



The Salvesen Mindroom Centre



Research priorities for learning difficulties

Children and Young People with Learning Difficulties (Scotland) Priority Setting Partnership (SMC Research Centre for Learning Difficulties)

PROTOCOL (Version 3, 8 May 2017)

1. Purpose of the PSP and background

The purpose of this protocol is to set out the aims, objectives and commitments of the Learning Difficulties (Scotland) Priority Setting Partnership (PSP) and the basic roles and responsibilities of the partners therein. It is recommended that the Protocol is reviewed by the Steering Group and updated on at least a quarterly basis.

The James Lind Alliance (JLA) is a non-profit making initiative, established in 2004. It brings individuals, their families, clinicians and other professionals together in Priority Setting Partnerships (PSPs). These partnerships identify and prioritise uncertainties, or 'unanswered questions', about issues that they agree are the most important. The aim of this is to help ensure that those who fund health research are aware of what really matters to the individuals, their families, clinicians and other professionals (e.g. appropriate educational and social work practitioners involved in the multidisciplinary care of children with learning difficulties). The National Institute for Health Research (NIHR – www.nihr.ac.uk) funds the infrastructure of the JLA to oversee the processes for priority setting partnerships, based at the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC), University of Southampton.

This PSP came together through discussion and collaboration between the University of Edinburgh and its partners in NHS, education services, the third sector and Scottish charity The Salvesen Mindroom Centre (formerly Mindroom). The partners wished to pursue the strategic objective of identifying and resolving learning difficulties and understanding how best to support children and young people up to age 25 years with learning difficulties and their families. Those with learning difficulties may have no formal diagnosis or may have multifactorial causes. They can be contributed to by a wide range of underlying diagnoses with many children having complex combinations of difficulties and includes children with forms of intellectual disability, children with specific learning difficulties including dyslexia and dyspraxia and developmental co-ordination disorder, communication difficulties including autism spectrum disorder, speech and language impairments and neuropsychiatric disorders such as attention deficit and hyperactivity disorder and other undiagnosed and diagnosed disorders such as fragile X syndrome and epilepsy. A learning difficulty can be a problem of understanding or an emotional difficulty that affects a person's ability to learn, get along with others and follow convention. All the children and young people would be unified under the term 'learning difficulties' in the sense of how it is utilised to include all children and young people with developmental and acquired cognitive impairment that affect their learning participation and outcomes

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2. Aims and objectives of the Learning Difficulties PSP

The aim of the learning difficulties PSP is to identify the unanswered questions about learning difficulties from the families of children and young people affected (up to age 25 years) and the perspectives of healthcare, educational and social work professionals and then prioritise those that the children and young people, families, and the professionals agree are the most important.

The objectives of the PSP are to:

- work with the families of children and young people affected and their clinicians and practitioners including from education and social work to identify uncertainties including the identification, the causes, the effects and the optimum ways of supporting learning difficulties.
- to agree by consensus a prioritised list of those uncertainties, for research
- to publicise the results of the PSP and process
- to take the results to research commissioning bodies to be considered for funding.

3. The steering group

The Learning Difficulties PSP will be led and managed by the following:

Families of children and young people representative:

- Christine Carlin, The Salvesen Mindroom Centre

Clinical representative:

- Anne O'Hare, SMC Research Centre for Learning Difficulties

The Partnership and the priority setting process will be supported and guided by:

- Katherine Cowan, The James Lind Alliance

The Steering Group

Parent representatives:

- Gael Gordon, Senior Lecturer in Optometry, Glasgow
- Craig McDonald, Chair of Fragile X Society
- Margaret McPheely
- Justin Williams, Consultant Child Psychiatrist, Aberdeen

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Healthcare representatives:

- Mandy Adamson, Senior Occupational Therapist, NHS Lothian
- Lynne Bremner, Senior Speech & Language Therapist, NHS Lothian
- Sarah Clegg, Consultant Community Child Health Paediatrician, NHS Lothian
- Gill Earl, Senior Speech & Language Therapist, NHS Lothian
- Leila Mackie, Senior Speech & Language Therapist, NHS Lothian
- Jay Shetty, Consultant Paediatric Neurologist, NHS Lothian
- Ereni Skouta, Consultant Adolescent Psychiatrist, NHS Lothian

Educational representatives:

- Martin Gemmell, Principal Educational Psychologist, City of Edinburgh Council
- Rosy Hume, Head Teacher, Rowanfield Primary School

Charity representative:

- Cathy Magee, Chief Executive, Dyslexia Scotland

The Steering Group will agree the resources, including time and expertise that they will be able to contribute to each stage of the process. The JLA will advise on this.

4. The wider partners

Organisations and individuals will be invited to be involved with the PSP as partners. Partners are groups or individuals who will commit to supporting the PSP by disseminating the PSP survey and helping the PSP to gather questions and uncertainties of practical importance relating to understanding, resolving and supporting learning difficulties. Partners represent the following groups:

- children and young people up to age 25 years who have learning difficulties
- young adults who have experienced learning difficulties
- parents/carers and families of individuals who have had learning difficulties
- medical doctors, nurses and professionals allied to medicine with clinical experience of learning difficulties and children's developmental disorders and allied professionals within Education and Social Work as appropriate who would be involved in the multidisciplinary assessment and support of children and young people with learning difficulties

It is important that all organisations which can reach and advocate for these groups should be invited to become involved in the PSP. The JLA Adviser will take responsibility for ensuring the various stakeholder groups are able to contribute equally to the process.

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Exclusion criteria

Some organisations may be judged by the JLA or the Steering Group to have conflicts of interest. These may be perceived to adversely affect those organisations' views, causing unacceptable bias. As this is likely to affect the ultimate findings of the PSP, those organisations will not be invited to participate. It is possible, however, that interested parties may participate in a purely observational capacity when the Steering Group considers it may be helpful.

5. The methods the PSP will use

This section describes a schedule of proposed stages through which the PSP aims to fulfil its objectives. The process is iterative and dependent on the active participation and contribution of different groups. The methods adopted in any stage will be agreed through consultation between the Steering Group members, guided by the PSP's aims and objectives. More details can be found in the Guidebook section of the JLA website at www.jla.nihr.ac.uk where examples of the work of other JLA PSPs can also be seen.

Step 1: Identification and invitation of potential partners

Potential partner organisations will be identified through a process of peer knowledge and consultation, through the Steering Group members' networks. Potential partners will be contacted and informed of the establishment and aims of the Learning Difficulties PSP and may be invited to attend and participate in an initial stakeholder meeting if this is being arranged.

Step 2: Initial stakeholder meeting / awareness raising

The initial stakeholder meeting / awareness raising will have several key objectives:

- to welcome and introduce potential members of the Learning Difficulties PSP
- to present the proposed plan for the PSP
- to initiate discussion, answer questions and address concerns
- to identify those potential partner organisations which will commit to the PSP and identify individuals who will be those organisations' representatives and the PSP's principal contacts
- to establish principles upon which an open, inclusive and transparent mechanism can be based for contributing to, reporting and recording the work and progress of the PSP.

Step 3: Identifying uncertainties in learning difficulties

Each partner will identify a method for soliciting from its members questions and uncertainties of practical importance relating to understanding, resolving and supporting learning difficulties. A period of 18 months to 2 years will be given to complete this exercise.

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The methods may be designed according to the nature and membership of each organisation, but must be as transparent, inclusive and representative as practicable. Methods may include membership meetings, email consultation, postal or web-based questionnaires, internet message boards and focus group work.

Existing sources of information about uncertainties relating to learning difficulties amongst children and young people will be searched. These can include question-answering services for children, young people and their parents/carers and for professionals; research recommendations in systematic reviews and clinical guidelines; protocols for systematic reviews being prepared and registers of ongoing research.

The starting point for identifying sources of uncertainties and research recommendations is NHS Evidence: www.evidence.nhs.uk.

Step 4: Refining questions and uncertainties

The Steering Group will need to have agreed exactly who will be responsible for this stage – the JLA can advise on the amount of time likely to be required for its execution. The JLA will participate in this process as an observer, to ensure accountability and transparency.

The consultation process will produce “raw” unanswered questions about causes, diagnosis, identification, outcomes, natural history and intervention (care and support) relating to learning difficulties. These raw questions will be assembled, categorised and refined into “collated indicative questions” which are clear, addressable by research and understandable to all. Similar or duplicate questions will be combined where appropriate.

Systematic reviews and guidelines will be identified and checked by Dr Ai Keow Lim, Professor Anne O’Hare and other appropriate members of the steering committee depending on the area being examined and their experience to see to what extent these refined questions have, or have not, been answered by previous research. Sometimes, uncertainties are expressed that can in fact be resolved with reference to existing research evidence – i.e. they are “unrecognised knowns” and not uncertainties. If a question about treatment effects or intervention (care and support) can be answered with existing information but this is not known, it suggests that information is not being communicated effectively to those who need it. Accordingly, the JLA recommends strongly that PSPs keep a record of these ‘answerable questions’ and deal with them separately from the ‘true uncertainties’ considered during the research priority setting process. Uses for the known uncertainties which arises from the process could be for the setting of Massive Open Online Courses (MOOCs) and dissemination for children and young people and their families/carers and representation organisations.

Uncertainties which are not adequately addressed by previous research will be collated and recorded on a template supplied by the JLA by Dr Ai Keow Lim, Professor Anne O’Hare and other appropriate members of the steering committee. This will demonstrate the checking undertaken to make sure that the uncertainties have not already been answered. This is the responsibility of the Steering Group, which will need to have agreed personnel and resources to carry this accountability. The data should be submitted to the JLA for publication on its website on

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completion of the priority setting exercise, taking into account any changes made at the final workshop, in order to ensure that PSP results are publicly available.

Step 5: Prioritisation – interim and final stages

The aim of the final stage of the priority setting process is to prioritise through consensus the identified uncertainties relating to understanding, resolving and supporting learning difficulties. This will be carried out by members of the Steering Group and the wider partnership that represents families of children and young people affected by learning difficulties and the professionals.

- The interim stage, to proceed from a long list of uncertainties to a shorter list to be discussed at the final priority setting workshop (e.g. up to 30), may be carried out over email or online, whereby organisations consult their membership and choose and rank their top 10 most important uncertainties. There are examples of how other PSPs have achieved this at www.jla.nihr.ac.uk in the Key Documents of the [Anaesthesia and Perioperative Care PSP](#) section and the [Childhood Disability PSP](#) section.
- The final stage, to reach, for example, 10 prioritised uncertainties, is likely to be conducted in a face-to-face meeting, using group discussions and plenary sessions.
- The methods used for this prioritisation process will be determined by consultation with the partner organisations and with the advice of the JLA Adviser. Methods which have been identified as potentially useful in this process include: adapted Delphi techniques; expert panels or nominal group techniques; consensus development conference; electronic nominal group and online voting; interactive research agenda setting and focus groups.

The JLA will facilitate this process and ensure transparency, accountability and fairness. Participants will be expected to declare their interests in advance of this meeting.

6. Dissemination of findings and research

Findings and research

It is anticipated that the findings of the Learning Difficulties PSP will be reported to funding and research agenda setting organisations such as the NIHR and the major research funding charities. The Steering Group will work to establish the research needs of those unanswered questions to use when approaching potential funders, or when allocating funding for research themselves, if applicable. The Steering Group members and partners will approach the academic community in framing the research questions from the priorities, as it is in this form that they are more likely to be adopted for commissioned research and external grants.

Publicity

As well as alerting funders, partners and Steering Group members are encouraged to publish the findings of the Learning Difficulties PSP using both internal and external communication mechanisms. The Steering Group may capture and publicise the results through descriptive

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reports of the process itself in Plain English. This exercise will be distinct from the production of an academic paper, which the partners are also encouraged to do. However, production of an academic paper should not take precedence over publicising of the final results.

7. Agreement of the steering group

Signed by the Steering Group

The undersigned agree to follow the Learning Difficulties Priority Setting Protocol.

Prof Anne O'Hare, SMC Research Centre for Learning Difficulties, University of Edinburgh

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Date:

Christine Carlin, The Salvesen Mindroom Centre

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Date:

Katherine Cowan, The James Lind Alliance

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Date:

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