

**ORIGINAL ARTICLE**

## **A model of processes that underpin positive relationships for adults with severe intellectual disability**

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### **Abstract**

**Background** Relationships develop through social interaction and assist with participation and inclusion. Little is known about how relationships develop between people with severe intellectual disability who have limited communication and others.

**Method** Interactions were observed between 6 adults with severe intellectual disability and paid workers or family members with whom those adults had positive relationships. Workers and family members were interviewed. The data were analysed through a grounded theory approach.

**Results** Data analysis led to the identification of 5 processes that underpin positive relationships: *recognising individuality, sharing the moment, connecting, feeling good, and sharing the message*.

**Conclusions** A relationship model with clearly identified processes and sub-elements provides a framework for teaching others how to have positive relationships with people with severe intellectual disability. The model could be applied in training to support relationships between workers and people with a disability and more widely with other community members.

**Keywords:** *severe intellectual disability, relationships, adult, grounded theory, interaction*

### **Introduction**

People with intellectual disability have an established right to social inclusion (United Nations, 2006). Central to increasing a sense of social inclusion is personal relationships. For people without intellectual disability, there is strong evidence that social support strengthens the development of personal relationships (Andersen, 1993; Duck, 1998, 2007; Kahn & Antonucci, 1980). Kahn and Antonucci (1980) defined social support as “interpersonal transactions” (p. 266) that include aspects of aid, affect, and affirmation. Aid refers to physical or instrumental support given or received, such as time, financial assistance, and information. Affective and affirming transactions are emotional interactions that attribute respect and value to an individual. The concept of giving and receiving social

support is known as *reciprocity* (Wellman, 1981). According to Heller, Price, and Hogg (1990), the real or perceived exchange of tangible or interpreted reciprocity is integral to supportive relationships and provides feelings of “competence, esteem and a sense of belonging” (p. 484). Although social support is reciprocal and integral to developing relationships, the reciprocal elements operating in relationships that involve people with intellectual disability are much less clear. Investigation of the relationships of people with mild intellectual disability (Amado, 1993; Garvey & Stenfert Kroese, 1991; Knox & Hickson, 2001; Moore & Carey, 2005) attests to their difficulties with forming and maintaining robust social relationships. For people with severe intellectual disability, these difficulties are magnified; they have few social relationships,

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and these are predominantly with paid workers and family members (Kennedy, Horner, & Newton, 1990; Krauss & Erickson, 1988; Krauss, Seltzer, & Goodman, 1992; Robertson et al., 2001). A contributing factor for these people is communication difficulty (McLean, Brady, & McLean, 1996). As a result of limited symbolic communication, they rely on the experience and ability of others to build relationships. Consequently, workers require skills in interacting with people and supporting them to develop relationships in the community.

Little is known about the processes that assist the development of relationships for people with severe intellectual disability. Studies with a focus on relationships have included people with varied levels of intellectual disability and communication skills. Researchers have identified characteristics associated with positive relationships between family and/or workers, and people with severe intellectual disability (Bogdan & Taylor, 1998; Dennis, 2002; Jameson, 1998; Krauss et al., 1992; Newton, Olson, & Horner, 1995; Taylor & Bogdan, 1989). In four studies, interpretative methods were used, including focus groups (Dennis, 2002), interviews (Newton et al., 1995), and both participant observation and interviews (Bogdan & Taylor, 1998; Taylor & Bogdan, 1989). In two studies, quantitative survey instruments were used (Jameson, 1998; Krauss et al., 1992). Characteristics of positive relationships identified in these studies were an acceptance of difference, and sometimes the celebration of difference (Bogdan & Taylor, 1998; Taylor & Bogdan, 1989); trust (Dennis, 2002; Jameson, 1998); adjustment of communication style (Dennis, 2002); mutual respect (Bogdan & Taylor, 1998; Dennis, 2002; Krauss et al., 1992); perceived reciprocity (Bogdan & Taylor, 1998); and recognition of individuality (Bogdan & Taylor 1998). These characteristics, singly or together, have not been utilised to further an understanding of how to build and support relationships. The aim of this study was to investigate the processes involved in positive relationships between people with severe intellectual disability who have limited communication and workers or family members, in order to understand how such relationships can be fostered.

## Method

### *Design and ethical approval*

A constructivist grounded theory approach was adopted to identify the processes involved in positive relationships (Charmaz, 2006). Ethical approval was obtained from the Human Research Ethics Committees of La Trobe University, Victoria, Australia,

and Monash University, Victoria, Australia, and the Human Research Ethics Committee of Scope, a Victorian nongovernment organisation.

### *Participants*

The participants were six adults with severe intellectual disability with symbolic but nonlinguistic communication skills (referred to as central participants), and the family members and paid workers with whom they had a positive relationship (see Table 1). In light of the difficulties in conducting formal assessments with people with severe intellectual disability, each central participant was assessed by the first author (speech pathologist) using observation, interaction, and administration of the following informant measures: the survey edition of the Vineland Adaptive Behavior Scales (VABS; Sparrow, Balla, & Cicchetti, 1984) and Triple C: Checklist of Communication Competencies (Bloomberg, West, Johnson, & Iacono, 2009). The VABS data indicated that all participants had a low level of functioning, with communication skills from the combined assessment data indicating skills commensurate with severe intellectual disability. Further, this combined information indicated that all central participants needed "extensive levels of support in multiple adaptive domains" (McLean et al., 1996, p. 580). The term *nonlinguistic* is used to describe communication in which conventional symbols are present (e.g., single spoken, signed, or pictured words), but not flexibly combined into novel utterances, thereby lacking "rule governed linguistic constructions" (Fischer & Corrigan, 1981, p. 263).

Informed consent on behalf of each central participant with intellectual disability was obtained from his or her next of kin. Workers and family members provided their own consent.

All central participants had physical and sensory impairments in addition to intellectual disability. They were aged from 20 to 44 years. Three lived in their family home and three in small group homes; all attended day services in Victoria, Australia. Convenience sampling was used to select the first central participant. Purposeful sampling was utilised in order to seek a specific typology or feature to explore in successive central participants (Morse, 2007). Specific criteria were distributed to speech pathologists and disability organisations in Victoria, Australia.

The other participants are referred to as personal affinity network members (affinity members). They were people who were observed to have a positive relationship with one of the central participants and met at least two of four criteria: (a) being named by the central participant when not in the affinity

**Table 1. Personal affinity member roles and characteristics, diagnoses, and residence of central participants**

Central participants	Age (yrs)	Diagnoses	Residence	Family members	Paid workers
Sandra	20	Intellectual disability Autism spectrum disorder Epilepsy	Family home	Mother Father Sibling Sibling's partner	Home support workers 3 Day support workers 5
Brian	23	Intellectual disability Scoliosis Visual impairment Epilepsy	Family home	Mother Father Grandmother Sibling	Home support workers 3 Day support workers 4 Day program coordinator 1
Colin	27	Intellectual disability Visual impairment Epilepsy	Group home	Grandmother Grandfather Aunts 2	House coordinator 1 Day support workers 2
Diane	44	Intellectual disability Spastic quadriplegia Epilepsy	Family home	Mother Father Aunts 2	Day support worker 1 Day program coordinator 1
Eric	24	Intellectual disability Spastic quadriplegia Epilepsy	Group home	Mother Father Stepfather Grandmother Sibling Sibling	Home support worker 1 Day support worker 1 Day program coordinator 1
Fayez	38	Intellectual disability Spastic quadriplegia Epilepsy	Group home		Home coordinator 1 Home support workers 3 Day program coordinator 1

member's presence; (b) interactions with the affinity member were positive, and during which central participants showed pleasure (Forrester-Jones, Jones, Heason, & Di'Terlizzi, 2004; Kennedy et al., 1990); (c) an interaction or activity with the affinity member lasted more than 15 minutes (Newton, personal communication, August 7, 2007); and (d) the affinity member had a special bond with the central participant or had known him or her for several years (Krauss & Erickson, 1988; Krauss et al., 1992). In total, 22 family members and 29 paid workers met the criteria for network members. Family members were aged from 18 to 78 years and, except for two (step-father and brother's partner), they had known the central participants all their lives. The workers comprised day support workers (DSWs), home support workers who went into family or group homes (HSWs), day program coordinators (DOs) and group home coordinators (HOs) (see Table 2). These workers had known the central participant from between five months and over 10 years. In comparison with Australian disability workforce data (Martin & Healy, 2010), workers in this study were similar in terms of age range and disability-related qualifications, but a higher proportion was male (20% male and 45% male, respectively).

#### Procedures

The first author collected data for each central participant over four to six months through

open-ended interviews and observations in family homes, group homes, day centres, and community settings. A total of 239 hours of observations lasting between 0.5 and 3 hours were conducted. The central participants' interactions in daily activities were observed. Field notes were recorded when interactions occurred or immediately after. The first author predominantly utilised observer-as-participant and complete observer roles (Johnson, Douglas, Bigby, & Iacono, 2011). Interviews with 48 affinity members provided supplemental information. Three family members had either insufficient English ( $n = 1$ ) or limited speech associated with intellectual disability ( $n = 2$ ) that precluded their participation in interviews. Two people participated in follow-up interviews. Interviews were unstructured and were from 30- to 75-minutes' duration. All interviews opened with the question "Could you tell me about your relationship with [name of central participant] and how communication in this relationship occurs?" The interviews were digitally recorded and transcribed verbatim.

Confidentiality was addressed by assigning pseudonyms to all named participants. In addition, certain identifying data have been withheld or changed. Unique three-part alphanumeric codes have been used to identify affinity members (e.g., CDSW12, which represents the central participant's initial + affinity member's role + number).

**Table 2. Paid worker characteristics**

Characteristics	Day support workers (n = 15)	Home support workers (n = 9)	Coordinators (n = 5)	Total workers (n = 29)	
	No.	Percent			
<b>Age (years)</b>					
<29	2	3	0	5	17
30–39	3	4	2	9	31
40–49	3	2	1	6	21
50–59	5	0	2	7	24
60+	2	0	0	2	7
<b>Gender</b>					
Female	6	7	3	16	55
Male	9	2	2	13	45
<b>Qualifications in disability</b>					
Degree/diploma	2	1	2	5	17
Certificate 3/4	10	6	3	19	66
None	3	2	0	5	17
<b>Time worked in disability sector</b>					
>11 mths	4	5	0	9	31
1 yr–2.11 mths	3	1	0	4	14
3 yrs–9.11 mths	6	2	1	9	31
10+ years	2	1	4	7	24
<b>Time known central participant</b>					
>11 mths	5	5	0	10	34
1 yr–2.11 mths	5	1	2	8	28
3 yrs–9.11 mths	5	2	1	8	28
10+ years	0	2	1	3	10

### Analysis

All transcripts were read independently by the second author prior to analysis. Insights from the data and literature were recorded in a journal as a form of memo writing (Charmaz, 2006). The data were entered into NVivo 8 (QSR International, 1999–2008), coded line by line, and examined for *in vivo* codes (descriptive terms used by interviewees), thereby allowing open and focused codes, and theoretical categories to be developed, as illustrated in Figure 1. A key strategy was ongoing data comparison from all sources and across participants. The authors come from the disciplines of psychology, speech pathology, and social work, and each has extensive experience of working with people with intellectual disability. Throughout the nonlinear analysis process, the authors met fortnightly to discuss coding categories, relevant literature, and further questions, such as "How is this issue the same or different for other participants and why?" This process continued until clear categories and subcategories emerged and data saturation was reached.

Charmaz's concepts of credibility, originality, resonance, and usefulness were part of the methodological process (Charmaz, 2006). Credibility was enhanced through regular discussions between the authors. Further credibility was gained through three feedback sessions, attended by 41 people who

had regular interaction with central participants, including 14 affinity members, during which the usefulness of insights gained from the descriptive data were discussed. Originality and resonance with other colleagues was confirmed during discussions following each of seven conference presentations.

### Results

Five processes supporting positive relationships were identified from the data: *recognising individuality*, *sharing the moment*, *connecting*, *feeling good*, and *sharing the message*. A model was developed to reflect the interactional nature of these processes underpinning positive relationships, and is presented in Figure 2. It was not clear, from the methods used in this study, whether these processes occur sequentially or simultaneously.

#### *Recognising individuality*

Recognising individuality was founded on the affinity members' perceptions of central participants' attributes or qualities that symbolised their individual personalities. "Character" was frequently used by affinity members to describe the central participant holistically as a unique individual. Having character was seen as a positive and attractive attribute that

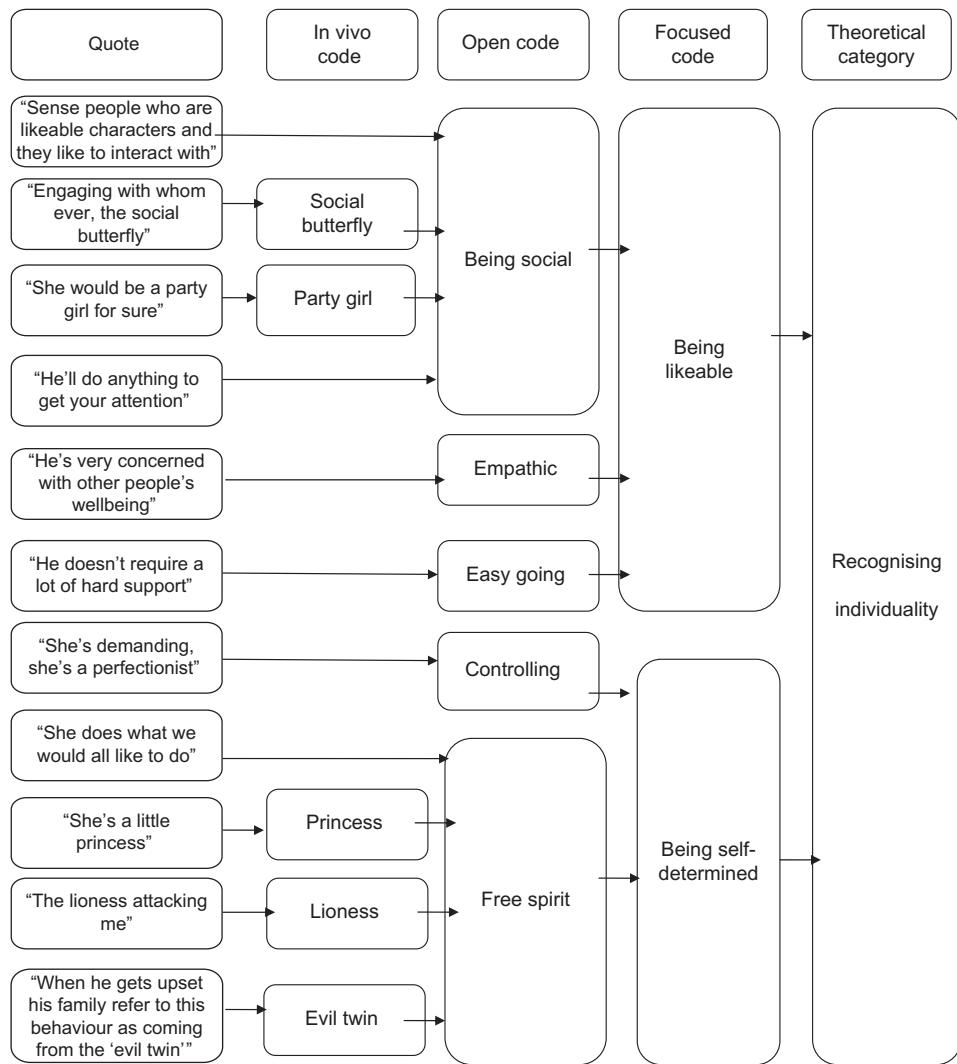


Figure 1. Example of a coding category: Recognising individuality.

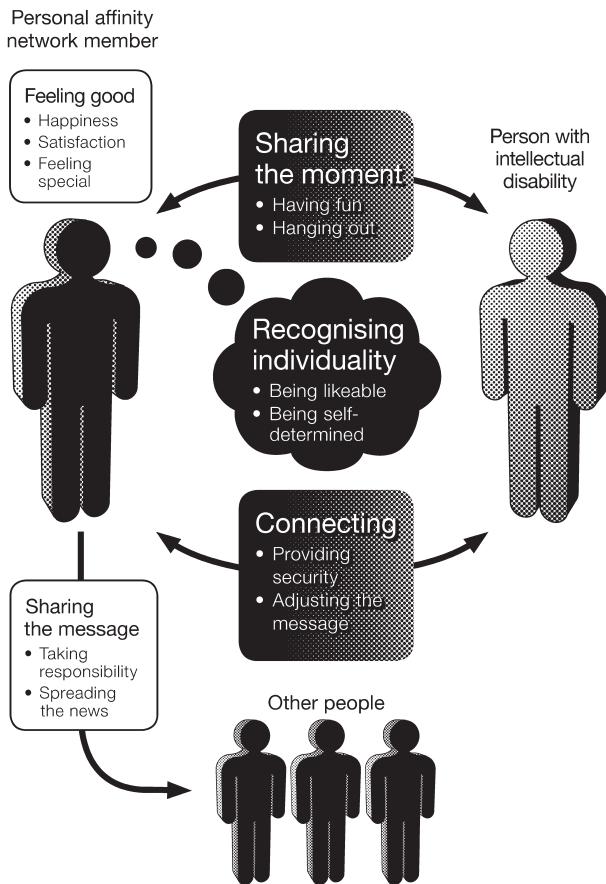
encouraged spending time with a central participant. A worker commented, "I tend to be spending more time with him than the other three. I think it's just because of his personality" (BDSW9). The attributes that signalled individuality were not always conventionally attractive, often comprising the opposing qualities of *being likeable* and *being self-determined*.

**Being likeable.** Likeability was associated with recognition of the central participants' inherent sociable and empathetic natures; for instance, someone who is "willing, he doesn't require a lot of hard support to initiate things" (EDO2). Sociability was perceived when central participants were observed to have frequent social interactions with a range of people, and epithets such as a "social butterfly" or "party girl" were applied. Central participant interactions that appeared to demonstrate caring and consideration for others also signalled likeability and individuality.

Family members remembered and valued empathic moments, often when someone had been in distress or unwell. One family member recalled the actions of her grandson, Colin, when she told him she was unwell, saying

"Nanna's not feeling well," ... I heard him in the kitchen. I'd said "where's Poppa, tell him Poppa, I'd like a cup of tea." Anyway I heard cups going and I said, "Oh Colin don't touch the electric jug or anything, or the hot water." Anyway he came in and his little hand was shaking with a cup of cold water with a tea bag. (CF18)

**Being self-determined.** Affinity members also acknowledged more challenging characteristics of central participants, typically including being self-determined, tenacious, and goal-directed, sometimes with little regard to other people's needs. Affinity members remained positive about the individuality expressed



**Figure 2.** A model of processes underpinning positive relationships.

despite awkward or difficult interactions. One worker affectionately described a central participant as a “Casanova” when he greeted unfamiliar women by putting his arm around their necks and gripping them tightly, sometimes scaring them. Another worker attributed her enjoyment of a central participant to him being “a sweet person” and “charismatic,” despite recalling an upsetting incident that exemplified his strong determination. She reported

We had an instance with some duck poo, and he really wanted that and we didn’t want him to have it because we knew it was going to go in his mouth, so another DSW just put her foot on it. He was there for ages and ages and he was absolutely determined and in the end, the DSW had to remove her foot and let him do what he wanted to do. (CDSW12)

Overall, affinity members demonstrated appreciation of central participants’ individuality through recognition of attributes that served to characterise them as complex and multifaceted, with attractive, admirable, and/or curious qualities. Recognition came from observing the individual with others, listening to each other’s stories, participating in social interaction, and spending time together.

### Sharing the moment<sup>1</sup>

The process of sharing the moment consisted of *having fun* and *hanging out*, which captured the experience of immediate and mutually enjoyable social interactions. Each element consisted of subsets of interactions. All affinity members experienced aspects of having fun, but mostly family members experienced hanging out.

**Having fun.** Laughter and a shared sense of humour were important to the relationship. Fun interactions were often short and undemanding, resulting in delight or joy. One worker attributed her enjoyment of work to a central participant’s ability to “put a smile on your face” (BDSW8). Having fun included *routine social interactions* and *comedy*. Routines were personalised and idiosyncratic interactions, including rhythmic play, games and songs, and mimicry, while comedic interactions contained four comedic typologies: vulgarity, pranks, jest, and banter.

**Routines.** Routines were repeated physical and/or vocal interactions, occurring in a variety of forms of pleasurable play. Each participant had a unique set of routines that were not necessarily shared with everybody. One worker discussed how she had developed her own rhythmic play interaction based on a central participant’s playful interaction with others: “[I] see other clients teasing him and pulling him, and you hear him yelling and making that ‘ah’ sound, that’s what I found really funny and I thought ‘I’m going to imitate that’” (BDSW10).

**Comedy.** Different forms of comedic interaction appealed to different affinity members. Although vulgarity (references to body parts or toilet humour) appealed more to central participants than affinity members, the laughter that ensued was contagious, as exemplified by one worker: “maybe Dean will burp and then Faye will start laughing and that makes Dean laugh and I enjoy sharing those experiences with them” (FHO2; Johnson, Douglas, Bigby, & Iacono, 2012).

Pranks were amusing tricks that resulted in the recipient feeling silly or embarrassed, and sometimes incorporated slapstick humour. These pranks were more common between family members and central participants, and often consisted of amusing context-specific family routines, for example:

Dad used to do the teaspoon with all of us and then he started doing it with Colin. He’d stir the cup of tea then he’d “tch” on your hand [*gesture of tapping the teaspoon on the back of the other person’s hand*]. Colin would start getting it and then Colin learnt to do

it back. He'd stir his tea and then watch and he'd a couple of times got [Gran]dad back before [Gran]dad got him. It was like "Ha ha, I got you first." (CF8)

As with jokes, jests had a storyline, but usually incorporated visual humour, requiring less abstract understanding than formal jokes. One worker described a jest that developed from comparing arm muscles:

So I'm like oh yeah. So I then squeezed his arms and then flexed mine ... and said like, you know, look at that sort of, look at those guns, and he looked at me, and then looked at my gut and then patted my gut [laughs] and with a wry smile walked away in front of everyone. (CDSW13; Johnson et al., 2012)

Banter relied on speech, so was always initiated by affinity members. It was characterised by exaggerated vocal tones and inflections, physical gestures, and facial expressions. Content included lighthearted chat or throwaway lines designed to produce a smile or a laugh from the respondent. An example from a family member was: "She loves when I go [gesticulates wildly] ... Like they're here and watching the footy and I'm saying 'stop yelling out' and 'ohhh' she's going, so I do it a couple of times to get her, she likes that" (DF12).

*Hanging out.* Hanging out involved mutually satisfying interactions that were less intense than having fun. These social interactions were mostly expressed between central participants and family members, and involved spending nondemanding, pleasurable time together with varying degrees of physical closeness. They fell into two distinct types: *contact* and *presence*.

*Contact.* The central participant usually initiated physical contact. One family member commented that as they had been separated for a 10-year period while growing up, she let her sister initiate a need for physical closeness, stating "She'll lift her arm up ... she'll say 'come here' and hug you and she'll start rocking you" (FF16).

*Presence.* Relationships with central participants involved affinity members being in close proximity and providing a comforting presence. The central participants who lived in group homes regularly visited family members, usually staying overnight. Family members discussed how they spent unstructured time either together or separately. One family member remarked that since she had been unwell, she had missed seeing her grandson regularly and how he was no trouble to her, as they happily coexisted.

She said, sadly, "There's no way they're going to let me have him back home again full time" (CF8).

Sharing the moment interactions appeared to support relationships and encouraged opportunities for discovering more about the central participant. In this way it was evident that recognising the individual and sharing the moment were closely intertwined.

### *Connecting*

The process of connecting appeared to strengthen and sustain the bond between an affinity member and a central participant. For example, a worker stated, "If you relate to him as well and relate sincerely, that builds a relationship and he connects with you. If you don't relate sincerely, he doesn't connect" (EDO2). The connecting process fell into two main categories: *providing security* and *adjusting the message*.

*Providing security.* To connect with central participants, affinity members provided security through trust and respect, a sense of belonging, and practical care. Family members also provided love. Workers highlighted a link between communication and trust. One worker stated that the development of mutual trust had helped the central participant to demonstrate speech skills, previously displayed only at home: "it took a little while and I think it was more just getting to know each other and him getting to know me and to trust me because he speaks to mum a lot" (BDSW8). Respect arose from recognising a central participant's specific needs. In relation to a central participant's challenging behaviour, a worker said, "I think we have a mutual respect, like I truly respect her need for space because I am not someone who likes being crowded" (SHSW2).

Affinity members also perceived that nurturing a sense of belonging enhanced feelings of security. One family member ensured that the male central participant had a specific niche in a predominantly female family by introducing quintessential male topics, such as guns, into conversations in order to provide a sense of camaraderie. He said, "Eric likes guns and no-one in his family likes guns" (EF7).

Family members talked about ways in which they loved the central participant. One encapsulated the relationship by saying "The word that comes immediately to me with Eric is love. And I think he's secure in knowing that I love him" (EF4).

Affinity members helped the central participant to feel secure and connected with him or her by providing quality practical care, including support for everyday activities. A central participant's brother said, "She'll always sort of come to me or whatever.

She knows that she can rely on me for stuff like that" (SF3). The elderly parents of one central participant stated they were the only ones who could adequately provide the routine care required to support their daughter; they perceived respite care services as failing because "they don't do things the same" (DF13). Workers also understood the importance of quality practical care, with one worker commenting:

I think it's really important that she feels safe, whether that be using equipment or just feeling that she's not going to be hurt by someone; all of those things. Not feeling threatened, not feeling, um, pressured to do things, yeah, I think that's what safety might be about. (FHSW9)

Affinity members recognised that their interactions with central participants were improved by providing both physical and emotional security. By adjusting the message, they also demonstrated an understanding that specific support of communication assisted their connection with central participants.

*Adjusting the message.* Affinity members were observed to adjust the way they communicated in order to connect more effectively with central participants. A paid worker stated, "So it's kind of me adjusting to him rather [than] him adjusting to me. That's how I felt it would work better for him and me" (BDSW6). Central participants also adapted their messages, although they had fewer strategies. For example, when Eric used a sign that was not understood, he located and pointed to a photo.

Although many affinity members reported that the central participants understood everything that was said to them, they nevertheless adjusted their communication to compensate for comprehension difficulties. This adjustment involved simplifying their language, repeating the message, allowing extra time for an interaction, predicting routine requests, and asking questions that required a simple yes or no response. One worker talked about keeping her utterances short in order to keep the person's attention: "It's clear language, I think, with her, as in short and precise, you know you go on and on about, because she loses concentration, so it's got to be simple and short, short language" (DDSW14). A family member talked about having multiple strategies and knowing how and at what point to adjust his communication, stating "With Sandra you always speak a bit slower because there's no point racing through something. Even if she understands, it takes a little while to process it" (SF3). The repetition of information was also widely used. One parent said, "I guess we'd be more repetitive. Maybe a little bit slower" (BF1).

Affinity members were more likely to use informal than formal augmentative communication strategies to clarify communication and strengthen their connection. Family members rarely used augmentative strategies, but most paid staff used a few basic strategies, such as objects, key word signs and gesture, and pictures or photos to help the central participants convey their message. An example from field notes shows how a worker used objects to clarify the central participant's choice of milkshake flavours: "Diane said something that was interpreted as chocolate. She was then shown a choice of objects, the chocolate sauce or the strawberry sauce and she reached out for the strawberry" (FN/2D).

Connecting was a two-way process that involved both parties providing reciprocal trust and respect, and also adjusting their message. Some affinity members felt there was more they could be doing to build connections. A worker emphasised the importance of using a range of communication techniques, but was aware that this did not happen routinely:

If we communicate properly with Eric we would all know his signs, and we would all use pictures much more frequently with him and we would all wait for him, and ... probably supply him with many more choices in his life. (ED02)

#### *Feeling good*

Connecting, recognising the individual, and sharing the moment resulted in a relationship in which all personal affinity members felt good. This positive emotional response promoted an interest in re-engagement. Feeling good was perceived in different ways, including *happiness*, *satisfaction*, and *feeling special*.

*Happiness.* The only reciprocal emotion perceived to be shared by all participants was happiness. It ensued from sharing time together and having connected relationships. One family member said, "we get joy to see her happy" (DF12). Similarly, workers commented on how the central participants' enjoyment triggered their own positive feelings. One worker said, "The sheer delight that she has sometimes, on something on television or something like that, it just makes me laugh" (SHSW2).

*Satisfaction.* The satisfaction workers derived from the relationship stemmed from successful one-to-one interactions, having variety and challenges in their work, and learning new things about themselves, which also provided motivation. A worker said, "Money's not my motivation of staying here 'cause I can get more money somewhere, but it's

just I relate to them<sup>[2]</sup> and they know me and we've been having all this" (EDSW11). Another worker stated, "You don't know what he's going to do. Every minute is totally different. So you just sort of go 'wow'" (CSW12).

*Feeling special.* Relationships with central participants could lead affinity members to feel special. Several workers reported feeling privileged to have a relationship with a central participant and talked about how feeling special resulted from being singled out at times because of their ability to understand this person's communication. One worker said, "So he will come to me to open the kitchen door because he knows that I know he wants to get in there. Somebody else might not know what Brian's doing there" (BDSW8). Another worker reported an increase in ability to interpret the central participant's complex behaviour. She said, "It is the privilege of just working with someone for many years and I think that's probably why other new workers have problems" (SHSW1). The term "privilege" also suggests a sense of being rewarded, sometimes only in the form of a facial expression, with one worker noting "It's a special thing to see" (FH02). Feeling special meant more than being satisfied at the end of the day; it signified being selected over other people and rewarded for putting in extra effort.

In summary, positive interactions made both affinity members and central participants feel good. When ties between workers and central participants developed, the workers felt privileged and special, and this encouraged them to share the central participants' message with others. Sharing the message provided a pathway through which other social network members could learn about the central participants' interactions and further their appreciation of his or her uniqueness.

#### *Sharing the message*

Sharing the message consisted of *taking responsibility* and *spreading the news*, and contributed to encouraging others to engage with the central participant. As many affinity members were restricted to one context (e.g., day support workers at the day centre), conveying information that might assist network members in different contexts presented a challenge.

*Taking responsibility.* Affinity members took on the responsibility of maximising the success of the central participant's interactions. Family members emphasised the importance of having information strategies that transcended individual workers and contexts as they struggled to interpret the

communication of a son or daughter. One parent stated she took on a "heavy burden of responsibility" in trying to communicate effectively with her son, describing the process as "like playing high stakes charades" (EF7). She further stated:

If I'm not in the moment of understanding what's been going on in his life, it's very difficult. That's why communication between members of Eric's community is very important, in fact it's critical, 'cause without that sometimes we're all up against it, trying to understand him. (EF7)

It was uncommon for workers to check their interpretation of a central participant's communication or clarify communication difficulties with others. One worker, for example, reported being worried about misunderstandings, stated "Sometimes he'd say 'yes, yes' sometimes say 'no' you know, because the whole day you, I don't know if anybody else does, but the whole day I sort of think, I wonder what he's talking about" (EDSW11). Workers, particularly HSWs, who frequently worked alone, often lacked opportunities to share information. Workers who took responsibility for conveying information usually had designated coordinating positions. Generally, family members would persist for longer than workers in clarifying communication attempts or in trying a broad range of strategies.

*Spreading the news.* Sharing an individual's rich history and experiences and documenting their communication skills involved sharing the news with others. Both spoken and written modes were used, with paid staff showing a preference for word of mouth. One coordinator described how a parent would phone her in the evening if a central participant was struggling to tell her about something that had happened during the day. She commented, "As the staff would walk out the door they'd say to me 'if Diane's mum rings it's because Diane saw this or she saw that'" (DDO3). Other affinity members preferred written documentation of idiosyncratic communication skills, with one worker developing a booklet of gestures and meanings. She talked about how she shared this knowledge with other workers: "I would be saying that he's got some basic signs that are important to him, which we've got that little book up, you know, and to have a look through 'my book'" (CHO1). Other workers in the group home who were not affinity members usually asked for help, rather than referring to documentation. News books containing daily (or weekly) information about the central participant's activities were used to convey information (in the form of text or photos) between homes or services. One family member reported

she had used the news book to solve a communication difficulty with her son, commenting "That's why his diary is so important from [the day centre], and often we can get somewhere from that" (EF3). Workers also commented on the importance of talking to family members, with one stating "They filled in the gaps for us" (CDSW13).

When affinity members from one context or activity took responsibility for sharing information with others, it resulted in more successful interactions and potentially more relationships for the central participant. Strategies that took time (such as writing news) were used less often by paid staff, who preferred to leave a message with another staff member or communicate by phone. Direct conversation provided the richest way to share information, encouraging others to share the moment and recognise the individual.

## **Discussion**

The model described in Figure 2 illustrates the processes that underpinned positive relationships in which family members and workers developed their relationships with adults with severe intellectual disability. The processes of supportive relationships were drawn from different data sources, interviews, and extended observations, providing complementary methods to verify the data (Johnson et al., 2011). The result was a non-linear model of discrete but overlapping processes that were individually robust. As the relationships were studied after they had commenced, the order in which the process occurred could not be established. In each relationship, the processes varied in order, intensity, and frequency. We believe that the greatest potential of this work comes not from the identification of these individual components or the order in which they occur, but from viewing the processes as a complete model, which may provide a roadmap for strengthening relationships.

### *Individual elements that enhance relationships*

Elements, such as recognising the individual and positively considering their less attractive behaviours, have been identified in this and in previous research as integral to accepting relationships and recognising humanness (Bogdan & Taylor, 1998; Taylor & Bogdan, 1989). As just explained, in recognising the individual, there is a pair of key, yet seemingly opposed characteristics. Duality, such as being likeable and being self-determined, allows for people to be seen as rounded individuals with both

endearing and challenging qualities. These key constructs clarify different ways in which a person may be appreciated and provide workers with a practical strategy by which to recognise individuality. The constructs add support to Klotz's (2004) argument that people with severe disability can be accepted for who they are and their "particular actions and behaviours ... acknowledged and engaged with as legitimate, meaningful and purposeful" (p. 101).

The process of sharing the moment shows how engagement occurred through diverse types of social interactions that did not rely on advanced speech skills. Activities such as vocal play and routine games have been identified in the child development literature (Bergen, 2006) and applied through intensive interaction with people with profound disability (Nind & Hewett, 1994), but previously have not been utilised with people with severe intellectual disability. The examples of routine and comedic interactions provide practical suggestions of ways to engage with people with severe disability (Johnson et al., 2012). Having fun has been recognised as an integral part of all relationships, rather than confined to relationships involving people with disability (Duck, 2007; Martin, 2007). The value that affinity members placed on having fun together suggests fun needs to be clearly articulated as a potential avenue to positive interaction and developing relationships. Legitimising mirth may result in greater worker satisfaction, a clearer understanding of their role, increased social interaction, and a more attractive workplace for new employees. A more complete discussion of the role of mirth in the workplace is reported elsewhere (Johnson et al., 2012).

The process of connecting fostered a sense of security and adjusted communication. Trust and respect underpinned providing security. Trust has previously been shown to enable people with limited understanding and/or expressive skills to reveal their communication abilities (Dennis, 2002; Jameson, 1998). Further, Andersen (1993), in outlining the dimensions of a relationship, noted that "To trust another is to make a relationship possible" (p. 12). Respect has similarly been identified as a mutual connector in social support research (Antonucci & Akiyama, 1987), and has been promoted as key to successful inclusion for people with a disability (Finlay, Antaki, Walton, & Stribling, 2008; Wolfensberger, 1972).

Training workers to adjust their message has been a focus of improving interactions, but often without success (Bartlett & Bunning, 1997; Purcell, Morris, & McConkey, 1999). Affinity members recognised the need to adjust their communication style in the

absence of prior training, perhaps because developing respect for and enjoying social interactions with a person with severe intellectual disability sensitised them to the interaction skills required. All workers and some family members had some intermittent involvement with speech pathology services. Still, the extent to which access to such services facilitated the affinity members' skills or whether developing a relationship encouraged adjustment to communication style requires further investigation.

The processes of sharing the moment, connecting, and feeling good provided emotional reciprocity. These results are in line with reports of reciprocity in the disability literature on social support (Bogdan & Taylor, 1998; Newton et al., 1995). Tangible reciprocity was not reported by affinity members, but they were rewarded through job satisfaction or feeling happy and special, which were possible drivers to sharing the message. Many family members took on greater responsibility than workers for facilitating the central participants' communication. Perhaps workers interacted in the here and now, in a similar way to the central participants, while family members' deeper emotional involvement and sense of responsibility resulted in a greater investment in the central participants' enduring happiness. Nonetheless, other workers, such as coordinators and program managers, took a more active role in sharing the message with families and across locations (e.g., day service to group home), which may have been due to the responsibilities inherent in their roles. Further research is needed into the skills, roles, expectations, and responsibilities of paid staff in relationship building, thereby shedding light on how to extend relationships for people with severe intellectual disability beyond workers to other community members.

#### *Implications of a model for building and strengthening relationships*

Overall, this relationship process model provides a framework from which to analyse current relationships and assist workers to develop skills in building and supporting relationships with people with severe intellectual disability. An investment in training workers in how to strengthen relationships could result in multiple rewards. One such reward might be workers continuing their relationships with people with disability after they have left the workplace in which those relationships were formed (Newton et al., 1995). The findings of this study also have application for building relationships involving people with speech difficulties associated with other forms of disability. Indeed, some aspects of

the model bear close similarity to the development of relationships described in the social psychology literature (Andersen, 1993; Duck, 1998). It would seem plausible, then, that the relationship processes of people with limited speech and intellectual disability might be similar to those found in people with speech.

There are several limitations to this study that also suggest further areas of research. First, given that only positive relationships were studied, no conclusions can be drawn about the differences between people with positive relationships and those who have less positive relationships. Future research may also investigate different worker characteristics by studying relationship motivations and dynamics of staff interpersonal behaviour. This model of relationship processes involved family members and workers only. It did not include friends without intellectual disability, as none could be located. Further study is required into processes that take place between different types of relationships. Furthermore, translating this relationship process model into a practical training tool and trialling it in the workplace would assist in revealing its usefulness in promoting relationships in everyday situations and identifying any systemic barriers to be overcome.

Relationships consist of dynamic, continuous, and complex processes that rely on communication and are products of personal experience (Duck, 1998, 2007). There remain challenges to fully understanding how to develop and strengthen a range of relationships for people with severe intellectual disability. Finally, it is contingent on policymakers and disability service organisations to ensure that the development of relationships is valued. Such valuing needs to be articulated to workers who can then provide practical support to build relationships for people with severe intellectual disability.

#### **Notes**

1. A broader discussion of this process that includes peers, family members, and workers can be found in Johnson et al. (2012).
2. Referring to a central participant and his two friends with severe intellectual disability.

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