

Joint Committee on Disability Matters

25th November 2021

OPENING STATEMENT

Bernard O'Regan

Head of Operations – Disability Services

Good morning Chair and members. Thank you for the invitation to meet with the Committee today to address matters relating to “aligning disability services with UNCRPD and in particular an up-date on progress regarding Disability Services”. I have recently taken up the role of Head of Operations replacing Dr Cathal Morgan who previously attended meetings with you.

I am joined today by:

- Ms Breda Crehan Roche, Chief Officer, Community Health Organisation, West
- Professor Malcolm MacLachlan, Clinical Lead for the National Clinical Programme for People with Disabilities

The UNCRPD requires that the rights and needs of people with disabilities are considered across all aspects of Government and its agencies. It reflects the shift from a medical, paternalistic model of service delivery, to a model where citizenship, rights, will and preference of the individual are at the core of policy and service provision. It puts the needs of people with disabilities at the core of public policy and the relevant service provision.

It has at its core that people with disabilities are citizens with the same entitlements as all other citizens, and it challenges States to make the necessary legislative, policy and funding decisions so that people with disabilities realise that citizenship, that right to “an ordinary life”.

The HSE welcomes the transfer of functions from the Dept. of Health to the Department of Children, Equality, Disability, Integration and Youth Affairs as being an important enabler in ensuring cross-departmental and whole of Government approaches to ensure that people with disabilities have equity of access.

HSE Disability Services are primarily focussed on the specialist service needs of the 60,000 people with disabilities with complex needs requiring specialist services based on individual needs. 600,000 other people with disabilities do not generally need access to specialist services, but do require access to mainstream services such as primary and acute care, older person’s services and so on.

The HSE Corporate Plan 2021 – 2024 commits to a vision of re-imagined disability services “to be the most responsive, person-centred model achievable with greater flexibility and choice for the service user. We will support people with disabilities to live a full life in the community with access to a range of person-centred community services and supports, across their life spans.”

Specialist services are provided within the context of Transforming Lives. This is the broad policy banner for a wide range of other policies including but not limited to:

- New Directions
- Time to move On
- Neuro-Rehabilitation Strategy and Implementation Framework
- Personalised Budgets
- Progressing Children’s Disability services (PDS)
- Autism policy

It is important to note that even though Ireland did not ratify the CRPD until 2018, these policies were developed in the context of, and aligned with, the CRPD which has set the strategic and operational direction for the services provided by the HSE and funded service providers.

In operationalising these policies, the primary activities of the HSE include:

- Over 1000 people transitioned from congregated settings to community-based living arrangements in line with promoting inclusion and participation in community life
- 19,000 people avail of day services. The 2013 New Directions policy outlines that the supports available in communities be mobilised so that people have the widest possible options for how they live their lives and spend their time. It places a premium on making sure that being part of one’s local community is a real option. It recognises that people with severe and profound disabilities may need specialised support throughout their lives.
- PDS is a significant programme of reform that changes the way we deliver services and supports for children and young people with complex needs through 91 Children’s Disability Network Teams. The reform of services in line with the PDS programme is an integral part of Sláintecare health reforms and is a key policy commitment in the

Programme for Government. It provides a clear pathway and fairer access to services for all children and young people with a disability, based on their needs, ensuring effective clinical teams work in partnership with families and with education staff to support children and young people to reach their full potential.

- Personalised Budgets Demonstration Project is an important initiative to pilot a range of options for personalised budgets to inform government decisions on the viability of various approaches in the future for those who wish to avail of them

The National Service Plan sets out the HSE investment and reform programme year on year. The HSE welcomes the significant additional investment in disability services in excess of €200m in the last two years, which has been utilised to advance alignment with UNCRPD by:

- Increasing personal assistant services to 1.7m hours and home supports to 3.12m hours
- Providing over 8000 residential places for those who need them, responding to urgent and emergency need, but also developing planned options that prevent people going in to crisis
- Developing respite services, balancing increased centre-based respite with more innovative respite options including intensive support packages, Saturday clubs, Home Sharing, Contract Families
- Establishing the Digital and Assistive Technology Committee to lead on the use of these technologies in promoting independence for people with disabilities
- Development of a neuro-rehabilitation service with 10 additional beds in Peamount and two community network teams being established initially
- Increasing the number of staff on the Children's Network Team by 285 with a commitment to significant further development in 2022.
- Establishing the Integrated Steering Group to oversee implementation of the recommendations of the Ombudsman report, Wasted Lives, on under 65s inappropriately placed in nursing homes
- The HSE has embraced the "nothing about us, without us" concept of participation through the number of committees which have lived experience representatives and the establishment of a project to ensure people with disabilities are fully included in the decision-making and policy setting within the HSE.

- The National Clinical Programme for People with disabilities was established in 2020 with a specific remit to ensure that CRPD is implemented in disability and cognate clinical programmes services and its governance structure explicitly reflects this.
- Focus on Assisted Decision-making implementation.

The HSE recognises that the Disability Action Plan 2022 – 2024 currently being developed will be instrumental in shaping disability services and aligning them with the convention.

I want to acknowledge the commitment and dedication of staff, non-statutory service providers and partners for the work they do each day in providing supports and services. The response shown in the face of Covid-19 and in pursuing a wide range of reforms gives us optimism for the future. I also note the increasing challenges of staff availability at the same time as the increasing need for well-trained staff to meet the emerging needs in the most appropriate settings.

The HSE and its funded agencies have made significant progress while also acknowledging the areas for continued focus.

We are happy to address any questions that the Committee wishes to ask.

Thank you.