

'I get a Little Help from my
Friends'

Adults with intellectual
disability discuss loneliness

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Method

- Loneliness Scale
- Semi-structures interviews:
 - Personal profile and demographics
 - Daily activities and occupation
 - Personal networks
 - Friendships
 - Background
 - Description
 - Experience

Participants

- 51 people with intellectual disability with limited to intermittent support needs
 - 22 male
 - 29 female
 - Age range 16 – 52 yrs
 - 42 attending Technical and Further Education college (TAFE)
 - 9 supported employment

(Assessed through records and Scales of Independent Behaviour-Revised)

Deduction from the literature

- Although people with intellectual disability more physically integrated and have opportunity for activities in their neighbourhoods and towns most are still not really part of their communities.

Question

- Do people with intellectual disability experience social isolation and if so does this give rise to an experience of loneliness?
- If loneliness is a consequence how do people with intellectual disability conceptualise this and what would they like to do about it?

Loneliness

- Loneliness an unpleasant experience arising from insufficient social interaction.
- It is a personal experience independent of either quantity or duration of social interaction.

(Peplau & Perlman 1982)

Loneliness Scale

- Asher & Wheeler 1985
- 15 core questions modified to read as first person questions
- Scale modified from 3 point to 5 point scale – card sorting response

Semi structured interviews

- Personal profile and demographics (confirmed by parents / teachers etc)
- Daily activities and occupation
- Personal networks
- Friendships
 - Background
 - Description of best friend
 - Experience of friendships
- Interviews of 'Most lonely' and 'Least lonely' groups (6 in each) analysed in detail

Findings

- Participants who attended special school reported higher levels of loneliness than those who attended mainstream school
- Participants whose primary day activity was TAFE reported higher levels of loneliness than those whose primary day activity was employment

- Ratings of loneliness decreased as reported duration of contact with friends increased
- Older people reported lower frequency of social activity
- Demographic factors did not significantly impact Loneliness scores
- No significant relationship between loneliness rating and the number of participants in a person's social network or the frequency of contact.

- 5 of 6 'Most lonely' people were female

- Describe friend as a loyal confidant who can be trusted, can talk openly and honestly about problems
- Had a friend but frequency of contact not meeting their socio-emotional needs

- 5 of 6 'Least lonely' people were male

- Describe friend as someone to share activities with
- High frequency of contact with friend
- Friend connects them with others – practical support

Description consistent with gender stereotypes of friendships in general population

- Distinct differences between perspectives and experiences of those in Most lonely and Least lonely group
 - Description of friendships
 - Expectations they had of friends
 - Personal experience in establishing, negotiating and maintaining friendships
- Loneliness least evident among those who perceived themselves to be part of a network of people each fulfilling a specific need
- Networks which included people with and people without an intellectual disability most effective in meeting people's social and emotional needs

- Many of the most lonely had difficulty maintaining relationships with people from their past who have intellectual disability
- Loneliness reported where there was discrepancies between expectation and experience

- Scale reliable for assessment and monitoring of loneliness experienced by adults with disability in receipt of services
- Scale could be used to evaluate effectiveness of programmes implemented to enhance quality of life