

'Towards good practice: how people with PMLD are living good lives and participating in telling their stories'





‘Social inclusion and making connections with a person who communicates without words.
The experiences and views of communication partners from her wider social circle.’







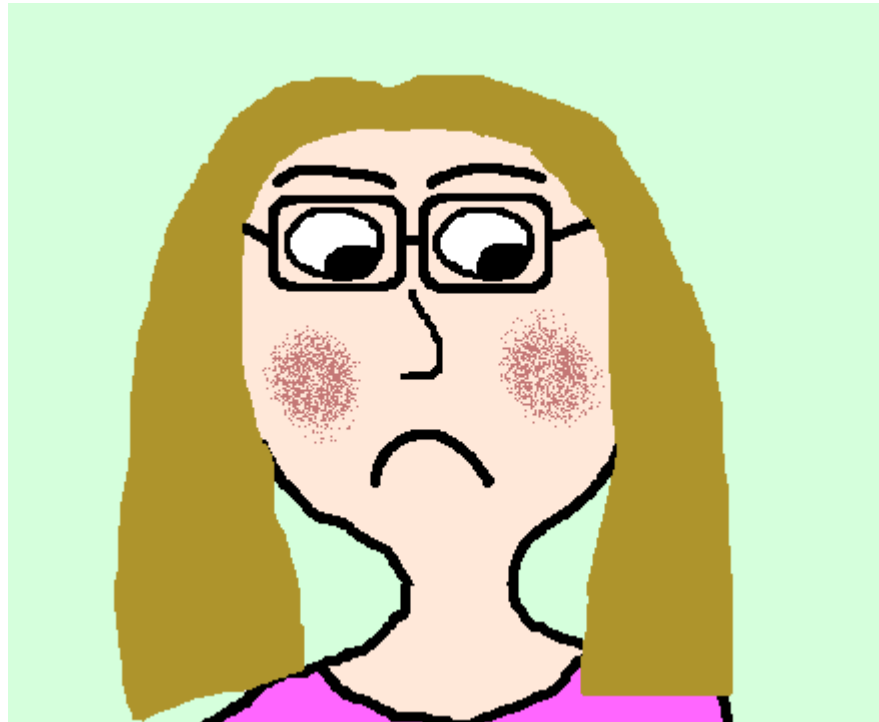


'When I did not know Johanna very well I underestimated how responsive she was or could be' (Julia).

'It is difficult because it is hard to understand her response' 'I feel really frustrated that I can't communicate with her. I would like to do more, but I don't know what to do' (Richard).

'I would have appreciated some quite well scaffolded direction. For example, she does not like being touched there, but she does like this or that would be nice' (Julia)

'When I did not know you very well, I had things going on in my head that I wanted to communicate and I did not know the right way to do it. I did not want to embarrass anybody. I did not want to do the wrong thing.' (Julia)



I do feel more relaxed having seen all the other people who are communicating. Being part of a group is a safe way to learn.’ (Julia)



Scope have found that people do have a fear of getting it wrong when they try to be with a person with PCLD.



Here is the link to their 2014 report:

'Current attitudes to disabled people'
<http://www.scope.org.uk/About-Us/Research-and-Policy/Publication-directory/Current-attitudes-towards-disabled-people>



'I would explain to them that if they are scared then they would not be so smiley. Then Johanna would not be so smiley and then maybe she would feel nervous too and not be herself. She would maybe be picking up their feelings. Then they would think that this is how she is normally and so it would go around and around into a bad place.'

The history of segregation and segregated services lead to barriers within the communication partner.

- **Lack of knowledge of disability issues and of the person with disabilities**
- **Anxiety and discomfort**
- **Avoid involvement**
- **Difficulties with empathy**

Difficulties directly related to the person disabilities.

- **Physical access problems**
- **The person with PCLD's reactions to their environment**

Difficulties that originate in the person with disabilities but affect the social interaction

- **Communication difficulties**
- **Behavioural problems.**

Reducing difficulties which originate in the communication partner.

- **Communication with a person with PCLD may be learnt over time.**
- **Offer opportunities to learn about communication strategies.**
- **Communication passports can improve communication and inclusion.**

Improving physical access.

- **Physical access to public and private buildings needs improvement.**

Increasing opportunities for inclusion.

- **Shared activity with a common purpose or intent may lead to friendship, improved communication and inclusion.**
- **Other societies can indicate new ways of being inclusive**

Increasing tolerance in society.

- **It is important that society gets used to seeing people with disabilities from an early age, in ordinary settings.**
- **There needs to be increased public knowledge of disability issues.**
- **Media could be used to portray positive images.**



- Have you ever felt that you have made connection or shared a joke with Johanna?

- What happened?

- How do you communicate with Johanna?

- Have you ever spent time as a friend with a person with PCLD?

- How would you help other people to include somebody like Johanna in your day to day life.



*'If **being loved** is the most important thing in our lives, then the most important thing is something we cannot do by ourselves or on our own'* (Hans Reindeers, 2011).

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