

“They pay me to be a dag”

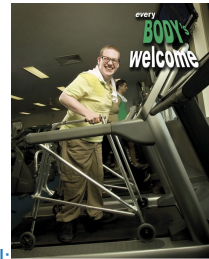
Relationships for people with a severe intellectual disability

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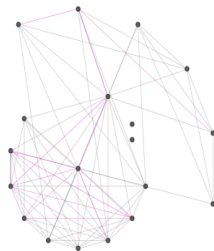
Community living

- Everyone is part of the community
- People with disabilities comprise 20 %
- 3% have an Intellectual Disability
- 1.8 % severe/profound level, Associated disabilities – speech; Complex communication needs

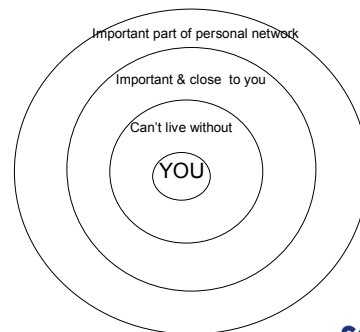


Social networks

- People with whom we are connected to, form a social network (50+)
- People in personal networks give and receive emotional/physical and tangible support
- Our relationships make us feel socially connected (social /community inclusion)



Personal network mapping



My focus

- What supports and maintains positive relationships between adults with an intellectual disability (who can communicate using symbols/words but not have conversations) and people they like.

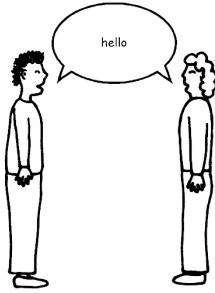


Data collection

- Data were collected over 2 years on 6 networks;
- Participant observation (213 hrs)
 - Field notes
- Range of locations e.g. home, day centres, social activities
- 57 interviews
 - Could you tell me about your relationship with ... and how communication in this relationship occurs?
- Documents
 - Personal plans
 - Individual assessments
 - Minutes of meetings
 - E-mails



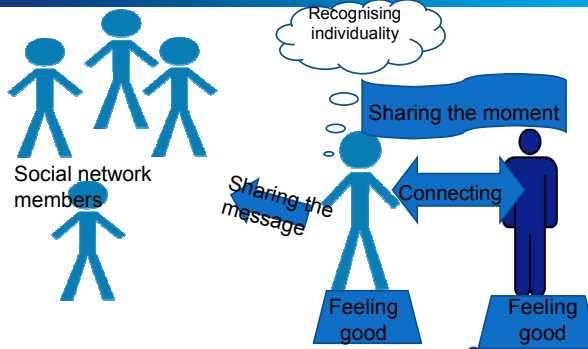
Social network members



- 57 Network members - Family members(22);Paid workers (29);Peers (6)
- 6-14 members in each network
- Family members(1-5); paid workers (2-8)
- 3 networks had peers with ID

scope
FOR PEOPLE WITH A DISABILITY

Relationship model



Social network members

Recognising individuality

Sharing the message

Sharing the moment

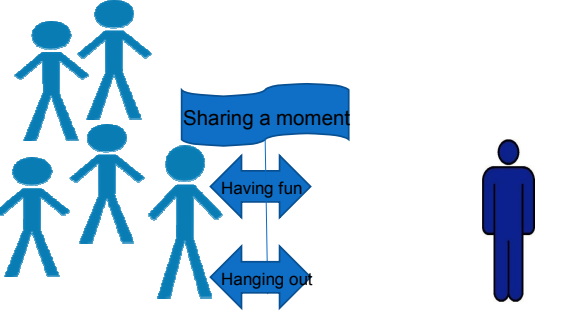
Connecting

Feeling good

Feeling good

scope
FOR PEOPLE WITH A DISABILITY

Step 1a. The central participant approaches a social network member and they share a moment



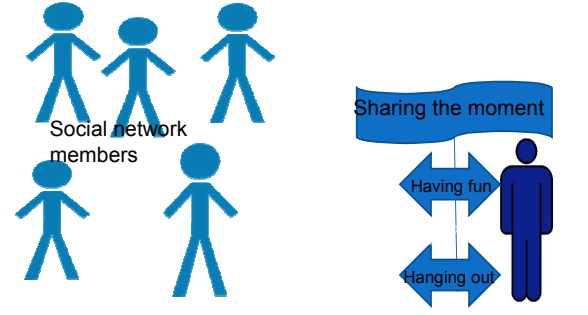
Sharing a moment

Having fun

Hanging out

scope
FOR PEOPLE WITH A DISABILITY

Step 1b. Or a social network member approaches the central participant and they share a moment



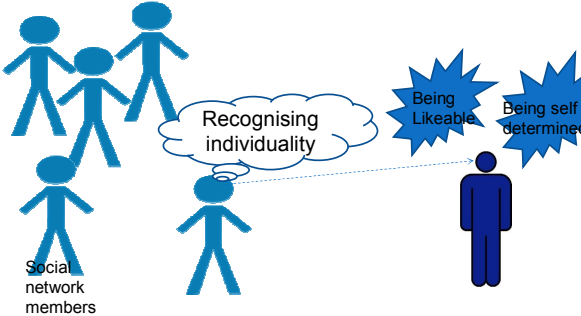
Sharing the moment

Having fun

Hanging out

scope
FOR PEOPLE WITH A DISABILITY

Or 1c. Social network member observes the central participant and recognises individuality



Recognising individuality

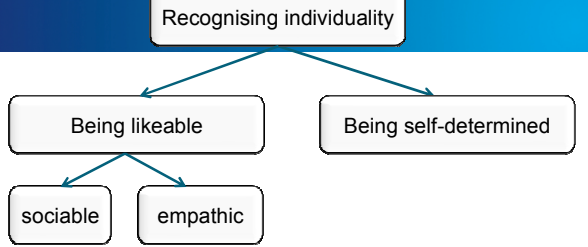
Being Likeable

Being self-determined

Social network members

scope
FOR PEOPLE WITH A DISABILITY

Recognising individuality



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graph TD
    A[Recognising individuality] --> B[Being likeable]
    A --> C[Being self-determined]
    B --> D[sociable]
    B --> E[empathic]
  
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scope
FOR PEOPLE WITH A DISABILITY

Recognising individuality

- Character
 - “He’s a character, he’s a character in his own way....he likes laughing and giggling and carrying on. To me he just seems to do his own thing”(BDSW9).
- Charisma
 - “I tend to be spending more time with him than the other three. I think it’s just because of his personality” (BDSW9).

Personal attributes-being likeable

- Having empathy
 - ‘Nanna’s not feeling well’.. Anyway, I heard him in the kitchen. I’d said ‘where’s Poppa, tell 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 easy-going
 - “I think the fact that he’s so willing, he doesn’t require a lot of hard support to initiate things” (EDO2)

Personal attributes - being self determined-

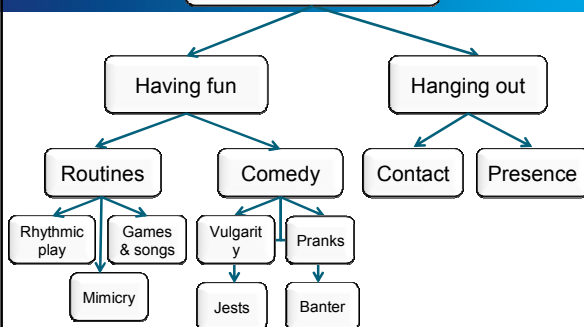


- She does what we would all love to be able to do and that is punch the person in the face who just stole your car park, or take your pants off when you’re hot and just sit there and not give a toss, stick your finger up your nose or scratch your backside in public or your front bits or whatever ... she just cracks me up.(SHSW2)

2a. The social network member who began by recognising individuality now shares a mutual moment with the central participant



Sharing the moment



Sharing the moment -having fun

Short term convivial encounters that result in mutual fun.

- All central participants and network members experienced having fun

- “When we have fun together it’s great. Like when we’re dancing and stuff it makes me feel that I’ve made a difference to her day” (SHSW1).

Sharing the moment-having fun-games and songs

- Well rehearsed songs or rhymes or greetings
- Unique twist
- “With the bus driver he does high five’s, low five’s and the bus driver sort of fakes every so often and pulls his hand away so then Colin starts laughing.” (CDSW12).

Sharing the moment-having fun-games and songs

- Row, row, your boat



Sharing the moment – having fun-mimicking

- She does find it amusing mimicking people, which I love. I find it really good and she doesn’t just mimic, she mimics certain things like a laugh or a stance, the other day, like last Tuesday her dad put his hands on his hips and I stretched and I went “Oooh” like that, so that was more exaggerated, and she went “Oooh” [laughs] yeah, I think its certain things she takes the quirkiness out of people’s personalities. (SHSW3)



Sharing the moment-having fun-comedy-vulgarity

- Dean loves to burp and fart and that burping and farting, you know, Fayeze finds incredibly ... and there’s a running joke that’s been going on for years anytime Fayeze burps, anyone within earshot will blame Dean and she finds that uproariously amusing. (FHO2)



Sharing the moment-having fun-comedy-pranks/practical jokes/slapstick



- She loves comedy like if someone trips, I know it’s a sick sense of humour but if someone trips or dongs someone on the head, she finds that funny. (FF16)

Sharing the moment-having fun-comedy-jests



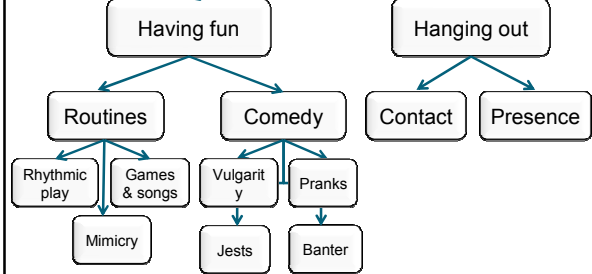
- He came up to me one day, ..and touched my arms and the muscles on my arms and squeezed them. And then squeezed his own. So I’m like oh yeah. So I then squeezed his arms and then flexed mine .. and said like, you know, look at that sort of, look at those guns ..and he looked at me .. and then looked at my gut and then patted my gut [laughs] .. and with a wry smile walked away in front of everyone.(CDSW13)

Sharing the moment-having fun-comedy-banter /jocular talk

Look probably silly things like I might say to her, you know, 'do you want a cup of tea?' and she might not answer me, and I'll say 'if you're not listening to me I'm not going to make you the cup of tea', and my husband might say 'don't give her a cup of tea, give her a beer'. See she finds that really funny ... Also 'oh tell her (me) to shut up', she'd find that funny (DF11)



Sharing the moment



Sharing the moment-hanging out

- Sometimes being in close contact
- Sometimes just being with others



Sharing the moment-hanging out together-presence

We've taken him to the football and we've set ourselves up and sat down to watch football and he's looked at us, got up, walked away, went over, sat right, almost right on top of a couple ..a married couple by the look of them, and sat right next to this bloke and watched the football with him ..know, and we went over and spoke to this bloke ...he said it wasn't a problem, it's OK, and Colin sat there and watched the football with them for the day.(CDSW13)



Group work

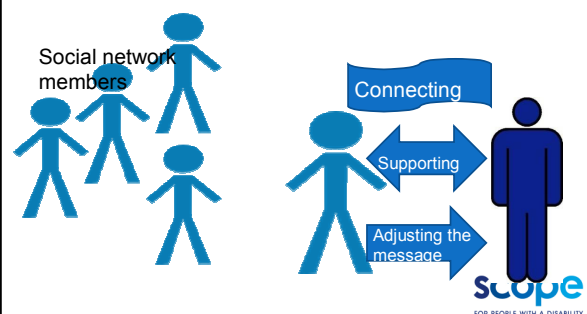
Talk about recognising individuality and sharing the moment

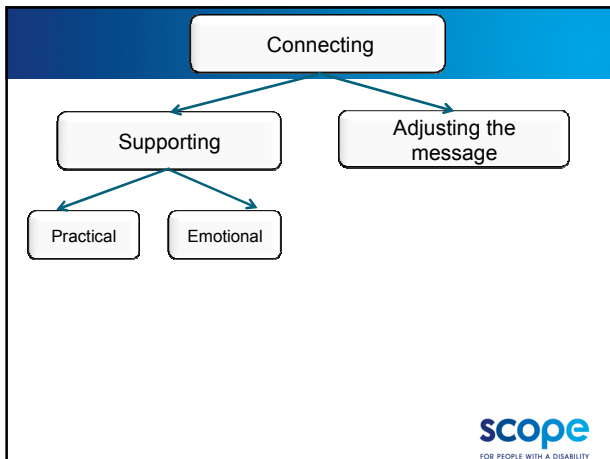
- What do you appreciate about the people you support and how do you do it?
- Share some examples



Remember individual's privacy

3. The network member and central participant engage in connecting.





Connecting

- “It is the privilege of just working with someone for many years” (SHSW1)
- “Initially she would be very apprehensive. She’d only ask for things maybe like drinks, and she’d probably be more accepting of what I suggested, rather than negotiating or asking for something more than I had offered” (FHSW9)
- Emotional support
 - Trust

scope
FOR PEOPLE WITH A DISABILITY

Connecting

Respect

- “ If you relate to him and relate sincerely, that builds a relationship and he connects with you. If you don’t relate sincerely, he doesn’t connect. He’ll relate but he doesn’t connect.” (EDO2)

scope
FOR PEOPLE WITH A DISABILITY

Connecting- Supporting- Practical

- Care & protection
- 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)

scope
FOR PEOPLE WITH A DISABILITY

Connecting- adjusting the message

- Adjusting the message
- Simplifying language
- Speed
- Predicting (Yes/no questions)

- “So you’re adapting what you do.....I think I am. I’m not sort of talking down to him, I’m just becoming a kid myself with him”. (BDSW9)
- “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 a short, short language”. (DDSW14)
- “It sometimes takes a couple of minutes for the message to get through”. (BDSW6)
- I guess over time you could start to learn to predict exactly what, she’s trying to communicate. I mean, often when she starts to cry, you can run through a list of things with her “are you uncomfortable?” and you can try and narrow it down to certain things.(FDO4)

scope
FOR PEOPLE WITH A DISABILITY

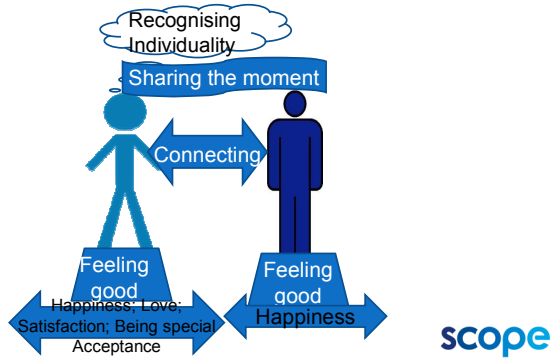
Connecting -adjusting the message

- Using AAC
- Key Word Sign & gesture
- Objects

- A HSW came into the living room and said ‘Want to come and have some lunch?’ There was no response. He tried again ‘Want to come and eat mate?’ Still no response. He then said ‘Colin’ and signed ‘food’ – in a few seconds Colin came to the table. (F/N7D)
- “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 chose the strawberry.” (F/N2D).

scope
FOR PEOPLE WITH A DISABILITY

4. Developing the relationship entails three processes that result in mutual feeling good. The first two processes do not occur in a set sequence and may occur simultaneously.



Feeling good

Happiness
(everyone)

- I think one of the things he gives me is he's bringing me back to live right now in the moment and enjoy what there is in that moment to enjoy. Whether that's laughter or whether that's sharing some experience or whatever it is. ... He just enjoys his life so much, or so much of it anyway and he's great fun to have around. (EF3)

Feeling good- satisfaction

Satisfaction

- "I like having the activity and the fact that every day is so totally different. You don't know what he's going to do. Every minute is totally different. So you just sort of go 'wow'." (CDSW12)

Feeling good- Being special

Being special

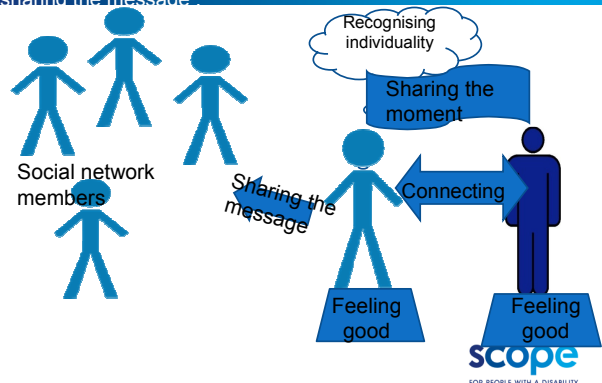
- "Oh yes, he does he calls me 'Ba'. He calls me 'Ba' makes me feel a real winner" (BDSW6).

Feeling good-Acceptance

Acceptance

- "She's just lovely. She's got a lovely smile and you, I can see her expressions when I come in the door... I like the way she looks at you. It's not a go away sort of thing." (FP6)

5. The relationship presents opportunities for others to be involved and enables others to get to know the individual by sharing the message.



Sharing the message facilitates interaction -high stakes charades

- I know what signs he's making when he's referring to his friend you know, if he wants to watch a particular movie, ... but quite often I have no idea. ... he'll be very excited about something and ah 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)

Sharing the message

- Talking to others
 - Across contexts
 - “But it's always good if we've discussed things during the day, Diane's mum would ring me of a night and say, 'she's driving us crazy about something' “(DDO3)
 - Within environments

Sharing the message

- Referring to documentation
 - Getting others to know how to relate
- “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 um to have a look through 'my book'”(CHO1).

What aspects of this model work for you ?

- Recognising the individual
- Sharing the moment
- Connecting
- Feeling good
- Sharing the message

Summary

- Adults with limited communication have positive relationships
- Social networks are small; family, paid workers, peers with intellectual disability
- Recognising individual characteristics and building a relationship take time.
- Having fun and hanging out are key components of social interaction.
- Interactions are short, repeated and about the here and now .
- Sharing the message encourages possibilities for larger networks

Implications for social inclusion

- Inclusion starts with relationships-
 - interaction maybe more important than visiting community spaces.
 - need to examine the functions of Day services- activities or relationships?
- Hanging out – predominantly family and peers
- Having fun needs to be legitimised as an activity
 - having fun is one of areas in Victorian Quality framework for disability services (evidence of service performance)
 - interaction be more prominent in "active support".
 - paid workers may be sought for their sense of humour

More workplace implications

- Develop opportunities for reflection
- Consider different ways to share/exchange information
- Provide++ support for those without family members
- Provide additional AAC resources
- Facilitate peer relationships
- Use support workers as mentors

Interaction in relationships

"What others are depends on
our relationships with them
and what we choose to
make of them"

- Or is It how we choose to support them?

• (Bogdan & Taylor, 1998 p.257)