



CDI Clinical Practice Guidance Document Cover Sheet

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National Clinical Programme for People with Disability (NCPD)

Generic Key Features of Disability Regional Enhanced Supports & Services (DRESS)



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1.0 Introduction

This document describes key features of Disability Regional Enhanced Supports Services (DRESS's) which are common across a range of specialised services and supports for children with disabilities. Features specific to specialised pathways are described in the specific DRESS documents relating to them. Currently DRESS documents have been developed for Complex Behaviour; Motor Management and Feeding, Eating, Drinking and Swallowing (FEDS). The NCPPD is creating services that contribute to realising human rights, affirm the value and strengths of neurodiversity and learn from the living experience of people with disabilities.

2.0 The Pathway to Enhanced Support Services

Children's Disability Network Teams (CDNTs) are community-based specialised interdisciplinary teams, working in partnership with young people and their families, to co-create disability services and supports based on an individual's needs.

CDNTs receive referrals on the basis of the National Access Policy which directs those with more complex needs to CDNTs, while those with less complex needs are referred to primary care (PC) services, which are often provided by professions working more independently of each other.

CDNTs have experience of providing services and supports to people with a very broad range of complex needs, and these teams should always be seen as the central source of provision for services and supports for children with complex disability. This is important for maintaining the coherence of services, the trust built up between practitioners and service users, and avoiding outward referrals onto waiting lists. However, at times it will be appropriate for CDNTs themselves and PCTs to seek and receive support from others who have highly specialised experience in a more narrowly focused area.

The Disability Regional Enhanced Supports Services (DRESS) will be available in each of the 6 Regional Health Authorities, and at the national level will be supported by Sharing Experience and Expertise in Disability (SEED) Centres. SEEDs will be networked Centres including expertise across the country comprised of service users, practitioners, researchers, and educators, bringing together essential but often disparate knowledge, in one virtual 'centre', often with several physical locations, but working collaboratively. This document builds on the previous HSE "Guidance for Specialist Supports 2016", updates it, and strengthens it in the context of recent developments in Children's Disability Services.

3.0 Human Rights-based approach

The National Clinical Programme for People with Disability (NCCPD) is committed to ensuring rights-based services and supports. Where possible these should be evidence informed and learn from good practices, both in Ireland, and elsewhere; while also considering differences in context, systems and resources in other jurisdictions. All services and supports should have a monitoring and evaluation element where people with disability have a role in designing, reviewing, and interpreting findings, and in making recommendations arising from the process.



The National Disability Services Quality Improvement Office (2020) has developed a document on “[A Rights Based Approach to Behavioural Support Guiding Principles](#)”. This document supports the advocating for a human rights-based approach (HRBA), the 5 core principles are reproduced in Appendix 1.

With the recent commencement of the Assisted Decision Making (Capacity) Act (2015) and Ireland’s ratification of the UNCRPD in 2018, the rights of service users, and especially the primacy of their agency in decision making, must be central to services and supports for people with disability. This includes in the context of complex behaviours, which have historically been associated with coercive behavioural, physical and chemical interventions (REF). The HSE’s Office of the National Quality Improvement Office (2021) has also developed a document on “[Preventing the Need for Restrictions: Guiding Principles](#)”. That document cites the definition of *restriction* used by the Australian Government (2014): “A restriction is any practice, strategy, intervention, inaction that has the effect of limiting, controlling, monitoring, preventing, impeding the movement, rights and/or freedom of a person to act voluntarily”.

HIQA (2016) has defined *restrictive practices* as “a practice that: limits an individual’s movement, activity or function; interferes with an individual’s ability to acquire positive reinforcement; results in the loss of objects or activities that an individual values or requires an individual to engage in a behaviour/action that the individual would not engage in given freedom of choice”. Examples of restrictive practices therefore include, locked doors, physical restraint, withdrawal of preferred activities, and the use of physical or mechanical means, or medication use, to restrict a person’s behaviour. The HSE guidance on restrictive practices also endorses the 5 PANEL (Participation, Accountability, Non-discrimination and equality, Empowerment, Legality) principles described above. It also outlines how to apply the concept of a “capable environment” (McGill et al, DATA) and how to develop appropriate governance and oversight, as well as many other useful suggestions.

Guidance on avoiding the use of coercive interventions has also been produced by the National Disability Services Quality Improvement Office (2020). The primary principles of that guidance are also endorsed in this document and are reproduced in Appendix 2.

4.0 Being Person Centred

Traditionally in disability, health and social services people were expected to ‘fit in’ with the needs of the service, the preferences of the professions running them and the types of interventions they wanted to provide. The essence of the person-centred approach is the service fitting the person. It is the person’s life circumstances, supporters or carers, resources and their strengths and abilities that will usually determine if there are benefits associated with the provision of services and supports. So, services which assume everybody is the same and that they can fit-in to “our service”, fail to leverage the potential of a person’s lived experience, and that the service is actually “their service” which must fit their needs, strengths, and circumstances.

A plethora of research indicates benefits of person-centred service include recognising individuality; seeing the person as an expert about their own experience of services; sharing



power and responsibility with them, including in family discussions; ensuring services are accessible, flexible, and easy to navigate; considering a person's whole experience of services to promote the coordination and continuity of those services. It also includes ensuring that the "physical, cultural and psychosocial environment of health services supports person-centred care"; and this means staff are supportive, are trained in effective communication and "striving to put people at the centre of their care" (p. 4, Health Innovation Network, 2022).

5.0 Terminology: Services and Caring

While in disability services some people benefit greatly from the care of others, be they family members, friends, or staff; there are many people with a disability for whom the idea of "caring for them" can seem paternalistic, disempowering, and inappropriate. Certainly, we should all "care about" each other, including people with disabilities, but it is also important to acknowledge that that some people, who others may consider as having a disability, may not consider themselves to have a disability. For instance, the neurodiversity movement is about recognising and valuing difference, and seeing positives and strengths in such difference, rather than equating difference with deficits, disorder, or disease. (HSE Draft Autism Protocol, 2022). Someone who is autistic may not accept a label of disability, or the idea that they require someone to "care for" them. The NCPPD is strongly aligned with the rights-based, person-centred, and building-on-strengths ethos of the neurodiversity movement.

Words are the building blocks of how we think. If we use words carelessly, we may think of people in a way that is not appropriate to or accepted by them; and in doing so we may diminish their dignity and respect for individuality. So, terminology is not simply a matter of political correctness, but nor is it something to be worried about. It is always easy to ask someone how they wish to be referred to, and what sort of language best describes their lived experience. These sorts of questions can reveal a lot and can contribute to building a good and open alliance between service users and service providers.

Readers are also referred to the National Disability Authority's (2022) "Advice Paper on Disability Language and Terminology" (<https://nda.ie/publications/nda-advice-paper-on-disability-language-and-terminology>).

6.0 Layered rather than Stepped Approach

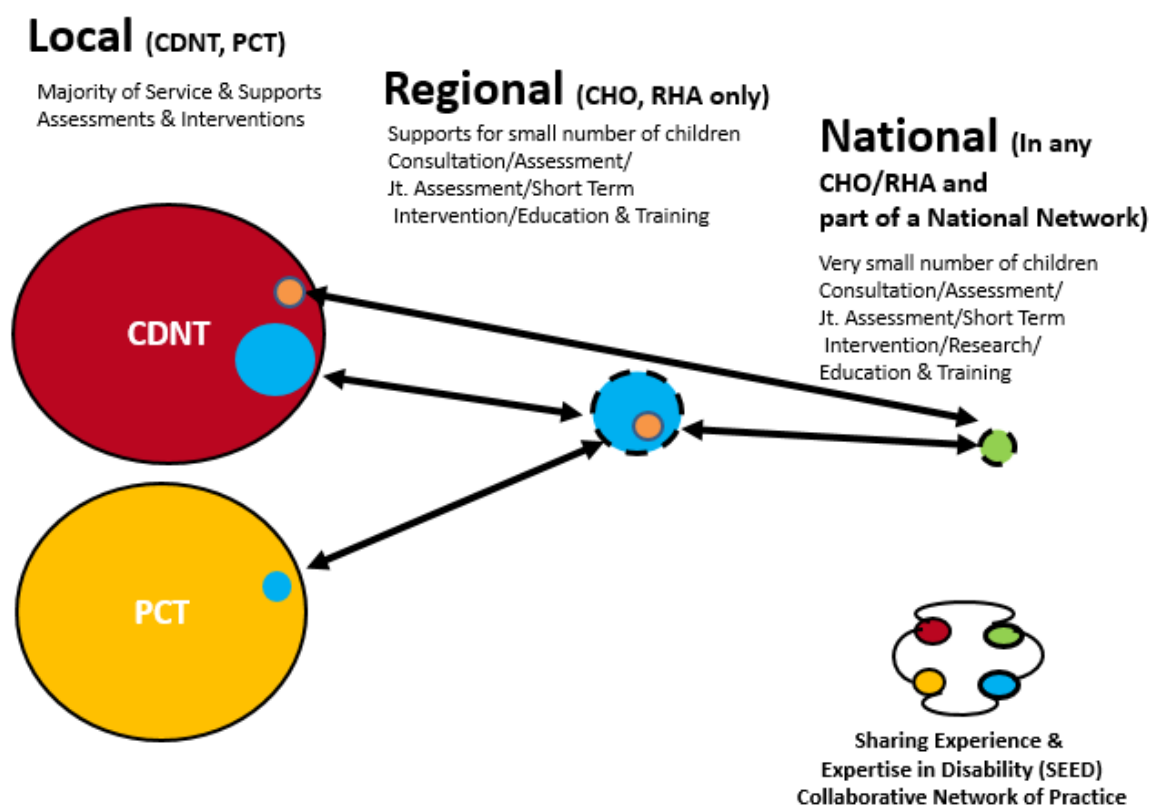
Several existing models of service and much research literature recognises the value of a tiered approach to service provision. In some instances, this is described as "stepped-care". However, this can be misleading as it is sometimes understood that different levels – steps – can only be provided once lower steps have been tried, or that people can only be on one step at a time. In fact, a layered model, where people may receive services and supports on different "steps" – e.g. a CDNT and DRESS – at the same time, is preferred and avoids the cessation of one "step" and waiting for another "step" to commence; which may also mean that people are put on waiting lists for the next step. The DRESS approach is a layered approach where a person will always be maintaining access to their usual service (CDNT or primary care or mental health) while they are getting services or supports from the DRESS.



7.0 General Framework for Disability Services

Figure 1 illustrate the general framework which has been agreed by the NCPPD Task Group on Specialised Services

Figure 1: High-level Schematic of Service Structure



7.1 The salient feature of the structures are as follows:

Local – In line with SlainteCare and Progressing Disability Services for children with disabilities shall be available on a needs-basis as close as possible to where children and their families live. Community Health Networks (CHNs) and Children’s Disability Network teams (CDNTs) are established on a local geographical basis in line with these policies, delivering the majority of services to children with disabilities.

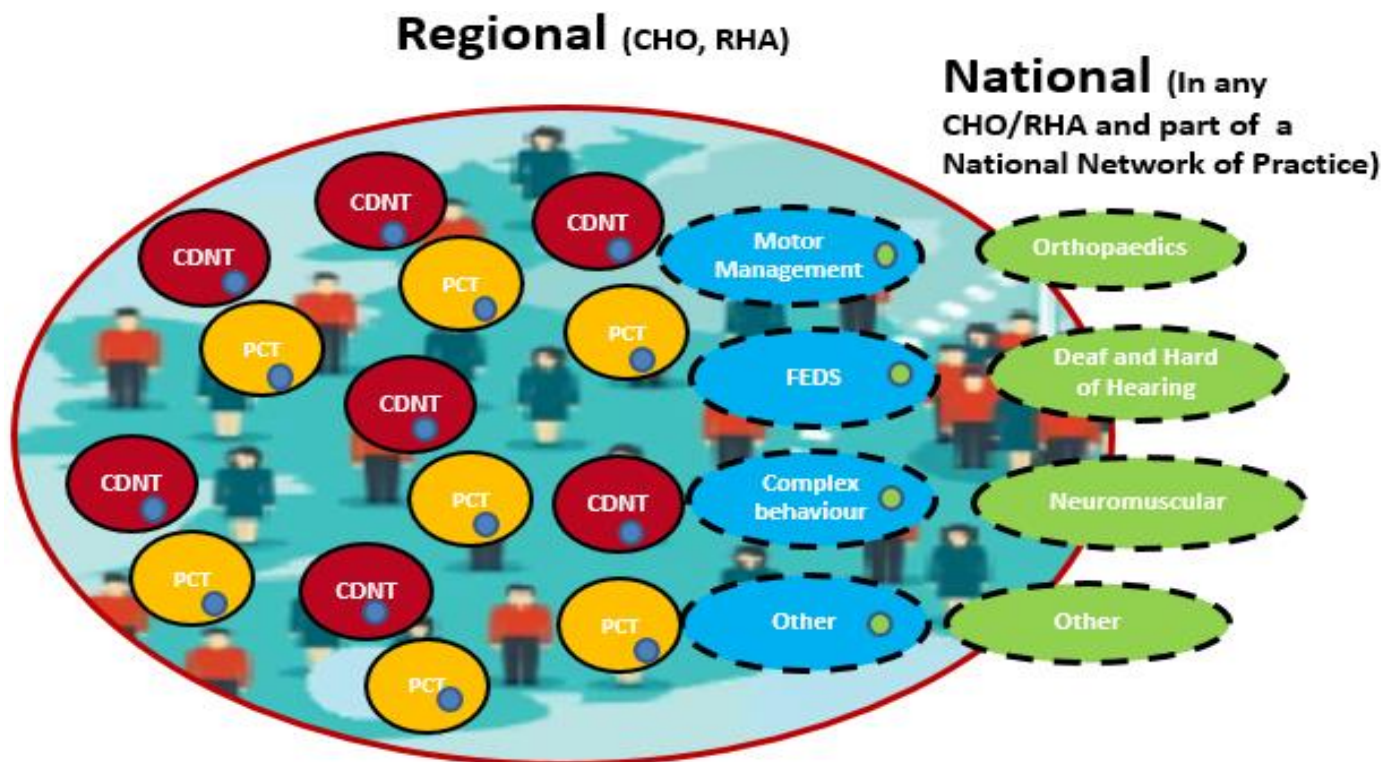
Regional – A smaller number of children will require access to specialised services and supports. By their nature in terms of population demand, critical mass of throughput needed to maintain competencies and required technical expertise, some of these services will be organised on a regional level.

National – Some tertiary specialised services may not be available in all regions, e.g. a Specialised interdisciplinary FEDS team with Paediatric and Dietetic Support and accessing a Videofluoroscopy Service, Orthopaedics. Centres with a special interest in a particular area will be increasingly organised nationally as a network of practice around a specific functional



area of expertise or practice. These networks will be supported to collaborate and take a national role in terms of providing guidance and support to practitioners and service users, standards, education, research, service development and policy advice. These networks will have lived experience, service provider, academic and international linkages. These networks, promoting good practices in highly specialised areas, are called SEED (Sharing Experience and Expertise in Disability) Collaborative Centres.

Figure 2: Middle-level schematic of service structure





8.0 DRESS - Establishment

Therapy capacity providing Disability Regional Enhanced Services and Supports to CDNTs and PCTs shall be structured in such a way to ensure service quality and sustainability. This entails dedicated and structured WTE, delivered by therapists with competencies in specific areas, who are supported to maintain and develop these competencies on an ongoing basis.

The exact determination of the allocation and spread of DRESS structures for a particular cluster of network teams or region will depend on local mapping and profiling and pre-existing specialised services. This will require a pragmatic approach with factors such as geographical spread, service delivery logistics and population profile being relevant.

The NCPPD recommends one overall DRESS structure per region for each area of specialised services (e.g. FEDS, motor management, complex behaviour), taking a population based view of service provision. This may require different units/service providers to come together in a region to ensure an overall population-based and coordinated approach to the delivery of specialised services and supports. This may require the establishment of an SLA with one Agency or a combination of Agencies (Interagency Agreement) with a particular experience/competence to provide specific DRESS services. The important principle is a consistent and coordinated service in any one region providing for the whole population of that region.

8.1 DRESS - Service Governance

Ultimately, the responsibility for service delivery for each region currently falls under CHO governance and the structures and service arrangements agreed within regions and between agencies. CHO governance structures for PDS are outlined in “Community Health Organisation of Governance of Children’s Disability Network Services” and the “Inter Agency Agreement” provides further detail on interagency working arrangements.

The identification of pathways to specialised services and supports are the responsibility of CHOs and the structures outlined therein. The regional Heads of Services (all care groups), Clinical Advisory Group, CDNM Operational Management Group, Lead and Partner agencies, Heads of Therapy, Clinical Specialist/Leads, providers of tertiary specialist services and family fora will be key stakeholders here.

As Regional Health Areas and new integrated governance structures evolve, the NCPPD recommends that DRESS structures are aligned to this context. DRESS pathways require an integrated and coordinated approach to service delivery between different care groups. The most effective overarching governance of these services, taking a population based view of needs, will be best served through integrated governance oversight.

8.2 DRESS Staffing

Different DRESS’s for different speciality areas – for example, Motor Management or Complex Behaviour – will require different skills mixes and these are indicated in the



respective DRESS specialised services documents associate with this “Key Features” document.

It is recognised that there are pros and cons to split posts – where a person may work part-time in a CDNT and part-time in a DRESS. A flexible approach should be taken to facilitate service needs, clinician availability and personal preferences. Regardless of whether DRESS posts are full or part-time, the full WTE of posts with dedicated and protected time should be provided within the DRESS service.

In the context of current limited resources a phased approach to the staffing of DRESS’s should be considered. Initial DRESS structures will require a quantum of staff to be drawn from CDNTs depending on local competency mapping and needs. The NCPPD recommends that this should be supplemented by a minimum number of dedicated posts at senior and Clinical Specialist level. DRESS’s will require Clinical Specialists to take a regional leadership role to coordinate and oversee the delivery of disability regional enhanced services and supports from a clinical perspective, supported by an administrator.

DRESS services should in time allow for rotations in and out of CDNTs and CHNs (even on part time basis) for the purposes of building competencies, spreading knowledge and skills and empowering local teams.

8.3 DRESS - Leadership

DRESS will be comprised of a range of practitioners with highly specialised skills working in a collaborative way with parity of esteem through adopting principles of co-leadership. The HSE’s People’s Needs Defining Change (2019) publication defines collective leadership as “the interaction of team members who share leadership roles. It means everyone taking responsibility for the success of the service as a whole – not just for their own jobs or work area. Responsibility and accountability function simultaneously at both individual and collective levels. It is not solely the role of the formal leader and is not defined by position or status. It is a dynamic team occurrence where leadership power is distributed and allocated to wherever expertise, capability and motivation sit within an organisation or team” (p. 11).

Where it is necessary to identify a lead for working with a particular service user in collaboration with a CDNT or PCT, this will be done on a competency basis in relation to the nature of the presenting difficulties. Different clinicians may be leads for different cases, and in other cases several clinicians may share leadership. This approach coincides with a significant body of research demonstrating that more democratic and ‘flat’ approaches to teamwork result in better clinical decision making and less clinical risk than the hierarchical approach traditionally adopted in many health service settings.

8.4 DRESS Management

As outlined above members of the DRESS may in some instances also be members of a CDNT, with an agreed portion of their time allocated to DRESS activities. Practitioners within a CDNT are accountable to the CDNT Manager in terms of how they allocate their time, prioritise their workload, etc. and this will continue to be the case for their CDNT work, and



they will be required to inform their CDNT Manager of their DRESS work commitments, to ensure that their case-load is appropriate to whatever portion of their time is allocated to DRESS.

There is an acknowledged need for flexibility in regions. Members of DRESS who are not members of CDNTs will have clear accountability arrangements established in line with the lead and partner agency model, CHO governance and inter-agency service arrangements.

8.5 DRESS Clinical Supervision

The NCPPD has produced guidance on clinical supervision and distinguished between this and disciplinary and managerial supervision (see [here](#)). Consistent with the co-leadership practice of the DRESS, clinicians will provide clinical supervision and be accountable to each other. In addition, individual clinicians will still be able to seek supervision from colleagues within their own discipline (as is currently recommended in CDNTs/PCTs) or through arrangements made by their line manager or Head of Discipline/Therapy Lead, as appropriate.

8.6 DRESS Culture/Ethos

The culture and ethos shall be one of joint service and support planning, and coordinated in line with complexity, with clear delegation and documentation of service components outlined in a joint service and support plan for each child. The approach to addressing needs shall be integrated in line with the layered model approach.

There shall be an emphasis on early and effective communication, in-reach, joint working and pragmatic and timely problem solving in the first instance rather than “referral on” to another service.

DRESS personnel and regional leads will have an explicit mandate to work with relevant managers and develop capacity and skillsets within local CDNTs and PCTs.

9.0 Annual Health Check for People with Disability

Usually a referral to a DRESS will have involved some level of service from a medical practitioner. Where this is not the case, then we recommend that any person receiving services from a DRESS should also be referred for medical examination to a General Practitioner, Community Medical Officer, Paediatrician or other medical specialist. This does not only apply to people with physical disabilities but to those with other sorts of disability too.



Appendix 1

The National Disability Services Quality Improvement Office's (2020) "A Rights Based Approach to Behavioural Support Guiding Principles" identifies 5 core principles, which may be applied in residential or community settings:

1. Accountability – Those responsible (duty bearers) for respecting, protecting and fulfilling human rights must be accountable for their actions or their failures to act. There should be effective strategies in place to identify rights infringements and remedies in place when human rights breaches occur. This includes advocating with the person.
2. Non-discrimination and equality – all individuals are entitled to their rights without discrimination of any kind. A HRBA requires that laws and practices guarantee full and equal enjoyment of human rights to vulnerable groups on the same basis as anyone else. In order to achieve this, these groups may require a special focus. All types of discrimination should be prohibited, prevented and eliminated.
3. Empowerment – everyone is entitled to claim and exercise their rights. People must be educated about their rights, equipped with the necessary skills to claim them and participate in the development of policies which affect their lives. This represents a shift from models which see people as being in need or as passive recipients of charity, but instead views them as people empowered to claim their rights.
4. Legality – Human rights must be at the heart of policymaking and service delivery. Approaches should be in line with the legal rights set out in Irish and international laws. This includes identifying and naming the rights that the person may not be supported to exercise or that may be restricted.
5. Legality – Human rights must be at the heart of policymaking and service delivery. Approaches should be in line with the legal rights set out in Irish and international laws. This includes identifying and naming the rights that the person may not be supported to exercise or that may be restricted.



Appendix 2:

Guidance on avoiding the use of coercive interventions has also been produced by the National Disability Services Quality Improvement Office (2020). The primary principles of that guidance, which may be applied in residential or community settings, are also endorsed in this document and are reproduced here in Appendix 2.

1. Restrictive practices are an infringement of a person's constitutional right to liberty and bodily integrity and should only be used when absolutely necessary.
2. Providers should, in so far as is practicable, seek to reduce or eliminate the use of restrictive practices.
3. Where restrictive practices are assessed as necessary, they should be implemented, where possible, in consultation with the person receiving care and with their informed consent.
4. Assessments should identify any physical, medical, psychological, emotional, social and environmental issues which may be contributing to the use of restrictive practices.
5. Any restrictive practice should be proportionate to the identified risk(s).
6. The use of restrictive practices should be subject to ongoing review to determine if they continue to be necessary and should be removed as quickly as possible when no longer required. Reviews should also be used as an opportunity to trial alternatives that are less restrictive and or for a shorter period of time.
7. Providers should: be aware of the use of restrictive practices in their centres; be assured that they are used in compliance with the regulations and National Standards; have a senior manager or a committee in place whose goal it is to reduce and or to eliminate the use of restrictive practices.
8. Staff should have access to appropriate training on the use of restrictive practices, including prevention and alternatives, and be supported in getting to know each person's needs and preferences.
9. Providers should collect and analyse data on the use of restrictive practices in order to identify patterns or trends.



Appendix 3 -Specialised Services and Supports Task Group Members

Membership	Representation
Mac MacLachlan (Chairperson)	Clinical Lead, National Clinical programme for People with Disability (NCPD)
Mike Walsh	Programme Manager, NCPD
Lorraine Dempsey	Parent and Lived Experience
Fionna Brennan	Child Health Ireland
Edel Quinn	CHO Heads of Service Disability
Briega Byrne	Progressing Disability Services Project Managers
Ann McGreal	Children's Disability Network Team Managers
Maeve Raeside	National Primary Care Operations
Tony McCusker, Laura Molloy (initially)	National Mental Health Operations
Ann Bourke, Angela O'Neill	National Disability Operations
Denise McDonald*, Siobhan Gallagher	Medical Subcommittee to NCPD* and Consultant Paediatricians
Therese O'Loughlin, Riona Morris (initially)	Umbrella Bodies Disability
Gillian O'Dwyer	Heads of Discipline, HSCP
Renjith Joseph	Physiotherapy Subcommittee to NCPD Disability Advisory Group (DAG)
Karen Henderson	Speech and Language Therapy Subcommittee to NCPD DAG
Mary McGrath	Occupational Therapy Subcommittee to NCPD DAG
Karen Cowan	Dietetics Subcommittee to NCPD DAG
Liam O'Callaghan	Nursing Subcommittee to NCPD DAG
Kate Falvey	Psychology Subcommittee to NCPD DAG
Rose Bradley	Social Work Subcommittee to NCPD DAG