



UNIVERSITY of LIMERICK
OLLSCOIL LUIMNIGH

40 years of Innovation
1972 - 2012

DEPARTMENT OF
CLINICAL THERAPIES



MSc Occupational Therapy

OT6054 Occupational Therapy Project 4

11002891

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22nd April 2013

Word Count: 5,017

Title:

How do people with intellectual disabilities in Ireland describe their relationships with support staff and their social networks?

Abstract

Background: Attitudes in Ireland towards people with disabilities are hardening. Through meaningful relationships individuals experience support, well-being, connectedness and belonging. These are experienced differently by every individual. The formation of relationships can be inhibited by obstacles. One of the important relationships identified by people with intellectual disabilities is support staff.

Aim: This research is part of a broader study across four years to understand how people with disabilities navigate stigma to create lasting relationships. The purpose of this strand of the larger study is to identify the important relationships for people with intellectual disabilities and understand how they describe their relationships with staff members.

Methods: A qualitative method was chosen to gather an understanding of the experiences. Six participants with intellectual disabilities were interviewed about different areas in their lives home, work, and their communities. Thematic analysis was completed with NVivo 9 used for data management.

Results: The participants saw staff as trusted, valued supports. Staff enabled community participation and engagement in valued activities. The participants identified that they needed staff to access the community. The scarcity of social networks was recognised, with staff often acknowledged as friends.

Conclusion: Social networks, friendships, employment and activities of people with intellectual disabilities need to extend beyond services and support staff. Perhaps Ireland should take a social capital approach instead of a social inclusion approach by supporting the person's social networks. Infusing Irish policies with the value of friendships and real social networks has extraordinary potential. Support, encouragement and enablement of people with intellectual disabilities are required to facilitate social inclusion. Occupational therapists and support staff are essential in facilitating change. Occupational therapists philosophy is to be client centred. Being skilled in activity analysis will support work towards full participation in meaningful occupations at home and in the community.

Introduction:

Attitudes towards people with disabilities in Ireland are hardening (NDA 2011). Compared with the 2006 study which indicated attitudes had improved. The National Intellectual Disability Database (NIDD) reports 26,484 people in Ireland with intellectual disabilities (Kelly et al 2010). There are barriers which restrict human rights for individuals with intellectual disabilities (Ali et al 2008). These often result from attitudes and stigmatisation held by others within the community. Greater inclusion and less segregation in society may change attitudes. People with intellectual disabilities generally attend disability services in Ireland, when in the community they are often with family or staff members (Lofgren-Martenson 2004). It is the social networks of people with disabilities that is considered the indicator of community inclusion; this is a challenge for disability services (Johnson et al 2010; Milner & Kelly 2009; Kam-shing and Sung-on 2002; Duggan NDA 2011; Linehan 2012; Carson & Docherty 2002). Choice making and opportunities to participate in the community for people with intellectual disabilities are greatly influenced by staff (Bigby et al 2009; Felce et al 2000; Stancliffe 1997; Stancliffe et al 2000). Staff are seen as valued and important to the lives of people with intellectual disabilities (Longo and Scior 2004; McVilly et al 2006a; McVilly et al 2006b; Clarkson et al 2009; Schwabenland 1999; Larson et al 1994).

There's an awareness of disability issues in Ireland and attempts towards greater inclusion, a recent survey showed 64% of respondents know someone with a disability. This has fallen since 2006 when it was 71%, while in 2001 it was 48% (NDA 2006; 2001). There is a need for inclusion (Goodley 2001; DOH 2001) and for people with disabilities to feel empowered and enabled to be contributing members of society. Inclusion is enabled by the important relationships in the lives of people with intellectual disabilities. In order to change Irish attitudes, a social capital approach is fitting. It refers to making connections within and between social networks. It focuses not on the person with the disability, but those in the community, enabling people to network and develop trusting relationships with other community members (Linehan 2012; Bigby 2008). The literature review will examine who people with intellectual disabilities see as important relationships and their barriers to creating these. The research question is how people with intellectual disabilities describe their relationships with support staff, and how their

social networks are created around the constructs of disability services. Below are the search strategies used for the literature review.

Databases Searched	ERIC, Science Direct, PsychInfo, Web of Knowledge, Academic Search Complete, CINAHL.
Journals Searched	Journal of Intellectual Disabilities, Disability and Society, Journal of Intellectual Disability Research, Research in Developmental Disabilities, British Journal of Occupational Therapy, The American Journal of Occupational Therapy.
Search Terms (multiple combinations utilised)	Intellectual Disability, learning difficulty, mental retardation, stigma, stereotypes, discrimination, relationships, friendships, family, intimacy, sexuality, staff, support workers, barriers, inclusion, disability services.
Time Period Searched	19 to present (to gather all research on this topic an expansive timeline was used, this was also to coincide with the UN Convention on the Rights of Persons with Disabilities)
Articles Selected for Inclusion	The articles chosen were based on methodological quality and significance to this study.

Literature Review

In 1993 the Irish government established the Commission on the Status of People with Disabilities, a pivotal event in disability history. The Equality Act 2004 came from an expression of marginalisation; this preserved the right for all citizens regardless of a disability. The UN Convention on the Rights of Persons with Disabilities (UNCRPD 2006) is a supportive international document for people with disabilities. Though the UNCRPD is not ratified in

Ireland the government have since been examining the changes that are required in legislation in order to ratify it. The Convention upholds the respect for every individual with a disability to freedom of choice, independence, full, effective participation, inclusion in society and enjoyment of all human rights (UNCRPD 2006).

Negative attitudes encompassing discrimination and stigmatisation can result in exclusion for people with disabilities. Stigma is a combination of feelings, behaviours and attitudes (Green et al 2005). It is a negative reaction to a perceived difference, existing as a result of power (Goffman, 1963; Link and Phelan, 2001). Stigmatisation may result in exclusion from a community or society, and is reported to negatively affect health, well-being and quality of life, both socially and psychologically (Dagnan and Sandhu 1999; Dagnan and Waring 2004; Timonem et al 2011; Nolan et al 2006; Scheff 1998; Ali et al 2008). Societal barriers are created as a result of stigma to disability (Jahoda et al 2010; Ali et al 2008; Kelly and Norwich 2004; Corrigan et al 2003; Starke 2011; Norwich and Kelly 2004). Stigma is recognized as a barrier for opportunities like building relationships, employment, and decision making (Gill et al 2002; Siperstein et al 2011).

Intellectual Disability and relationships

Meaningful relationships are rewarding, influential towards quality of life, well-being and societal connectedness (Helliwell and Putnam 2004; Hartup and Stevens 1997; Duck 1991). Those who have these relationships cope better with stress, anxiety and social comparison (Rickwood et al 1996; Hughes 1999; Duck 1991). It prevents isolation, feelings of not being accepted and loneliness, which are often experienced by people with intellectual disabilities (Knox et al 2001; Chappell 1994; Verdonchnot et al 2009; Heiman et al 1998; Nunkoosing et al 1997; Carr 1995; Norwich and Kelly 2004; McVilly et al 2006; Jobling et al 2000). These relationships for people with disabilities are reported rare, and supports given to encourage the formation of these are lacking (Whitehouse et al 2001; Duvdevany and Arar 2004; Chappell 1994). People with disabilities chose friends with disabilities, over those without a disability (Salmon 2013; Siperstein et al 2007; Cutts and Sigafos 2001; Turnbull et al 2000; Stewart et al 2010). These exist and are successful though sometimes devalued in literature (Milner & Kelly 2009; Clement & Bigby 2009; Johnson et al 2010).

Support staff are described as important, valued, supportive, and are seen to protect people with intellectual disabilities emotionally and physically (Longo and Scior 2004; McVilly et al 2006a; McVilly et al 2006b; Clarkson et al 2009; Schwabenland 1999; Larson et al 1994). Most people with an intellectual disability live under supervision of staff or family members, meaning relationships are rarely spontaneous often created at planned events (Lofgren-Martenson 2004). This results in social networks being limited to service providers and families. Difficulties exist in forming relationships if not adequately supported, or enabled outside the service setting to connect and develop social skills, which are reported to impact inclusion and creating relationships (Abbott and McConkey 2006).

The concern for family and staff should be, facilitating community connectedness over physical integration (Cummins and Lau 2003; Verdonschnot et al 2009). There is reported impact on health and well-being of staff members, from burnout, stress and sick leave resulting in a high turnover (Devereux et al 2009; Innstrand et al 2004; Hastings et al 2004; Rose and Rose 2005; Hatton and Emerson 2010; Hatton et al 2004; Rose et al 2004). If support staff are important to the lives of people with disabilities, surely their health and well-being impact the person with intellectual disabilities, their quality of life and service provision. There is evidence that disability services, can in fact prevent the opportunity to develop meaningful relationships (Bigby 2008; Clement and Bigby 2008; Lemay 2009). People with intellectual disabilities believed staff should have a supportive and inclusive role and not prioritise a caring role (McConkey and Collins 2010; Lemay 2009; Abbott and McConkey 2006). Social inclusion is one of the challenges of disability organisations. Carson and Docherty (2002) emphasise that if not tackled, then isolation and disengagement from society will continue. Supported employment and leisure for people with disabilities can lead to an increase in social networks and reduce prejudice (Pettigrew et al 2006; Shadish and Bootzin 1984; Forrester-Jones et al 2004; Srivastava 2001).

This paper draws on qualitative interview data to understand how participants with intellectual disabilities describe their relationships with staff and how service systems shape relationship opportunities, linking to current Irish policy.

Methodology

This study is framed within critical theory. This paradigm emphasises empowerment of marginalised communities with the goal of creating social justice and equity (Guba and Lincoln 2000; Meekoosha and Shuttleworth 2009). Within critical theory the voice of the participant and the researcher are mixed (Guba and Lincoln 2000; Pothier and Devlin 2006). This paradigm evolved over many years and is well-aligned with the UNCRPD (2006).

Research Design

The study used a qualitative method generating rich subjective data, giving descriptive narratives of experiences with forming relationships with staff and others (Taylor 2007; Coffey and Atkinson 1996; Ritchie and Lewis 2003; Hesse-Biber and Leavy 2011). A philosophical concept of occupational therapy is to understand subjective experiences and qualitative research is considered invaluable in health care (Taylor 2007).

Data Collection

The method of data collection was six in depth, face-to-face, semi-structured interviews with participants with an intellectual disability. This was considered the most suitable method for capturing relationship descriptions and the point of view of the person (Hesse-Biber and Leavy 2011; Bowling 2002). It allowed for flexible responses, creating an environment for free expression and broad questions for descriptive data (Hesse-Biber and Leavy 2011; Brymann 2004; Hammersley and Atkinson 1995; Kvale 1996; Corbin et al 2007). Participants were able to query and seek clarification throughout the interview. Riessman (1993) acknowledged how qualities of doubt provide rich, diverse, accurate and contextual depth. Brymann (2004) describes this method of interviewing as seeing through the other's eyes. The interview guide was developed by the principal investigator, an experienced practicing occupational therapist and MSc students. The researcher used tools during the interviews, to generate greater knowledge of the topic for analysis: interview guide, people in my life chart and a weekday planner.

Participants

It can be difficult to recruit participants with intellectual disabilities for research, due to barriers like consent and access (Lennox et al 2005). Despite these, the researcher recruited six participants with intellectual disabilities from the Republic of Ireland. The researcher contacted various organisations, completing information sessions in the services. Participants who fitted the criteria were invited to participate.

Data Analysis

The method of analysis was systematic; it focused on clarifying the data through coding, developing categories, and gradually constructing themes (Boaduo 2011). The interviews were recorded, transcribed, cleaned and uploaded to the qualitative data analysis software Nvivo9. The analyses consisted of coding, describing and categorising recurring themes throughout the data (Taylor 2007; Emerson et al 1995; Braun & Clarke 2006; Coffey and Atkinson 1996).

Trustworthiness

To ensure the data was accurately represented and the participant's experiences authentic, the transcripts were analysed and checked by research peers. Triangulation of the data demonstrated how robust the themes were. This was done with use of the interview tools (Taylor, 2007). Discussing themes with the participants as they arose and paraphrasing to ensure the meaning was correct, comparing recordings, transcripts and analysis of the interviews also addressed credibility of themes. Additionally the researcher kept field notes and a reflective journal about the interview process (Taylor 2007; Emerson et al 1995). Consistent use of a reflective journal, recording analytical memos and documentation of discussions with an experienced qualitative researcher created an audit trail that demonstrates rigorous analysis (Emerson et al 1995).

The researcher

This journal also enabled reflection on the researcher's own relationship with the topic. I have a brother with an intellectual disability. I grew up recognising the stigma he experienced and his reactions to it. The barriers that he faced towards inclusion were evident every day both to me and to him. He was considered to be different or to be 'special'. I went on to study and work as a

social care worker with people with disabilities for 5 years and I am currently completing a MSc in occupational therapy. This experience created a broader vision and enabled me to realise every experience as unique but that there may be similar barriers. I was encouraged to broaden the knowledge on the experiences of people with intellectual disabilities and their important relationships. I remained aware of my situation and beliefs within this study and used the journal to develop a deeper understanding of how my personal experience and the research process intersected.

Ethical Considerations

Ethical approval for this study under the larger study was obtained from the University of Limerick Education and Health Sciences Research Ethics Committee. Participants were provided with an accessible information letter and consent form with pictures embedded. Informed consent was obtained in writing from all participants prior to beginning the interviews. The participants took part on a voluntary basis and were informed of their right to withdraw at any time. Confidentiality of the participants is assured by assigning pseudonyms, removing identifying information from transcripts and not divulging anything about the interview to family or staff (Wiles et al 2008; Oliver 2010; Guillemin and Gillam 2004).

As the participants' have an intellectual disability, capacity to consent was assessed and considered, the researcher opted not to interview 2 people as they appeared hesitant in the understanding of the study or the researcher was doubtful. The researcher asked each participant to repeat back their understanding, assessing the compatibility of feedback. Communication is essential during the consent and interview process, in order to ensure clarity and not to distort what is said (Cole et al 2003). As this group are considered members of a vulnerable population there were considerations to protect both the participants and the interviewer. The interviewer has Garda Clearance, and the interviews were held in places comfortable and safe for both involved.

Results

The two major themes that were identified: (1) relationships with staff employed by disability services and (2) the nature of activities with support staff. There were sub themes coded under

both of these: (1) a) staff as a friend and support b) staff as an enabler c) staff as an authority figure. (2) a) activities organised and disability specific b) social networks, constructed by activities. Table below are participant profiles.

Pseudonym	Gender	Age	Housing	Service/Work	Activities	Important Relationships
Alex	Male	18-25	Lives in family home with parent	Disability day service 5/7 days.	No activities in the evenings after day service.	Family
Paula	Female	25-35	Newly -in independent living with another service user supported by service	Disability service, part time work, and volunteers	All organised disability specific sports and activities; No activities without a staff member or parents, hopes to start independently accessing community soon.	Family, House mate Staff (listed before friends) At end of interview identified boyfriend as important (only sees him in service)
Jack	Male	18-25	Lives in family home with parent and sister	Disability service 5/7 days	No activities in the evenings after day service.	Family Staff (before friends) Friends Would like a girlfriend has had in the past
Sophie	Female	25-30	Lives in residential service	Disability service (24/7)	No activities outside of services without staff.	Staff (mentioned first) Father Friends Identified boyfriend as important (only sees in services)
Tim	Male	25-	Lives with	Disability	No activities outside of disability services	Family Staff

		30	parents	service 5/7	without staff.	Friends Would like a girlfriend
Mary	Female	20-25	Lives with one parent	Disability service 5/7	No activities outside of disability services without staff.	Family Staff Friends Identified boyfriend (only sees in service)

Staff as a support/friend:

The participants highlighted staff as an integral part of their lives. Six participants perceived staff as a friend and a good support. A sense of safety existed when support staff were present during community participation, as described by Sophie, ‘Staff, family and friendly faces and the social services...they keep you safe’. Relationships with staff were important; staff were listed before friends for five participants. One participant listed the researcher as a friend, before any other friends, after 2-3 meetings. In total there were 21 interactions with the six participants, between information and consent sessions as well as the interview. One participant identified staff as family and referred to some as a parent to her. Six participants highlighted that they would turn to staff at times when they needed help. Alex stated that ‘you can do new things and can get help’ when support staff are there.

Disability services, social networks and organised structured activities with staff:

The disability organisations were significant in all the participants’ lives. They encouraged connecting with others in the service, as well as community activities. Staff were present during all these times. All activities enjoyed by participants were run by a disability organisation. These were often incorporated into programme and the participants identified having to do things each week that they didn’t like. Sophie stated how she would try to ‘sneak’ off for a walk to get away from her programme, ‘I ask can I put it in my timetable ... It’s more appropriate so I don’t have to be sneaking and I can be honest’. Outside of organised activities and plans for structured groups, the participants spent time alone, watching TV, playing video games. There was a level of separation from the community when not supported by staff or by family for all six. Few

opportunities were identified to meet new people outside of the organisational settings, which meant that most interactions were with staff members and other people with disabilities. The six participants engaged both in evening or weekend activities which were identified either with a staff or family member. Jack and Mary identified doing other activities in the community, with friends and without staff. However, Mary's mother stated after the interview that she always has a staff or family with her. Jack referred to meeting up with friends from school as 'yeah I bump into them', this was noted to be on a very rare occasion and he later said 'now I hardly talk to them' and that he would hang out 'more likely with my dad's friends'.

The activities and programmes that the participants took part in were scheduled and timetabled; how the activities were decided upon was not identified, but choice was indicated. Tim specified 'staff don't know my favourite programme'. Five participants wanted to do more of other activities on a weekly basis but did not have the opportunity due to time, other service users and resources. Additionally, they would not partake in these activities without staff or family. Paula expressed that 'I'd like to go to the cinema and stuff like that' while Alex said 'I wouldn't mind going more' (to matches).

Four of the participants said they did activities that they didn't enjoy, such as writing, reading and the gym. They indicated they had to participate in these activities as others in the service wanted to, or staff had made the choice and they had to go along with it.

Vocationally, five participants completed work experience organised by staff. This was unpaid but one participant got a part time job 2 days per week afterwards. Another participant received 25 Euro after 6 months of 1 day per week. Five participants identified would like a paid job outside of their disability service, but still want to attend the service. They spoke to staff about meaningful paid work, but for work experience did not have an option of interest just what was available. The sixth participant hadn't had the discussion about work with staff at all.

Staff: surveillance and enablement: 'can't do it without them'

Though staff were highlighted as a support and a friend to the participants, they were also identified by all participants as authority figures. This was described by the participants such as Tim stating 'staff would tell her not to do things... or if I'm being silly they say don't be silly'.

Staff would inform the participants if something was not to happen. Mary voiced how she is ‘not allowed have that in here’ (hold hands/ kiss a partner, in day or evening services).

The participants identified staff to help them do things like access the community and complete programmes above family members. There was a sense that the participants could not do these things without staff present as Mary said ‘someone has to bring you’ and that ‘we have to go with staff in case we get hit by a car’ (in the community). Sophie referred to this also stating ‘Thursday is good for getting out for sneaky walks, well with staff though, staff are there’.

There were low reports of been enabled that they could do, or would be supported to do, activities in the community alone or with peers and without staff. For instance Tim expressed ‘we do need staff’.

Discussion

Through the six interviews clear patterns emerged about the important role staff and service providers play in the lives of the participants. Through asking the participants about their weekly planner and the people in their lives, staff and the service came up repeatedly.

Staff, Social networks and Social inclusion

As the six participants are all linked in to disability services it was not surprising that staff are mentioned in the interviews. It became clear through data and thematic analyses how important staff were. All six participants identified staff as a friend and a support in their lives, people with whom they share leisure activities and social events. There are similar findings in other research, as people with intellectual disabilities valued staff, reported feelings of support and of being protected by them (Longo and Scior 2004; McVilly et al 2006a; McVilly et al 2006b; Clarkson et al 2009; Schwabenland 1999). The participants expressed a need for staff to support them to engage in society, in their community and to promote their quality of life. The staff were reported to encourage participation through organised activities and events. These activities involved others with disabilities and staff members were always present in some form, paid or voluntary. There was an identified level of separation from the community in all six interviews, when the participants were not supported by staff/service or a family member. This would

suggest that most interactions are with staff, other people with disabilities and families, leaving little room for spontaneous, new relationships to form. Research connects with this, showing friendships to be with others who have a disability (Salmon 2013; Siperstein et al 2007; Cutts and Sigafos 2001; Whitehouse et al 2001; Duvdevany and Arar 2004; Chappell 1994).

Extensive research examines loneliness for people with intellectual disabilities, and how this loneliness can impact quality of life and is often linked to exclusion from society (McVilly, et al 2006; Heiman and Margalit 1998; National Federation of Voluntary Bodies 2009; Jobling et al 2000). The six participants in this study did not express overt feelings of exclusion or use the term loneliness; however, they voiced longing for more activities or time in the community. This was not clarified to be time with staff or family but the participants highlighted the reliance on others to support them. Though loneliness was not explicitly named, outside of the organised activities by the services, the six participants spent time alone at home or with family members doing passive activities like watching TV. If engaging only with those that are paid to know them, this may be a source of deep loneliness for people with intellectual disabilities (National Federation of Voluntary Bodies 2009; Jobling et al 2000).

Through the six interviews the scarcity of social networks was identified, with staff often listed before friends. It is the social networks of people with disabilities that are considered to be an indicator of community participation (Johnson et al 2010; Milner and Kelly 2009; Kam-shing and Sung-on 2002; Duggan NDA 2011; Linehan 2012). There appears to be a need for friendships and links outside of staff and family, in particular in the evening and on weekends where the participants spent more time alone, and less time in the community, there were similar findings in previous research (Schwabland 1999; St. Quintin and Disney 2003; Forrester-Jones et al 2006). Other research linked this to programmes focused on social skills and moving away from emotional attachment which could be considered the basis of relationships (Forrester-Jones et al 2002). These social skills programmes do not often translate into a natural environment (Whitehouse et al 2001; Linehan 2012). In one study participants with an intellectual disability, perceived having difficulties with social skills impacting inclusion and relationships (Abbott and McConkey 2006).

It appears from the interviews that social participation is linked to the social support received from staff and family. The data suggested that staff were focused on social participation and inclusion but they remain doing with or doing for people with disabilities. It is difficult for staff to support participation and choices when: service user groups are not compatible having differences in abilities, when there is insufficient support staff, low resources, increased risks as seen by policies and now negative attitudes in society (Bigby et al 2009; Felce et al 2000; Stancliffe 1997; Stancliffe et al 2000; NDA 2011). In order for there to be any change to the lives of people with intellectual disabilities these challenges have to be tackled.

Where do we go from here?

Literature focuses on promoting links in the community for people with disabilities and on creating relationships with non-disabled peers (Clement and Bigby 2009; Johnson et al 2010; Chappell 1994). All six participants identified other friends that had a disability but their relationships only existed in the service or at organised events. With this in mind, are the friendships between people with disabilities devalued or forgotten about? (Milner and Kelly 2009; Clement and Bigby 2009; Johnson et al 2010). McVilly et al (2006) indicated that while the individuals are in a disability service these friendships are supported, encouraged and advanced, but outside the service they are not maintained. There is evidence that disability services can in fact prevent the opportunity to develop meaningful relationships (Bigby 2008; Clement and Bigby 2008; Lemay 2009). Therefore there is a vital missing link to enabling and empowering people with intellectual disabilities to access the community and friendships without support staff.

Perhaps staff fear that during this current economic downturn, if they enable service users their jobs could become redundant. It may not always be possible, but if staff were to enable people with intellectual disabilities to independently participate in society, there would be available staff for people that require a service. Furthermore there are staff available for expansion and progression of disability services in Ireland towards a more inclusive society. In order to promote social inclusion for the people with disabilities staff must also be supported, well supervised, given adequate training and provided with stress management interventions themselves (Linehan 2012). Research shows that staff who are given good support and training have shown positive

outcomes for service users regarding engagement in activities (Totskia et al 2008; Hastings 2010).

Social inclusion is one of the challenges of a disability organisation, Carson and Docherty (2002) states if not challenged disengagement from society will continue. The literature would suggest that supported employment and leisure for people with intellectual disabilities can lead to increased social networks (Shadish and Bootzin 1984; Forrester-Jones et al 2004; Srivastava 2001). Pettigrew et al (2006) found that people with disabilities making connections and having direct contact in society results in less prejudice and more inclusion.

The impact of Irish Policy on inclusion and moving towards Social Capital

The NDA (2007) makes recommendations that society should be accessible to all individuals especially those with disabilities, to enable and encourage all members of society to live as free responsible citizens. The belief is that changing society in this way will reduce exclusion and discrimination for those with disabilities, improving relationships and social connecting. Limitations in resources are not an excuse to delay implementation of the UN Convention on the Rights of Persons with Disabilities (UNCRPD 2006). An NDA (2011) study suggests taking a social capital approach instead of a social inclusion approach for people with disabilities. This may be the way forward in order to create an equal inclusive society in Ireland. The focus of social capital is not on the person with the disability but rather on the people in the community. This approach has been valued by those with disabilities (Heslop 2005). An example of a social inclusion approach involves a person with an intellectual disability being ‘escorted’ to an activity, whereas a social capital approach involves ‘actively facilitating’ the person to create a network of friends to go to this activity with (Linehan 2012; Duggan NDA 2011; Bates and Davis 2004). Disability organisations and staff should attempt to increase the formation of social capital for individuals, and move beyond programmes and services. The community is where true social capital is created (CQL 2007). Duggan (NDA 2011) spoke about not traditionally supporting the person with a disability but supporting the social network around the person including staff and professionals (Lord 1999).

Implications for Occupational Therapy

Incorporating all the information of this research project, it is clear that occupational therapy skills would benefit all intellectual disability services and there is a major scope for practice. Looking towards the future of working with, and enabling independent skills for people with intellectual disabilities, occupational therapists are experts at activity analysis, and have extensive knowledge on the importance of engaging in meaningful activities as an essential part of promoting health, survival and well-being (Yerxa 1993; Wilcock 1993). Occupational therapists strive for quality of life and a balanced lifestyle, understanding that the participants in this study experienced separation, and did activities alone could be linked with deprivation and loneliness, which can lead to helplessness and decreased psychological well-being (Whiteford 2000; Wilcock 2006; Hearle et al 2005; O'Sullivan & Hocking 2006; Whiteford 1997). Occupational therapy's philosophy is to be client centred and work towards full participation in meaningful occupations and in the community. If occupational therapists work with clients and staff to get this right we can develop a system where individuals with intellectual disabilities are confident in their abilities and independent at home and in the wider community. It is important for occupational therapists in Ireland to not only be advocates and supports for people with intellectual disabilities but to encourage and educate other staff members on the power of occupation, individuality and a sense of belonging (Primeau 1996; Mee and Sumsion 2001; Glass et al 1999; Mozley 2001).

Limitations of the study

This qualitative study with six participants should inform our understanding of these individual experiences. As a sister to a person with an intellectual disability, a staff member who works with people with intellectual disabilities and a final year MSc occupational therapy student, it is possible that I made assumptions and did not ask enough probing questions. As the participants knew my background this may have also altered their answers. That said, the interview guide was designed to ensure that a broad range of experiences could be discussed. Also a reflective journal assisted in addressing my personal thoughts. The larger study aims to tackle some of the limitations of this six participant study by broadening the sample size, and incorporating other disabilities in order to gather and compare experiences.

Conclusion:

This paper examined six participants' views of their relationships with staff, their social networks and the activities in which they partake. Social networks, friendships, employment and activities of people with intellectual disabilities need to extend beyond services and support staff. Lasting and diverse social connections are required to establish greater social inclusion for people with intellectual disabilities. Support, encouragement and enablement of people with intellectual disabilities is required to facilitate social inclusion. This can be through a social capital approach creating real connecting, real friendships and by being an active member of society. This can begin with ratifying the UN Convention on the Rights of Persons with disabilities. Through use of the media, people with intellectual disabilities and their allies have the ability to shape policy and practice (Forrester-Jones et al 2004; Forrester-Jones et al 2006; Duggan NDA 2011; UNCPRD 2006). Policies currently focus on de-institutionalisation, community participation and independent living. Infusing these policies with the value of friendships and real social networks has extraordinary potential (Bigby 2008). Occupational therapy with our client centred ethos is essential to work towards full participation in meaningful occupations at home and in the community. Staff and family members will continue to be some of the important relationships in the lives of people with intellectual disabilities. Nevertheless, other important relationships and friendships need to take shape and be promoted and what's more, like everyone they ought to be enjoyed in all settings.

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