

# Structure, power and practice: Designing a new rights-based national clinical programme for people with disability in Ireland

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**I**n Ireland the state health service (AKA Health Service Executive, or HSE) operates through a plethora of state provided, state-funded, independent and private providers. National Clinical Programmes (NCPs) are the mechanism through which clinical design, leadership and innovation are supported across providers. Clinical programmes have been developing over the last decade and now exist in 31 areas, such as anaesthesia, critical care, diabetes, heart failure, and neurology. An NCP has a Clinical Lead, a Programme Manager, Clinical Advisory Group and Multidisciplinary Working Group.

In March 2020, a new clinical programme in disability was commenced. The scope of the programme is all types of disability, including intellectual (learning), sensory,

physical, and cognitive disabilities; autism, people experiencing long term effects from head injury, or in minimally conscious states, and some people with rare genetic disorders. The disability programme was the first programme in Ireland where the clinical lead role was competency-based and appointed through an open competition, that is, open to all professions. The other programmes have had, and continue to have, clinical leads appointed on the basis of professional background (medicine, with a couple of co-leads in nursing). Here I describe how the National Clinical Programme for People with Disability (NCPPD, aka the disability programme) has evolved and how it has tried to incorporate a rights-based approach, including challenging power and privilege in governance and team structures, and supporting new interdisci-

plinary practice. My account is a personal one as the first clinical lead for the programme.

### **Terminology and hegemony**

So ‘National Clinical Programme for People with Disability’ is a bit of a mouthful, but chimes with the terminology of the United Nations Convention for the Rights of Persons with Disability (CRPD). Whilst I would have preferred not to have the word ‘clinical’ in the title, for now, this was necessary to establish the programme as having equal status and clout in relation to other programmes in the service. While in the UK ‘disabled people’ is preferred, in most countries ‘people/persons with disability’ is used (for a brief discussion on such terminology, see MacLachlan, 2021).

While ‘clinical’ certainly does not mean ‘medical’, one of the challenges has been to de-medicalise mindsets; including among psychologists. The ‘medical-model’ is hegemonically woven through clinical settings and different terminology is required to make people aware of this, challenge it and instil a rights-based ethos. Thus ‘care’, is services and supports; ‘treatment’ is intervention; ‘co-morbidity’ is co-occurring. ‘Diagnosis’ may be classify or identify or describe or, more usefully, formulate. However diagnosis is not necessarily incompatible with these alternatives and may be informative (for instance, for people with Down’s Syndrome or Prader Willi Syndrome). But diagnosis will rarely be decisive in the needs-led, person-centred approach we have been developing. It does however remain a key to unlock some gateways to services and supports, something we are working to change.

Conceptual clarity is often lacking in clinical training, leading to a bungling together of ideas that have important differences. So while illness or disease may lead to disability, most people with disabilities don’t have illnesses or diseases associated with their disability, and most are usually well, not unwell. People with disabilities do sometimes have difficulties associated with ‘impairments’ in functioning, often resulting in social exclusion and a lack of opportunity to participate in society. People

with disabilities also do greatly benefit from medical interventions, and sometimes these are associated with their disability.

So positioning medicine as a discipline which is greatly valued, while not subverting other disciplines to its current structural dominance, is a difficult balance. It is difficult for service users as well as service providers, of all disciplines. Some of my medical colleagues are actually more supportive of this than some of my other colleagues. I have been disappointed to find that some clinical psychologists are among those in the health and social ‘care’ professions who cling, most limpet-like, to medical terminology and are reluctant to eschew the power associated with it.

### **Structure and dominance**

The conventional governance for national clinical programmes in the Irish system is that the clinical lead is a medical practitioner, and the clinical advisory group (CAG) is comprised of medical practitioners (generally medical consultants) nominated by the relevant professional medical colleges (e.g. college of psychiatrists, college of paediatrics). The Clinical Advisory Group itself has a multidisciplinary advisory group feeding into it. This latter group has some influence, but no power, as the decision-making power resides with the Clinical Advisory Group and the Clinical Lead. This structure therefore secures power within one profession and conflates the interests of postgraduate professional medical colleges with the responsibility of the clinical programmes to design services for the population. Obviously these interests are not always coterminous. Such a structure therefore is a rather blatant example of social dominance (Sidanius & Pratto, 2001), reflecting the social capital and habitus of medicine as an institution (Bourdieu, 1994.) and subjugating other disciplines through ideological power (Boyle & Johnstone, 2020; Foucault, 1973). This structure effectively filters the views of other disciplines through a single disciplinary lens; ultimately priming those from other disciplines to think through medical models, a process that can also be described as ‘disci-

plinary capture’ (see Rochford & MacLachlan, 2022, for a brief discussion in the context of clinical teams).

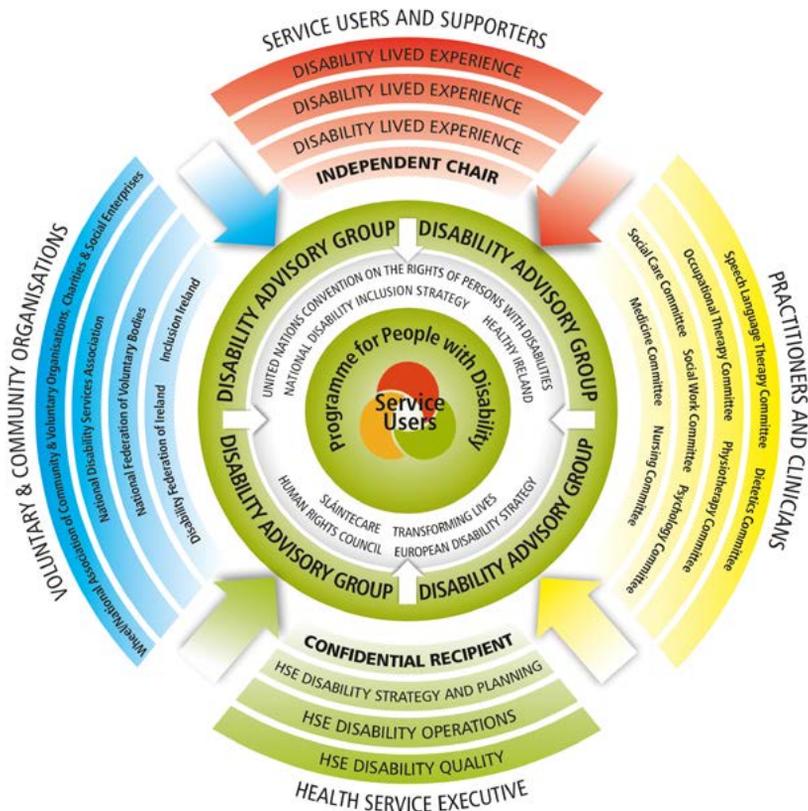
Implementation of the CRPD is the core business of the disability programme. The CRPD promotes a social- and rights-based model of disability, often not aligned with the traditional ‘medical model’. It was therefore important to have designed a structure for the governance of the programme, that would incorporate the values of participation of people with disability (‘nothing about us without us’), establish parity of esteem between different professions, and allow us to benefit from the benefits of diverse perspectives in healthcare decision making (Mitchell et al., 2015); whilst also embracing the need to change the systems through constructive disruption. There is now strong evidence that more democratic and distributed models of

leadership in clinical teams results in both more effective decisions and reduced clinical risk (Manser, 2017; Salas et al., 2018; van Rensburg et al., 2016; Kearns et al., 2021). Put simply, drawing on the diversity in teams though non-hierarchical working is better clinical practice.

### **The Disability Advisory Group Structure**

As noted already, the ethos of the CRPD made a strong case for the clinical lead to be appointed on a competency basis and for this to be an open competition. Once this position was appointed, the power vested in the clinical lead and the programme manager (Michael Walsh) meant that we could effectively design our own structure for the programme. After consultation with a range of different stakeholders the structure we developed is shown in Figure 1 below.

Figure 1: A schematic of the structure of the Disability Advisory Group (DAG) for the National Clinical Programme for People with Disabilities (NCPDP) in Ireland



There are four types of representation on the Disability (we preferred not to use 'clinical') Advisory Group (DAG). Their advice is framed – but not constrained – by key international (UNCRPD, European Disability Strategy and the Human Rights Council) and Irish (Sláintecare, Transforming Lives and the National Disability Inclusion Strategy) policies and instruments. Three members of the DAG are nominated through an open call to civil society organisations representing people with lived experience of disability. Four members are from service providing umbrella organisations funded by the HSE, but constitutionally independent from it, with one general community development umbrella organisation. There are three positions representing HSE disability operations, quality (which overlap) and strategy; and one for the post of Confidential Recipient (who receives confidential complaints made regarding disability and older people's services, and who is a person with a disability). There are nine different professions represented, each by an individual, who is also the chairperson of a profession-specific subcommittee of between 5–8 members, who are nominated by their professional representative organisation. In the case of psychology, they are nominated by the Psychological Society of Ireland (PSI) and the committee of the Heads of Psychological Services in Ireland (HPSI); the latter comprised of mostly clinical but also some counselling psychologists.

The DAG meets quarterly to advise the disability programme (clinical lead, programme manager and project officer) and is chaired by an independent chair who is a person with lived experience of disability. Currently this is the CEO of the autism advocacy organisation AsIAM (As-I-Am). We establish Task Groups, to address specific tasks. Currently we have groups on developing the role of digital and assistive technology, the development of specialised services, and developing a model of services and supports for adults with disability. At the beginning of Covid-19 we established a Task Group to develop clinical guidance on conducting remote assessments in disability services.

## **Reconfiguration of Community Disability Teams**

Prior to the establishment of the programme there was already a progressive programme of reform underway. Over the last two years we have had the opportunity to support and strengthen that reform. One of the central structures for this has been the reconfiguration of a mismatch of different types of disability services for children – which previously had pockets of excellence, some weaknesses, and in some cases gaps with no service at all. This was restructured into 91 Children's Disability Network Teams (CDNTs). These teams comprise between 15–35 clinicians, who are in the most part from the disciplines of psychology, occupational therapy, speech and language therapy, physiotherapy, and social work, with administrative support. Depending on the historical provision of staff in the area, the teams may also involve nursing and dietetics, and have sessional inputs from paediatricians. We are working to standardise the teams to include all these professions, with hopefully some input from psychiatry too. As they are community-based specialist networks they also work with general practitioners and interface with primary care teams. The Clinical Lead for the CDNTs – referred to as the CDN Manager – is recruited on a competency basis and may be drawn from any profession. They have overall clinical responsibility for the work of the team, whilst individual clinicians are also of course responsible for their own practice.

These teams are rights-based, needs-led, person-centred and interdisciplinary rather than multidisciplinary, and they work collaboratively with families towards agreed goals through family centred practice. Many of our network teams only reconfigured towards the end of 2021 and so the process of restructuring – often working with new colleagues, and in new ways, and in new settings – has been difficult for many service providers. It has also increased waiting lists in some areas and been frustrating and distressing for service users. As the new teams adjust to the new structure and adapt their practice and cultural expect-

tations, we expect services to improve, and for the experience of providing the service to also improve. At time of writing, I would say that most practitioners and many service users embrace the ethos but are struggling with the practicalities and disruption that such large-scale change has caused. While we do not lack the financial resources to employ more staff, we do have a real shortage of qualified 'health and social care professionals' (HSCPs) and we greatly need to increase our pipeline of supply from professional training courses. This is another issue we are advocating for.

### **Collaboration with WHO**

The World Health Organization's Europe Region office is currently developing a 'European Framework for achieving the Highest Possible Standard of Health for People with Disabilities'. One of the modules within this initiative will be on Leadership & Governance. Our clinical programme has been asked to collaborate with WHO Euro through co-chairing a working group on 'Rights-based Leadership & Governance', which will apply to disability services, but will also be relevant to cognate services, such as rehabilitation, mental health, aging, and children's services. The group will comprise of a range of Irish and international expertise in this area. In many countries transition to a right-based model of service is a struggle. The output from this working group will provide guidance on rights-based leadership and governance structures that can support this transition. We also intend to produce a 'tool' to measure this. While the work of this group is only getting underway, I imagine that it will address issues such as governance structures across government departments, person-centred and needs-led services, service user representation, interdisciplinary working, competency-based leadership, democratic decision-making within teams, and the role of professional bodies, among others. We will also need to address privilege and power dynamics; including the structures, cultures and practices necessary for promoting real implementation of the CRPD within disability and other services.

### **Emerging dos and don'ts**

For myself as the clinical lead for the NCPPD I have developed a few guiding principles – dos and don'ts – over the last two years; and so I tentatively share these admittedly half-baked ideas.

The first is *don't use your own profession as a frame of reference*. It is very easy to think through your own profession, and what particular models of service, allocation of resources or appointments to new positions, will mean for the standing of your own profession, or indeed your own reputation with colleagues. This is certainly a challenge for some of my medical clinical lead colleagues.

Another principle is *do think systemically* and to relate this to using available resources as effectively, efficiently, and equitably as possible. Such systems-thinking has brought me into conflict, particularly with psychologists, regarding the relative allocation of clinical time to assessment and to intervention, especially in the context of very long waiting lists in some areas. It is perhaps the difference between wanting to do the very best for the person sitting in front of you, and wanting to do the very best for the population needing the service. Neither is wrong, both are correct, but they do often have very different and difficult implications for how services are provided and experienced.

A third is *don't tolerate bullying, professional dominance, or disciplinary capture*, and don't be 'nice' about understanding the structural forces that sustain them and constrain others from addressing them. I believe that unless a clinical lead models intolerance for oppressive behaviours, then service users (who are often marginalised through their own experience of oppression) are unlikely to receive services that are truly empowering, person-centred, and effective.

Fourth, *do be inclusive, about everything!* While often very time consuming in the short run, it is time saving, more just and effective in the long-run. Being inclusive of course means supporting the participation of people with disability in decision-making processes. It also means identify some allies in 'the

system' who can help you change things, but equally it means genuinely seeking to understand, address or allay the fears of those who don't want to change.

My final guiding principle – but I am hopeful to identify more! – *do have a Theory of Change* (Breuer et al., 2015) to guide what you are doing. You may not want to share this theory with others, and it may change as other things change, but it will help you think through how structures and power relations influence and sustain the current situation. It will also help you think through how most effectively to harness the resources you can muster.

### Conclusion

I appreciate that not all clinical psychologists will want to embrace structural and power issues in their efforts to improve their own or other's clinical practice. For those who do, such issues determine the settings and

conditions in which we work (MacLachlan & McVeigh, 2021); and these in turn influence the experience and effectiveness of disability services, or indeed any type of service. It is humbling to think that Kurt Lewin (1943) embraced these sort of ideas and provided the roots for theories of change, about 80 years ago. We are yet to really embrace them in the clinical sphere in helping us create the sort of organisational and culture change that is so necessary to design and deliver right-based services.

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