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**Kent**

Tizard  
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## Involving People

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# Seldom Heard Project

- The Challenging Behaviour Foundation and the Tizard Centre have been working on new and creative ways to improve how we listen to these individuals. We have been supported by an advisory group which includes family carers, providers, Mencap and PMLD Link.

# Aims

- Having their views heard by NHS England via a report.
- Getting a personalised tool with ideas about how best to gain their views and support better communication, choice and control. This can be used by families and caregivers to make sure their views and preferences are always taken into account in the future.
- Helping to show how everyone's views and preferences can be heard.
- Helping influence how the NHS delivers support to people with learning disabilities and autistic people.
- Influencing better support and ensuring services are designed that truly meet the person's needs and preferences.

# Participants

- Participants were varied in terms of age, communication partner (e.g. family member or paid supporter), age (children and adults), where they lived (e.g. at home with families, in residential adult services or residential schools and whether they attended any day provision. All participants were described as having at least severe learning disabilities with at least two with more profound learning disabilities. Some communication partners had daily contact with the individual and some had less contact.

# Working with individuals

Detailed interview about:

Communication and interaction skills;

Current methods of involvement;

Issues in relation to the key questions;

Priorities;

Trying things out and feeding back.

# Communication and Interaction Skills

- Communication skills varied. All participants had complex communication challenges. Some participants had formal ways of communicating and interacting e.g. able to communicate using single words (or Makaton signs) or short phrases. Other participants were much more reliant on other people to interpret and make sense of their vocalisations, body movements and facial expressions etc. These participants were not able to use formal methods of communication

# Current methods

- Often informal;
- Different approaches between home and non-home;
- Individual immediate daily decisions vs longer-term planning;
- Very dependent on 'services' capacity to listen and respond creatively and flexibly;
- Lack of 'agreed methods of communication' (formal or informal);
- General good strategies needed for unfamiliar communication partners + specific strategies for that individual.

# Issues in relation to the key questions

- Contrast between when others listen and when they do not;
- Contrast between when events are planned and where they are not;
- Planned events that do not do the above usually result in very negative experiences – no better than unplanned health events;
- Recognition that although the above are focused in ‘listening’ to communication partners – these are essential ‘core strategies’ that need to be in place to create optimal environment so that person with learning disabilities will be enabled to use the communication and interaction skills that they have;
- Lack of information on best interests, particularly for those moving from child to adult services;
- Trauma of people’s poor experiences of healthcare;
- Unmet needs/lack of consideration given to sensory issues.



# Developing methodologies

- Talking Mats;
- Observations from existing pre-recorded videos with communication partner and researcher viewing these together than communication partner providing commentary;
- Comparing and contrasting good and poor experiences of health care;
- Specific suggestions for developing communication methods;
- Suggestions from researchers for more video recordings;
- Data recording of positive vs negative experiences of daily events;
- Planning for health visits that will be taking place within the duration of this project;
- Review of speech and language therapy reports;
- “Grab bag” in place for unplanned visits;
- Communication ‘key issues’ document preparation for health professionals.

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