

Everyday practices of exclusion/inclusion: women who have an intellectual disability speaking for themselves?

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This article discusses a small in-depth research study with five women who have an intellectual disability. Recognising the potential limitations of narrative approaches an inclusive arts-based methodology, supplemented with semi-structured interviews, and was employed to enable the women to speak for themselves about issues that were of interest to them. Thematic analysis of the data showed that the women experienced practices of social and emotional exclusion, and inclusion, in their everyday lives. While disappointing, this is not surprising. Of particular interest to the researchers were the women's strategies for living with, and sometimes resisting, such practices. We suggest that further research which elicits such resistant practices and working with women to strengthen them could be useful for people interested in notions of inclusion.

Keywords: women; intellectual disability; learning difficulties; arts-based research; social inclusion; exclusion

Points of interest

- Living and working in the community can be both isolating and inclusive.
- Five women who have an intellectual disability and who live in Australia talked about their lives.
- The women talked to the researchers in art workshops and interviews. They found talking in the art workshops much easier and more enjoyable than talking in interviews.
- They included and excluded at work, at home, in their leisure time and in making friends and having relationships.
- The article is important as the women also talked about what they did when they felt angry, or not included, or if carers, employers or the public made things difficult for them. It is useful to share this information with others.
- It is also important as it uses art to help people to talk about what they want to talk about.

Introduction

If somebody just stopped and asked us they would find out that we actually know a lot. (Lara, research participant¹)

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The research discussed in this article represents a small in-depth qualitative study where the researcher sought to understand the lives of five women who have an intellectual disability. We sought this understanding by giving the women epistemic privilege; that is, we centred them as experts of their own experiences. As we wanted to hear about these women's lives from their perspective and in their own words, an arts-based research process, augmented by one-to-one in-depth interviews, was used. This enabled the women to speak how, and about what, they chose. The women chose to focus on the themes of work, friendship, identity and everyday life. While we had not originally sought to find out about issues of inclusion/exclusion, this theme emerged from the data analysis. The women spoke of a multitude of everyday practices that excluded them from society. Interestingly, we also noticed that the women often inhabited grey areas within the concept of inclusion/exclusion. While we found that the 'illusion of inclusion' (Metzel and Walker 2001 in Smith 2005, 88) was strong, it is not quite as simple as it sounds. Yes, the women research participants were excluded from many areas of life non-disabled people may take for granted, but they were included too. When they were excluded they were often aware of what was going on and had developed strategies, such as humour and using advocacy services, to deal with exclusionary practices. This is important as it positions the women as having awareness and agency.

We take a social constructivist position regarding the exclusion of women who have an intellectual disability. By that we mean that exclusionary practices are the result of socio-cultural processes that produce and re-produce exclusion for some groups in our society. These processes manifest, and are experienced, in everyday social relations. As such, we are interested in exploring these processes; how do people 'do' exclusion and how do people experience exclusion? If social exclusion is a social phenomenon then it seems important to work towards understanding the everyday practices that construct and continue exclusion from the women's point of view. In this way we explore the personal and subjective dimensions of exclusion. Here we discuss day-to-day exclusionary practices the women experienced, how they were included in society and the practices they used to resist exclusion. While our findings and discussion relate to the five women involved, we believe that there will be resonances for other women who have an intellectual disability in the western world.

The global movement of deinstitutionalisation, community integration and mainstreaming involved:

gradually creeping away from the isolated schools, asylums and colonies of old ... carrying with it too the hope ... that knocking down the material (spatial) barriers between intellectually disabled people and mainstream society would also result in the dismantling of immaterial (social) barriers. (Philo & Metzel 2005, 82)

Thirty years on it would seem that while people are 'living and working *in* the community ... they may not necessarily feel part of the community' (Hall and Kearns 2001, 240). Hall and Kearns suggest that deinstitutionalisation has resulted in an 'asylum without walls' (2001, 237). While people who have an intellectual disability are more physically present in society than they were 30 years ago, they often remain 'socially isolated and largely invisible' (Hall and Kearns 2001, 240). Smith agrees and draws on personal experience to proclaim that intellectually disabled people 'live at the margins of normative landscapes ... found only at disciplined

borders' (2005, 87–88). He argues that, despite deinstitutionalisation and the global disability movement, 'large numbers of them remain in segregated communities . . . they have not been *socially* included: instead there is an "illusion of inclusion"' (Metzel and Walker 2001 in Smith 2005, 88). This is disappointing to say the least; but what does this actually mean to people who have an intellectual disability. How do they experience this so-called illusion?

Towards an inclusive research methodology?

You go to these meeting and you have all these 'normal' people standing up and talking about us as if we are not there. (Lara)

Research *on* the lived-experiences of people with an intellectual disability, let alone research *with* them, is limited. In the scholarly literature we hear little from their point of view, about pain, loss, pleasure, frustration (Hall and Kearns 2001, 241) love or humour. Of particular relevance here is that people who have a disability are generally 'under-recognised in studies on social exclusion' (Susinos 2007, 18); their voices are also under-represented in scholarly journals, with few notable exceptions (see, for example, Dotson, Stinson, and Christian 2003; Hall 2004; Susinos 2007; McVilley et al. 2006). Here we seek, albeit in a small way, to add to the growing body of knowledge (see, for example, Welsby 2010; Roets, Reinaart, and Van Hove 2008; Roets and Van Hove 2003; Atkinson, McCarthy, and Walmsley 2000) of the everyday experiences of inclusion/exclusion experienced by women who have an intellectual disability. In so doing we explore notions of inclusion/exclusion from their point of view *and* include them in the research process and to some extent in this article as they speak, at times, alongside us. As authors, however, we acknowledge that our voices and interpretations are dominant as we hold authorial power. Even though we have included the words of the women in this article, it is us – Janette and Debbie – who have written this article.

Historically, people who have an intellectual disability have often not been asked for their thoughts, feelings or experiences. Much of the resultant silence has meant that people who have an intellectual disability have not been seen as competent, reliable or trustworthy research participants. This has meant that research has been done *about* them often from a parent, professional or advocate perspective (for a fuller critique, see Grundy, McGinn, and Pollon 2005; Oliver 1992; Rambo Ronai 1996). While it is encouraging to note the current move towards non-disablist, inclusive research practices (see, for example, Bjornsdóttir and Svendsdóttir 2008; Susinos 2007; McVilley et al. 2006; Grundy, McGinn, and Pollon 2005; Hall 2004; Walmsley and Johnson 2003), historical practices still mean that people with an intellectual disability have seldom been seen as full subjects in their own lives.

Our desire in the research discussed here was to find a way to enable five women, who identified as having an intellectual disability, to tell us about their lives. To tell us what was important to them, in their own words, and engage them as experts of their own experiences (McVilley et al. 2006). We wanted to listen to the voices of people rendered invisible (Hall and Kearns 2001) and tap into 'the knowledge and experiences of peoples engagement with places and spaces – their everyday lifeworlds' (Dyck 1995 in Hall and Kearns 2001, 234). This is not without challenges. Not all social actors find the more usual forms of interviews

and oral histories the best way to tell their stories (see McCarthy 1998; Maynard 2002). This may be the result of never having been asked, and therefore not having the chance to develop the skills. And, sometimes it is physically and intellectually challenging for people to say what matters to them and why. As such, interviews can fall short of enabling multiple voices in society to be heard. Interviews privilege the spoken word, and with it those who are able to speak in a particular way. However, making use of multiple textual forms can enable people to speak for themselves, defining their lives in their own words.

Our particular interest here is developing understandings about the process of social exclusion from people who experience exclusionary practices, in their own words, 'to understand what does and does not matter to them and why' (McCarthy 1998, 571). Susinos adopted a biographical narrative research model in her search to understand just this, as it allowed her to 'analyse social exclusion from the view point of the main actors' (2007, 117). However, recognising the potential limitations of relying solely on narrative-based interviews, we developed a creative arts-based research format, not to do art therapy but to use artistic processes to create discursive spaces that would enable the women to speak if and how they wanted (see Welsby 2010 for more detail on the arts-based process).

Method

I live with my partner we've been together for about 8 years. I have one son and two grandchildren who call me Nana. I take my grandchildren for the weekend every fortnight. They can be a bit of a handful but I love having them. I'm the eldest, Mum and Dad are still alive and I have two brothers and two sisters. It was hard being the eldest; you always had to set an example. (Lara)

The five women in this research, aged between 28 and 52, lived in the suburbs of Sydney, were receiving a Disability Support Pension and worked part-time in either the Business Services Sector² or open employment. Two of the women lived in supported accommodation, one lived with her parents and the remaining two lived independently in the community.

A series of five workshops were held fortnightly and were co-facilitated by an experienced art teacher. Participants were provided with a range of different art mediums and techniques that they could choose to work with. The aim was to provide as open a space as possible where each woman could exercise some level of choice and self-determination. Themes, including work, friendship, identity and everyday life, were suggested by the women at the first workshop and informed the art-making. Between workshops, one-to-one semi-structured interviews were conducted. The interviews took place where the participants chose, usually in a coffee shop. The interviews lasted approximately one hour. Field notes, photographs and transcripts of interviews served as data, which were thematically analysed in a data-driven process that enabled themes to emerge. The artworks were not primary data. Instead, art-making was the vehicle for the women to tell stories about their lives.

The workshops were successful in enabling women to speak. While working on individual works, around a large table, stories were shared and discussed and the conversation flowed from topic to topic, creating a sort of collaborative introspection that stimulated individual storytelling and the sharing of experiences.

The following excerpt demonstrates this sharing of experiences and curiosity about each other's lives:

- Shirley: How's the line dancing going?
 Cindy: It's good I really enjoy it. How's TAFE?
 Kay: Terms finished now. Just waiting on my results.
 Lara: How do you think you went?
 Kay: Good. I'm sure I passed.

Like Judith Davidson, we found that producing artwork did enable the women to 'organise their thoughts so that in describing their drawings (or other artworks) they can elaborate on their ideas to an extent that they could not have done without an opportunity to present the idea visually' (Davidson 2004, 60).

The one-to-one interviews, held between workshops, were used to clarify things said in workshops and/or to check that it was alright to use the material in the research. They were also used if a participant was unable to attend a particular workshop. The interviews were not very successful in generating conversations or enabling the women to speak freely even though open-ended questions were used: 'what is one thing you like about work?' and 'what do you do before morning tea?' often elicited 'nothing' or 'no' as answers.

Research ethics

The research was approved by the University of Western Sydney Ethics Committee. All participants were provided with a plain language statement about the research and signed informed consent forms. The plain language statement was written in consultation with the local disability rights service, who gave advice on wording, layout and fonts. Three of the women elected to have a support person or carer present during this initial process, to explain what they were agreeing to. The other two women considered themselves independent and did not have any other support involved.

A potential concern with the style of research design employed here is that the relaxed atmosphere and the smallness of the group could put the participants at ease and potentially off guard. This may have resulted in the women saying more than they would in a formal interview or focus group. This is of particular concern for women who, at times, saw the process not as research but more like friends talking around a table: '[t]his is nothing like the research I did before; they just asked me lots of questions. This is a lot more fun and you get to meet new people' (Lara). To address this, informed consent became a continual negotiated process at the beginning of each workshop and interview (see Konza 2005). For example, at the beginning of each workshop and interview, the women were reminded that this was a research project and they were asked what *they* wished to talk about. Interestingly this became a point of contention for two of the women, one of whom said 'We're not stupid we've already done this every time'. The workshops were not audio-recorded; rather, field notes were written immediately after the workshop. These notes recorded statements, conversations and experiences directly related to the negotiated theme of the day. This, we believe, helped to work against more private conversations being recorded for our later view. The interviews were audio-recorded, but this was not seen as especially problematic; in a one-to-one session,

the recorder is more obvious – on the table between two people – and the interviewer asks the individual for permission to turn it on, thus drawing attention, again, to the research nature of the conversation.

The women's experiences of inclusion/exclusion

While many issues such as love, loss, work, friendship, home, popular culture, cooking, family and art-making were discussed, for the purposes of this article we focus on the theme of exclusion/inclusion that emerged through a thematic interpretation of the data. While exclusion/inclusion is our naming of the theme, the theme itself stood out throughout the field notes and interview transcripts. The women talked of this theme in the language of rights: for example, 'it's my right to see my friends' and then they would speak of how this was difficult as they could not use public transport and their carer would not always drive them.

The women were included as workers, as people who live in houses, people who consume goods, people who have friends, families, lovers and people who have an emotional life. However, the extent and quality of inclusion is questionable. These women were subject to many practices of exclusion, which sometimes seemed deliberate. These practices are historical, economic and/or due to inequities of power and privilege. The women in this study were aware of many of these practices, critiqued them, offered strategies for change and even made jokes about them.

Working to live

Unsurprisingly, people with an intellectual disability have similar reasons for seeking and valuing work and wages as non-disabled people in the community: 'You work to get money. If you don't have any how can you live?' (Kaye). For the women in this study, the primary benefit for working was to earn money to cover their day-to-day living cost. However, people who have a disability are more likely than non-disabled people to be employed in part-time work, with their main source of income coming from government pensions and allowances (Australian Bureau of Statistics. 2004, 3–5). Women with disabilities are usually employed part-time in general clerical work and the service sector earning considerably less than their non-disabled equivalents (Baldwin 1999, 17). As such, for the women in this study, poverty was their 'close companion' (Community Affairs References Committee. 2003, 363).

Working in open employment, Kaye and Lara were in a position to increase their incomes, make choices and be more involved in community life. However, neither of them earns enough to be able to live without the Disability Support Pension. Lara, who was highly skilled in the disability sector as an advocate, auditor, and trainer, did not think she would be able to find full-time employment that provided her with the level of income she would need if she no longer received the Disability Support Pension. Although the women in this study were long-term employees, none of them had worked in, or been offered, full-time positions. None of them had ever been promoted. The very nature of being excluded from full-time work effectively keeps these women financially poor. For Shirley, Cindy and Jill, who worked in Business Services, their estimated level of income at the time of this study was under the minimum Australian wage (Centrelink. 2007).³

Practices of exclusion at work

The women employed in Business Services worked for approximately \$3.20 per hour. They worked in a closed environment with little chance of advancement beyond the assembly line. Shirley, Cindy and Jill's daily routine of packing products into boxes or plastic bags is typical of the light manual work that has been the historical basis of employment for many people with intellectual disabilities:

I had to leave that place. It was horrible. So boring just putting things in bags every day. I would go mad if I had to stay there. It was hard I was a good worker so they didn't want me to go. (Kaye)

One of the functions of Business Services is to support employees to learn skills that will help them to be included in the open employment market, although this does not appear to be monitored in Australia. Working in Business Services rarely leads to work in open employment (Bray 2003; Olney and Kennedy 2001). The push to become commercially viable has resulted in managers and supervisors often being 'reluctant to lose their 'best' workers' (Hyde 1998, 209), resulting in many people with a disability being discouraged from moving elsewhere as can be seen in Kaye's comment above.

It clearly does not need to be this way. Lara and Kaye both heard of their current positions in open employment through word of mouth. Being actively included in the community outside their workplace helped them move and find more satisfying work. Kaye was a volunteer in a programme called Community Voices, which involved going to speak to people in the community about having an intellectual disability:

We went to different places to talk to people about our community work. We use the voice it is the main thing the voices. It is the voice. I tell them about our organisation. My part of intellectual disability you know how I feel. They find someone with a disability and go up and talk. They go to training . . . for community voices. They tell me how to talk that's how I started and then I go to different organisations and talk. I've been to schools, uni and different associations like the Chinese Association. (Kaye)

It was through this work that Kaye heard about the position of an Administration Assistant. She applied and was successful. Just after Kaye started at her new position she used the services of another self-advocacy office to support her to construct a plan so she could move closer to work, study at Technical and Further Education College (TAFE) and live independently.

We found a marked difference between the women who worked in Business Services and those who worked in open employment. Kaye self-manages her working day, using a computer diary as a tool to list, prioritise and forward-plan any tasks that she is required to complete, and therefore the intervention from Kaye's supervisor is minimal. Kaye is actively included in staff meetings and is treated as part of a team. As a result, Kaye felt a valued member of staff and was proud of the new skills she had learnt and the challenges the job presented.

Kaye's working environment supported her to evaluate her skills, recognise her limits, set and attain goals, accept responsibility, communicate her preferences and needs, and then monitor and evaluate her progress. If she is unable to get through her workload and has any difficulties in prioritising work, she speaks with her

supervisor: 'If there are any problems I bring them up at the staff meeting or I speak to my boss' (Kaye). This has a flow on effect into other areas of her life where Kaye has to make choices and decisions. Being in open employment also means the opportunity of a career path, something the women were excluded from in Business Services. None of the women could remember an immediate supervisor or manager in Business Services having a physical or intellectual disability. This can mean that opportunities for a career path or any sort of advancement are non-existent. Although Lara had become a state delegate for the Miscellaneous Workers Union while working in Business Services, she was never given the opportunity for advancement from the workshop floor: 'I would really like to be a supervisor. I think I would be good at it. . . It is really important for people with an intellectual disability to have role models' (Lara).

Cindy, Shirley and Jill's stories demonstrate exclusion from meaningful, well-paid work with any chance of advancement, or movement to another employer. The culture and practices of their workplaces creates dependency and lack of self-autonomy (Kilsby and Beyer 2002, 125). Their day begins as they sit down at a work table waiting to be given work; the routine is rigidly structured from there. Their workplaces appear to have strictly monitored practices of control. Some of these seemed nominally related to occupational health and safety:

Last week I wore my new sandals to work and they sent me home. Can you believe it there is no work but they sent me home anyway because it is against Occupational Health and Safety to wear open toe shoes in the warehouse. It's silly we weren't doing any work I was only going to be sitting and reading a book all day. (Jill)

Others were seemingly related to productivity:

We get shouted at a lot for talking at work even when there is no work we have to sit quietly. (Cindy)

Even the big boss shouts at us. We are always being shouted at for going too slow or making a mistake or talking. Shhhhhh. (Jill)

When talking about work, one woman said: 'my dream is to work with children. I told my supervisor a long time ago that I want to find another job. I have to be patient and wait until they sort something out'. She had expressed her desire to change jobs to people in her workplace and her accommodation provider but that was a while ago. The women in the research group encouraged her to get help, suggesting strategies such as using advocacy services. However, the woman told us that getting help from an advocacy agency to move jobs is fraught. As she is required to ask permission to use her home phone, she may, or may not, be allowed to contact the advocacy agency. If she was able to contact an advocacy agency she would be unable to get to their offices as she has to rely on her carer for transport. While it is unknown whether her carer would, or would not, take her, we do know that the accommodation agency was aware of her desire to change jobs. During this research there were no steps taken by her support agency to help her in changing her workplace. In fact, a staff member of the accommodation support service said: 'she does really like working where she does, she just says that because there is no work there at the moment'. One of these moments lasted for the 12 weeks of field work!

Consuming as a practice of inclusion

Living on an extremely limited income, with little chance of advancement, means that many of the things that non-disabled people take for granted – such as meeting friends for coffee, having takeaway, buying lunch and going to the movies, shopping in a variety of shops not just discount stores, being able to take purchases home and not putting them on lay-by – are often out of their reach. However, it was in their role as consumers that these women were included, albeit in a restricted way, in day-to-day living. The following conversation could be any five women catching up with each other:

Jill: I'm going Christmas shopping on Thursday.

Lara: Do you have a lot to get?

Jill: No not much.

Shirley: I love shopping.

Cindy: Clothes shopping is my thing.

Lara: Me too.

Kaye: Shoes.

Shirley: Music and lipstick.

The women had clear ideas on how they liked to spend their income: 'my thing is clothes I love to go clothes shopping' (Jill). Some saved or used lay-by for purchasing large items such as jewellery, holidays, Christmas presents or household items: 'I like to buy jewellery. At the moment I have a green emerald and diamond ring on Lay-by. I pay a small amount off each payday' (Lara).

The women also worked to provide a routine and rhythm in their lives and to meet some of their social needs. Work also had an impact on their identity and their self esteem: 'I don't work just for money. It's the only way I get to see my friends' (Cindy). Meeting people and interacting with co-workers is an important reason for going to work (Robinson and Fitzgerald 2001, 75). All of the women enjoyed good humour, lunch-time conversations and birthday celebrations.

Anger: an excluded emotion

Despite her best efforts Jill, who lived in supported community accommodation, had been ignored by the man who lives next door to her for the two years that she has lived in the street. When Jill says hello or waves, the neighbour stops what he is doing and goes inside until she has gone. Rather than being offended Jill sees his behaviour as a source of humour and enjoys taunting him by saying a friendly hello and waving whenever she sees him, just to watch him run inside. When asked whether they get angry or upset by the practices of others, the women replied that although sometimes they did get angry they usually laughed it off:

Well you have to laugh it off especially if you live in supported accommodation if they do get angry and someone complains they are more than likely to get stuck in anger management classes. It's Ok for 'normal people' to be as rude as you like but it is not OK for people with an intellectual disability to get angry. (Lara)

On reflection, even asking if they got angry was naive. It seems anger is an emotional response purposively excluded from people's repertoire. For example:

I went to get an identity card at the RTA.⁴ We waited in line for $\frac{3}{4}$ hour and then when our number was called we found out that they don't do that there any more. I was so angry. I hit the roof. I couldn't believe it. It's so frustrating. (Cindy)

This experience resulted in Cindy being placed back into anger management classes. Her carer felt it was unacceptable for her to lose her temper and shout at the person behind the counter. Cindy, who was 28, had wanted to go dancing at the local night club with her friends but was unable to do so as she did not have proof that she was over the age of 18. For Cindy it was not a simple matter of getting the forms and filling them out as she has difficulties with reading (in particular, small print) and writing. She had to rely on her carer to fill any forms out on her behalf. This meant that a number of months passed between the time her carer obtained the forms from the RTA, her parents posting her birth certificate to her, the forms being completed and, finally, when her carer was able to take her to the RTA to get the Photo Identification Card. Then, after waiting nearly an hour to speak to someone she was told that she was not able to get the card. On hearing this, Cindy became angry and upset. For some of us this may seem an understandable reaction. For Cindy, with her history of 'challenging behaviours', getting frustrated and losing her temper meant she was again placed in behaviour management classes.

For Cindy, being sent back to her parents, who were abusive, was a constant threat. Although Lara, who worked as an advocate, explained that the organisation running her supported accommodation had a duty of care and could not knowingly send her back into a dangerous situation, Cindy nevertheless lived in fear:

If I lose my temper or don't do as I'm told one too many times they'll tell me to go. What can I do? I know I have rights but I have nowhere to go but home and I can't go back there. I have to be careful and do what I'm told whether I like it or not. I have no choice. (Cindy)

Whether the threat of being sent back to live with her parents was true, imagined or implied is immaterial. Cindy was genuinely fearful of her situation and of her carer. The women did share strategies they used for dealing with frustrating situations such as this one below:

- Lara: Often when you tell someone you have an intellectual disability their attitude changes.
- Kaye: Yeh DOCS⁵ they're the worse.
- Lara: And Centrelink.⁶ I have to go there for work. Oh you only tell them if you have to. Normally they start shouting at you and speaking really ... really ... slowly.
- Kaye: I get that all the time even in shops.
- Lara: Depending on what you need and how I'm feeling. I tell them there is no need to shout! I am not deaf. I only have an intellectual disability.
- Shirley: That's a good one I'll have to remember that.
- Lara: Well it's true. There's no need to shout and talk to us like we're children. We're not stupid.

Maintaining social relationships

Maintaining relationships was another aspect of these women's lives that was not simple. On the last day of the workshops, Lara asked whether the women would like to stay in touch as she wanted to continue with the friendships she had formed.

However, Cindy and Jill had a house rule that they were not allowed to give out their telephone numbers without prior approval from their carers. When Shirley commented that 'we're friends so why can't I call you?', Cindy replied 'we're not allowed to give out our telephone numbers to anyone except family'.⁷ Jill elaborated by saying 'our carers don't know who people are, so you can't give out your address or phone numbers to anyone'. Speaking about his later, Jill was asked how she stays in touch with her friends if she is not allowed to use the telephone. She replied 'well I couldn't say anything in front of Cindy but I just tell people to call after 8 by that time D ... has gone home!' All of the women in the study discussed how important friendships were to them. Cindy enjoys speaking with people and is often in trouble where she works: 'I'm always in trouble for talking but it's the only time I get to see my friends'. Talking is discouraged, with Cindy often being told throughout the day to be quiet by her supervisors. With little chance for socialising outside working hours, for Cindy work was an integral part of 'catching up' and a way to spend time with her friends.

Both Jill and Cindy relied on their carers for transport and taxis to travel to and from work. Public transport is limited in the suburb where Jill lives so she relies on the goodwill of her carer for transport to social outings, appointments and shopping. While Cindy lives on a major public transport route she still has to rely on her carer for transport. She is not allowed to catch public transport due to the notion of perceived risk. This reliance on carers and always having to ask permission excludes Jill and Cindy from being autonomous, restricting their social movements. For many of us, finding time in our daily lives is the most difficult part of maintaining friendships. We take for granted the ability to jump in a car, catch a taxi, use public transport, a telephone or email, write a letter or invite friends over for dinner. For the five women who took part in this study, this simple, pleasurable activity is fraught with difficulties and barriers to social inclusion.

Cindy and Jill's inclusion in the wider community is also limited as their social activities, such as Friday Night Club, line dancing and craft classes, are run by their accommodation service providers. They live and work in isolation and social exclusion where often the only non-disabled people they come in contact with hold positions of power. The argument that is used as justification for the exclusionary practices experienced by Jill and Cindy is that of safety from potential danger. Clearly the management of risk has become a restrictive barrier to live what is generally perceived to be a 'normal' life. Paradoxically, these types of everyday practices can heighten risk as they do not provide the necessary life experiences for people to learn the skills of character judgement, how to make and maintain friendships, manage money or use public transport. A 'shrinking social world' can leave people with an intellectual disability in a vulnerable position and open to abuse (Dyck in Hall 2004, 302).

Conclusion

Terms such as fringe-dwellers, in the shadows, socially isolated, excluded and marginalised are terms often used by academics, policy-makers and community workers when describing the lives of people with an intellectual disability. Through the artwork and stories the women told in this research, we saw many ways in which everyday social practices do exclude them, keeping them at the social margins. This was especially true at work, in developing and maintaining friendships

and having an emotional life. Some of these practices we have highlighted here using the words of the women themselves. However, this is only one truth. The women in this study did not define their lives in these terms; instead, they defined themselves by who they were and what they did – as mothers, sisters, workers, dancers, singers, friends, aunties, lovers, girlfriends. Furthermore, they were not passive recipients of practices that exclude. Instead we found that they actively resisted using humour and advocacy. Perhaps further research where the ‘priority is social change and barrier removal’ (Shakespeare and Watson 2002, 15) could help to further identify how people who have an intellectual disability are already working against being excluded and develop strategies to include and strengthen these practices in the future.

Notes

1. Research participant’s names have been changed to protect confidentiality.
2. Previously known as Sheltered Workshops.
3. In fact, the income level of Australian’s who have a disability is one of the lowest in the Organisation for Economic Co-operation and Development countries (Human Rights and Equal Opportunity Commission 2005).
4. The Roads and Traffic Authority (RTA) is the government body that regulates drivers licenses in New South Wales.
5. The Department of Community Services (DOCS) is a state-based government organisation.
6. Centrelink is part of the Federal (National) Department of Human Services. It administers government social security payments to individuals. It also assists people in finding work.
7. Ironic, as Cindy’s family were abusive and she was fearful of them.

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