

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

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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 as [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

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