporter then has the authority to require the Children's Panel to hold a Hearing. 34,106 Hearings took place in 2016-17 (Scottish Children's Reporter Administration, 2017). The Hearing is conducted in private. The Panel consists of three trained volunteer lay members. The Children's Reporter and other invited attendees are also present. The child is invited by statute but may not attend, often for safety/protection reasons. Parents/carers and the social worker commonly attend. The Hearing has a limited number of decisions at their disposal: to request more information and defer the Hearing before a decision is made on whether a supervision order is needed; to make a supervision order; or to decide that formal compulsory supervision is not necessary and to discharge the case.

Given its 45-year history, Scotland's Children's Hearings System has changed remarkably little. From its inception in 1971, its ethos has sought to place the child's needs and views at the centre of the decision-making process, within what is intended to be a fully participatory, transparent procedure (Kilbrandon, 1964). As is well documented, these needs are often heightened due to the child's life experiences. They may have suffered physical, emotional or sexual abuse, been neglected, may be involved with the justice system due to offending; need respite from a difficult family situation, or have complex disabilities that require specialist care. The onus is on the local authority to co-ordinate services to identify and meet these often multiple, continually developing needs.

Long term outcomes for looked-after children and young people

The higher risk of poorer short term and long term outcomes for children who have spent time in care is well documented. They are at significantly higher risk of poorer mental health outcomes (Office of National Statistics, 2004; Stanley, Riordan, & Alaszewski, 2005; Ford, Vostanis, Meltzer, & Goodman, 2007; Tarren-Sweeney, 2008), lower levels of academic attainment (Berridge, 2007; Scottish Executive, 2016), and at greater risk of social, emotional and behavioural disorder (Millward, Kennedy, Towlson, & Minnis, 2006; Ford et al, 2007; Sempik, Ward, & Darker, 2008) than the general population. The associations between looked-after status and these outcomes are clearly complex and placement instability, trauma, abuse, neglect and attachment issues are influencing factors in such outcomes. The wide-ranging negative effects of abuse and neglect on child development are beyond doubt.

Speech, Language and Communication Needs in Looked-After Children and Young People

Although the negative effects of maltreatment on language and communication abilities are well evidenced (Law & Conway, 1992; Veltman & Browne, 2001; Hwa-Froelich, 2012; Lum, Powell, Timms, & Snow, 2015), a far less investigated phenomenon is speech, language and communication needs (SLCN) of looked-after children and young people. This is concerning given that these are highly likely to be a mediating factor in poor short term and long term outcomes outlined above.

SLCN is the umbrella term used to describe the difficulties some children and young people have with listening, understanding and communicating with others. Children with SLCN may have difficulty with only one speech, language or communication skill or with several (Afasic, 2018). For some children, their difficulties may be 'mild and limited to particular situations' (Centre for Youth and Criminal Justice, 2017, p. 9), but, for many children with SLCN, their difficulties are 'persistent, pervasive and complex' (Centre for Youth and Criminal Justice, 2017, p. 9). Children with SLCN are likely to need support to develop the complex and numerous skills involved in communication. Each child also has unique strengths (Afasic, 2018).

Looked-after children with communication needs can have difficulty understanding what is being said to and asked of them. They can also have difficulty making themselves understood. Common difficulties include learning and using complex vocabulary, social communication skills, naming and managing emotions (including self-control), self-awareness, vocabulary, concepts related to time, working memory and the ability to retain, process, recall and sequence information. Communication needs are often hidden and older children in particular may have developed masking techniques for these needs. Some looked-after children communicate through behaviour that may result in offending (Royal College of Speech and Language Therapists, 2017).

In the US, Amster, Greis, and Silver (1997) found language delay in over 50% of over 200 children under 31 months in foster care. Hagaman, Trout, DeSalvo, Gehringer, and Epstein (2010) administered a language skills screen to 80 young people entering residential care, 54% of participants were at risk for language impairment. In the only study of SLCN in looked-after children in Scotland to date, McCool and Stevens (2011) investigated communication impairment in 30 young people in residential care, using a carer-administered questionnaire. Communication impairment was indicated in 19 of the 30, with eight profiles suggestive of Autistic Spectrum Disorder. In nine out of ten available case histories of those demonstrating impairment, no concerns had been raised regarding their communication; in the one remaining case, no referral to SLT had been made, despite recorded concerns.

South of the Border, a recently adopted, well-received, model in Yorkshire (No Wrong Door) which delivers an integrated health and social care service to looked-after children and young people, found that 58.4% of their charges had SLCN, with the majority being previously unidentified (Department for Education, 2017). This indicates a sizeable over-representation of SLCN in this population compared to a rate of 10% in the overall child population (Norbury, Gooch, Wray, Baird, Charman, Simonoff, Vamvakas, & Pickles, 2016).

Both authors are Speech and Language Therapists and the second author has several years of experience as a Panel Member. We were therefore interested in the first instance to investigate integration between the Hearings System, social work and NHS Speech and Language Therapy services. Freedom of Information enquiries to all Scottish local authorities found there were very few referrals from the Hearings System particularly, and social work services more generally, to NHS SLT services (Clark & Fitzsimons, 2016).

Given the complex nature of the decision-making process, and a reliance on oral discussion as the main means of communication, this study aims to investigate the views of Panel Members and Children's Reporters on speech, language and communication needs of children attending Hearings. Specifically:

1. To explore perspectives on the communication skills a child needs to participate fully throughout the Hearings process.
2. To find out whether Panel members and Children's Reporters had had concerns about a child's communication during a Hearing.
3. To explore Panel Members' and Children's Reporters' knowledge of means to support children's communication in the Hearings system.

Within these aims, specific questions targeted the respondents' views.

Method

Ethical approval

Ethical approval was obtained from Queen Margaret University Ethics Committee, the Scottish Children's Reporter Administration and Children's Hearings Scotland.

Data collection

The first author attended by invitation a session of Hearings. An online survey was created and piloted with two Children's Reporters and one Panel Member. A revised survey was then placed by Children's Hearings Scotland and the Scottish Children's Reporter Administration on their respective intranet systems. The survey was also disseminated by the authors using Twitter and Facebook with permission from Children's Hearing Scotland and the Scottish Children's Reporter Administration. The survey was open from January to April 2017. All participants were asked if they would be willing to take part in a follow-up phone discussion. Fifteen phone calls took place. This data is currently under analysis to be presented elsewhere.

Respondents

Twenty-one Panel Members (PMs) and 15 Children's Reporters (CRs) responded. One CR questionnaire was excluded, as information was incomplete, giving a total of 35 completed questionnaires.

Table 1 gives demographic data for all respondents. Six were aged 65+, eight between 55-64 years, nine between 45-54, eight between 35-44 and four between 25-34. None were between 18-24 years of age. Nine out of 21 PMs and 12 out of 14 CRs were women.

Numbers of Hearings the respondents had participated in varied widely. Overall CRs had attended more than PMs, with a range of 14-750 for PMs and 50-4500 for CRs. Individual data on which local authority the respondents were located in is not reported here to maintain confidentiality. A wide area of Scotland was represented, with the majority in the Central Belt of Scotland, as well as responses from Orkney and Shetland, the Western Isles, the Highlands, Fife, Tayside, Perth and Kinross, Argyll and Bute, and East Ayrshire.

Table 1 – Demographic details of Panel Members and Children's Reporters respondents

Participant	Role	Age	Gender	Number of hearings attended
1	Panel Member	35-44	M	250
2	Panel Member	45-54	M	72
3	Panel Member	65+	M	750
4	Panel Member	65+	M	575
5	Panel Member	45-54	M	180
6	Panel Member	35-44	F	100+
7	Panel Member	65+	F	144
8	Panel Member	55-64	M	14
9	Panel Member	65+	M	150-200
10	Panel Member	45-54	M	120
11	Panel Member	45-54	F	30+
12	Panel Member	55-64	F	220
13	Panel Member	35-44	F	55
14	Panel Member	45-54	M	150
15	Panel Member	55-64	F	300
16	Panel Member	35-44	M	30+
17	Panel Member	65+	F	A lot
18	Panel Member	65+	M	Several hundred
19	Panel Member	55-64	F	30+
20	Panel Member	25-34	F	140
21	Panel Member	55-64	M	20
22	Children's Reporter	-	M	Over 1000
23	Children's Reporter	35-44	F	50
24	Children's Reporter	54-45	F	Over 3000
25	Children's Reporter	55-64	F	Approx 4500
26	Children's Reporter	35-44	M	1600+
27	Children's Reporter	25-34	F	1500
28	Children's Reporter	55-64	F	100s
29	Children's Reporter	25-34	F	500
30	Children's Reporter	35-44	F	400+
31	Children's Reporter	45-54	F	Approx 4300
32	Children's Reporter	45-54	F	1200-1600

Participant	Role	Age	Gender	Number of hearings attended
33	Children's Reporter	35-44	F	100s
34	Children's Reporter	Excluded as information incomplete		
35	Children's Reporter	55-64	F	Over 500
36	Children's Reporter	25-34	F	500

Findings

Aim 1: To explore perspectives on the communication skills a child needs to participate fully throughout the Hearings process

Respondents were asked 'what are the speech, language and communication skills you think a child needs to participate effectively before, during and after the Hearing?'. The written, qualitative responses were analysed and coded using a thematic analysis approach (Boyatzis, 1998; Braun & Clarke, 2001). While the focus was on which communication skills a child needs to participate fully in the Hearings process, related issues arose within the responses. As these provided useful data, where appropriate, they are reported below. PMs' and CRs' responses are considered together as similar themes emerged from the two groups.

The primary skill needed was thought to be a child's ability to express him/herself, with all respondents recognising the importance of these skills at each stage of the Hearings process. Respondents used the following verbs to describe what skills a child needs: talk, explain, verbalise, speak, ask, take part [in conversation], express [themselves] and answer [questions]. Responses largely centred on the ways in which children could effectively make their views known; in these descriptions, children's views were not solely confined to getting across their material needs, but also discuss emotional expression and personal opinion, as the following quotes show:

'ability to talk and explain their wants/needs and their concerns. Ability to ask questions. Ability to […] take part in a conversation';

'Ability to speak clearly and express their hopes and fears';

' […] to be able to answer questions openly and honestly';

'Having the relevant communication skills to articulate their feelings is important, and possibly to agree disagree with what is being said around/about them'.

A number of responses also mentioned 'body language' and 'non-verbal communication', with comments including 'the child's non-verbal communication is also noted by the Panel; listening, talking and body language'; and [I am] 'always aware of their body language'.

Language comprehension skills were also recognised as crucial and were described variously as listening, understanding, being understood, following conversation, concentration skills, processing information and coping with 'inputs':

'The ability to listen to and understand when an appropriate adult shares the information with them. The ability to listen or absorb information';

'After a Hearing it is important a child can understand the outcome, when it is explained to them in the terms relevant for their age/stage';

'Age appropriate understanding given age appropriate communication from adults';

'coping with multiple "inputs" ranging from professional to lay'.

A relatively small number of respondents (5 PMs, 3 CRs) mentioned literacy skills as an important contributing factor to participation. Those who discussed reading and writing focus on two main elements: use of the standard 'All About Me' form that may be filled out by a child to express their views on how they have been feeling, if they understand why they are attending a Hearing, if they have issues with their living situation, with school, or have any other issues they wish to discuss. This may be filled out either online or in written form. Secondly, respondents contribute views about the importance of reading abilities to understand background reports and other documentation.

An important theme not directly concerned with communication skills per se, concerned the child's understanding of Hearings process and procedures, reasons for attendance and outcome of the Hearing. Many respondents were of the view that prior preparation and an appreciation of the reason for and purpose of the Hearing were important factors affecting the child's successful participation, with several framing their responses in terms of the child's age/development:

'This is about a combination of the age and ability of the child coupled with how well they are prepared for a Hearing by the system which is attempting to support them';

'Depends on the age, but the ability to understand why they are there helps them to communicate effectively';

'They need to have an understanding (suitable to their age) of the purpose of the Hearing, i.e. that it is there to help them and make things better for them';

'Good language skills probably most important if need to understand what being told about the reports and follow proceedings of the Hearing'.

A further theme not questioned directly was confidence in a Hearing. This was seen as a key skill which was a high expectation of the child:

'In terms of communication skills, in my experience it requires a child with a high degree of confidence to put forward their views in front of a group of strangers. This is rare';

'They need to be encouraged to speak to social work or school openly – which is a big ask for a child';

'The confidence to ask questions when they don't understand';

'the confidence to speak to the panel, whether in front of the whole Hearing or by themselves'.

Aim 2: Whether Panel Members and Children's Reporters had had concerns about a child's communication during a Hearing.

Sixteen respondents had often had concerns about a child's communication during a Hearing (8 PM, 8 CR) and a further fifteen (10 PM, 5 CR) had sometimes had concerns. One CR said they had always been concerned. Three

PMs said they had rarely been concerned. The respondents were also asked if they would welcome further information about a child's SLCN beforehand. Sixteen said always (9 PM, 7 CR), seven said often (4 PM, 3 CR), eleven sometimes (8 PM, 3 CR) and one said rarely (CR).

Aim 3: Panel Members' and Children's Reporters' knowledge of means to support children's communication in the Hearings

Respondents were asked whose primary responsibility it is to provide information before a Hearing on whether a child has an SLCN. The most common view was the social worker should do this (11 PM, 10 CR), followed by parents/carers (5 PM), Panel Members (2 PM), Children's Reporters (1 PM) or the child's school (1 CR). Three respondents said responsibility was shared by all involved with the child, including the family.

Two PMs had experience of an SLT being at a small number of Hearings (e.g. 4 or 'occasionally'). One commented 'no, it's rare for ANY health professional to attend'.

Five CRs reported SLTs had attended Hearings in their experience. Again, comments reflect that this is unusual: 'maybe 1% of Hearings', 'rarely, but supplied reports when requested', 'yes – very rarely', 'yes – 10 Hearings', '4-5 Hearings', 'once', 'yes, although not directly supporting child – there as submitted report'.

Although this was not targeted directly, many respondents referred to the importance of support and advocacy for the child in the Hearing itself. There is an expectation that an adult should provide support for the child. While a social worker is favoured as the main adult to provide support, this was not the only view with 'safeguarder', 'advocate', 'an adult', 'class teacher', 'the family', and 'a trusted person' were also given as possible sources.

Respondents were asked what promotes good communication in a Hearing. Themes arising were getting the physical environment 'right' with child friendly seating, mutual respect and setting the 'right tone' at the start. One PM captured the recurring themes in saying:

> relaxed friendly atmosphere. Panel Members speaking the appropriate level for the child. Avoid using complicated language or jargon. Showing an interest in and listening to the child. Being patient allowing the children to gather their thoughts and express them. Encourage and reassure the child. Explain yourself clearly to the child. Be non-judgemental. Stay calm.

Barriers to good communication can be broadly grouped into two themes. The first of these was seen as the formality of the Hearing including seating arrangements, formal and 'difficult' language and too many adults being present. The second theme was around the high levels of anxiety and emotion for the child and the parents/carers before, during and after the Hearing.

Finally, when asked if they are aware that anyone can refer a child to the NHS SLT services, only 10 out of 35 said yes (5 PMs, 5 CRs).

Discussion

It is clear that some Panel Members and Children's Reporters have considerable insight into the communicative demands placed upon a child or young person before, during and after a Hearing. Responses often emphasise the child-centred ethos of the Children's Hearings System, the importance of ascertaining the child's views through a variety of methods and attempting to ensure that the child understands what is happening during what is very often a highly emotive experience for them.

Panel Members and Children's Reporters are physically present for only one stage of this process, the Hearing itself; their perspectives therefore reflect a view that is heavily skewed towards this setting but they also show an appreciation of the skills required in participating in every stage of the process. What is immediately apparent from the responses is the generally high level of expectation of the language competence of children who attend Hearings, particularly in terms of expressive and receptive language skills. In addition: the high level of demands on literacy in understanding the written documentation sent out to children and carers; understanding of the Hearing procedure — the reason for the Hearing, how it proceeds, and decisions reached; the importance of self-confidence in speaking up before, during and after the Hearing; and the significance of the presence of an adult to provide support and interpret events and decisions made by the Panel. One personal quality in particular — confidence to speak up before, during or after a Hearing — is also viewed as important and there was recognition of how challenging this is likely to be for a child.

Children's Hearing Scotland has emphasised the core importance of gaining the child's views in the decision-making process directly relating to their welfare. The Children (Scotland) Act 1995 aligned this approach more closely with the overarching principles of the UN Convention on the Rights of the Child (1989), in particular Article 12, where a child 'who is capable of forming his or her own views' has 'the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child'. Article 12(2) goes on to state that not only does the child have this right, but his or her views must then be afforded consideration 'in any judicial and administrative proceedings affecting the child' (UNICEF, 1989). Most recently, the Children's Hearings (Scotland) Act 2011 has specified that the Hearing must:

> so far as practicable and taking account of the age and maturity of the child—
> (a) give the child an opportunity to indicate whether the child wishes to express the child's views,
> (b) if the child wishes to do so, give the child an opportunity to express them, and
> (c) have regard to any views expressed by the child.
> (Children's Hearings (Scotland) Act, 2011, s.27, (3))

Griffiths and Kandel (2000) outline the difficult situations reported by children and young people in the Hearings System that may be seen as arising from the often conversational, semi-informal approach taken. Factors such as i) disagreement with a pre-established narrative without becoming confrontational; ii) anxiety/fear about consequences of the Hearing as an inhibiting factor; iii) conflicting loyalties within the Hearing room; iv) sociolinguistic aspects of panel member communication, e.g. accent, use of 'posh' vocabulary and social distance are seen as not only affecting the child or young person's communication in the present, within the room, but also the impression given to

Panel Members of that child's willingness to engage or comply with an order. These factors are daunting enough for any child; for a child with an unsupported language or communication disorder, this presents circumstances in which a child's welfare will inevitably be compromised by the Hearings process itself.

In this context, one highly striking feature of the responses is therefore how rarely, if at all, respondents cited pragmatic abilities (e.g. use of narrative skills, evidence of successful codeswitching behaviours, turn-taking, topic introduction and maintenance, facial expression, eye contact) as required skills for effective participation. It is, of course, unrealistic to expect PMs and CRs to use the term 'pragmatic skills', but the absence within the responses of any iteration or description of these skills is striking, and highlights an apparent tension between ethos and practice in the Hearing room, where the discussion is framed as informal, but is often led by the Panel. These are skills that are necessary for meaningful participation in discussions that take place in the room. It could be argued that the ethos of the Hearings System — placing the child at the centre by means of an informal discussion — lends itself to opportunities to exercise these abilities, as they form the backbone of effective and participatory discussion. It is essential that PMs and CRs are trained to recognise and support these particular linguistic skills of children as it is incumbent upon them to safeguard and promote each child's welfare in any decision and in the decision-making process itself.

While written and oral, face-to-face communication take precedence in responses, there is a significant absence of discussion of the ways in which Children's Hearings Scotland and the Scottish Children's Reporter Administration has made significant moves to present relevant information about Hearings to children in a greater variety of modes beyond those mentioned. Online videos and appropriately designed separate All About Me forms for children and young people are featured on the Scottish Children's Reporter Administration website; leaflets about a range of topics, such as attending Hearings, describing the rights of a young person and defining a Compulsory Supervision Order, are available to download. The level of written language in the 'All About Me' form (Scottish Children's Reporter Administration, 2017) is still worryingly high, with lengthy, multi-clausal sentences, and abstract vocabulary: for example 'right' being used, as in: 'You have the right to bring someone along with you to your Hearing to help and support you'. This level of language would be very difficult, if not impossible, for a child with speech, language and communication needs to understand. This difficulty itself would likely lead to increased anxiety and/or frustration for the child before the Hearing itself.

The move to increase participation further — before, during and after the Hearing — contained within the recent Digital Strategy for the Children's Hearings System (Scottish Children's Reporter Administration, 2016), is very welcome. The Strategy aims to achieve greater participation through increased use of electronic means of communication and to extend its existing online presence. Proposed additions include an online introduction that allows a walk-through of the Hearings process, opportunities for children and carers to view Panel Member biographies and chat online to a Reporter. In addition, use of video statements as an alternative or to augment traditional 'All About Me' written forms, and use of videoconferencing software rather than the demand for the physical presence of child and carer, have been proposed. Opportunities for greater use of alternative means of communication such as easy-read documentation and visual support, however, are not detailed within the strategy, and would be welcomed. Care should be taken to ensure both the grammar and vocabulary in new resources are age and developmentally appropriate for the children using them. Speech and Language Therapists are the professionals with the specific expertise to support these developments.

There is a clear need for urgent action on the following issues: a thorough and more robust evidence base must be developed that examines further the intersection points between looked-after children and young people and their SLCN to better serve their welfare in the decision-making process; to improve the training of Panel Members and Children's Reporters in order to ensure that the SLCN of these vulnerable children and young people are identified and met in the decision-making process more effectively than at present; the routine inclusion of a Speech and Language Therapist to support a child with SLCN in the Hearings System; creation of greater opportunities outside the Hearing room for looked-after children and young people to participate in the decisions made about their welfare in a communication environment appropriately supportive of their needs.

At a local level of service integration, the study has implications for those working directly with the children and families. It is better to err on the side of caution and assume a child will need support with their communication, rather than assume they will not. As one Panel Member commented, 'Every child probably has a speech, language and communication need'.

The Royal College of Speech and Language Therapists has a professional duty to raise awareness of the open referral system operated by NHS SLT services. SLTs should work with social work and child and youth care workers in supporting them to feel more secure in making a referral to NHS SLT services if they are concerned about a child's communication, and themselves supporting parents to do likewise. The Royal College of Speech and Language Therapists (2017) recommends that the team supporting looked-after children has access to specially commissioned speech and language therapy services. This should enable children and young people to be screened for communication needs when they enter care, including referral to speech and language therapy services for a full assessment where the screen has identified this as necessary to support differential diagnosis. The second recommendation is for training: those working with, caring for, and supporting looked-after children should be trained in awareness of speech, language and communication needs and how to respond to them so that the places where they spend most of their time, school and home, are able to meet their needs (Royal College of Speech and Language Therapists, 2017). Training would also help support those working directly with the children and young people in preparing for hearings, for example, in identifying communication support strategies which are helpful for them. SLCN training should also be integrated into the nationwide advocacy service for Children's Hearings which is intended to be operational by 2019. If an advocate 'might go to a hearing with a child or young person to support them and to help them express their views' (Scottish Executive, 2012), it is essential advocates have a secure knowledge of SLCN and how to support these. Training is likely to be most effective if delivered by Speech and Language Therapists at two points: firstly in initial training/undergraduate education for those involved in working directly with children and young people participating in Hearings; secondly, as part of their continuing professional development requirements. The third recommendation (Royal College of Speech and Language Therapists, 2017) is that SLTs should provide direct support for looked-after children with a SLCN. This should take place before, during and after Hearings in order to ensure their welfare is served throughout the Hearings process.

Lastly, it is important to bear in mind that there is a high likelihood that parents and siblings of looked-after children may have SLCN of their own and that these needs may be unidentified and therefore unmet, as outlined in the Royal College of Speech and Language Therapists' (2016) Intergenerational Cycle of Speech, Language and Communication, Outcomes and Risks. They are therefore likely to require support themselves, in their daily lives and in specific situations, for example, when a parent attends a Hearing.

The study has a number of limitations. Firstly, although the number of Panels the PMs and CRs had participated in was relatively large, the number of respondents was small. While there are around 2,500 Panel Members currently active in Scotland (Children's Hearings Scotland, 2017), and 120 Children's Reporters (Scottish Children's Reporter Administration, 2017), the study captures the views of a small proportion of these groups. Children's Hearings Scotland advised that Panel Members were often asked to take part in research and so requests for participation were disseminated at an appropriate frequency to accommodate this.

Given the highly qualitative nature of the study and the difficulties with access to larger groups, further planned research in this area will utilise an initial questionnaire and subsequent focus group approach in order to provide further opportunities for greater elaboration on key issues by Panel Members and Children's Reporters.

Further investigation of this topic should involve other key decision makers within the Hearings System to reflect other professionals' involvement in the different stages of the process: the views of social workers on the communication needs of the children and families they work with should be sought. The views of the children and young people themselves should also be sought. At the time of this study, the authors distributed a questionnaire to children and young people in care via social media and also through the Centre for Youth and Criminal Justice. As no responses were received, it may be that a multi-agency approach would prove more successful in gathering the views of children and young people in the future. Evaluation of support in place for SLCN of children and young people and their parents before, during and after Hearings would inform future practice.

Conclusion

Panel Members and Children's Reporters have concerns over the speech, language and communication needs of children they work with in Hearings. It is essential that such children's welfare is safeguarded in a meaningful way during Hearings. We must go beyond the minimum requirements set out in the Children's Hearings (Scotland) Act (2011) (UK Government, 2011) in order to fully enable the child to participate in a full, effective and high quality manner. A strengthened role for Speech and Language Therapists in the Hearings System is vital; firstly, working directly with the children themselves, ensuring timely identification, assessment and management of speech, language and communication needs, and secondly, providing SLT profession-specific training and support to Panel Members, Children's Reporters, social workers and advocates to enable them to identify where there is concern over a child's communication and be secure in referring the child to Speech and Language Therapy services.

About the author

I am a Senior Lecturer at Queen Margaret University and a Speech and Language Therapist. I am interested in how communication needs are recognised and supported in Scotland's care system, particularly in Children's Hearings. I also work with young adults who have been in care and are now at university and how they view communication skills and how these have affected their education and friendships.

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Animal Magic- Benefits for children, who have experienced trauma or who are on the autistic spectrum of being around and caring for animals.

Mary Morris

Abstract

The article advocates taking a positive, proactive approach to having animals and pets in the lives of looked after children. Links are made with the new Health and Social Care Standards. The life enhancing difference that animals can make for some looked after children in promoting their self-esteem and resilience are explored.

Keywords

Animals, feeling safe and happy, Health and Social Care Standards, life enhancing.

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Introduction

This article celebrates the positive difference that being around and caring for animals can make for looked after children. It explores the benefits and makes a case for a proactive approach. It is intended to be thought provoking and encourage care professionals and providers of services for looked after children to seek out ways animals can play a role in the lives of looked after children. It is structured around some of the new Health and Social Care Standards (2018); making links between these, and the life enhancing benefits for many looked after children of having animals in their lives.

The Health and Social Care Standards

The Health and Social Care Standards published in April 2018 set out what everyone using care services in Scotland should expect when using health, social care or social work services in Scotland. The Standards are underpinned by five principles: dignity and respect; compassion; be included; responsive care; and support and wellbeing. They aim to drive improvement, promote flexibility and encourage innovation in how people are cared for and supported. The Health and Social Care Standards are based on human rights and the wellbeing principles; they set out what people should experience from their care and support. The new standards take a risk benefit approach.

Standard 2.24: I make informed choices and decisions about the risks I take in my daily life and am encouraged to take positive risks which enhance the quality of my life

For looked after children and young people this is especially important. Looked after children are individuals with aspirations, talents and hopes waiting to be encouraged and developed. They may have experienced trauma and loss and have had lots of different people caring for them. They may have missed out on positive early childhood experiences or not been able to take advantage of opportunities. Keeping pets and being around animals takes commitment, money and energy but has a range of advantages for looked after children. Contact with animals can provide something special and magical in addition to human interaction and can enhance relationships.

There are challenges for the sector and for scrutiny bodies in the new Health and Social Care standards that have concepts of compassion, empowerment and love at their core. These are not always easy to evaluate. For scrutiny bodies such as the Care Inspectorate there is a fundamental shift in focus from seeing whether something is done correctly to asking how successful interventions are in improving outcomes and experiences for people. For a scrutiny body there is also a need to support improvement and raise aspiration.

Standard 1.6: I get the most out of life because the people and organisation who support and care for me have an enabling attitude and believe in my potential.

One of the ways children can get the most out of life is by interaction with others. Growing up with a pet can bring emotional, social and educational benefits according to a study by Purewal, Christley, Kordas, Joinson, Meints, Gee and Westgarth (2017). Chandler (2005) outlines the psychosocial life stages and how being around animals can support achieving these and incorporating positive qualities into developing personalities. So, pets can have benefits for most children and support healthy child development. Additionally, there are particular benefits for looked after children, meaning it is important careful consideration is given to how animals can play a part in their lives. For example there are opportunities in caring for animals to make rewarding choices and develop positive self-esteem. For some looked after children this can be transformative. When children give and receive nurture and affection from animals they can feel lovable and happy. They can build trust which in turn can be transferred to other relationships.

Some looked after children do have opportunities to care for pets and be around animals but it is a matter of chance rather than part of a planned, informed approach. This article challenges care professionals and services working with looked after children to consider whether looked after children are having positive experiences with animals as part of their childhood. Gilligan (2000) emphasises the importance of looked after children having a secure base and that animals are an important element of this, promoting their self-esteem and resilience.

The needs of looked after children are often complex. Their backgrounds and experiences are diverse but many have experienced multiple, serious adversities including trauma and loss. Kennedy and Priestley (2015) demonstrate that looked after children are significantly more likely to have physical health conditions, poorer mental health and face multiple barriers when it comes to addressing these. This standard is therefore particularly relevant for them.

Standard 1.29: I am supported to be emotionally resilient, have a strong sense of my own identity and wellbeing, and address any experiences of trauma or neglect.

Perry (2001) was influential in enhancing understanding of the impact of trauma on children's brain development. His work helps explain attunement and responses to complex communication needs. He outlined how traumatised children pay greater attention to the non-verbal cues from their environment. They need help to process information differently and develop the parts of the brain so they understand and internalise new verbal and cognitive information. To do this they need to achieve calmness. There is strong anecdotal evidence that being with animals makes many people feel happier and calmer. This evidence is further supported by emerging scientific evidence that interacting with animals can lead to strong levels of oxytocin release. This is the hormone that can enhance emotional wellbeing and our ability to feel empathy for others. Daley Olmert (2009) outlines that this hormone also has physical health benefits, reduces stress hormones and has a strong anti-inflammatory impact. Research undertaken by Demello (1999) concluded that systolic and diastolic blood pressure as well as heart rate decreased when animals were present.

There are various studies on Adverse Childhood Experiences (ACEs) which demonstrate a long term, powerful and cumulative association between childhood trauma and adult mental and physical ill health and behaviours (Danese, Morffit, Harrington, Milne,Polancqk,Pariante,Poulton and Caspi 2009). Intervention and support using a range of methods is therefore critical in understanding and addressing these issues. Animals for some children are one of the ways they are supported to overcome adversity in childhood and lead successful adult lives. For some children it is easier and safer to engage with animals. Being safe and feeling safe are different things.

Standard 2.8 I am supported to communicate in a way that is right for me at my own pace, by people who are sensitive to me and my needs.

The calming and non-threatening presence of animals for some children can be soothing and helps provide some internal control over their emotional response. Caring for and communicating with an animal, for example when grooming a horse or stroking a dog, allows the child to have a safe space and a break from some of their own inner emotions. Children can be heard by animals without being interrupted or feeling judged. Levinson (1969) identified animals as showing spontaneous behaviour, being available for interaction, providing unconditional love and being loyal and affectionate.

Standard 3.10: As a child or young person I feel valued, loved and secure.

The new Health and Social Care Standards reflect the voices of care experienced people that their care is based on love and trust.

Enabling children who have experienced complex trauma, as many of our looked after children have, to feel valued, loved and secure can be challenging. As this article has outlined, trauma can affect brain development. Children can present in a range of ways that makes it hard for them to receive nurturing experiences. Some children who display trauma based behaviour, such as behaving in a hostile and rejecting manner or being withdrawn, struggle to allow caring adults to connect with them. Some of these children will however allow animals with their spontaneous non-threatening communication in as a bridging experience and then start to form other connections and attachments. There are therefore compelling arguments for services working with looked after children to explore options to include animals as part of children’s experiences. In the Care Inspectorate’s (2018) resource, *Animal Magic* there are examples of looked after children’s voices directly outlining why pets and animals are important to them.

The report and accompanying podcasts are available on the CELCIS website [https://celcis.org/knowledge-bank/search-bank/animal-magic-report/].

There is evidence that animals can support healthy child development for all children, enhance empathy and lead to fun and laughter. For looked after children the traumatic experiences they are more likely to have experienced can dominate their sense of self and they need different experiences to create a more balanced and healthy identity. Animals can offer this in extraordinary ways. They can provide something special and unique that is different and enhances happiness. For looked after children animals can be part of a therapeutic response that allows them to feel loved, secure and valued. This article invites you to consider the benefits of some animal magic for the looked after children you support.

About the author

Qualified in social work since 1990, Mary has worked in a range of childcare settings with looked after children. Mary also has extensive experience of regulation and scrutiny. Mary is part of the management team within the Children's Directorate of the Care Inspectorate. Mary led on the Care Inspectorate's resource, Animal Magic published in July 2018.

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Book Review

Book title:

Sköld, J., & Swain, S. (Eds.), (2015). Apology and the legacy of abuse of children in 'Care'. Basingstoke: Palgrave Macmillan.

Dr Hawthorn reviewed her personal copy of this book.

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I firstly have to acknowledge some interest in this book as I co-authored two chapters. In saying that, I have also found it very helpful in my own work in this field.

While there has been recognition over the years that some children have been unsafe in residential care (Kendrick and Hawthorn, 2012), until the late 1980s, there was little public awareness of the abuse of children in public care. Since then there has been a myriad of inquiry reports, media articles and academic writing on the subject, both within the UK and internationally. This compilation is however a useful addition to the literature in that it locates historical institutional abuse within the field of transitional justice and examines investigation, apology and redress in respect of historical abuse of children in care across Western countries in the last 20 years.

The publication is an edited collection of chapters drawing on a wide range of experience; care leavers advocates, historians, archivists, museum professionals, social workers, academics, lawyers and psychologists who have been involved in practice or research in respect of apology and redress processes in Australia, Canada, Denmark, Ireland, the Netherlands, Norway, Scotland and Sweden. The breadth of knowledge, skill and experience among the contributors indicates the importance of inter-professional collaboration in understanding historical abuse of children in 'care'. There are three sections; Transitional Justice and the Legacy of Child Welfare; National Particularities and Challenges for Professionals. This provides a helpful coherence to a publication that could otherwise become a series of fragmented essays.

The international nature of the publication gives an opportunity to compare and contrast approaches. This also helps in the process of critically reflecting on the cultural context of historical child abuse within the UK as we learn about child care practices historically across Europe and other Western countries. Possibly not surprisingly, this often involves groups of children who were marginalised and ostracised because of national priorities at the time. The Child Migrant Scheme in the UK can then be seen in the context of the removal of groups of children from indigenous families in Norway, Australia and Canada with the aim of assimilating them into the dominant mainstream by eradicating parental and community involvement in their development. Issues of morality also emerge. The children of German occupying soldiers and Norwegian mothers found themselves ‘excluded, stigmatized, abused and marginalised in relation to education, health and work opportunities’ (Ellingsen, 2004 in Simonsen and Pettersen, 2015, p.118). Many were separated from their families and placed in institutions while others ‘judged to be of sufficient biological quality’ were placed for adoption (Simonsen and Pettersen, 2015, p.118). This may be surprising to some considering the progressive child protection legislation in Norway since the early 20th century.

This book would be of interest to students, academics and the range of professionals now involved in supporting survivors of historical institutional abuse in the process of completing their personal narrative and accessing justice.

About the author

Moyra has worked for many years as a social worker, residential practitioner and manager, and in therapeutic work with traumatised children and their families. Her research interests include hearing the voices of disabled children and looked after children through creative activities and projects. Since 2005, Moyra has worked along with survivors of institutional abuse and other stakeholders to develop An Action Plan on Justice for Victims of Historical Abuse of Children in Care.

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Simonsen, E., & Pettersen, K. (2015). The politics of apology: The Norwegian case. In J. Sköld & S. Swain (Eds.), Apology and the legacy of abuse of children in ‘Care’. Basingstoke: Palgrave Macmillan.

Book Review

Book title:

Radical help: How we can remake the relationships between us and revolutionise the welfare state, by Hilary Cottam. London: Virago. ISBN: 978-0349009070

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Rarely does a book about the modern ills of the welfare state excite to this degree. Cottam's accessibly written analysis of the lack of fit between Beveridge's plan for a welfare state that responded to discrete problems with specific 'neutral, depersonalised transactions' for health, income, housing and education designed to 'level opportunity and combat poverty' (p. 45) and today's chronic health conditions, persistent and elevated rates of inequality in relation to income, housing and education. Instead, Cottam argues, we need a welfare state that focuses on the relationships of kindness and care between people, and between institutions and people. Today's problems, she says, need 'collaboration, we need to be part of the change and we need systems that include all of us' (p. 46). Participation must be easy, intuitive and natural. Through a series of 'Experiments' covering major issues such as 'family life', 'growing up', 'good work', 'good health' and 'ageing well', all based on the principle of giving people the support and resources to take power into their own hands and 'build their own way out' (p. 62), Cottam convincingly argues that there is a different way to do welfare. The way to establish collaborative solutions is termed a Design Process, with four broad areas of work: framing the problem or opportunity, idea generation, prototyping and launch, and replication. Not all the experiments go to plan. When a highly popular young people's 'experiment' helping them find employment networks and skills, and along the way improved confidence and capability, was presented to local authority leaders and referring partner agencies, they walked out, alarmed that young people they were responsible for were associating with others not their own age, and doing things unsupervised in other parts of the city. The young people were perceived to be at risk. Challenging the rules of established practices in regard to risk and safeguarding was a step too far. Cottam describes this as a bruising experience but also one from which she learned to bring the 'same ethos and values closer to existing systems' (p. 106). This is an important lesson for all those who seek reform or revolution in ways of doing welfare in the UK. To me the parallels with social pedagogy are clear. Both are relationally and collaboratively focused, aimed at working with and developing people's own skills and capabilities, emphasise reflection as a key skill for learning, and challenge institutionalised ways of doing things. For residential care, it would pay dividends to try out Cottam's methods. The prize is great indeed. Cottam concludes 'a relational way of working, thinking and designing is one that creates possibility for change, one that creates abundance … it is through creating a welfare system for this century, through sharing and working with one another that we find ourselves and we make a good life' (p. 277).

About the author

Claire Cameron is Professor of Social Pedagogy, Thomas Coram Research Unit, UCL Institute of Education, UCL, London. She researches looked after children's lives, the education of children in care, children's workforce, and related issues.