

## Research priorities for learning difficulties



### Information Sheet

#### What is The Salvesen Mindroom Centre?

The Salvesen Mindroom Centre, formerly known as Mindroom, is a Scottish charity that combines research, education and outreach support for families living with learning difficulties. The charity works in collaboration with The University of Edinburgh on research into learning difficulties.

For this project, the charity and university are also working alongside the James Lind Alliance who are experts in this type of work.

#### What is the Research Priorities for Learning Difficulties Project?

The Salvesen Mindroom Centre and the University of Edinburgh want to find out what research is important to people living with learning difficulties and those working alongside them.

At least five children in every classroom have some kind of learning difficulty and there are many unanswered questions about the conditions and challenges they face.

Across Scotland we're asking people who have learning difficulties, their families and the professionals working alongside them, to complete a survey telling us what they want researchers to find out about learning difficulties.

By bringing all the responses together, the project will identify the top 10 research priorities for learning difficulties amongst children and young people.

The top 10 research priorities will inform future research work into learning difficulties including the work of The Salvesen Mindroom Centre.

#### Who can get involved?

You can get involved by completing our survey if you are:

- a child or young person with learning difficulties
- an adult who experienced learning difficulties as a child



## Research priorities for learning difficulties

- a parent/carer of a child or young person with learning difficulties
- a professional working with children or young people with learning difficulties (e.g. in education, health or the third sector)

### What is this survey about?

This survey is about you. It is about future research being focused on what matters to you.

It is your opportunity to tell us what questions about learning difficulties you would like answered by research.

Your questions can relate to anything you choose. Some areas you might want to consider are questions related to:

- causes
- identifying or diagnosing learning difficulties
- the effect of everyday life (e.g. in education, work, relationship, health and wellbeing)
- what helps (e.g. interventions, therapies, treatments, care and support)

or anything you'd like to know the answer to.

You will be asked to provide us with a maximum of three questions. They do not have to be in order of importance.

### What do you mean by learning difficulty?

There are many definitions of learning difficulty, but for this project we have 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



## Research priorities for learning difficulties

- acting impulsively

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

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

It may also be a symptom of a more complex condition.

### **How do I get involved?**

If you want to take part, go online to fill in the survey at the address below or fill in a paper survey form. You can contact us to get a copy of the paper survey.

### **Do I have to take part?**

It is up to you to choose if you wish to take part. You are free to withdraw at any time, without giving a reason. Completing the survey will be considered as consenting to participating in the study and allowing the questions and comments you supply to be published on The Salvesen Mindroom Centre website, the JLA website and in related publications.

### **Will my taking part in the study be kept confidential?**

Yes. All personal information will be kept strictly confidential in line with the Data Protection Act 1998. However you don't need to give us your name. You can choose to complete the survey anonymously.

## Research priorities for learning difficulties



### What happens to the results of the survey?

When we receive the survey responses, we will sort through them and produce a list of the most common questions and themes. We will also gather a list of all of the questions submitted that have already been answered by research. These 'answered' questions will be shared with community organisations, professionals and survey participants who opt in to updates on the project.

After this we will ask people to take part in a second survey to tell us which, from the list of questions unanswered by research, they think are a priority. It is up to you whether you would like to take part in the second survey. You can tell us on the first survey if you are happy that we contact you again.

After we have gathered the information from the second survey, we will invite young people with learning difficulties, their families and health, education, social work and third sector professionals, to a workshop to prioritise the top ten questions. We will publish the top 10 results on the Salvesen Mindroom Centre website, the James Lind Alliance website and in related publications. By participating in this survey you are agreeing to allow us to publish your question(s) and any associated comments you make. Your identity will not be published.

### Further information

If you have any questions, please contact

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# Research priorities for learning difficulties

## The Process

