

## **Action Plan for Disability Services 2024-2026 Stakeholder Event DPO Network remarks by Chair, Jacqui Browne, May 22, 2024**

The DPO Network welcomes the opportunity to provide a collective DPO lens on the Action Plan for Disability Services 2024 – 2026. As a Network, we are committed to work together to bring a shared DPO analysis to achieve the implementation of the UNCRPD.

It is welcome that the Action Plan states its aim to be consistent with the values of the UNCRPD and the forthcoming National Disability Strategy (NDS). It is also welcome that it references the existing policy landscape around disability services and commitments to achieving services that are about meeting our needs to “live ordinary lives in ordinary places, as independently as possible” while ensuring our voices are heard in planning and improving services.

The honesty in the Action Plan to recognise that much of this reform committed to in Transforming Lives hasn’t happened, is welcome. However, simply stating that “legacy issues” were the reason for lack of change in service delivery landscape simply is not acceptable.

If we take it that all of us in the room here are genuine in our belief that change is necessary and that this Action Plan is a driver for that change, then we need to have an honest open reflection on what those barriers to change in achieving goals in Transforming Lives. We need to name those barriers and by naming them, we can remove those barriers so that this plan will have a real impact on our lives.

For the ambitions of this Action Plan to be realised we need an honest, transparent discussion on why previous ambitious plans stemming from Transforming Lives have failed or stalled. We are in a post-UNCRPD landscape, with a new National Disability Strategy that will be our first attempt to progressively realise the UNCRPD. For the first time ever, we now have begun a process of realising a social model approach to our lives by moving disability from the Department of Health into a Department tasked with advancing Equality.

From the DPO Network perspective one of the major and obvious absences in previous HSE Strategies was the collective voice of disabled people either in policy development, implementation, or monitoring. Post UNCRPD ratification we can all agree that the landscape has fundamentally altered and the emergence of DPOs as collective autonomous spaces has and will continue an upward trend from disabled people being (often passively) consulted towards disabled people in our authentic collective spaces co-creating systems and structures that will realise the UNCRPD.

The active involvement of disabled people through our DPOs also need to be met with huge cultural shifts in the organisations that provide HSE funded services. The Action Plan sets

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out many ambitious targets but one missing from it is commitments under the Irish Human Rights Equality Commission Act (2014), specifically Section 42 (The Public Sector Duty). Disability Services Organisations as part of their Public Sector Duty need to create a clear timeline to look at targets to employ disabled people in their organisations and ensure there are effective pathways to ensure disabled people are supported to take on key leadership roles within the organisation. Disabled people from both within and outside the organisation should be actively pursued to apply for all positions within Disability Services Organisations. Disabled people should be actively recruited into all roles, but there are specific roles that must be led by disabled people. In terms of offering guidance and support at transition points in education or employment, disabled professionals can provide peer guidance and support not only to disabled children and young adults but also a connection to parents in CDNTs, specifically in providing frameworks of what is possible (with appropriate supports) for young disabled people exploring their future lives, including independent living from an early age. A link with local DPOs for parents and young disabled people in the longer term will be essential to shift critical thinking of parents about potential lifecourse pathways for their children by engaging with disabled adults who know better than anyone how best to navigate systems and structures. Who better than disabled adults to offer advice to young disabled people about “supports to pursue education and employment ambitions, as an alternative to entering day services for life”.

It is no longer acceptable in the 21<sup>st</sup> Century that State funded disability services are almost exclusively governed and staffed by non-disabled people. There are scores of highly qualified disabled people, unemployed and underemployed, that could and should in paid and in governance positions be key drivers of change. I think all of us here would question if every single service delivered to women was staffed and governed by men, yet at no point in this Action Plan is there a reference to how disabled people are going to lead in the delivery of the Action Plan for Disability Services 2024-2026.

The proposed DCEDIY / HSE review of “management information requirements and performance indicators to manage and monitor services and putting in place (of) improved systems” needs to include measures in relation to the recruitment of disabled people and measures to ensure governance of disability services by disabled people, not just for disabled people.

Similarly, the commitment in the Action plan (A15.3) that the lived experience of disabled people is included in the decision making that is relevant to them. The role of DPOs locally and nationally is central to realising this action. But we need to be clear, DPOs need to be resourced to do this. To really drive the implementation of the UNCRPD, DPOs need multiannual sustainable funding. We need time and space so we can build our collective capacity, so that when we send our representatives to regional and national structures, they are bringing our collective voice. For too long in the past, representation has relied on the individual lived experience of a handful of disabled activists. This is not sustainable nor is it

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reflective of commitments under the UNCRPD. Whilst resourcing of DPOs is outside of the scope of the Action Plan, it is disappointing that our mandate to represent disabled people isn't specifically reinforced throughout the Action Plan.

The prominence of real independent living supports such as Personal Assistance, Assistive Technology and Personalised Budgets within the plan is of huge significance, given that these are the services that many disabled people demand to give them the chance to live their lives, which also give greater chances for disabled people to be included in society, including accessing employment. The development of a real PAS framework over the lifetime of the Action Plan is welcome but 800,000 additional Personal Assistance hours as a metric can mask (as we know from previous years) whether disabled people are getting the hours they need for a real PA service.

The suggestion that there will be investment in "900 additional residential care places to tackle unmet need and ensure supply keeps pace with demographic change" is baffling. How is this consistent with the UNCRPD and A Time to Move on? Rather than progressing the Government policy of de-congregation, are we building more institutions - at huge capital and staffing costs - that we will need another strategy in 2032 to explore how we will "move on" from them?

If there is a serious commitment to supported and independent living, moving disabled people from institutions with supports to live in their own homes, needs to be the urgent priority investment. Otherwise, we are going to lurch from crisis to crisis, reacting to the immediate with no attempt to strategically invest in inclusion.

I think the insight of the late Bishop Desmond Tutu is appropriate here:

*"There comes a point where we need to stop just pulling people out of the river. We need to go upstream and find out why they're falling in."*

Disabled people are being forced into nursing homes because we have never invested in accessible, appropriate, or adequate housing or community supports. We have never invested in community supports like Personal Assistance and parents have ended up providing decades of supports for their disabled children into adulthood. Too many disabled people have not been supported to live their own lives, and so when their parental or family supports are no longer there, the crisis response is to place people in an institution. We all know this cycle. We all know what needs to be done, and it isn't going to be done by building more institutions.

Similarly, the "1,200 additional day service places each year to ensure places for school leavers who require them" almost defeats other commitments made in the CDNTs to work in the context of mainstream education, Further Education and Training (FET) and employment opportunities as an "alternative to entering day services for life". There is a real fear from

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DPOs that by creating day service places we reduce any real appetite for change within ETBs, FET providers, local area-based partnerships and so on to actively include us in their plans. We know from the ESRI report that greater connection and involvement of disabled people in mainstream services also reduces levels of ableism. The DPO Network are of the view that the Action Plan for Disability Services needs to move away from any long-term investments that further segregate disabled people from their communities. We should be learning, playing, working, and socialising where we live, regardless of our ages, with our non-disabled peers.

For the ambitions of this Action Plan to be realised we need an honest, transparent discussion on why previous ambitious plans stemming from Transforming Lives have failed or stalled. We are in a post-UNCRPD landscape, with a new National Disability Strategy. This is our first attempt to progressively realise the UNCRPD in Ireland. For the first time ever, we now have begun a process of realising a social model/human rights based approach to our lives by moving disability from the Department of Health into a Department tasked with advancing Equality.

We have emerging, confident Disabled Persons Organisations, including DPO Network members who are committed to utilising our expertise to co-create policies, systems and structures that will progressively realise the UNCRPD. This Action Plan can potentially deliver on some of the changes we as disabled people require to live the lives of our choosing. However, unless disabled people are resourced to be empowered to drive that change, the fear is that we will continue to throw good money after bad and change the language of services without really changing what we do.

On that note, Service Level Agreements (SLAs) with disability service providers should make specific reference and create an obligation on any State funded disability service provider to engage with DPOs and support the involvement of disabled people accessing services to engage with their DPOs.

Members of the DPO Network have repeated documented cases of service providers actively blocking people from getting involved in our work, so there's no point pretending it doesn't happen. It does.

So as DPOs grow (and are resourced) we need to point out that the industry doesn't get to choose for disabled people about what they can get involved in. This is very important as a significant number of disabled people or service users are a "captive audience" (literally and figuratively).

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