



The Salvesen Mindroom Centre

Project delivered by



THE UNIVERSITY
of EDINBURGH

In partnership with



James
Lind
Alliance
Priority Setting Partnerships

Research Priorities for Learning Difficulties in Children and Young People

Shortlisting Survey

Tell us your top ten!

Within this survey are 40 research questions about learning difficulties. Please tell us the 10 research questions that are most important to you. On average it takes about 10 minutes to complete the survey.

Who can take part?

We would like you to complete this survey if you are:

- a child or young person who has learning difficulties
- an adult who has experienced learning difficulties as a child
- a parent/carer of a child or young person with learning difficulties
- a professional working with a child or young person with learning difficulties e.g. those working in health, education, social work or the third sector.

Additional information

Go to www.SalvesenMindroom.org for an **online version** of the survey, **more information**, including Q&As and a **child-friendly version** of this form or call: Ai Lim on 0131 536 8898 or email: LD_research@ed.ac.uk

Learning difficulties definition

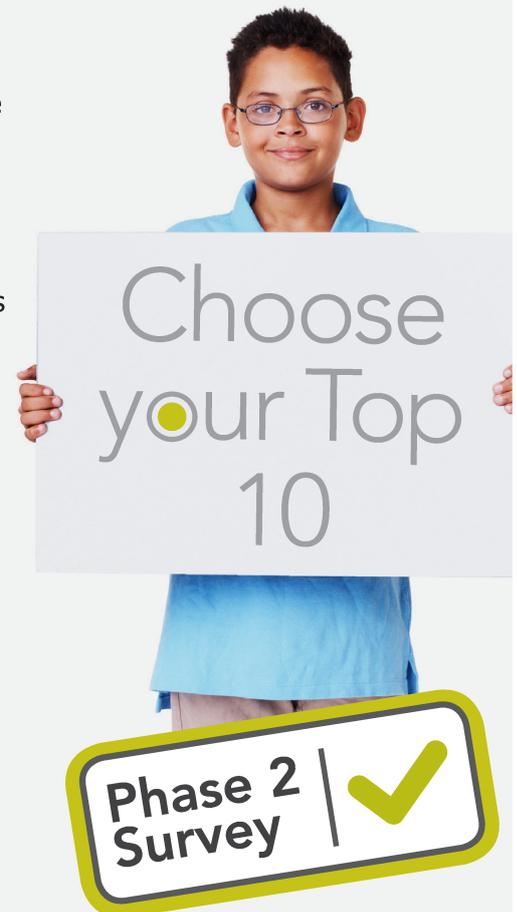
For this survey, learning difficulties means a problem of understanding or an emotional difficulty that affects a person's ability to learn, get along with others and follow convention. On a day-to-day basis, this may be many things – struggling with reading, writing or numeracy, not being able to concentrate for long periods, losing track of time, forgetting what has just been learned or acting impulsively.

A learning difficulty may be associated with many conditions such as dyslexia, autism spectrum disorder (ASD) etc., and the person affected may, or may not have a diagnosis.

Survey closes: 18 May 2018

The Salvesen Mindroom
Centre (formerly Mindroom)
Scottish Charity No. SC030472

The University of Edinburgh
Scottish Charity No. SC005336



Survey Background

The questions in this questionnaire have been gathered from a survey completed last summer by people who have learning difficulties, their families and the professionals working alongside them.

828 questions were submitted and, following analysis, have been summarised into the 40 questions in this survey. We have checked to ensure they have not already been answered by research.

Consent

It is your choice whether you fill in this survey or not. We will always keep your answers anonymous.

Section A - Your 10 most important research questions

From the following list, please tick up to 10 research questions that you think are the most important.

Please note: We have used different colours to make the questions easier to read. It does not make any difference if they are in white or yellow.

What are the causes of learning difficulties amongst children and young people?

What are the chances of learning difficulties being passed down from parent to child?

How can we best identify early features, symptoms and signs of learning difficulties amongst children, young people and their families/carers?

What is the best way to assess learning difficulties in children and young people?

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?

- 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?
- What strengths do children and young people with learning difficulties have?
- How can we monitor and predict outcomes for the transition of a child and young person with learning difficulties to adult life?
- How do learning difficulties affect the everyday life of children and young people living with a learning difficulty and those involved in their care?
- How does a learning difficulty affect or interfere with a child or young person's ability and experience in learning?
- What is the effect of living with a child or young person with learning difficulties, on members of their family or carers?
- What is the best educational and community environment for children and young people with learning difficulties?
- Which parenting approaches and strategies are most helpful for young parents or carers who themselves have learning difficulties?
- What are the best practices in planning for the future (i.e. transition) for young people as they leave school in order to achieve the best possible employment prospects?
- How can we understand what it is like to live with learning difficulties from a child or young person's perspective?

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?

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?

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?

How can we best support choice and decision making for children and young people with learning difficulties?

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?

How can interventions be planned for children and young people with learning difficulties and complex needs?

How do learning difficulties affect interaction between children and young people and their peers, including within online social networks such as Facebook and Snapchat?

Which strategies are effective in helping children and young people with learning difficulties live independent lives?

- 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?
- 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?
- How can we make best use of resources to support children, young people and their families when a learning difficulty has been identified?
- What resources help children and young people with learning difficulties understand their condition?
- How can toy manufacturers identify the needs of children with learning difficulties and produce toys that meet these needs?
- What are, and how common are, the physical and mental health conditions that often present alongside learning difficulties in children and young people?
- Why are children and young people with learning difficulties more likely to experience mental health problems?
- What are the triggers, mechanisms and relationships of physical and mental health conditions that often present alongside learning difficulties in children and young people?
- How do learning difficulties affect sleep in children and young people and what are the best ways of treating these sleep difficulties?

- What are the incidence, causes, interventions and therapies for sensory difficulties and do these impact on learning?
- 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?
- 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?
- 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?
- Which strategies are effective in preventing stigma and bullying towards children and young people with learning difficulties?
- 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?
- 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?
- 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

Section B - Anonymous information about you

This question will help us check we have a wide range of people taking part in this survey.

Please note: If you are completing this form on behalf of someone else, please complete the form with their details (gender, age etc.) rather than your details.

1. Did you complete our survey to gather research questions during summer 2017?

- Yes
- No
- Don't know

2. Who are you?

- A child or young person (please answer questions 3-7)
- An adult who experienced learning difficulties as a child (please answer questions 3-7)
- A parent/carer (please answer questions 8-14)
- A professional (please answer questions 15-16)

Please note: the following questions are optional

Children and young people with a learning difficulty and adults who experienced learning difficulties as a child

3. What is your gender?

- Male
 Female
 Other (Please specify) _____
 Prefer not to answer

4. How old are you?

(Please note: Adults don't need to answer this question)

- Prefer not to answer

5. What is your ethnicity?

- White
 Mixed/multiple ethnic groups
 Asian or Asian British
 Black African, Black Caribbean or Black British
 Other (Please specify) _____
 Prefer not to answer

6. What is your postcode?

7. What learning difficulty(ies) do you have?

- I do not know
 Prefer not to answer

Children and young people and adults who experienced learning difficulties as a child - Please now turn to Section C on page 12.

Parents and carers

About you:

8. What is your gender?

- Male
 Female
 Other (Please specify) _____
 Prefer not to answer

9. What is your ethnicity?

- White
 Mixed/multiple ethnic groups
 Asian or Asian British
 Black African, Black Caribbean or Black British
 Other (Please specify) _____
 Prefer not to answer

10. What is your postcode?

| | | | | | | | | |
|----------------------|----------------------|----------------------|----------------------|----------------------|----------------------|----------------------|----------------------|----------------------|
| <input type="text"/> |
|----------------------|----------------------|----------------------|----------------------|----------------------|----------------------|----------------------|----------------------|----------------------|

About the child/children you were thinking about when completing Section A:

11. What is their gender?

- Male
 Female
 Other (Please specify) _____
 Prefer not to answer

12. How old is the child or young person?

(Please write ages of all children you were thinking about)

| |
|--|
| |
|--|

- Prefer not to answer

13. What is their ethnicity?

- White
- Mixed/multiple ethnic groups
- Asian or Asian British
- Black African, Black Caribbean or Black British
- Other (Please specify) _____
- Prefer not to answer

14. What learning difficulty(ies) does the child or young person have?

- I do not know
- Prefer not to answer

Parents and carers - Please now turn to Section C on page 12

Professionals**15. If you are a professional working with a child or young person who has learning difficulties, what is your profession?**

(Please tick all that apply)

Education

- Classroom assistant/Pupil support assistant
- Educational psychologist
- Support for learning staff
- Teacher

Health

- Audiologist
- Child and adolescent mental health staff
- Clinical psychologist
- Clinician
- Community learning disability nurse
- General practitioner
- Health visitor
- Nurse
- Occupational therapist
- Optometrist

- Paediatrician
- Physician
- Physiotherapist
- Psychiatrist
- School nurse
- Speech and language therapist

Social Work

- Social worker

Third Sector/Voluntary Sector

- Practitioner
- Volunteer

Other

(Please specify) _____

- Prefer not to answer

16. What is your work postcode? (if you have many workplaces, please use your primary work postcode)

| | | | | | | | | |
|----------------------|----------------------|----------------------|----------------------|----------------------|----------------------|----------------------|----------------------|----------------------|
| <input type="text"/> |
|----------------------|----------------------|----------------------|----------------------|----------------------|----------------------|----------------------|----------------------|----------------------|

Please now turn to Section C on page 12

Section C - Additional details

17. Would you be interested in taking part in the final project workshop to agree and rank the final top ten research priorities? (More details can be found on the survey information sheet or at www.SalvesenMindroom.org)

Yes No

If **yes**, please give us your name and email below.

Your contact details*:

| | |
|---|---------------|
| Name: | |
| Email address: (Please complete in capital letters) | |
| If you don't have an email address – please give us your postal address and/or telephone number | |
| Postal address: | |
| City/Town: | |
| Postcode: | Phone number: |

Thank you for completing this survey!

Updates about this survey, including the results, will be available online at www.SalvesenMindroom.org

Please return your completed survey by 18 May 2018

- by email to: LD_research@ed.ac.uk
- by post to: Dr Ai Keow Lim
The Salvesen Mindroom Centre
c/o Child Life & Health
University of Edinburgh
20 Sylvan Place
Edinburgh EH9 1UW
- by freepost envelope. For an envelope call 0131 536 8898 or email LD_research@ed.ac.uk

*Data Protection: Your contact details will be kept confidential and secure by The University of Edinburgh in accordance with the UK and European Data Protection laws. We will only use your contact information to provide you with future updates about this project and the information we hold on you will be destroyed once the project has been completed (by 31 December 2019.) You can withdraw your consent to us holding your data at any time using the contact details above. If you believe your data has not been handled correctly you have the right to complain to the Information Commissioner's Office (ico.org.uk).

 @LD_Research