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Families affected by learning difficulties help shape research agenda

Young people with learning difficulties and their families have helped to identify key areas of research that could improve their lives.

Ten research priorities – which include devising approaches to tackle bullying and creating the best learning environments – will be used to inform new research initiatives at the University of Edinburgh and worldwide.

The list is the result of a consultation to better understand the needs of people living with learning difficulties and professionals who support them.

Estimates suggest as many as one in five children in Scotland has a learning difficulty, which are often linked to conditions such as dyslexia, ADHD and autism.

Tests to spot early signs of difficulties and identify the best ways that professionals can support families were highlighted as key goals in the consultation.

More than 700 responses were received from across Scotland during the consultation, which was promoted by charities, professional organisations and on social media.

The project was led by The Salvesen Mindroom Centre and the University of Edinburgh in partnership with the James Lind Alliance, a non-profit organisation that helps set research priorities.

Project leader Professor Anne O’Hare, Director of The SMC Research Centre for Learning Difficulties at the University of Edinburgh, said, “It is vital that people with learning difficulties are given a voice and are involved in research design from the outset. We are delighted to now have clear priorities for our research going forward and are hopeful that the project will lead to improvements in diagnosis and support.”

Christine Carlin, Chief Executive of The Salvesen Mindroom Centre, said, “Today’s launch is an exciting step towards ensuring that every person with a learning difficulty in Scotland receives the recognition and the support they need to achieve their potential. We look forward to working alongside the University of Edinburgh and wider research community to make that happen.”

Ranked among the top universities in the world

Sam McGovern, ambassador for Dyslexia Scotland and a young person who helped choose the top 10 priorities, said, “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.”

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Additional notes:

The 10 research priorities for learning difficulties are:

1. What knowledge, skills and training do educational professionals need to identify the early signs of learning difficulties and provide optimal support for children and young people affected to help them achieve the best possible outcomes?
2. What is the best educational and community environment for children and young people with learning difficulties?
3. How can multiple types of professionals work together with parents and carers to improve identification, diagnosis, interventions and treatments and achieve the best outcomes for children and young people with learning difficulties?
4. Which early interventions are effective for children and young people with learning difficulties, at what ages and stages are they best introduced and what are the long-term outcomes?
5. What knowledge, skills and training do health, social work and "third sector" (e.g. charities and support services) professionals need to understand the best support to give children and young people with learning difficulties and their families/carers?
6. How can parents, carers, brothers and sisters and extended families of children and young people with learning difficulties, be best supported to achieve their best quality of life before, during and after the diagnosis or identification in home, school and community contexts?
7. How can we best identify early features, symptoms and signs of learning difficulties amongst children, young people and their families/carers?
8. What is the best way to assess learning difficulties in children and young people?
9. Which strategies are effective in preventing stigma and bullying towards children and young people with learning difficulties?
10. Which strategies are effective in helping children and young people with learning difficulties live independent lives, including during times of transitions?