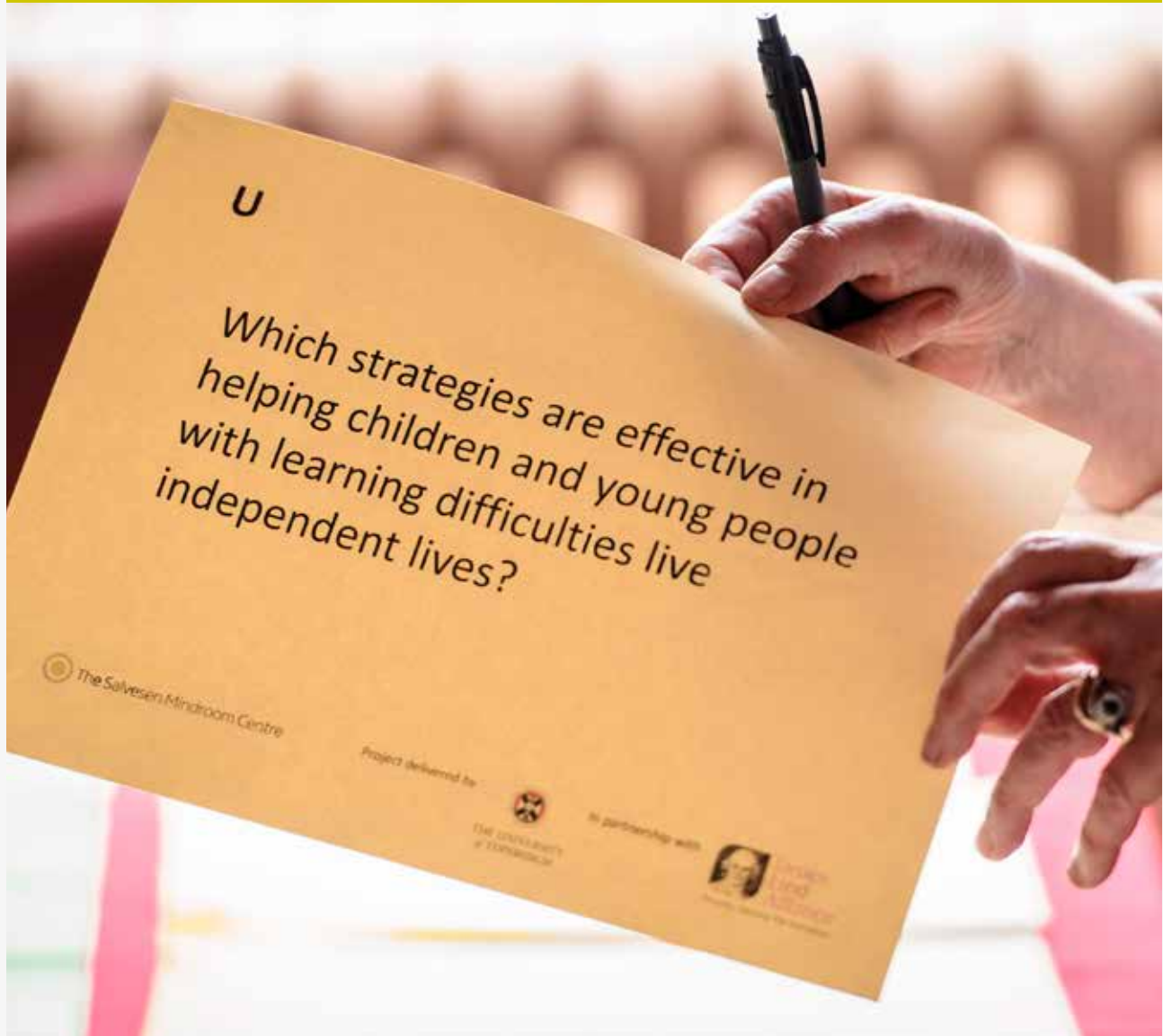




Research Priorities for Learning Difficulties

Final Report



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Thank you also to the individuals and organisations who helped promote the project, our steering group members and the James Lind Alliance.

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Top 10 priorities for learning difficulties research

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?

"It is so good that young people have had as much of a voice in setting the top 10 as parents and professionals"

Young person with learning difficulties

Why set priorities for learning difficulties research?

It is estimated that as many as 1 in 5 children and young people in Scotland lives with a learning difficulty – a massive section of our society.*

Individuals affected by learning difficulties, their families, and professionals in health and education report that children and young people are often not given the support they need with their learning difficulties. This can mean that people may not reach their full potential in life, to the detriment of themselves, their family members and society.

There are many unanswered questions about learning difficulties and what they mean for children and young people and their families. It is widely agreed that more needs to be done to reduce the barriers caused by learning difficulties. However, at the start of this project it was less certain what should be done first in order to make the most difference, and what areas mattered most to those personally and professionally affected.

This research priority setting project was designed to address this issue by identifying the unanswered questions about learning difficulties from the children and young people affected and from their families. Questions were also collected from healthcare, education, social work and third sector professionals who work with children, young people and their families.

The project prioritised the questions that survey respondents and representative young people, families and professionals, agreed to be the most important. The result is a list of the top 10 research priorities for learning difficulties.



*Based on Scottish Government figures for children with additional support needs.

What do we mean by learning difficulties?

There are many inconsistencies in the definitions of learning difficulties, and so for this project we defined a learning difficulty as 'a problem of understanding or an emotional difficulty that affects a person's ability to learn, get along with others and follow convention'.

On a day-to-day basis, that can be many things including:

- struggling with reading, writing or numeracy
- not being able to concentrate for long periods
- losing track of time
- forgetting what has just been learnt
- acting impulsively

If diagnosed, a learning difficulty may be associated with many neurodevelopmental conditions such as:

- attention deficit hyperactivity disorder (ADHD)
- autism spectrum disorder (ASD)
- developmental coordination disorder (DCD/dyspraxia)
- Down's syndrome
- dyscalculia
- dysgraphia
- dyslexia
- epilepsy
- foetal alcohol spectrum disorder
- fragile X syndrome
- speech and language impairments
- intellectual disability
- Tourette syndrome

Many children do not have a formal diagnosis but are identified when at school as having, in Scotland, additional support needs (ASN) or, in other parts of the UK, special educational needs (SEN).

Learning difficulties can also be a symptom of a complex condition such as a chromosomal disorder. Or, they can result from illness or injury to the brain (often referred to as 'acquired disorders').

Additionally, children and young people can belong to groups at high risk of having a learning difficulty, particularly those affecting speech and language development. For example, children born preterm (before 37 weeks), those exposed to maltreatment and those with preschool developmental concerns may be at higher risk.

Many learning difficulties are also the result of more than one condition and it is more often the case than not, that children will have coexisting conditions. For example, ADHD plus ASD, or DCD plus dyslexia may commonly be seen together. Learning difficulties are also frequently linked with mental health issues or psychiatric disorders.

Identifying the priorities

Getting started

The James Lind Alliance is a non-profit making initiative established in 2004. It brings patients, carers and clinicians together in Priority Setting Partnerships (PSPs) to identify and prioritise the Top 10 uncertainties, or unanswered questions, about medical conditions or treatments.

The aim of these partnerships is to make sure that health research funders are aware of the issues that matter most to patients (or people living with a condition), their families and healthcare professionals.

Our project, however, brought innovation to this format by involving professionals from the education sector in addition to those from the health sector. This recognised that our top 10 needed advice from everyone who is involved in making a difference to the development, health and wellbeing of children and young people with learning difficulties.

Our project's first task was to invite key individuals, representing parents, education, healthcare and charities, to form a steering group to oversee the project.

We were particularly keen that the voices of young people with learning difficulties were heard during the project and that their views were reflected in the results. To achieve this we took steps at every stage to remove barriers to their involvement and actively encourage their participation. These activities are discussed in the following sections but include versions of literature for children and young people, a focus group and strong representation at the priority setting workshop.



The first survey

The first major step of the project was to gather the unanswered research questions about learning difficulties from people across Scotland. This was done through a survey that was made available both online and in paper versions, between mid-May 2017 and the end of July 2017 (with a short extension for underrepresented groups until the end of September 2017).

We asked for responses from:

- children and young people with learning difficulties
- adults who had experienced learning difficulties as a child
- parents and carers of a child or young person with learning difficulties
- professionals working with a child or young person with learning difficulties e.g. those working in health, education, social work or the third sector

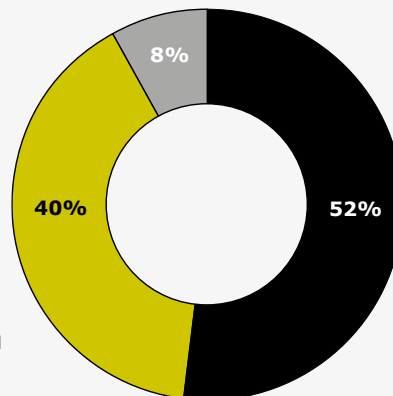
A specific survey and other promotional materials were produced for children and young people using simplified language and layout to encourage their participation. All project materials can be viewed on the James Lind Alliance website. See page 15 of this report for details.

The survey was promoted across Scotland by steering group members, organisations working alongside children and families affected by learning difficulties and organisations representing health, education and professionals working with children and young people. These included organisations such as The Royal College of Paediatrics and Child Health, the Children and Young People's Commissioner Scotland and the National Parent Forum of Scotland.



367 individuals responded to the survey, submitting 828 questions. The mix of respondents was:

- 52% professionals
- 40% parents and carers
- 8% children, young people or adults who experienced learning difficulties as a child.



The respondents reflected the Scottish population in terms of ethnicity and there was a good geographical spread with 28 out of 32 local authorities represented. A wide range of responses came from across the spectrum of the Scottish Index of Multiple Deprivation and the responses also represented families affected by many different learning difficulties.



Processing the survey results

In any survey there will be questions submitted that go outside the area of the study. For this survey the focus was on children and young people up to age 25 years. Of the 828 questions submitted, 63 of the questions asked were not relevant to this project and were classified as being 'out of scope'. These included questions that referred to adults ageing with learning difficulties or questions around a local authority's economic policy and decisions around support services.

Of the remaining 765 questions, some were asked lots of times by many people, often just in slightly different ways. The project team grouped together these similar questions and an overarching question was written for each group. Some questions were only asked once and these were kept in their original form. At the end of this process we had a single list of 40 questions.

The next task was to check this list of 40 questions against existing research results from across the world from the last three years, to see if any of them had already been answered. It was found that none of the questions had been comprehensively answered already by research. Some had been answered for a specific condition but not for the other conditions within the project definition of learning difficulties. For example, a research paper could be found on dyslexia but not for ADHD or autism, fragile X syndrome, cerebral palsy, foetal alcohol spectrum disorder, epilepsy, etc.



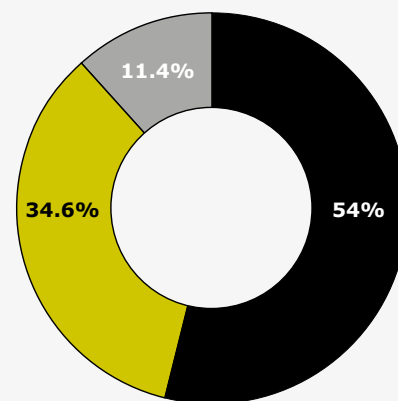
The second survey

After the review of existing research was completed, all 40 questions were left on our 'long list'. With this list we created a shortlisting survey which asked people to choose their top 10 questions from the final 40.

We asked for responses from the same categories of people that we had approached during the first survey i.e. children and young people with learning difficulties, adults affected as children and parents, carers and the professionals working alongside them. The second survey was also sent out to individuals who responded to the first survey and had asked us to stay in touch. It was also promoted through the same networks of professional organisations and steering group contacts as before.

By the closing date, 361 people had completed the survey and the mix of respondents was:

- 54% professionals
- 34.6% parents and carers
- 11.4% children, young people or adults who experienced learning difficulties as a child.



The survey respondents were then split into two categories: one, professionals and two, family group. The family group was made up of children and young people, parents and carers and adults who experienced learning difficulties as a child.

In processing the results, each time a question was selected by a survey participant, it was given a point. The points were then totaled up for each question. Separate totals were kept of the 'professionals' responses and of 'family group' responses.

The next step was to rank the questions from the highest (most popular) to the lowest (least popular). Separating these results for the two categories of respondents allowed the steering group to see which questions scored highly for professionals and which for the family group. The steering group reviewed the results and determined that a list of 25 questions would go to the final workshop. These 25 questions included the top ten priorities of the professionals group and the family group.

"Great to have such a mixed group of people participating .. [The workshop] also challenged some perceptions I had over what questions others would prioritise"

Consultant Paediatrician in Community Child Health

The priority setting workshop

In June 2018, the workshop to decide the final top 10 research priorities was held in Edinburgh. Young people with learning difficulties, parents and carers took part along with professionals from health, education, and third sectors. The 25 participants were recruited via the steering group or via the shortlisting survey where respondents had indicated an interest in taking part in the workshop.

The participants were sent the final 25 questions a few days before they came to the workshop and asked to think about how they would rank them in order of importance. During the workshop, the group came to agree that two questions about transitions should be collapsed into one question, leaving 24 prioritised shortlisted questions.

The workshop involved each participant taking part in two different small group discussions where they listened to other people's views on which questions were most and least important and where they could also express their own opinions. Each small discussion group then ranked the questions. Following this the workshop participants all joined together as a whole to share their thinking. This process helped the full group reach agreement on which questions should be a priority as people balanced their own views and experiences with those of other people. The facilitators were on hand to make sure everyone had a chance to participate.

Young people accounted for one in five of the participants at the workshop. Even when faced with challenges in spoken and written language, they actively contributed their views, making this workshop one of the most inclusive of young people to date, amongst all those conducted by the James Lind Alliance.



The final top 10 priorities are listed on page four of this report.

The 14 remaining questions, which did not make the top 10, are listed below in order of importance as agreed at the priority setting workshop.

11. What are the factors contributing to the delay for children and young people with learning difficulties in referral for, and differences in, a learning difficulties assessment and diagnosis, support and interventions?
12. How does a learning difficulty affect or interfere with a child or young person's ability and experience in learning?
13. Which family, school and community supports are effective in preparing children, young people and their families/carers to transition through different stages of schooling/education and through children and young people's services into adult services?
14. Why are children and young people with learning difficulties more likely to experience mental health problems?
15. What effect does having a formal label or a diagnosis have on children and young people living with a learning difficulty and those involved in their care and the public?
16. Which information and communication technologies (ICT) (e.g. augmentative and alternative communication (AAC) devices, ICT-based communication aids, assistive technology, iPads/writing aids/tablet/phone) are effective and how can they best be accessed by children and young people with learning difficulties?
17. How can we improve public awareness about learning difficulties and what is the impact of any improvement in awareness on the wellbeing of people with learning difficulties?
18. What are the best measures of outcomes (e.g. academic skills, peer relationships, quality of life, classroom participation) for children and young people with learning difficulties?
19. Which parenting approaches and strategies are most helpful for young parents or carers who themselves have learning difficulties?
20. Which strategies are effective in increasing the support available for children and young people with learning difficulties, and their families/carers, in out-of-school activities?
21. How can we understand what it is like to live with learning difficulties from a child or young person's perspective?
22. What strengths do children and young people with learning difficulties have?
23. What percentage of children and young people with learning difficulties receive the appropriate care and support that meets their needs at home, in clinic, in education and at work?
24. How do learning difficulties affect the everyday life of children and young people living with a learning difficulty and those involved in their care?

Next steps

The research priorities for learning difficulties project hopes that by identifying the top 10 priority research questions, research will now focus on the issues that matter most to children and young people with learning difficulties, their parents and carers and the professionals who work alongside them.

- We encourage research funders to include these priorities in their research strategy and to target these topics for future research funding.
- We encourage researchers to focus their efforts on answering the highest priority questions and to mention this project in their applications for funding. If a researcher receives funding to address any of the listed priorities, we ask that they please inform the James Lind Alliance.
- We encourage funders, researchers and all interested parties to share this report with others and to raise awareness of the need for more learning difficulties research in Scotland, the UK and internationally.
- We encourage health and education professionals to continue to work together and alongside researchers for the benefit of all people living with learning difficulties. This is particularly important as the questions identified by this project, and the resulting research, are more challenging than that for a single disease or health condition.

If you have any queries or comments about this work please contact:

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Further information about the project can be found at www.jla.nihr.ac.uk/priority-setting-partnerships/learning-difficulties-scotland/

If you would like more information and advice about learning difficulties, please contact The Salvesen Mindroom Centre on 0131 475 2330 or email directhelp@mindroom.org

"It's so unusual for service users to be 'properly' involved in research decisions and I think this is a very valuable way of doing things"

Third sector professional

Appendix

The remaining 15 questions, which made up the final 40 questions sent out as part of the second survey, are listed below. Only a total of 39 questions remain as during the workshop process two questions were combined into one. (see page 12 for details)

The questions are ranked in order of importance from the results of the second survey with some questions being given equal placing. (e.g. 26 and 30)*

25. How can we make best use of resources to support children, young people and their families when a learning difficulty has been identified?
- 26*. How can we monitor and predict outcomes for the transition of a child and young person with learning difficulties to adult life?
- 26*. How can we best support choice and decision making for children and young people with learning difficulties?
28. How do learning difficulties affect sleep in children and young people and what are the best ways of treating these sleep difficulties?
29. What are the triggers, mechanisms and relationships of physical and mental health conditions that often present alongside learning difficulties in children and young people?
- 30*. What resources help children and young people with learning difficulties understand their condition?
- 30*. What are, and how common are, the physical and mental health conditions that often present alongside learning difficulties in children and young people?
32. What are the incidence, causes, interventions and therapies for sensory difficulties and do these impact on learning?
33. What is the effect of living with a child or young person with learning difficulties, on members of their family or carers?
34. How common are learning difficulties and the physical and mental health conditions that often present alongside learning difficulties in children and young people? Have they increased? If so, why has there been an increase?
35. How can interventions be planned for children and young people with learning difficulties and complex needs?
36. How do learning difficulties affect interaction between children and young people and their peers, including within online social networks such as Facebook and Snapchat?
37. What are the causes of learning difficulties amongst children and young people?
38. What are the chances of learning difficulties being passed down from parent to child?
39. How can toy manufacturers identify the needs of children with learning difficulties and produce toys that meet these needs?

All materials related to this project can be viewed online at
www.jla.nihr.ac.uk/priority-setting-partnerships/learning-difficulties-scotland

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