

Getting in touch

Interactions between adults with congenital deafblindness and
Disability Support Workers

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Overview

- Background to the study
- Research questions
- Study One
 - Research aims and methods
 - Findings
- Study Two
 - Research aims and methods
 - Findings
- Future directions



Background to the study

- Researcher's background
- Key issues from the literature
 - Congenital deafblindness and communication
 - Most research is with children
 - Most research is quantitative
(Janssen et al, 2004, Vervloed et al, 2006, Chen, Klein and Haney, 2007)
 - Disability Support Worker : client interactions
 - Demonstrated need to improve communication
 - Most research quantitative
(Romer and Schoneberg, 91, Jones et al, 99, Healy and Noonan Walsh , 2007)
 - Quality of Life
 - Dearth of literature specifically focusing on people with deafblindness
 - Current measures of potential value
(Reinders, 2002, Petry 2006, Maes et al, 07)

Research questions

- 1. To what extent do adults with congenital deafblindness experience “the good life” as constructed by Reinders 2002?
- 2. What are the current durations and qualities of interactions between adults with congenital deafblindness and the staff who support them ?
- 3. What are the perspectives of Disability Support Workers’ on their interactions with adults with congenital deafblindness
- 4. How do we measure quality of life for adults with congenital deafblindness ?

Study One. Research aims and methods

- Aims
 - 1. To determine the duration and natures of interactions between adults with CDB and the staff who support them.
 - 2. To evaluate the use of a coding system used with adults with severe intellectual disabilities
- Methods
 - Quantitative observational study – multiple single case design
 - Ethics approval
 - Participants – 9 adults with CDB and 9 staff
 - Filming adults with congenital deafblindness during weekday afternoons
 - Coding filmed staff and client behaviours according to the coding schedule devised by Jones et al, 1999.
 - Measuring frequency and duration of interactions

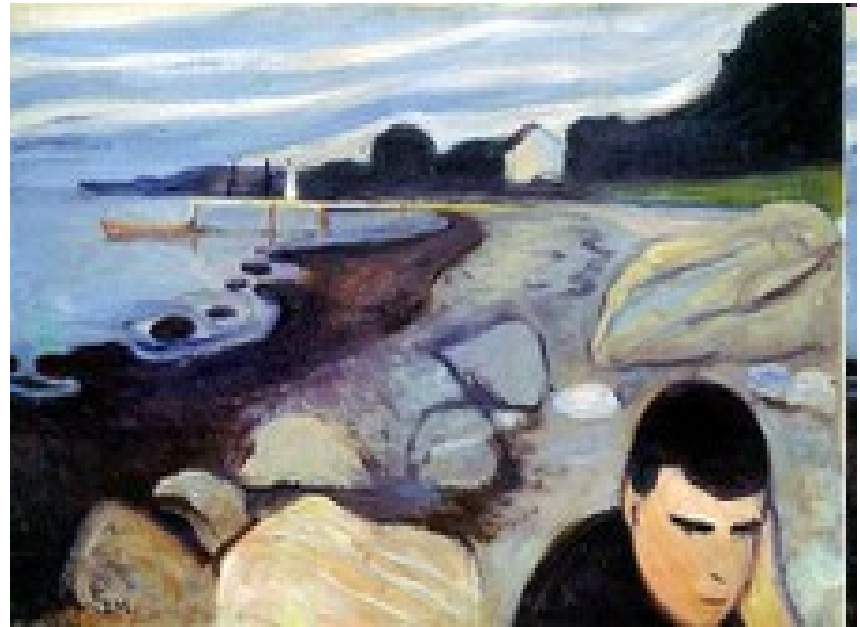
Study One; Findings

- Data collected
 - 34 x 10 minute videos
 - 12 x 100% disengagement
 - 9 x interaction
- Interactions
 - 244 secs / 20400 secs 1.2% of total time
 - Jones et al – 17.5% of total time



Study 1: Findings

- Nature of Interactions
 - Assistance 0.79%
 - Working 0.2%
 - Conversation 0.2%
 - Restraint 0.01%
 - Praise 0%
- Duration of interactions
 - 2 – 78 secs, Mean – 12.5 secs



Study One: Findings

- Inter rater reliability
 - Overall percentage agreement - 89%
 - Cohen's Kappa – Client behaviours
 - Disengagement .89 sig - .01
 - Non social personal .96 sig - .001
 - Non social domestic 1 sig - .001
 - Challenging behaviour .41 sig .13
 - Non social other < .48 sig .001

Study One: Findings

- Inter rater reliability
 - Cohen's Kappa – Staff behaviours
 - Assistance .43 sig .001
 - Processing .46 sig .26
 - Restraint .01sig .93
 - Conversation .28 sig .42
 - Limitations of quantitative study
 - Query to what extent being observed changes staff behavioru
 - Does not account for what is occurring during longer interactions during personal care routines in the unfilmed areas
 - Measuring engagement does not give adequate insight into quality of life
 - Does not account for why the interactions between staff and the adults with congenital deafblindness are so limited

Study Two: Research aims and methods

- Aims

- 1. To ascertain the taken for granted assumptions, values and perspectives of staff influencing their interactions with adults with CDB

- Methods

- 8 staff interviewed about their work with adults with CDB
- Phenomenological study employing methods of analysis described by Glaser 1978 and Charmaz 2006

Interview analysis involved:

- coding the interviews line by line
- inducing substantive categories
- writing memos during coding to support the analytic process - --
----- inducing analytic categories from the disability support
workers taken for granted assumptions about the situation,

Study Two: Findings

- Qualitative analysis
 - 4 central and inter related themes
 - Tacit knowledge
 - Client preferences
 - Client abilities
 - Client states
 - Construction of client happiness
 - Tacit knowledge
 - Absence of negative behaviours



Study Two: Findings

- Accounting for disengagement
 - Disengagement perceived as “relaxing”
 - Client’s perceived as not wanting to engage
 - Staff perspectives on who is in control
- Imperatives of the role
 - Personal care and domestic chores are priorities
 - The role and value of social interaction
 - The significance of routine

Future directions - questions raised

- Issues around inter observer agreement
- Are longer, higher quality interactions occurring at other times of the day in other parts of the house?
- Would staff agree with this interpretation of the interviews?
- How are the values and assumptions of staff impacting on their interactions with the adults they support?
- How do we measure quality of life for adults with congenital deafblindness ?
- What implications do the findings in these studies have for staff training and development?