

Creating a shared National Vision for Children and Young People with a Learning Disability in Wales

Learning Disability Programme, Improvement Cymru, NHS Executive

Overview

The Problem: Access to healthcare services for children and young people with a learning disability varies widely across Wales, including differences in expertise, multi-disciplinary support, multi-agency collaboration, and workforce configuration.

The Brief: Our journey started with the **Learning Disability Strategic Action Plan (2022-2026)**, aiming to bring together health, social care, and education to create a comprehensive, integrated, Wales-wide approach to provide equitable access to services, empowering children and young people with a learning disability to reach their full potential

Objectives & Methods

Aim: To improve the long-term wellbeing and health of current and **future generations** of children and young people with a learning disability in Wales.

Method: Underpinned by the principles the **James Lind Alliance Priority Setting Partnerships (PSPs)**, our participatory approach engaged a diverse range of stakeholders, placing a particular emphasis on insights from lived experiences.

Through this method, children, young people, professionals, and families were empowered to develop a collective vision, identifying key priority areas and coproducing a set of care principles forming a 'National Vision' for all services to support sustainable change.

Activities undertaken: Over a period of eighteen months, small scale surveys, listening events, workshops and discussions with stakeholders from voluntary organisations, schools, parents/carers, healthcare, social care and children and young people to find out **"what matters"**. Based on the diverse needs of our audience, we utilised three simple questions: What is good? What is bad? What needs to change?



Results

A **National Vision and Action plan** was developed with the aim of influencing future policy and the design and delivery of services.

Enhanced community engagement:

Membership to the community of practice for children and young people matured and grew, increasing multi-agency connections and networking opportunities.



Relationships were strengthened: between sectors, particularly between health and education, leading to further opportunities for ongoing collaboration and improvement projects.

Parents reported they felt **'listened to'** and liked that there was a direct feedback loop to the Learning disability ministerial advisory group (LDMAG) to influence policy.

Shared resources: Parents and carers helped to develop an online collaboration tool, to share resources and content such as research papers, documents and access to helpful websites.



Conclusion

Through the method of co-production, children, young people, and families were empowered to take ownership and contribute to discussions about how we can achieve sustainable and meaningful change through collective action.

Lessons learned: Future considerations should focus more on the process of incorporating feedback from children and young people with profound and multiple learning disabilities and the experiences and challenges faced by different ethnic groups.

Use accessible language: It is essential to language which is easily understood and make it as accessible as possible; using strategies like easy read, core boards and other communication aids made it possible to access a wider audience.

Next Steps

To regularly update stakeholders on the national vision status. Establish feedback loops for continuous learning and improvement. Identify meaningful outcome measures for ongoing monitoring. Ensure safe data sharing to inform and enhance service design and delivery for children and young people with a learning disability at local, regional, and national levels.

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