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Applying Evidence to the Aspiration for Equity in Children's Disability Services

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Applying Evidence to the Aspiration for Equity in Children's Disability Services

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Abstract

Developmental disability is a universal issue, affecting millions of children, adolescents and families globally. Many children and young people will require access to and support from disability services. Development of such services has often been piecemeal and requiring reconfiguration, which is a complex process. The aim of this research was to evaluate the evidence-base underpinning the programme of disability reconfiguration in Ireland. A review of relevant policy documents highlighted limited analysis of research and practice evidence to inform policy development and implementation. Many challenges have arisen during reconfiguration such as lengthy waiting lists and high staff turnover. While there are plans in train to increase disability resourcing, it is contended that a root and branch review of the underlying policy is undertaken, with a focus on integrating best available research and practice evidence.

Keywords: disability, policy, evidence-base

Points of Interest:

- Millions of children and adolescents globally need access to disability services including physiotherapy and speech and language therapy
- National disability policies will impact availability and resourcing of disability services, as well as how and where services are delivered
- Policies informed by research and practice evidence will lead to development of better quality polices and thus better services for children and adolescents with disabilities

Applying Evidence to the Aspiration for Equity in Children's Disability Services

Introduction

'While some children have received an excellent service, others have received none'
(Senator Erin McGreehan, Oireachtas Joint Committee on Disability Matters, 9th November 2021).

Globally, approximately 316.8 million children and adolescents live with a disability (World Health Organization and the United Nations Children's Fund, 2023). Many children with disabilities will require access to specialist healthcare services to address issues related to their disability and develop life skills relating to learning, independence and communication (World Health Organization, 2011). For instance in Ireland, many non-statutory bodies receive government funding to provide disability services (Mulvany et al., 2007). Consequently, children's disability services have often developed piecemeal, with a range of service providers and variable access criteria. This mirrors healthcare service development in many other areas (Kohen et al., 2010) and issues such as delayed diagnostic processes, lengthy waiting lists and ineligibility for access to disability services are commonly reported factors (World Health Organization and the United Nations Children's Fund, 2023). Such issues often give rise to reconfiguration efforts to address inequities (Baeza, 2023). However, health services reconfiguration involves large scale and complex change processes (Perry et al., 2022). In this paper, the Irish reconfiguration of children's disability services is examined as a case study with a specific focus on the use of research and practice evidence to inform the reconfiguration process.

Children's disability services in Ireland have developed extemporaneously and are provided by both statutory (HSE) and non-statutory (e.g. Brothers of Charity, Enable Ireland) organisations. This led to service disparities and inequalities in service access, often geographically determined. Progressing Disability Services for Children and Young People (PDS) is the national programme reconfiguring Irish paediatric disability services (Cantan and Bolger, 2017). PDS rollout began in 2009, with the aim of providing equitable service access throughout the country. As of December 2021, the reconfiguration process was deemed complete, with all 91 disability teams working under the new model. Teams are referred to as Children's Disability Network Teams (CDNT).

Significant challenges arose during reconfiguration and continue to persist (Inclusion Ireland, 2022). Reports from advocacy and non-statutory bodies reports such as Inclusion Ireland (2022), as well as media reports about individual families, strongly indicate that implementation of PDS is an ongoing challenge (McDonagh, 2022). Most concerningly, there are reports of some children having less access to services than prior to PDS (Buckley et al., 2021). Children are reported as waiting on varied lists for services instead of an integrated system (Horgan-Jones, 2023). The HSE state in their National Service Plan 2024 that there are "significant gaps in service currently experienced by children and families"

Prior to PDS many children attending Special Schools received school-based therapeutic services, which then ceased. Families have reported dissatisfaction with this and concern regarding the impact on children's development (O'Connor, 2022). The Irish Prime Minister (Taoiseach), Micheál Martin, described this decision as "diluting the service" available to children attending Special Schools (Phelan, 2022).

The implementation of PDS is underpinned by the policy and procedure documents developed by the Health Service Executive (HSE) as the architects of PDS. As evidence-based practice is well established and expected within healthcare (Schalock et al., 2011), we would expect to find the evidence base for PDS and decisions informing practice within these documents, e.g. reasoning for cessation of school-based therapy in Special Schools. As noted by Perry and Weiss (2007) '*evidence-*

based practice means that we question what we do … We make decisions based on the best data available (taking into account its possible limits) and we share our knowledge with others and learn from each other' (p.171). Therefore, the aim of this review was to analyse key PDS policy and procedure documents to determine the evidence-base for PDS.

Methodology

This document review was guided by the document analysis process developed by Moilanen et al. (2022).

Phase 1: Determining the Purpose, Data, and Study Design

Purpose	To determine if the policies and procedures underpinning progressing disability services are evidence based
Research question	**What is the evidence base for progressing disability services?**
Document type & design	Grey literature: publicly available policies and procedures of progressing disability services hosted by HSE. Empirical literature: not relevant
Focus	Linkage of policies and procedures of progressing disability services to best practice evidence / guidelines. If there is an absence of these the researcher will contact experts in the field to determine if such documents exist

Phase 2: Determining the Selection Strategy

Time limits	These were set by the HSE available documents, i.e. the earliest available PDS document would be the starting point and continue to the present day.	
Sampling strategy	Purposeful document selection	
Entity of documents	All document components including appendices	
Inclusion and exclusion criteria	**Inclusion**	**Exclusion**
	Policy or procedure PDS document published by HSE HSE PDS supporting materials, e.g. Minutes of National Reference Group on Multidisciplinary Services for 6-18 Year Olds meetings	Not published by HSE HSE PDS document which is not a policy or procedure Legislative documents Recruitment materials, e.g. job descriptions
	English language	Written in a language other than English

Phase 3: Selecting or Developing the Extraction Matrix

The data extraction matrix included the following headings: Year of publication; Name of policy or procedure; Reference to supporting literature – yes/no; If yes, reference for each piece of literature referenced within the document; Extract illustrating how the literature is used. An example of the data extraction matrix is illustrated in Table 1 below.

Table 1: Example data extraction matrix

Year	Name	Evidence referenced	Evidence Source	Extract
2021	**National policy for Children's Disability Network Teams on family engagement and attendance**	Yes	Progressing Towards Outcomes Focussed Family	Family centred practice is a core and fundamental principle of the CDNT model of service'

			Centred Practice: An Operational Framework. HSE. 2020	
			Outcomes for Children and Their Families. Report on an Outcomes-Focused Performance Management and Accountability Framework for Early Intervention and School Age Disability Network Teams. HSE. 2013	5. Children, families and service providers all benefit most when services are based on true collaborative partnerships between families and professionals
			10 Things You Can Do to Be Family-Centred. CanChild Center for Childhood Disability Research. Law, M., Rosenbaum, P., King, G., King, S., Burke-Gaffney, J., Moning-Szkut, T., Kertoy, M., Pollock, N., Viscardis, L., & Teplicky, R., 2003	Example of what can be done to be more family centred regarding appointments Families- Inform CDNT of your preferences for meeting times and location CDNT- Try to offer families a choice of in person or online and times to meet. Ask what works best for them.

Phase 4: Pilot Testing the Selection Strategy and Extraction Matrix with Sub-Data

The selection strategy and extraction matrix were tested on 10% documents (n=3). This confirmed data extraction matrix was fit for purpose, added additional heading to categorise type of supporting literature used.

Fifth Phase: Collecting and Analysing the Data

Data was collected from the HSE dedicated webpage, ‘Key National Documents’. Each document was reviewed, and data extracted as per the matrix headings above, which had been formatted as an Excel spreadsheet. Supplementary information from records held by the Health Service Executive was sought through the following avenues:

A Parliamentary Question was prepared by the authors and submitted by Deputy Carol Nolan on 29th November 2023 as follows:

- *To ask the Minister for Children; Equality; Disability; Integration and Youth to outline what national or international evidence or research, apart from data in the UN Convention on the Rights of Persons with Disabilities, the National Disability Strategy 2004, the Education for Persons with Special Education Needs Act 2004, and the Disability Act 2005, was undertaken or considered in devising the progressing disabilities services programme; what models of implementation elsewhere, if any, were examined; his views on the conceptualisation of the PDS programme; and if he will make a statement on the matter.*

A Freedom of Information request was submitted by the authors to the HSE on 20th December 2023 as follows:

- *Under the Freedom of Information Act (and for academic research purposes), I request copies of records relating to the conceptualisation and early planning of the Progressing Disabilities Services (PDS) programme as a reconfiguration and new model for service delivery; and any national or international evidence or research or models of implementation elsewhere that were considered or examined at that stage in the planning process. I understand that such records would relate to the period from January 2007 to end of June 2009. I would prefer to receive the records electronically. For research purposes, I am trying to establish if the PDS model of delivery was based on direct experience elsewhere or was it conceived and devised as an inaugural model by the HSE.*

Data was analysed using a deductive approach comprised of quantitative descriptive analysis and qualitative content analysis. Data extraction was completed by both authors.

Sixth (Integrated) Phase: Ensuring Rigour of the Study

Rigour of the type of the documents	Given the purpose of the review it is appropriate that all included documents are from the HSE, as they are the architects of PDS and produced the overarching policies and procedures	
Rigour of document selection and analysis	Selection bias	All documents published by the HSE under the heading of ‘Key National Documents’ were considered and only those which did not meet inclusion criteria excluded. To optimise comprehensiveness of this project the researchers sought additional information via a Parliamentary Question and a Freedom of Information request to the relevant legislative and state bodies.
	Data bias	There was significant variability in document length, style of writing, referencing of sources (footnotes,

		bibliography, in-text citation). Researchers conferred regularly to address these challenges.
	Interpretation bias	Researcher familiarity with the context of PDS was seen as a mitigating factor in this regard
	Reporting bias	The researcher's familiarity with PDS posed a challenge here in terms of potential bias in the researcher reporting in a way that supported own personal beliefs. This required ongoing researcher reflection and peer debriefing throughout the process. The researchers also liaised with professionals who had been involved in disability services during the period of PDS development and roll-out

Seventh (Integrated) Phase: Method Specific Research Ethics

- Research permission and ethical approval was not needed as documents used were publicly available. Upon completion of the review a copy will be made available to the HSE and identified stakeholders.

Findings

Document context

Twenty-eight documents were screened in October 2023 (Table 2). Documents are publicly available and hosted on an HSE webpage titled 'Key National Documents', which states that 'These reports and guidance documents have all been developed at a national level to support Local Implementation Groups and to establish consistency and equity across the country. (https://www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/documents/).

Table 2: Data screened

Included	**Excluded**
1. Community Healthcare Organisation Governance of Children's Disability Network Service	Children's Disability Network Manager Job Specification
2. Framework for Collaborative Working between Education and Health Professionals	PDS Local Implementation Plan
3. Guidance on Reconfiguration of Services	Self-audit tool for Children's Disability Network Teams
4. Guidance on Specialist Supports	
5. Guidelines for local implementation groups on developing a governance structure and policies for children's disability services	
6. Guidelines on parent and service user representation on local implementation groups	
7. HSE Joint Working Protocol between Primary Care, Disability and child and Adolescent Mental Health Services	
8. HSE/Tusla Joint Working Protocol	
9. Interim Guidance for Children's Disability Network Teams on the Key Contact Role	
10. Joint Working Protocol between Health, Better Start Early Years Specialists and Department of Children and Youth Affairs (DCYA)	
11. National Guidance for CDNTs on Individual Family Support Plans Revised	
12. National policy for Children's Disability Network Teams (CDNTs) regarding children accessing private, independent, complementary and alternative therapies	
13. National policy for Children's Disability Network Teams on family engagement and attendance.	
14. National Policy on Access to Health Services for Children with Disability or Developmental Delay	
15. National Policy on Discharge and Transfer from Children's Disability Network	

16. National Policy on Prioritisation of Referrals to Children’s Disability Network Teams	
17. National Policy on the Lead Agency Model 2019	
18. National Team Development Programme	
19. Outcomes for Children and Their Families September 2013	
20. Policy Framework for Children’s Disability Network Teams	
21. Progressing towards Outcomes-focussed Family-centred Practice	
22. Report of Reference Group on Multidisciplinary Services for Children aged 5 to 18 Years 2009	
23. Report of the National Advisory Group on Specialist Supports for Deaf Children 2017	
24. Telepractice: A Practical Guide for Children’s Disability Teams	

Three documents were excluded as they did not meet the inclusion criteria and 25 documents were included. Included documents were published from 2009-2023 (Table 3). 13 documents were overarching policy documents addressing issues such as access criteria. Seven documents were guidance documents for specific roles, e.g. key contact and ways of working, e.g. telepractice. Three documents focused on joint working between CDNTs and other services, e.g. private therapy providers. One document related to working with Deaf children specifically. These records were augmented by documents provided through parliamentary and Freedom of Information requests. This led to the provision of 38 supporting documents which had been used to inform development of PDS and the minutes of eight meetings of the National Reference Group on Multidisciplinary Services for 6-18 Year Olds from October 2008 to June 2009. The minutes of two meetings prior to October 2008 could not be sourced.

Table 3: Year of document publication

Year	**Document**
2009	Report of the National Reference Group on Multidisciplinary Disability Services for Children aged 5-18
2011	Guidelines for local implementation groups on developing a governance structure and policies for children’s disability services
2013	Framework for Collaborative Working between Education and Health Professionals
2013	Guidelines on parent and service user representation on local implementation groups
2013	Outcomes for Children Outcomes for Children and their Families and their Families
2014	Guidance note on the reconfiguration of services under this programme
2016	Guidance on Specialist Supports
2016	National policy on prioritisation of referrals to Children’s Disability Network Teams
2017	Joint Working Protocol Primary Care, Disability and Child and Adolescent Mental Health Services
2017	National Policy on Discharge/Closure and Transfer from Children’s Disability Network Teams Revised

2017	Report of National Advisory Group on Specialist Supports for Deaf Children to National PDS 0-18s Working Group
2019	National Policy on the Lead Agency Model
2019	National Team Development Programme Children's Disability Network Teams
2020	Progressing towards Outcomes-focussed Family-centred Practice
2020	Joint Protocol for Interagency Collaboration Between the Health Service Executive and Tusla – Child and Family Agency to Promote the Best Interests of Children and Families
2020	Joint Working Protocol between HSE and HSE funded Service Providers, Better Start Early Years Specialists and Department of Children and Youth Affairs for provision of health service supports for children with a disability under AIM
2020	Telepractice: A practical guide for children's disability teams
2021	National policy for Children's Disability Network Teams on family engagement and attendance
2021	National Guidance for Children's Disability Network Teams on Individual Family Support Plans
2021	CHO Governance of Children's Disability Network Services
2021	National policy for Children's Disability Network Teams (CDNTs) regarding children accessing private, independent, complementary and alternative therapies
2021	National Policy on Access to Services for Children & Young People with Disability & Developmental Delay
2022	Policy Framework for Service Delivery of Children's Disability Network Teams
2022	Interim national guidance for Children's Disability Network Teams on the Key Contact role
2023	Roadmap for Service Improvement 2023 – 2026

Overview of evidence within PDS documents

Overall, 291 references were cited within the 25 Key National documents (Figure 1). A breakdown of the percentage of references by type is summarised in Table 4. Three documents did not reference evidence:

- Guidelines on parent and service user representation on local implementation groups (2013)
- National Guidance for CDNTs on Individual Family Support Plans (2023)
- The Roadmap for Service Improvement 2023 - 2026 Disability Services for Children and Young People (2023)

Statutory body publications were the most commonly used evidence sources (37%) and found in 17 of the 25 documents. This included reports from government departments such as the Department of Health and Department of Children and Youth Affairs and health professional regulators such as CORU (Health & Social Care Professionals. Peer-reviewed sources such as journal publications were the next most commonly cited (29%) and found in 10 of the 25 documents (Table 5). These references were of particular interest as these represent a higher level of evidence than documents based on individual or group opinion or experience and have been evaluated through peer-review prior to publication. Reference to other PDS documents accounted for 17% of the references across 16 documents.

Figure 1: References citations within 25 Key National documents

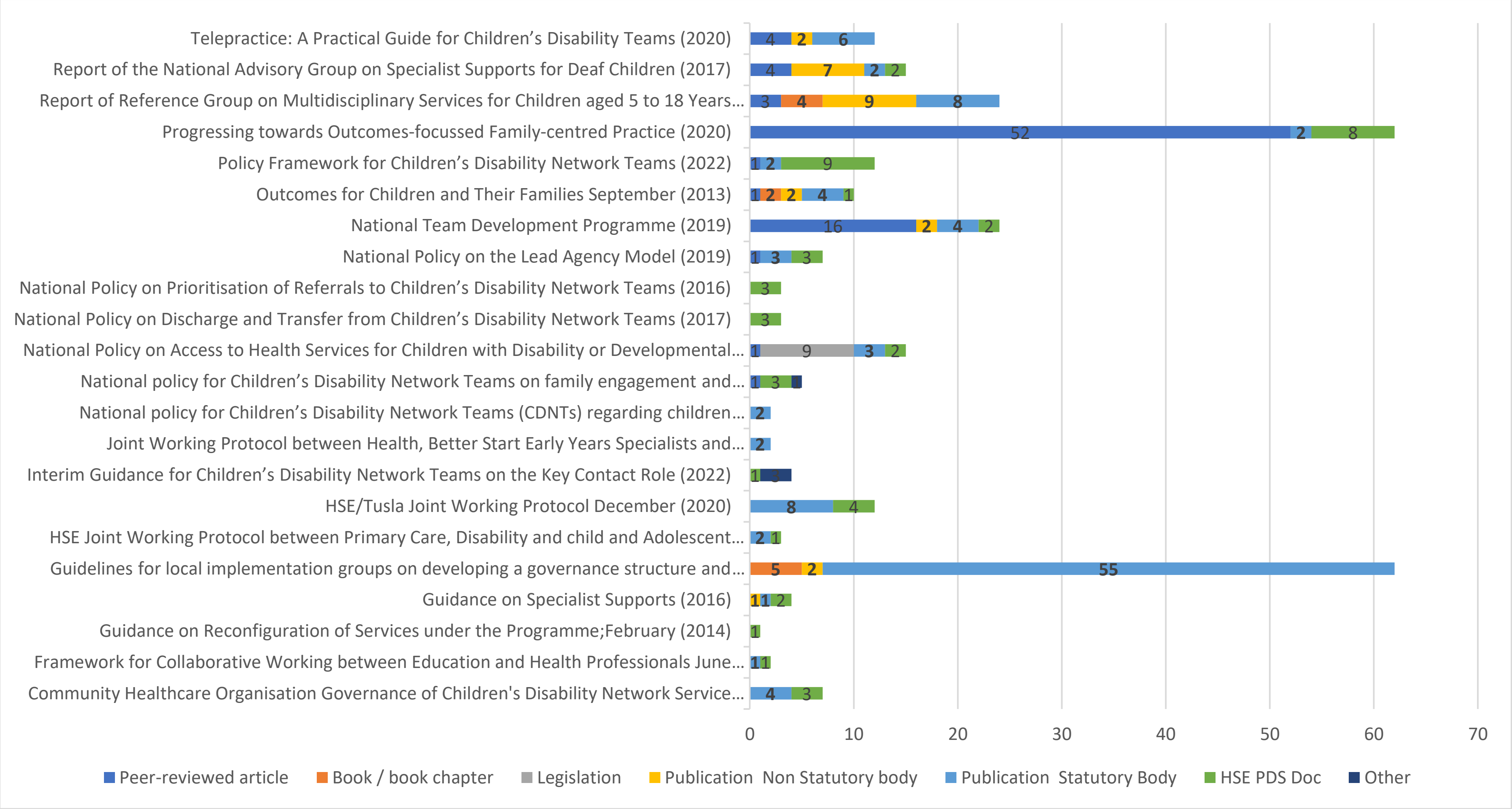

Table 4: Types of evidence

Peer-reviewed	**Book /chapter**	**Legislation**	**Non-statutory body**	**Statutory body**	**HSE PDS document**	**Other**
84 (29%)	11 (4%)	9 (3%)	25 (9%)	109 (37%)	49 (17%)	4 (1%)

Table 5: Peer-reviewed evidence

Document	**Category**	**Citations**
1. Progressing towards Outcomes-focussed Family-centred Practice	Policy	52
2. National Team Development Programme	Policy	16
3. Report of the National Advisory Group on Specialist Supports for Deaf Children 2017	Condition specific	4
4. Telepractice: A Practical Guide for Children's Disability Teams	Guidance	4
5. Report of Reference Group on Multidisciplinary Services for Children aged 5 to 18 Years 2009	Policy	3
6. National policy for Children's Disability Network Teams on family engagement and attendance. June 2021	Policy	1
7. National Policy on Access to Health Services for Children with Disability or Developmental Delay 2019	Policy	1
8. National Policy on the Lead Agency Model 2019	Policy	1
9. Outcomes for Children and Their Families September 2013	Policy	1
10. Policy Framework for Children's Disability Network Teams	Policy	1

Content Analysis: Application of Evidence

In reviewing the use of evidence within the documents, the majority of them linked to evidence via citing or footnoting a reference following a statement, e.g. National Policy on the Lead Agency Model '*The interdisciplinary team approach is supported by national and international best practice*[2]' (p.8).

Critical review and synthesis of existing evidence to inform recommendations was limited. An example of critique and synthesis was found in the document 'Progressing towards Outcomes-focussed Family-centred Practice'. The authors state that*:*

> *'Informed by the academic literature and learning from an empirical project completed in CHO 3 on collaborative goal setting, this document presents an operational framework1 or guide for how Children's Disability Network Teams (CDNTs) can work to progress outcomes-focused FCP' (p.5*).

For example, they stated that*:*

> *'In reviewing the aforementioned literature, it is evident that how FCP is conceptualised … the methodologies employed by researchers in exploring this phenomenon have clear consequences on the perceived efficacy of FCP and recommendations for practice' (p.15).*

This document also used in-text citations effectively to signpost evidence sources effectively and concludes by synthesising findings into a suite of recommendations to form operational guidelines for implementing outcomes focused family practice in PDS.

The 'Report of Reference Group on Multidisciplinary Services for Children aged 5 to 18 Years' is described as '*The foundation for the PDS programme's planned changes'* and as such warranted detailed analysis for this review and exploration of how evidence was utilised. This 72-page report cited 20 documents to support recommendations. These documents came from Ireland (n=9), USA (n=3), UK (n=3), Scotland (n=3) and Netherlands (n=1). Eight were produced by non-statutory bodies such as the National Council for Special Education and Scottish Society for Rehabilitation. Six were produced by statutory agencies such as the Department of Health. Three documents were peer-reviewed journal articles and two were non-peer-reviewed books.

Within the Report it is not clear how evidence from existing models of service delivery for disability services informed the process. Review of supporting documents retrieved via a Freedom of Information request revealed that there had been exploration of national and international models of service delivery. For example, one document circulated to the Reference Group explored children's disability services in the UK, USA, Canada and Australia based on *'information sourced from service web sites, reports, articles and personal contacts'.* Data was also collated on Irish services which were deemed to already have an integrated model prior to reconfiguration, including services in counties Limerick and Meath. How this evidence informed the final report is not specified. In creating the final model underpinning PDS it is stated in the report that the group:

> '*used fictitious scenarios to test out the proposed structure of services and determine service pathways for children'* (p.17)

This process is confirmed in the Minutes of the Reference Group meeting from 6th November 2008.

> *'[Person A] drew out a diagram of the proposed structure … and the group discussed how the different teams would co-ordinate to provide care of the individual child. [Person Y] gave scenarios of children with different needs and the group worked out how each child would come into services and which level they would require'.*

The underlying evidence for some key recommendations in the Report are not cited. For example, in the report of the reference group it is stated that '*Children should receive their health services as close to their home as possible*' leading to the withdrawal of in-school therapy services from Special Schools. This appears to contradict one of the terms of reference of the group

> "To deliver on the obligations of the EPSEN Act, health and education are required to work closely to identify and address children's needs"

In reviewing later documents it appears that there was a modification of this policy:

> *'local arrangements whereby these children [attending special school] may access services from the Children's Disability Network Team nearest to that special school may be agreed.* (National Policy on Access to Services for Children & Young People with Disability & Developmental Delay.)

However, the most recent PDS document, the *'Roadmap for Service Improvement 2023-2026'*, outlines that

> '*[It] remains a priority to restore health and social care supports historically provided in special schools as directed by the Government*

The Report concludes with a set of appendices highlighting sources which informed calculations on prevalence of childhood disabilities and also contained examples of fact sheets provided by services and models of services such as the school-based intervention model of Australian Novita children's services.

The most recent PDS document, the Roadmap for Service Improvement 2023 – 2026

> '*There are significant challenges at this time for Children's Disability Network Teams to achieve … the Roadmap is a targeted Service Improvement Programme to achieve a quality, accessible, equitable and timely service for all children'.*

Within the roadmap it is stated that:

> *'The principles of equity of access, effective and efficient use of limited resources and promotion of family centred interdisciplinary services are strongly evidence based'*

While this statement is correct, it is not supported with examples and integration of relevant evidence within the document. The roadmap does not cite any evidence sources on which it has based its recommendations for ensuring these principles are actualised within PDS. Given the complexity and competing nature of some principle this is significant. For example, '*promotion of family centred interdisciplinary services'* while ensuring '*effective and efficient use of limited resources'.* Overall, this gives an impression of continuation of PDS policy in the absence of evidence integration. The implications of this are explored in the next section.

Discussion

'I can see the policy is not working and I am trying to fix it'
(Minister of State Anne Rabbitte at Oireachtas Joint Committee on Disability Matters, 2nd June 2022).

PDS policy appeared grounded in the assumption that by reconfiguring existing disability services to create uniform teams, children would have equal access to services. Based on this proposition, service reconfiguration occurred incrementally between 2009 – 2021. This review highlights a lack of interrogation of these assumptions by reference to research or practice evidence. Often the evidence base for health service delivery is equivocal (Fraser et al., 2017). However, this should not result in a situation where available evidence is not appraised or applied to inform policy and practice. This review indicated some consideration of evidence via individuals researching existing service delivery models and reporting back to the Reference Group, tasked with developing a model of service. However, this falls short of a systematic use of evidence to inform policy which service providers are increasingly aware of integrating into healthcare policies (Lewin et al., 2015). A guiding principle for any large scale and complex health service reconfiguration project would be the need for a systematic approach to sourcing evidence locally, nationally and internationally, followed by a critical analysis of relevance and applicability to the local context.

With the aim of addressing geographical service disparities, reconfiguration was undifferentiated across the country and services during the roll out of PDS. In the documents reviewed we did not find evidence of the decision being informed by evaluation and critique of existing service delivery models as they could be applied to the Irish context. In theory there seemed to be an assumption that equality (giving everyone the same service) would lead to equity (giving everyone what they need based on individual needs). There is evidence that this practice has not succeeded, and may have created a situation where many children have less access to services. In a 2022 Inclusion

Survey, parents described service access as an ongoing postcode lottery. For example, 33% of respondents in Ulster were not receiving any services, while this figure was 55% in Munster. In Munster, 90% of respondent families had to wait more than a year for services, in comparison to 82% in Leinster (Inclusion Ireland, 2022). Services also need to be responsive to emerging research and practice evidence. For example, current PDS documents reviewed do not reflect recent changes in conceptualisation of disability including increased awareness of neurodiversity, issues of ableism and impact on therapeutic inputs (Cherewick and Matergia, 2023). Overall the emerging evidence indicates that PDS has not achieved its intended aim and may not be a fit-for-purpose service delivery model to meet the current and future needs of children and young people with disabilities.

Given the well-documented challenges of health service reconfiguration and the complexity of children's disability services individually, the approach taken did not fully recognise the complexity of the task. It would have been more accurate to have considered reconfiguration of disability as a 'wicked problem', that is, one which defies simple or traditional solutions and definitive resolution (Varpio et al., 2017). For example, providing a family centred, interdisciplinary service while also ensuring effective and efficient use of limited resources. These issues require nuanced decision-making regarding how services are delivered and prioritised. In the 2023 Roadmap the HSE state that both principles are evidence-based but fail to cite the supporting evidence. This is a relevant omission as there are many and differing types of evidence for these principles and they are also principles which have evolved over time. For example, understanding key features of interdisciplinary working has grown (Nancarrow et al., 2013). Given the scope and importance of these issues, it is not enough to say that policies are evidence-based, decision-makers need to show how evidence has informed policy. Only then can we fully disentangle why some aspects of policy may be working and others are not. Currently there appears to be a disconnect between stating an evidence-base and applying evidence to complex situations.

Indeed, an unchallenged assumption of PDS within the documented reviewed was that reconfiguration in of itself was equivalent to improving service quality and access. While service reconfiguration can contribute to overall healthcare improvement, it must be combined with measures to strengthen how care is delivered, cultivate a culture of improvement and be grounded in the best available evidence (Imison, 2015). When reconfiguration lacks a robust evidence base against which to plan and evaluate the reconfiguration process, it creates a significant risk for clinical services, including those who deliver and access them (Imison et al., 2014). This can be seen in the current PDS situation regarding staff retention and wait times for services. The absence of evidence-based implementation strategies for PDS likely further contributed to challenges (Anaby et al., 2019).

Moreover, for children with rare conditions, access to a specialist team may be more important than services being local. While the ideal would be local specialist services for all children, the low prevalence of certain conditions, especially in a country with a relatively small population, limits the feasibility of this (Buckley et al., 2021) '*Both parents and service providers have expressed concern regarding the implementation of Progressing Disability Services. For relatively rare conditions … the proposed new multi-disciplinary teams … may not encounter enough cases for professionals to develop or maintain sufficient knowledge of their client's complex needs'.* This has impacted on staff morale and been a factor with regard to staff retention (Health Service Executive, 2022). It is clear that the local context needs to be accounted for when determining how local services are configured, recognising that there is not one 'ideal' which will address all needs.

Collaboration between education and healthcare services was a stated aim of PDS '*health and education are required to work closely to identify and address children's needs'.* However, there is growing evidence that cross sector collaboration has been negatively impacted. In February 2024 the Department of Education *'identified concerns in relation to the accuracy and the consistency of the data provided on a national basis by the CDNTs'* and issued an instruction that CDNT data will not be used as an evidence source when allocating additional teaching supports for children with complex needs (Department of Education, 2024). This unilateral decision by the education sector, illustrated a failure *'to work closely'* between health and education. It also indicates a lack of confidence by a critical stakeholder in a key deliverable of the CDNTs as the implementers of PDS where accuracy and consistency are foundational.

Furthermore, the policy reversal relating to therapeutic services in Special Schools is an illustrative example of why it matters to have evidence-based models underpinning policy decisions. Therapy services for Special Schools were school-based prior to PDS, they then ceased to be school-based and were provided by the CDNT aligned with the child's home address and they are now being reinstated in Special Schools. This has created a period of significant disruption and distress to children, families, school staff and therapists. Neither the cessation nor reinstatement of therapy services has been presented with corresponding research or practice evidence. As such this limits transparency and trust in decision-making for staff and families

It is not suggested that there is one specific model which if implemented would be a panacea for disability services. The multi-factorial nature of these services requires flexible and evolving models, but this does not preclude applying and adapting evidence-based models. The approach taken by the National Council for Special Educational Needs in their recently completed policy review regarding special schools and classes provides a useful example. The Council's final policy advice paper is underpinned by a systematic literature review and an International Administrative Review of specialist provision for students with special educational needs in 12 jurisdictions (National Council Special Education, 2023) with the authors stating that '*advice is informed by extensive research, consultation and an examination of similar international education systems*'. We could not find evidence that PDS was underpinned by such an approach, rather cursory and non-systematic searches informed much of the decision making. A key recommendation of the Global Report on Children with Developmental Disabilities was the need to strengthen the capacity of disability services to provide inclusive and people-centred evidence-based care, which can be responsive to evolving healthcare needs (World Health Organization and the United Nations Children's Fund, 2023)

Recommendations

Three recent publications, Roadmap for Service Improvement (Health Service Executive, 2023), Action Plan for Disability Services 2024 – 2026 (Government of Ireland, 2023) and Our National Service Plan 2024 (Health Service Executive, 2024), have all highlighted the challenges being experienced by those accessing and working in PDS. While these publications outline necessary actions such as filling vacant posts, the current review has highlighted foundational issues relating to how PDS was conceptualised. As of March 2023, responsibility for policy on specialist disability services in Ireland was transferred from the Department of Health to the Department of Children, Equality, Disability, Integration and Youth. This may create opportunities for developing a new culture of evidence-based policy for children's disability services. Disability service-delivery model should be based on:

  - Systematic and comprehensive research to identify current disability models of service delivery internationally,
  - Critical analysis of service delivery models with a view to determining applicability to the local context and understanding the need for differentiation across this large and complex population
  - Meaningful engagement with key stakeholders including clinicians, parents/carers and children and young people with disabilities, incorporating their perspectives on what features are required for an effective service
  - Engage with multi-sectorial stakeholders to integrate evidence from relevant bodies beyond health care, e.g. education bodies.
- During service reconfiguration, it is imperative to ensure that features of existing services that are delivering successfully for clients are maintained and integrated into any new model, or if ceased that this is a decision well supported by practice and research evidence.
- Programmes of reconfiguration need to be rolled out in conjunction with quality improvement and change management strategies.
- Consider relevant policy frameworks which can be used to comprehensively understand complex issues and support generation of meaningful solution, such as Bacchi (2016) 'What's the problem represented to be?' (WPR) approach.
- In the complex area of disability, new developments in delivery models and frameworks are happening at the international level, hence, there is an ongoing need to monitor and evaluate these developments and be able to adapt service delivery methods in order to achieve improvements and greater effectiveness for children and families in the Irish context.

In the Irish context, an aim of the Roadmap for Service Improvement is to '*commission and complete an independent review of the CDNT service model'.* Extending the scope of this review to include the recommendations outlined above, especially in relation to identifying and analysing current disability models of service delivery internationally. More broadly, the recommendations for service reconfiguration are likely applicable to other areas of health and social care and jurisdictions.

Conclusions

PDS was an aspirational vision to achieve equity across children's disability services. However, aspiration needs to be matched with evidence, especially when dealing with complex health services like children's disability services. As the HSE seeks to address some of the visible challenges relating to the level of service being provided and staffing it is imperative that it tackles the 'wicked' problem of developing a fit for purpose and evidence-based delivery model for the complex area of children's disability service.

Author's contribution

NOL developed the idea for the paper. NOL and GM were involved in data-sourcing, screening and analysis. NOL and GM collaborated to develop all drafts of the manuscript and both authors approved the final version of the manuscript.

Declaration of interest

The authors declare no conflict of interest

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