

What are the challenges of living with a neurological condition in the community

Lived experience voices*



Challenges

Not enough specialist services

- Frustration at the lack of expertise and services available.
- Reluctantly paid for private services, as fearful of their condition regressing.



It's difficult to find out what services are available

- It's very difficult to identify what services were available to them in the community.
- Feelings of abandonment following discharge



I have to contact multiple organisations for different things, none of which are connected and there is no one point of contact. I have to figure out what it is that I maybe want and then figure out how to access it



There are not enough long terms supports

- No long-term management plan
- Living with their disability for the rest of their lives is not factored into their overall treatment.



It feels like when the emergency is over there are no services. We go home and live with the disability every day



Many obstacles to access services

- Constant fight and battle to access services.
- Challenges in physically attending services
- Accessible transport is very limited.

Improvements Needed

More specialised staff

Access to **full range of specialist services** in the community to maintain independence.

Person-centred follow-ups

Follow-up calls by specialist services a few weeks post discharge would help reinforce the discharge messages

Increase knowledge on services available

A **service directory** on services available to address the frustration and being overwhelmed when discharged from hospital/specialist services

More peer support networks

Support networks are a key component to benefiting from and accessing Neuro-Rehabilitation Services.



We formed a very good group of patients in there because we could share our experiences with each other



*Background information

The Neuro-Mapping Project (2024) aimed to further understand the current service and support pathways that occur between community services for those with neuro rehabilitative needs, to support integrated care in the community. 56 people with neurological conditions and 137 service providers across CHO 2,3 and 6 engaged with the project team. Summary and full report available by clicking QR code or <https://www.disability-federation.ie/our-work/neuro-mapping-project/>

What's happening next

The HSE National Neuro-Rehabilitation Steering Group had oversight of the project and the recommendations will inform their workplan. For more information and updates contact Ciara.lynch@hse.ie; mrogers@nai.ie; cathymcgrath@disability-federation.ie

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