



Research Priorities for Learning Difficulties Project

Project participant feedback & interviews

Workshop Feedback

"I found it a very enjoyable day and learned a huge amount about the subjects under discussion from the other participants, especially the young people with learning disabilities who were involved. I thought it was very useful to have such a clearly structured, tried and tested process led by very able facilitators who had run it many times before, as this helped to allay any fears about whether we were trying to simplify the un-simplifiable.

I felt very happy with the end result we came up with and I thought the facilitators did a good job of helping us to own it (especially with the group photograph which I look forward to seeing). I thought the day was good in not trying to achieve too much - one task essentially - which made it manageable and allowed everyone space to contribute. It's so unusual for service users to be 'properly' involved in research decisions that I think this is a very valuable way of doing things and I'm pleased to have been part of it."

Parent

"We loved being part of this amazing project, thank you so much for including us in it. My son is very proud of his contribution to the final results."

Parent

"It was a very interesting and informative day. Very well organised and clearly set out with specific goals in mind. Great to have such a mixed group of people participating and hearing different views and priorities. Also challenges some perceptions I had over what questions others would prioritise. People happy to discuss differing points of view but end on compromise at times and were always respectful of each other's views."

Health Professional

"I thoroughly enjoyed taking part in the recent workshop. I felt the organisers were particularly welcoming and helpful. The organisation of the day and the groups, including facilitation, was excellent.

I did think there were too many questions to rank prior to the workshop, and it seemed that other people also preferred to look at their top and bottom 3 questions. Perhaps there were too many questions for the workshop event. Professionally, and personally, it was enriching to hear the views of a range of participants – particularly parents and young people. I did wonder about the balance of participants, for example health and education, as I realise we are all likely to have different priorities in terms of our own work."

Education Professional

"I enjoyed my day taking part in the day organised to discover research priorities for learning difficulties as it not only important but valuable for the right research to be carried out to have a positive impact on the young people.

The day was well structured and encouraged a collegiate atmosphere.

There were a variety of participants from all sectors with an interest in learning disabilities that allowed for debate around the possible research priorities.

To hear the views of those taking part as they related to their own personal circumstances did provide food for thought and made for interesting discussion. People did give their opinions and I feel although difficult at times the conversations did provide fair solutions backed up with reasoning."

Professional

"I found that the workshop was very useful in establishing the main research priorities that could be agreed by all the participants who were there on the day. It was good to see the way in which people gradually altered their views as a result of the discussion and finally found priorities with which they were happy. This was largely as a result of the facilitators who guided the participants gently towards consolidating the views of the majority.

The process of narrowing down the priorities to ten was never going to be easy with such a diverse group, but even though all the research areas were important we all found that it was possible to reach agreement, and no-one went away feeling their views had not been heard."

Professional

Interviews with Young People

Stuart and Matthew

What learning difficulties do you have?

We both have fragile x which means we find some things hard to do and mum or dad help us a lot.

Can you describe in your own words what the workshop day you went to was about?

Sorting lots of questions into order and to find out what people might want to do in research.

What did you think of the workshop day?

It was a long day – we were able to help a bit in the morning (with dad's help) with what questions we think are important but then found the afternoon hard as didn't really understand what was happening [ordering/prioritising of questions].

How did it make you feel to be part of the day and part of the workshop?

Cool! We like being part of things to do with fragile x and even though we couldn't do science in school mum and dad say this is better as it is real science in action.

What research into learning difficulties would you like to see happen?

Stuff about being adults. We will have fragile x forever so questions also need to be about life in general [transitions, employment, independent living, comms/technology] and not all about school/early years. Dad says we are going to spend a lot of our life away from school so need to understand learning difficulties generally better for day to day living.

Sam

How did you first hear about the project?

I was emailed by Dyslexia Scotland and asked if I would be willing to take part in a workshop to pick the research priorities.

What were your initial impressions?

Really interesting and I was very happy talking about my own dyslexia and opinions and that people listened. I'd imagined lots of high professionals and I wasn't sure if I'd have to just listen.

If was hard to whittle down the priorities as lots were really good.

What did it mean to you as a young person to be asked to choose the priorities?

Brilliant as a young person and with family members who also have dyslexia. It is so good that young people have had as much of a voice in setting the top 10 as parents and professionals. Kids, as much as adults, know what is important when you have a learning difficulty. Young people having a voice and speaking up about what things help is very important.

Were there any particular things that stood out from the day for you?

Speaking to the wide variety of people. I spoke to an educational psychologist and it was nice to have a conversation on a different level as previously it has always been about tests. Also fascinating to hear their thoughts in the coffee breaks. One other young person stood out as fantastic. They were 13 or 14 with lots to say about their own opinion and it was great to hear everyone discuss his opinions. It was amazing he was asked at 13/14 as I was surprised at 20 years old to be asked. I think it might have given him the confidence to speak to other people about his learning difficulties.

What are your hopes for the research priorities?

That people will pick them up and believe it will benefit the education of people with dyslexia and general awareness. In this day and age when one in ten kids is dyslexic and lots of people go through life undiagnosed, I want people to be more accepting. It would be great it that can come out of the priorities as well.

Young Person 4

Can you describe in your own words what the workshop day you went to was about?

It was about telling what is important to people with Learning Difficulties so that the university knows what to study.

What did you think of the workshop day?

All the questions were good and important. It was interesting to hear other people's opinions. The room was huge and it looked really old on the outside but new on the inside. It was good to come back into a big group out of the little groups as some of the reasons people gave I hadn't heard.

How did it make you feel to be part of the day and part of the workshop?

Because I have learning difficulties if felt good that I was invited to decide what was important to be worked on for other people with learning difficulties. It felt a

little weird being one of only four kids there.

What research into learning difficulties would you like to see happen?

I was fine with the top 10. I'd like to see all children with learning difficulties take 10 minutes out of school and go to a place and meet and get to know each other and talk about what they need. Just 10 minutes though so that it wasn't being out of school all day.