

Joint Production of Research Priorities to Improve the Lives of Those with Childhood Onset Conditions that Impair Learning: The James Lind Alliance Priority Setting Partnership for 'learning Difficulties'

Lim et al. (2019)
<https://doi.org/10.1136/bmjopen-2018-028780>

For which topic were research priorities identified?

childhood-onset conditions that impair learning

In which location was the research priority setting conducted?

Europe - United Kingdom

Why was it conducted at all?

Childhood onset conditions that affect learning are common and associated with reduced health and wellbeing, for the individual and their families. Many are heralded by delayed development in the preschool years and most developed health services operate universal and targeted developmental screening and surveillance programmes to facilitate early identification and intervention. Most school age children with learning difficulties will be educated in mainstream schools, in line with the UNICEF position that children with disabilities receive their education alongside their peers, but there is highly variable practice internationally with a sevenfold difference in children and young people (CYP) recorded as having special educational needs across Europe. There is under-ascertainment for conditions such as intellectual disability across the world, with explanations thought to include stigma and discrimination. The aetiology and the impact of these conditions are complex, with a host of biological and psychosocial determinants reducing academic attainments, which themselves result in poorer life chances, that then impact further on health and wellbeing. Families affected by learning difficulties can be stressed and uncertain about their choices and professionals voice concerns about their expertise in supporting those CYP with learning difficulties and educational needs.

What was the objective?

to engage children and young people with conditions that impair learning, their parents/carers and the health, education, social work and third sector professionals to identify and prioritize research questions for learning difficulties

What was the outcome?

a ranking list of 10 research questions

How long did the research prioritization take?

October 2016 - September 2017

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: setting up PSP: steering group established, stakeholders and partner organizations identified. Step 2: collecting uncertainties: survey inviting participants to submit up to three questions they would like answered by research about learning difficulties, 828 research priorities proposed. Step 3: data processing: out-of-scope removed, submissions allocated into nine themes, 40 indicative questions formulated, check against evidence, longlist of 40 questions approved. Step 4: interim ranking: via survey, participants were asked to choose up to 10 of the 40 questions that they most wanted research to address, points for each stakeholder group tallied separately generating family group total and professional group total for each of the 40 questions, 25 questions taken forward. Step 5: final prioritization: workshop: participants provided with 25 questions in advance and asked to rank them individually in order to ensure they were familiar with the data, during workshop small group discussions and ranking, aggregate ranking computed, new small group discussion and rankings, consensus on top 10

Which stakeholders took part?

CYP with learning difficulties and their families, clinicians and practitioners. Survey: 367 participants (11 CYPs, 18 adults who experienced learning difficulties as a child, 147 parents and carers, 191 professionals like audiologists, mental health staff, clinical psychologists, clinicians, nurses, occupational therapists). Interim ranking: 361 participants (10 CYPs, 31 adults who experienced learning difficulties as a child, 125 parents and carers, 195 professionals like audiologists, mental health staff, clinical psychologists, clinicians, nurses, occupational therapists). Workshop: 25 participants: 5 young people, 6 parents, 2 speech and language therapists, 1 occupational therapist, paediatrician, consultant child and adolescent psychiatrist, 2 educational consultants, 1 additional support service leader, 1 pupil support assistant, 1 educational psychologist, 1 teacher, 1 additional support for learning teacher and 2 third sector professionals; 3 of the young people were supported by their parent and another young person was supported by a pupil support assistant.



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