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Quality of communication support for people with intellectual and developmental disabilities living in adults social care

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Dr Jill Bradshaw



# Overview

- Background – why this research
- Methods – what we planned
- Results
  - The participants
  - Quality of Communication support
- Understanding our findings

# The quality of communication support – what do we know from research?

- Communication from staff matching service user need – 1/3.
- Service user communication getting a response – 50%
- Vast majority of communication from staff verbal (over 80%).

# What are communication passports?

- Tool for supporting people who cannot easily speak for themselves by making information from formal assessments easily accessible to all. They contain information about the person in a very clear way.
- Provide a positive introduction to the person and so does not just include information on challenges and disabilities.
- Include information about the person's own views and preferences.
- Describe how to communicate, including ways to present information and how to best present information to that person.
- Include information from all of the places where individuals spend time (e.g. home, work, social care).
- Done well, communication passports are easy to read, informative, useful and fun.

# What do we know about communication passports?

- Parents and practitioners are positive about communication passports;
- Most studies did not look at impact of the communication passports;
- Only 3 studies included adults.

(Bradshaw *et al.*, in submission)

# Methods

- Compare people who used and who did not use communication passports in terms of:
  - Communication partner views of communication;
  - Observations;
  - Assessments;
  - Service user views.

# Participants

- Approached 24 eligible services, supporting 224 people, of whom 53 were described as being passport users. Four services agreed to take part. Support provided by 5 providers.
- There were 29 service users in total, with 10 passport users.
- We interviewed 60 staff (average length of interview 24 minutes, range 11-31).
- Staff had worked in services for an average of 12 years (range 2 months to 35 years) and had worked in their current post for an average of 7 years (range 2 months to 30 years).
- We interviewed 5 family members (average interview 31 minutes, range 25-35).
- We interviewed (using Talking Mats) 4 service users.

# Service users

- 52% male and 48% female
- 96% white British
- Average age 57 (range 39-86)
- ABS score average 117 (range from 27-201)
- **ABS scores below 151 = 22**
- Physical disability 24%
- **Hearing loss 7%**
- Visual loss 21%
- Mental health difficulty 21%
- **Autistic 17%**
- Epilepsy 17%
- **At least one behaviour described as challenging 93%**



# The quality of communication passports (n=9)

- Passports were generally very poor
- Limited individualisation, not accessible, information on communication vague
- Staff communication *was not rated as more appropriate* if person had a communication passport
- Staff communication *was not rated as more appropriate* if person had a speech and language therapy assessment

## The observations (n=24)

- Those who were more able were significantly more likely to be receiving better support ( $z=2.065$ ,  $p=0.039$ ,  $n=24$ )
- Two people were observed to receive good support for choice (8%)
- Three people (12%) did not have any choice offered during the observations.
- Although staff were clear that people needed Augmentative and Alternative Communication (AAC), only 4% of all staff communication included any formal AAC (in this case signed communication) – that was for just one individual.

# Where do staff learn about communication? (n=29)

- Learning from files or from other staff or learning as you go
- Only three staff mentioned getting information about communication from families (5%)
- Only three staff mentioned getting information from SaLT report (relating to 2 individuals)
- Only two staff mentioned training in communication

# Understanding our findings

- Staff perception of role
  - “I have finished all my jobs on the unit and so there is nothing left to do”*
  - “I think he might be a bit bored”*
- My choice vs your choice
  - “it’s their choice to watch television”*
  - “you can’t tell staff what we have to do, you have to wait and see who is going to take you”*
  - “she does use Makaton but not many of us do”*
  - “I can’t sign, I don’t sign”*
- In the moment
  - “He would expect it now and he would not stop asking for it”*
- Perceptions of communication
  - “I don’t have a problem communicating with him but how much of it he takes in, I don’t know”*

## **Summary: Quality of support for communication, including communication passports, was generally poor**

- This was a reflection of:
  - lack of knowledge about service user communication strengths and needs;
  - lack of knowledge about how to address communication needs;
  - missed opportunities to engage in communication and interaction;
  - lack of knowledge about (and value given to) AAC;
  - misunderstandings about choice;
  - lack of knowledge about the need for structure and predictability;
  - differences in understanding about the role of staff in supporting engagement in activities, communication and relationships.

# Implications:

- Better (statutory) training about communication and interaction, with practice leadership to support and motivate staff to implement good support;
- Create opportunities for communication and interaction, staff need skills in AAC and providing positive and enabling environments;
- Better information is needed regarding individual's communication strengths and needs, both from formal assessments and from sharing information across teams and between families and those working in services;
- Future research is needed. A useful starting point might be to find better ways of identifying information about service user communication. Following this, researching interventions around supporting staff to better understand and meet service user communication.