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Seldom Heard

Introduction

Everyone has the right to have a say about their own life and about wider issues that impact on them. This includes children, young people and adults with severe learning disabilities and profound and multiple learning disabilities. In reality, we know that these peoples' perspectives are seldom heard. This can be because people think it is impossible, but this is not true, it just requires more skilled and creative approaches.

In 2017 we published a report called Valuing the views of children with a learning disability showing how a range of people were using different methods to understand the views of children with learning disabilities. In 2021 we will publish a report called Stop Look and Listen to me. This report details methods developed by the Challenging Behaviour Foundation and the Tizard centre to understand the views and perspectives of young people with severe learning disabilities. We did this as a pilot for the Seldom Heard project.

In recognition of the need to get better at seeking the views of children and adults with learning disabilities and more complex communication challenges, NHS England has funded the Seldom Heard project. The Seldom Heard project builds on existing good practice around listening to and involving people with severe and profound learning disabilities. We all need to be more creative to make sure we listen properly to everyone, especially about decisions that make a difference to peoples' lives. This includes people who might not have their views and preferences considered, for example:

- Children and adults with severe learning disabilities;
- Children and adults with profound and multiple learning disabilities;
- People with learning disabilities who are also autistic.

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.

The Seldom Heard project will use these methods to find out about the views and preferences from nine people. We will try to find out how to deliver better support to people with learning disabilities.

Children and adults who take part will benefit by:

- Having their views heard by NHS England. We will write a report;
- Getting a personalised tool with ideas about how best to gain their views and how to 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.

This article reflects on our learning to date, with a particular focus on identifying families, consideration of whether or not individuals would like to take part and the impact of the pandemic.

Identifying communication partnerships and explaining the project

We had help from our advisory group to understand the definitions and to clarify the individuals we were looking for in this project. Our advisory group had highlighted that they felt that many projects had not included people with the most complex communication challenges. In order to do this, we advertised through our existing networks.

We had an initial phone call with interested people. This was to:

- talk through the project;
- check shared understandings about this group.

That this was an exploratory project and needed an individualised process. We were aware that individuals (paid supporters and family carers) had limited time available and so this initial meeting was brief. Those interested were then contacted to go through consent processes. As expected, this group of people are those with the most complex communication needs which therefore means that people were unable to comprehend the abstract nature of the project and therefore unable to consent. Therefore best interest processes were followed as needed. Independent checks were carried out on best interest decisions.

For the best interest process, we needed quite a sophisticated understanding of each person's communication and interaction skills, particularly around indicators of pleasure/distress. At the same time, people expressed interest in this project because they wanted to develop their shared understandings of such issues and so some information was less clear at this point.

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. Some communication partners had daily contact with the individual and some had less frequent contact.

We wanted our processes to be complete so that individuals had all the information that they needed. However, providing detailed information was not always consistent with our commitment to making the process as easy as possible for those who had expressed an interest in the project as it took time to go through all the information.

Something about during this during pandemic

This project started in early 2020. As the reality of the pandemic became clearer, the project paused until November. We then (hopeful of a more normal life) started to identify possible families with the hope of being able to do at least some direct engagement work in early 2021. It became apparent as we moved back in to lockdown that the project needed to take place online, particularly as people with severe or profound learning disabilities had been identified in the group of people who were clinically extremely vulnerable.

Whilst we were confident about our ability to work through communication partners, we were also aware that:

- Everyone was tired and all experiencing challenging circumstances;

- Unpaid carers for this group always have very many challenges on their time and these have been amplified by loss of services;
- People with PMLD have also lost so much and the need for this project has become even greater .

Moving forward

Our online engagements are about to start and we aim to report our findings in Summer 2021. We will co-produce this process with communication partners, identifying what the focus of gaining views should be and any opportunities to find out views directly from the individual. This might include asking communication partners to observe the individual in different situations and think about the evidence there is that the individual might have preferences for what has happened in each situation.

We plan to disseminate our project widely and we are setting up a project website where people will be able to sign up for updates.

Families told us that it was important that information about the project was circulated from trusted networks. We have had a huge response which is a good indication that this issue is something that is very important. However, we are of course aware that this might mean we have contacted families/individuals who are already known to us. On balance, we felt that at this stage, we needed to demonstrate that we can do this work. Our plan moving forward (subject to funding) is that that we can then disseminate and plan for wider engagement. In doing this, we want to be able to demonstrate to other organisations what is possible and to support them to consult much more widely with this group.

The Seldom Heard project builds on existing good practice around listening to and involving people with severe and profound learning disabilities, including:

Supporting people with profound and multiple learning disabilities: core and essential service standards, Doukas et al (2017) (www.pmlmlink.org.uk/wp-content/uploads/2017/11/Standards-PMLD-h-web.pdf)

Mencap and BILD's 'Involve me' project – see the practical guide, evaluation and top tips summary (<https://www.mencap.org.uk/advice-and-support/profound-and-multiple-learning-disabilities-pmlD/pmlD-involve-me>)

Raising our sights: communication how-to guide (https://www.pmlmlink.org.uk/wp-content/uploads/2017/10/2012.340-Raising-our-sights_Guide-to-communication_FINAL-1.pdf)

Communicating with people with the most complex needs: what works and why this is essential, Professor Juliet Goldbart (https://e-space.mmu.ac.uk/198309/1/Mencap%20Comms_guide_dec_10.pdf)

Communication as a human right, Sue Thurman, PMLD Link, Spring 2011
<https://www.pmlmlink.org.uk/issue/speaking-up-being-heard/>

[Valuing the Views of Children with a Learning Disability Report \(challengingbehaviour.org.uk\)](http://challengingbehaviour.org.uk)

Stop Look and Listen to me (not yet published)

The Seldom Heard Project Group

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