

The potential for person-centred planning to support the community participation of adults with an intellectual disability

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Darren McCausland 
Trinity College Dublin, Ireland

Mary McCarron
Trinity College Dublin, Ireland

Esther Murphy
Trinity College Dublin, Ireland

Philip McCallion
Temple University, USA

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Abstract

Person-centred planning (PCP) puts individuals with an intellectual disability at the centre of service and support planning, identifying how individuals wish to live their lives and what is needed to make that possible. PCP has been identified as having the potential to facilitate improved social inclusion and community participation. A mixed-methods approach combined quantitative analyses with qualitative case studies of individuals with severe-profound intellectual disability to assess the impact of PCP on community participation for adults with an intellectual disability at a disability service in Dublin. We conclude that PCP may provide a good basis to plan community participation and, with the right supports in place, may provide opportunities for people with complex needs to improve their community participation. Supports including familiar staff and family are critical to the success of PCP for people with complex needs, and their absence may undermine the best intentions of PCP for this population.

Keywords

person-centred planning, PCP, social inclusion, community participation, intellectual disability

Introduction

Social inclusion and participation in community contributes to better quality of life (McCrorry et al., 2014; Schalock et al., 2002; WHOQOL Group, 1998) and is an established right for people

Corresponding author:

Darren McCausland, Centre for Ageing and Intellectual Disability, School of Nursing & Midwifery, Trinity College Dublin, 24 D'Olier Street, Dublin 2, Ireland.

Email: DMCCAUS@tcd.ie

with disabilities (United Nations, 2006). However, people with intellectual disabilities are often denied these rights and remain excluded across a range of social contexts including fewer friendships (Merrells et al., 2019; White and Forrester-Jones, 2019) and intimate relationships (McCausland et al., 2018), and limited participation in community (McCarron et al., 2019).

Person-centred planning (PCP) is an approach to service planning and supports for people with intellectual disability that puts the individual at the centre. A PCP process aims to discover how an individual wishes to live their life and what may be needed to make that possible, with the aim of influencing positive change in the person's life and supporting services (National Disability Authority, 2005). PCP has been identified as having the potential to facilitate improved social inclusion and community participation (Claes et al., 2010).

This paper assesses the impact that person-centred planning had on the community participation of adults with an intellectual disability attending a service provider in Dublin, Ireland.

Social inclusion and community participation

The literature regarding social inclusion for people with an intellectual disability has been marked by inconsistency and lack of conceptual clarity (Amado et al., 2013; Overmars-Marx et al., 2014). For conceptual clarity, here we adopt the concept of social inclusion offered by Simplican et al. (2015), which proposed social inclusion as the interaction of two key life domains – *interpersonal relationships* and *community participation*. Community participation, which is the primary focus in this paper, is further defined structurally by Simplican et al. (2015) as taking place within 'segregated', 'semi-segregated' or 'mainstream' contexts, rather than the usual binary distinction of mainstream versus segregated settings. Three forms of semi-segregated activities are proposed: a) activities taking place in community settings but only involving paid staff and/or family with people with intellectual disabilities; b) activities within segregated facilities but including community members, for example volunteers and researchers; or c) cyber communities (Simplican et al., 2015), for example internet-based communities connecting virtually through social media such as Facebook. Semi-segregated activities may help to cultivate a sense of belonging, confidence, and group identity, and lead to future participation in integrated settings (Hall, 2013; Simplican et al., 2015). Participation may be manifested through a variety of activities (e.g. leisure, employment, school, cultural), and on one of three different levels of involvement – as *presence* in a community setting, as *encounter* (with strangers) in community settings, or as *involvement* in community activity that promotes the development of interpersonal relationships (Simplican et al., 2015). This conceptual distinction recognises that a spectrum of 'community participation' is possible within a variety of settings and situations, rather than being a rigidly defined, black-and-white construct; and this is important in the context of the current study.

Inclusion and participation in community for people with disabilities is an established right (United Nations, 2006) and policy goal internationally. However, people with intellectual disability remain relatively excluded compared to people without disability (Amado et al., 2013; Overmars-Marx et al., 2014; Tatlow-Golden et al., 2014; Verdonschot et al., 2009). People with disability are more likely than those without disability to be lonely and socially isolated, with low social support and low social connectedness (Emerson et al., 2020); which affects both younger and older people with intellectual disability (Robinson et al., 2018; Wormald et al., 2019). Recent studies have shown that people with intellectual disability may face difficulties forming friendships (Merrells et al., 2019), have smaller and less diverse social networks (White and Forrester-Jones, 2019), and express dissatisfaction with existing friendships (Friedman and Rizzolo, 2018;

Robinson et al., 2018). Regarding community participation, while a recent systematic review identified an association between deinstitutionalisation and improved quality of life (McCarron et al., 2019), mixed outcomes were also identified along with little evidence that deinstitutionalisation has led to real inclusion within the community (Bredewold et al., 2020; McCarron et al., 2019). Community exclusion may be perpetuated by perceptions of people with intellectual disability as being different, difficult to approach and prone to inappropriate behaviour, although some neighbours are open to engagement (Overmars-Marx et al., 2018). Studies internationally continue to identify limited community participation for people with intellectual disability (Bredewold, 2021; Merrells et al., 2019; Umb Carlsson, 2021).

Strategies to improve social inclusion including person-centred planning

A limited body of strategies to improve social inclusion and community participation has been identified in the literature, although some have shown good potential (Alexandra et al., 2018; Bigby et al., 2018; Howarth et al., 2016). One of the few strategies to show potential for improving inclusion and participation was PCP (Bigby et al., 2018; Howarth et al., 2016). PCP has been described as a 'process of continual listening and learning; focused on what is important to someone now and for the future; and acting upon this in alliance with their family and friends' (Sanderson, 2000); and 'a way of discovering how a person wants to live their life and what is required to make that possible' (National Disability Authority, 2005). Some potential uses and benefits have been identified in the literature. PCP may improve communication, family involvement and social networks (Claes et al., 2010). It may provide opportunities for social inclusion or greater independence (Bigby and Knox, 2009; Robertson et al., 2006); and while it may have positive impacts regarding community participation, such effects are moderate (Ratti et al., 2016). It has been shown to increase involvement in activities, improve personal opportunities, self-esteem, individual choice and self-determination (Claes et al., 2010; Espiner and Hartnett, 2012; Ratti et al., 2016; Robertson et al., 2006; Wehmeyer et al., 2006). However, developing a person-centred organisational culture in which PCP may thrive is a commonly cited challenge (Dowling et al., 2007; McCarron et al., 2013; Ratti et al., 2016). PCP has also been criticised for excluding people with more complex needs including severe intellectual disability and communication and behavioural issues (Claes et al., 2010), while there have been calls for more research on its effectiveness and real impact on people's lives (Ratti et al., 2016; Taylor and Taylor, 2013).

Study aim

Within this context, the aim of this study was to examine the impact of person-centred planning on the social inclusion of adults with an intellectual disability following its introduction within an organisation in Dublin supporting approximately 800 people with intellectual disability and families (the service provider). Supports include provision of residential services within both the local community and within the grounds of the organisation, respite services, adult day programmes in a range of settings and education services for children. The PATH (Planning Alternative Tomorrows with Hope) approach (Pearpoint et al., 1993) was the model of PCP introduced to the service (see McCausland et al. (2019) for a description). Post implementation of a service-wide training programme on the fundamental principles of a person-centred approach and its practical application through the PATH process, and the introduction of a standardised and quality assured approach to PCP, the study aim was achieved by (1) analysing secondary data on the social inclusion outcomes of PCP for service users with all levels of intellectual disability within the

Table 1. Demographic profile of participants (n = 169).

	%	n
Gender		
Male	50.9	86
Female	49.1	83
Level of intellectual disability*		
Mild-Moderate	31.7	53
Severe-Profound	68.3	114*
Residence Type		
Community	36.1	61
Campus	63.9	108

*Level of intellectual disability was not reported for two individuals.

service; and (2) conducting in-depth case studies to explore the social inclusion outcomes for a sub-sample of service users with severe-profound intellectual disability.

Methods

Ethical approval for the study was granted by the Research Ethics Committee (REC) of the host University and the REC of the partner service provider. The study implemented a mixed methods design comprising two elements: First, statistical analysis of a PATH administrative dataset; and second, qualitative case studies of people with severe-profound intellectual disability who used the service.

Sample & recruitment

An administrative dataset containing the PATH data of 169 service users who had completed and reviewed their PATH plan was analysed. The mean age of participants was 50.1 years (Std. Dev. 12.42), ranging from 21 to 93 years. Table 1 outlines a profile of the sample.

In phase two, case studies of seven individuals with a severe-profound level of intellectual disability were developed to qualitatively explore the outcomes and impacts of PCP on their community participation. A sampling frame was created of individuals in the dataset who (a) included community integration goals within their PATH, and (b) have a severe-profound level of intellectual disability. Seventeen eligible individuals were randomly selected, while maintaining a balance regarding gender, residence type, and family participation in PATH. These individuals and their families were invited to participate in interviews to discuss the PCP process and outcomes achieved. Consistent with a study target of 6–8 cases, a final sample of seven individuals and their families consented to take part in this stage of the study. Subsequently, staff who supported each of the seven individuals' PATHs were also invited to take part in semi-structured interviews. In most cases, two interviews were used to create the case studies: one interview with the person with intellectual disability and a family member who supported their participation; and a second interview with one staff member (two staff in one case). In all cases, staff participants in the case studies were very familiar with the individual and had been involved in their PATH process.

Data collection

Qualitative case studies were used to explore how and why particular outcomes emerged and to understand the underlying contexts for these (Baxter and Jack, 2008). The aim of the case studies was to explore how community participation had been achieved through development and implementation of such goals in the PCP process. Interview data from service users, family members and support staff contributed to the development of individual case studies. Semi-structured interviews were used as this allowed the opportunity to adapt lines of inquiry, follow-up on specific points and explore underlying motives (Lofland and Lofland, 1995), guiding the interview as a purposeful conversation (Bingham and Moore, 1959). Interviews lasted between 30 and 75 minutes, taking place in locations chosen by interviewees. Data was audio recorded and transcribed verbatim for analysis. In total, 13 interviews with service users, family members and staff were conducted. Seven of these interviews were with staff members and six with family (five of which also included the service user). While all seven service users were invited, two out of the seven could not participate due to health circumstances, meaning five persons with intellectual disability were interviewed. The individuals with intellectual disability who participated in the interviews with their family member had severe-profound intellectual disability. All had some degree of communication difficulty, however questions were directed to them and they were able to respond using words, sounds and gestures, and they were supported in responses and interpretation by their family members, who also elaborated on information provided.

Analysis

An anonymised Microsoft Excel database of 169 service users with a completed and reviewed PATH was provided by the service provider to the research team. This was cleaned and imported to SPSS for analysis. A descriptive profile of the data was performed using frequencies and cross-tabulation using Chi-squared tests for significance of associations. A binomial logistic regression model was developed to identify factors associated with having a PATH goal of social participation in the community; whereby having a community participation goal or not was the dependent variable, and independent variables included gender, age (<50 years; 50+ years), level of intellectual disability (mild-moderate; severe-profound), residence type (campus; community), personal barrier to PATH (yes/no) and organisational barrier to PATH (yes/no).

Case study development was based on thematic analysis of interview data, uncovering ‘patterned meaning’ (Braun and Clarke, 2006) by identifying emerging issues and cross-cutting themes. *Verbatim* interview data was analysed line-by-line and coded thematically. Particular attention was given to identifying factors facilitating and hindering community participation goals. Emerging cross-cutting themes were identified, for example facilitating factors including familiar staff and family involvement or barriers including staffing and other resources. Analysis was structured by the interview schedule, developed following the review of literature and secondary data analysis. Subsequently, the research team explored these themes to ascertain their impact at individual and organisational level. Where there were differences of opinion between staff/family participants, weight was given to the views expressed by the individual with intellectual disability; however, these differences were rare.

Results

In this section, study findings are presented according to the two broad approaches used in the study. First, we report findings from the statistical analysis of the service dataset, providing a

description of goals and barriers identified in person-centred planning, and an exploration of factors associated with community participation goals. Second, we outline findings from the case studies of seven individuals with severe-profound intellectual disability, to examine whether PCP supported their community participation.

Community participation as a goal of person-centred planning

In total, 66.9% (139/169) included at least one community participation goal ('social (community')') in their person-centred plan (Table 2). A majority (62.1%, 105/169) also identified a holiday in a community setting as a goal; and 17.8% (30/169) identified a social goal that took place in both community and non-community places. Two other common goals were likely to involve a degree of community participation, though the extent of this could not be determined from the dataset. These were goals related to family (68%, 115/169) and personal independence (62.7%, 106/169), which included independent living activities, decorating bedrooms and outdoor spaces, public transport and travel. Several other less common goals also had potential for community participation, including goals related to living arrangements, personal development, religion, employment and relationships. It was notable, however, that social goals within service-run facilities were identified by three-quarters of participants (74.6%, 126/169), making these goals more common within PATHs than community-based social goals. These 'social (service)' goals took place within the environment of the organisation or one of its satellite services (e.g. café or restaurant). Furthermore, around half of the sample (49.7%, 84/169) included a 'holiday (service)' goal, which was a short break/holiday at the organisation's holiday home in the west of Ireland, as opposed to a mainstream setting.

Table 2 also highlights significant differences in types of PATH goals based on age, residence type and level of intellectual disability. With respect to age, the older group (aged 50+ years) were more likely to have a social (community) goal as well as goals related to personal independence, personal possessions, a service-based holiday, review (of their care/support), and religion. The younger group (aged <50 years) were significantly more likely to have goals of a community-based holiday, personal development, a social goal located in both the community and service ('social (both)'), and employment.

Regarding residence type, campus-based residents were significantly more likely to have goals related to family (e.g. seeing family more; reconnecting with family), a holiday (service) goal, a personal possession goal, and a goal related to a change in their support (e.g. more one-to-one support). Community-based residents were significantly more likely to have goals including a holiday (community), personal development, employment and an intimate/romantic relationship.

Regarding level of intellectual disability, participants with severe-profound intellectual disability were significantly more likely to have PATH goals in relation to family, holiday (service), support and self-care. Participants with mild-moderate intellectual disability were significantly more likely to have a holiday (community) goal, and goals related to personal development, employment and an intimate/romantic relationship.

Community-based residents and those with mild-moderate intellectual disability had higher rates of social (community) goals; however, these differences were not statistically significant.

Potential barriers to person-centred planning. A large majority of participants (84.6%, 143/169) identified (at the planning stage) potential barriers to achieving the goals set out in their person-centred plan. Table 3 outlines the types of barriers that were identified and differences by residence

Table 2. PATH goals by age, residence type and level of intellectual disability.

Goal Type	<50 Years % (n = 67)	50+ Years % (n = 102)	Community % (n = 61)	Campus % (n = 108)	Mild-Moderate % (n = 53)	Severe-Profound % (n = 114)	Total (n = 169)
Personal Interest	85.1	80.4	77.0	85.2	81.1	82.5	82.2
Social (service)	73.1	75.5	72.1	75.9	66.0	78.1	74.6
Family	62.7	71.6	55.7	75.0**	56.6	73.4*	68.0
Social (community)	55.2	74.5**	72.1	63.9	71.7	64.9	66.9
Personal Independence	50.7	70.6**	62.3	63.0	56.6	64.9	62.7
Holiday (community)	73.1	54.9*	85.2	49.1***	79.2	53.5**	62.1
Personal Possession	37.3	62.7**	41.0	59.3*	45.3	57.0	52.7
Holiday (service)	37.3	57.8**	16.4	68.5***	26.4	60.5***	49.7
Support	26.9	38.2	11.5	46.3***	9.4	44.7***	33.7
Living Arrangements	35.8	30.4	41.0	27.8	35.8	30.7	32.5
Personal Development	46.3	21.6**	60.7	14.8***	64.2	16.7***	31.4
Self-care	31.3	28.6	21.3	34.3	17.0	35.1*	29.6
Review	19.4	34.3*	23.0	31.5	28.3	28.9	28.4
Social Both	32.8	7.8***	18.0	17.6	22.6	14.9	17.8
Religion	4.5	16.7*	8.2	13.9	11.3	12.3	11.8
Employment	22.4	3.9***	26.2	2.8***	30.2	2.6***	11.2
Day Service	10.4	10.8	14.8	8.3	13.2	9.6	10.7
Health	10.4	4.9	8.2	6.5	9.4	6.1	7.1
Relationship	6.0	2.0	8.2	0.9*	9.4	0.9*	3.6

*p < 0.05; **p < 0.01; ***p < 0.001.

Table 3. Potential barriers to PATH goals, by age, residence type and level of intellectual disability.

Barrier Type	<50 Years % (n = 67)	50+ Years % (n = 102)	Community % (n = 61)	Campus % (n = 108)	Mild- Moderate % (n = 53)	Severe- Profound % (n = 114)	Total (n = 169)
Myself	55.2	41.2	41.0	50.0	45.3	46.5	46.7
Familiar Staff	38.8	25.5*	14.8	39.8***	15.1	37.7**	30.8
Staffing	28.4	30.4	16.4	37.0***	13.2	37.7**	29.6
Organisation	23.9	29.4	27.9	26.9	15.1	32.5**	27.2
Health	7.5	17.6*	11.5	14.8	7.5	16.7	13.6
Family	3.0	0.0	3.3	0.0	3.8	0.0	1.2

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

type and level of intellectual disability. The most common barrier, included in almost half of plans (46.7%, 79/169), was ‘myself’, which referred largely to behaviours that challenge and other individual characteristics such as anxiety and other mental health difficulties that may have impeded an individual achieving his/her goal. Issues related to staff support were also common, with familiar staff (30.8%, $n = 52$) and adequate staffing levels (29.2%, $n = 50$) included in 3 out of 10 plans. Just over a quarter of plans (27.9%, $n = 46$) identified the organisation as a potential barrier to achieving PATH goals.

While more campus-based residents (87%, 94/108) identified barriers to PATH success than community-based residents (80.3%, 49/61), the difference was not statistically significant. However, more than double the rates of campus-based residents identified ‘familiar staff’ and ‘staffing’ as barriers to their person-centred goals, compared to community-based residents ($p < 0.001$). A similar pattern was evident with regard to level of intellectual disability, where participants with severe-profound intellectual disability had approximately three times the rates for ‘familiar staff’ and ‘staffing’, and more than double the rate for ‘organisation’, when compared to participants with mild-moderate intellectual disability ($p < 0.01$). In terms of age, more participants in the younger group (91%, 61/67) identified potential barriers to the success of their person-centred goals than older participants (80.4%, 82/102) ($p < 0.05$). Younger participants were more likely to cite ‘familiar staff’ ($p < 0.05$); while older participants were more likely to cite health as a barrier ($p < 0.05$).

As may be seen in the table, with regard to residence and degree of intellectual disability, differences in potential barriers to the success of person-centred goals were quite substantial and were organisational in nature rather than personal; whereas differences based on age were less pronounced with a combination of both organisational and personal barriers.

Factors associated with planning for community participation. Findings of the regression model exploring factors associated with planning a social (community) goal are outlined in Table 4. The model explained 12% (Nagelkerke r^2) of the variance in whether participants had a social (community) goal. We found that age was the only significant predictor of having this type of goal when all other independent variables were controlled for, including level of intellectual disability, residence type, sex, and both personal and organisational barriers. Older participants (aged 50 years and above) were more likely to include a social (community) goal in their person-centred plan (OR = 3.24, $p < 0.01$).

Table 4. Factors associated with having a social (community) PATH goal (n = 167).

	Has a social (community) goal	
	Odds Ratio (95% CI)	p Value
Gender		
Male	1.0	
Female	1.38 (0.69–2.75)	0.36
Age		
<50 years	1.0	
50+ years	3.24 (1.52–6.94)	0.002
Level of intellectual disability		
Severe-Profound	1.0	
Mild-Moderate	1.62 (0.61–4.29)	0.33
Type of Residence		
Campus	1.0	
Community	1.41 (0.57–3.47)	0.45
Personal Barrier		
No	1.0	
Yes	0.60 (0.30–1.20)	0.15
Organisational Barrier		
No	1.0	
Yes	0.84 (0.39–1.79)	0.65

Nagelkerke $r^2 = 0.12$.

$p < 0.05$ is significant. All significant factors in bold.

Outcomes of person-centred planning. The types of barriers identified at the planning stage of PATH, or potential barriers that may impede success, were analysed above. There was limited data available regarding barriers that were experienced by the full sample in the implementation of their person-centred goals. However, the mean number of actual barriers encountered was low ($M = 1.32$, $SD = 1.14$, $n = 167$), with no significant differences based on residence or disability.

The mean number of goals (of all types) included in person-centred plans was 8.55 ($SD = 4.06$, $n = 168$). The majority of goals, around six, had been achieved ($M = 6.32$, $SD = 3.86$, $n = 168$) with an average of around two goals not achieved, or still in progress ($M = 2.09$, $SD = 1.78$, $n = 168$). Regarding residence type, there was no significant difference in the number of goals achieved; but participants in campus residences as compared to those in group homes had a significantly higher rate of goals that were not achieved ($+0.58$ goals, $p < 0.05$). There was a greater difference in outcomes with regard to degree of intellectual disability. Participants with mild-moderate intellectual disability had on average 1.5 more goals in their person-centred plan than participants with severe-profound intellectual disability ($p < 0.05$) and achieved almost two goals more in implementation ($+1.92$, $p < 0.01$).

Outcomes of PCP goals, including community participation goals, were explored in greater depth in the case studies, discussed below.

Supporting community participation for people with complex needs

This section reports on the case studies of people with severe-profound intellectual disability, with a focus on how PCP impacted community participation for these individuals. A

Table 5. Profile of case study participants with severe-profound intellectual disability.

Jim	Community	Mid-60s. Severe intellectual disability. Behaviours that challenge. Living in a shared house in the community. Attends day services. No family involvement.
Maeve	Community	Mid-40s. Severe intellectual disability. Living in shared house in the community. Attends day services.
Yvonne	Community	In her 30s. Severe intellectual disability. Behaviours that challenge. Lives in shared house in the community. Attends day services.
Harry	Campus	Mid-50s. Severe intellectual disability. Shares a house on campus with three other men. Attends day services.
Jane	Campus	Late 50s. Profound intellectual disability. Behaviours that challenge. Shares a bungalow on campus with eight women. No longer attends day services.
John	Campus	Late 50s. Profound intellectual disability. Behaviours that challenge. Lives in a two-storey house on campus with six other men. Does not attend day services.
Liam	Campus	Early 60s. Profound intellectual disability. Lives in a shared house on campus. No longer attends day services.

Table 6. Community participation goals in person-centred plans of case study participants (n = 7).

Community Participation Goal	Participants
Eating out in a restaurant	6
Attending music events	4
Attending sporting events	3
Shopping trips	3
Family holidays	2
Going out to the pub	2
Maintaining work in the community	1
Day excursions tailored to interests (e.g. zoo)	1
Self-care (e.g. hairdresser, spa treatments)	1

pseudonymised profile of the seven individuals portrayed in the case studies is outlined in Table 5. Amongst this group, three people lived in shared community residences and four lived in shared accommodation on campus (all separately); median age was 50 years; four were men and three were women; four were reported to have severe and three profound intellectual disability; and four were reported to have behaviours that challenge. Most of this group had family involvement in the person-centred (PATH) planning meeting and had ongoing contact with family, who also contributed to the implementation of PATH goals. Of the seven, only Jim had no family involvement at all. Full profiles and details of each individual case study are provided in McCausland et al. (2019).

Community participation goals were common in person-centred plans amongst this group, with all participants having at least one goal of this type (compared with two-thirds of all participants). Table 6 provides a summary of the community participation goals included in the person-centred PATH plans of this group. It shows that the most common community participation goal was to eat out at a restaurant, included by six participants; followed by outings to music and sporting events as well as shopping trips.

Table 7. Enabling and challenging factors for community participation goals.

Enabling factors	Challenging factors
Familiar staff	Unfamiliar staff
Preparation for PATH	Staffing resources
Communication and sharing information	Access to transport
Family involvement	Changing health status
Activity planning	

All seven case study participants achieved at least one of their community goals. However, some remained ongoing and the degree of support required by these individuals meant that implementation often took a significant amount of time and planning. For example, participation goals for this group often required one-to-one support and sometimes two staff members to support, such as where the person had behaviours that challenge. Analysis of the seven cases identified a number of key factors that either enabled or challenged successful implementation of community participation goals (Table 7).

Key enablers of community participation goals. Five factors were identified across the case studies that were key to supporting the successful implementation of community participation goals.

Familiar staff. In six of the case studies, familiar staff was identified as a vital factor for establishing and achieving person-centred goals of community participation. This was about support staff knowing the person at the heart of the PCP process well, and the person with intellectual disability knowing the support staff. This was illustrated in Yvonne's case, where she was supported by her keyworker of many years:

The people that were at the PATH knew her really well. I [have been] her key worker for a long time and I would know her really well so I'm lucky in a way; her mam, the other staff member and myself, we are all on the same page. (Case Study: Yvonne. Keyworker)

In Yvonne's case and in Jim's case, the support of familiar staff highlighted how knowledge of the individual may help to facilitate a calmer PCP process, especially where the person has behavioural support needs.

Jim [did] the pre-PATH with his key worker . . . What [he would] like short term, long term. They ask you all about your friends, your family . . . Things you like to do, things you want to do . . . [He's] calmer when he's just on a one-to-one, with people he knows. (Case Study: Jim. House Manager)

Preparation for PATH. The case studies demonstrated that the process prior to the person-centred meeting, involving PATH training and a pre-PATH questionnaire, was essential to adequately prepare the individual and support personnel and to develop achievable community participation goals. The practical and accessible approach to training helped to alleviate doubts and reservations about PCP that many staff had. Sufficient lead-in time facilitated staff learning about the PATH process, including how best to support service users to identify goals and how they could be achieved with support from family and familiar staff, in particular community participation goals. This was demonstrated in six of the seven cases including Harry, Liam, Jane, Maeve, Yvonne and Jim. In Liam's case:

Training with the PATH coordinator here and he explained the whole process because I wasn't sure . . . when it's explained to you properly it's good . . . they were very manageable . . . they are a really good way of getting things to happen; it was a lovely way of sitting down . . . kind of made it concrete . . . It was good and it was a good way to [identify] future goals. (Case Study: Liam. Day Service Staff)

Case studies also highlighted the potential role that family could play in this preparation phase, which ultimately supported better understanding and fulfilment of service users' participation goals.

We would get family involved into the pre-PATH; you see the whole thing is that everybody is involved. (Case Study: Liam. Day Service Staff)

Communication and sharing information. The case studies highlighted how good communication between all parties involved – the person with intellectual disability, staff and family members – was vital to success in setting and achieving community participation goals. The recording and sharing of information was essential, including likes and dislikes, daily activities and achievement of tasks or goals. Evidence of good communication and sharing, and how this supported community participation goals, were noted in all case studies. In Harry's case, for example:

. . . It took me and my colleague probably about three weeks to get to the bulk of information from Harry's perspective. What he wanted. Once we had done that we gave that same information to the family to see what else did they think. (Case Study: Harry. Support Worker)

Family involvement. Good communication between staff and the family of this group of participants was shown to help with every aspect of the PATH process and was particularly important in supporting community participation goals. While varying degrees of family involvement were reported, better community participation was achieved when family played a stronger role in supporting their relative to participate in social activities outside services.

Harry's sister, for example, was heavily involved with him and very proactive, and was a key support for Harry's goals of bowling and taking regular holidays. Harry's keyworker highlighted the importance of family in this regard.

I love having the families involved because they come up with ideas even from the past . . . a much wider picture. Harry's family have always been heavily involved . . . they have great ideas and willing enthusiasm from them . . . regular visitors, Harry goes home every weekend. (Case Study: Harry. Support Worker)

Similarly, Liam's family provided ongoing support throughout his life and were actively involved in facilitating the development of his person-centred plan and the achievement of his community participation goals despite the advance of dementia, including going to a concert and eating out at restaurants.

His sister and his brother have massive impact in his life . . . they are fabulous. (Case Study: Liam. Day Service Staff)

Activity planning. Several cases highlighted the importance for this group of preparation and planning for community activity goals within the PATH process. This included allowing adequate lead-in time for introducing new activities. Yvonne's goal of going to a new restaurant illustrated

what may be required. She was initially prepared for the activity by being shown a photograph of the restaurant, so she could familiarise herself with where she was going; and the new activity was incrementally planned and introduced through small manageable steps, building slowly towards its achievement without being overwhelming. This approach was also evident in the cases of Harry and Liam. Setting realistic and achievable goals was an important factor in setting PATH goals that involved planning new activities such as these; which once again reinforced the importance of having staff who were familiar with the individual and who knew what may or may not be achievable for them.

She loves routine, so you come in on a Monday and it's swimming, multi-sensory . . . She communicates very well and then going out for her picnics and her social, going to restaurants and that, we are following Yvonne, she's got one favourite restaurant . . . got to be with people that know her very well . . . Going out still it's two staff for her to get her into the community for social integration . . . when we go out usually she'd have another staff around. (Case Study: Yvonne. Keyworker)

The converse of this was seen in cases, for example with Jane and John, where particular activities were not carefully planned and/or were carried out with unfamiliar staff; when the individuals involved were more prone to exhibit behaviours that challenge. Evidence of careful planning in advance of social activities was present in six out of the seven case studies.

Key challenges with community participation goals. The case studies illustrated several positive examples of community participation being achieved through person-centred goals planned using PATH, with a positive effect for this group overall. However, a number of factors arose that posed significant challenges to achievement of community participation goals, some of which, as noted above, were the converse to enabling factors cited. Four identified key challenges to achieving community participation goals were: unfamiliar staff; staffing resources; access to transport; and changing health status.

Unfamiliar staff. Whereas familiar staff was identified above as the most important enabler of community participation goals for this high support needs group, the opposite was true where familiar staff were not available to support individuals. Difficulties often arose when staff who had little or no knowledge of the person with intellectual disability were expected to play a central role in implementing community participation goals for these individuals.

As noted above, having knowledgeable and familiar staff supporting the individual offered a better chance of developing attainable community goals and successfully implementing them afterwards. Having unfamiliar staff in these key support positions became a particular concern due to turnover of keyworkers within the organisation, as well as the occasional use of agency staff. In some cases, a consequence of having unfamiliar staff supporting this group was the triggering of behaviours that challenge and the curtailment of community participation activities; while in other cases the person with intellectual disability simply preferred not to engage with unfamiliar staff.

"She was here the other day; you weren't mad on her?" ("No, no," Harry says). "You see it's familiarity, you know. If he's not familiar with the person . . . Let's say X or Y (referring to his support workers) took holidays and the agency were going to bring you instead. Which would you prefer?" ("Stay in, I'd prefer to," Harry says) . . . has an impact because if there was a change of staff during the week it upsets him and it goes on and on all weekend. (Case Study: Harry. Harry and his sister)

Staffing resources. Some case studies highlighted difficulties with staffing resources and how this impacted on the ability to achieve goals for this group, many of whom needed one-to-one and greater staff ratios when engaging in community participation activities. Examples of staffing resources impacting on community participation goals were evident in the cases of Harry, Yvonne and Jane; and the lack of funding for one-to-one support with community participation was cited by both staff and family participants during data collection.

Trying to get other people and its two staff that have to go with Jane to do things . . . we definitely need more staff because it's not just Jane, it's everybody is trying to do the same thing. Everybody is on the same path of trying to do PATH, to try to get you know goals achieved or even to start them off, so you just need staff. And we are always going around saying are you on that day, or are you on that day, so that you can help out or if they have to go somewhere. (Case Study: Jane. Keyworker)

Access to transport. Some of the case studies also identified practical difficulties related to transport and travel, which impacted on their ability to complete community participation goals. For John, this was a difficulty related to his behaviour support needs, making it hard for him to travel by bus. For others, including Harry and Jane, the challenge was one of being able to access a bus within the organisation given a shortage and high demand.

In the end we've no transport and we can't get buses, trying to book buses in advance is a disaster . . . well when you go to book them and somebody else has gone off with the bus or it's off the road . . . just silly things . . . we could have got so much more done with the bus because I had to cancel. (Case Study: Jane. Keyworker)

Changing health status. The statistical analysis earlier identified health as a potential barrier to implementing person-centred goals through PATH for a minority of participants (approximately one in seven). The case studies, in particular Liam's case, highlighted how a significant change in health during the course of a person-centred process presented a serious challenge to implementing community participation goals. Liam was diagnosed with dementia, which was at an early stage when he created his PATH plan. However, further onset severely impacted his abilities and the degree of community participation that was possible for him.

When Liam's PATH was done, Liam was in the early stages of dementia at that stage . . . it was just at the beginning . . . he's wheelchair-bound now. Liam wouldn't have been able to tell us . . . beginning to change at that stage you know, he was beginning to get forgetful and he was getting a bit cross . . . you see he likes going to concerts and things, he likes going on the tram or the Luas or the train or whichever . . . He was very good at it, he sort of interacted on that but with dementia . . . it would be very hard to bring him . . . (Case Study: Liam. Day Service Staff)

The impact of such a dramatic change in health status and ability highlights the need for plans to be updated as status changes, something suggested by Liam's family.

. . . need to decide how to deal with . . . as it (dementia) develops rather than acting according to plans made earlier. (Case Study: Liam. Liam's brother and sister)

While the case studies identified these potentially significant barriers and challenges to the implementation PATH goals, there was nonetheless a high level of goal achievement and

satisfaction expressed by individuals, their families and staff, especially with respect to the added focus that person-centred planning placed on community participation for this group.

Discussion

This study examined the impact of PCP on the community participation of adults with an intellectual disability following the introduction of the PATH model of PCP within their supporting service provider. The study found that community participation was a key goal of PCP among participants. However, participation was often planned and implemented either a) in segregated settings with staff, other service users and sometimes members of the public also using the facilities, or b) in community facilities (e.g. restaurants, cafes, pubs, shopping centres) but usually involving only paid staff, other service users and sometimes family. Using the Smplican et al., 2015 model of social inclusion, community participation for participants in this study was situated primarily within 'semi-segregated' contexts, with involvement that could be described as *presence* or *encounter*, and little *involvement* of the type that promoted lasting interpersonal relationships with community members. However, this type of participation has been identified in the literature as valuable in its own right as well as potentially leading to more involved community participation in the future (Bigby and Wiesel, 2019; Hall, 2013; Smplican et al., 2015). This suggests that PCP may support improved community participation and social inclusion for this population.

Types of goals developed in person-centred planning

Our analysis of goals developed through person-centred planning found that the vast majority of participants had goals of community participation. These were either explicit goals of participation in community settings and activities or, as more frequently found, within the environment of the service provider and its satellite facilities, some of which were situated within the local community and some in segregated settings. As such, the study found a tendency for planning for social inclusion to focus predominantly on settings within or associated with the service provider; which, as suggested in the case studies, were environments that were better known and considered 'safe' by support staff. However, taken at face value this may raise some questions: Does this approach undermine the nature and purpose of PCP, by compromising person-centred principles in order to support easier implementation of goals? If so, is this a trade-off worth making to ensure delivery of goals? The evidence of the case studies suggests that, for people with severe-profound intellectual disability and more complex needs including mental health and behavioural needs, familiar environments (as well as familiar people) were particularly important for supporting delivery of their community participation goals. This suggests that this cohort in particular experiences a more limited form of community presence without any 'real involvement' in their community, something which has been criticised in the literature (Amado et al., 2013; Bredewold et al., 2020; McCarron et al., 2019). However, recent literature on 'encounter' suggests that this type of involvement may be beneficial in its own right while also providing a basis for development of deeper involvement (Bigby and Wiesel, 2019). The evidence of the case studies presented here supports this positive view of such forms of community participation.

Apart from the explicitly 'social' goals, there was also a range of other goals that had additional potential for community participation. Again, these were planned for a mix of contexts ranging from segregated to integrated, with many implemented within the 'semi-segregated' contexts identified by Smplican et al. (2015). The bivariate analyses revealed a number of differences between cohorts within the overall sample with regard to the types of goals included in PCPs. We

found no significant differences based on residence type or level of intellectual disability regarding rates of community-based social goals. However, whereas campus-based residents and those with severe-profound intellectual disability were more likely to have goals of a service-based holiday, community residents and participants with mild-moderate intellectual disability were more likely to have community-based holiday goals. The latter groups were also more likely to have other goals that were most likely community based including employment and an intimate/romantic relationship; whereas the former were more likely to have family and service related goals. This may reflect the tendency for those with more ability and less support needs to 'dream big' and be supported to do so in their PCP process, while planning for those with more challenging needs identified more practical goals that were achievable for them.

However, the regression model findings that age was the strongest predictor of having a community-based social goal, and that the older cohort were *more* likely to have such goals in their plans, may contradict this suggestion and present something of an anomaly. The literature suggests a reduced degree of social inclusion as people age (McCausland et al., 2018; Ward et al., 2019). One possibility for contradictory findings here is that younger study participants were more involved in community already, and thus had less need to plan for such involvement through person-centred planning. This suggests that PCP may be of greatest value to those with potentially the greatest marginal gain, while being of limited value to those who are already involved in community to a greater degree. However, additional research is needed to confirm this, especially given findings here that campus-based residents with severe-profound intellectual disability were *less* likely to have community goals, and previous findings which suggested that people with more complex needs tended to be excluded from PCP (Claes et al., 2010).

Person-centred planning as a support to participation for people with complex needs

The statistical analysis found that participants with severe-profound intellectual disability were more than twice as likely than those with mild-moderate intellectual disability to identify organisational barriers ('familiar staff', 'staffing', 'organisation') to successful PCP outcomes, while 'myself' was the most common barrier for both groups. While this analysis examined potential rather than verified barriers, findings from the case studies support the idea that inadequate organisational supports for individuals with complex support needs may present the most significant barrier to achieving PCP goals – while the converse was also true, where good organisational supports for individual needs facilitated goal achievement. This was particularly highlighted regarding needs of individuals with mental health and behavioural difficulties for consistent and familiar staff. For example, the success of Yvonne's PATH goals was directly related to the strong communication and well-developed relationship between her family and key worker, who knew Yvonne for many years. Whereas John, who reported several staff turnovers, found his participation in community and other social activities was severely impeded.

Difficulties illustrated by the case studies also help to explain the analysis that found people with severe-profound intellectual disability had achieved fewer PCP goals. Our findings that these types of organisational factors impeded community participation supports previous studies that associated social inclusion with support received including staffing (Amado et al., 2013; Kozma et al., 2009; McVilly et al., 2006; Noonan Walsh et al., 2010), and found that inadequate organisational support may restrict opportunities for community participation (Overmars-Marx et al., 2017; Talman et al., 2019). It signals that the fundamentals of good support must be in place for PCP to succeed and where good support is not in place then PCP may struggle to make any real

impact, although it should be reiterated that the majority of goals were achieved for the participants in this study.

Of the other factors identified within the case studies as enablers or barriers of PCP, the role of family emerged as a key influence in both the planning and implementation of community participation goals. Several case studies highlighted the importance of family presence and participation, while the absence of family in one case highlighted what may be lacking when this type of support is not available. This supports previous research which identified the benefits to social activity of regular family contact, both for the direct activity itself, as well as providing oversight of the support their family member receives (Bigby, 2008). However, family are not always available or have other responsibilities, and people with intellectual disabilities have been found to have fewer natural support such as family available, particularly as they age (Duggan and Linehan, 2013; McCausland et al., 2018). Therefore, the evidence from the case studies highlights a need for services practicing PCP to encourage and support family participation, strategically reaching out where necessary, as a strong family role will improve the chances of achieving PCP goals of community participation. This reflects the need to instil a person-centred culture across organisations to underpin PCP processes (Dowling et al., 2007; McCarron et al., 2013; Ratti et al., 2016).

Study strengths and limitations

The mixed-methods design of this study facilitated a thorough examination of both the organisation-wide impact of PCP on community participation goal planning and implementation, and also an in-depth exploration of the context and reasons underlying particular outcomes for individuals with complex needs. The study was inclusive of participants with intellectual disability, and in particular gave voice to a cohort with severe-profound intellectual disability who are often excluded from PCP studies. At the same time, the study also included a broad range of stakeholders directly involved in the PCP process, including individuals with intellectual disability, family members, keyworkers and other support staff, day service staff and managers.

While the case study interviews were inclusive, the limited timeframe for the study facilitated only one meeting with each participant with intellectual disability. Given the profile of this group and the nature of communication difficulties present, communication may have been further enhanced by multiple meetings where the researcher and participant could develop their rapport and understanding of preferred communication styles and techniques – for example, it emerged that one participant used the Irish intellectual disability sign language, *Lámh*. Future studies with this cohort may benefit from allowing more time to develop communication techniques between participants with these difficulties.

Conclusions

From this study we conclude that person-centred planning may provide a good basis for planning community participation for adults with intellectual disability and, with the right support in place, may provide opportunities for people with more complex needs to improve their level of community participation. Having the right supports in place, from planning through to implementation, is critical to success for PCP, especially for people with more complex support needs. The absence of familiar staff, family and other supports is likely to undermine the best intentions of PCP for this population.

The analysis of goals highlighted a tendency for plans to include ‘safer’ and more manageable goals and activities for people with complex support needs. The case studies also revealed that the types of activities included in community participation goals were largely of a one-off or occasional nature, rather than activities that participants engaged in regularly. This may indicate that, for most of these individuals, engagement in community remained infrequent even where participation was planned for as part of PCP. The case studies illustrated that this infrequent participation in community was largely due, in a context of scarce resources, to the resources required to plan and implement community participation activities for people with complex needs including behaviours that challenge. So, while PCP encourages people to ‘dream big’ and to broaden their horizons, practically it remains difficult to plan beyond the safe activities and known environments within a service or community. However, even ‘semi-segregated’ participation of the type identified here may provide a basis and stepping-stone to even more involved participation in the future. That said, there was no evidence that individuals were discouraged from pursuing desired activities.

Finally, the study highlights that periodic and ongoing review of person-centred plans and goals is essential to maintaining the relevance of PCP for individuals, rather than viewing completion of a plan as an endpoint. Periodic review may be particularly important for PCP responding to the changing health status of individuals, such as following a diagnosis of dementia. Given recent experiences of the COVID-19 pandemic and the associated disruption to support systems and social opportunities, notwithstanding new opportunities provided through growing availability and use of communication technologies, regular review of existing person-centred plans is now more important than ever before.


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ORCID iD

Darren McCausland  <https://orcid.org/0000-0002-3394-3991>

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