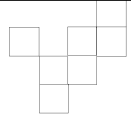


A Person First: Parents' views on carers' communication with their sons and daughters with complex communication needs

Juliet Goldbart & Sue Caton

Research Institute for Health & Social Change

Manchester Metropolitan University, U.K.



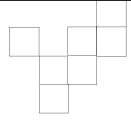
The project brief

In relation to communication and people with the most complex needs –

What works and why this is essential?

Commissioners and funders:

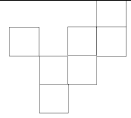
Mencap and the Office of the National Directors, Valuing People Now,
Department of Health



Communication & the most complex needs

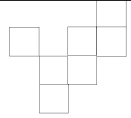
Children and adults with

- Profound disabilities
- Severe autism
- Severe learning disability and challenging behaviour



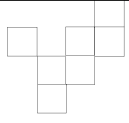
Information sources

- Survey of intervention literature
- Interviews and focus groups with parents and family carers
- Email “interviews” via the PMLD Network
- Email “interview” with international group of peer reviewed writers/researchers
- Data from UK S< survey



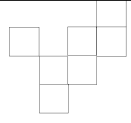
Questions

- What are the most useful strategies in communicating with your son or daughter?
- What do you think other people should know about your son or daughter's communication?
- What communication strategies help your son or daughter to have some participation in the community?
- If your son or daughter has a direct payment or personalised budget, what are you looking for in terms of communication skills when they employ carers or personal assistants?



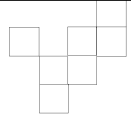
Data Collection and Analysis

- Focus groups and some interviews were audio-recorded. In some interviews detailed notes only were taken.
- Email responses were cut and pasted from the email into Word files to preserve anonymity.
- The data were pooled and content analysed



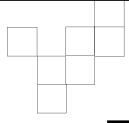
Issues arising

- Ways of capturing and sharing information
- Formal or named approaches
- Informal approaches or strategies
- Staff training
- Communication and community participation
- Other concerns



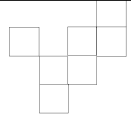
Capturing and Sharing Information

- Communication passports, communication dictionaries, hospital passports quite extensively used and valued
- It enabled hospital staff to “see my son as a person” (parent)
- No research but see Ashcroft, 2002; Millar and Aitken, 2003; Russell, 2002.



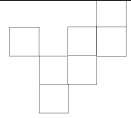
Formal or named interventions

- Parents were familiar with specific approaches used with their sons and daughters.
- Signing (15 BUT 2 have reservations and 5 idiosyncratic); Photos or symbol books (8); PECS (8 BUT 4 have reservations); High-tech AAC (5); Intensive Interaction (2); Switches (2); Music Therapy (2); Objects of Reference (1).
- None mentioned narrative approaches.



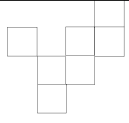
Informal strategies

- Taking time to become familiar with the individual, their personality and communication style
- Consistency
- Use of familiar routines
- Clear, simple input
- Music
- Opportunities to make choices



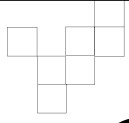
Staff training – key points

- People who know the individual well should be closely involved in training.
- Nothing can be achieved unless staff had a positive, caring attitude.
- Well supported by research (e.g. Bloomberg et al, 2003; Chadwick and Jolliffe, 2008; Forster and Iacono, 2008; Hostyn and Maes, 2009)



Staff training priorities

- Knowledge & Skills: Specific approaches to signing and AAC; Intensive Interaction; PECS; that CBs may communicate pain.
- Attitudes & characteristics: Consistent, patient, positive and inclusive, empathetic, caring, committed to people with complex needs, seeing service users as the priority, trustworthy, understanding of health and behavioural issues, able to form relationships.

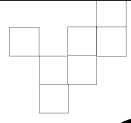


Communication and community participation 1

“‘community’ is founded upon relationships rather than a place or an activity.”

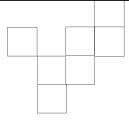
Connecting People (Wightman, 2009)

“It must be very frustrating to be on the periphery but not participating.” (Parent)



Communication and community participation 2

- Activities and settings which are both physically and intellectually accessible
- Trained and responsive communication partners who are familiar with community settings and resources
- A smile and a recognizable greeting
- Portable AAC &/or communication passport



Other concerns

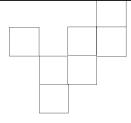
- Communicating with health professionals

“How can you trust them when they’re trying to write her off all the time?”

New project: Knowing when I’m sick & helping me stay healthy

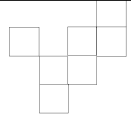
- Negative judgements of health & social care staff

“Why do we have professionals when it's families that find solutions?”



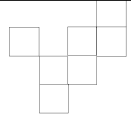
Key issues for parents

- Communication with people with the most complex needs is most successful with familiar, responsive partners who care about the person with whom they are communicating.
- Informal communication strategies are crucial
- Communication or hospital passports must be available and used.
- Parents want to contribute to staff training.



Implications

- We need to attract, train and retain high-quality staff who are committed to providing diverse and satisfying communication opportunities for the people for whom they work.
- In health settings, the lives of people with learning disabilities must be valued.
- Would greater involvement of parents in recruitment and training help this?
- What else do we need?



Thanks to

- the many parents and family carers who gave their valuable time and sent us information and resources
- the researchers who sent such detailed and informative responses
- Challenging Behaviour Foundation, PMLD Network and PAMIS
- the expert readers for their feedback
- Beverly Dawkins of Mencap and Sue Carmichael from Department of Health