

Mediating Community Participation: Practice of Support Workers in Initiating, Facilitating or Disrupting Encounters between People with and without Intellectual Disability^s

Christine Bigby* and Ilan Wiesel†

*Living with Disability Research Centre, La Trobe University, Vic, Australia; †City Futures, University of New South Wales, NSW, Australia

Accepted for publication 7 November 2014

Promoting community participation for people with intellectual disability through encounter with strangers is an integral part of the mission of disability support workers. This paper offers detailed micro-level analysis of the practices of support workers when they accompany a person with intellectual disability outside their home and explores the subtle differences which make some staff practices more effective than others in promoting more convivial encounters with strangers. Based on 160 h of observations of twenty-six adults with intellectual disability in a variety of public places,

and interviews and focus groups with their support workers, the paper points to some of the critical judgements support workers need to make when considering whether, when and how to initiate or intervene in such encounters.

Keywords: community participation, encounter, people with intellectual disability, social inclusion, support workers practice

Introduction

Social inclusion has been an important strand of disability policy in many Western countries since the 1980s. For people with intellectual disability, it has been envisioned in a broadly similar manner as participation in community life. In Australia for example, the 1986 Disability Services Act aimed to assist people with disability 'to live as valued and participating members of the community'. Similarly, an objective of the reformed Australian disability service system is to 'support the independence and social and economic participation of people with disability' (National Disability Insurance Scheme Act 2013). These visions reflect the principle of 'full and effective participation and inclusion in society'

of people with disabilities (United Nations 2006) that countries which are signatories to the United National Convention on the Rights of Persons with Disability are committed to enacting.

The ill-defined nature of both social inclusion and community participation for people with intellectual disability (Levitas 2005) is evident from the absence of consistent frameworks and methods of measurements in the empirical research (Verdonschot *et al.* 2009). One of the most commonly used frameworks has been O'Brien and Lyle's (1987) distinction between 'community presence', the use of facilities in the community available to everyone and 'community participation', being part of a growing network of relationships that includes people with and without intellectual disability (Clement & Bigby 2009; Kozma *et al.* 2009).

Little progress has been made in Australia and other Western countries in achieving community participation as defined by O'Brien (1987). Many of the early research findings that show despite greater community presence,

^sCorrection added on 27 January 2015, after first online publication: Ilan Wiesel's name was incorrectly placed at the affiliation section and this has now been corrected in this version.

people with intellectual disability 'often remain socially outside looking in', remain salient (Myers *et al.* 1998, p 393; Gray *et al.* 2014; Verdonchot *et al.* 2009). Person-centred planning processes that were the centrepiece of UK disability policy reform in the early 2000s have had limited success in extending the social networks of people with intellectual disability to include those without disability (Robertson *et al.* 2007). The skills, motivation and priorities of front-line support workers are perceived as important factors influencing the participation of service users (McConkey & Collins 2010). Conversely, poor staff practices, inadequate training or supervision and staff misinterpretation of policy aims are identified as reasons for the failure to move beyond community presence (Bigby *et al.* 2009; Clement & Bigby 2009; Craig & Bigby 2014; Walker 1999).

Aside from person-centred active support (Mansell & Beadle-Brown 2012), which is often wrongly interpreted as most relevant to participation within the home, little research has focussed on the staff skills, or the elements and strategies that disability services need to deploy to effectively enable people with intellectual disability to participate in the community (Dusseljee *et al.* 2011; McConkey & Collins 2010). Some evidence does suggest that research into these factors is beginning to gain traction, particularly in respect of planning for participation and inclusion in community groups (Zakrazsek *et al.* 2014; McConkey & Collins 2010; Craig and Bigby 2014; Bigby *et al.* 2014).

Very little is known about the nature of community presence: how people with intellectual disability are present in public places and what exists along the continuum from presence and participation or the potential for presence to be a catalyst for building social relationships (Todd 2000). In a rare and early study, Saxby *et al.* (1986) used structured observations to explore use of public places, such as cafes, by people with severe and profound intellectual disability. They found that many participants with intellectual disability engaged in the substantive activities of those places and interacted with people there, albeit at a very low level (on average <1 min in a 45-min period). Todd's (2000) ethnographic study of excursions of special school children into the community drew attention to the way staff actions facilitated or limited contact between students and members of the public. In mediating contact and managing tensions when students fractured taken for granted rules of social interaction, the work of staff was likened to that of tour guides, acting as 'danger minimizing mediators, policing the boundaries

between groups' (Todd 2000, p 616). He found too that staff preferred to take students to familiar places where they would be recognized, and members of the public were less likely to melt away as they arrived or become the audience for students' rule transgressions.

More recently, a survey study of three Melbourne suburbs and a regional town found that many community members were aware of the presence of people with intellectual disability in places such as shopping centres and cafes (Wiesel & Bigby 2014). Some described deliberately acknowledging the presence of a person with intellectual disability by engaging in positive interactions such as smiling, opening a conversation or offering assistance. Examples were also described where repeated contact between community members and an individual with intellectual disability in public places had led to the person becoming known by name and a member of a loose social network of acquaintances. Significantly, the study found that community members were often unsure how to interact with people with intellectual disability, felt constrained by the presence of staff or worried they would cause embarrassment or not know how to disengage.

Developing ways to effectively support participation of people with intellectual disability and identifying necessary staff skills can be informed by reframing the long-standing binary of community presence and participation. Bigby & Wiesel (2011) suggest the concept of 'encounter' from urban studies (Fincher & Iveson 2008; Valentine 2008), as a different way of thinking about interactions between people with and without intellectual disability in the community, and understanding how to advance social inclusion. Encounter refers to social interactions between strangers in public places, which consist of fleeting contact or longer and more convivial moments where a common purpose is shared. These are neither simply anonymous free mingling (usually seen as community presence), nor interaction based on established relationships (usually seen as community participation). Jacobs 1962 suggested that although each encounter may count for little, the sum form an important dimension of a person's social life. A small pilot study using unstructured observations to explore the encounters of five people with intellectual disability identified fleeting encounters and service transactions, some of which had moments of conviviality. Also, observed were more negative exclusionary encounters, those that were unfulfilled – almost occurring but not quite, and encounters that happened in a 'distinct social space' with other people with intellectual disability and their support workers (Wiesel *et al.* 2013).

Fleeting encounters and service transactions may be an important aspect of social inclusion, for two reasons. Firstly, such contact provides people with intellectual disability the opportunity to become known to others in their community and to form new relationships. Indeed, the first step in every friendship is an encounter between strangers. Secondly, contact with strangers, even when it does not lead into lasting relationships, can be seen as a meaningful everyday activity through which people experience moments of conviviality, recognition, affirmation and a sense of belonging, all of which can be understood as important aspects of social inclusion. Promoting encounter with strangers can therefore been seen as an integral part of the mission of disability services and the support workers they employ.

Using the concept of encounter, this study aimed to explore the practices of support workers when they accompany a person with intellectual disability outside their home, and identify the subtle differences which make some staff practices more effective than others in promoting fleeting or convivial encounter between people with and without intellectual disability.

Methods

The study was exploratory and descriptive. The primary method of data collection was unstructured observations of people with intellectual disability and their support workers in a variety of community settings. This differed from approaches that have used interviews with people with intellectual disability to capture first-hand accounts of encounter (Abbott & McConkey 2006; Hall 2005) or interviews with community members to gain their experiences of encounter with people with intellectual disability (Wiesel & Bigby 2014).

Recruitment and participants

Participants were twenty-six adults with intellectual disability, twenty of whom were male, and their support staff. They were recruited from the two disability service organizations that were the Industry Partners for an Australian Research Council Linkage grant. Two of the participants lived in a cluster of independent living units, and the rest in six group homes which were spread across three localities in metropolitan Melbourne and a regional town in Victoria. Participants were aged between 20 and 65 years. Information about their intellectual disability was collected from their support workers. Several

participants were described as having mild intellectual disability, good communication skills, able to carry out most activities within and outside their home independently and requiring only limited support for activities such as money management, banking and managing relationships. Other participants were described as having a moderate intellectual disability, significant difficulties with communication and requiring active support for most activities. Five participants, who all lived in the same group home, were described as having 'challenging behaviours'.

Ethical approval was given by the human research ethics committee of the two universities involved in the study, and informed consent was gained by each participant or where necessary the person who normally made decisions on their behalf. Data were collected by the second author and an experienced researcher, who joined participants when they went out into the community and observed their interactions with strangers, members of the public, shop assistants or other business proprietors. Participants with intellectual disability and their support workers were aware of the observer's role, who following at some distance attempted to remain uninvolved with the participant or those they encountered. As support workers may have modified their conduct in response to being observed – that is the Hawthorn effect (Sanders 2009) – the data are perhaps best interpreted as reflecting support workers' conscious attempts to achieve best practice, as well as some of their more habitual practices. It is likely, however, that after many hours of observations, support workers would have become more accustomed and less conscious to the presence of the observer. In most situations, the strangers encountered were not informed of the role of the observer and would most likely have thought the researcher was a support worker or an unrelated passer-by. Observations were unstructured, and qualitative descriptive fieldnotes, written during the observation or as soon as possible after, were used to record details of all interactions between participants and strangers as well as the actions and interaction of staff with participants and strangers. Over 160 h of observations took place between 2010 and 2013 in various types of places and venues around the localities where participants lived.

Concerns about the credibility and reliability of observers' interpretations in ethnographic research have been well documented in the social sciences (LeCompte & Goetz 1982). The interpretations of an observer inevitably represent only their own unique and narrow perspective, and the very specific physical, social and

interpersonal contexts within which data were gathered. One strategy commonly used by ethnographers to strengthen the internal and external validity of observations is to 'enlist the aid of local informants to confirm that what the observer has seen and recorded is being viewed identically and consistently by both subjects and researcher' (LeCompte & Goetz 1982, p. 42). Following this approach, we conducted one-on-one interviews with the seven front-line managers of participants' supported accommodation and held a focus group with a group of support workers in each locality. At the focus groups, snapshots of the observation data were presented and support staff were given the opportunity to validate or challenge the observers' and authors' interpretation. To limit the scope of the paper, we have not included detailed analysis of the interviews and focus groups themselves.

The fieldnotes from the qualitative observation and interview transcriptions were analysed using Nvivo software (QSR International Pty. Ltd. Version 9, 2010). All notes and transcriptions were coded thematically, using 36 different codes. The findings presented in this paper derive primarily from analysis of 207 records coded under the general theme 'support'. These transcripts were categorized under subthemes which correspond with the structure of this paper: initiation of encounter, facilitation of encounter and prevention or obstruction of encounter. Our interpretation of these observation transcripts forms the core of this paper. The observation transcripts themselves are presented in detail, allowing readers to critically judge our interpretation and consider alternative interpretations of their own. All identifying information for participants and localities has been removed, and data extracts are identified by a code that denotes the source as an interview or observation and the initial of the location (thus OB would be observation in location B).

Findings

The observations reflected the findings from the pilot study (Wiesel *et al.* 2013) about the different types of encounter people with intellectual disability experience in the community. We report here on the encounters that were fleeting in the different types of public places that people with intellectual disability are present in, such as parks, shopping malls or pubs, or that were part of service transactions in commercial premises such as café's and supermarkets. Many of these encounters involved moments of conviviality between the person with intellectual disability and a stranger. The practices

of support workers in these encounters fell into three broad categories: initiating, maintaining or disrupting encounters. Each of these and the accompanying strategies used by support workers are described in the sections below.

Initiating encounter

Disability support workers actively initiated encounters between people with intellectual disability and strangers in public places. They used a variety of strategies to prompt strangers to interact with a person with intellectual disability or to include them in a conversation that was already occurring; a direct introduction or the more subtle use of gesture or eye contact. In this fieldnote for example, the support worker introduces Larry by name to the shop assistant encouraging him to enter into a conversation that Larry does not know how to continue.

At the counter Larry says hello to the young male shop assistant, who smiles back and tells him how much the coke is. Larry hesitates as if waiting for more conversation, so the support worker steps forward and introduces Larry. The shop assistant shakes Larry's hand and says pleased to meet you. (OB)

In addition to this type of active initiation of encounter, some support workers created an atmosphere that invited strangers using the public space to become involved in an activity or conversation that was happening between the support worker and the person with intellectual disability. In the interview below, for example, a support worker describes how she and the person with intellectual disability she was supporting both created a mood of humour at a supermarket checkout. In doing so, they effectively drew the women standing behind them in the queue into an encounter. She said,

Often, people just smile... because they've seen something normal, and fun. ...I was loading and he [person with intellectual disability] was putting the stuff on [the conveyor belt], and we were just mucking around, but he said 'Salmon!', And I said: 'Yes, but that's for me'; and then he went: 'Drink!', and I went: 'But that's for me', (laughter), and he goes: 'How come you get all the good stuff?'. I noticed that the lady behind him was just smiling, and thought it was fantastic, so of course as he

turned and she was smiling, so he then started talking to her... and then she asked him a question about who was I, and he went: 'Oh, she's my supervisor', and I went: 'Slash/mother, dragon-lady/counsellor/sister', ...there was a joy, and then when we finished, he just gave her this beautiful smile. (IC)

Similarly, the fieldnote below describes a situation in a pub where the support worker is playing a poker machine with a person with intellectual disability, and creates an atmosphere of fun around them, that generated an audience who were subtly invited to join in the excitement of the game.

The game is very monotonous, but the support worker tries to liven it up by narrating the game: 'that was a close one!' He's teasing Eugene whenever Eugene tries to 'steal' a turn in pushing the buttons. When their credit is nearly finished, they suddenly win close to \$20 credit, and when the new credit is nearly gone, they manage another win that raises their credit to over \$70. They're both very excited as the game proceeds, and their excitement seems to attract a small crowd ... An unrelated old man stands about a meter away from the support worker and Eugene, following the game with obvious interest but without any comment. (OS)

In addition to trying to influence the actions of strangers, support workers sometimes prompted people with intellectual disability to initiate encounter. This was most common in commercial premises where they encouraged a person with intellectual disability to conduct a transaction such as ordering food or drink or paying for an item, as illustrated in this supermarket example.

They then go off to find the spaghetti. They can't seem to find it ... Gavin, at support worker's urging, initiates the conversation with the supermarket staff member. Gavin is able to make himself understood, and the staff member tells him that the pasta has been moved so she will have to go look for them. (OS)

Attempts to initiate an encounter were not always successful, relying on the willingness of those who are likely to be involved. As the example below shows, Mark was invited but unwilling to join a conversation initiated by the support worker with children in a park.

The support worker and Mark approach a piece of equipment that two children are on. They don't move away and interact easily with the support worker. Mark stands off and cannot be coaxed to be involved even though the support worker directs some comments to him in an effort to include him in the conversation.

Facilitating encounter

Once an encounter had begun, support workers can play an important role in enabling its continuation and effective management by the person with intellectual disability. The tactics of 'encounter support' varied from a 'hands-off' approach where support workers played a relatively passive role, to 'hands-on' interventions where they were actively involved in shaping the interaction.

Hands off – passive presence, monitoring and reassurance

Support workers did not always actively intervene but in some cases stood back and simply kept an eye on an encounter. It appeared, however, that their presence helped to allay concerns that strangers had about interacting with a person with intellectual disability whose behaviour was 'different' or risked being interpreted as threatening or inappropriate. This is illustrated in the fieldnote below, where the presence of a support worker 'reassured' a stranger that it was safe to interact with Larry.

Larry stops [a female stranger] by standing in front of her. He asks her for her birthday then for her age. She is very uncomfortable and looks around for help. The support worker steps forward, letting her know (non-verbally) that he is there. She relaxes a little, and answers Larry's questions briefly. He tried to shake hands. She does so very briefly, then leaves abruptly. (OW)

Interpreting actions

Support workers intervened directly in an encounter when they perceived it necessary to act as an 'interpreter' to assist a person with intellectual disability and a stranger with whom they were interacting to better understand each other's words, gestures or actions. This could be rephrasing to make comments more understandable or translating behaviour or actions

into words to clarify meaning. The fieldnote below illustrates this, as the support worker explains to Leslie the reason for the stranger's behaviour.

We get close to the nursery and a young man walks past. Leslie says hi but the man ignores him. The support worker explains to Leslie that he had 'ear things in his ear' (headphones) and so could not hear him. Leslie accepts this readily, and walks into the nursery. (OW)

More commonly, it was a stranger who turned to the support worker to seek an explanation of the behaviour of a person with intellectual disability, to confirm that they had correctly understood the person or that it was ok for the person to go ahead and do what seemed to be intended. This was particularly the case for financial transactions where shop assistants often did not trust the authority of the person to undertake the transaction independently and sought approval from the support worker as the recognized 'authority'.

Support workers could adopt a more proactive interpretative stance to avoid any misunderstandings of behaviour that might be construed as threatening or unacceptable and could therefore be met with a negative response by a stranger. Interpreting retained the possibility of a positive encounter and appeared to be preferential to attempting to control or prevent what could be seen as unconventional behaviour of people with intellectual disability. This example from a café illustrates a support worker acting as an interpreter to a stranger and enabling an encounter to continue.

While waiting at the café counter, a woman walks past. Peter puts his hand on her arm and she stops and looks at him questioningly. The support worker explains that he wants to roll up her sleeves. The woman makes no comment but allows Peter roll up one of her sleeves. Peter is very happy now and turns back to pick up his glass of water. The woman – who was juggling a tray full of food and drinks in her other arm while Peter rolled up her sleeve – walks away with a smile. (OB)

In the example below, the support worker makes no attempt to prevent Larry from 'borrowing' another person's private property without their permission. Rather, he only interpreted Larry's behaviour, which probably enabled the encounter to continue but perhaps gave too little information or reassurance to the stranger who appeared to be left feeling a little uncomfortable.

As we walk home we come across a park bench where an older couple are seated. The woman has a Fanta bottle with some drink still in it on the bench next to her. Larry approaches the bench and stands in front of the woman. She jumps up looking very frightened and defensive. The support worker explains that it is ok. The woman visibly relaxes when she notices the support worker but she remains very wary and does not speak. Larry holds out his hand for her to shake which she does very reluctantly. Larry picks up the bottle of Fanta and the woman seems at a loss as to what to do. The support worker explains that he will not drink it. However, the woman remains wary. Larry takes the lid off the bottle and reads the numbers under the cap. The support worker tells the woman he just wants to read the numbers but the woman is quite clearly unhappy. Once Larry is finished, he replaces the lid and hands the bottle to the woman. He says bye and walks away. The woman is visibly shaken and takes a seat. She watches Larry until he turns the corner. (OW)

'Educational' interventions

Some interventions aimed to change behaviours of the person with intellectual disability or a stranger. The comments of the front-line manager in the example below illustrate an attempt to 'educate' a member of the public to interact more respectfully.

I noticed that the man serving wanted to take the envelope off her, and I went: 'Please don't do that, Nellie is quite capable of doing this, and loves to do it'... And I think that what struck him was, first he thought that she couldn't do it, so he was coming from that [good] intent. ... but then, when he realised that she could do it, beautifully, and he just gave her a great big smile. (IC)

The fieldnote below describes a support worker using various tactics to shape the behaviours of both the bank teller and the person with a disability, physically positioning himself to encourage them to have direct eye contact, redirecting Daisy's attention to the transaction, and the teller's questions to Daisy:

The Teller asks the support worker for Daisy's identification. The support worker directs the question – pointedly and deliberately – to Daisy.

Daisy has to get her identification from her purse and appears unsure of what she is doing. The support worker prompts her gently. Daisy gets out her identification and hands it to the Teller. The Teller continues to ignore Daisy, not maintaining any eye contact ... Then she asks the support worker about the money. The support worker again deliberately involves Daisy in the conversation. (OB)

As the fieldnote below illustrates, educational practices can be disrespectful and end up with the support workers publicly criticizing the person with intellectual disability.

Angie decides it is now time for a coffee. She has \$4 left in her bank bag... Angie says, 'iced coffee?' The girls says, 'yes', looking relieved and hurries away. The support worker hears this and comes over... 'do you have enough money for it?' [It is \$4.60]. The support worker is upset with her as she only has \$4 budgeted for the coffee. 'Do you have any more money Angie?' She asks – 'how are you going to pay for it?' Angie does not look upset, but she looks around in her handbag for more money, and finds a \$1 coin. She shows it triumphantly to support worker who nods and reminds her that she can't order a coffee if she doesn't have the money for it – telling her she's lucky she found the extra money. (OS)

Interventions such as this that try to educate a person with intellectual disability to be more 'respectable', 'mature' or 'normal' in their interaction with others can interrupt the natural flow an encounter, cause embarrassment to either party, or put a stranger in a difficult position. The example below shows how the support worker's intervention to manage what she considered to be inappropriate behaviour in a service transaction – hugs, silliness and playful conversation – undermined Nellie's dignity and brought into question the behaviour of the hairdresser who until the intervention was quite at ease with the encounter and rapport she had developed with Nellie.

Nellie walks into the hairdressers. She is obviously very familiar with the hairdresser and says Hello to the hairdresser. The support worker stays in the background as Nellie and the hairdresser interact. Nellie gives the hairdresser a hug. The support worker steps forward quietly, did you ask first

Nellie? The hairdresser says, we normally have two hugs before we start, don't we Nellie?... While her hair is being rinsed Nellie loudly proclaims 'ow'. The hairdresser seems to understand that this is one of the ways that Nellie expresses herself and not necessarily an expression of pain. She checks if Nellie is ok, then keeps going while Nellie laughs. 'It's not dirty', says Nellie. 'Not now', says the hairdresser. Nellie keeps talking along this vein until the support worker intervenes, saying, 'You need to stop being silly or we'll have to go home.' Nellie and the hairdresser ignore her... When they are finished, the hairdresser takes the drape off Nellie who understands the cue and stands up. She immediately reaches to hug the hairdresser. The hairdresser says, 'lets finish first then hug, ok?' The support worker intervenes quietly as Nellie appears to be hyped up again, saying 'calm down Nellie'. (OC)

A support worker trying to 'educate' a person with intellectual disability in public can put strangers in the difficult position of deciding whether or not they should cooperate. While the hairdresser tactfully ignored the support worker's comments, strangers can sometimes be left confused as the following example illustrates.

Sarah becomes restless, and goes to the counter and says 'Veggie burger'. The cashier takes the order, but Sarah doesn't have any money and the support worker tells her 'Sarah, why don't you wait until we're all ready to order?' The cashier seems a bit confused about whether to take the order or not – she decides to wait. (OS)

Obstructing encounter

Support workers practices can also prevent or terminate an encounter.

Prevention of encounter

Support workers may intervene to deliberately prevent an encounter taking place when it is perceived as incompatible with the schedule, or, as in the two examples below, as potentially confrontational.

Next time I see them they are walking out through the reception area. The support worker calls out 'thank you, good night' to the staff. She gets smiles

in return. Peter wanders over to the front reception counter and looks behind it. The support worker calls him nosey and redirects him towards the door before staff have a chance to react either positively or negatively. (OB)

Mark walks immediately into the St John's room and walks towards the employees. Two people in uniforms look up, but the support worker intervenes before any interaction takes place. (OB)

A common prevention tactic involved the support worker placing themselves between the person they were supporting and a stranger, to act as a physical barrier to block any opportunity for direct interaction. The two examples below illustrate this blocking practice.

We walk past the cupcake stall which Mark appears to ignore. However, he suddenly doubles back. The support worker quickly 'herds' him away from the table – placing herself between the cupcakes and Mark. The people on the stall just watch without comment. (OB)

There is a man with walking sticks and a lady with a child walking together. The support worker deliberately moves to the other side of Tom – so that he is between the group and Tom. (OB)

Another strategy was to remove the person with intellectual disability from a venue to prevent the potential of encounter. In the example below, the support worker identified a problem in the mood of the person with intellectual ability which might lead to confrontational encounters, and took action to avoid this happening.

Jessie is restless and the support worker asks her if she wants to wait outside. (OC)

Termination of encounter

Support workers terminated encounters which they perceived as likely to delay a schedule or another activity perceived as more important. For example,

Angie sees someone she knows outside the shopping centre. She goes over to talk ... The

support worker stands in indecision, obviously impatient to get going. ... Angie sits down on the bench beside the other woman. The support worker gets very annoyed and is obviously trying to find a way to bring Angie back, however she is very conscious that I am there. She looks at me and says, 'I'll just go tell Anne that you need to get going'. I respond immediately, telling her that I am not at all impatient and have lots of time...The support worker is obviously displeased with this answer, and calls out to Angie anyway ... (OS)

Support workers might also terminate an encounter in which a person with intellectual disability is perceived to be behaving inappropriately. In this example, the support worker not only physically positioned himself to prevent direct interaction between Ken and a stranger, but also initiated his own conversation with the stranger as a distraction:

Ken sees a little girl with her head down on her Dad's shoulder. Ken rubs her back and the two smile at him. The support worker has come up behind them and takes over the interaction – talking to the little girl and her father, and standing in Ken's way. Ken walks away unnoticed. (OW)

A further tactic was for the support worker to enter into an encounter with a stranger 'on behalf' of a person with intellectual disability, effectively preventing their direct interaction with a stranger.

Discussion

These findings reflect Saxby *et al.*'s (1986) study that people with intellectual disability are often actively present in public places and suggests that with the right type of support, they can participate in many of the transactions or fleeting encounters that occur, some of which will have moments of conviviality. Our findings poignantly demonstrate the potential identified by Todd (2000) for encounters between people with and without intellectual disability in public places to be limited or facilitated by staff who accompany them. They illustrate, too, the significant judgment and skill that must be exercised by support workers in deciding whether and how to initiate, facilitate or obstruct an encounter between a person with intellectual disability and a stranger in a public place.

Co-presence of people in a space does not in any way ensure interaction between them. Indeed, in many

public places of the modern 'Western' city, strangers are not expected to interact with each other. Non-interaction is often understood as respecting another person's privacy (Laurier & Philo 2006). Thus, while initiating interaction is permissible, it must be done with tact so as not to appear intrusive. Support workers who proactively initiated encounters used a high level of sensitivity to the subtle cues people use when offering, accepting or declining 'permission' for social interaction (Goffman 1971). Many also demonstrated creativity and enthusiasm by proactively creating atmospheres that were inviting for strangers to enter.

Not all people with intellectual disability need support to initiate, participate in or to manage encounters with strangers. Many, particularly those who have extrovert personalities or strong communication skills, are capable of doing this on their own. Our observations suggest, however, that some strangers benefit from the reassuring presence, interpretative or facilitative assistance of a support worker to enable them to more easily engage in an encounter initiated by a person with intellectual disability. As Todd (2000) so vividly suggested, much of the work of those accompanying people with intellectual disability is managing tensions when conventions of social behaviour are broken. In this respect, support workers have to make critical judgements about the risks and benefits of intervening in an encounter and weigh up the 'differences' that strangers in public places are able to handle alone. We also identified instances where support workers prevented or terminated encounter, for various reasons such as fear of confrontational encounters or desire to get on with their planned schedule. These practices may be due to a lack of support worker insight about their own practices or about the importance of encounter, which, although may appear to be mundane, fleeting or insignificant, is also an important aspect of social participation.

We observed support workers taking risks about not intervening and weighing up whether, when, in what way to initiate or facilitate encounters. Social participation has seldom been explored at this micro-level of detail and may be seen as having little relevance to people with higher support needs (Bigby *et al.* 2009). As a result, support workers are given little guidance about making the types of judgements or practicing in the ways we observed. Aspects of these practices have clear parallels to elements of existing practice frameworks such as person-centred active support (Mansell & Beadle-Brown, 2012). It is relatively easy to see from our examples, how the skills associated with its

essential elements such as: 'every moment has potential' for a person to be engaged; providing 'graded assistance' that is just enough of the right kind to enable a person to succeed; and providing opportunities to exercise 'choice and control' over as many aspects of life as possible, are relevant to support worker practice in public places. The support worker in the bank, for example, provided just enough cues to both Daisy and bank teller enable them to interact successfully, or by interpreting Peter's behaviour for the lady whose sleeves he wanted to roll up, but not intervening the support worker gave just the right amount of support to make the encounter successful. However, training associated with person-centred active support is relatively silent on the types of judgements and strategies that were used by support workers to effectively initiate and facilitate encounter between people with intellectual disability and strangers (Mansell & Beadle-Brown 2004). Seldom do training materials bring into focus the roles of support workers in reassuring, educating or interpreting behaviour for strangers that facilitate encounters and, which in the longer term, may add to the confidence community members in interacting with people with intellectual disability.

We identified three general types of encounter facilitation practices: first, *passive monitoring* of the encounter whereby the support worker avoids a direct and explicit role in the interaction; second, the support worker acting as an *interpreter*, assisting both sides in the encounter communicate more effectively; and third, the support worker *intervening* in the encounter in attempt to modify the behaviour of the person they support or the stranger encountered. Support workers in our study juggled the three types of facilitation practices according to their skill and judgment of the given situation. Our analysis raises challenging questions about the ethics of when and how to apply each of these facilitation practices that may be useful to consider in training or supporting workers to reflect on their practice.

The tenets of person-centred active support, that support workers should provide just the right amount of support for success, suggest they should minimize their intervention in an encounter between a person with intellectual disability and a stranger as much as possible. The practice of passive monitoring enables people with intellectual disability to negotiate the encounter on their own terms, while the support worker is ready to provide targeted assistance only if a moment of need arises. Implicitly, the support worker's presence provides reassurance for strangers who are less experienced in encounter with people with intellectual disability. Interpretation is another form of minimalist intervention

where the support worker limits their role to relatively 'neutral' interpretation when the communication skills of a person with intellectual disability are limited, or their mode of communication takes the form of unconventional behaviours and easily misunderstood. The Australian ethical code for professional interpreters that requires remaining as faithful as possible to the meaning of messages they interpret, 'preserving the content and intent of the source message or text without omission or distortion' (AUSIT 2012, p. 5), may be a useful source of guidance for the interpretative practices of support workers. If support workers can interpret communications between a person with intellectual disability and strangers without distorting the meaning of messages, they will make space for more direct and genuine communication to occur.

The practice of intervening in encounter to modify the behaviour of a person with intellectual disability or a stranger represents a more challenging ethical terrain. On the one hand, in the face of disrespectful, exclusionary and potentially harmful behaviour, support workers may feel obliged to intervene and try to remediate the situation by turning it into a learning experience for all parties. On the other hand, attempts to educate people with intellectual disability or members of the public, through public punishment or criticism, are problematic. Rather than promote more inclusive encounters between people with and without intellectual disability, such practices can be embarrassing and degrading to those who are involved and may discourage either party from pursuing future encounters.

Our analysis of observations highlights the role of disability support workers in supporting encounters. We acknowledge, however, that their actions are only of the many factors influencing the nature of encounters between people with and without intellectual disability (Wiesel & Bigby 2014). Further exploration is required to situate the micro level of support practices in the wider meso- and macro-contexts of the disability services system and its organizational structures and cultures. Issues such as funding, training and management potentially enable or constrain what can be achieved by individual support workers in their day to day practice.

Conclusions

Through interpretation of observational data that captured the actions of support workers accompanying people with intellectual disability in public places, this paper has offered new empirical evidence and conceptual insight into the their practices of initiating,

facilitating and obstructing encounters. By naming and categorizing these support practices and shedding light on what are at times subtle differences which make some effective and others problematic, the paper provides a foundation for developing and improving support worker practices of supporting social inclusion.

Some of our observations showcase support workers applying their sensitivity and skills to initiate and facilitate encounter between people with intellectual disability and strangers, in effective, respectful ways, often in the face of very challenging circumstances. Other observations point to problematic practices, which limit opportunities for encounter. Such inconsistency is underpinned by the low priority attributed to social inclusion among the many other roles of disability support workers (McConkey & Collins 2010; Clement & Bigby 2009) as well as the absence of the demonstrable application of existing practice frameworks to guide support workers in promoting encounter and the associated training materials. This paper has made a first step in filling this gap. There is scope for further research to examine other roles support workers can play in the preparation for encounter, such as through training and up-skilling of people with intellectual disability, planning and preparation of places to be visited and activities outside the home before they leave.

Commitment to the social inclusion of people with intellectual disability is central to disability policy and must become a guiding principal in the design and practice of disability support services. Promoting encounter between people with and without intellectual disability is one way of progressing their social inclusion, by extending their social networks as well as creating opportunities to experience moments of recognition and conviviality (Bigby & Wiesel 2011).

Acknowledgments

The research for this paper was funded by a Linkage grant from the Australian Research Council and contributions from Industry partners, Jewish Care and Yooralla. We acknowledge the contribution of Dr Rachel Carling Jenkins in undertaking the data collection for this study as part of her former position as a research fellow at La Trobe University.

Correspondence

Any correspondence should be directed to Christine Bigby, Director Living with Disability Research Centre (e-mail: c.bigby@latrobe.edu.au).

References

- Abbot S. & McConkey R. (2006) The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of Intellectual Disabilities* 10, 275–287.
- AUSIT (2012). *AUSIT Code of Ethics and Code of Conduct*, informahealthcare.com/userimages/ContentEditor/1345559775482/CJID_instructions_for_authors2012.pdf (accessed 16 January 2014).
- Bigby C. & Wiesel I. (2011) Encounter as a dimension of social inclusion for people with intellectual disability: beyond and between community presence and participation. *Journal of Intellectual and Developmental Disability* 36, 263–267.
- Bigby C., Clement T., Mansell J. & Beadle-Brown J. (2009) 'It's pretty hard with our ones, they can't talk, the more able bodied can participate': staff attitudes about the applicability of disability policies to people with severe and profound intellectual disabilities. *Journal of Intellectual Disability Research* 54, 363–376.
- Bigby C., Wilson N., Stancliffe R., Balandin S., Craig D. & Gambin N. (2014) An effective program design to support older workers with intellectual disability participate individually in community groups. *Journal of Policy and Practice in Intellectual Disability* 11, 117–127.
- Clement T. & Bigby C. (2009) Breaking out of a distinct social space: reflections on supporting community participation for people with severe and profound intellectual disability. *Journal of Applied Research in Intellectual Disabilities* 22, 264–275.
- Craig D. & Bigby C. (2014) She's been involved in everything as far as I can see: Supporting the active participation of people with intellectual disabilities in community groups. *Journal of Intellectual and Developmental Disability*. Doi:10.3109/13668250.2014.977235.
- Disability Services Act (1986). Commonwealth Act. Canberra, Australia.
- Dusseljee J., Rijken P., Cardol M., Curfs L. & Groenewegen P. (2011) Participation in daytime activities among people with mild or moderate intellectual disability. *Journal of Intellectual Disability Research* 55, 4–18.
- Fincher R. & Iveson K. (2008) *Planning and Diversity in the City: Redistribution, Recognition and Encounter*. Palgrave Macmillan, Basingstoke.
- Goffman E. (1971) *Relations in Public*. Basic Books, New York.
- Gray K., Piccinin A., Keating C., Taffe J., Parmenter T., Hofer S., Enfield S. & Tonge B. (2014) Outcomes in young adulthood: are we achieving community participation and inclusion? *Journal of Intellectual Disability Research* 58, 734–735.
- Hall E. (2005) The entangled geographies of social exclusion/inclusion for people with learning disabilities. *Health and Place* 11, 107–115.
- Jacobs J. (1962) *The Death and Life of Great American Cities*. Jonathan Cape, London.
- Kozma A., Mansell J. & Beadle-Brown J. (2009) Outcomes in different residential settings for people with intellectual disability: a systematic review. *American Journal on Intellectual and Developmental Disabilities* 114, 193–222.
- Laurier E. & Philo C. (2006) Possible geographies: a passing encounter in a café. *Area* 38, 353–363.
- LeCompte M. D. & Goetz J. P. (1982) Problems of reliability and validity in ethnographic research. *Review of Educational Research* 52, 31–60.
- Levitas R. (2005) *The Inclusive Society?*, 2nd edn. Basingstoke, Palgrave.
- Mansell J. & Beadle-Brown J. (2004) *Person Centred Active Support, Training Pack*. Pavilion Publishing, London.
- Mansell J. & Beadle-Brown J. (2012) *Person Centred Active Support*. Jessica Kingsley, London.
- McConkey R. & Collins S. (2010) The role of support staff in promoting the social inclusion of persons with an intellectual disability. *Journal of Intellectual Disability Research* 54, 691–700.
- Myers F., Ager A., Kerr P. & Myles S. (1998) Outside looking in? Studies of community integration of people with learning disabilities. *Disability and Society* 13, 389–414.
- National Disability Insurance Scheme Act (2013). Commonwealth Act, Canberra, Australia.
- O'Brien J. & Lyle C. (1987) *Framework for Accomplishment*. Responsive Systems Associates, Decatur, Georgia.
- Robertson J. M., Emerson E., Elliott J., Hatton C., McIntosh B., Swift P., Krinjen-Kemp E., Towers C., Romeo R., Knapp M., Sanderson H., Routledge M., Oakes P. & Joyce T. (2007) *The Impact of Person Centred Planning for People with Intellectual Disabilities in England: A Summary of Findings*. Lancaster University, Lancaster.
- Sanders K. (2009) The effects of an action plan, staff training, management support and monitoring on restraint use and costs of work-related injuries. *Journal of Applied Research in Intellectual Disabilities* 22, 216–220.
- Saxby H., Thomas M., Felce D. & De Kock U. (1986) The use of shops, cafes and public houses by severely and profoundly mentally handicapped adults. *British Journal on Mental Subnormality* 32, 69–81.
- Todd S. (2000) Working in the public and private domains: staff management of community activities for and the identities of people with intellectual disability. *Journal of Intellectual Disability Research* 44, 600–620.
- United Nations (2006). *Convention on the Rights of Persons with Disabilities*, Available at: <http://www.un.org/disabilities> (accessed on 20 August 2007).
- Valentine G. (2008) *Living with difference: reflections on geographies of encounter*, *Progress in Human Geography* 32, 323–337.
- Verdonschot M., de Witte L., Reichrath E., Buntinx W. & Curfs L. (2009) Community participation of people with an intellectual disability: a review of empirical finding. *Journal of Intellectual Disability Research* 53, 303–318.
- Walker P. (1999) From community presence to sense of place: community experiences of adults with developmental disabilities. *Journal of the Association for Persons with Severe Handicaps* 24, 23–32.

- Wiesel I. & Bigby C. (2014) Being recognised and becoming known: encounters between people with and without intellectual disability in the public realm. *Environment and Planning A* **46**, 1754–1769.
- Wiesel I., Bigby C. & Carling Jenkins R. (2013) 'Do you think I'm stupid?: urban encounters between people with and without intellectual disability. *Urban Studies* **50**, 2391–2406.
- Zakrazsek A., Hammel J. & Scazzero J. (2014) Supporting people with intellectual and developmental disabilities to participate in their communities through support staff pilot intervention. *Journal of Applied Research in Intellectual Disabilities* **27**, 154–162.