

‘Being friends means helping each other, making coffee for each other’: reciprocity in the friendships of people with intellectual disability

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Abstract

Friendship is an issue of concern for many people with intellectual disability. The aim of the research presented in this paper is to understand how people with intellectual disability experience friendship and what friendship means for them. A focus group was held with seven people with intellectual disability, who are members of a self-advocacy group. An inductive thematic analysis approach was used to analyse the data. The people that the research participants identified as their friends were fellow self-advocates, family members, support workers and co-workers. They also identified behaviours and actions that foster friendship and those that undermine it. The analysis shows how the research participants identified as friendships those relationships which had an element of reciprocity, while linking a lack of reciprocity with the absence of friendship. It is very important for non-disabled people to understand the perspectives of people with intellectual disability they live and work with.

Keywords: Intellectual disability; friendship; reciprocity

Points of interest

- Friendships are important for everyone, including people with intellectual disability. Therefore it is important to consider how people with intellectual disability view friendship.
- In a focus group about friendship, the people with intellectual disability who took part identified different types of friends, including co-workers, family members, self-advocacy group members, and support workers.
- They also identified friendly behaviours and actions, such as helping each other, having a good time together, and joking with each other. On the contrary, some of them also identified behaviour which does not help friendship.
- The concept of friendship is based on reciprocal relationships, those in which the research participants feel that they are treated as equals.
- It is important for non-disabled people to listen to what the people with intellectual disability they know have to say about friendship.

Introduction

The loneliness that is experienced by many people with intellectual disability is well documented in the research literature. Among others, Gilmore and Cuskelly (2014) report that there are more people with intellectual disability who are chronically lonely than in the rest of the population. Likewise, Mason et al. (2013, 108) state that for people with intellectual disability loneliness is ‘a significant problem’, while McVilly et al. (2006a, 2006b) and Simpican et al. (2015) report that friendship is an area of concern for people with intellectual disability. At the same time, friendship is an important aspect of social inclusion and of the opportunity for people with intellectual disability to assert their rights as citizens (Browne and Millar 2016).

It is therefore important to understand how people with intellectual disability experience friendship and the meanings that they ascribe to these experiences. This helps throw light on the factors that facilitate the forming and development of friendships for people with intellectual disability, and the factors that hinder these processes. The objective of this study, which was carried out in Malta, was therefore to explore the views of people with intellectual disability on the subject of friendship and on their experiences of friendship. This objective is in line with the importance that Knox and Hickson (2001) place on understanding the points of view of people with intellectual disability on the subject of friendship. As these authors state, taking the step to understand these viewpoints is an important aspect of the work to dismantle barriers to friendship for people with intellectual disability.

The viewpoints about friendships of people with intellectual disability have in fact been discussed by various researchers, such as those whose studies are referred to in this article. Most of these discussions, including the one being presented here, stem from analyses and interpretations of non-

disabled researchers. Such discussions run the risk of perpetuating the power imbalance that usually obtains between non-disabled people and people with intellectual disability. Presenting research in an inclusive manner contributes to redressing this imbalance (Nind 2014). Inclusive research is an approach that I wholeheartedly endorse and which I have used and am still using (see, for example, Azzopardi-Lane and Callus 2015; Callus 2017; Deguara et al. 2012). However, I do believe that there is also value in research when non-disabled academics (such as myself) reflect on these viewpoints and interpret them from their own position. What is important of course is that in the process of reflecting on and discussing these viewpoints, one retains a non-judgmental position.

For this article, I have taken steps in order to ensure such a position and to privilege the voices of the people with intellectual disability who participated in the research. These steps, which are explained in the Methods section, include adopting a qualitative research methodology, using the social model of disability as the conceptual framework, using inductive thematic analysis, and reflecting upon my own positioning within the research process. Furthermore, the findings are presented separately from the analysis. The presentation of findings entails a level of interpretation of course, through the process of selecting which data and which quotations to present and how to present them. But presenting them separately, even at the risk of some repetition in the subsequent analysis, enables the voice of the research participants to emerge more clearly.

As mentioned earlier, this research was conducted within the context of previous studies that explore the views on friendship of people with intellectual disability. It is to the findings from these studies that we now turn.

Background

Friendship is as important a part of the well-being of people with disability as it is for any other person (Foley et al. 2012). As Knox and Hickson (2001, 276) report, for people with intellectual disability ‘the presence of meaningful friendships is an essential element of their well-being’. In their review of the literature on the social inclusion of people with intellectual disability in their neighbourhoods, Overmars-Marx et al. (2014) identify various factors that act as barriers and facilitators to this inclusion that emerge from the different studies they reviewed. Not surprisingly, one of the important factors is the lack of or the availability of friends.

As Knox and Hickson (2001) also remark, the increased presence of people with intellectual disability in the community has not necessarily resulted in an increase of friendships for them. This is because even for those people with intellectual disability who are not physically excluded from their societies, there are restrictions to fostering friendships. One of the restrictions that Mason et al. (2013, 113) report on is people with intellectual disability not feeling safe with non-disabled people because they may be taken advantage of – ‘if they’re a bit stronger than you in the head’, as one of the respondents put it. On the contrary, many people with intellectual disability still tend to be excluded socially. This is reported, for example, by Hall (2010) in the United Kingdom as well as by van Asselt-Goverts et al. (2015) in the Netherlands.

A significant obstacle that is highlighted by several researchers is the lack of opportunity to foster and maintain friendships. McVilly et al. (2006a, 2006b) discuss the lack of time that people with intellectual disability can spend with their friends. Additionally, Knox and Hickson (2001) refer to the lack of privacy and lack of time with close friends. The obstacles to spending time with friends may be very practical ones. The women with intellectual disability who participated in the study conducted by Welsby and Horsfall (2011) cite two such obstacles: the problem of transport,

especially not being able to use public transport unsupported and then not finding anyone to give them a lift; and the problem of money, not having enough money to go out and socialise with one's friends.

As a result of these and other restrictions that people with intellectual disability experience, '[m]any have few friends outside their family and those paid to care for them' (Hall 2010, 49). Almost by default, these persons become the ones whom people with intellectual disability consider to be their friends. As Milner and Kelly (2009) argue, disabled people tend to be restricted in the physical spaces that they inhabit. As a result, relationships and friendships tend to develop only within particular settings and remain bound to those settings. Similarly, Campbell (2012) reporting research carried out in Scotland points out that one of the most valued aspects of day centres is friendship, while Cramm et al. (2009) in their study based in the Netherlands report that people with intellectual disability who are in employment consider it important for co-workers to be friendly. One of the participants in the study by Welsby and Horsfall (2011) even mentions going to work as the only means of seeing her friends. Another source of friendship comes from support members of self-advocacy groups. For example, in research carried out in Malta, Borg and Pellicano (2015, 73) report on a person with intellectual disability identifying one of the support members of her self-advocacy group as 'her best friend ... a great source of support'.

Friendships are of course also formed among people with intellectual disability themselves. The value placed on these friendships varies. Over two decades ago, Chappell (1994) lamented the fact that the friendships of people with intellectual disability tend not be valued. More recent discussions on this subject indicate that the situation is more complex. Knox and Hickson (2001) in their Australia-based study report that the four people with intellectual disability who participated in their research prefer friendships with non-disabled people and do not give equal

value to their friendships with other people with intellectual disability even if, according to the authors, these friendships play a significant role in their lives. Bates and Davis (2004) explore in their research how friendships of people with intellectual disability with those living in their neighbourhood can be a means of social inclusion and therefore of the recognition of their social capital. On the contrary, McVilly et al. (2006b) state that the people with intellectual disability involved in their research prefer friendships with other persons who also have an intellectual disability. One of the research participants in Borg and Pellicano's (2015) study remarked that she preferred to open up with other people with intellectual disability because they do not judge her. McVilly et al. (2006b) also remark on the way that these friendships are more likely to last.

Policy-makers, service providers, and other organisations working with people with intellectual disability are aware of these issues, and many have policies and measures in place that actively support people with intellectual disability to develop and maintain friendships. The importance of such initiatives is noted by, among others, Duggan and Linehan (2013) and Bane et al. (2012), both studies being based in Ireland. Mason et al. (2013) in the United Kingdom and McVilly et al. (2006b) in Australia also signal the importance of providing support for the friendships of people with intellectual disability. Such support can be provided through befriending schemes and social skills training (Mason et al. 2013). Significantly, McVilly et al. (2006b) report that people with intellectual disability appreciate the provision of support for them to develop and maintain their friendships. The studies reviewed by Overmars-Marx et al. (2014) also highlight the need for people with intellectual disability to be supported in developing personal skills and competencies that facilitate the development and nurturing of friendships.

When it comes to the qualities that people with intellectual disability seek in friends, among those identified in the research literature are the ability to engage in 'dyadic communication' (McVilly

et al. 2006b, 700) and having ‘[a] person you can trust to keep secrets’ (McVilly et al 2006a, 198). The research participants in the study carried out by Bane et al. (2012) identify another two qualities in good friends: people who provide support and who are there for you when you need them, and people with whom you carry out leisure activities.

Method

In order to study the views of people with intellectual disability on the subject of friendship and on their experiences of friendship, a qualitative research methodology was employed. Beail and Williams (2014, 93) state that ‘[q]ualitative methods have played a role in bringing the unknown about people who have intellectual disability into the known’. By its very nature, qualitative methodology enables researchers and research participants to explore the selected research topic in depth. It also allows much scope for rephrasing questions and seeking clarifications to or further details about statements that are made.

Focus groups

The research tool used for this study was the focus group. As Lisoletti (2003) explains, focus groups enable participants to discuss the chosen research topic in interaction with each other. Thus, the researcher does not obtain individual perspectives as in the one-to-one interview, but ‘multiple views’ (2003, 2). Lisoletti (2003, 1) also explains that focus group participants can ‘share and respond to comments, ideas and perceptions’. Participants can therefore share and develop their views and perspectives together. This possibility for interaction was felt to be particularly suited for the aim of the research; that of investigating the views of people with intellectual disability on the topic of friendship. A similar method was used by Mason et al. (2013) to investigate a related research question.

Purposive sampling was used to recruit the focus group participants. They were recruited through a self-advocacy group. The seven members who responded were invited to take part in the focus group, which lasted an hour. They signed a consent form which acknowledged their right not to answer questions that they did not want to answer and their right to anonymity, and which included their permission for the focus group to be audio-recorded. Invitation letters and consent forms were written in easy-to-read Maltese.

Because the seven research participants came from the same self-advocacy group they knew each other well. As explained earlier, they were also known to me. This created a relaxed atmosphere which facilitated the mutual sharing of information. Attending to the relationships among focus group participants and between them and the researcher is important (Lisoletti 2003). It is even more important to do so when conducting research with people with intellectual disability. As Rapley (2014) argues, it is easy for the unequal power relationships that people with intellectual disability experience in their everyday lives to replicate themselves in research. This is especially the case because researchers tend to be non-disabled people who hold a social position which is superior to that held by the people with intellectual disability participating in the research (Callus 2017).

Using the focus group as a research tool helps address this power imbalance by enabling the participants to create interactions with each other without the direct intervention of the researcher. In my study, achieving more equitable power relationships was also facilitated by the fact that the research participants already knew each other and myself well, because I have worked with many of them on various self-advocacy initiatives for more than a decade. Additionally, as members of a self-advocacy group, all seven research participants have considerable experience in public-speaking and participating in meetings about issues that are of concern for persons with disability.

Furthermore, the focus group was held at the premises where the self-advocacy group members usually hold their meetings, and therefore a place where they felt at home.

Limitations

Inevitably, focus groups also have their limitations. Participants may not feel comfortable expressing certain opinions or recounting certain experiences in front of others. They may also make certain statements which are motivated, even if unwittingly, by social desirability (Chung and Monroe 2003). Moreover, some people may feel more comfortable talking to someone on a one-to-one basis and tend to withdraw when in a group. As a result, unless the researcher prompts certain focus group participants to speak, for example by posing questions directly to them, the views of some people may remain unrepresented. .

Conducting focus groups with people with intellectual disability has its own challenges. The interactive nature of focus groups requires participants to be articulate and to be able to express themselves easily in a verbal manner. Some people with intellectual disability find it difficult to express themselves so easily. In their review of the use of qualitative research methods with people who have an intellectual disability, Beail and Williams (2014) refer to limited attempts to use communication aids to facilitate participation. Using such methods in a group can be difficult and rather impractical. As a result, the more articulate people with intellectual disability tend to participate in focus groups (Beail and Williams 2014). This was in fact the case for the participants in my study.

The participants

While all seven research participants can be placed in the category of ‘people with intellectual disability’, the life experiences of the group were quite heterogeneous. The focus group comprised five female and two male participants. A better gender balance would have been ideal, but the composition of the focus group depended on which members of the self-advocacy group registered an interest in participating. The ages of the participants varied: the youngest was in her early twenties and the oldest in her late fifties. The other five participants were in their late twenties or in their thirties. Five of the research participants lived with both or one of their parents, another lived on her own and another in supported accommodation in the community. All seven participants went out and about in their hometown on their own. Four of them also used public transport on their own, another used it only to travel to and from work, while the other two participants did not know how to use public transport on their own and depended on being given lifts or being accompanied on public transport. Two participants were full-time employees, another three had part-time employment and the other two attended a day centre for persons with intellectual disability.

Focus group procedure

Given that the aim of the study was to study the views of people with intellectual disability on the topic of friendship, and the fact that, as explained in the following, an inductive approach to thematic analysis was used, the focus group was carried out in an unstructured manner. Participants had already been informed of the topic of the focus group. At the start of the meeting I therefore restated my aim of the research and asked them ‘What do you understand by the word “friendship”? What does it mean to you when you say “so and so is my friend”?’.

Any subsequent questions that I posed derived from the points made by the focus group participants and were mostly requests for clarification or prompts for elaboration on these points. There were also moments when I asked some participants to remain within the research topic if I felt that the point being made strayed far from the subject. Whenever I noticed that a participant who wanted to make a point was interrupted, I prompted that person to speak at the next available moment. I also took care to prompt the quieter focus group participants to speak if they had been silent for a significant amount of time. At certain junctures, I provided a synthesis of a number of related issues raised by the research participants and prompted them to focus more directly on these issues.

Thematic analysis

A thematic analysis approach was used to analyse the findings. As Clarke and Braun (2013) state, thematic analysis is not bound with a specific methodological or theoretical approach. This study was embedded within the conceptual framework of the social model of disability, which recognises that the difficulties disabled people face in society arise not so much from their individual impairments but from the socially constructed barriers they experience in their everyday lives (Oliver 2009). Furthermore, this conceptual framework privileges the voice and experiences of disabled people themselves (Stone and Priestley 1995).

Braun and Clarke (2006) identify six steps to thematic analysis: familiarisation with the data; coding; searching for themes; reviewing themes; defining and naming themes; and writing up. In order to ensure my familiarisation with the data, I carried out the transcript of the focus group recording myself, immediately attributing pseudonyms to each research participant. When the researcher does the transcription herself there is the added advantage that the confidentiality of the

data is maintained because no one other than the researcher hears the recording. For the identification of the themes, I used an inductive approach, starting with the data and moving to a theoretical explanation based on the analysis of that data (Schutt 2004). Familiarisation with the data is especially important for inductive thematic analysis because it helps to ensure that the themes identified really do arise from the discussions of the focus group participants and the issues they raised.

With regards to language, because the focus group was conducted in Maltese, the transcript was also written in Maltese. Only the direct quotations presented in this article have been translated into English. Some linguistic features can get lost in translation and sometimes what is lost is relevant to the research findings and their analysis, therefore in one instance an explanation of the original statement in Maltese is provided. The themes elicited from the focus group are now presented and discussed, following a presentation of the main findings.

Perspectives on friendship

The themes that emerge from the discussion which took place during the focus group elicited themes that can be placed under two overarching themes: the groups of people whom the research participants consider as being their friends; and the behaviours and actions that the participants consider to be markers of friendship. The findings presented in the following are categorised under these two main headings.

People who are friends

Co-workers

Of the five participants who are in employment, three referred to their co-workers as their friends. For Jean, the fact that she is treated well by her (non-disabled) co-workers marks them as her friends. Frances also referred to how well she is treated by her co-workers, some of whom are disabled and some non-disabled. She added how she appreciates the time they take to explain the work she is assigned, especially when it involves new tasks. Jeremy also added co-workers to his category of friends. Interestingly, he specifically included his boss in this category. For him, the fact that he calls his boss by his given name rather than his title and surname is a sign of friendship. Furthermore, as seen later, both Jean and Jeremy also pointed out the fact that they socialise with their co-workers outside working hours as a marker of their friendship with them.

Self-advocacy group members

Most of the research participants also identified their fellow self-advocacy group members (including those taking part in the focus group) as their friends, with Melissa saying ‘because I really feel at ease with you’. I used this point to prompt a discussion about whether their friends are mostly disabled people or not. For Melissa, William, and Carla, their friends are mostly disabled people. Carla identified her disabled friends as being members of the self-advocacy group and those who attend the same day centre as her. Incidentally, Frances also added the support members of the self-advocacy group as being among her friends.

Family members

Family members were identified as friends by some of the focus group participants. Jean referred to her mum and her cousins as her friends. She said that she enjoys the time she spends with them, especially going shopping with her mum, and going to barbecues, parties, and day trips which her cousins invite her to, adding that her cousins have included her in their activities from when she was little. She stated ‘We’re close. We’re very close.’ Margaret also mentioned her mum as her friend, while Carla (whose mother has passed away) referred to her married sister as her friend – she loves going to her house and spending time with her sister’s family. On the contrary, Frances and Jeremy both explicitly left the members of their respective families out of the category of friends.

Support workers

For those participants who use a service for people with intellectual disability, such as a day centre or residential services, some of the support workers are also their friends. Jeremy identified the support workers in his residence as his friends, except for one who constantly criticised him and who was indiscreet with confidential information about him. One of the incidents with this support worker is recounted later. Carla also emphasised her friendly relations with the support workers at the day centre she attends. The ones whom she names as her friends are those who she says help her. Being able to share jokes with support workers is important for Carla, as can be seen later. For Margaret, who also attends a day centre, all of the support workers are her friends because, as mentioned earlier, she said that they are all helpful. She remarked how sorry she was to see one of them leave to take up a post in another organisation, and how much she was missing her.

Intimate relationships

Some of the research participants also briefly explored the link between friendship and intimate relationships. William identified his girlfriend as his best friend. Jeremy pointed out how friendships can develop into intimate relationships, later expressing a wish that he too would have a girlfriend. Margaret brought up an issue regarding Stephen, her former boy- friend. She sent him a text message to let him know that she was going on holiday to England with her family because, she said, 'he is still my friend'. Stephen promptly sent her a friend request on Facebook and she was wondering whether it was because, having just left his present girlfriend, he was interested in getting back with Margaret herself again. Recounting this incident led Margaret to make the observation that some parents assume that a male friend of a woman with intellectual disability is her boyfriend, and *vice versa*.

Acting as friends

Helping each other

Following my initial question regarding what is friendship, the research participants started with the helping aspect of friendship. Carla immediately described a friend as 'someone who helps me', to which she soon added 'and you help them'. Margaret added to this idea by saying that 'those who help you are your friends'. Later on, she remarked that the support workers at her day centre are her friends because 'they all help you'.

Having a good time together

Going out and having a good time were also identified as markers of friendship. Jean counts her mum and her cousins among her friends because she enjoys the leisure activities they do together. Similarly, both Margaret and Carla identified outings organised by the support workers at their respective day centres as occasions where they enjoy having a good time with their friends. Carla encapsulated this as ‘Going out together. Making new friends. And we go somewhere as friends. We go out to eat and similar.’ For Jeremy and Jean, going out in the evening with their co-workers is also an important part of their friendship with them. Jeremy mentioned how even co-workers who sometimes rub him the wrong way at work become his friends on social occasions. He said ‘When we go out together, it’s totally different’.

Joking with each other

Being able to joke with your friends was also mentioned during the focus group discussion. William, who frequents a club run by the village brass band, described how his friends there like to tease him. He said he goes along with it but when he has had enough he tells them ‘let’s go and have a coffee’. William added that sometimes he pays for the coffee, and sometimes his band club friends do. For Carla, joking is an even more reciprocal affair. She referred to one of the younger support workers at her day centre, Felicity, who sometimes jokingly refers to Carla (who is in her late fifties) as ‘granny’. Carla’s usual retort is equally flippant: ‘I do not take childish people seriously’. Carla’s anecdote is very much appreciated by the other focus group participants who burst into laughter and applause, with Margaret soundly endorsing it with a ‘Well done!’.

Unfriendly behaviour

The issue of undesirable treatment was also raised, especially by Frances who spoke about how she fell out with a group of friends who have intellectual disability because they used to call her names. 'I've never forgiven them', she asserted. This prompted a discussion, initiated by Carla, about whether friends can treat you badly. This in turn also prompted Margaret to speak about an experience where she fell out with friends who have an intellectual disability because they used abusive language towards her.

Another aspect of undesirable treatment that was highlighted in the discussion was being shown a lack of respect. Jeremy spoke about an incident that had occurred at a time when he was being closely monitored by staff at his residence because he had run up several debts.

While he acknowledged the need for the support workers to monitor his purchases, he expressed resentment at the lack of discretion with which one of them shared personal information about him:

She saw me coming in with something. And she had to write it down in the notebook. I get that. But there was no need for her to call the supervisor and tell her in front of everyone 'Jeremy has bought that object'.

Jeremy's complaint about this particular support worker is in contrast to how he spoke about his co-workers and his boss when they draw his attention to something he does not do right. He said: 'It's true we need a bit of a rap on the knuckles if we do something wrong. But we're still friends'.

Reflections on friendship

A striking feature of the various themes regarding friendship that were discussed by the focus group participants, as already presented, is that they are all based on the concept of reciprocity, even if this concept is not articulated explicitly. Given that most people with intellectual disability live lives which are heavily circumscribed by others (Callus 2013) and therefore experience relationships which are unequal, it is significant that the research participants in the present study place so much emphasis on reciprocity, albeit implicitly. They identify those relationships which place them on a more equal footing with others as friendship, and exclude from this category relationships and behaviours which place them at the wrong end of unequal relationships. Thus, it is reciprocal relationships that the research participants favour, a stance which is not surprising given the importance of reciprocity in friendships (Chappell 1994). Reciprocity is also identified by Bates and Davis (2004) as a crucial ingredient in promoting the social inclusion of persons with intellectual disability. The analytic themes presented in this discussion therefore explore the different aspects of reciprocity in friendship.

Reciprocal help

As noted earlier, the idea that friends are people who help you featured strongly in some of the responses provided by the focus group participants. It kept recurring in particular in what Carla and Margaret had to say about friendship. What is significant is that, apart from the practical benefits of having someone to help you, these focus group participants also refer to reciprocity in giving help – that is, they help their friends as much as their friends help them. This indicates that they do not see their being helped as a sign of their dependence but as an act that arises naturally out of their interaction with friendly others.

Far from seeing the need for help and support as a sign of weakness, these research participants identify it as a marker of friendship. After all, as many disabled activists have been saying for a long time, disabled people's need for assistance from others for carrying out activities of daily living should not undermine their independence (see, for example, Finkelstein 1981; Morris 1997). There is also a degree of reciprocity in this sort of assistance because the non-disabled helper listens to the person's wishes and acts according to them rather than imposing their will. Communication is therefore not one-way traffic, but a two-way affair.

Crossing boundaries

Carla's placing of those professionals who help her within her circle of friends raises issues regarding the boundaries that are usually considered to be appropriate for staff to maintain with the disabled people they work with. The issue of boundaries is best illustrated by Jeremy's earlier remark regarding the incident with the support worker who talked openly about information which he preferred to keep confidential. Jeremy acknowledged the duty that the support worker had to monitor his purchases, given the debts that he had to pay off. But he also expressed his resentment towards the lack of discretion with which she shares the personal information about him. This attitude on the part of the support worker rules her out from being considered by Jeremy as one of his friends.

People with intellectual disability find themselves in situations where personal information about them is shared among professionals. As Taylor et al. (2007, 78) state: 'At times nothing we say is confidential'. At the same time, when it comes to their getting to know more about the people who work with them on a daily basis, there is no reciprocal flow of information, which also renders them powerless, as reported by Bonello, Bonello, and Callus (2012). In some cases, people with

intellectual disability may not even be allowed to share their own personal information with their peers. Such a situation is reported by Welsby and Horsfall (2011), where one of the women with intellectual disability interviewed pointed out that she was not allowed to give her telephone number to anyone outside her family, and therefore could not get her friend to call her.

Bowler and Nash (2014) and Parkes and Jukes (2008) see personal (as opposed to professional) caring as posing potential boundary problems. Boundaries must be kept of course, especially because any possibilities for the development of abusive relationships must be eliminated. However, discussions of boundaries rarely if ever take into account the points of view of the people with intellectual disability at the receiving end of services. From the standpoint of people with intellectual disability, personal caring can be a marker of the friendships they want to foster with their support workers. Adhering strictly to pre-set professional boundaries is at odds with the reciprocal relationships that these focus group participants seek in the support workers whom they consider to be their friends. This reciprocity is also a means of adjusting the power imbalance that usually obtains in the relationship between the two.

Sharing jokes

The issue of laughter and disability is of course a sensitive one because disabled people have traditionally been considered easy targets for comedy in ways that disabled people themselves often find offensive (Albrecht 1999). The joking referred to in the focus group, especially by William and by Carla, is acceptable for them because it is reciprocal. Carla's anecdote about her and Felicity's 'granny and child' joke is a clear illustration of this reciprocity. Before recounting this story, Carla had identified Felicity as a support worker who is her friend. The age gap between the two would make it biologically possible for Carla to be Felicity's grandmother. People with

intellectual disability run the risk of being viewed as eternal children because of their continued dependence on others. Both Felicity and Carla reverse this notion in their shared joke: Felicity addresses Carla as a grandmother (the very opposite of being a child). In addition, the expression that Carla uses – ‘I don’t take childish people seriously’ (*jien ma nieħux għat-tfal*) – is a common one in the Maltese language and is used to de ate jibes, whether they are said in jest or not (Aquilina 1987, 461). Coming from Carla, the expression takes on an added significance, because it is not her but the support worker who is depicted as being still a child.

Through a shared joke, Carla and Felicity reinforce their friendship and turn on its head the idea of people with intellectual disability as eternal children. Carla’s anecdote also chimes in with one of the points raised by Taylor et al. (2007, 74) when the service-users interviewed state: ‘We don’t want staff to stop the joking: it’s good when staff can take a joke.’

Shared leisure time

The research participants identified various people as being their friends, namely family members, support workers, co-workers, self-advocacy group members, and, in the case of William, his girlfriend and members of his band club. Friendships are therefore formed from within the restricted spaces which the participants inhabit. In their New Zealand study, Milner and Kelly (2009) also point out that the people with intellectual disability they interviewed named family members and staff as their friends. A common factor in this selection of friends is that the persons identified by the participants are ones with whom they have a good time and with whom they engage in leisure activities, as reported also by Bane et al. (2012). Thus, Jean picks out her mother and her cousins because these are the family members she shares leisure time with. Jeremy and Jean speak of their co-workers as being their friends because from time to time they go out in the

evening together.

Additionally, Carla and Margaret both refer to evening activities that are organised by their day centre staff as an aspect of their friendship with support workers. Their reference challenges the clear-cut categorisation of service-users on the one hand and staff on the other. For the support workers, the evening activities take place during their working hours: they are paid for supporting people with intellectual disability to engage in evening leisure activities at the day centre or in the community. But Carla and Margaret, for whom these activities take place during their leisure time, the time spent together with support workers during these activities is an aspect of their friendship. This echoes the findings in the research by Campbell (2012) cited earlier.

The challenge to the usual strict categorisation of staff and service-users is similar to that reported by Woodin (2006) regarding the relationship between disabled people and the personal assistants whom they directly employ. In Woodin's research, both the disabled people (as employers) and the personal assistants (as employees) described their relationship as both 'an employer-employee relationship and as a friendship. Some respondents suggested that it was a unique relationship, and certainly employers and assistants struggled at times to make descriptions fit into neat pre-existing categories' (Woodin 2006, 120-121). In Carla's and Margaret's cases, the situation is rather different because they are not the employers of their support workers. This perhaps makes the fact that they see their relationship with these workers as one of friendship even more significant.

Friendships in structured environments

While, as seen in this discussion, the element of reciprocity comes out very strongly in the understandings of friendship proffered by the seven research participants, there is an important consideration that needs to be taken into account. This is the fact that the activities and situations

in which these participants seek out friendships are invariably initiated by non-disabled people. In fact, with the exception of William's reference to the band club, none of the references to friendships are related to informal settings in which the research participants meet and socialise with their friends. The absence of such references is significant because it indicates a situation where the seven research participants' opportunities for making friends tend to be restricted to their interactions with the people they come into contact with within the structured settings they inhabit, such as the family home or other place of residence, the day centre or place of work, and the self-advocacy group, among others. A similar situation is reported by the participants in Welsby and Horsfall's (2011) study.

In the literature reviewed earlier, reference was made to studies that point out the importance of providing support for persons with intellectual disability to develop and foster friendships. While this is not a need that was mentioned by the focus group participants who took part in my study, it is an issue that is relevant nonetheless. The very fact that friendships which arise from informal interactions did not form part of the focus group discussion strongly indicates that for people with intellectual disability to have a truly rich experience of friendship they should be provided with the support they need to take part in activities which do not necessarily take place in structures and environments that have been pre-determined for them. In the absence of such support, the importance for non-disabled people who interact with persons with intellectual disability within the structures and environments they inhabit to listen to what these persons have to say about their relationships with them takes on added importance. In fact, it is with a discussion of considerations for non-disabled people that this article ends.

The other side of reciprocity: challenges for non-disabled persons

The discussion in the focus group, and the analysis of that discussion presented in this article, show the rich and varied understandings of friendship that were articulated by the seven research participants. While different participants placed emphasis on different aspects of friendship, there is the common theme of reciprocity in the relationships that they identified as friendships. These are the relationships by means of which the research participants feel valued, those which enable them to interact with people with whom they enjoy spending time. The importance of reciprocity in the friendships and relationships of people with intellectual disability is also highlighted by the participants in Milner and Kelly's study:

They also emphasised that finding ways to reciprocate within relationships was both the glue that bound friendships and key to humanising important relationships. (2009, 56–57)

The experiences of friendships presented by the research participants and the understandings that they assigned to these experiences thus present a challenge to how non-disabled people think of their relationships with the people with intellectual disability with whom they interact on a daily basis. The discussion in this section of the article is focused on their friendships with non-disabled people because it is mainly non-disabled people, especially those who live or work closely with people with intellectual disability, to whom this article will be of interest. This focus of course does not in any way diminish the importance of friendships amongst people with intellectual disability themselves, which the research participants also mentioned. -

The findings presented and discussed show how discerning these participants were in deciding who is their friend and who is not. They did not indiscriminately include anyone they come into contact with as their friends. Furthermore, they also pointed out what constitutes unfriendly

attitudes and behaviour. As seen earlier, clear patterns emerge from the findings – the non-disabled people who qualify as their friends are the ones whom they enjoy spending time with, the ones from whom they have respect, and the ones with whom they have a degree of reciprocity in their relationships with them. The starting point in judging who is their friend therefore seems to be not the role that the non-disabled person plays in their life, but the type of relationship that exists with that person. The formal categories of family member, support staff, colleague, or self-advocacy support member become secondary to that of friend. For Jean, her mum, her cousin, and her colleagues are all her friends. Likewise, for Jeremy and Carla, some of their support workers are their friends.

While the present research did not extend to canvassing the views of the non-disabled persons mentioned in the focus group, it is reasonable to assume that they do not see themselves first and foremost as the friends of the focus group participants: that if Felicity was to be asked about her relationship with Carla, she would identify herself as her support worker rather than as her friend; that Jeremy's and Frances' colleagues would not identify them primarily as their friends; and nor would Jean's cousins or Carla's sister.

As pointed out earlier, Chappell (1994) critiques the stance that values the friendships of people with intellectual disability with non-disabled people more than the friendships of people with intellectual disability between themselves. As she rightly states, this stance shows 'an important misunderstanding of the nature of friendship as a voluntary relationship of mutual affection which is founded on shared interests and experiences' (1994, 431–432). Interestingly, the participants in the present study extended this concept of friendship to some of the non-disabled people in their lives as well. There is of course one word in this quotation that posits a challenge for non-disabled people – it is the word 'mutual'. Fostering mutual relationships calls for a re-categorisation of the

roles that non-disabled people cast themselves in within their interactions with people with intellectual disability. This re-categorisation in turn calls for non-disabled people to examine the nature of their relationships and interactions with the persons with intellectual disability whom they live or work with. This examination should focus especially on how the persons with intellectual disability concerned perceive those relationships and interactions, and on how they would like them to be. Like some of the studies cited in this article, this research enabled a group of people with intellectual disability to present their views about friendship. However, one must ask the question of how often they have the opportunity to air these views in their everyday lives, especially with the very people whom they identified as their friends.

While the specific views of these seven Maltese people with intellectual disability cannot be assumed to be representative of the views of other people with intellectual disability, there is one conclusion that can be generalised. This is the conclusion that those who, in different ways, spend a lot of time with people with intellectual disability should seek to understand how the latter interpret their relationship, value these interpretations and seek ways of becoming better friends with them. Also, as someone who herself collaborates closely with people with intellectual disability, it is an understanding that I have to seek and act upon myself.

References

- Albrecht, G. L. 1999. "Disability Humor: What's in a Joke?" *Body & Society* 5 (4): 67–74.
- Aquilina, J. 1987. *Maltese English Dictionary*, Volume One A-L. Malta: Midsea Books Ltd.
- Azzopardi-Lane, C., and A. M. Callus. 2015. "Constructing Sexual Identities: people with Intellectual Disability Talking about Sexuality." *British Journal of Learning Disabilities* 43 (1): 32–37. doi:10.1111/bld.12083.
- Bane, G., M. Dooher, J. Flaherty, A. Mahon, P., McDonagh, M. Wolfe, M., Deely, R., Hopkins, G., Minogue, M., Curry, et al. 2012. "Relationships of People with Learning Disabilities in Ireland." *British Journal of Learning Disabilities* 40 (2): 109–122. doi:10.1111/j.1468-3156.2012.00741.
- Bates, P., and F. A. Davis. 2004. "Social Capital, Social Inclusion and Services for People with Learning Disabilities." *Disability & Society* 19 (3): 195–207. doi:10.1080/0968759042000204202.
- Beail, N., and K. Williams. 2014. "Using Qualitative Methods in Research with People Who Have Intellectual Disabilities." *Journal of Applied Research in Intellectual Disabilities* 27: 85–96. doi:10.1111/jar.12088.
- Bonello, A., I. Bonello and A. M. Callus. 2012. "Inclusive Education: The Insider Experience of Two Students in Malta." In *Roots to Inclusive Education: A Question of Wellbeing*, edited by A. Azzopardi, 31–35. Saarbrücken: Lambert Academic Publishing.
- Borg, B., and M. S. Pellicano. 2015. *'I Am a Grown-up Now!'* *Understanding the Aspirations of Youth with Intellectual Disability for Their Future Compared with What Others Plan for Them*. Unpublished dissertation, University of Malta, Malta.
- Bowler, M., and P. Nash. 2014. "Professional Boundaries in Learning Disability Care." *Nursing times* 110 (21): 12–15. <http://www.nursingtimes.net/download?ac=1281698>
- Braun, V., and V. Clarke. 2006. "Using Thematic Analysis in Psychology." *Qualitative Research in Psychology* 3: 77–101. doi:10.1191/1478088706qp063oa.
- Browne, M., and M. Millar. 2016. "A Rights-Based Conceptual Framework for the Social Inclusion of Children and Young Persons with an Intellectual Disability." *Disability & Society*. DOI:10.1080/09687599.2016.1232190.

Callus, A. M. 2013. *Becoming Self-Advocates: People with Intellectual Disability Seeking a Voice*. Oxford: Peter Lang.

Callus, A. M. 2017. “Developing Inclusive Research Methods: Collaborating with People with Intellectual Disability as Co-Researchers.” *Sage Research Methods Case Study*.

Campbell, M. 2012. “Changing Day Services: Do You Agree?” *Journal of Intellectual Disabilities* 16 (3): 205–215. doi:10.1177/1744629512455894.

Chappell, A. L. 1994. “A Question of Friendship: Community Care and the Relationships of People with Learning Difficulties.” *Disability & Society* 9 (4): 419–434. doi:10.1080/09687599466780431.

Chung, J., and G. S. Monroe. 2003. “Exploring Social Desirability Bias.” *Journal of Business Ethics* 44 (4): 291–302. <http://link.springer.com/article/10.1023/A:1023648703356>

Clarke, V., and V. Braun. 2013. “Teaching Thematic Analysis: Over-Comeing Challenges and Developing Strategies for Effective Learning.” *Psychologist* 26 (2): 120–123. <http://eprints.uwe.ac.uk/21155/3/Teaching%20thematic%20analysis%20Research%20Repository%20version.pdf>

Cramm, J. M., H. Finken ügel, R. Kuijsten, and N. J. A. van Exel. 2009. “How Employment Support and Social Integration Programmes Are Viewed by the Intellectually Disabled.” *Journal of Intellectual Disability Research* 53 (6): 512–520. doi:10.1111/j.1365-2788.2009.01168.x.

Deguara, M., O. Jelassi, B. Micallef, and A. M. Callus. 2012. “How We Like to Live When We Have the Chance.” *British Journal of Learning Disabilities* 40 (2): 123–127. doi:10.1111/j.1468-3156.2012.00743.x.

Duggan, C., and C. Linehan. 2013. “The Role of ‘Natural Supports’ in Promoting Independent Living for People with Disabilities; a Review of Existing Literature.” *British Journal of Learning Disabilities* 41 (3): 199–207. doi:10.1111/bld.12040.

Finkelstein, V. 1981. “Disability and the Helper/Helped Relationship. an Historical View.” In *Handicap in a Social World*, edited by A. Brechin, P. Liddiard, and J. Swain, 58–63. Milton Keynes: Hodder and Stoughton in association with the Open University Press.

Foley, K., A. Blackmore, S. Girdler, M. O’Donnell, R. Glauert, G. Llewellyn, and H. Leonard. 2012. “To Feel Belonged: The Voices of Children and Youth with Disabilities on the Meaning of Wellbeing.” *Child Indicators Research* 5 (2): 375–391. doi:10.1007/s12187-011.9134-2.

Gilmore, L., and M. Cuskelly. 2014. "Vulnerability to Loneliness in People with Intellectual Disability: An Explanatory Model." *Journal of Policy and Practice in Intellectual Disabilities* 11 (3): 192–199. doi:10.1111/jppi.12089.

Hall, E. 2010. "Spaces of Social Inclusion and Belonging for People with Intellectual Disabilities." *Journal of Intellectual Disability Research* 54 (s1): 48–57. doi:10.1111/j.1365-2788.2009.01237.x.

Knox, M., and F. Hickson. 2001. "The Meanings of Close Friendship: The Views of Four People with Intellectual Disabilities." *Journal of Applied Research in Intellectual Disabilities* 14 (3): 276–291. doi:10.1046/j.1468-3148.2001.00066.x.

Lisoletti, L. 2003. *Using Focus Groups in Research*. London: Continuum.

Mason, P., K. Timms, T. Hayburn, and C. Watters. 2013. "How Do People Described as Having a Learning Disability Make Sense of Friendship?" *Journal of Applied Research in Intellectual Disabilities* 26 (2): 108–118. doi:10.1111/jar.12001.

McVilly, K. R., R. J. Stancliffe, T. R. Parmenter, and R. M. Burton-Smith. 2006a. "'I Get by with a Little Help from My Friends': Adults with Intellectual Disability Discuss Loneliness." *Journal of Applied Research in Intellectual Disabilities* 19 (2): 191–203. doi:10.1111/j.1468-3148.2005.00261.x.

McVilly, K. R., R. J. Stancliffe, T. R. Parmenter, and R. M. Burton-Smith. 2006b. "Self-Advocates Have the Last Say on Friendship." *Disability & Society* 21 (7): 693–708. doi:10.1080/09687590600995287.

Milner, P., and B. Kelly. 2009. "Community Participation and Inclusion: People with Disabilities Defining Their Place." *Disability & Society* 24 (1): 47–62. doi:10.1080/09687590802535410.

Morris, J. 1997. "Care or Empowerment? A Disability Rights Perspective." *Social Policy and Administration* 31 (1): 54–60. doi:10.1111/1467-9515.00037.

Nind, M. 2014. *What is Inclusive Research?*. London: Bloomsbury.

Oliver, M. 2009. *Understanding Disability from Theory to Practice*. 2nd ed. London: Palgrave Macmillan.

Overmars-Marx, T., F. Thomése, M. Verdonschot, and H. Meininger. 2014. "Advancing Social Inclusion in the Neighbourhood for People with an Intellectual Disability: An Exploration of the Literature." *Disability & Society* 29 (2): 255–274. doi:10.1080/09687599.2013.800469.

Parkes, N., and M. Jukes. 2008. "Professional Boundaries in a Person-Centred Paradigm." *British Journal of Nursing* 17 (21): 1358–1364.

Rapley, M. 2014. *The Social Construction of Intellectual Disability*. Cambridge: Cambridge University Press.

Schutt, R. K. 2004. *Investigating the Social World*. 4th ed. Thousand Oaks, CA: Sage.

Simplican, S. C., G. Leader, J. Kosciulek, and M. Leahy. 2015. "Defining Social Inclusion of People with Intellectual and Developmental Disabilities: An Ecological Model of Social Networks and Community Participation." *Research in Developmental Disabilities* 38 (1): 18–29. doi:10.1016/j.ridd.2014.10.008.

Stone, E., and M. Priestley. 1995. "Parasites, Pawns and Partners: Disability Research and the Role of Non-Disabled Researchers." *British Journal of Sociology* 47 (4): 699–716. doi:10.2307/591081.

Taylor, J., V. Williams, R. Johnson, I. Hiscutt, and M. Brennan. 2007. *We Are Not Stupid*. London: People First Lambeth.

van Asselt-Goverts, A., P. Embregts, A. Hendriks, K. Wegman, and J. Teunisse. 2015. "Do Social Networks Differ? Comparison of the Social Networks of People with Intellectual Disabilities, People with Autism Spectrum Disorders and Other People Living in the Community." *Journal of Autism and Developmental Disorders* 45 (5): 1191–1203. doi:10.1007/s10803-014-2279-3.

Welsby, J., and D. Horsfall. 2011. "Everyday Practices of Exclusion/ Inclusion: Women Who Have an Intellectual Disability Speaking for Themselves?" *Disability & Society* 26 (7): 795–807. doi:10.1080/09687599.2011.618731.

Woodin, S. L. 2006. *Social Relationships and Disabled People: The Impact of Direct Payments*. Doctoral Dissertation, University of Leeds. <http://www.leeds.ac.uk/disability-studies/archiveuk/woodin/FinalThesis.pdf>.