

Health passport for people with intellectual disabilities in Ireland



Location & scale

Ireland, northern region (Cavan, Donegal, Leitrim, Monaghan and Sligo)

Type of disability

People with intellectual disabilities

Involved actors

- Health Service Executive (HSE): National Quality Improvement Team - Disability Services
- Nursing and Midwifery Planning and Development Unit (NMPDU) North West
- Local services in Letterkenny University Hospital and Sligo University Hospital
- Public Health Agency Northern Ireland

1. Description

The HSE Health passport is a communication tool developed to help people with intellectual disabilities express their health and social care needs when they visit a healthcare setting. It also helps healthcare staff to understand the needs of patients with intellectual disabilities and make reasonable adjustments before any assessment, examination, treatment or care.

The Health passport includes five sections designed in Easy-read:

1. All about me
2. Communication
3. Medical history
4. Looking after me
5. Keeping me safe and happy

The [HSE Health Passport is available in hard copy](#) or as a free [app in Google Play Store](#) or [Apple App Store for iPad and iPhone](#). Additional [guidance notes are also available to complete the health passport](#).

2. Origin

- People with intellectual disabilities often have worse health outcomes than the general population. For instance, many are more likely to die 20 years earlier.
- Contributing factors to premature death include poor quality health care and inappropriate care adjustments.
- A [health passport was first developed and evaluated in Northern Ireland](#) between 2017-2018.
- The health passport was then adapted, piloted and rolled-out in the North West region of Ireland.
- In 2019, the NMPDU North West funded the Health Passport initiative under the service improvement and innovation fund.
- The project received long-term national funding, under Slainte Care, to expand the Health Passport throughout the country in 2022, which included funding for staff to roll it out.
- In 2023 an Expert Advisory Group was set up to capture the learning to date, identify improvements that needed to be made and support the expansion of the Health Passport nationally.

3. Impact

- Strengthening person-centred, safe and effective health care.
- Increased users' autonomy, awareness, and communication of their health and social care needs.
- Increased staff awareness and knowledge to make reasonable adjustments.
- The National Expert Advisory Group are identifying ways to measure the effectiveness of the passport in four cohorts - people with intellectual disabilities lived experience, staff in hospital (wards and A&E), staff in GP practices, and families/carers.
- Monitoring of the effectiveness of the Health Passport will identify the changes in health

outcomes or hospital experience among the target group and healthcare staff.

4. Impact statement

“Our experience of the first time using the Health Passport was very positive. My son Martin who has Intellectual Disability, was sent to the Emergency Department and had his Health Passport with him [...] The information on his Health Passport allowed treatment to begin immediately as Martin was then diagnosed with pneumonia. It also gave important information such as to put drip in Martin’s left side and to take his temperature on his right side as in a stressful situation we forget to mention these important details. The doctor that attended Martin thought the Health Passport was a great idea and was grateful that all his important information was at hand.”

Kathleen McBride – Donegal, Ireland.

5. Critical success factors

- Strong governance through a National Clinical Programme for People with disabilities.
- Participation of people with learning disabilities and their family/carers in the health passport pilot project.
- Collaboration among multiple stakeholders and broad endorsement in the country.
- Political will from the Minister with responsibility for disabled people which resulted in long term national funding being granted.
- Strong advocacy of people with disabilities and their families, and requests from staff in hospitals and GP practices for support in communicating with people who had disabilities.

6. Lessons learned

- There must be buy in from staff in hospitals and GP practices; they must be aware of the Health Passport, take the time to read it and it must be ensured that the Health Passport works for healthcare staff in busy environments in order to improve the experience of people with intellectual disabilities.
- Another key learning is that digital literacy training to people with intellectual disabilities and their families/carers must be provided. The uptake on use of the App was low due to the limitations of people being fearful of the technology.
- The Health Passport could be piloted and used for other long term conditions such as dementia, mental health illness and users with complex needs.

7. Limitations

- Need for digital literacy training for the App

- Need for health passport to be in Word and not PDF format to allow users to update information, print off and bring with them to appointments. It is not a static document and individual's needs change and therefore, there must be opportunities to update the information.

Sources & links

[Health Passport Intellectual Disabilities](#) – HSE

[Vide of HSE Health Passport for people with intellectual disabilities](#) (1:54 minutes) in YouTube

[Launch of the HSE Health Passport and “Mission Possible” short film](#) – HSE

[Video of the Health Passport launch– Mission Possible](#) (5:19 minutes) in YouTube

Acknowledgments

We would like to thank the National Disability Services Quality Improvement Office and Down Syndrome Ireland for their feedback and contributions to this good practice example sheet.

Similar resources

Australia

- [My Health Matters folder](#) – Council for Intellectual Disability Australia; made by people with intellectual disabilities for people with disability. [Watch My Health Matters Video](#) (2:22 minutes) in YouTube.

- [People with disability - Julian’s Key Health Passport](#) – Queensland Government, Australia. [Read the tool’s trial evaluation factsheet](#).

- [Health Toolkit: Health record – About me](#). Down Syndrome Australia.

- [A2D Together Folder for People with a Disability](#) - Admission2Discharge Australia.

Spain

- [Health Passport in Spanish: “Mi pasaporte para ir al médico”](#) – Dincat Plena Inclusió Catalunya.

United Kingdom

- [Hospital Passport – Mencap UK](#). Watch [Hospital passports: Victoria’s story](#) (3:59 minutes) in YouTube.