New Service Developments for **Complex Behaviour**

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Process - Development

Some other issues for possible discussion

1. Rights-based leadership and governance – re CAMHs
2. AoN Update
3. Piloting New Autism Protocol
4. Disability/Mental Health/Primary Care interaction - new agreed position

Process – Development of new framework for complex behaviour

- National Clinical Programme for People with Disability
- Specialised Services and Supports for Children's Disability Services **Task Group** established under the Disability Advisory Group (DAG)
  - Building on Existing Guidance – 2016
  - Uneven access to specialised services beyond CDNTs
  - Learn from and incorporate existing good practices – don't break things that work!
  - Survey of 91 CDNTs identified risk/need/previously unknown demand
- Sub-Working Groups
  - Motor management Pathways group
  - FEDS Pathways group
  - Complex Behaviour Pathways group
- Additional existing pathways alignment
  - Deaf and Hard of Hearing
  - Vision and Co-occurring Conditions

Process – Consultation and Approval

- Consultation and Discussion with multiple stakeholders at multiple forums, e.g. National Disability Operations, PDS National Steering Group, CHOs Heads of Service, CEOs Voluntary Organisations, Other
- Workshop on Implementation Challenges
- Disability Advisory Group – Multiple Stakeholders
- NCAGL
- CCO Forum

4 Documents – in brief

- **Generic Key Features of Disability Regional Enhanced Supports & Services (DRESS)** – This document describes key features of Disability Regional Enhanced Supports Services (DRESS's) which are common across a all specialised services.

- **Disability Regional Enhanced Supports and Services (DRESS) for Motor Management –** this document presents a framework and pathways guidance for motor management services – e.g. spasticity and contracture management, complex casting, orthopaedics, medical management of motor problems.

- **Disability Regional Enhanced Support and Services (DRESS) for Feeding, Eating, Drinking and Swallowing (FEDs) -** this document presents a framework and pathways guidance for managing issues related to feeding, eating, drinking and swallowing difficulties – e.g. management of oropharyngeal dysphagia, aversive eating disorders, nutrition, videofluoroscopy, PEG management.

- **Disability Regional Enhanced Services and Supports (DRESS) for Complex Behaviour -** this document presents a framework and pathways guidance for the management of complex behaviours – e.g. extreme destructive, aggressive, dis-inhibited, impulsive or self-injurious behaviour associated with any person with a disability.

DRESS – Generic Key Features

- Human Rights-based approach
- Being Person Centred
- Terminology: Services and Caring
- Layered rather than Stepped Approach
- General Framework for Disability Services
- DRESS Establishment
- DRESS Service Governance
- DRESS Leadership
- DRESS Staffing
- DRESS Supervision
- DRESS Management
- DRESS Culture/Ethos

“Complex Behaviour”

- Complex behaviour refers to behaviours that are variously described as “challenging behaviour”, “unwanted behaviour”, “behaviours of concern” or “disruptive behaviours”; it also incorporates destructive, aggressive, disinhibited, impulsive and self-injurious behaviour.
- Such behaviours may be unsafe for the person engaging in them, and/or for other people, they may be destructive of property or undermining other people’s sense of psychological safety.
- Complex behaviours are often associated with attempts to communicate unmet needs, and are often triggered by events, circumstances, or environments outside the person’s own control.
- Complex behaviours can occur in any person and often have a functional basis, meaning they are intended to achieve an outcome, communicate dissatisfaction or frustration, due to difficulty making needs known to others.
- May also have physical or mental health associations.
- While much of the literature relevant to complex behaviours relates to challenging behaviour among people with intellectual disability, such behaviours also may occur among people with other types of disability, and those without a disability.

- We recognise that the term “complex behaviour” is not neutral, and nor are the other commonly used alternatives.
- However, whatever the terminology used, when behaviour is considered within the context of human rights, person-centred services and affirmation of neurodiversity, the focus is shifted from within the child/person to the wider ecosystem around them.
- The is importance because it can transform reductionist and deficit-focussed thinking, to focus instead on the reasons behind the behaviour and its overall impact on the wellbeing and development of the child/person.

CDNT Survey March 2022

"Currently does your team have a pathway or referral process to additional services or supports or other agencies beyond your CDNT, relating to managing complex behaviours or presentations that are challenging, other than CAMHS and MHID?"

The respondents to the survey were CDNT managers:
We had responses from 75 out of 91 CDNT managers nationally.
Only a quarter (24%) responded "Yes";
while the majority (69%) said "No" and
another 7% responded, "Don't Know".

"What do you feel is needed in terms of regional or national guidance/support/ direction to assist in managing children with particularly complex presentations and behaviours that challenge?"

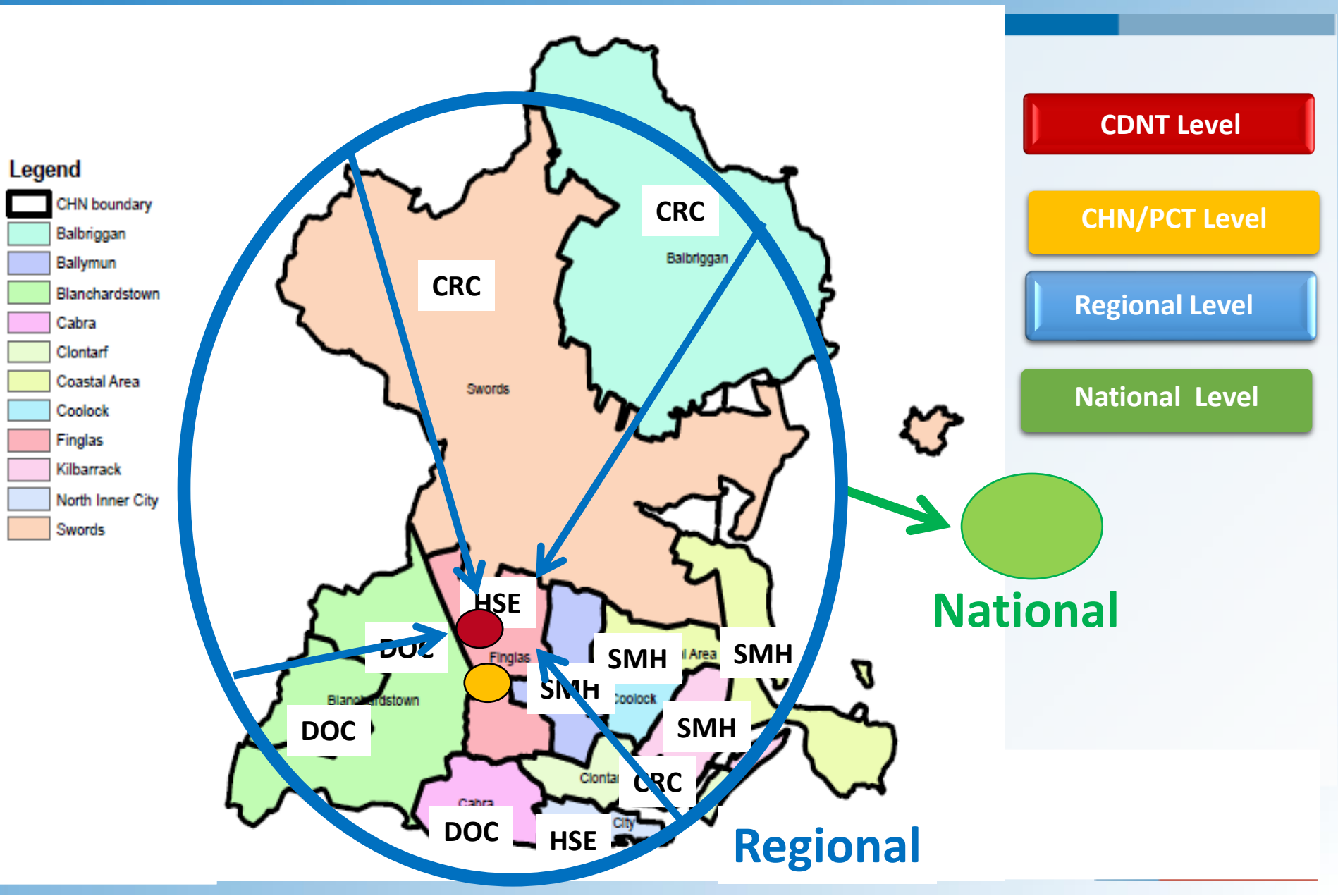
"Establishment of specialist support service"
"A Pathway/service delivery framework at CHO level"
"Sharing of training for families"
"Training for all staff allocated to the team"
"Each CDNT should have a minimal amount of behaviour support therapists - appropriate ratio to caseload numbers"
"Clear tiered training pathway for teams to build competencies in this area"
"Willingness of CAMHS to engage in joint working"
"National guidance document to look at pathway"
"All existing policies regarding joint working are implemented fully"
"Easier access for children and young person with ASD to mental health supports"
"Acknowledgment of the difficult role the parents and siblings have supporting a child with complex needs/ behaviours "
"All behaviours that challenge need to be addressed at the local level first and this requires resources to be in place at each team level"
"Enhance Interdisciplinary team approach to management on Concerning Behaviour".
"it is becoming apparent that being on the caseload of two separate teams (CDNT and CAMHS) is not going to meet their needs, a team that combines these approaches would better meet their needs."
"Training for CDNT clinicians - everyone on a team needs to have a shared understanding

CHO9 Survey

In 2020, a multidisciplinary working group from Community Health Organisation 9, developed a document on Provision of Complex Behaviour Supports (CHO9, 2020), which identified a number of factors in defining complex behaviour support needs. An audit identified that:

Half (51%) of all children and young people receiving support from disability services in CHO9 presented with complex behaviour support needs, with 34% requiring preventative support, 13% targeted support, and 4% of children presenting with complex behaviour requiring more intensive specialist support.

Concept (for Illustration)



Structure

Local (CDNT, PCT)

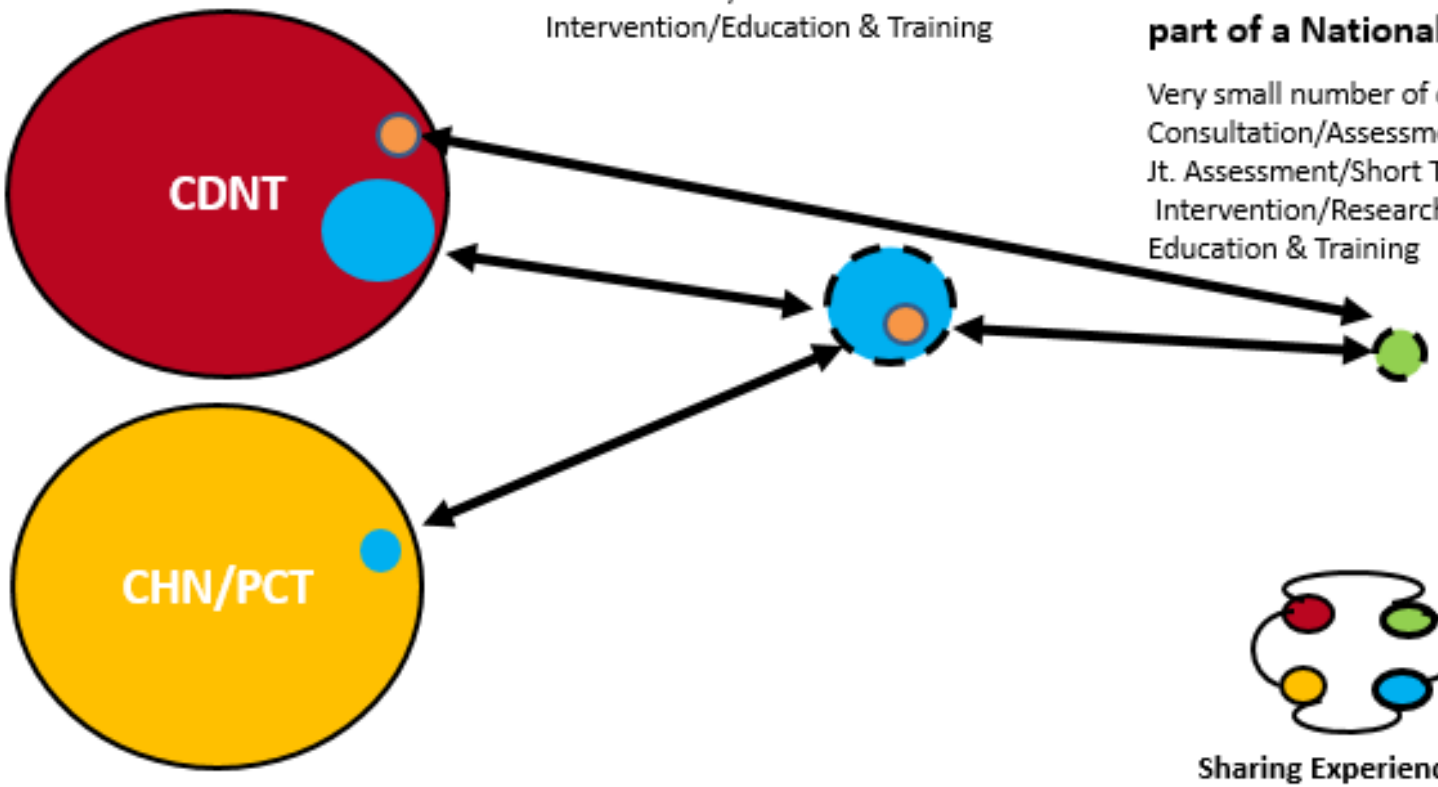
Majority of Service & Supports
Assessments & Interventions

Regional (CHO, RHA only)

Supports for small number of children
Consultation/Assessment/
Jt. Assessment/Short Term
Intervention/Education & Training

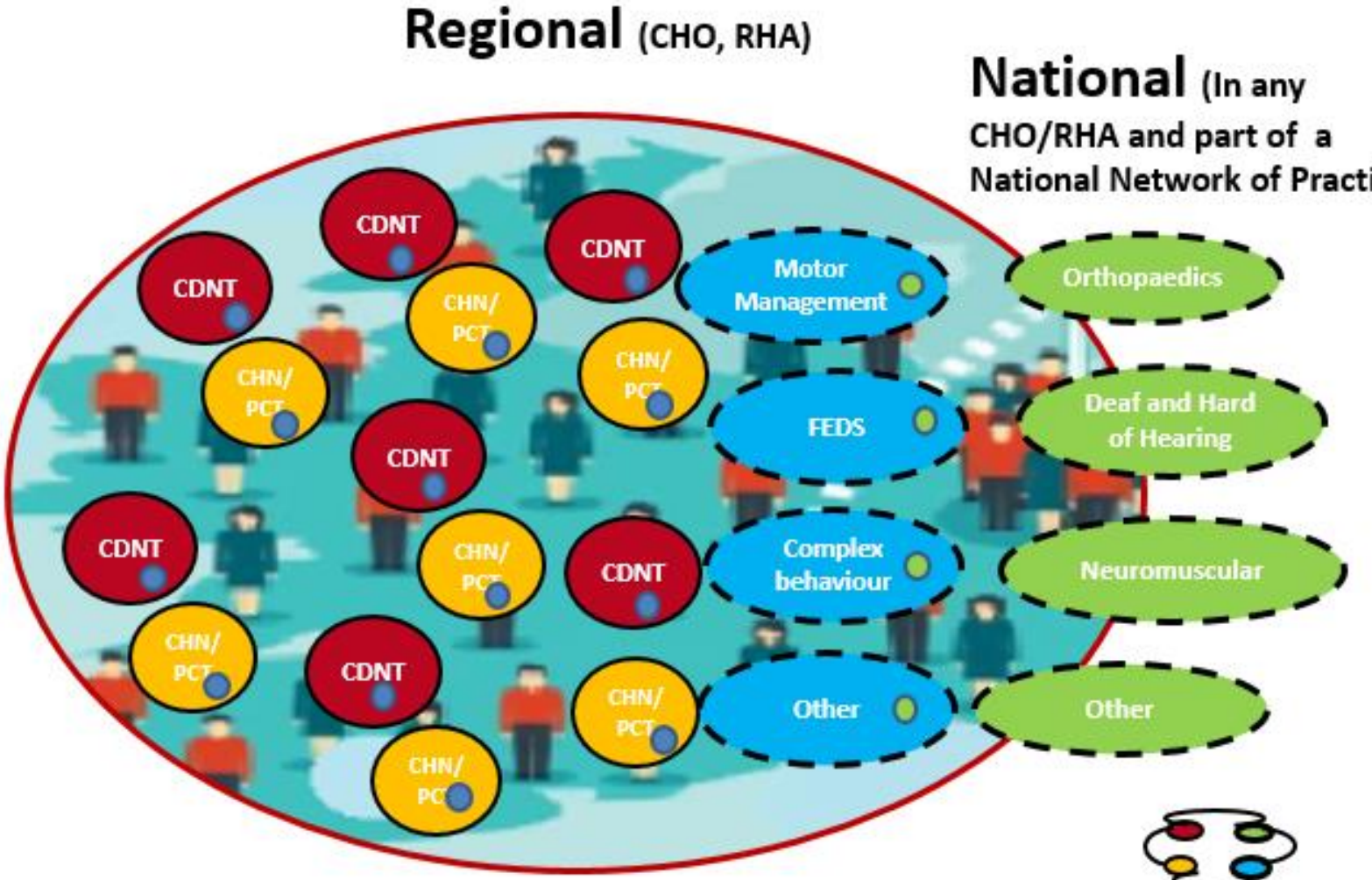
National (In any CHO/RHA and part of a National Network)

Very small number of children
Consultation/Assessment/
Jt. Assessment/Short Term
Intervention/Research/
Education & Training

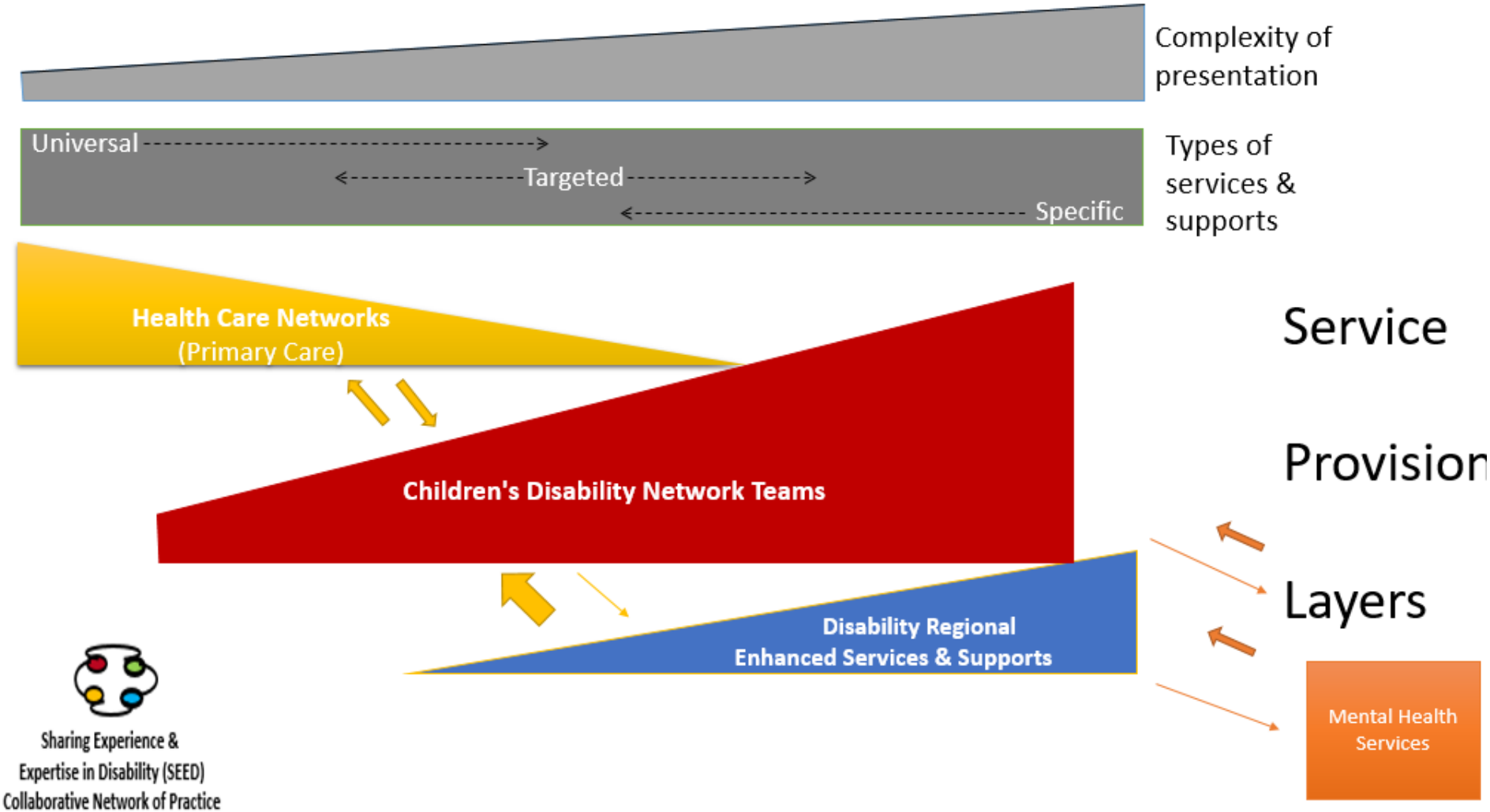


Sharing Experience & Expertise in Disability (SEED) Collaborative Network of Practice

Structure


Regional (CHO, RHA)
National (In any CHO/RHA and part of a National Network of Practice)
CDNT
CHN/ PCT
Motor Management
Orthopaedics
FEDS
Deaf and Hard of Hearing
Complex behaviour
Neuromuscular
Other
Other
Sharing Experience & Expertise in Disability (SEED) Collaborative Network of Practice

DRESS Framework for Complex Behaviour



Sharing Experience & Expertise in Disability (SEED) Collaborative Network of Practice

Table 3 A layered approach for services and supports.

Level of Supports and Services	Provision level and examples of criteria	Examples of Interventions
Services and support which benefits MANY people and are often described as UNIVERSAL, in the sense that they are potentially helpful to all. These include services and supports that may be PREVENTATIVE and reduce the likelihood of complex behaviour developing.	Levels: CHN, CDNT Behaviours which result in mild difficulties in participation in one or more settings (home, school, community) May require low levels of supervision / strategies to support behaviour management.	Preventative supports including on-line resources and parent/carer education & training groups. Supported primarily through recommendations to on-line resources, consultation & regular reviews. Parent General Advice Clinics Example; Triple P/Parents Plus/Hanen/Early Bird/Lámh/PBS/Emotional Regulation/ADL's. Collaborative & Proactive Solutions (CPS)

SOME people who share similar types of difficulties may benefit from a range of <u>TARGETED</u> services and supports.	Levels: CHN, CDNT, DRESS Behavioural difficulties which result in the child being delayed/different from their peers. Result in moderate difficulties in participation in most settings (home, school, community) and across most social, educational, family and daily activities. Negatively impact performance across some other areas of function and participation. Are externalised. Are not developmentally appropriate. Pose a moderate risk to self or others. May require moderate levels of intervention, supervision and strategies to support behaviour management. May require timely intervention to address risk, but risk is not deemed urgent.	Team consultation in development & review of behavioural supports. Interdisciplinary assessment of the reasons contributing to the behaviour. Intervention built on a range of evidence-based practices including changes to the environment, skills development, proactive and non-aversive reactive management strategies, such as the low arousal approach Targeted Advice Clinics Targeted workshops e.g. Timid Tigers/Non-violent resistant training/PBS/ Facing your Fears/ Friends for Life Collaborative & Proactive Solutions (CPS)

FEW people will require very SPECIFIC and individualised services and supports to address complex behaviour	Levels: CDNT, DRESS Behavioural difficulties resulting in the child being markedly developmentally delayed or different from their peers. Results in sever difficulties in participation in all settings (home, school, community0 and across all social, educational, family and community settings and daily activities. Negatively impact performance across all areas of function and participation. Are externalised, oppositional, aggressive, socially inappropriate. Are not developmentally appropriate. Pose a significant risk to self and others. Require urgent intervention to address risk. Require maximum levels of intervention, high levels of supervision and high-level strategies to support behaviour management.	More in-depth specialist assessment as required for case formulation. Intensive therapeutic interventions Modelling/coaching of interventions May include enhanced multi-element support plans or similar. Advice on use of or avoiding use of any restrictive practises. Collaborative & Proactive Solutions (CPS)

Appendix 1 -Specialised Services and Supports Task Group Members

Membership	Representation
Mac MacLachlan (Chairperson)	Clinical Lead, National Clinical programme for People with Disability (NCPPD)
Mike Walsh	Programme Manager, NCPPD
Lorraine Dempsey	Parent and Lived Experience
Fionna Brennan	Child Health Ireland
Edel Quinn	CHO Heads of Service Disability
Briege 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 NCPPD* and Consultant Paediatricians
Therese O'Loughlin, Riona Morris (initially)	Umbrella Bodies Disability
Gillian O'Dwyer	Heads of Discipline, HSCP
Renjith Joseph	Physiotherapy Subcommittee to NCPPD Disability Advisory Group (DAG)
Karen Henderson	Speech and Language Therapy Subcommittee to NCPPD DAG
Mary McGrath	Occupational Therapy Subcommittee to NCPPD DAG
Karen Cowan	Dietetics Subcommittee to NCPPD DAG
Liam O'Callaghan	Nursing Subcommittee to NCPPD DAG
Kate Falvey	Psychology Subcommittee to NCPPD DAG
Rose Bradley	Social Work Subcommittee to NCPPD DAG

Summary & SEEDs

1. Children's Disability Network Teams (CDNTs) are community-based specialised interdisciplinary teams – we need to maintaining the coherence of services, the trust built up between practitioners and service users, and minimise outward referrals onto waiting lists.
2. CDNTs may seek support from others who have highly specialised experience in more narrowly focused areas. - DRESSs – one in each RHA.
3. At the national level CDNTs and DRESSs will be supported by a community of practice called Sharing Experience and Expertise in Disability (SEED) Centres, also in the specialised areas. 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.
4. These structures have been developed and supported through the broad consultation processes described above . They provide a short, medium and longer-term structure for service delivery and development.