# Children's disability services in Ireland November 2014

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# **Summary Report**

#### I.I. Introduction

The HSE is developing a national network of community based 'network', early-intervention and school age disability teams. The aim of this service structure is to:

- Address the health and social care needs of children and young people with disabilities aged 0-18 years in a coherent and equitable manner throughout the country
- To achieve better outcomes for both service users and professionals
- To reduce costs

The HSE programme aims to:

- Develop cost effective, population based and integrated family and child centred children's disability services
- Consider relevant data in order to determine and propose the number, size and composition of early intervention and school based teams and the number of therapists required in Ireland

This report is a contribution to the HSE's programme of work on developing community based early intervention and school age disability teams. The report comprises a literature review on community disability services for children; estimations of the number of children with disabilities who need services and the therapists needed for early intervention and school age disability teams, using the following data sources:

- The 2011 Irish Census
- The disability databases
- The Growing Up in Ireland (GUI) Survey
- Waiting lists

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<sup>&</sup>lt;sup>1</sup> Since the publication of the Primary Care Report in 2001 a goal of Irish health policy has been to establish Primary Care Teams (PCTs) and organise groups of PCTs into health and social care networks (HSCN). The Early Intervention and School Age Disability Teams are community teams that operate at the level of the HSCN. The publication of the Community Healthcare Organisations Report & Recommendations of the Integrated Service Area Review Group in 2014 reemphasises the vision of a primary health system built around PCTs but also emphasises standardisation of pathways and service delivery across network areas.

- Population projections
- Figures from the research literature

In Ireland, statutory and non-governmental agencies deliver early intervention and disability services. There is a wide variation in the services available in different parts of the country and for different categories of disability, so while there are excellent services for some children in one area, there may be little or none in another area.<sup>2</sup> For an overview of the development of services for children with disability see, for example, a review of these services by Carroll et al.<sup>3</sup>

In 2010, the HSE established a National Programme called 'Progressing Disability Services for Children and Young People'. The programme is based on the recommendations of the 2009 Report of the Reference Group on Multi-disciplinary Services for Children aged 5 to 18 Years, which also includes services and supports for children under five years. The aim of the programme is to continue the organizational restructuring of children's disability services in order to deliver equitable family-centred services for children and young adults with complex disabilities in every part of Ireland.

The implementation of Progressing Disability Services for Children and Young People over recent years had progressed further in some parts of the country than others.

The HSE has been promoting formal communication and collaboration within and between Network disability teams and other services such as primary care teams (PCT), child and adolescent mental health services (CAMHS), children's specialist disability services, tertiary and acute services and other health and education professionals. The Community Healthcare Organisations Report argues for a more integrated approach across traditional service areas and recommends that the heads of Social Care, Primary Care, Health and Wellbeing and Mental Health would be part of an integrated management team for the network.<sup>5</sup>

<sup>3</sup>Carroll, C., Murphy, G., Sixsmith, J. (2013) The Progression of Early Intervention Disability Services in Ireland, Infants & Young Children, 26 (1), 17–27

<sup>&</sup>lt;sup>2</sup>www.hse.ie/progressingdisabilityservices/

<sup>&</sup>lt;sup>4</sup> www.hse.ie/progressingdisabilityservices/

<sup>&</sup>lt;sup>5</sup> The Community Healthcare Organisations Report and Recommendations of the Integrated Service Area Review Group, published in October 2014, sets out how health services, outside of acute hospitals, will be organised and managed. It provides a framework for new governance and organisational structures in order to improve service delivery www.hse.ie/eng/services/publications/corporate/CHOReport.html

In some areas, Children Disability Services have signed memoranda of agreement around the care of children with disabilities with PCT and CAMHS services. In June 2013, a sub-group of the Progressing HSE Disability Services Programme published a framework for collaborative work between education and health professionals, at national and local level. The HSE are developing an outcomesbased performance reporting system for accountability of the network children's disability teams throughout the country.

# 1.2. General findings on children's disability services from the literature

# Internationally, widely used strategies to maximise children's disability services within available resources include:

- Establishing clear pathways for accessing services
- · Carrying out initial assessment of needs and prioritise clients
- Establishing waiting list procedures such as review and recall
- Using group therapy as well as individual sessions
- Using caseload management strategically, for example, balancing clients with complex/long term needs with clients with more easily addressed needs
- Planning for discharge with discharge criteria, policies and procedures

# Aspects of service delivery that influence the effectiveness of disability teams include:

- Involvement of the family and the quality of the family-team partnership
- Involvement of relevant teachers and schools and the quality of teacher/school-team partnership
- Inter-disciplinary working versus single disciplinary service delivery
- Group versus individual therapy
- Access and discharge criteria
- Governance and technology
- Possible use of therapy assistants

Early Intervention Services and family centred approaches: There are many benefits for children who receive early intervention services. There are also many links between family-centred approaches and positive child and family outcomes. It is important that policy makers and practitioners do not assume that services are family and child-centred. Measures used to assess whether services are person/ child and family centred include Measure of Processes of

Care (MOPC) <sup>6</sup>, Individualised Care Scale (ICS), Person-centred Care Assessment Tool (P-CAT) and Person-centred Climate Questionnaire (PCCQ). <sup>7</sup> The role of outcomes in developing children's services and the benefits of early intervention services and family centred approaches are contained in Appendix I on disability services for children.

Inter-disciplinary<sup>8</sup> teamwork: The literature in health-related areas demonstrates the considerable benefits/potential benefits of interdisciplinary teamwork. Effective inter-disciplinary teams make coordinated and coherent decisions and plans with individual clients. Effective partnership working within inter-disciplinary teams involves building up an understanding of the different roles each professional plays in supporting the child or young person with a disability. There are barriers to developing effective teams but training helps in forming effective teams.

The potential benefits of community-based, early intervention and school age teams for service users, include:

- A comprehensive and equitable service for children and young people with disabilities
- Early intervention and ongoing intervention where required
- Team communicating around the child with a holistic approach
- Reduced number of appointments
- Parents' awareness of multiple goals incorporated into one activity
- The effective management of behavioural difficulties

The potential benefits of interdisciplinary work for therapists/Allied Health Professionals (AHPs) include:

<sup>&</sup>lt;sup>6</sup> Measure of processes of care http://www.canchild.ca/en/measures/mpoc56\_mpoc20.asp

<sup>&</sup>lt;sup>7</sup>The Health Foundation (2014) Helping measure Person-Centred Care health.org.uk/public/cms/75/76/313/4697/Helping%20measure%20person-centred%20care.pdf?realName=Inet6X.pdf

<sup>&</sup>lt;sup>8</sup> There is confusion around the difference between interdisciplinary and multidisciplinary teamwork and some use the terms interchangeably. Interdisciplinary team approaches integrate separate discipline approaches into a single consultation. The patient is involved in discussions regarding their condition and the plans about their care. Only interdisciplinary client interventions develop a collaborative care plan between all disciplines. Multidisciplinary team approaches utilise the skills and experience of individuals from different disciplines, with each discipline approaching the patient from their own perspective and, most often, organise separate consultations.

- Awareness of each other's roles and goals with children
- Shared responsibility, planning, evaluation and documentation and reduced number of phone calls, e-mails and correspondence
- Holistic approaches and positive mutual learning environments
- Ability to reflect within sessions while other therapist are engaged with child
- Reduced stress levels with effective team working

Increasingly, policy makers and practitioners consider the following three roles for therapists/Allied Health Professionals (AHPs):

- Universal provision for all children irrespective of need and including preventative/improvement measures
- Targeted provision for children requiring additional support within mainstream settings, guided by therapists
- Specialist support within mainstream or special settings can involve a high level of direct intervention by specialists and frequent and sustained consultation by specialists with non-specialist staff such as teachers and teaching assistants. Specialist work can be individual or group work. Children should not receive specialist support if universal or targeted support alone can meet their needs

Appendix I presents findings on the role that outcomes play in developing services; providing quality care for children with disabilities; family and childrencentred early intervention services; teamwork in children's disability services and therapists/allied health professional services. Appendix 2 contains information on teams.

# I.3. Issues to consider when planning children's disability services

Research conducted by the National Disability Authority (NDA) shows that there is a need to increase the number of therapists in the disability network, early intervention and school age teams.

However, the NDA also outlines that proposing the composition and size of disability network teams and the required number of therapists and teams, is a complex task and an inexact science. It is of note that, in Australia in 2010 the 'Workload Measures for Allied Health Professionals' (AHP) project explored

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<sup>&</sup>lt;sup>9</sup> The National Health Workforce Planning and Research Collaboration carried out this project. This Collaboration was a tri-partite partnership between the Australian Health Workforce Institute, PricewaterhouseCoopers (PwC) and Health Workforce Australia. It was set up to

data sources on workload measures for AHP. The project mapped and summarised data sources and recommended priorities for future data collection. However, the conclusion of the (AHP) project was that, given the serious caveats that exist, the report could not present accurate estimates of workload or make recommendations on workforce numbers.<sup>10</sup>

The NDA outlines the caveats that illustrate why it is not possible to make exact and absolute predictions in Ireland and, given these caveats, the NDA emphasises the need:

- To make explicit, the rationale for estimations on size, team composition and core team members
- To put in place measures to routinely collect robust outcomes and workforce data

The following are the issues that must be considered when estimating the number of therapists and teams and the composition of teams:

#### **Outcome measurement**

Outcomes measurement is a crucial element in determining the required composition and size of teams. It is essential that key outcomes are established and that outcome measurement is an integral part of new structures. Currently, there is little research relating team composition and size to outcomes or relating workloads and caseloads to outcomes. There are very few studies of AHPs linking staffing ratio to clinical outcomes.

In Ohio in the USA, the Dept of Education gave grants to 21 educational agencies to trial various approaches to establishing workload/ caseload ratios. A report (October 2014) outlines which workload/ caseload approaches provided the best outcomes for students. While methodological limitations prevented the research team from fully recommending one or more of the alternative caseload ratio

undertake national health workforce research including advice and development on future supply and demand models for the health workforce.

<sup>&</sup>lt;sup>10</sup>National Health Workforce Planning and Research Collaboration (2010) Workload Measures for Allied Health Professionals Final Report.

ahwo.gov.au/documents/Publications/2011/Workload%20Measures%20for%20Allied%20Health% 20Professionals%20Final%20Report.pdf

Mudge, A.I., Laracy S., Richter K., Denaro C. (2006) Controlled trial of multidisciplinary care teams for acutely ill medical inpatients: enhanced multidisciplinary care. Internal Medicine Journal, 36:558-563 as cited by Cartmill, L., Comans, TA., Clark, MJ., Ash, S. Sheppard, L (2012) Using staffing ratios for workforce planning: evidence on nine allied health professions www.ncbi.nlm.nih.gov/pmc/articles/PMC3398270/

approaches and accompanying strategies, positive outcomes were identified when considering the data as a whole. <sup>12</sup>

Measuring user experience, can guide service improvement because research shows that clinical outcomes are linked to people's experience of care. <sup>13</sup> A systematic review of primary care and hospital studies found consistent positive associations between client experience, safety and clinical effectiveness for a wide range of conditions, settings, outcome measures and study designs. <sup>14</sup> However, measuring patient experience often requires a cultural shift from concentrating on gathering feedback to using it effectively.

A systematic review of instruments for measuring patient experience identified core components as follows:<sup>15</sup>

- Characteristics of interactions (patient-professional relationship, professional care, information and advice, communication skills, trust)
- Organisational aspects (accessibility/availability, office characteristics, office organisation/waiting time, office staff, medical and technical facilities)
- Overarching assessments (success of outcome, general satisfaction and willingness to recommend service)

In Ireland, the Department of Health asked the National Co-ordinating Group of the HSE Progressing Disability Services for Children and Young People programme, to develop a performance reporting system for accountability of the network inter-disciplinary children's disability teams throughout the country. 'Outcomes for Children and Their Families' is the name of the proposed system and is based on:

- International best practice and evidence
- · Consultation with service users, families and staff

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 $<sup>^{12}\</sup> http://education.ohio.gov/Topics/Special-Education/News/Caseload-Ratio-Project-and-Study$ 

<sup>&</sup>lt;sup>13</sup>See, for example, Riskind P, Fossey L, Brill K. (2011) Why measure patient satisfaction? J Med Pract Manage 26(4), 217-220 as cited by the Health Foundation (2013) Measuring Patient Experience health.org.uk/public/cms/75/76/313/4300/Measuring%20patient%20experience.pdf

<sup>&</sup>lt;sup>14</sup> Doyle C, Lennox L, Bell D. (2013) A systematic review of evidence on the links between patient experience and clinical safety and effectiveness, BMJ Open, 3(1): e001570 as cited by the Health Foundation (2013) Measuring Patient Experience health.org.uk/public/cms/75/76/313/4300/Measuring%20patient%20experience.pdf

<sup>&</sup>lt;sup>15</sup> The Health Foundation (2013) Measuring Patient Experience health.org.uk/public/cms/75/76/313/4300/Measuring%20patient%20experience.pdf

#### Consultation with researchers

The National Co-ordinating Group of the HSE Progressing Disability Services for Children and Young People programme has recommended the phasing in of the Outcomes for Children and Their Families system over a number of years. This commenced in 2014 with demonstration sites across the fifty-six already reconfigured network teams. Outcome measurement is crucial, as it will demonstrate whether early intervention and school age disability teams are achieving the desired outcomes for children and young people with disabilities. The first part of Appendix I contains more information on outcomes.

### Team composition and size

Across jurisdictions, research evidence or good practice is not always the basis for determining healthcare team composition and size. For example, a national survey on multi-disciplinary mental health teams in England, found that there was a shortage of several therapists on teams, compared to policy targets and previous research. However, the numbers of nurses greatly exceeded target numbers. Existing supplies of different professionals and disjointed workforce planning is often the basis for determining a workforce rather than organising the workforce in a way that addresses needs. <sup>16</sup>

Currently, there is no explicit rationale for deciding which AHPs and other professionals are core to early intervention and school-age teams. Would, for instance, input from an educational psychologist/educator on school aged teams, improve child outcomes or would improved structures for collaboration between teams and professionals within the health sector, and between the health and education sectors, deliver better outcomes? Is the same composition of professionals required on both the early intervention and school age disability teams?

Data on therapists/allied health service professionals' activity

In Ireland, recommendations in the 2001 Bacon Report on the labour market and some of the allied health professions (physiotherapists, occupational therapists and speech and language therapists) are still pertinent. Recommendations include the need to improve the database of statistics in relation to the supply and demand for these professions (to know how many people are working at any

<sup>16</sup> Evans S, Huxley P, Baker C, White J, Madge S, Onyett S, Gould N. (2012) J Health Serv Res Policy. Apr 17, Suppl 2, 23-9 Abstract www.ncbi.nlm.nih.gov/pubmed/2257271

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time, the manner in which funding of these therapists take place, and to develop methodologies for the estimation of demand).<sup>17</sup>

Comprehensive and accurate data on therapists/AHPs activity is poor, particularly in community settings. Data currently available nationally and internationally, is not sufficiently robust to make firm recommendations on the required number of teams and therapists and on the ideal composition of teams.

There is a scarcity of research into staffing ratios for therapists/ allied health professions (AHPs), some of whom are core to network disability teams. This contrasts with the successful use of staffing ratios in nursing and medicine. <sup>18</sup>

There is no consensus in the literature on the correct approach to develop ratios. Approaches used to agree workforce ratios for therapists include:

- Experimental trial
- Current clinical practice
- Using staff classifications
- Consensus

In addition, the status of the allied health professions varies across jurisdictions. In Scotland, allied health professionals are 'agents of change in health and social care'. In New Zealand, front-line allied health professionals manage budgets, service provision, planning outcomes, and accountability and auditing. In Ireland, at present, allied health professionals do not have clinical representation at service and regional level, nor are they represented in an advisory capacity in the Department of Health. <sup>19</sup> The structures recommended by the 'Community Healthcare Organisations Report' strengthen clinical leadership by including a Lead (leader) for Quality and Professional Development as part of the management team, to whom a medical lead, nursing lead and AHP lead, report.

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<sup>&</sup>lt;sup>17</sup>Peter Bacon and Associates (2001) Final Report: Current and Future Supply and Demand Conditions in the Labour Market for Certain Professional Therapists www.lenus.ie/hse/bitstream/10147/42517/1/1885.pdf

<sup>&</sup>lt;sup>18</sup> Cartmill, L., Comans, TA., Clark, MJ., Ash, S. Sheppard, L (2012) Using staffing ratios for workforce planning: evidence on nine allied health professions www.ncbi.nlm.nih.gov/pmc/articles/PMC3398270/

<sup>&</sup>lt;sup>19</sup> Pillinger, J (2012) The Future of Healthcare in Ireland: Position paper on the health crisis and the government's plans for healthcare (Prepared for Impact Trade Union) impact.ie/files/healthpdf/reform/FutureofHealthcare.pdf

#### Workload/caseload

For professionals to be effective in their role, they must have sufficient time to do their work and receive quality support and advice. When this is not the case, research shows that consequences include high turnover rates, absenteeism, increased sick leave and levels of stress as well as a reduction in the quality of practice and outcomes.

A caseload approach considers the number of clients served by a therapist or team, while a workload approach considers the numbers of clients and all other duties of the therapist or team.

The American Speech Language and Hearing Association (ASHA), defines workload as, all activities required and performed by school-based Speech and Language Pathologists (SLPs) and other professionals. ASHA defines caseload as the number of students with Individualized Education Programs (IEPs), Individualized Family Service Plans (IFSPs), and 504 Plans served by school-based SLPs and other professionals through direct and/or indirect service delivery options. <sup>20</sup> In Australia, an optimal and safe workload for social workers is one that matches the cases that have the greatest urgency with the number, type and mix of cases and other duties, experience and competence of the practitioner. <sup>21</sup> One definition for the "workload" of a special education teacher in the US is "the total number of minutes required for all responsibilities including direct and indirect services, evaluation time, IEPs managed, travel time, parental contact and other services in the IEPs of eligible students receiving direct special education services." <sup>22</sup>

In 2014, a survey of speech and language therapists in schools in the USA found that 79% of clinical service providers used a caseload approach, 16% used a workload approach and 5% used both approaches.<sup>23</sup>

An appropriate caseload/workload depends on a number of factors. Firstly, it depends on whether one is considering individual or team caseload/ workload. Most research on workloads and caseloads, centres on service models where

<sup>&</sup>lt;sup>20</sup> Professional issues: caseload and workload www.asha.org/practice-portal/professional-issues/Caseload-and-Workload/

<sup>&</sup>lt;sup>21</sup> Supervision and principles of work allocation for Child Protection practitioners dhs.vic.gov.au/\_\_data/assets/pdf\_file/0005/464909/cp\_principles\_of\_work\_allocation.pdf

<sup>&</sup>lt;sup>22</sup> Special Education Caseloads Taskforce http://education.state.mn.us/MDE/Welcome/AdvBCT/SpecEdCaseLoadsTaskForce/054226

<sup>&</sup>lt;sup>23</sup> ASHA (2014) Schools Survey: SLP caseload characteristics asha.org/uploadedFiles/2014-SLP-Schools-Survey-Caseload-Report.pdf

health professionals work individually. However, increasingly, children's services are using interdisciplinary teamwork. Research on individual caseload and workload has been a source of inquiry since the early 20<sup>th</sup> Century and there is a considerable body of research. However, there is relatively little research on team caseload and workload or the impact of teamwork on workload/caseload.<sup>24</sup> It will be some time, before a robust body of research is available that shows the links between outcomes and teamwork and the links between teamwork and workloads/ caseload. In addition, similar to the findings for staff ratios, "caseload/ workload management continues to be determined primarily by factors such as funding allocations available for occupational therapists, physiotherapists and speech and language therapist positions".<sup>25</sup>

Secondly, the literature shows that effective leadership, systems and processes make a significant difference to therapists' ability to deliver high quality practice. Organisational systems and processes that support the management of therapists' caseloads/workloads include robust information systems. Good data is crucial to managing workloads and caseloads. High quality, relevant, integrated, usable data and information, supports strategic oversight and decision-making.<sup>26</sup>

In the literature, systems for managing caseloads/workloads fall into two main categories. The first requires managers to manage workloads using their understanding of the individual strengths and skills of their teams. The second uses a formal and systematic approach to case measurement, considering complexity, risk and therapist capability. Both methods consider similar types of factors, with the primary difference being individual professional judgement versus an actuarial model.<sup>27</sup> When establishing workload or caseload size, one needs to consider the following variables:

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<sup>&</sup>lt;sup>24</sup> Funke, G., Knott, B., Salas, E., Pavlas, D. (2010) Conceptualisation and Measurement of Team Workload www.dsto.defence.gov.au/attachments/Funke%20-%20conceptualisation%20and%20measurement%20of%20team%20workload.pdf

<sup>&</sup>lt;sup>25</sup> Page 5, Burnett, D., Klaiman, D (2009) on behalf of the CAOT, CPA and CASLPA Steering Committee of the Interprofessional Caseload Management Planning Tool: The Development of an Interprofessional Caseload Management Planning Tool in Occupational Therapy, Physiotherapy and Speech-Language Pathology in Canada: Background Document. Accessed 20<sup>th</sup> Feb 2014 at www.caot.ca/pdfs/CMPT%20Background%20Paper%20Feb%202010.pdf <sup>26</sup> Chief Social Worker (2014) Workload and Casework review: Qualitative Review of Social Worker Caseload, Casework and Workload Management /www.msd.govt.nz/documents/about-msd-and-our-work/newsroom/media-releases/2014/workload-and-casework-review.pdf

<sup>&</sup>lt;sup>27</sup> From the literature as cited in Office of the Chief Social Worker (2014) Workload and Casework review: Qualitative Review of Social Worker Caseload, Casework and Workload

- Child and family factors the range and complexity of needs of individual children and their families
- Service model factors for example, if the service delivery model adopted by the agency emphasised prevention services, this would increase the percentage of time spent on non-client related activities
- Service delivery environment factors for example, the number and distance between community settings where therapy services are to be provided
- Therapists skills and experience
- Team factors
- Administration factors

Measurements for work, staffing and caseload vary significantly across jurisdictions and across professions. In 2008, British Columbia produced preferred paediatric therapy practice guidelines based on the literature on therapy workload and the input of the paediatric therapy community. The practice guidelines are applicable to Early Intervention and School programs and could inform, to some extent, paediatric therapy services in other settings. <sup>28</sup> The Preferred Practice Guidelines for BC Paediatric Therapists is a tool to support manageable workloads within the context of a variety of caseload management strategies including:

- Waitlist and caseload prioritization tools
- The effective use of therapist assistants and administrative support
- Efficient documentation methods
- The use of technology to support client and non-client related activities

In summary, the important issues in determining the composition and size of disability network teams and the required number of therapists and teams, as outlined above, include:

- Lack of robust data on the number of children requiring network level interventions
- Lack of evidence of the impact of teamwork and group work on workload/caseload and staffing requirements

Management /www.msd.govt.nz/documents/about-msd-and-our-work/newsroom/media-releases/2014/workload-and-casework-review.pdf

<sup>&</sup>lt;sup>28</sup> BC Paediatric Therapists Helping Kids Reach their Potential Promoting Manageable Workloads Project Phase 2 - Preferred Practice Guidelines for BC Paediatric Therapists December 2008 www.therapybc.ca/pdf/PreferredPracticeGuidelines.pdf

- Lack of evidence of effect of greater parent involvement in therapy delivery on staffing levels
- Lack of clear evidence on team composition and size
- Lack of information on what works best for children outcomes data
- Lack of integrated IT systems it is of note that early intervention and school-age teams could benefit enormously from the judicious use of robust IT systems.
- Lack of evidence of the roles of assistant therapists
- Lack of clear evidence on team composition

In addition, these teams cannot work efficiently without the necessary administration, management and coordination staff and but estimating the requirements for these staff and systems was beyond the remit of this research

# 1.4. Data used to estimate therapists for children's disability services

Regardless of the problems in estimating the composition of teams and the required numbers of therapists and teams, as outlined above, it is clear that there is a need to increase the number of therapists.

The National Disability Authority examined a number of different data sources on children with disabilities or special needs in the 0-18 age group in Ireland to produce a range of estimates of the number of children who may need the service of a multidisciplinary disability team and therapists that could be required for those teams.

Data sources examined included:

- National Intellectual Disability Database and the National Physical and Sensory Disability Database – Health Research Board (2012)
- Census (2011)
- National Disability Survey (2006)
- Growing up in Ireland Survey 9-year old cohort (2007)
- NCSE data on children with special education needs 2012
- Limited international data on therapists per head of population

While no single data source is perfect, when the different data sources are looked at together, the picture obtained is more consistent. The data sources help set boundaries to the range in which the true level of therapy need would lie. While it is difficult to get a precise picture of the totality of need and unmet need, the data offers a firmer guide as to:

- · the therapy mix required
- the relative shortages of different therapy skills
- how any increase in the number of therapy posts might be planned

# 1.5. Numbers of therapists needed for children's disability services

The National Disability Authority concludes that available data sources on children with disabilities point to a proportion of 2.7% to 4.1% of children aged 0-18 who need access to children's interdisciplinary disability therapy services.

Estimates all point to a significant shortfall in therapy provision, exacerbated by the non-filling of the significant proportion of regular vacancies (about 10%) due to maternity and other leave. The figures are less precise in predicting the exact scale of expansion needed, as different assumptions using Irish data provide a range of estimates, and international ratios vary widely. The figures, however, provide a solid basis for estimating the composition of any expansion in therapy numbers across different specialties. The largest deficits are in speech and language therapy, psychology and occupational therapy.

The National Disability Authority advises:

- A policy of filling of vacancies due to maternity and parental leave be introduced – estimated annual cost c €5.5m
- That 100 additional posts be provided in 2015. The cost in a full year would be about €5.5m but less in calendar year 2015 depending on when recruitment starts and how long it takes
- These posts should be divided in the following proportion

Speech/language therapist	27
Occupational therapist	27
Physiotherapist	6
Social worker	7
Psychologist	25
Public health nurse	8
Dietician	I
Total	100

• The geographical distribution of any new posts should encourage the reconfiguration of children's disability services and the creation of broadly similar ratios of therapists to children in different regions and geographical areas

- However, where there are high concentrations of social disadvantage, a higher ratio of therapists to population would be required
- Additional ancillary supports such as a targeted 'community mothers
  programme' or similar additional supports for vulnerable families, should be
  considered to enhance the family's capacity to follow the programme
  recommended by the therapy team
- As child development and early learning are intrinsically intertwined, consideration should be given to the employment of early education specialists on early intervention teams (there were 9 of these employed in early intervention teams in 2012)
- Future planning should build-in provision for the impact of demographic change

# 2. The Research Project

### 2.1. Purpose of the research

The purpose of this project is to contribute to the HSE Programme 'Progressing Disability Services for Children and Young People' by undertaking the following tasks:

- Conduct a literature review on the development of disability services for children including the composition, configuration and outcomes of early intervention and school age disability teams and recommended caseloads for therapists. It is important to note that while there is some literature on caseloads for individual therapists, there is a limited literature on team caseloads
- Consider pertinent data that might contribute to determining the number, size and composition of early intervention and school-age teams in Ireland. This includes considering the functioning of the already established Early Intervention and School Age Disability Teams for their strengths, weaknesses, size, composition, structure and functioning
- Examine the size and distribution of the 0-5 and 6-18 year old populations in Ireland from the 2011 census and from the Growing Up in Ireland Survey
- Examine the current ratio of therapists to children in children's network disability services and propose ratios based on the literature and on calculations from available data sources.

#### Based on the above tasks:

- Outline the issues in developing population based, integrated child (and family) centred, cost effective and efficient disability services for children
- Estimate the composition, size and number of early intervention and school
  age disability teams and regional sub-specialist teams that are required to
  provide a nationwide service for children with disabilities in Ireland. The subspecialist teams are to provide local teams with direct specialist intervention,
  consultation and training.

# 2.2. Background

Disability health services for children are organised and delivered differently across the country because of the way they have been initiated and developed. Some organisations provide services for a specific group of children who have a particular kind of disability, or they only operate in one part of the country. This

means, that while there are excellent services for some children in one area. there may be little or no service at all for other children in other areas.

The aim of the 'Progressing Disability Services for Children and Young People' programme, is to achieve a national unified approach to delivering disability health services, so that there is a clear pathway to the services they need, for all children, regardless of where they live, what school they go to or the nature of their disability or delay."29 To develop effective children's disability services, that address the health, social and educational issues of children with disabilities, we need to address the following:

- Development of coherent pathways for children with disabilities for referral and access to services and the development of portable standardised and streamlined assessments of need
- Eligibility criteria to be used for accessing services: "There is some tension between the perception of a need for a medical diagnosis as a trigger to accessing support and a service delivery model that addresses the needs of children and young people with a disability"30
- Decide between excellent provision to a limited number of children, or good provision to everyone who needs it
- Establish what the composition of early intervention and school based disability teams should be
- Determine how therapists and other professionals can best be supported to develop effective and efficient team working skills
- Provide guidance for the local development of services which include collaboration between disability services and other children's services
- Choose cost effective IT solutions for use in early intervention and school based disability services
- Effective management of autism, including diagnosis and provision of the required early intervention and school disability services

<sup>&</sup>lt;sup>29</sup> Progressing Disability Services for Children and Young People Accessible at http://www.hse.ie/progressingdisabilityservices

<sup>&</sup>lt;sup>30</sup> The Scottish Government, 2011, Report of the National Review of Services for Disabled Children, p.7

# 3. Calculating therapists needed for children's network disability services in Ireland

### 3.1. Current therapy staffing (2012)

The HSE provided data on the number of whole-time equivalent therapy posts by category and grade, from a data collection exercise they carried out in 2012. In that year, the HSE employed just over 1,700 people in children's disability services, including about 1,100 in therapy grades, as well as medical, social care, pre-school staff and ancillary staff.

Table 1: Nos. employed in children's disability therapy services 2012

Specialty	WTEs
Speech and language therapists	253.3
Occupational therapists	234.3
Physiotherapists	173.6
Psychologists	160.8
Social workers	98.8
Nurses	174.1
Dieticians	4.9
Social care workers and care assistants	211.7
Paediatricians	10.2
Psychiatrists	5.2
Other frontline	347.7
Management, admin and support	43.0
Total	1,717.5

Source: HSE (Does not account for losses due to maternity leave)

Since this 2012 data, further reductions in staff took place, as some HSE therapy staff transferred from children's specialist services into primary care, and there was an embargo in place on filling vacancies, e.g. on retirements. Unlike the area of education, the embargo also disregarded demographic growth in the child population. However, in 2014, there was an allocation of €4m to recruit an additional 80 therapy posts in children's disability services. The calculations of shortfall in therapy posts in this report have been made from the 2012 baseline in the survey, and have not factored in the net effect of losses to primary care or retirements, nor the gains from the additional therapy posts approved during 2014.

In addition to HSE-funded posts, a number of disability organisations, such as Down Syndrome Ireland, fundraise to supplement official provision of children's therapies.<sup>31</sup>

# Almost one in ten staff on leave at any one time

HSE-funded therapy staff, who are on maternity, parental or sick leave are not generally replaced.<sup>32</sup> This is in contrast to the position in education, where the norm is to replace teachers or special needs assistants who are on maternity leave and, similarly, in the National Advocacy Service for People with Disabilities, eplacement cover has generally been sanctioned for maternity and long-term sick leave absences.

#### Random distribution of unfilled vacancies

There is a high incidence of maternity and parental leave in children's multidisciplinary disability teams, as it is a service predominantly staffed by women. HSE figures for 2012 show that almost one in ten staff (9.6%) is not available at any given time, primarily due to maternity or parental leave absences. This level of absence has a significant impact on the volume of service available, and on the adequate functioning of multidisciplinary teams. These absences will occur randomly across different geographic areas and different specialties. So, it can happen that a team in one area will have no speech and language therapists available for a year, with a consequent increase in the waiting list.

Even if the underlying staff complement in multidisciplinary services were adequate to address needs, the high level and random pattern of staff absences weakens the ability to deliver services. When non-replacement during leave is added to a system where teams are already too small to meet needs, it compounds the difficulties experienced by children and families in accessing appropriate supports.

A policy of filling of maternity leave etc. leave should be a priority The National Disability Authority advises that a policy of replacing therapy staff on leave should be a priority for development of multidisciplinary services for children with disabilities.

# 3.2. Responding to demographic change

The underlying population aged 0-18 years is growing by about 1.8% a year. In the mid-1990s, when today's 18 year olds were born, the number of births was

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<sup>&</sup>lt;sup>31</sup> Inclusion Ireland (2014) The Case of Speech and Language Therapy

<sup>&</sup>lt;sup>32</sup> In recognition of the problems this causes, there has been some recent relaxation with some limited maternity cover provided where it has been possible to forecast requirements.

around 50,000 a year, and now births are running at about 70,000 a year. To maintain a stable ratio of therapy staff to the child population, the overall staff complement would need to keep pace with the underlying growth in the child population (40% per year).

The CSO's population forecasts of the growth in the number of children of school age (5 to 19) between 2011 and 2021 covers a narrow range, with a growth ranging from 16.3% to 18.7%. These forecasts are reliable, as most of the children involved are already born, while migration may give rise to a small degree of variation. Forecasts of the child population in the early intervention age groups are more difficult to make, as these children are not yet born, and the trajectory of birth rates over time is uncertain, and can be influenced by future economic conditions which are also uncertain. Central Statistics Office assumptions underlying their population projections, give a range for the 0-4 age group that range from a fall of 3% to a fall of 13%.<sup>33</sup> See Appendix 3.

# 3.3. Which children require support from a network disability team

The HSE's new model for children's therapy services, envisages children with less complex needs availing of therapy services via their primary care team; with children with more complex needs availing of the services of an interdisciplinary disability team (serving children with complex need whatever their diagnosis) within the geographical area. Key underlying factors in estimating the demand for therapists are:

- What proportion of children require multidisciplinary therapy supports
- What proportion of children require these supports from a disability team
- Which therapy supports are required

#### 3.4. Model of service

The model of service applied will influence how many therapists are required for a given level of need. Interdisciplinary approaches might be expected to provide more efficient service models than independent disciplinary interventions.

A model of practice focusing primarily on one-to-one work with children would require a higher ratio of therapists to children than a service model that works with parents, helping them to build practices into the child's daily routine and reinforcing therapy sessions in this way. Families vary in their capacity to support a child with a disability and engage with therapeutic routines, so a higher degree of professional input may be required in some cases. This may mean that in areas

<sup>&</sup>lt;sup>33</sup> CSO Population projections 2016 to 2046 www.cso.ie

with a concentration of social disadvantage, a higher therapist to child ratio may be required. Indices of geographical disadvantage such as the HP index could be used to identify areas where a higher ratio of therapists to children might be required.<sup>34</sup> Additional lay supports, targeted to assist vulnerable families, along the lines of the community mothers' scheme, could also enhance a family's capacity to follow through a recommended therapy programme with the child.

# 3.5. Assessment of need process and NCSE resource allocation

Statutory assessments of need under the Disability Act 2005, began in 2007 for children then aged under 5years, but continue to apply to any child born since 2002. HSE reports issued under s13 of that Act, which are designed to quantify the extent of need and any shortfall, have consistently drawn attention to the significant proportion of therapy time, devoted to conducting statutory assessments, which has the capacity to draw resources away from therapeutic interventions and building parental competence. The National Disability Authority's research on assessment of need, showed that one of the factors driving labour-intensive assessments, was the link between specific diagnoses and entitlement to specific levels of resource teaching and other school supports. The National Council for Special Education has recommended a new model of allocation of special teaching resources to schools, based on the school's profile rather than individual diagnoses. If this new model is accepted and introduced, it remains to be seen, whether, the pressure to secure assessments for particular diagnoses, particularly for autism, could diminish.

# 3.6. Irish and international data used to generate estimates

This report uses different Irish statistical sources of information on children with a disability, to try and identify what the service gaps are, and what proportion of children in each age group may require multi-disciplinary services. The data sources used include the Disability Databases, the Census, the National Disability Survey, National Council for Special Education, and a special analysis of the micro-data from the Growing Up In Ireland Survey of 13 year olds. The individual data sources and their strengths and weaknesses are discussed in Appendix 4.

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<sup>&</sup>lt;sup>34</sup> see <a href="http://trutzhaase.eu/deprivation-index/overview/">http://trutzhaase.eu/deprivation-index/overview/</a> for a description of the index

<sup>&</sup>lt;sup>35</sup> NDA (2011) Report on the practice of Assessment of Need under Part 2 of the Disability Act 2005

 $<sup>^{36}</sup>$  NCSE (2014) Delivery for students with special educational needs – a better and more equitable way.

We also looked at the available international data on therapist-to-population ratios, and on therapist caseloads. Estimates of the proportion and number of children likely to need multidisciplinary disability services can be linked to therapist caseloads, to generate alternative estimates of therapist numbers required.

For the purposes of estimation, the sections that follow assume that early intervention teams, cover children aged 0-6, and school-age teams cover those aged 7 to 18.<sup>37</sup>

### 3.7. Estimated service gaps, from disability databases

The National Intellectual Disability Database (NIDD) and the National Physical and Sensory Disability Databases (NPSDD) collect information on the number of children registered on the particular databases.

#### Coverage

Participation in the databases is voluntary. It may also be the case that children are more likely to be recorded where a definite diagnosis has emerged, than recording of younger children experiencing some developmental delay or other issues but without a firm diagnosis. Coverage of the NIDD is regarded as excellent – over 99% up to date collection rate, from disability service providers. However, collection of data for the NSPDD is patchy, and it is not clear to what extent non-registration might be skewed or whether those who are registered are a reasonably representative sample of the population of interest. The 2012 and 2013 reports, concentrate on the data in respect of the number of recently-updated records, and estimates that about one in five of potential registrants is registered and up-to-date.<sup>38</sup> In the calculations that follow, we have assumed that this scale-up factor applies equally to adults and children. We also tested use of a scale-up factor of 6.25, reflecting estimates the Health Research Board had made in earlier years, that the underlying registrable population was about 42,000. However, scaling by 5 or 6.25 made negligible differences to the calculations.

# Autism Spectrum Disorder (ASD)

ASD is not recorded as a category as such in the databases, but those with autism and an intellectual disability would be recorded in the NIDD, while the NSPDD would have people with ASD captured under headings such as emotional behavioural disorder, speech and language difficulty, and dyspraxia, although this

 $<sup>^{37}</sup>$  A cut-off age of 19 rather than 18 would add 5.5% to the underlying child population.

<sup>&</sup>lt;sup>38</sup> NSPDD report 2012, p. 13 states there were 6,897 up to date records but 34,168 people eligible for registration on the database - a multiple of 4.95, which we have rounded to 5 for the purposes of our calculations.

coverage may not be fully complete. It is estimated that about 1% of children have an ASD. The degree of therapy support required, may vary, depending on where the child is on the spectrum, and on the number and extent of any comorbidities.

Recorded gaps in service – need service or enhanced service

The national disability databases ask information on children and adults who are

- Receiving a therapy service
- Receiving a service but requiring an enhanced service
- Not receiving but requiring a service

This data for 2012, along with data supplied by the HSE on the number of Whole Time Equivalent (WTE) therapy posts in children's disability services, has been used to provide estimates of the number of additional therapy posts that might be required. While there are important caveats around this data, these calculations offer a reasonable guide to inform the **mix** of therapy professionals in any expansion of provision.

### **Approach**

Both the NIDD and the NPSDD databases collect information on the number of people receiving specialist disability therapy services, the numbers who require their existing service enhanced, and the numbers who require a service, but do not get it. While the published data for 2012 for the NIDD does not give a breakdown as between adults and children, this was supplied by the Health Research Board which manages the two databases.<sup>39</sup> These data were used to estimate the percentage increase in the current service required.

The NDA took, as a starting point, an assumption that children who needed an enhanced service were just getting half of the therapy support they needed. We assumed that the shortfall in each specialty would be the same. This approach sidestepped the question of caseload - for each specialty, it took a pro-rata approach to existing workload and potential workload to be undertaken. For the baseline calculations, the percentage increase in services required was thus estimated as ( $\frac{1}{2}$  those requiring enhanced services + all those requiring new

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<sup>&</sup>lt;sup>39</sup>The National Intellectual Disability Database report 2012, p. 85 has data on therapist use and need, aggregated as between adults and children – the HRB gave us the data separately for children. Tables 3.1, 3.2 in the 2012 National Physical and Sensory Disability database report measure therapy use and need for this group. However, as the coverage is low as discussed in the text, we multiplies it by factors of 5 and 6.25 to get a range of calculations of aggregate need across physical, sensory and intellectual disability. The NIDD for 2013 gives a similar breakdown.

services) as a percentage of those currently receiving each individual form of therapy.

We also tested whether it made any difference if we assumed the 'need an enhanced service' children needed 33% more service (were already getting two thirds of what they needed) or needed 66% more service (were currently only getting a third of what they needed). In each case the calculations assumed that the proportionate shortfall for those needing enhanced therapy services was the same across all different therapies. While changing this made a difference to projected overall therapist need, it made no difference to how the estimated shortfall was apportioned between different specialties.

### Shortfall as percentage of current provision

The calculations took the recorded shortfall (no service + proportion of enhanced service need) as a proportion of current provision for each therapy category, aggregated across the weighted mix from the NIDD and NPSDD. This percentage increase was then applied to the number of each type of therapist employed in disability services, from data supplied by the HSE to the NDA.

Table 2: Children requiring services and percentage expansion required - grossing up NPSDD by 5

	need + enh x .5	need + enh x .33	need + enh x .66	need + enh x .5	need + enh x .33	need + enh x .66
Speech/language therapist	10,052	9,136	10,914	63%	57%	68%
Occupational therapist	7,993	7,331	8,616	68%	63%	74%
Physiotherapist	2,114	1,951	2,267	20%	19%	22%
Social worker	2,701	2,494	2,896	39%	36%	42%
Psychologist	7,434	6,911	7,925	91%	84%	97%
Pub health nurse	1,191	1,116	1,262	26%	25%	28%
Dietician	2,013	1,829	2,185	73%	67%	80%

Need+ enh = need a service plus need an enhanced service

Table 3: Children requiring services and percentage expansion required – grossing up NPSDD by 6.25

	need + enh x .5	need + enh x .33	need + enh x .66	need + enh x .5	need + enh x .33	need + enh x .66
Speech/language therapist	11,702	10,607	12,733	64%	58%	70%
Occupational therapist	9,217	8,477	9,914	68%	63%	74%
Physiotherapist	2,243	2,068	2,407	19%	17%	20%
Social worker	2,889	2,669	3,095	38%	35%	41%
Psychologist	8,622	8,052	9,159	93%	87%	99%
Pub health nurse	1,330	1,244	1,410	26%	24%	28%
Dietician	2,343	2,146	2,528	74%	68%	80%

Table 4: Expansion required in therapist nos., grossing up NPSDD by 5, and applying varying ratios to existing numbers of therapists

	WTE	need +	need + enh	need +
	2012	enh x .5	x .33	enh x .66
Speech/language therapist	258	163	148	177
Occupational therapist	234	160	147	173
Physiotherapist	174	35	33	38
Social worker	99	39	36	42
Psychologist	161	146	136	156
Pub health nurse	175	46	43	49
Dietician	5	4	3	4
Total – factor of 5	1,106	593	546	639
Total – factor of 6.25	1,106	594	547	642

The predicted additional therapy posts required, on the assumptions made about partially met need, are grossed up by a factor of 5 or a factor of 6.25. Following this, figures suggested for additional therapy numbers that could be required, range from 546 to 642 additional therapy posts.

It should be noted, that these figures for additional therapy numbers required, are relative to the baseline number of therapy WTEs from the HSE's 2012 survey of numbers employed in this service.

#### Cost - €28-€34m

Using the consolidated pay scales, assuming that all posts would be filled at a basic grade, on the mid-point of the scale, would give a ball-park estimate of €26 million a year to fill the therapy gap, taking the lower of the estimates of number of therapists required. However, presumably if recruitment on that scale were to be considered, there would need to be a mix of senior and entry-level posts in

order to provide supervision. Assuming posts would be filled on the ratio of 2:1, between basic and senior therapy grades,<sup>40</sup> it would raise the annual cost to about €28.5 million to fill the therapy gap, based on that lower estimate of additional therapists required. Using the higher estimate of number of therapists needed, the ballpark annual cost would be about €33.5m.

It is estimated that the cost of filling maternity leave posts etc. would be approximately  $\leq$ 5.5m a year, using a similar basis for costing.

#### Better data for service planning

The data presented in this paper points to a sizeable therapy gap, but with caveats about its absolute size, and with the available sources of data, it is not possible to be much more precise.

It is not clear to what extent reorganisation and a more parent-centred model of delivery, could result in a more effective reach of services with the current workforce. As children's disability services are reconfigured to a national model, there is the opportunity to introduce a standard way to assess and record therapy needs and common definitions and understanding of what constitutes a waiting list, or to consolidate needs for enhanced therapy services into low, moderate and high ranges, to enable better forecasting. The new common delivery model, should also facilitate cross-disciplinary working across the services as a whole. It will also be possible to develop common systems to measure outcomes being achieved, and to identify what approaches and inputs are most effective with particular groups. These factors should help crystallise, to a more accurate extent, what is the total number of therapists needed to deliver the new model in an effective way. The uncertainty about the ultimate optimal size of the service, should not be an argument against a prudent scale of expansion at this stage, which could enable some of the more pressing needs to be met.

## Meet some of the estimated gap - c 100 posts

It is clear, that whatever the caveats about the exact magnitude, there appears to be a significant level of unmet need. If 100 additional posts were to be provided in 2015, that would meet very real needs and it would enable earlier intervention with young children. Additional provision on this scale would be very unlikely to result in overstaffing. An additional resource of the order of 100 extra posts, would only reflect between a fifth and a sixth of the calculated shortfall relative to the 2012 baseline.

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<sup>&</sup>lt;sup>40</sup> The current ratio between grades is of the order of two senior to each basic grade post

The total annual cost in a full year of recruiting an additional 100 permanent posts would total about €5.5m. a year. The cash cost in 2015 would be lower, depending on how long it took to recruit and fill new posts. If, on average, the new posts were filled by July, the cost in 2015 would be about €2.7m, but the carryover cost into 2016 and subsequent years would be an additional €5.5m compared to the 2015 budget.

A combined package of covering maternity etc. Absences, plus an additional 100 permanent therapy posts, would thus cost about €8.2m in 2015 and €11m in a full year.

Forecasting the composition of any additional posts

If 100 new therapy posts were to be added, this would be the appropriate ratio:

27 Speech/language therapist 27 Occupational therapist **Physiotherapist** 6 Social worker 7 **Psychologist** 25 Pub health nurse 8 Dietician I Total 100

Table 5: Ratio for 100 new therapy posts

### 3.8. Census 2011

The census can be used in several different ways to estimate the number of children who may require specialist multi-disciplinary services. First, by looking at the number of children with disabilities who have more than one form of impairment, as these are the group who are more likely to require multi-disciplinary support from a specialist disability team. A second way, could be to infer from the kind of impairment, whether specialist disability services might be required. A third approach, would be to apply a particular percentage, (whether emerging from other analysis or a widely-used rule of thumb), to the age distribution of the child population; to estimate how many children might be likely to require early intervention or school age services.

Census information on disability status has some drawbacks:

- Small changes in wording can cause big changes in estimated prevalence.
   There was some change in wording between 2006 and 2011
- There is some evidence of changes in recorded prevalence of disability for children between 2006 and 2011, particularly in the 'learning disability' category (see Appendix 3)

- The Census information is based on questions answered by parents, rather than by direct assessments of the child's needs or condition
- It is probable that the number of very young children with a disability is underestimated, for example, if parents are not clear whether a child's development is delayed or there is an underlying condition, or they find it difficult to acknowledge that their child may have a disability
- There may be children without a disability, but with developmental delay, who
  could benefit from a specialist early intervention service, but would not have
  been recorded in the Census as having a disability

Table 6: Children with a disability by single year of age and more than one form of impairment/disability recorded

Age	Total persons	Total persons with a disability	% with a disability	Persons with more than one impairment	% of persons with more than one impairment
Under I	72,410	1,156	1.6	520	0.7
I	72,645	1,532	2.1	696	1.0
2	72,566	1,937	2.7	862	1.2
3	71,457	2,503	3.5	1,190	1.7
4	67,251	2,956	4.4	1,434	2.1
5	64,937	3,201	4.9	1,564	2.4
6	64,976	3,640	5.6	1,752	2.7
7	64,441	3,937	6.1	1,844	2.9
8	63,816	4,239	6.6	1,959	3.1
9	62,600	4,545	7.3	2,093	3.3
10	61,429	4,668	7.6	2,165	3.5
11	60,834	4,702	7.7	2,095	3.4
12	61,234	4,629	7.6	1,969	3.2
13	59,992	4,731	7.9	2,086	3.5
14	59,002	4,682	7.9	2,068	3.5
15	57,227	4,637	8.1	2,074	3.6
16	56,005	4,314	7.7	1,927	3.4
17	55,865	4,428	7.9	1,979	3.5
18	56,840	4,681	8.2	2,069	3.6
Total	1,148,687	66,437	5.8	32,346	2.8

Source: Census 2011, CSO

In 2011, there were just over 32,000 children recorded with more than one type of disability, or 2.8% of the relevant population.

### Which children are likely to need therapy services

It may be possible to generate estimates of which of these children may require therapy services. For example, a proportion of children with hearing problems may require speech and language therapy; a proportion of those with physical disabilities may require physiotherapy, occupational therapy or speech and language therapy; children with intellectual disabilities may require speech and language therapy, occupational therapy and psychology; children with emotional, psychological or mental health issues may require psychology, and so on. Not all children with a disability will require specific therapeutic intervention, and for others primary care may be the appropriate therapy they require.

The NDA did not follow this line of inquiry in more detail, as other data sources provided a more accurate fix on which children may need specialist disability services.

### Applying a rule of thumb

One rule of thumb which is not necessarily accurate, but based on a best guess of the numbers of relevant children, based on international prevalence studies is that 4% of children might require specialist disability therapy services. <sup>41</sup> Reported international ratios and prevalence rates, can however, vary dramatically from one jurisdiction to another. For instance, a recent paper looking at USA statistics, found that the proportion of infants and toddlers likely to be eligible for equivalent services ranges from 2% to 78% across the USA, while the proportion of children enrolled in services ranged from 1.5% to 7%. <sup>42</sup>

Using 4% as an estimate of the number of all children who will need intervention services, yields an estimate of 14,000 children who may need early intervention services and 32,000 who may need school aged intervention services (total 46,000). However, work on the Growing Up in Ireland Survey data (see below), allows us get a more nuanced calculation of what proportion of the 13-year old age cohort may require multidisciplinary disability services, and to project that to the age distribution in the early intervention and school-age categories.

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<sup>&</sup>lt;sup>41</sup> For instance Newacheck and Taylor (1992) argue that chronic conditions fall along a continuum that begins with those that have essentially no impact on the child and ends with those that affect the child and the family profoundly. Using this continuum approach, they found that 31% of US children with chronic conditions can be divided into three groups: 20% with mild conditions that result in little or no bother or activity limitations; 9% with conditions of moderate severity that result in some bother or limitation of activity, but not both; and 2% with severe conditions that cause frequent bother and limitation of activity. Comparing there findings with others they argue that 2% is at the low end of the prevalence studies. See http://ajph.aphapublications.org/doi/pdf/10.2105/AJPH.82.3.364

<sup>42</sup> http://www.pediatricsdigest.mobi/content/131/1/38.short.

### 3.9. National Disability Survey 2006

The National Disability Survey 2006 offers some questions on therapy use and need by impairment type (data covers children and adults together), which could be applied to the Census data on children with different impairments to estimate the numbers who have or who might require therapy services.

The National Disability Survey has some limited data on respondents' views of whether they needed additional therapy supports. The data is not readily available disaggregated as between adults and children. The data does not cover all impairments nor all therapy types – the selection of questions was guided by what experts in particular categories of impairment saw as the most important areas of support for that impairment. For example:

- Access to speech and language therapy for people with impaired speech or communication
- Access to physiotherapy and occupational therapy for people with impaired mobility or dexterity

While these estimates are crude and do not take into account the different needs of adults and children, they do suggest that there is a need for an increase of approximately 30-40% in Physiotherapists, OT, Psychologists and Social Workers.

Table 7: People (all ages) with impaired mobility or dexterity

	Moderate difficulty %	Severe difficulty %	Total difficulty %	AII %	Nos.	unmet need %
Has access to Physiotherapy	25.9	33.3	33.7	31.2	57,300	
Needs and doesn't have Physiotherapy	14.4	18.4	17.1	16.7	30,700	34.9
Has access to Occupational therapy	10.1	13.5	17.6	13.9	25,600	
Needs and doesn't have Occupational therapy	7.7	11.3	10.9	10.0	18,500	42.0

Source: NDS 2006

Table 8: People (all ages) with an intellectual or learning disability

	Mild difficulty %	Moderate difficulty %	Severe difficulty %	Total difficulty %	All %	Nos.	unmet need %
Has access to Physio etc43	10.8	10.3	16.7	26.4	14.6	10,500	
Needs and doesn't have Physio etc	6.7	6.9	13.3	9.2	9.4	6,700	39.0
Has access to OT	12.8	18.9	27.5	34.8	22.8	16,300	
Needs and doesn't have OT	8.0	11.4	15.2	16.8	12.8	9,200	36.1
Has access to SLT	11.9	21.1	26.4	16.7	20.8	14,900	
Needs and doesn't have SLT	7.0	9.3	13.4	25.3	12.3	8,800	37.1
Has access to Psychology	20.8	27.2	32.1	20.9	27.0	19,400	
Needs and doesn't have Psychology	4.9	8.9	14.7	18.6	11.4	8,200	29.7

Source: NDS 2006

Table 9: People (all ages) with a mental health condition

	Mild	Moderate	Severe	Total	All	Nos.	Unmet
	difficulty	difficulty	difficulty	difficulty	%		need %
	%	%	%	%			
Has access to Physio etc44	12.2	14.1	16.1	20.4	14.5	16,100	
Needs and doesn't have	8.9	8.9	11.8	5.6	9.7	10,700	39.9
Physio etc							
Has access to OT	8.8	13.2	16.4	14.0	13.2	14,700	
Needs and doesn't have	10.0	11.4	15.2	13.9	12.4	13,700	48.2
OT							
Has access to	9.0	16.8	20.0	14.2	15.9	17,600	
Psychology							
Needs and doesn't have	7.4	9.6	12.2	6.8	9.8	10,900	38.2
Psychology							
Has access to	9.3	13.9	20.3	17.7	15.0	16,600	
Social worker							
Needs and doesn't have Social worker	7.2	9.4	13.3	6.4	10.0	11,100	40.1

Source: NDS 2006

<sup>43</sup> Physiotherapist, instructor or educator

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<sup>&</sup>lt;sup>44</sup> Physiotherapist, instructor or educator

## 3.10. Growing up in Ireland Survey

The NDA used several questions in the Growing Up in Ireland (GUI) surveys that are useful for estimating the number of children who will need the services of a interdisciplinary team. Relevant questions include:

- Does the Study Child have any on-going chronic physical or mental health problem, illness or disability?
- What is the nature of this problem, illness or disability?
- Does this problem, illness or disability hamper the Study Child in his/her daily activities?
- How many conditions or disabilities does Study Child have?
- In addition, the Wave 2 questionnaire (at 13 years old) asked about a series of therapy or teaching supports received in and out of school

The National Disability Authority explored the microdata from Wave 2 of the child cohort data, to explore further what could be inferred about likely need for multi-disciplinary therapies, and any likely shortfalls in services being delivered.

Table 10 looks at the number of conditions or disabilities that the study child has.

Number Percent 0 45,066 80.9 14.0 7,781 2 1,771 3.2 620 1.1 4 or more 490 .9 55,728 Total 100.0

Table 10: Number of conditions or disabilities

Source: Source: GUI 13

Overall 80.9 percent of all 13 year old children do not have any disability and 19.1 percent of children were recorded as having some level of disability (table 20). 14 percent had one form of disability only, 3.2 percent had two or more of the listed impairments or disabilities and 2 percent had 3 or more disabilities.

Some impairments are relatively minor, and generally treated in primary care, for example childhood asthma or a stutter. So, the NDA looked at the data on severity of impact of disability – whether a child was not hampered by their condition(s), was hampered to some extent, or hampered severely. Children with minor impact impairments are likely to require primary care only. Children, who are severely hampered in daily life by their impairments, are likely to require

specialist disability services, while, in between, the number of impairments and the severity of impact on daily life when combined can help establish what proportion of this age cohort would be likely to require specialist disability therapy.<sup>45</sup>

Table 11 looks at the number of children who are hampered in their daily activities when they are 9 years old and when they are 13 years old.

Table II: Is the child hampered in his/her daily activities by this problem, illness or disability? (per cent of total population)

	9 year olds	13 year olds
Yes, severely	0.7	0.8
Yes, to some extent	4.3	5
	5.0	5.8

Source: GUI 13 and 9 year old data - note grossed to represent total population of 13 and 9 year olds

There is a slight increase in the number of children between the ages of 9 and 13 years who are hampered in their daily activities. Even though children may be hampered by a disability or impairment, it does not follow that all these children will need the services of an interdisciplinary team.

Table 12 looks at number of disabilities and whether the child is hampered in daily life. This shows that although there is a very good overlap between the number of disabilities and being hampered, it is not a perfect overlap: some children without disabilities are hampered and some children with 4 or more disabilities are not hampered in their daily activities.

The question is which of these children will need the interventions of a multi-disciplinary team. Children with multiple disabilities who are hampered in their daily activities are likely to need the services of such a team. Some children with a single condition who are hampered in their daily activities may need multiple interventions. For example, a child with ASD may require occupational therapy for sensory issues, speech and language therapy for communication, and psychology input to help with behaviour. Finally, it is also highly likely that children who are severely affected in their daily life would need the interventions of a multi-disciplinary team.<sup>46</sup>

46 A further complication is that some of the children with multiple disabilities are recorded as having multiple learning disabilities and they need learning support. As few of these children say

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<sup>&</sup>lt;sup>45</sup> The eligibility criteria for interdisciplinary teams needs to be established and standardised across the country. Once this is done it will be clearer who is eligible for services.

Table 12: Is the child hampered in his/her daily activities by this problem, illness or disability, by how many conditions or disabilities does Study Child have?

Number of conditions or disabilities	Yes, severely	Yes, to some extent	No	Total	Number
0	0.2%	2.4%	97.4%	100%	45,066
I	1.7%	11.8%	86.6%	100%	7,781
2	3.8%	17.5%	78.7%	100%	1,771
3	7.6%	47.3%	45.1%	100%	620
4 or more	23.2%	38.9%	37.9%	100%	490
Total	0.8%	5.0%	94.2%	100%	55,728

Source: GUII3

There were 1,024 children aged 13 who have multiple disabilities who are hampered in their daily lives, this increases to 1,132 if all children with ASD who are hampered are added. This increases further to 1,377 if all children with ASD are included. Finally, if all children who are severely hampered are added this totals 1,563 children.

If we look at the group of children with multiple disabilities who are hampered in daily living; plus all children with autism; plus children who are severely hampered, we see that nearly 14% receive no support in or outside school (table 13). The most frequent support received cited was Resource Teaching/ Learning Support followed by Special Needs Assistant. This highlights that we have been relatively good at support learning and children in school but less good at supporting children's health-related needs.

they are hampered in daily living, they are unlikely to need the support of an interdisciplinary team.

Table 13: Children with multiple disabilities who are hampered + all children with autism + children who are severely hampered

Number receiving		%
School based Resource Teaching/ Learning Support	954	61.0
School based Special Needs Assistant	527	33.7
School based Technical Assistance	135	8.6
School based Visiting Teacher	147	9.4
School based Transport Service	315	20.2
School based Speech and Language Therapist	262	16.8
School based Behavioural Management Programme	76	4.9
School based School psychologist	282	18.0
National Educational Psychological Service	267	17.1
Other( school based)	108	6.9
Doesn't receive any school based supports	278	17.8
Speech and Language Therapist	237	15.2
Occupational Therapist	261	16.7
Physiotherapist	167	10.7
Psychologist	411	26.3
Psychiatrist	270	17.3
Extra tuition/private tuition	126	8.1
Other	92	5.9
Doesn't receive any supports (outside school)	618	39.5
No support in or out of school	218	13.9

Source: GUI

The following table summarises the estimates of the number of 13-year-old children who need early intervention services.

Table 14: Alternative estimates of the number of children who need multi-disciplinary disability services from the GUI survey

	number	%
Children with multiple disabilities who are hampered	1,024	1.8
Children with multiple disabilities who are hampered + children with autism who are hampered	1,132	2.0
Children with multiple disabilities who are hampered + children with autism	1,377	2.5
Children with multiple disabilities who are hampered + all children with autism + children who are severely hampered	1,563	2.8

Source: GUI 13

Therefore, approximately 2.8% of 13 year old children are likely to need the interventions of an interdisciplinary team. Some of these children may only need education interventions, where as some of the children with one disability who

are somewhat hampered may need the interventions of an interdisciplinary team.<sup>47</sup>

If 2.8% of 13 year olds need intervention, the next stage is to calculate how many of the total population of 0-18 need intervention. Disability rates change as children age (table 15) 1.6% of children under 1 are diagnosed as having a disability and this increases to 8.2% of 18 year olds. In 2011, 7.9% of 13 year olds were listed as having a disability.<sup>48</sup> A larger fraction of the younger cohort should be taken, as part of the role of the early intervention team will be diagnosis. If we take the number of children with disabilities who are aged 0 to 6 and 2.8% of all other children, this results in a potential population for interdisciplinary interventions of 2.9% of all children.

Table 15: Children with a disability by single year of age

	Total	No. with a disability	%
Under I			
year	72,410	1,156	1.6%
I year	72,645	1,532	2.1%
2 years	72,566	1,937	2.7%
3 years	71,457	2,503	3.5%
4 years	67,251	2,956	4.4%
5 years	64,937	3,201	4.9%
6 years	64,976	3,640	5.6%
7 years	64,441	3,937	6.1%
8 years	63,816	4,239	6.6%
9 years	62,600	4,545	7.3%
10 years	61,429	4,668	7.6%
II years	60,834	4,702	7.7%
12 years	61,234	4,629	7.6%
13 years	59,992	4,731	7.9%
14 years	59,002	4,682	7.9%
15 years	57,227	4,637	8.1%
16 years	56,005	4,314	7.7%
17 years	55,865	4,428	7.9%
18 years	56,840	4,681	8.2%

Source Census 2011

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<sup>&</sup>lt;sup>47</sup> 15 children of the 1563 reported only learning related disabilities.

<sup>&</sup>lt;sup>48</sup> GUI 13 was collected in 2011-2012 so the numbers are comparable.

# 3.11. Data from education system special needs

There were an estimated 931,000 children in the school going age group in 2012.

The National Council for Special Education has published data on the number of children with different types of special education need, relating to the school year 2012-13. These cover children in mainstream classes who get resource teaching; children in special classes; and children in special schools. It should be noted that there is no data from this source on the number of primary school children in mainstream classes with borderline or mild general learning disability, as their resource teaching is allocated through the General Allocation Model on a standard formula without individual assessments.

Table 16: Estimated no. of school children receiving special education supports 2012-2013

	Resource teaching Primary	Resource teaching Post- primary	Special classes All main- stream schools	Special schools	Total	% of age cohort
Assessed Syndrome	195	66	0	0	261	0.03%
Autism/Autistic Spectrum Disorders	4,919	2,148	2,112	507	9,686	1.04%
Emotional/Behavioural Disturbance	4,107	2,717	34	0	6,858	0.74%
Hearing Impairment	707	432	89	120	1,348	0.14%
Moderate General Learning Disability	540	221	136	2,255	3,152	0.34%
Multiple Disabilities	2,180	731	23	72	3,006	0.32%
Other	206	22	0	0	228	0.02%
Physical Disability	3,327	2,278	8	288	5,901	0.63%
Severe Emotional/Behavioural Disturbance	839	436	5	373	1,653	0.18%
Severe/Profound General Learning Disability	24	7	28	312	371	0.04%
Specific Speech and Language Disorder	4,934	931	434	0	6,299	0.68%
Visual Impairment	293	220	0	40	553	0.06%
Borderline or mild GLD or specific learning disability	Resource teachers via general allocation model	10,010	809	3127	13,946	-
Total	22,271	20,219	3,678	7,665	53,833	

The type of educational disability listed may give some broad guide as to whether these children may require specialist disability therapy services. Children with autistic spectrum disorders may require behavioural support, speech and language therapy, or occupational therapy, depending on the specific situation. If we assume that children with mild general learning disability, and children with a severe visual impairment do not require an ongoing therapy support, but children

in all other categories do, then the proportion of the age cohort requiring therapy input would come to 6.4%.<sup>49</sup>

Without more detailed information, it is not possible to make an assessment of the proportion of children who would require therapy input from a specialist disability team, as distinct from a primary care team.

## 3.12. GUI data 9-year olds - education perspective

The Education Research Centre, St Patrick's College, has used the microdata from the Growing Up in Ireland data set on 9 year olds, looking at special education needs (Cosgrove et al for the NCSE, 2014<sup>50</sup>).

The data on children with social, emotional or behavioural difficulty (SEBD) was derived from teachers' and parents' reports on the SDQ questionnaire done as part of the study, and whether there was reported ADHD. The data on general learning disability was derived from teachers' and parents' reports of a learning difficulty (11% of the age cohort) and excluding those with a specific learning difficulty such as dyslexia.

The data from this analysis gives the following breakdown (N is the number of children in the sample of 9-year olds).

This highlights, that approximately one-third of children who received special education supports have either a specific leaning disability, or a physical or sensory disability and no other disability. This would reduce the prevalence of children who need the support of an interdisciplinary disability intervention team from 6.4% to 4.1%.

<sup>&</sup>lt;sup>49</sup> The overall school going population can be taken as those aged 4 to 18. Figures from the 2011 Census for those aged 3 to 17 gives a good estimate of the population aged 4-18 in 2012, the reference period for the National Council Special Education (NCSE) data (on the assumption of minimal deaths or net migration).

 $<sup>^{50}\</sup> ncse. ie/wp-content/uploads/2014/11/NCSE-Educational-Outcomes-Children-with-SEN.pdf$ 

Table 17: Children with various special education needs

	Children this need only	Children this need only	Children this need plus others	Children this need plus others
	N	%	N	%
Physical or sensory disability or dyspraxia	68	0.8	182	2.1
Medium-risk social, emotional, behavioural difficulty or ADHD	619	7.2	321	3.7
High-risk social, emotional, behavioural difficulty or ADHD	371	4.3	264	3.1
General learning disability	246	2.9	161	1.9
ASD/Asperger's	3	-	66	0.8
Speech/language disorder	77	0.9	237	2.8
Dyslexia	171	2.0	190	2.2
Other specific learning disability	119	1.4	213	2.5

Cosgrove et al for the NCSE (2014) Education experiences and outcomes for children with special education needs – a secondary analysis of data from the Growing Up in Ireland Study

# 3.11. Range of estimates of % who need interdisciplinary disability services

While it is difficult to get a precise picture of the number of children who need intervention services, many of the data sources result in similar estimates (table 18).

Table 18: Estimates of the proportion of children requiring children's disability services

Source	Estimate of child population
Census multiple disabilities	2.7%
Growing up in Ireland	2.9%
Education special needs	4.1%

Therefore, the estimates for the number of children vary between 2.7 and 4.1%. This is a wide margin of estimates and highlights the need to review the estimates as new data sources emerge and services become embedded.

# 3.12. International practice

In addition to the data sources on the number of children who need services when looking at the need for therapists, there is also some limited international evidence.

## International population ratios

Figures on the overall ratio of different therapists to population in other developed countries provide some limited indication as to what extent Ireland is out of line with norms elsewhere. An overall shortage of a particular therapy skill across all populations served, is likely to translate into a scarcity of that skill in specialist disability therapy services.

The data below (tables 19 and 20) set out Ireland's therapists per head of population in an international context. One caveat, is that these data refer to the global number of therapy specialists as a percentage of the population of all ages, irrespective of whether they work with adults or children, in generic primary care, in specialist disability care, or in other settings, or in public or private practice. Indeed, countries with a high proportion of elderly people may require more physiotherapists per head of population. So, the data presented here do not set out a comparison of ratios appropriate to children needing specialist disability therapy.

Another important caveat, is that countries can differ in how their therapy services are organised. This includes the roles taken by individual specialties, to what extent therapists are employed in teams, to what extent the activities of therapists are complemented by auxiliary therapist grades, and the balance of one-to-one therapy, group sessions, and work with families around therapeutic routines.

It is clear from the data presented in the tables below, that there are very wide variations indeed, in the proportion of the named specialties per 100,000 population in different jurisdictions. Thus, while the ratio of physiotherapists per head in Ireland is higher than in England or New Zealand, it is about a fifth what it is in Finland. Ireland's speech and language therapy ratio is a little bit lower than in the UK, Canada, or New Zealand, but about half that of the US.

Table 19: No. of selected therapists per 100,000 population, c 2005

	Physiotherapists	Speech and language therapists	Psychologists
Ireland	51	19	16
Finland	234		
Norway	212		
Denmark	176		
Iceland	175		
Belgium	174		
Sweden	174		
Switzerland	138		
Netherlands	120		
Germany	91		
France	76		
Austria	73		
Italy	69		
UK	60	23	14
Spain	55		
Greece	47		
USA		35	14
NZ		24	
Canada		20	

Source: HSE Report on Workforce Planning for Future Health Needs <a href="http://www.hse.ie/eng/staff/Resources/hrstrategiesreports/Workforce\_planning\_for\_future\_healthcare\_needs.pdf">http://www.hse.ie/eng/staff/Resources/hrstrategiesreports/Workforce\_planning\_for\_future\_healthcare\_needs.pdf</a>

The Bacon Report (2001) looked at ratios in four jurisdictions in about 2000.

Table 20: Therapists per 100,000 population, c 2000

	Physiotherapists	Occupational	Speech and
		therapists	language therapists
Ireland	35.0	14.9	8.1
England	29.7	8.7	9.6
New Zealand	29.7	15.7	11.4
Indiana, US	44.0	34.0	29.0

Source: Peter Bacon (2001) Supply and demand for therapy health professionals, Table 2.7

## Therapists per child in other jurisdictions

The literature listed recommendations and sources for the number of therapists. Table 21 lists these. For ease of comparison, all estimates have been converted to therapists per 100 children.

Table 21: various therapists per 100 children in different jurisdictions

Country	Type of therapist	Early	School Aged
<b>,</b>	'' '	Intervention	Teams
		Teams	
British Columbia -	All	2.85-4	1.8-2.2
sole therapist –			
recommended			
British Columbia -	All	2.5-3.3	1.5-2
team member –			
recommended			
Scotland- actual	Physiotherapist	0.7-1.7	0.7-1.7 (mean=1.5)
		(mean=1.5)	
Scotland – actual	Occupational Therapy	0.7-3 (mean = 1.7)	0.7-3 (mean = 1.7)
Scotland – actual	Speech and language	0.4-2.7 (mean = I)	0.4-2.7 (mean = I)
England and Wales -	Speech and language	0.6-2.7	
actual		(benchmark 2.5	
		for senior S<)	
UK- managers	Speech and language	1.7-2.5	
opinion			
USA actual	Occupational Therapy	-	2.3(mean)
USA (2004) actual	School Psychologist		0.06 (mean)
USA (OHIO)	Psychologist	1.3	0.8
mandated			
USA recommended ASHA	Speech and language	2.5 or more	
USA actual ASHA	Speech and language		1.9-5 (median 2)
New Zealand actual	All (including	2.3	2.9 for complex
	educational		needs, 2 for behaviour
	psychologist)		services
			2.9 for
			communication
New Zealand actual	Speech and language	4-5	2.5-3.3
New Zealand actual	Educational	5-6.7	5-6.7
	psychologist complex		
	preschool and school		
Slovakia actual	Educational		0.2
	psychologist		2.7
Slovakia actual	Special education		0.5
Ad	including S<		F /: 1: · 1 N
Australia actual	All		5 (individual)
			Intensive 10-12.5
Indianal and other	Do a disposicio	0.07	Mixed case loads 2.85
Ireland submission	Paediatrician	0.07	0.07
(recommended) (see			
appendix 3)	Source: NDA review of inte		

Source: NDA review of international literature

In summary, for 100 children who need the services of early intervention or school aged teams, the following ratios of therapists to children are based on both actual ratios internationally and on 'recommended' estimates (based on experience and research) as recorded in the international literature. The lower ratios reflect actual ratios and the higher figures reflect recommendations.

Table 22: Summary of international data on therapists per 100 children

Type of therapist	Actual ratio per 100	Recommended ratio
	children range	per 100 children range
Physiotherapists	0.7-2.9	1.5-3.3
Occupational therapists	0.7-3	1.5-3.3
Speech and language	0.4-5	1.5-3.3
therapists		
Psychologists	0.06-6.7	1.5-3.3
Social workers		1.5-3.3

Several disciplines that could usefully make a contribution to the intervention teams are not included as there is little in the literature on recommended caseloads for these professionals. These include nurses, family support workers and early education specialists.

#### 3.13. Conclusion

Despite the data problems referenced in this paper and in NDA's wider review, it is clear that an increase in therapists is warranted. There needs to be substantial recruitment and training of appropriate therapists for early intervention and school aged teams.

#### **Data** issues

Data caveats include

- Lack of robust data on the number of children requiring network level interventions
- Lack of evidence of the impact of teamwork and group work on staffing requirements
- Lack of evidence of effect of greater parent involvement in therapy delivery on staffing levels
- Lack of clear evidence on team composition
- Lack of information on what works best for children
- Lack of integrated IT systems
- Lack of evidence of the roles of assistant therapists

Regardless of these problems, the GUI evidence quoted suggests that there are approximately 34,000 children who need the services of an interdisciplinary intervention team. Like all the estimates in this paper, there can be a margin of error around it.

Our best estimate of the number of additional therapists required would be of the order of 550 to 650, but there are caveats around this data.<sup>51</sup>

#### Distribution of a national ratio across geographical areas

Some children with disabilities live in families which are experiencing significant disadvantage in other ways. Examples could be where a parent has a mild intellectual disability, a mental health condition, or a chaotic lifestyle related to substance abuse. Children in such families may require greater inputs of multi-disciplinary supports, such as social work input, additional face to face therapy hours, than children with comparable clinical needs in other families. Support through a 'parent to parent' type programme can also assist the family in reinforcing therapy through the child's daily routine.

Some, but not all, such parental disadvantage is likely to be correlated with wider social disadvantage. Therefore, the National Disability Authority advises that the standard national ratio of therapists to children, could be modified by a measure of geographically-based social disadvantage such as the HP Deprivation Index in order to work out the appropriate ratio for those Network areas with a level of social disadvantage that is significantly above average.

Some geographical areas are also large and complex to administer. These areas might need higher ratios to allow for additional travel time.

### Revisit estimates in light of experience and additional data

As Progressing Disability Services is implemented, it will be important to collect standardised information on provision, need, and outcomes, to help guide a more robust system of forecasting therapy requirements and service planning.

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<sup>&</sup>lt;sup>51</sup> Early intervention and school age teams cannot exist without the necessary administrative, management and coordination staff but estimating the requirements for these staff did not form part of this project.

# 4. Workforce planning and children's disability services

# 4.1. Defining Workloads/Caseloads and their management

While 'caseload' refers to the number of clients served through direct or indirect service delivery options, 'workload' refers to all the wider activities related to provision of client services.

Workload is the full complement of responsibilities performed by individuals in their daily job.<sup>52</sup>As well as face-to-face direct services to clients, workload includes activities necessary to support programs, implement best practice and to ensure compliance with legislative and professional standards. An increase in caseload will increase the overall workload.<sup>53</sup>

The workload ratio represents the percentage of time spent on client related tasks, compared to non-client related tasks. Client related tasks include assessment, intervention, and consultation activities, including, but not limited to, preparation, documentation, and travel specific to a client. Non-client related activities are integral to the functioning of an agency's operation but do not involve the delivery of services to a client.

Caseload models that determine caseloads by calculating the number of contact hours with individuals or groups,<sup>54</sup> account for direct services only and may not reflect best practice. Indirect and consultative modes of therapy may offer

<sup>&</sup>lt;sup>52</sup> American Speech-Language-Hearing Association (2002) "A workload analysis approach for establishing speech-language caseload standards in the schools: Guidelines." <a href="https://www.asha.org/policy">www.asha.org/policy</a>. www.asha.org/docs/html/GL2002-00066.html

<sup>&</sup>lt;sup>53</sup> Cirrin, F., Biehl., Estomin, E., and Schraeder, T. (2003). Speech-language caseloads in the schools: a workload analysis approach to setting caseload standards. Semin Speech Lang., 24,155-80 as cited in Toward Best Practices For Caseload Assignment And Management For Occupational Therapy In Canada

www.caot.ca/pdfs/CAOT CASELOAD MANAGEMENT REPORT.pdf

<sup>&</sup>lt;sup>54</sup> Braithwaite J., Hindle D., Phelan P. D., Hanson R. (1998). Casemix funding in Australia. Medical Journal of Australia, 168(11): 558-562 and Duckett, S., Gray, L., & Howe, A. (1995). Designing a finding system for rehabilitation services: Part 1: Rationale and recent developments. Australian Health Review, 18(3): 30-44 as cited in Bundy, A., Brentnall, B., Hemsley, B., Marshall, E. (2008) Therapy Services in the Disability Sector: Literature Review NSW Department of Ageing, Disability and Home Care

benefits for caseload management in the longer term, enabling provision of a broader service to a greater number of people.<sup>55</sup>

"At an organisational level, healthcare services need to support therapy staff in engaging in all types of service delivery (direct, indirect, and consultative). If a therapist's work in providing an indirect or consultative service is not 'counted' as 'therapy', it will be devalued. If staff accounting for their time can only count their direct, hands-on, and face-to-face occasions of service, they will prioritise these services over services that do not involve face-to-face contact with a person/family. If therapists' must meet a minimum number of 'direct' therapy hours they will prioritise this over indirect or consultative services" 56.

Definitions of workload and caseload management include:

- Productive and efficient use of time and resources to maximize and achieve successful client outcomes: the systematic synthesis of client and service information should assist in designing effective and efficient service delivery.
   Such a delivery system should accomplish positive outcomes within available health agency resources and professional guidelines<sup>57</sup>
- Co-ordinating the provision of care to more than one client: moving cases through the care process is the essence of effective caseload management. Throughput should be measured at all stages of the care process to ensure that individual cases meet their goals<sup>58</sup>
- An approach that attempts to balance quality interventions with cost effectiveness<sup>59</sup>
- The process of managing care for a number of clients or patients whose care is governed at individual and population level with reference to a population health model<sup>60</sup>

<sup>57</sup> Cavouras, C. (2003). Foundations for safe nursing Journal of Clinical Systems Management, 5, 13-15 as cited in Toward Best Practices for Caseload Assignment and Management for Occupational Therapy in Canada. Prepared for the Canadian Association of Occupational Therapists by Management Dimensions, in collaboration with D. Parker-Taillon and Associates, June 2005 www.caot.ca

<sup>58</sup> Henke, R. O., Connolly, S. G., & Cox, J. S. (1975). Caseload management: The key to effectiveness. Journal of Applied Rehabilitation Counselling, 6(4), 217–227

<sup>&</sup>lt;sup>55</sup> Bundy, A., Brentnall, B., Hemsley, B., Marshall, E. (2008) Therapy Services in the Disability Sector: Literature Review NSW Department of Ageing, Disability and Home Care <sup>56</sup>, ibid, p. 64

<sup>&</sup>lt;sup>59</sup> See Toward Best Practices For Caseload Assignment And Management For Occupational Therapy In Canada (2005) caot.ca/pdfs/CAOT\_CASELOAD\_MANAGEMENT\_REPORT.pdf

There is no hard research evidence to guide workload or caseload management in therapy services for adults or children.<sup>61</sup> In addition, much research is on service models where health professionals work individually, while children's disability services increasingly use teamwork to deliver services. Thus, it will be some time before there is a body of research demonstrating relationships between team composition and size, team caseloads and client outcomes.

# 4.2. Research on Allied Health Workloads and Caseloads

Published literature on allied health workloads and caseloads can be categorised by five themes:<sup>62</sup>

- Methods of Measurement: Methods range from the ratio-based approach (e.g. beds or activity to staff ratio) to diagnostic or case-mix based approaches where workload measures are categorised by diagnostic sub-groups
- Staffing ratios: This is concerned with establishing guidelines and recommendations on workload/caseload sizes and staffing requirements. Two secondary topics are the variations in actual staffing levels and the extent to which this deviates from recommended levels
- Factors influencing workload/caseload: This examines the factors that influence the intensity of service utilisation by clients, which has a direct effect on the workload of allied health professionals
- Stress and burnout: the prevalence and effect of stress and burnout among allied health workers because of poor workload management
- Data and surveys: This includes data sources on allied health utilisation and on allied health workforce supply and their accuracy

Methodology approaches to workload measurement Methodological approaches to workload measurement include:<sup>63</sup>

<sup>60</sup> Population Health Information Tool (PHIT); Changing Practice to Support Service Delivery (2011), Office of the Nursing and Midwifery Services Directorate, HSE, Dr Steevens' Hospital, Dublin. ichn.ie/uploads/20695%20ONSMD%20PHIT%20Doc%20Final%20Publication.pdf

20Professionals%20Final%20Report.pdf

<sup>&</sup>lt;sup>61</sup> Dyson, M., Duckett, S. J., Allen, FC L. (2000) A therapy-relevant casemix classification system for school-age children with disabilities. *Archives of Physical Medicine and Rehabilitation*, 81: 634-643 and Murchland, S. Wake-Dyster, W. (2006) Resource allocation for community-based therapy. *Disability and Rehabilitation*, 28(22): 1425-1432 as cited in Bundy, A., Brentnall, B., Hemsley, B., Marshall, E. (2008) Therapy Services in the Disability Sector: Literature Review NSW Department of Ageing, Disability and Home Care

<sup>&</sup>lt;sup>62</sup> National Health Workforce Planning and Research Collaboration (2010) Workload Measures for Allied Health Professionals Final Report. ahwo.gov.au/documents/Publications/2011/Workload%20Measures%20for%20Allied%20Health%

- Ratio-based
- Procedure-based
- Diagnostic or case-mix based
- Categories of care based

Ratio-based workload is the ratio of staff to activity. The activity variable is normally a 'proxy' measure such as patients. Ratios are often externally referenced, for instance from a set of professional standards. Ratios are best used in circumstances where activity level and type is comparatively stable. Simple to use and apply, the only data required is the measure of activity. However, these ratios make no accommodation for local differences and therefore are likely to be too low or high in most settings. Moreover, no productivity comparison between institutions is possible.<sup>64</sup>

Procedure-based workload measurement tools look more directly at the procedures and functions of the work performed to deliver health care services. Estimates of the labour required to perform the procedures (in units of time) use facility specific studies or professionally set standards of practice. This approach is best used where the functions to be performed are comparatively set and routine. The data collection for estimation of time per procedure can be costly, or contentious, if based on expert judgement. However, standards set potentially good benchmarks against which to assess productivity. Assessment of the time to complete the procedures can be done for different staff mix circumstances. Average time to complete procedures or tasks may not reflect individual facility physical layout, skill level of staff, case mix and severity of illness.<sup>65</sup>

Diagnostic or case-mix based methodologies for workload estimates, are linked to diagnostic sub-groups. Cost weights, in the form of hours of professional care required to appropriately treat or serve each diagnostic sub-group, are established. Total staff requirements are calculated by multiplying the hours per diagnostic group and anticipated case mix. The data collection for this approach is resource intensive. However, increasingly case mix funding mechanisms are used. Data is collected as a basis of setting up the financial system and workload measurement can 'piggy back' off the financial system. Time estimates for labour requirements against different diagnostic categories can be controversial and may not reflect alternative patterns of care (for instance different skill mix options).

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<sup>&</sup>lt;sup>63</sup> Human Capital Alliance (2006) Workload Capacity Measures for Use in Allied Health Workforce Planning

human capital alliance. com. au/downloads/DH39%20 Workload%20 Capacity%20 Measures. PDF the properties of the properti

<sup>&</sup>lt;sup>64</sup> Ibid, page 18

<sup>&</sup>lt;sup>65</sup> Ibid, page 18

On the other hand, where a close relationship exists between funding and actual (or projected) case-mix, then macro level workload estimates based on this source should be best.<sup>66</sup>

Categories of care-based measures utilise a ratio approach of staff to patients. These take into account different patient conditions, basic care needs and/or therapeutic intervention requirements. They can establish differentiation between patient and client acuity levels. The data collection for this approach is generally resource intensive. It can be used for rapid staffing adjustments in response to regular (normally daily) changes in patient numbers and condition. These methods are used in circumstances where patient throughput is high and variable. It is difficult to see how this method, as normally applied, could be used to deliver macro level estimates of labour requirement.<sup>67</sup>

In 2010, a systematic review of literature on individual community professionals' caseload management (i.e. behaviours related to assessment, treatment and discharging of clients) was published.<sup>68</sup> This literature was mainly experience-based as opposed to research-based. Findings suggested that team-based approaches might facilitate effective caseload management. The theme of caseload measurement tools constituted the largest number of papers (n=11). Caseload measurement covered two dimensions: size (i.e. number of cases on a professional's caseload) and 'weight' (i.e. size multiplied by case complexity). Caseload weight stemmed from an argument that caseload size alone is not a meaningful measure due to differences between individual cases. There was little evidence to support currently used caseload management tools.

In 2005, the Canadian Association of Occupational Therapists examined practices in caseload management among various therapists. They e-mailed associations representing health professions internationally including occupational therapy, physiotherapy, and speech language pathology in Australia, New Zealand, United Kingdom and the United States. The results show that, while caseload management is an issue of great interest, the majority of organizations do not have caseload guidelines in place.<sup>69</sup>

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<sup>66</sup> ibid, page 18

<sup>&</sup>lt;sup>67</sup> Ibid, page 18

<sup>&</sup>lt;sup>68</sup> Niina Kolehmainen, Jill Francis, Edward Duncan, Cynthia Fraser (2010) Community professionals' management of client care: a mixed-methods systematic review Services Research & Policy, 15(1)47-55. www.aura.abdn.ac.uk/bitstream/2164/2037/1/Kolehmainen2010.pdf <sup>69</sup> Toward Best Practices For Caseload Assignment And Management For Occupational Therapy In Canada (2005) www.caot.ca/pdfs/CAOT CASELOAD MANAGEMENT REPORT.pdf

To assist in the planning of therapy service provision, such as in the allocation of resources and staffing, studies in British Columbia (BC), Canada, tried to gain an understanding of what is a manageable caseload and workload for therapists. In 2006, BC researchers recommended that there should be a province-wide focus on achieving consensus in balancing caseload and workload, waitlist prioritisation and development of guidelines. 70 The potential benefits of having caseload guidelines would include a therapist's improved sense of providing an effective level of service and greater job satisfaction.<sup>71</sup>

In 2008, British Columbia produced the 'Preferred Practice Guidelines for BC Paediatric Therapists' which are based on the literature on therapy workload and on the input of the paediatric therapy community. The resulting practice guidelines are applicable to Early Intervention Therapy programmes which provides OT, PT, and SLP (EIT) and School-Age Therapy programmes which provides OT and PT (SAT) and could be used to inform paediatric therapy services in other settings. 72

The Guidelines Report is a tool to support manageable workloads within the context of a variety of caseload management strategies. Such strategies include waitlist and caseload prioritization tools (clinical decision-making matrix, intervention intensity rating), the effective use of therapist assistants and administrative support, efficient documentation methods and the use of technology to support the client and non-client related activities.

The guidelines for Early Intervention and School Age Therapy Programmes were presented in Workload Ratios and Caseload Size Tables. Caseload size ranges include figures for children considered 'active,' (indicating that they have received some level of service that month) and figures for children considered 'inactive,' (indicating that they are being monitored, but did not require any level of service that month). Figures were for full-time (35 hours) clinical therapists as well as those in a 'sole-charge'<sup>73</sup> therapist position (Table 23).

<sup>72</sup> BC Paediatric Therapists Helping Kids Reach their Potential Promoting Manageable

<sup>&</sup>lt;sup>70</sup> BC's Paediatric Therapists, Helping kids reach their potential, Final Report (2006) www.therapybc.ca/pdf/PMWFPT FinalReport.pdf

<sup>71</sup> ibid

Workloads Project Phase 2 - Preferred Practice Guidelines for BC Paediatric Therapists December 2008 www.therapybc.ca/pdf/PreferredPracticeGuidelines.pdf 73 'Sole-charge' is a term used in Canada for therapy posts with additional seniority and

autonomy, so it is perhaps comparable to a senior therapy post in an Irish context.

Table 23: Workload Ratio and Caseload Size<sup>74</sup>

	Early Intervei Therapy (EIT		School Aged Therapy (SAT)	
	Clinical therapist	Sole charge therapist	Clinical therapist	Sole charge therapist
Workload Ratio % of time spent on client related vs. non- client related tasks*	70% : 30% to 80% : 20%	65% : 35% to 75% : 25%	70% : 30% to 80% : 20%	65% : 35% to 75% : 25%
Caseload size No. of children	30 – 40	25-35	50-65	45-55
receiving service per month	20-25 active 10-15 inactive	15-20 active 10-15 inactive	25-35 active 25-30 inactive	20-25 active 25-30 inactive

<sup>\*</sup> Travel time is accounted for in both the percentage of time used to conduct client related activities and non-client related activities.

In 2008, a pilot project (Phase I) investigated the feasibility and support for a points-based caseload measure for paediatric OTs and PTs working in community based practice in British Columbia. There were positive results in Phase I. Phase I. Phase 2 investigated the intra-rater reliability of the measure and of the workload manageability scale, and began the process of supporting validity hypotheses. In 2011, a research summary was published on phase 2 of the Workload Assessment Tool for Therapists (WAT-T) where the results were also positive, determining the reliability of the Tool. Phase 3 of the research project has the goal of determining the ideal point-based caseload guidelines for OTs, PTs and SLPs in early intervention in British Columbia. The principles of this Tool may be transferable to school age therapists, although further research is necessary to

T=Workload%20Assessment%20Tool%20for%20Therapists.pdf

<sup>&</sup>lt;sup>74</sup> BC Paediatric Therapists Helping Kids Reach their Potential Promoting Manageable Workloads Project Phase 2 - Preferred Practice Guidelines for BC Paediatric Therapists December 2008 www.therapybc.ca/pdf/PreferredPracticeGuidelines.pdf

<sup>&</sup>lt;sup>75</sup> Phase I of the WAT- T project was a Master of Rehabilitation Science research study completed by Kathy Davidson, a Paediatric Physiotherapist with agency support from the Office of the Provincial Paediatric Therapy Recruitment and Retention Coordinator (PPTRRC)

<sup>&</sup>lt;sup>76</sup> Davidson, K. F., & Bressler, S. I. (2010). Piloting a points-based caseload measure for community based paediatric occupational and physiotherapists. Canadian Journal of Occupational Therapy, 77, 174-180. doi: 10.2182/cjot.2010.01.00

WAT-T: The Workload Assessment Tool for Therapists Establishment of reliability and validity in a points-based caseload measure for paediatric rehabilitation therapists February 2011 Research Summary Submitted to the Office of the Provincial Paediatric Therapy Recruitment and Retention Coordinator. www.therapybc.ca/pdf/WAT-

establish appropriate points guidelines for that context.<sup>78</sup> The research question guiding the overall project is the determination of the size of a manageable caseload for these therapists. The WAT-T project has an underlying assumption that the same child may be more or less complex to a therapist with different experience and expertise, and that the workload that each child creates for a therapist is subjective. The WAT-T tool assists therapists in assigning points to each child on their caseload, to determine the total number of points on their caseload, rather than the total number of children.

In Canada, in 2009, a document was published on developing an inter-professional caseload management tool in Occupational Therapy, Physiotherapy and Speech Language Pathology (OT, PT and SLP). Different professional associations had done background work and the steering group for the project, drawn from the three associations, undertook a literature review based on a framework suggested by the Human Capital Alliance in 2006. Handle and synthesis of the literature according to this framework in OT, PT, S-LP, and other professions notably nursing reveals efforts and multiple approaches to promote effective caseload management. Despite these diverse and innovative methodologies, there is no single superior model that suits all practice contexts and service delivery systems. The evidence confirms that effective caseload management in OT, PT, and S-LP remains a complex and variable process, in which many factors must be considered including: client classification system, flexibility, client complexity, population health perspective, simplicity, evidence-based, provider experience, and organizational factors".

The tool consists of a seven-step process which combines elements from several of the models used in Canada.<sup>80</sup> In 2011, this process was further developed. The Caseload Management Planning Tool (CMPT) currently consists of a three-step

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<sup>&</sup>lt;sup>78</sup> WAT-T: The Workload Assessment Tool for Therapists Establishment of reliability and validity in a points-based caseload measure for paediatric rehabilitation therapists February 2011 Research Summary Submitted to the Office of the Provincial Paediatric Therapy Recruitment and Retention Coordinator. therapybc.ca/pdf/WAT-

T=Workload%20Assessment%20Tool%20for%20Therapists.pdf

Burnett, D., Klaiman, D (2009) on behalf of the CAOT, CPA and CASLPA Steering Committee of the Interprofessional Caseload Management Planning Tool: The Development of an Interprofessional Caseload Management Planning Tool in Occupational Therapy, Physiotherapy and Speech-Language Pathology in Canada: Background Document. Accessed 20<sup>th</sup> Feb 2014 at www.caot.ca/pdfs/CMPT%20Background%20Paper%20Feb%202010.pdf

<sup>&</sup>lt;sup>80</sup> Burnett, D., Klaiman, D., (2009) The Development of an Inter-professional Caseload Management Planning Tool in Occupational Therapy, Physiotherapy and Speech-Language Pathology in Canada: Background Document.

www.caot.ca/pdfs/CMPT%20Background%20Paper%20Feb%202010.pdf

process that matches available human resource time to clients' time requirements, based on the complexity of interventions.<sup>81</sup> The steps are:

- Determine human resources time
- Determine client intervention time (classify clients, rate complexity of interventions and estimate intervention times
- Match client intervention times to human resources time

The calculations to determine human resources time are online.<sup>82</sup> The CMPT provides a mechanism to model caseloads, to determine the time and human resource requirements for effective caseload/workload management. It provides a structured, evidence-informed approach to caseload or workload management from individual provider and service perspectives. It will evolve according to changing practice, professional and service trends. It guides users through a structured process to determine:

- The number of clients that individual therapists can manage effectively, or
- The number of therapists required to manage the client needs of a particular service

The CMPT is intended to be used primarily by managers and administrators for human resources planning and workload allocation. Clinicians may also use the CMPT to examine and reflect on their caseload and practice management and in collaboration with managers, to discuss strategies to address workload intensity. It is applicable to health professionals and support personnel working with clients on an individual or group basis.<sup>83</sup>

ssot.sk.ca/+pub/Educational%20events/June%20CMPT%20final%20for%20dec.pdf

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<sup>&</sup>lt;sup>81</sup> 2011 Caseload Management Planning Tool in Occupational Therapy, Physiotherapy and Speech-Language Pathology in Canada (This is the product of a collaborative partnership among the Canadian Association of Occupational Therapists (CAOT), the Canadian Association of Speech-Language Pathologists and Audiologists (CASL PA) and the Canadian Physiotherapy Association (CPA). This project was made possible through funding under a contribution agreement with Health Canada, which is gratefully acknowledged CAOT managed the project.)

<sup>82</sup> ibid

<sup>&</sup>lt;sup>83</sup> The CMPT was developed over a two-year period through a complex process. The process involved evidence synthesis in a background paper that provided the foundational basis for the CMPT ongoing input from an Advisory Committee; feedback from more than 3000 online survey responders; pilot application of the CMPT by 15 services in nine clinical sites representing diverse practice settings and geographical regions of Canada; and, continued guidance by an oversight Steering Committee representing the three professions. Information on the CMPT Project, including the Background Paper, is available at: caot.ca and physiotherapy.ca and caslpa.ca

In the Australian mental health system, three caseload index models all used selected factors from among the following caseload measurement variables:

- Contact frequency
- Response difficulty
- Intervention type
- Competence/ seniority
- Caseload maturity
- Location of clients
- Roles other than case management.<sup>84</sup>

There is a scarcity of research into staffing ratios for therapists/allied health professions (AHP), some of whom are core to network disability teams. This contrasts with staffing ratios in nursing and medicine. For example, staffing ratios have been used successfully to determine appropriate staff numbers in nursing in the acute care setting. <sup>85</sup> A study examined whether allied health workforce ratios existed and if these ratios could be used in allied health service planning. The methods applied in developing the ratios were derived from four approaches: consensus, experimental trial, current clinical practice and those developed using staff classifications. <sup>86</sup> The research found, that there is little data available on allied health requirements in general community settings and in general hospital settings. There was only one study of AHPs where a staffing ratio was linked to clinical outcomes. Thus, there is a need for research on staffing ratios and their relationship to health outcomes across community and hospital settings. It is not possible from the research evidence, to use workforce ratios to plan for allied health requirements in general settings, such as general community settings. <sup>87</sup>

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<sup>&</sup>lt;sup>84</sup> King, R., Meadows, G., and Le Bas J. (2004). Compiling a caseload index for mental health management. Australian and New Zealand Journal of Psychiatry, 38, 455-462 as cited in Toward Best Practices For Caseload Assignment And Management For Occupational Therapy In Canada www.caot.ca/pdfs/CAOT\_CASELOAD\_MANAGEMENT\_REPORT.pdf

<sup>&</sup>lt;sup>85</sup> Cartmill, L., Comans, TA., Clark, MJ., Ash, S. Sheppard, L (2012) Using staffing ratios for workforce planning: evidence on nine allied health professions www.ncbi.nlm.nih.gov/pmc/articles/PMC3398270/

bidi <sup>86</sup>

<sup>87</sup> ibid

"Caseload/workload management has and continues to be determined primarily by economic factors, that is, by funding allocations available for occupational therapists, physiotherapists and speech and language pathology positions". 88

Workload and caseload management is important for a host of reasons including good outcomes for clients. In addition it is important to utilise therapists (and other healthcare professionals) in a prudent and informed manner in order to minimize attrition and encourage the retention of skilled workers.<sup>89</sup> The literature shows that very large workloads and caseloads can lead to stress and sick leave, which in turn increases the work of those who remain. Extended periods of workplace stress can lead to burnout with subsequent recruitment and retention issues.<sup>90</sup>

## Factors influencing workload/caseload

A number of factors need to be considered when establishing a caseload size. This includes, but is not limited to:

- child and family factors
- team factors
- service delivery models
- service delivery environment factors
- documentation management factors.

These can be summarised as follows: 91

# Child and family factors

• Complexity and the number of areas to address and support the child (e.g., feeding, seating, behaviour, computer access, home equipment)

Physiotherapy and Speech-Language Pathology in Canada: Background Document. Accessed 20<sup>th</sup> Feb 2014 at www.caot.ca/pdfs/CMPT%20Background%20Paper%20Feb%202010.pdf

<sup>&</sup>lt;sup>88</sup> Page 5, Burnett, D., Klaiman, D (2009) on behalf of the CAOT, CPA and CASLPA Steering Committee of the Interprofessional Caseload Management Planning Tool: The Development of an Interprofessional Caseload Management Planning Tool in Occupational Therapy,

Physiotherapy and Speech Language Pathology in Canada: Background Document, Accessed 20th

<sup>&</sup>lt;sup>89</sup> Burnett, D., Klaiman, D., (2009) The Development of an Inter-professional Caseload Management Planning Tool in Occupational Therapy, Physiotherapy and Speech-Language Pathology in Canada: Background Document .

www.caot.ca/pdfs/CMPT%20Background%20Paper%20Feb%202010.pdf

<sup>&</sup>lt;sup>90</sup> Burnett, D., Klaiman, D (2009) The Development of an Inter-professional Caseload Management Planning Tool in Occupational Therapy, Physiotherapy and Speech-Language Pathology in Canada. Accessed 20<sup>th</sup> Feb 2014 at

www.caot.ca/pdfs/CMPT%20Background%20Paper%20Feb%202010.pdf

<sup>91</sup> ibid

- Current and future equipment needs (prescription, fabrication, fit, training and monitoring of devices)
- Complex health needs that require consultation with a variety of team members and tertiary services
- Developmental and environmental transitions
- Child's health status, pre and post surgical rehabilitation needs
- Communication and language services for the child and family
- The family's level of involvement and need for ongoing information and training to help them understand and support their child's needs
- Intensity and frequency of intervention required

#### **Team factors**

- Availability of a person to coordinate services with the family
- Size and variety of team members, including private practitioners
- Number of different agencies providing services to the child and family
- Amount of frequency of training the intervention team requires

## Service delivery model factors

- Emphasis on prevention activities at the community level involves a greater amount of time spent on population based services and therefore would mean a smaller caseload
- Emphasis on direct service delivery to the child in the form of one-to-one direct therapy, group therapy, treatment blocks and/ or ongoing weekly sessions

# Service delivery environment factors

- number of environments where therapy services are delivered
- distance between the locations where therapy services are delivered

## Therapist skill level factor

· level of experience to address a range of child and family needs

#### **Documentation and administration factors**

- amount of detail required for reports
- availability of report templates and standard handouts/ training materials
- data collection for the agency and for funding sources.

Special consideration is required for therapists acting as department heads or programme managers, and part-time employees. Suggested guidelines for the proportion of time assigned to administrative and management duties are offered

for therapists who split their time between clinical services and the administrative activities that come with managing a department or program area (e.g., supervision, hiring, organizational duties). Some practical suggestions are provided to assist with mitigating the issue of non-client related activities dominating a part-time therapist's workload".92

## 5. Actual Workloads/Caseloads

## 5.1. UK: England and Wales

A UK study, 93 in 2000, showed that the size and nature of caseloads of children with speech and language needs is changing. Researchers in the study suggested that an increasing demand for SLT services is exacerbated as more children with speech and language difficulties are placed in mainstream schools. The models of service delivery varied across the case study sites in England and Wales and were influenced by resources and the staff in post. Over two thirds of SLT departments provided a service to mainstream schools and approximately 60% of the children receiving such a service at primary and secondary level had a statement of special educational need. The main shortfall was provision to children in secondary school and those with emotional and behavioural difficulties. 94 While prevalence data suggested a figure of 10% of the "child" population as being potential cases for SLT, caseloads reported in the study suggested that the figures being referred were considerably lower than this. 95 The ratio of therapist to child population varied from 1,000 to 9,500 children per therapist, with an average of 4,257. The size of SLT caseloads varied significantly across England and Wales: from 37 per wte SLT in Trust London, to 172 per wte SLT in Trust Wales. Caseloads and waiting lists for SLT provision were highest for the 0-4 year olds. 96 The size of the caseload was positively correlated with the size of the base rate population and the number of therapists available in the service. However, it is not possible to deduce the direction of causality from this: are more therapists employed because there are more referrals or are there

<sup>&</sup>lt;sup>93</sup> Law, J., Lindsay, G., Peacey, N., Gascoigne, M., Soloff, N., Radford, J., Band, S., Fitzgerald, L. (2000) Provision for Children with Speech and Language Needs In England and Wales Facilitating Communication Between Education and Health Services 2000 dera.ioe.ac.uk/4475/1/RR239.pdf <sup>94</sup> ibid

<sup>&</sup>lt;sup>95</sup> ibid - the main aim of this study was to provide an overview of the nature and extent of speech and language therapy provision across England and Wales. The study involved a survey of Local Education Authorities (LEAs) and Health Trust SLT departments, 15 case studies and 5 regional workshops with key stakeholders. 96 ibid

more referrals occurring because there are more SLTs available to meet their needs?<sup>97</sup>

The researchers considered an appropriate level of caseload, and stated that the often cited benchmark figure of 40 children per SLT as the optimum number of clients per therapist, had demonstrable validity in relation to senior practitioners. However, given the range of needs of different groups of children with speech and language difficulties, it is difficult, the research findings suggest, to be prescriptive. For example, caseload may be lower for clients needing specialised input or higher for clients requiring more generic input such as children with delayed language development. Similarly, the figure would be lower where a high level of direct involvement was needed, or higher where an effective indirect model was in place. 99

A 1984 national survey in the UK, suggested that 75% of managers considered 40-100 cases to be an appropriate notional caseload for speech and language therapists while 41% considered loads of 40-60 cases to be appropriate. Guidelines were given as:

- A caseload per therapist of 40-60 children for pre-school and school aged population up to the age of 16 years
- A caseload per therapist of 10-14 in the case of children with severe speech and language disorders and autism
- A caseload of 25-49 per therapist working with children with intellectual disability.<sup>101</sup>

#### 5.2. UK: Scotland

In a 2003 Scottish study, caseloads varied between the type of NHS therapist and across regions. This is shown in Table 24. The Scottish research showed that:

98 ibid

<sup>97</sup> ibid

<sup>99</sup> ibid

Hughes A (1984) Analysis of notional caseload study West Berkshire Health Authority. Referred to in Speech and Language therapy Department (1985) Survey of Speech Therapy referrals from primary schools Unpublished report, Bristol and Weston Health Authority Hughes A. Stuffins G. Analysis of National Caseload Study. Association of Speech Therapy Managers, London; 1984 as cited in the 1994 Eastern Health Board Irish Study on Speech and Language Therapy: The Way Forward. www.lenus.ie/hse/bitstream/10147/45687/1/8567.pdf

- There are shortages of experienced therapists, recruitment difficulties in rural areas and growing numbers of referrals (there are some children waiting for 32 weeks of longer to receive an initial appointment from an NHS therapist)
- There are high percentage vacancy rates for therapists in children's services, particularly in remote and rural areas
- There is too small a pool of therapists to draw upon, to fill posts requiring some experience and expertise
- There are too few opportunities for therapists to develop paediatric experience
- The majority of therapists are female and under 40 years and maternity leave and other temporary absences are not well covered.

Table 24: Caseloads at April 2002 in Scotland for physiotherapists, occupational therapists and speech and language therapists <sup>102</sup>

	NHS PTs	NHS OTs	NHS SLTs
Mean number of	66 (range 30 –	60 (range 33-134)	93 (range 37-
cases in Scotland per	168)		236)
WTE			
Western Isles	30	55	6 l estimated
Tayside	33	34	37 not
			accurate
Shetland	Not available	125	136 estimated
Orkney	33	55	236
Lothian	59	41	57
Lanarkshire	Not accurate	43	106
Highland	Not accurate	68	Not available
Greater Glasgow	Not accurate	45	95
Grampian	Not accurate	71	106
Forth Valley	96	33	62
Fife	63	45	57
Dumfries and	33	57	84
Galloway			
Borders	168	134	72
Ayrshire and Arran	69	62	103
Argyll and Clyde	80	38	87

<sup>&</sup>lt;sup>102</sup> A 2003 Scottish Executive Review of Speech and Language Therapy, Physiotherapy and Occupational Therapy for Children and Speech and Language Therapy for Adults with Learning Disabilities and Autistic Spectrum Disorder scotland.gov.uk/Publications/2003/08/18065/25750

#### 5.3. The USA

In 2004, analyses determined that there were 1,621 students per school psychologist in the United States, which represents an 11% decrease from the 1,816 reported for 1999. The ratio of psychologists to students varied widely from state to state. <sup>103</sup>

A study among 105 occupational therapists and occupational therapy assistants working in schools in Colorado, found that the average caseload was 44 students. Most frequently served were kindergarten (5 to 6 years of age) through third-grade students (8 to 9 years of age), with perceptual or communicative disabilities. The occupational therapists delivered services most often in pullout treatment areas. The therapists spent most of their work-week providing direct services. <sup>104,105</sup>

The North Carolina (NC) Department of Education published a school based OT guide, as well as a formula to use for calculating an appropriate caseload number based upon different factors. <sup>106</sup> Like Ohio, NC Department of Education has a ratio of 50 students per I occupational therapist.

The Dept of Education in Ohio mandates that service providers provide direct services<sup>107</sup> in accordance with the ratios shown in Table 25:<sup>108</sup>

http://www.nasponline.org/publications/cq/cq336numsp.aspx

<sup>&</sup>lt;sup>103</sup> Charvat, JL (2005) NASP Study: How Many School Psychologists Are There? NASP Communiqué, Vol. 33, March 2005. Accessible at

<sup>&</sup>lt;sup>104</sup> "Pull out therapy" means a treatment or intervention that is provided in a separate room to the mainstream classroom.

Spencer, KC., Turkett, A., Vaughan, R., Koenig, S. (2006) School-Based Practice Patterns: A
 Survey of Occupational Therapists in Colorado *The American Journal of Occupational Therapy* January/February 2006, Volume 60, Number 1 ajot.aotapress.net/content/60/1/81.full.pdf
 George, BM Managing Caseloads And Service Delivery Partnerships In School Based Practice.

George, BM Managing Caseloads And Service Delivery Partnerships In School Based Practice. Accessible at

http://www.oota.org/Managing % 20 Caseloads % 20 and % 20 Service % 20 Delivery % 20 Partnerships % 20 in % 20 School % 20 Based % 20 Practice.pdf

<sup>&</sup>lt;sup>107</sup> Specially designed instruction provided to the students as designated on the students IEP. Specially designed instruction means adapting, as appropriate to the needs of an eligible child the content, methodology or delivery of instruction

<sup>&</sup>lt;sup>108</sup> Service providers shall serve no more than the numbers represented in the table. However, service providers may need to serve less based on the workload factors in the provision of specially designed instruction

Table 25: Provision of direct services in accordance with the following ratios

Services	School	OR	Preschool
	Age		
Occupational therapist	50	OR	40
Physiotherapist	50	OR	40
Speech and Language therapist	80 - 50 for	OR	50
	complex		
School psychologist	125	AND	75
Adapted Physical Education	100	OR	100
Audiologist	100	OR	75
Orientation and Mobility	50	OR	40
Work Study Coordinator	75	OR	N/A
Vocational Special Education	50	OR	N/A
Coordinator			

Source: Ohio Admin. Code 3301-51-09 (1) (3-4) edited

The Dept mandates that school age intervention specialists provide direct services in accordance with particular ratios. These are shown in Table 26.

The Ohio Department of Education lays out rules for determining caseloads for staff who serve preschool and school age children. 109

In practice, differences remain between the AHP board and the Ohio Department of Education, Office for Exceptional Children, on how appropriate caseloads are defined and determined for OT and PT. This has led to OTs and PTs supervising multiple occupational therapy and physical therapy assistants and, thereby, being responsible for large numbers of students. There are cases of OTs and PTs coordinating services for over 200 students. There are instances of OTs and PTs assigned caseloads for direct services far exceeding Office for Exceptional Children standards. This contravenes the laws and rules that regulate the practice of these professions in Ohio. 110

Therapy Practice Position Paper otptat.ohio.gov/Portals/0/Pubs/School%20Based%20OT-

PT%20Caseload%20Position%20Paper%20June%202011.pdf

Ohio Dept of Education (2011) Determining caseloads for related services staff who serve
 both preschool and school age children. ohioslha.org/pdf/PRepSchools/Sharedcaseloadsteps.pdf
 Determination of Appropriate Caseload for School-Based Occupational Therapy and Physical

Table 26: School-age intervention specialists shall provide direct services in accordance with the following ratios

Caseload ratios for intervention specialists					
Disability Category	By school level		Per instruction period		Age range per instruction period
	Elementary Middle Jr.	High School	Elementary Middle Jr.	High School	60 mnths
	High	School	High	School	
Cognitive disabilities	16	24	12	16	60 mnths
SLD	16	24	12	12	60 mnths
HI, VI, OH, OHI	10	10	8	8	60 mnths
Emotional Disturbance	12	12	10	10	60 mnths
Multiple Disabilities	8	8	8	8	60 mnths
Autistic, Deaf-Blind, TBI <sup>112</sup>	6	6	6	6	60 mnths
Multiple categories	16	24	16	24	60 mnths

Source: Ohio Admin. Code 3301-51-09 (1-2)

What is of interest is the work undertaken in Ohio to determine optimal caseload ratios. The Caseload Ratio Steering Committee, formed by the Ohio Department of Education, decided that ratios should be flexible to accommodate variations in the intensity of needed services and to address the reality that most districts had moved to a system that provides services in inclusive settings. Twenty one educational agencies received grants to study processes for calculating the FTE of service provider caseload ratios. These 21 agencies studied workloads and caseloads of OTs, PTs, SLPs, School Psychologists and others. They have implemented workload-reducing strategies and developed different approaches. The majority of strategies are based on the workload philosophy of: time for workload duties + time for services = the total number of hours in a

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<sup>&</sup>lt;sup>111</sup> HI=hearing impairment, VI =visual impairment, OH=other health impairment, OHI =other health impairment major

<sup>112</sup> TBI=traumatic brain injury

<sup>113</sup> ibid

service provider's work-week.<sup>114</sup> The various approaches have been evaluated against student outcomes to see which approaches of workload/ caseload balance provide the best outcomes for students.<sup>115</sup> A report (October 2014) outlines which workload/ caseload approaches provided the best outcomes for students. While methodological limitations prevented the research team from fully recommending one or more of the alternative caseload ratio approaches and accompanying strategies, positive outcomes were realized when the data was considered as a whole.<sup>116</sup>

The National Outcomes Measurement Systems [NOMS] project, carried out by the American Speech and Hearing Association (ASHA) in 2000,<sup>117</sup> suggested that flexible work models in which SLT can modify practice according to the need of the child are more sustainable with caseloads of 40 or less. Caseloads of more than 40 children, imposed a model of group-working on those providing the SLT services - that is, therapy provision was likely to be made to children in groups eliminating the possibility of individual support.<sup>118</sup> In 2004, ASHA showed that in the USA, ASHA-certified school-based SLPs had median monthly caseloads of 50 with a range from 20-53.<sup>119</sup>

In Illinois, in 2009, the State Board of Education specified that the number of children served by a speech-language pathologist, shall be based on the speech-language needs of each child and, that, the other provisions of the Administrative Code notwithstanding, at no time shall the caseload of a speech-language pathologist exceed 60 students.<sup>120</sup>

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See, for example, a presentation entitled "Ohio's Caseload Ratio Project: The Results, The Implications, and Where Do We Go From Here? Presented at the OSLHA Annual Convention: 3/13/2014. http://www.ohioslha.org/pdf/Convention/2014%20Handouts/Symposium1.pdf
 http://education.ohio.gov/Topics/Special-Education/News/Caseload-Ratio-Project-and-Study

http://education.ohio.gov/Topics/Special-Education/News/Caseload-Ratio-Project-and-Study http://education.ohio.gov/Topics/Special-Education/News/Caseload-Ratio-Project-and-Study

Boswell S, (2000) Crushed by growing caseloads The ASJA Leader 5, 18 p I and 6 See also www.asha.org/nctecd/treatment\_outcomes.htm

<sup>&</sup>lt;sup>119</sup> American Speech-Language-Hearing Association. (2004). 2004 schools survey report: Survey methodology, respondent demographics, and glossary <a href="www.asha.org/NR/rdonlyres/A700FE99-C454-44EF-959884B195E8D87F/">www.asha.org/NR/rdonlyres/A700FE99-C454-44EF-959884B195E8D87F/</a>0/SchoolsSurveyWorkforce.pdf as cited in Edgar, D., & Rosa-Lugo, L. (2007). The critical shortage of speech-language pathologists in the public school setting: Features of the work environment that affect recruitment and retention. Language, Speech, and Hearing Services in Schools, 38, 31-46

Overview of Special Educator Work Load Plan Requirements August 31, 2009. http://www.isbe.net/spec-ed/pdfs/work\_load\_plan\_overview.pdf

In the USA, in various studies with speech-language pathologists (SLP), the following findings were reported and/or observations made:

- Caseload is more accurately conceptualised as only one part of a SLPs workload<sup>121</sup>
- Caseload affected the ability of 75% of SLPs to engage in collaboration with other teachers 122
- Many states and school districts interpreted the maximum as a minimum and increased caseloads until many clinicians were "at breaking point" 123
- Earlier identification of children with multiple disabilities, the role of speech–language pathologists (SLP) in literacy, and increased recognition of the needs of children with multiple disabilities are resulting in large caseloads, greater time demands and additional workload responsibilities for SLPs<sup>124</sup>
- The four highest ranked challenges in the school setting for SLPs, included workload activities (paperwork, time, planning, and collaboration), caseload, other professionals understanding SLP role and salary<sup>125</sup>
- The increase in the number of children identified with disabilities, school cutbacks on funding, excessive caseload size, significant administrative responsibilities, increased paperwork, and lack of resources to do the job, are factors contributing to higher levels of stress and burnout in school-based SLP 126
- The current trend of increasing caseloads and the expanded responsibilities of SLPs are factors contributing to high rates of attrition<sup>127</sup>

<sup>&</sup>lt;sup>121</sup> Ehren, B. (2001, January). Reducing caseloads (Special Interest Division 16). ASHA Leader.

<sup>&</sup>lt;sup>122</sup> Chiang, B., & Rylance, B. (2000). Wisconsin speech-language pathologists' caseloads: Reality and repercussions. Oshkosh, WI: University of Wisconsin–Oshkosh

Annett, M. M. (2003, April 15). Beyond School Caseloads: Looking at Total Workload. The ASHA Leader. www.asha.org/Publications/leader/2003/030415/030415.htm

<sup>&</sup>lt;sup>124</sup> Blood, G., Ridenour, J., Thomas, E., Qualls, C., & Hammer, C. (2002). Predicting job satisfaction among speech-language pathologists in public schools. Language, Speech, and Hearing Services in Schools, 33, 282-290

<sup>&</sup>lt;sup>125</sup> Edgar, D., & Rosa-Lugo, L. (2007). The critical shortage of speech-language pathologists in the public school setting: Features of the work environment that affect recruitment and retention. Language, Speech, and Hearing Services in Schools, 38, 31-46

<sup>&</sup>lt;sup>126</sup> Goldberg, B. (1993, November). Recipe for tragedy: Personnel shortages in the public schools. Asha, 36–40.

<sup>&</sup>lt;sup>127</sup> American Speech-Language-Hearing Association. (2002). Scope of practice in speech-language pathology. ASHA Leader(Suppl. 22), 29–36.

 Age of participants, years at a job and caseload were predictive of job satisfaction among 382 SLPs from 10 school districts in Central Florida.

### 5.4. New Zealand

Specialist staff in Table 27 include physiotherapists, occupational therapists, speech and language therapists and educational psychologists. Caseloads range from 35 per specialist staff to 50 with an average caseload of 41 children.

Table 27: Caseloads for specialist staff<sup>129</sup> providing special education services in New Zealand<sup>130</sup>

Service	Caseload	Extra information
Early Inter-	12-13,000 children per year (4% of the	Includes children with
vention	birth to school entry population) with 300	complex needs,
	specialist staff	communication needs, and
		behaviour needs
	This equates to a caseload of approx 43	Birth to school entry (5years
	children per specialist staff	of age for most)
Complex	7000 students (1% of school age	Children verified for the
needs	population)	Ongoing Resourcing Scheme
(school)	200 specialist staff approx	giving entitlement to
		ongoing specialist and para-
	This equates to a caseload of	professional support, plus
	approximately 35 children per specialist	extra teacher time -5 years
	staff member	to end of school
Behaviour	8-10,000 students (1% of school age	5years to end of school
services	population)	(target 5-14 years)
(school)	200+ specialist staff	
	This equates to a caseload of	
	approximately 50 per specialist staff	
	member	
Communica	5500-7000 students (1% of school age	5 years to end of school
tion services	population) 200 specialist staff	(target 5-8 years)
(school)	This equates to a caseload of	
	approximately 35 per specialist staff	
	member.	

<sup>&</sup>lt;sup>128</sup> Edgar, D., & Rosa-Lugo, L. (2007). The critical shortage of speech-language pathologists in the public school setting: Features of the work environment that affect recruitment and retention. Language, Speech, and Hearing Services in Schools, 38, 31-46

<sup>130</sup> This information was supplied from the New Zealand Ministry of Education, Regional Operations, Special Education Division.

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<sup>129</sup> Specialist staff include PT/OT/SLT/educational psychologists

The numbers given in Table 28 show lower caseloads for specialists and in particular for educational psychologists, with caseloads of 15-20 for a mix of complex and moderate, school aged and early intervention.

Table 28: Caseloads for staff in early intervention and school based services in New Zealand <sup>131</sup>

Profession	Caseload	Extra information
Speech-	30 -40	Mix of complex and moderate
language		Mix of school aged and early intervention
therapist		Mix of team cases and comm. only cases
		On average, a SLT should be picking up about 4
		cases per month. This is going to vary example an
		experienced SLT may have a higher proportion of
		complex needs cases and so may not pick up as
		often. It might be better to think about pickup rates
		as a team rather than individuals
Early	20- 25	Mix of complex and moderate
intervention		Mix of lead worker or other
teacher		
Educational	15-20	Mix of complex and moderate
Psychologist		Mix of school aged and early intervention

#### 5.5. Australia

In Table 29 below, caseloads are 8-10 for intensive complex case management. However, in the absence of definitions of what is complex and intensive etc it is difficult to compare these different caseloads.

Table 29: Caseloads for case management services in adult and school age community service teams in South Australia<sup>132</sup>

Case type	Ratio of staff to client
Individual case management	1:20
Intensive complex case management	1:8/10
Mixed caseloads - case management, monitoring, and	1:35
maintenance	

<sup>131</sup> ibid

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<sup>&</sup>lt;sup>132</sup> This information is derived from Rochelle Hay, the program manager for children's disability services in South Australia. She noted that these figures are not based on specific research but on what is happening in the different territories in Australia.

5.6. SlovakiaTable 30: Some figures for services and therapists in Slovakia 133

Number of Special educational	121
counselling centres	
Number of all clients (from birth to	71660
completion of school education)	
Number of children of age 0-3 years	1266
Number of special educators including	391(71,660/391 =1:183children)
speech therapists	
The number of therapists for	11(71,660/391=1:6515 children)
behaviour problems	
The number of social teachers	14(71,660/14=1:5119 children)
Number of psychologists	157 (71,660/157=1:456 children)

<sup>&</sup>lt;sup>133</sup> This information was provided by Maria Stefkova, National Institute Education Slovakia and National Coordinator for the European Agency for Development in Special Needs Education

# Appendix 1: Disability services for children

This appendix presents findings on:

- The central role that outcomes play in developing effective services
- The provision of quality care for children with disabilities
- Family and child-centred early intervention services
- Teamwork or inter-professional collaboration in children's services
- Good practice in the Allied Health Professions(AHP)/therapy services
- The changing status of AHP/therapy services

#### 1. The role of outcomes in developing children's services

An outcome is a result. It is not a service, an intervention, an activity nor an output. An outcome refers to the impact of an activity or service, on a child's development or behaviour or functioning.<sup>134</sup> It is a benefit experienced as a result of services and supports provided to a child or family.<sup>135136</sup>

Any framework for identifying and measuring outcomes for children with disabilities, should focus on a person's individual talents, capabilities and interests once their basic "foundational" needs and "fundamental" outcomes have been met. Fundamental outcomes include, for example: 137

- Communication
- Physical wellbeing
- Emotional wellbeing
- Socialising

Being safe from exploitation

<sup>&</sup>lt;sup>134</sup> Parker, R., Ward, H., Jackson, S., Aldgate, J. & Wedge, P. (Eds.) (1991). Looking after children: Assessing Outcomes in Child Care. The Report of an Independent Working Party established by the Department of Health. London: HMSO

<sup>135</sup> Early Intervention Colorado Child and Family Outcomes Measurement. www.eicolorado.org/index.cfm?fuseaction=Family.content&linkid

<sup>&</sup>lt;sup>136</sup> Greene, S. Stewart, B Barnardos' Needs-Led & Outcomes-Focused Approach. www.barnardos.ie/assets/files/publications/free/childlinks\_body17.pdf

<sup>&</sup>lt;sup>137</sup> The Scottish Government (2013) Developing an Outcomes Model for Disabled Children and Young People in Scotland www.scotland.gov.uk/Resource/0043/00434117.pdf

The Barnardos Assessment Framework's (BAF) considers five dimensions of children's development: behavioural, emotional, educational, physical and social. It promotes the central principal of identification of needs first, outcomes second and services third. This Assessment Framework considers needs, outcomes and services in a systematic manner and considers that it is vital to adhere to the sequence to ensure that services are needs-led and outcomes focused. When the desired outcomes are considered for a child or family, appropriate services/interventions can then be planned and offered: 138

- First, identify the need in the child's life, for example, increased social skills
- Then consider the desired outcomes, for example, the child plays with peers
- When the outcomes are clarified, consider the services that are required to attain the outcome, for example, child attends a friendship group. It is important to adhere to this sequence to ensure that services offered are needs-led and outcomes-focused.

Cook and Miller (2012) distinguish between personal outcomes and outcomes for services, organisations or nations. These different outcome 'levels' are interrelated.

Engaging individual children with disabilities in the process of defining their outcomes is at the core of a personal outcomes model. Even though the starting point is the individual child, the child exists in a network of people: familial, social, and professional. A personal outcomes approach requires a shift in service provision so that the focus is on working with individuals, identifying what they want and then how to get there. Ideally, the achievement of personal outcomes should inform the achievement of outcomes from services, organisations and nations. Challenges in applying this framework to children and young people with disabilities include: 140

- A child's multiple needs and the number of professionals and agencies involved, as well as the views of parents/carers
- The difficulty in ensuring that children with complex communication impairments have their voices fully heard

<sup>138</sup> ihid

<sup>&</sup>lt;sup>139</sup> Cook, A. and Miller, E. (2012) Personal Outcomes Approach: Talking Points. Edinburgh: Joint Improvement Team as cited by The Scottish Government (2013) Developing an Outcomes Model for Disabled Children and Young People in Scotland www.scotland.gov.uk/Resource/0043/00434117.pdf

<sup>&</sup>lt;sup>140</sup> The Scottish Government (2013) Developing an Outcomes Model for Disabled Children and Young People in Scotland www.scotland.gov.uk/Resource/0043/00434117.pdf

 Measuring soft outcomes. If measurable results are required, there may be concern that the most vulnerable users might miss out on having soft outcomes assessed because they are more challenging to measure.

Miller (2011)<sup>141</sup> cites the following benefits at all outcome levels:

- For people who use services and their families, being involved in defining the outcomes they want, which can be empowering and result in increased support
- Working with individuals to develop outcome-focussed plans, and reviewing the outcomes achieved, which can achieve clarity of purpose
- An outcomes approach, which can help organisations to focus on the differences they make to people's lives.

In 2013, the Scottish Government published a report on developing an outcomes model for children with disabilities in Scotland, it concluded: 142

- There is no absolute list of outcomes appropriate to all children with disabilities and there is no single outcomes model suitable for all situations. Currently developing outcome models is a work in progress
- For many children with disabilities, fundamental outcomes need to be achieved as a foundation before others outcomes can be attained. For example, effective communication is a fundamental outcome for many children with disability. Other fundamental outcomes vary according to the nature of the disability. Attaining fundamental outcomes ensures that children with disability have a basic quality of life. This is the priority and other outcomes should follow this.
- The development of an outcomes model requires collaboration across and between agencies; leadership within the team developing it; and, engagement from the professional staff involved. Active engagement from within each agency is required including the front-line staff of the agency.

The Scottish Government promotes 'Getting it Right for Every Child' (GIRFEC). GIRFEC has 8 wellbeing indicators: "Safe, Healthy, Achieving, Nurtured, Active, Respected, Responsible and Included" (SHANARRI). GIRFEC provides:

Children and Young People in Scotland

<sup>&</sup>lt;sup>141</sup> Miller, E. (2011) Measuring Personal Outcomes: Challenges and Strategies. Glasgow: IRISS as cited by The Scottish Government (2013) Developing an Outcomes Model for Disabled

<sup>&</sup>lt;sup>142</sup>The Scottish Government (2013) Developing an Outcomes Model for Disabled Children and Young People in Scotland www.scotland.gov.uk/Resource/0043/00434117.pdf

- A framework for naming outcomes using the SHANARRI indicators through a tool called My World Triangle which can be used to gather information to understand what is happening to a child and family
- A tool called the Resilience Matrix to document, analyse and summarise the strengths and pressures in a child's situation, from information gathered using the My World Triangle tool plus specialist assessments. The information collected is grouped under four headings: resilience, vulnerability, protective environment and adversity.

How these indicators are applied to children with disabilities need to be defined. For example, what does healthy mean for a child with a life-limiting condition? What does achieving mean for a child with complex multiple impairments? The government proposes that a partnership between disability organisations (including children and parent-led groups) and public agencies could identify where outcomes work or where they are being developed in each field of disability and for all age groups and then jointly plan, develop and implement such work. This would consolidate ongoing outcomes work and allow people newly addressing outcomes measurement to avoid redoing work.

Early intervention services in Colorado have clear child and family outcomes measurement and work towards these outcomes. Currently family outcomes are measured yearly. Child outcomes are measured when a child enters the service and again when a child leaves the service.

#### The three child outcomes are:

- A child has positive social relationships
- A child acquires and uses knowledge and skills
- A child takes appropriate action to meet his or her needs.

#### The three family outcomes are:

- A family knows their rights within the Early Intervention Colorado system
- A family communicates their child's needs
- A family helps their child learn and develop.

# 2. Suggestions on providing quality care to children with disabilities

In a 2012 UK Care Quality Commission Report<sup>143</sup>, suggestions on service improvement from parents included coordination of service, parents' involvement in care and communication, the quality of care and provision and diagnosis and access to services. Parents' suggestions included:

- A referral system where the patient is assisted at every step and followed up and where the various services involved ensure that they work well together
- Information provision on what is available and how to access support, advice and support, "honesty, truth and help around the needs of my child"
- Holistic/person centred services take into account the needs of the family. "We were not given time to ask questions", "We did not receive counselling"
- Good communication skills—the ability to empathise, listen and to be open to other ideas.

In the UK, a 2011 report from the National Network Parent Carer Forum<sup>144</sup> made recommendations around providing good-quality care to families with a disabled child:

- "Smarter use of scarce resources parent carers are often asked the same questions by different providers and there is no systematic cross reference."
- "Strategic involvement of expert parent carer representatives at policy design stage, and in monitoring patterns of service delivery."

The focus of the 2011 UK Disabled Children and Health Reform report<sup>145</sup> was also on how to improve services. There were recommendations on leadership, on commissioning and on information provision and support to children with disabilities and their families, to ensure that they understand the way in which the health system works.

www.cqc.org.uk/sites/default/files/media/documents/health\_care\_for\_disabled\_children.pdf 

144 Contact a Family (2011) Parent carer forum involvement in shaping health services 

www.pinpoint-cambs.org.uk/sites/default/files/Shaping%20Health%20services%20final.pdf (This report is based on the results of a survey sent out to 151 parent carer forums and highlights the 
work carried out by parent carer forums in shaping health services and the challenges forums 
have experienced in raising children's issues through LINks)

<sup>&</sup>lt;sup>143</sup> Health care for disabled children and young people: A review of how the health care needs of disabled children and young people are met by the commissioners and providers of health care in England.

<sup>&</sup>lt;sup>145</sup> The Children's Trust, Tadworth (2011) Disabled Children and Health Reform: Questions, Challenges and Opportunities. www.thechildrenstrust.org.uk

Barnardos proposed the development of a national structure in Ireland that would address the lack of a reference development model for children's services and the variation in services and standards delivered by local services. <sup>146</sup> Their recommendations include:

- Establish a model stating the principles and values which should underpin children's services
- Outline outcome performance measures for services delivered through statutory and voluntary sectors
- Establish a model that determines how and where resources should be allocated
- Introduce a common system for assessing the needs of children or reporting on outcomes
- Establish a single common accessible universal information database showing good practice and policy developments across the services hosted by an agency delivering services
- Develop an input model that ensures complementary services rather than
  duplicating services. Currently there is no 'input model' detailing level of staff,
  services and investment. Neither are there indicators or a directory of
  statutory and voluntary services. This makes it impossible to assess outcomes

## 3. Effective practice for AHP or therapy services

Therapy services or the services provided by Allied Health Professions form an important part of children's disability services. These services are provided by a diverse group of professionals, who provide different contributions to health and social care, and can span organisational boundaries.

Bundy et al reviewed the research literature on best practice for therapy services in the disability sector. <sup>147</sup> Best practice was defined as, the available evidence plus clinical reasoning, plus knowledge of local and individual factors.

Key findings to guide the development and provision of therapy services include:

<sup>147</sup> Bundy, A., Brentnall, B., Hemsley, B., Marshall, E. (2008) Therapy Services in the Disability Sector: Literature Review NSW Department of Ageing, Disability and Home Care

<sup>&</sup>lt;sup>146</sup> Barnardos: Reorganising Child and Family Support Services Discussion Paper August 2011 www.barnardos.ie/.../Reorganising%20Child%20and%20Family%20Support%20Services%20Ba... This report by Barnardos is on Child and Family Services not Children's Disability services but the issues are similar

- Family-centred and person-centred practices are best practice but clinical practice often falls short of this
- Therapy should be tailored to each person's needs and is generally more effective when it is delivered in natural settings and targets functional goals
- Services need to be coordinated and accessible
- Self-efficacy and self-advocacy are important in the design and delivery of services
- Families generally do not find information timely or accurate
- Therapy staff need to share a common understanding of disability
- Direct, indirect and consultative modes of service delivery are all valid treatment options. Available research suggests indirect and consultative services are at least equally effective as direct services although most practice and effectiveness research relates to direct therapy<sup>148</sup>
- In practice, indirect and, in particular, collaborative consultation are underutilised and should be considered viable adjuncts or alternatives to traditional direct therapy services
  - Direct therapy, whether individual or group, is best suited for interventions to increase or maintain skills
  - Indirect therapy is well suited for interventions to provide practice in everyday settings
  - Collaborative approaches to therapy aim to solve everyday problems and build self-management skills
- To manage caseloads and achieve optimum outcomes for persons with a disability, therapists need to be supported in the provision of all forms of therapy service delivery through organisational structures, policies and procedures
- Measures of productivity need to reflect that different services are appropriate in different circumstances, and that functional outcomes are of the highest priority
- Therapists generally require more training and experience with collaborative consultation

<sup>&</sup>lt;sup>148</sup> Bundy et al (2008) found that therapists use various types of therapy such as direct, indirect and consultation therapy. The proportion of time spent in direct contact with the person/ family varies with service delivery philosophy and type. Different forms of therapy, implemented by a range of personnel in different ways were all found to be effective across a range of settings.

- Principles of demand management can be used to increase information and access to services, ensure effective service coordination and delivery, manage 'inappropriate demand' which is defined as both the demand for services that are not necessary and lack of demand for services that are indicated. Demand management strategies that seek to maximise services include:
  - 'Intake' of clients: pathways for initial client contact, initial assessment of needs, and prioritisation of needs
  - **'Flow-through' of clients**: waiting list procedures (e.g., review and recall), use of individual or group therapy sessions, indirect therapy, and consultative models of service delivery, and caseload management (e.g., balancing more complex or long term needs with simple or easily addressed needs)
  - 'Discharge' of clients: planning for discharge, review and recall, and discharge criteria, policies and procedures. 149

Transition from one service to another is an important issue and professionals working with children increasingly recognise the importance of smooth transfers.<sup>150</sup>

### 4. The changing status of the Allied Health Professions

"There is little agreement on what comprises the allied health workforce at either the stakeholder, jurisdictional or national level". 151

Therapy services in the past have often been considered as those provided by occupational therapists, physiotherapists and speech and language therapists. However, the range of professionals registered as AHPs is expanding and varies across jurisdictions. For example, in England, there are twelve diverse statutory-registered AHPs who deliver care to patients across a variety of settings. In Wales<sup>152</sup> and in Ireland<sup>153</sup> there are seven groups of AHPs. In Scotland, there are

<sup>&</sup>lt;sup>149</sup> Bundy, A., Brentnall, B., Hemsley, B., Marshall, E. (2008) Therapy Services in the Disability Sector: Literature Review NSW Department of Ageing, Disability and Home Care

<sup>&</sup>lt;sup>150</sup> European Agency for Development in Special Needs Education (2010) Early Childhood Intervention - progress and developments 2005-2010, Odense, Denmark: European Agency for Development in Special Needs Education

<sup>&</sup>lt;sup>151</sup> Page 8, Human Capital Alliance (2006) Workload Capacity Measures for Allied Health – Final Report Department of Human Services, Victoria, Australia

<sup>&</sup>lt;sup>152</sup>These seven services (physiotherapy, occupational therapy, speech and language therapy, dietetics, orthotics, podiatry and orthotic services, and art therapies) are reviewed in A Strategy for the Therapy Services 2011-2016.

www.wales.nhs.uk/sitesplus/documents/866/A%20Strategy%20for%20the%20Therapy%20Service s%20in%20Aneurin%20Bevan%20Health%20Board%20Final%20%282%29.pdf

eleven groups.<sup>154</sup> A therapy service provider in Western Australia called Therapy Focus employs 80 therapists all in Speech Pathology, Physiotherapy and Occupational Therapy and contracts psychological and other allied health services as required.<sup>155</sup>

"While grouping and considering the various 'allied health' professions as a single entity can be conceived as beneficial by workforce planners, since it potentially reduces the number of forms of labour that have to be considered in the production function for delivery of health services, it more likely hinders the development of appropriate workforce planning solutions." <sup>156</sup>

For the purpose of our research we are interested in allied health professionals (AHP) and other healthcare professionals who work in community disability services for children, for example, speech and language therapists, physiotherapists, occupational therapists, social workers, psychologists etc.

The status of the allied health professions varies widely across professions and jurisdictions and defining allied health labour is a challenging endeavour. In addition, comprehensive and accurate data on allied health service activity is poor, particularly in community settings. These realities affect the development of community children's disability services in Ireland as well as in other jurisdictions.

In New Zealand, front-line AHP manage budgets, service provision, planning and outcomes and accountability and auditing. <sup>157</sup> In Ireland, AHP are not represented in an advisory capacity in the Department of Health. Likewise, they do not have clinical representation at service level and at regional level. <sup>158</sup>

In Scotland, allied health professions are being portrayed as 'agents of change in health and social care' under the Scottish Government's 2012-2015National Delivery Plan for the Allied Health Professions:

<sup>&</sup>lt;sup>153</sup> The 7 groups are Physiotherapy, Speech and Language Therapy, Occupational Therapy, Dietetics, Orthotics and Radiography and Radiation Therapy.

<sup>&</sup>lt;sup>154</sup> The groups are Arts Therapy, Dietetics, Physiotherapy, Podiatry, Prosthetics and Orthotics, Occupational Therapy, Orthotics, Diagnostic and Therapy Radiography and Speech and Language Therapy.

<sup>&</sup>lt;sup>155</sup> Therapy Focus Strategic Plan 2012-2014. therapyfocus.org.au/assets/pdf/therapy-focus-strategic-plan-2012-2014web.pdf

<sup>&</sup>lt;sup>156</sup> Page 10, Human Capital Alliance (2006) Workload Capacity Measures for Allied Health – Final Report, Department of Human Services, Victoria, Australia

<sup>&</sup>lt;sup>157</sup> Pillinger, J (2012) The Future of Healthcare in Ireland: Position paper on the health crisis and the government's plans for healthcare. (Prepared for Impact). www.impact.ie/files/healthpdf/reform/FutureofHealthcare.pdf
<sup>158</sup> ibid

- "Scotland's AHPs are working at the edge of a paradigmatic shift in the public sector, towards enablement and personalisation, promoting an asset-based approach, self-management, resilience and independent living and preventing over-reliance on hospitals and professional intervention
- "AHP directors and AHP leaders, working across health and social care, will be key to enhancing the AHP contribution to the joint planning and delivery of services, particularly for those with complex needs, long-term conditions, dementia and for children and young people
- "AHPs have a key contribution to make to the wider public health agenda, improving health and well-being by, for example, promoting physical activity and healthy nutrition, providing cancer prevention and vocational rehabilitation services, and enabling children to get the best possible start in life and achieve their full potential
- "AHPs' expertise in rehabilitation and enablement will be key to supporting the vision of health and social care integration and delivering on the nationally agreed outcomes for integration
- "Reducing inappropriate admissions and unnecessary care costs are key to affordable and sustainable services in the future. AHP interventions can significantly reduce unnecessary admissions to hospital and diminish dependency on care services, resulting in significant savings in health and social care
- "As first-point-of-contact practitioners, AHPs make a vital contribution to faster diagnostics and earlier interventions in primary care. They work closely with general practitioners and community teams to provide alternative pathways to secondary care referral and prevent admissions in areas such as falls prevention and musculoskeletal services." 159

In Canada, occupational therapists consider that research shows that they can offer solutions to healthcare issues and suggests greater scope for occupational therapy in the management of outcomes in complex and chronic diseases. <sup>160</sup> They argue from the evidence that they can provide cost-effective practical solutions to simple and complex problems and that currently they are underutilised. The Scottish Government point out that as of March 2012, there were approximately 10 000 AHPs working in acute and primary care settings

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<sup>&</sup>lt;sup>159</sup> Pages 8-9, Scottish Government (2012) AHPs as agents of change in health and social care: The National Delivery Plan for the Allied Health Professions in Scotland, 2012–2015. The Scottish Government Edinburgh. scotland.gov.uk/Resource/0039/00395491.pdf <sup>160</sup> Rexe, K., McGibbon Lammi, B., Zweck, C. (2013) Occupational therapy: Cost-effective solutions for changing health system needs. Healthcare Quarterly, 16(1), 69-75. doi: 10.12927.hcq.2013.23329 Accessed 20th February 2014

across NHS Scotland and around 500 AHP practitioners in social care, predominantly occupational therapists who, despite comprising only 1% of the total social care workforce, addressed 35% of all adult referrals. <sup>161</sup>

Currently, there is some interest in professional role revision, particularly of the allied health professionals and assistants. This stems in part from a desire to reduce medical workloads; to extend the range of services available to patients; to improve the quality of care and/or to reduce costs. It also comes from an increasing recognition of the roles that AHP can play in developing effective and efficient healthcare services. Changes to allied health professional roles include:

- Substitution a person from one professional background performs tasks traditionally performed by another type of health professional
- Supplementation extending the range of service provision within one delivery system.

A 2010 review, of revision of professional roles in health care, found one systematic review on role revision of allied healthcare professionals (physiotherapists, paramedics and radiographers). 162 Physiotherapists and paramedics were judged as substitution and radiographers as a mixture of substitution and supplementation. All three types of AHP, when suitably trained, appeared to assess, diagnose and treat patients as safely and effectively as physicians. No detrimental effect was found in extending the roles of non-medical professionals. In some cases, there was a positive effect on the quality of patient care. Gains in service efficiency may be achieved if doctors stop providing services that can be transferred to other health professionals and, instead, invest their time in activities that they alone can perform. 163 In rural locations in Australia, there has been piloting of trained allied health assistants working under the supervision and delegation of allied health professionals in larger sites. Introduction of vocational qualifications for allied health assistance and disciplinespecific allied health assistance, such as physiotherapy assistance, enables communities to access essential services closer to home. 164

<sup>&</sup>lt;sup>161</sup> Page 8, Scottish Government (2012) AHPs as agents of change in health and social care: The National Delivery Plan for the Allied Health Professions in Scotland, 2012–2015. The Scottish Government Edinburgh. scotland.gov.uk/Resource/0039/00395491.pdf

<sup>&</sup>lt;sup>162</sup>Laurant, M., Harmsen, M., Faber, M., Wollersheim, H., Sibbald, B., Grol, R (2010)Revision of professional roles and quality improvement A review of the evidence. health.org.uk/publications/revision-of-professional-roles-and-quality-improvement/
<sup>163</sup> ihid

<sup>164</sup> ibid

Successfully implementing new ways of working is dependent on professional respect, understanding of each others' roles and building trust. Understanding and respect can be supported with good clinical governance, planning, team meetings and activities. <sup>165</sup> When changing the delineation of roles; which professional completes which task; task substitution etc, should be considered. This will help maximise the various skills in the team and provide better care.

### 5. Family and child centred early intervention services

There is international agreement on the importance of a child's earliest years and therefore on early intervention children's services. <sup>166</sup> Econometric research shows, that high quality early intervention programs save society significant amounts of money over time and are a way to overcome disadvantage. <sup>167</sup>

Early intervention services for children with disabilities have been defined as:

- The provision of support and resources to families of infants and young children including informal and formal social support networks, that impact both directly and indirectly on parent, family and child functioning 168
- Child and parent orientated activities that are implemented to support the child's disability or development<sup>169</sup>

Dunst<sup>170</sup>, Bailey<sup>171</sup>, Turnbull<sup>172</sup> and others<sup>173</sup> developed integrated models for early intervention services that focus on child, parent and family capacity building

NSW Ministry of Health (2011) Health Professionals Workforce Plan Taskforce Discussion Paper to inform and support the NSW Government's Health Professionals Workforce Plan www0.health.nsw.gov.au/resources/workforce/hpwp/pdf/hpwp discussion.pdf

<sup>&</sup>lt;sup>166</sup> For example, I) Meisels, SJ., Shonkoff, JP. Early childhood intervention: A continuing evolution In, Shonkoff, J., Meisels, SJ, (eds). (2000) Handbook of Early Intervention Childhood Intervention, 2<sup>nd</sup> edn. Cambridge University Press, Cambridge, UK. 2) Guralnick, MJ (eds.). (1997) The effectiveness of Early Intervention. Brookes, Baltimore. 3) McCollum, J. (2000) Influencing the development of young children with disabilities: current themes in early intervention. Child and Adolescent Mental Health, 7, 4-9. 4) Blauw-Hospers CH, Hadders-Algra M (2005). A systematic review of the effects of early intervention on motor development in Developmental Medicine and Child Neurology, 47(6), 421-432

<sup>&</sup>lt;sup>167</sup>The Economist Intelligence Unit (2012) Starting well: Benchmarking early education across the world. Accessed 9th August 2012 www.lienfoundation.org/pdf/news/sw\_report.pdf <sup>168</sup> Dunst, C. J., Trivette, C. M., and Jodry, W. Influences of social support on children with disabilities and their families, In Guralnick, M. (ed.) "The effectiveness of early intervention", Brookes, Baltimore, 1997

<sup>&</sup>lt;sup>169</sup> This definition is in De Moor, JM., Van Waesberghe, BT., Hosman, JB., Jaekan, D., Miedama, S. (1993) Early intervention for children with disabilities: manifesto of the Eurlyaid working party. International Journal of Rehabilitation Research, 16, 23-31

as the major outcome for measuring success. The Family Centred Model of Early Intervention, identifies the family and the child as the target of intervention and parents acquiring competencies that enable them to support the development of their children is crucial. Dale, proposed a negotiated collaborative model with the premise that parents and professionals have separate but potentially valuable contributions to make.<sup>174</sup> In the family centred model, parents, siblings, teachers and others all have a role to play as well as therapists.

The shift towards family-centred children's services continues to develop. <sup>175</sup> A parent and family focus first appeared during the 1940s. <sup>176</sup> The perspective of parents as crucial to children's learning emerged in the 1960s. This orientation increasingly recognised that professionals should work very closely with parents to promote the child's development and should be able to identify and respond to parents needs. <sup>177</sup>

Moore and Larkin (2005) summarised key bodies of work on family-based or family-centred practice. <sup>178</sup> These include:

 Carl Dunst and colleagues' work which emphasises the need to embed intervention and support in the everyday environments of the child and family and the importance of mobilising family and community resources <sup>179,180</sup>

 $<sup>^{170}</sup>$  Dunst, CJ (1999) Placing parent education in conceptual and empirical concept Topics in Early Childhood Special Education, 19, 141-147

<sup>&</sup>lt;sup>171</sup> Bailey, D.B., McWilliam, P.J., Winton, P.J., & Simeonsson, R.J. (1992). Implementing Family-Centred Services in Early Intervention: A Team-Based Model for Change Cambridge, Massachusetts: Brookline Books

<sup>&</sup>lt;sup>172</sup> Turnbull, A.P. & Tunbull, H.R. (2000). Families, Professionals and Exceptionality: Collaborating for Empowerment (4<sup>th</sup> Ed.). Upper Saddle River, New Jersey: Merrill/Prentice Hall. <sup>173</sup> See section on family centred services in the literature review of this report

Dale, N. (1996). Working with Families of Children with Special Needs. London: Routledge

<sup>&</sup>lt;sup>175</sup> The work of Bronfenbrenner has had a major influence on the development of services that focus on the child's family context as the basis of their learning. Bronfenbrenner understood that children develop as part of distinct ecological settings and are influenced by family systems, social networks, community settings, parent child interactions as well as by direct intervention and teaching. See Bronfenbrenner. U. (1979), The Ecology of Human Development. USA: Harvard University Press.

Blacher, J., Baker, BL., (2002) The Best of AAMR: Families and Mental Retardation: A
 Collection of Notable AAMR Journal Articles across the 20th Century (383pp). Washington,
 DC: American Association on Mental Retardation.

<sup>&</sup>lt;sup>178</sup> "Moore, T., Larkin, H., (2005) More than my child's disability…": A comprehensive literature review about family centred practice and family experiences of early childhood intervention services Victoria, Australia Scope (Vic) Ltd.

- Don Bailey and colleagues at the Frank Porter Graham Centre at the University of North Carolina,<sup>181</sup> who developed approaches to train practitioners in family-centred practice
- Ann and Rud Turnbull and colleagues at the Beach Centre in Kansas, <sup>182</sup> who are parents of a child with a disability and focus on the relationship between parents and practitioners
- Mary Law and Peter Rosenbaum's team at the CanChild Centre for Childhood Disability Research at McMaster University in Canada, <sup>183</sup> who work primarily in rehabilitation settings and emphasise the importance of families receiving a range of general and specific information
- The Family Resource Coalition (now Family Support America), <sup>184</sup> who work with families in need of support. Their emphasis is on building on existing strengths of families and children rather than focusing on deficits.

<sup>179</sup> Dunst, C.J., Trivette, C.M. & Deal, A.G. (1988) Enabling and Empowering Families Cambridge, Massachusetts: Brookline Books

Dunst, C.J. (2000). Revisiting 'Rethinking Early Intervention' Topics in Early Childhood Special Education, 20(2), 95-104

<sup>181</sup> For example: I) Bailey, D.B., McWilliam, P.J., Winton, P.J., & Simeonsson, R.J. (1992). Implementing Family-Centred Services in Early Intervention: A Team-Based Model for Change Cambridge, Massachusetts: Brookline Books; 2) McWilliam, R.A. (1992). Family-Centred Intervention Planning: A Routines-Based Approach, Tucson, Arizona: Communication Skill Builders; 3) McWilliam, P.J. & Bailey, D.B. (1993). Working Together with Children and Families: Case Studies in Early Intervention Baltimore, Maryland: Paul H. Brookes. 4) McWilliam, P.J., Winton, P.J., & Crais, E.R. (1996) Practical Strategies for Family-Centered Intervention. San Diego, California: Singular Publishing Company; 5) Winton, P.J. (1992). Working with Families in Early Intervention: An Interdisciplinary Pre service Curriculum (2nd Ed.) Chapel Hill, North Carolina: Frank Porter Graham Child Development Center, University of North Carolina. <sup>182</sup> For example, I) Allen, R.I. and Petr, C.G. (1996) Towards developing standards and measurements for family-centered practice in family-support programs In G.H.S. Singer, L.E. Powers and A.L. Olson (Eds.) Redefining Family Support: Innovations in Public-Private Partnerships Baltimore, Maryland: Paul H. Brookes. 2) Turnbull, A.P., Turbiville, V. & Turnbull, H.R. (2000). Evolution of family-professional relationships: Collective empowerment for the early 21st century. In J.P. Shonkoff and S.J. Meisels. (Eds.). Handbook of Early Childhood Intervention (2nd Ed) Cambridge, UK: Cambridge University Press. 3); Turnbull, A.P. & Tunbull,

<sup>183</sup> Rosenbaum, P., King, S., Law, M., King, G. & Evans, J. (1998). Family-centred service: A conceptual framework and research review. Physical and Occupational Therapy in Paediatrics, 18 (1), 1-20.

Upper Saddle River, New Jersey: Merrill/Prentice Hall.

H.R. (2000). Families, Professionals and Exceptionality: Collaborating for Empowerment (4th Ed.).

<sup>184</sup> I) Family Resource Coalition. (1987). What are the assumptions of the Family Resource Movement? Chicago, Michigan: Family Resource Coalition. 2) Family Resource Coalition. (1996). Guidelines for Family Support Practice. Chicago, Michigan: Family Resource Coalition. (1997). Companion Guide to Guidelines for Family Support Practice.

As family-centred practice has become the accepted service philosophy in children's services, many other authors have contributed to furthering knowledge around early childhood intervention 185

This growing body of research links family-centred practice to positive child and family outcomes. <sup>186</sup> A meta-analysis of 18 studies showed that using family-centred practice improved self-efficacy beliefs, programme satisfaction, parent perceptions of child behaviour and functioning, and parenting behaviour. <sup>187</sup> Another meta-analysis of 47 different studies linked family-centred practice to greater family satisfaction, stronger family beliefs of self-efficacy and sense of control, and greater family perceptions of helpfulness of supports and services. <sup>188</sup>

Chicago, Michigan: Family Resource Coalition. 40 Dunst, C.J. (1995). Key characteristics and features of community-based family support programs. Chicago, Michigan: Family Resource Coalition

185 Baird, S. & Peterson, J. (1997). Seeking a comfortable fit between family-centred philosophy and infant parent interaction in early intervention: Time for a paradigm shift? Topics in Early Childhood Special Education 17(2), 139-164; Beckman, P.J. (2002). Providing family-centered services. In M.L. Batshaw (Ed.). Children with Disabilities (5th Ed.). Baltimore, Maryland: Paul H. Brookes; Beckman, P.I., Robinson, C.C., Rosenberg, S. & Filer, J. (1994). Family involvement in early intervention: The evolution, of family-centered service. In L.J. Johnson, R.J. Gallagher, M.J. LaMontagne, J.B. Jordan, J.J. Gallagher P.L. Hutinger and M.B. Karnes (Eds.). Meeting Early Intervention Challenges: Issues from Birth to Three (2nd. Ed.). Baltimore, Maryland: Paul H. Brooke; Epps, S. & Jackson, B.J. (2000). Empowered Families, Successful Children: Early Intervention Programs That Work. Washington, D.C.: American Psychological Corporation; McBride, S.L. (1999). Research in review: Family-centred practices. Young Children, 54(3), 62-70; Powell, I.Y. (1996). A schema for family-centred practice. Families in Society, 77(7), 446-448. 186 Research showing positive outcomes has been summarised by, for example, Moore, T., Larkin, H. (2005) in More than my child's disability, Scope, Victoria scopevic.org.au/mychild.pdf and Espe-Sherwindt, M. (2008) in Family-centred practice: collaboration, competency and evidence Support for Learning, 23 (3) p.1-9 familieswiki.pbworks.com/f/Family-Centred+Practice.pdf ) included Dunst, CJ., Trivette, CM. (2005) Characteristics and consequences of family-centred help-giving practices. Casemakers, I, 6, I-4. Access at www.fippcase.org/casemakers/casemakers\_vol1\_no6.pdf]; King, G., King, S., Rosenbaum, P. and Goffin, R. (1999) Family centered care-giving and well-being of parents of children with disabilities: linking process with outcome. Journal of Pediatric Psychology, 24, 1, 41-53; Wilson, LL., (2005) Characteristics and consequences of capacity building parenting supports. Casemakers, I, 4, I-3. fippcase.org/casemakers/casemakers voll no4.pdf

<sup>187</sup> Dunst, CJ., Trivette, CM., Hamby, DW. (2006) Family Support Program Quality and Parent, Family and Child Benefits. Asheville, NC: Winterberry Press as cited by Espe-Sherwindt, M. (2008)

Dunst, CJ., Trivette, CM., Hamby, DW. (2007) Meta analysis of family-centered help giving practices research. Mental Retardation and Developmental Disabilities Research Reviews, 13, 370–378

Based on the accumulating evidence of the benefits of family based practice, the US Council for exceptional children recommended the following: 189

- Families and professionals should share responsibility and work collaboratively
- Practices should strengthen family functioning
- Practices should be individualised and flexible
- Practices should be strengths-based.

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<sup>&</sup>lt;sup>189</sup> Moore, T., Larkin, H., (2005) More than my child's disability...": A comprehensive literature review about family centred practice and family experiences of early childhood intervention services Victoria, Australia Scope (Vic) Ltd.

## **Appendix 2:Teamwork**

### **Explaining teamwork**

The WHO (2010)<sup>190</sup> uses the term inter-professional collaboration (IPC)<sup>191</sup> to describe the situation of professions using a team approach with a common purpose and commitment. IPC is the process by which different professional groups work together to positively affect health.<sup>192</sup> A team approach involves 'formally coordinated service delivery, provided by various disciplinary professionals who collaborate to varying degrees to provide appropriate services'.<sup>193</sup>

Collaboration between different professionals can be defined as a style for direct interaction between at least two coequal parties, voluntarily engaged in sharing decision-making as they work towards a common goal. Principles to enable collaboration include:

- Form a committed team true commitment from all to work as a team
- Identify and work on a joint problem tap into each other's expertise
- Informal and formal exchanges which communicate roles
- Leadership –address institutional barriers, reflect on effectiveness of teamwork. 195

Regardless of the collaboration model used, the need for teamwork is built upon the assumption that no one profession or discipline has all of the necessary skills

<sup>&</sup>lt;sup>190</sup> World Health Organisation (2010) Framework for action on inter-professional education and collaborative practice. Geneva: WHO

<sup>&</sup>lt;sup>191</sup> Inter-professional collaboration is also known as inter-professional practice

<sup>&</sup>lt;sup>192</sup> Zwarenstein M., Goldman J. & Reeves S. (2009). Interprofessional collaboration: effects of practice-based interventions on professional practice and healthcare outcomes. Cochrane Database of Systematic Reviews, Issue 3. Art. No.: CD000072. DOI: 10.1002/14651858.CD000072.pub2.

<sup>&</sup>lt;sup>193</sup> Allen et al, 1997 as cited in Bell, A., Corfield, M., & Richardson, N. (2009). Collaborative transdisciplinary intervention in early years-putting theory in practice. Child: care, health and development, 36 (1), 142-148.

<sup>&</sup>lt;sup>194</sup> Friend, M., & Cook, L. (2007). Interactions: Collaboration skills for school professionals (5th ed.). Boston: Allyn and Bacon.

Boshoff, K. and Stewart, H. (2012), Key principles for confronting the challenges of collaboration in educational settings. Australian Occupational Therapy Journal. doi: 10.1111/1440-1630.12003

and knowledge to meet the complex needs of clients. <sup>196</sup> The goal of collaborative practice is that professionals from different disciplines work together and communicate frequently to optimize client care. The team should focus on achieving certain outcomes and overcoming problems. Each member contributes his or her knowledge and skill and takes into account the others' contributions to facilitate holistic management of a person's complex health problems. <sup>197</sup> The value of collaborative practice lies in its potential to offer multiple perspectives on clinical issues and create opportunities for enhancing collaborative care. <sup>198</sup>

While current thought and practice considers that inter-professional teams or IPC are more likely to provide consistent and continuous care to clients, the literature provides limited evidence of the actual impact of IPC on client care and outcomes. 199

Definitions of different kinds of teams along a continuum may be helpful. However, in reality, the actual process of team working is not clearly defined. In some instances, team members may find that they adopt different approaches depending on the needs of the client/client group. However, the concept of a continuum can be useful and may support team members to consider how they are functioning. The level of collaboration between team members is one of the defining criteria and perhaps, for some teams in the early stages of development, it may be helpful to consider how well they are doing around basic information sharing, providing feedback and consulting on shared care arrangements.<sup>200</sup>

Team development goes through the stages of forming, storming, norming and performing and training for teamwork has been shown to be effective in a range

hse.ie/eng/services/ysys/SUI/Library/participation/team.pdf

Interdisciplinary Team Work: A Discussion Paper for Social Workers nlasw.ca/pdf/Interdisciplinary Teamwork.pdf

<sup>&</sup>lt;sup>197</sup> Chan, A., BPharm, Wood, V. (2012) Preparing Tomorrow's Healthcare Providers for Interprofessional Collaborative Patient--Centred Practice Today UBCMJ | MARCH 2010 1(2) www.ubcmj.com

<sup>&</sup>lt;sup>198</sup> Hammick M. Interprofessional Education: Concepts, Theory and Application. Journal of Interprofessional Care 1998; 12(3): 323-332.

<sup>199</sup> Greiner AC, Knebel E, editors. Health Professions Education: A Bridge to Quality.

Washington, DC: Institute of Medicine of the National Academies; 2003.

<sup>&</sup>lt;sup>200</sup> IMPROVING TEAM WORKING A Guidance Document 2010.

of environments including commercial aviation and military operations  $^{201}$  and increasing client safety.  $^{202}$ 

#### Teamwork: Benefits and barriers

The potential benefits of teamwork are self-evident although there are also barriers to achieving effective teams. Benefits of teamwork to professionals and service users include:<sup>203</sup>

- Continuity of care
- The ability to take a comprehensive, holistic view of the service user's needs
- The availability of a range of skills and mutual support and education
- Support from colleagues is an important source of reward to team members

#### Barriers to teamwork include:

- Professional rivalry and mistrust
- Lack of support for team-working from key professionals and health managers/ administrators
- Confidentiality issues
- Lack of knowledge of what other health professionals do and what unique skills they have to offer
- Lack of training in team working is a significant barrier to effective teams.<sup>204</sup>

The NDA spoke to therapists in different parts of Ireland. A member of the Sligo EIT team reported on the joint experience of herself and her colleagues on interdisciplinary work:<sup>205</sup>

## Benefits of interdisciplinary work for the service user:

- · Reduced number of appointments
- Team communicating around the child
- Holistic approach

<sup>&</sup>lt;sup>201</sup> Medical teamwork and patient safety www.ahrq.gov/research/findings/final-reports/medteam/index.html

 $<sup>^{202}</sup>$  Manser, T (2009) Teamwork and patient safety in dynamic domains of healthcare: a review of the literature. Acta Anaesthesiol Scand. Feb; 53(2):143-51

<sup>&</sup>lt;sup>203</sup> ibid

<sup>&</sup>lt;sup>204</sup> ibid

<sup>&</sup>lt;sup>205</sup> Personal communication from Sligo EIT team

- Quality time, which can enable one therapist to explain session activities, while another therapist is working with the child
- Parents' awareness of multiple goals incorporated in one activity
- Children focus longer, as tasks are aimed at appropriate developmental level
- Better management of behavioural difficulties
- Good team working reduces parental anxiety and stress levels

#### Benefits of interdisciplinary work for therapists:

- Awareness of each other's roles and goals with children
- Holistic approach
- Shared responsibility e.g. anxious / demanding parents
- Overlap between areas of development
- Shared planning, evaluation of client and documentation
- Reduce number of phone calls, emails and correspondence
- Allows carryover of discipline specific goals or activities (annual leave, sick leave or one to one sessions, visits)
- Grounded understanding of goals in action
- Generating new activities which creates a more diverse work experience
- Positive mutual learning environment and ability to reflect within sessions momentarily while other therapist engaged with the child
- Good team working reduces stress levels of clinicians and creates a more positive working environment
- Joint note writing

## Benefits interdisciplinary work for Disability Services:

- Waiting lists- child removed by all disciplines at one time versus unidisciplinary segmented approach
- Clients goals are identified earlier enabling them to be addressed sooner and more appropriately
- Groups are generated more readily due to understanding of client's needs
- Priority of disciplines needed at specific times in the child's development
- Unrecognised areas of need create difficulties for uni-disciplinary working
- Sessions are more holistic and richer
- Ease of Scheduling service provision i.e. groups, school visits, preschool visits, assessment for education

 Good team working reduces stress levels of clinicians and creates a more positive working environment.

#### Drawbacks interdisciplinary work for therapists:

- Adapting to other clinicians and their way of working e.g. personality, education, approaches, experiences
- Ability to recognise discipline specific goals within sessions
- Co-therapist versus lead therapist being interchangeable and being comfortable with the change in roles
- Personal factors
- Role threatened
- Previous negative experiences of joint working
- Varying waiting lists
- Difficulty in communicating information to team members
- Regular meetings arranged to plan intervention and block common dates
- Mutual respect of preparation time and clean up time
- Trying to find common ground
- Discipline specific focus i.e. own agenda

## Drawbacks interdisciplinary work for Disability Services:

 Management of conflict and difficulties in establishing team working and joint goal setting

In 2006, the Mental Health Commission in Ireland concluded that research supports teamwork as the most effective means of delivering a comprehensive mental health service. In 2010, the HSE published 'Improving team working; a guidance document', as part of the commitment by the HSE Organisational Change Function within Human Resources, to develop materials to build capacity to manage change and promote service improvement. 207

## Types of teams

Multidisciplinary teams 'share common goals but work independently. Therapists act within their professional domains and interact only formally with other team

<sup>&</sup>lt;sup>206</sup> MHC (2006) A discussion paper on Multidisciplinary Team Working: From Theory to Practice MHC Dublin mhcirl.ie/File/discusspapmultiteam.pdf

The guidance has been developed by Caitríona Heslin and Anne Ryan based on applied work in the Dublin North East region. hse.ie/eng/services/ysys/SUI/Library/participation/team.pdf

members e.g. in meetings.<sup>208</sup> Parents receive information related to a specific area of development and a plan is drawn up which relates to a specific discipline.<sup>209</sup> The low level of interaction among team members can result in the child and family providing identical information to multiple professionals. Service planning and delivery may not be based on a comprehensive, holistic understanding of the child and family's strengths and needs.<sup>210</sup>

Interdisciplinary teams share common goals and communicate with each other and with families with whom they work. Interaction is planned within the team. There are formal arrangements for communication, assessment, planning and intervention. There is increased parental involvement. While each professional may deliver services independently, assessment and intervention results are shared and discussed among the team members. This model requires that team members share core skills in areas such as counselling, family support work, communication and working with parents. Families meet with the whole team, sub-groups of it or a team representative. Interdisciplinary work facilitates the exchange of information among team members. While team members act within their professional domains, they collaborate actively and frequently in planning and implementing interventions. Each member of the interdisciplinary team takes responsibility for coordinating their information and intervention with that of other members of the team. All team members are considered to have equally valued status.

Trans-disciplinary teams share common goals and use a systematic process for sharing roles and crossing disciplinary boundaries to maximise communication,

<sup>&</sup>lt;sup>208</sup> Speech-Language Pathology Services in Schools: Guidelines for Best Practice, 2011

<sup>&</sup>lt;sup>209</sup> Tuchman, L. (1996). in Rosin, P., Whitehead, A., Tuchman, L., Jesien, G., Begun, A. and Irwin, L. (1996). Partnerships in Family Centred Care - A Guide to Collaborative Early Intervention Maryland: Brookes

<sup>&</sup>lt;sup>210</sup> Early Intervention Therapy Program Guidelines, 2009.

<sup>&</sup>lt;sup>211</sup> Tuchman, L. (1996). in Rosin, P., Whitehead, A., Tuchman, L., Jesien, G., Begun, A. and Irwin, L. (1996). Partnerships in Family Centred Care - A Guide to Collaborative Early Intervention Maryland: Brookes

Reilly, C. (2001). Transdisciplinary approach: An atypical strategy for improving outcomes in rehabilitative and long-term acute care settings. Rehabilitation Nursing, 26(6), 216–220, 244. Reilly, 2001

<sup>&</sup>lt;sup>213</sup> Dale, N. (1996) Working with Families of Children with Special Needs, Partnership and Practice. London: Routledge Dale; Widerstrom, A H., Mowder, B.B. and Sadall, S. R., (1991). At risk, Handicapped Newborns and Infants: development assessment and intervention. Prentice Hall; NJ.

<sup>&</sup>lt;sup>214</sup> Early Childhood Intervention Progress and Developments 2005-2010

<sup>&</sup>lt;sup>215</sup> Virginia Department of Education, Office of Special Education and Student Services (2011) Speech-Language Pathology Services in Schools: Guidelines for Best Practice

interaction and co-operation. Therapists produce a single integrated intervention plan. Individual disciplines contribute according to the agreed needs of the child. This approach provides a framework for professionals to share and integrate the expertise of the team members.<sup>216</sup> Decisions are made by consensus and family participation is crucial.<sup>217</sup> One professional may work as a key-worker with the family. The parents are included as team-members. It is assumed that all team members, including the person with the disability and his/her family, will contribute to an intervention plan tailored to the needs of the child and family. Unlike any of the other teams, in the trans-disciplinary approach the potential also exists for the 'case manager' to be the person with a disability or a parent or carer.<sup>218</sup> Taking on a case manager role helps to achieve continuity of care over the long term and a focus on the individual's needs in the process. Management of one's own care needs also leads to self-advocacy, self-determination, independence and full participation. Trans-disciplinary working demands close team communication.<sup>219</sup> Team members overlap and cross over traditional roles. Boundaries between the roles of team members are blurred.<sup>220</sup> The characteristics of trans-disciplinary teams include:<sup>221</sup>

- · Interdependence across disciplines and with clients
- Integrated interventions with an emphasis on natural settings
- Functional goals
- A holistic approach to the person/family and others supporting them
- Family-centred and culturally appropriate practice.

Such partnerships and teamwork require "abdication of paternalistic approaches in favour of collaborative relationships, empowerment, participatory involvement

<sup>&</sup>lt;sup>216</sup> Bell, A., Corfield, M., & Richardson, N. (2009). Collaborative transdisciplinary intervention in early years-putting theory in practice. Child: care, health and development, 36 (1), 142-148.

<sup>217</sup> Tuchman, L. (1996). in Rosin, P., Whitehead, A., Tuchman, L., Jesien, G., Begun, A. and Irwin, L. (1996). Partnerships in Family Centred Care - A Guide to Collaborative Early Intervention Maryland: Brookes

<sup>&</sup>lt;sup>218</sup> Koskie, J. & Freeze, R. (2000). A critique of multidisciplinary teaming: Problems and possibilities. Developmental Disabilities Bulletin, 28(1): I-I7 as cited in Bundy, A., Hemsley, B., Brentnall, J., & Marshall, E., (2008). Therapy Services in the Disability Sector: Literature Review. NSW Department of Ageing, Disability and Home Care.

adhc.nsw.gov.au/\_\_data/assets/file/0007/228139/10\_Therapy\_Services\_Disability\_Sector.pdf North Tipperary Early Intervention Service (2006)

Wooster, 2001 Speech-Language Pathology Services in Schools: Guidelines for Best Practice, 2011).

<sup>&</sup>lt;sup>221</sup> ASHA, 2006; Koskie & Freeze, 2000) (Speech-Language Pathology Services in Schools: Guidelines for Best Practice, 2011).

and competency enhancement approaches."<sup>222</sup> It involves "a move away from the expert model of professionals gathering information and making decisions about service provision."<sup>223</sup> Collaborative consultation differs from expert consultation, where a professional evaluates needs, develops interventions, and provides one-on-one intervention or makes recommendations to school staff. Collaborative consultation can be coordinated within the routines of the special education or regular education classroom.<sup>224</sup>

#### Developing services for children with disabilities

The trend in service delivery in home, healthcare and school settings is moving to one where the child, the family and a range of professionals and agencies work together and share decision-making. Allied health professionals and other health professionals caring for children with disabilities and complex needs in community settings, need to recognise the importance of information sharing: This requires a climate of inter-professional trust and mutual respect and requires arrangements like the co-location of health and social care professionals. "If partnership working is valued and valid, there has to be an identifiable outcome for children and young people, which is more than what would be gained by services being provided separately. This has been described as collaborative advantage and this concept should be central to evaluating the impact and outcomes for young people which are the result of partnership working". <sup>226</sup>

Children and young people with disabilities often require services and support from a range of agencies and from various disciplines prior to school as well as during their school years, so services delivered using inter-professional

Dunst, C., Trivette, C. and Johanson C. (1994). Parent Professional Collaboration and Partnerships. (in) Dunst, C. Trivette, C. and Deal, A. (Eds.). Supporting and Strengthening Families: Vol. I. Methods Strategies and Practices, Cambridge, MA: Brookline Books. pp. 197-211

<sup>&</sup>lt;sup>223</sup> Walls, M., O' Connor, M (20040 Building Blocks to Best Practice Introducing an "Integrated Holistic Model" of Early Intervention with Children and Families. www.cecde.ie/gaeilge/pdf/Questions%20of%20Quality/Walls.pdf

<sup>&</sup>lt;sup>224</sup> Bober, P. Corbett, S (2011) Occupational Therapy and Physical Therapy: A Resource and Planning Guide Second Edition Wisconsin Department of Public Instruction Madison, Wisconsin sped.dpi.wi.gov/files/sped/pdf/ot-pt-guide-2nd-edition.pdf

<sup>&</sup>lt;sup>225</sup> Law, J., McCann, D., O'May, F., Smart, C., Buchan, J., (2009) Service Provision for Children and Young People with Complex Needs in a Community Setting from The Perspectives of Nursing and Allied Health Professionals www.scotland.gov.uk/Publications/2009/06/05154149/0

<sup>&</sup>lt;sup>226</sup>The Scottish Government (2010) Guidance on partnership working between allied health professions and education Scottish Government Edinburgh - www.scotland.gov.uk/Resource/Doc/313416/0099357.pdf

collaboration could be more efficient. There is evidence that inter-professional collaboration:<sup>227</sup>

- Improves workplace quality by creating a collaborative culture between professions
- Increases provider satisfaction by improving provider roles, inter-professional collaboration and/or quality of care
- Reduces the cost of patient care
- Enhances the quality of the workplace and increases provider satisfaction and attracts graduates to rural areas so is an effective health human resources planning and management strategy.<sup>228</sup>

Internationally, there is agreement that the way forward is to develop population-based, collaborative person-centred services that deliver relevant, timely, cost-effective and efficient services to everyone that needs them. In Scotland, a 2003 report<sup>229</sup> recommended:

- Local Authorities and the NHS should develop integrated approaches to the provision of therapy and other related interventions for children
- AHP professional bodies, NHS Boards and Local Authorities should work in partnership
- The structure and skill mix within individual therapy professions should be reviewed to ensure effective and efficient use of resources and ability to meet demand
- The funding for Speech and Language Therapy to education authorities for pupils with 'Records of Needs' should be integrated with funding for SLT to other children
- A systematic approach to workforce analysis and development should be adopted for paediatric therapists and other therapists working with children

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<sup>227</sup> ibid

<sup>&</sup>lt;sup>228</sup> Suter, E., Deutschlande, S., Mickelson, G., Nurani, Z., Lait, J., Harrison, L., Jarvis-Selinger, S., Bainbridge, L., Achilles, S., Ateah, C., Ho K, Grymonpre. R. (2012) Can inter-professional collaboration provide health human resources solutions? A knowledge synthesis. Journal Interprofessional Care., 26(4), 261-8 and Suter, E., Deutschlander, S (2010) Can inter-professional collaboration provide health human resources solutions? Western Canadian Inter-professional Health Collaborative (WCIHC) www.cihc.ca/wcihc/pdfs/FinalSynthesisReportMarch2010.pdf <sup>229</sup>Scottish Executive Review of Speech and Language Therapy, Physiotherapy and Occupational Therapy for Children and Speech and Language Therapy for Adults with Learning Disabilities and Autistic Spectrum Disorder, 2003, scotland.gov.uk/Publications/2003/08/18066/25805

 Strategic planning arrangements need to be established to ensure the involvement of key stakeholders and effective and efficient delivery of services by therapists.

In 2005, the European Agency for Development in Special Needs Education produced The Early Childhood Intervention Analysis of Situations in Europe Report. Drawing on effective services in 19 European countries, the report recommended five key aspects that contribute to effective outcomes for children with a disability: <sup>230</sup>

- Interdisciplinary work
- Coordination of health, education and social sectors
- · Availability of services
- Proximity
- Affordability.

The purpose of developing children's services in this way is to benefit children by

- Empowering children and their families
- Achieving more responsive services
- Improving access to specialist services
- Avoiding multiple assessments
- Reducing waiting times.<sup>231</sup>

Some research on teams in the health and social care services

In the UK in 1999 a report, the Effectiveness of Health Care Teams in the National Health Service (NHS), was published. Lt contained a literature review on the benefits of team work and research results analysing relationships between inputs and processes, inputs and outputs and processes and outputs in 390 UK NHS teams and 7,000 NHS personnel. In addition, NHS clients were consulted. The theoretical model used to guide the research and understand team functioning comprised:

 $<sup>^{230}\</sup> www.european-agency.org/publications/ereports/early-childhood-intervention/eci\_en.pdf$ 

<sup>&</sup>lt;sup>231</sup> Miller, C., McNicholl, A (2003) Integrating children's services: issues and practices. London, Office for Public Management Ltd

<sup>&</sup>lt;sup>232</sup> Borrill, CS., Carletta, J., Carter, AJ., Dawson, JF., Garrod, S., Rees, A., Richards, A., Shapiro, D., West, MA (1999) The Effectiveness of Health Care Teams in the National Health Service. homepages.inf.ed.ac.uk/jeanc/DOH-final-report.pdf
<sup>233</sup> ibid

- Group processes such as leadership, clarity of objectives, participation, task orientation, support for innovation, reflexivity, decision making, integration and communication
- Inputs such as health service environment, organisational context, team task and team composition
- Outputs such as overall effectiveness, clinical outcomes, team member mental health, innovation, team member turnover, and cost effectiveness.

#### Findings from this research included:

- Health care teams were more effective and innovative across virtually all domains of functioning the clearer the team's objectives and the higher the level of
  - participation in the team
  - commitment to quality
  - support of innovation
- Those working in teams had better mental health than those working in looser groups or working individually. The benefits appeared to be due to:
  - Greater role clarity
  - Better peer support
  - Buffering from the negative effects of organisational climate and conflict
- Those working in well functioning health care teams were more likely to stay working in these settings than professionals in poorly functioning teams
- Communication, integration and regular meetings in Primary Health Care and Community Mental Health were associated with higher levels of effectiveness and innovation, yet the quality of meetings was often poor
- Diversity of professional groups in Primary Health Care was linked to high levels of team innovation. In newly formed Community Mental Health Teams, this relationship did not appear
- Where there was no clear leader or where there was conflict over leadership in Community Mental Health and Primary Health Care, team objectives were unclear and there were low levels of effectiveness, innovation, participation and commitment to quality and poor team member mental health<sup>234</sup>

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<sup>&</sup>lt;sup>234</sup> ibid

• Bigger teams experienced greater strains on effective communication. While in most sectors, teams tend to be divided once they reach 12 or 13 members, some of the health care teams were 20, 30 or more members in size. These would be more correctly termed 'organisations': In and of itself, this would not be a problem, if there were people adequately trained to manage large operations and there was effective leadership.<sup>235</sup>

Education/training for inter-professional collaboration (IPC)/teamwork If health care professionals are to work together and share expertise in a team environment, it makes sense that their education and training should prepare them for effective teamwork.<sup>236</sup> While changes in education and training have taken place, a considerable proportion of training and practice in various health disciplines continues in the medical model so therapists' actions tend to be less team based, person-centred, family-centred and strengths-based than is required.<sup>237</sup>

The Canadian Inter-professional Health Collaborative has identified the following competencies necessary for inter-professional collaboration in their newly emerging national competency framework:<sup>238</sup>

- Understanding one's own role, the roles of those in other professions, and using this knowledge appropriately to establish and meet patients' goals
- Integrating and valuing, as a partner, the input, and the engagement of patients and families in designing and implementing care
- Understanding the principles of team dynamics and group processes to enable effective inter-professional team collaboration
- Understanding and applying leadership principles that support a collaborative practice model
- Communicating with other professionals in a collaborative, responsive and responsible manner

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<sup>&</sup>lt;sup>235</sup> ibid

<sup>&</sup>lt;sup>236</sup> Romanow RJ. Building on Values: The Future of Health Care in Canada. Ottawa: Commission on the Future of Health Care in Canada; 2002.

Bundy, A., Brentnall, B., Hemsley, B., Marshall, E. (2008) Therapy Services in the Disability Sector: Literature Review NSW Department of Ageing, Disability and Home Care (p. 60)

Canadian Interprofessional Health Collaborative (CIHC). A National Inter-professional Competency Framework: Draft for Discussion. 2009. Unpublished as cited in Chan, A., BPharm, Wood, V. (2012) Preparing Tomorrow's Healthcare Providers for Interprofessional Collaborative Patient--Centred Practice Today UBCMJ | MARCH 2010 1(2) ubcmj.com

 Actively engaging self and others in positively and constructively addressing inter-professional conflict.

The literature confirms that skills and attitudes necessary for teamwork between professionals should be introduced at the undergraduate level. <sup>239</sup> It is suggested that this should be through inter-professional education and practical experience as well as through modelling of inter-professional collaboration at the faculty level. While this need is acknowledged, to some degree, within the health disciplines, it is not often addressed across different sectors e.g. health and education. The literature stresses that training and support is required at both undergraduate and postgraduate/professional level to foster methods and strategies to support effective team functioning. <sup>240</sup>

Inter-professional education (IPE) brings students from different disciplines together to learn with, from and about each other. By engaging in IPE that is explicit, interactive, and relevant to their future practice, students can:<sup>241</sup>

- Learn new knowledge and develop new abilities;
- Develop the interpersonal skills needed to work with others;
- Gain experience working in team settings in which group members share common goals; and
- Learn how to work with others to maximize the performance and output of the group.

While measuring changes in skills, knowledge, and attitudes is a complex issue, many benefits to students have been reported as a result of inter-professional training programs. Students who participate in IPE activities show increases in knowledge about the roles of other health professionals, have a greater respect for the contribution of other health care professionals, and understand the

Collaborative Patient--Centred Practice Today UBCMI | MARCH 2010 I(2) www.ubcmj.com

<sup>&</sup>lt;sup>239</sup> Hillier SL, Civetta L, Pridham L. A Systematic Review of Collaborative Models for Health and Education Professionals Working in School Settings and Implications for Training. Education for Health 10 (online), 2010: 393. educationforhealth.net

Webb N. Group Collaboration in Assessment: Multiple objectives, processes and outcomes. Educational Evaluation and Policy Analysis. 1995 Summer; 17(2):239-261 as cited in Chan, A., BPharm, Wood, V. (2012) Preparing Tomorrow's Healthcare Providers for Interprofessional Collaborative Patient--Centred Practice Today UBCMJ | MARCH 2010 I(2) www.ubcmj.com Stone N, Sims J, McNair R, Nesbitt P. Education for a sustainable rural workforce by building team working capacity [Online]. 2002 [cited 2009 Oc 7]. gp.unimelb.edu.au/research/ripe/RIPEWONCApaperFinal.doc as cited in Chan, A., BPharm, Wood, V. (2012) Preparing Tomorrow's Healthcare Providers for Interprofessional

importance of working collaboratively to achieve optimal health outcomes. <sup>243</sup> Through IPE, students can develop competencies that will enable them to work collaboratively throughout their chosen careers. Therefore, the need to define the essential competencies required for collaborative practice and to develop and implement educational interventions to ensure their adoption is widely recognised. <sup>244</sup>

#### Developing teamwork skills in the health services

"Teams hold the potential to improve the value of health care, but to capture the full potential of team-based care, institutions, organizations, governments, and individuals must invest in people and processes that lead to improved outcomes. To target expenditures and plan wisely for outcome-oriented team-based care, top priorities should be the targeting of team-based care to situations in which it promotes the most efficiency, effectiveness and patient engagement (including shared decision making)".<sup>245</sup>

There are different approaches to optimising Human Resources (HR) in healthcare: Policy-makers and managers use different methods and initiatives to optimise the available workforce and achieve the right number and mix of personnel needed to provide care. A literature review found that initiatives (such as staff-mix, number of personnel, mixing qualifications, balancing junior and senior staff, mixing disciplines, skill flexibility such as role substitution) often focus more on staff types than on staff members' skills and the effective use of those skills. <sup>246</sup>

To use human resources most effectively, health care organisations should consider an approach that accounts for factors beyond narrowly-defined HR

<sup>&</sup>lt;sup>243</sup> Dalton L, Spencer J, Dunn M, Albert E, Walker J, Farrell G. Re-thinking approaches to undergraduate health professional education: Interdisciplinary rural placement program. Collegian 2003; 10(1): 17-21 and Slack M, Cummings DM, Borrego ME, Fuller K, Cook S. Strategies used by interdisciplinary rural health training programs to assure community responsiveness and recruit practitioners. Journal of Interprofessional Care 2002; 16(2): 129-38.

Wood V, Flavell A, Vanstolk D, Bainbridge L, Nasmith. The road to collaboration: Developing an interprofessional competency framework. Journal of Interprofessional Care 2009; 23(6): 621-629.

<sup>&</sup>lt;sup>245</sup> Mitchell, P., Wynia, M., Golden, G., McNellis, B., Okun, S., Edwin Webb, C., Rohrbach, V., Von Kohorn, I. (2012) Core principles and values of effective team-based healthcare. http://www.iom.edu/~/media/Files/Perspectives-Files/2012/Discussion-Papers/VSRT-Team-Based-Care-Principles-Values.pdf

<sup>&</sup>lt;sup>246</sup> Dubois, CA., Singh, D. (2009) From staff-mix to skill-mix and beyond: towards a systemic approach to health workforce management http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2813845/

management practices and which also include organisational and institutional conditions." <sup>247</sup> "The evidence suggests that no matter which workers are employed or what their roles are, it is by tackling organisational issues (structures, management, resources, professional development opportunities) that an efficient and effective workforce can be generated". <sup>248</sup> For example: <sup>249</sup>

- Organisation-level factors that support teamwork such as organisational structures, management/strategies, and resources/tools strongly influence both the development of health care teams' collaborative practices as well as their outcomes
- Organisational characteristics that foster empowerment, decision ownership, job autonomy/discretion and participation boost healthcare workers' productivity by engaging them in a responsible and responsive manner
- A climate high in autonomy and supportiveness is positively related to job performance
- Managerial style, evaluation and reward systems, accountability, decision latitude, and opportunities for employee may all influence an individual worker's level of commitment and motivation, and, therefore, levels of skills retention, skills utilisation, and skills development across an entire workforce
- Health care workers may also be more motivated to perform well if
  organisations and managers provide a clear sense of vision and mission,
  increase staff members' participation in decision-making, encourage
  teamwork, foster innovation, provide career structures and opportunities for
  promotion, and use available sanctions for poor performance in ways that are
  fair and consistent.

<sup>249</sup> Dubois, CA., Singh, D. (2009) From staff-mix to skill-mix and beyond: towards a systemic approach to health workforce management ncbi.nlm.nih.gov/pmc/articles/PMC2813845

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Dubois, CA., Singh, D. (2009) From staff-mix to skill-mix and beyond: towards a systemic approach to health workforce management ncbi.nlm.nih.gov/pmc/articles/PMC2813845/
 P.14. ibid

# Appendix 3: Census data 2006 and 2011 compared

Comparing Census 2011 with the data from Census 2006 show that there are differences between the two censuses in the age-specific prevalence of disability recorded, which cannot be fully explained by the differences in a number of the disability questions as between the two periods.<sup>250</sup> That upward drift may be attributable to more children on the borderline being included in the disability category in 2011 than in 2006 – it seems less likely that children with substantial support needs would have been classed differently in the two Census years.<sup>251</sup> So census figures on children with a disability need to be treated with some caution given this fluidity.

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<sup>&</sup>lt;sup>250</sup> Census 2006 had 'blindness or severe vision impairment' and 'deafness or a severe hearing impairment' in a single category whereas they were two separate categories in 2011. Intellectual and learning disability constituted a single category in 2006, but formed two separate categories in 2011.

<sup>&</sup>lt;sup>251</sup> The proportion of children aged 0-19 recorded with a disability rose from 4.1% in 2006 to 8.1% in 2011. Those recorded with an emotional, psychological or mental health condition rose from 0.5% to 1.5% between 2006 and 2011, those with learning OR intellectual disability increased from 2.5% to 4.4% and the proportion in the 'other illness or disability' category rose from 1% to 2.5%, and those recorded with physical disabilities rose from 0.5% to 0.8%. On the other hand, the proportion with difficulty dressing, bathing or getting around inside the home – those with more severe levels of impairment – remained stable between 2006 and 2011 at 0.6%.

# Table 33 Comparison between Census 2006 and Census 2011 prevalence of childhood disability by category

While changes in some wording took place in 2011, and some combined categories were split, the shaded areas show % differences in recorded prevalence for equivalent categories in 2006 and 2011. While small increases in prevalence are shown for 0-19 year olds in each category, learning disability seems to be the main driver, followed by the 'other chronic disability or illness' category

	Pwd 2006	Pwd 2011	2011 less 2006	Blind et c & deaf etc 2006	blind etc 2011	Deaf etc 2011	blind & deaf rates 2011 less 2006	phys 2006	phys 2011	phys 2011 less 2006	learning or ID 2006	ID 2011	Learning 2011	2011 less 2006 ID+Learn	m health 2006	M health 2011	m health 2011 less 2006	Other 2006	Other 2011	Other 2011 less other 2006
Under I	1.0%	1.6%	0.6%	0.2%	0.1%	0.1%	0.0%	0.2%	0.4%	0.2%	0.3%	0.3%	0.2%	0.2%	0.1%	0.1%	0.0%	0.4%	0.6%	0.2%
l year	1.3%	2.1%	0.8%	0.2%	0.1%	0.1%	0.0%	0.4%	0.6%	0.2%	0.4%	0.4%	0.3%	0.4%	0.1%	0.1%	0.0%	0.6%	0.9%	0.3%
2 years	1.6%	2.7%	1.1%	0.3%	0.2%	0.2%	0.0%	0.5%	0.6%	0.2%	0.6%	0.6%	0.6%	0.6%	0.1%	0.2%	0.1%	0.7%	1.2%	0.5%
3 years	2.2%	3.5%	1.3%	0.4%	0.2%	0.2%	0.1%	0.5%	0.7%	0.2%	0.9%	0.9%	1.0%	1.0%	0.2%	0.4%	0.2%	0.8%	1.6%	0.8%
4 years	2.7%	4.4%	1.7%	0.4%	0.3%	0.3%	0.1%	0.5%	0.8%	0.3%	1.3%	1.1%	1.5%	1.4%	0.3%	0.6%	0.3%	0.9%	1.9%	0.9%
5 years	3.3%	4.9%	1.7%	0.5%	0.4%	0.3%	0.2%	0.6%	0.8%	0.2%	1.6%	1.3%	1.9%	1.6%	0.4%	0.8%	0.4%	1.0%	2.0%	1.0%
6 years	3.7%	5.6%	1.9%	0.6%	0.4%	0.4%	0.3%	0.6%	0.8%	0.2%	2.0%	1.4%	2.4%	1.8%	0.4%	0.9%	0.5%	1.1%	2.1%	1.0%
7 years	4.0%	6.1%	2.1%	0.5%	0.4%	0.4%	0.3%	0.5%	0.8%	0.3%	2.3%	1.5%	3.0%	2.2%	0.5%	1.0%	0.5%	1.1%	2.1%	1.0%
8 years	4.7%	6.6%	2.0%	0.6%	0.5%	0.4%	0.2%	0.6%	0.7%	0.1%	2.9%	1.7%	3.5%	2.3%	0.6%	0.9%	0.3%	1.1%	2.0%	0.9%
9 years	5.2%	7.3%	2.0%	0.6%	0.5%	0.4%	0.2%	0.6%	0.8%	0.1%	3.4%	1.9%	4.0%	2.5%	0.5%	1.1%	0.6%	1.1%	2.1%	1.0%
10 years	5.7%	7.6%	1.9%	0.6%	0.5%	0.4%	0.3%	0.6%	0.8%	0.2%	3.9%	2.0%	4.3%	2.4%	0.6%	1.1%	0.5%	1.2%	2.2%	0.9%
II years	5.9%	7.7%	1.8%	0.6%	0.5%	0.4%	0.3%	0.6%	0.8%	0.2%	4.1%	2.0%	4.3%	2.2%	0.6%	1.1%	0.5%	1.2%	2.2%	1.0%
12 years	6.0%	7.6%	1.6%	0.6%	0.4%	0.3%	0.2%	0.6%	0.7%	0.1%	4.1%	1.9%	4.4%	2.2%	0.6%	1.0%	0.4%	1.2%	2.1%	0.8%
13 years	5.8%	7.9%	2.1%	0.6%	0.5%	0.4%	0.3%	0.6%	0.7%	0.2%	4.0%	1.9%	4.5%	2.5%	0.5%	1.0%	0.5%	1.2%	2.1%	1.0%
14 years	5.7%	7.9%	2.2%	0.5%	0.4%	0.4%	0.3%	0.5%	0.7%	0.2%	3.8%	1.8%	4.6%	2.6%	0.6%	1.1%	0.5%	1.1%	2.2%	1.1%
15 years	5.7%	8.1%	2.4%	0.6%	0.5%	0.4%	0.3%	0.6%	0.8%	0.2%	3.7%	2.0%	4.6%	2.9%	0.6%	1.1%	0.5%	1.1%	2.1%	1.0%
16 years	5.0%	7.7%	2.7%	0.5%	0.5%	0.4%	0.4%	0.6%	0.8%	0.2%	3.2%	1.8%	4.1%	2.8%	0.6%	1.1%	0.5%	1.0%	2.1%	1.1%
17 years	4.7%	7.9%	3.3%	0.5%	0.4%	0.4%	0.4%	0.6%	0.8%	0.1%	2.8%	1.9%	4.2%	3.2%	0.6%	1.3%	0.7%	1.0%	2.1%	1.1%
18 years	4.8%	8.2%	3.4%	0.7%	0.5%	0.4%	0.2%	0.7%	0.8%	0.1%	2.7%	1.9%	4.2%	3.4%	0.6%	1.2%	0.6%	1.1%	2.3%	1.2%

	Pwd 2006	Pwd 2011	2011 less 2006	Blind et c & deaf etc 2006	blind etc 2011	Deaf etc 2011	blind & deaf rates 2011 less 2006	phys 2006	phys 2011	phys 2011 less 2006	learning or ID 2006	ID 2011	Learning 2011	2011 less 2006 ID+Learn	m health 2006	M health 2011	m health 2011 less 2006	Other 2006	Other 2011	Other 2011 less other 2006
19 years	4.6%	8.1%	3.6%	0.6%	0.5%	0.4%	0.3%	0.7%	0.8%	0.2%	2.2%	1.8%	3.7%	3.2%	0.8%	1.5%	0.7%	1.2%	2.5%	1.3%
0-19	4.1%	6.0%	1.9%	0.5%	0.4%	0.3%	0.2%	0.5%	0.7%	0.2%	2.5%	1.5%	2.9%	1.9%	0.5%	0.8%	0.4%	1.0%	1.9%	0.9%

# Table 34: Comparison between Census 2006 and Census 2011 prevalence of childhood disability by category

While changes in some wording took place in 2011, and some combined categories were split, the shaded areas show % differences in recorded prevalence for equivalent categories in 2006 and 2011. While small increases in prevalence are shown for 0-19 year olds in each category, learning disability seems to be the main driver, followed by the 'other chronic disability or illness' category

	Pwd 2006	Pwd 2011	2011 less 2006	Blind et c & deaf etc 2006	blind etc 2011	Deaf etc 2011	blind & deaf rates 2011 less 2006	phys 2006	phys 2011	phys 2011 less 2006	learning or ID 2006	ID 2011	Learning 2011	2011 less 2006 ID+Learn	m health 2006	M health 2011	m health 2011 less 2006	Other 2006	Other 2011	Other 2011 less other 2006
Under I	1.0%	1.6%	0.6%	0.2%	0.1%	0.1%	0.0%	0.2%	0.4%	0.2%	0.3%	0.3%	0.2%	0.2%	0.1%	0.1%	0.0%	0.4%	0.6%	0.2%
I year	1.3%	2.1%	0.8%	0.2%	0.1%	0.1%	0.0%	0.4%	0.6%	0.2%	0.4%	0.4%	0.3%	0.4%	0.1%	0.1%	0.0%	0.6%	0.9%	0.3%
2 years	1.6%	2.7%	1.1%	0.3%	0.2%	0.2%	0.0%	0.5%	0.6%	0.2%	0.6%	0.6%	0.6%	0.6%	0.1%	0.2%	0.1%	0.7%	1.2%	0.5%
3 years	2.2%	3.5%	1.3%	0.4%	0.2%	0.2%	0.1%	0.5%	0.7%	0.2%	0.9%	0.9%	1.0%	1.0%	0.2%	0.4%	0.2%	0.8%	1.6%	0.8%
4 years	2.7%	4.4%	1.7%	0.4%	0.3%	0.3%	0.1%	0.5%	0.8%	0.3%	1.3%	1.1%	1.5%	1.4%	0.3%	0.6%	0.3%	0.9%	1.9%	0.9%
5 years	3.3%	4.9%	1.7%	0.5%	0.4%	0.3%	0.2%	0.6%	0.8%	0.2%	1.6%	1.3%	1.9%	1.6%	0.4%	0.8%	0.4%	1.0%	2.0%	1.0%
6 years	3.7%	5.6%	1.9%	0.6%	0.4%	0.4%	0.3%	0.6%	0.8%	0.2%	2.0%	1.4%	2.4%	1.8%	0.4%	0.9%	0.5%	1.1%	2.1%	1.0%
7 years	4.0%	6.1%	2.1%	0.5%	0.4%	0.4%	0.3%	0.5%	0.8%	0.3%	2.3%	1.5%	3.0%	2.2%	0.5%	1.0%	0.5%	1.1%	2.1%	1.0%
8 years	4.7%	6.6%	2.0%	0.6%	0.5%	0.4%	0.2%	0.6%	0.7%	0.1%	2.9%	1.7%	3.5%	2.3%	0.6%	0.9%	0.3%	1.1%	2.0%	0.9%
9 years	5.2%	7.3%	2.0%	0.6%	0.5%	0.4%	0.2%	0.6%	0.8%	0.1%	3.4%	1.9%	4.0%	2.5%	0.5%	1.1%	0.6%	1.1%	2.1%	1.0%
10 years	5.7%	7.6%	1.9%	0.6%	0.5%	0.4%	0.3%	0.6%	0.8%	0.2%	3.9%	2.0%	4.3%	2.4%	0.6%	1.1%	0.5%	1.2%	2.2%	0.9%
II years	5.9%	7.7%	1.8%	0.6%	0.5%	0.4%	0.3%	0.6%	0.8%	0.2%	4.1%	2.0%	4.3%	2.2%	0.6%	1.1%	0.5%	1.2%	2.2%	1.0%
12 years	6.0%	7.6%	1.6%	0.6%	0.4%	0.3%	0.2%	0.6%	0.7%	0.1%	4.1%	1.9%	4.4%	2.2%	0.6%	1.0%	0.4%	1.2%	2.1%	0.8%
13 years	5.8%	7.9%	2.1%	0.6%	0.5%	0.4%	0.3%	0.6%	0.7%	0.2%	4.0%	1.9%	4.5%	2.5%	0.5%	1.0%	0.5%	1.2%	2.1%	1.0%
14 years	5.7%	7.9%	2.2%	0.5%	0.4%	0.4%	0.3%	0.5%	0.7%	0.2%	3.8%	1.8%	4.6%	2.6%	0.6%	1.1%	0.5%	1.1%	2.2%	1.1%
15 years	5.7%	8.1%	2.4%	0.6%	0.5%	0.4%	0.3%	0.6%	0.8%	0.2%	3.7%	2.0%	4.6%	2.9%	0.6%	1.1%	0.5%	1.1%	2.1%	1.0%
16 years	5.0%	7.7%	2.7%	0.5%	0.5%	0.4%	0.4%	0.6%	0.8%	0.2%	3.2%	1.8%	4.1%	2.8%	0.6%	1.1%	0.5%	1.0%	2.1%	1.1%
17 years	4.7%	7.9%	3.3%	0.5%	0.4%	0.4%	0.4%	0.6%	0.8%	0.1%	2.8%	1.9%	4.2%	3.2%	0.6%	1.3%	0.7%	1.0%	2.1%	1.1%
18 years	4.8%	8.2%	3.4%	0.7%	0.5%	0.4%	0.2%	0.7%	0.8%	0.1%	2.7%	1.9%	4.2%	3.4%	0.6%	1.2%	0.6%	1.1%	2.3%	1.2%
19 years	4.6%	8.1%	3.6%	0.6%	0.5%	0.4%	0.3%	0.7%	0.8%	0.2%	2.2%	1.8%	3.7%	3.2%	0.8%	1.5%	0.7%	1.2%	2.5%	1.3%
0-19	4.1%	6.0%	1.9%	0.5%	0.4%	0.3%	0.2%	0.5%	0.7%	0.2%	2.5%	1.5%	2.9%	1.9%	0.5%	0.8%	0.4%	1.0%	1.9%	0.9%

## Appendix 4: Assessment of individual data sources

There are a number of different data sources that can be used. These can offer some guide as to what number or proportion of children may require the intervention of specialist disability teams. None of these data sources is perfect, however by looking at a number of these data sets together, it may be possible to narrow the range of estimates in relation to therapy needs.

In summary, these data sets are:

#### 1. Disability databases - Health Research Board

These constitute the National Intellectual Disability Database (NIID) and the National Physical and Sensory Disability Database (NPSDD), and they collect data on those receiving specialist disability services or on a waiting list for same, broken down by type of service. For the purpose of the analysis in this paper, we used the data from the 2012 reports, which was what was available when the analysis was conducted. There would have been little difference had we done a similar analysis with the 2013 data.

#### **Pluses**

These data are the only sets which measure specifically the use of, and demand for, specialist disability therapy services. These figures are broken down across the different therapy professions. The coverage of the intellectual disability population who are receiving or on a waiting list for services with disability service providers is high, with over 99% of data updated at least annually.

#### **Minuses**

Coverage and updating of the NPSDD by HSE staff is patchy, and the Health Research Board which manages the databases estimates only one in five eligible persons is covered. Participation in the databases is voluntary. The figures are likely to particularly underestimate younger children.

#### 2. Census 2011

This gives data on children with disability as volunteered by their parents, broken down by type of disability and by single year of age.

#### **Pluses**

The most comprehensive data set, covering all children.

#### **Minuses**

The data does not indicate whether children have a level or complexity of need that would require specialist disability therapy inputs. The disability label is up to

parents, and the evidence shows that reported age-specific disability rates for children changed substantially between 2006 and 2011. While this was affected to some extent by changes in definitions used between the two Censuses, there is also evidence that where the disability term remained the same between 2006 and 2011, a substantially higher proportion of children in a given age group were labelled as having a disability in 2011.<sup>252</sup>

#### 3. National Disability Survey 2006

This survey was conducted by interviewing a sample of those reporting a disability in 2006 (or their parents as appropriate). About 2,400 people were interviewed for the subsample of those aged 17 or under. Data was collected across 9 different areas of functional difficulty, and by degree of severity of impact.

#### **Pluses**

This was a large-scale random sample of children with disabilities, with some of the questions asking about use and requirements for some specific therapies..

#### **Minuses**

As the sample frame was drawn from Census 2006, there may be similar issues of variability in the rate of self-declared disability. The therapy questions were not comprehensive, covering just some individual therapies and for some of the impairment groups.

# 4. Growing up in Ireland Survey – 9-year old cohort (2007) and 13 year old cohort (2011)

The Growing Up in Ireland Survey surveyed some 8,500 children, of whom about 2,400 (28%) were considered to have some form of disability or special education need. The same children were then re-surveyed four years later.

#### **Pluses**

This is a reasonably large sample, providing detail on the nature of the child's condition or special education need, and the number of such conditions, which can offer some guide as to therapy needs and the need for multidisciplinary support. Wave 2 (13 year olds) had specific questions covering therapies. As a longitudinal study, there is information on changes over time. The data from Wave 2 can also be related back to corresponding figures in the census for children of the same age with a disability. Access was provided to the microdate to enable NDA do its own detailed analysis.

 $<sup>^{252}</sup>$  See appendix xx for changes between the two census, which illustrates that much of the increase is due to changes in intellectual disability and learning disability category.

#### **M**inuses

While data in Wave 2 on 13-year olds provides evidence on therapy use in and out of school but there is little to indicate the adequacy of therapy nor the level of unmet need.<sup>253</sup>

#### 5. NCSE data on children with special education needs - 2012

The National Council for Special Education has published data on children being supported with respect to special education need. Where the support levels are linked to a particular diagnosis, there is information on that specific diagnosis.

#### **Pluses**

Comprehensive data for school-age population.

#### **Minuses**

No direct link between nature of special education need and requirement for therapy. Data for school-age group only. The linking of resources to specific diagnoses provides an incentive to acquire a particular disability label (e.g. autism), while no data is available on the severity of a particular need.

<sup>253</sup> There is a question that asks if the totality of supports the child receives are adequate, but it is not possible to identify which particular supports are adequate nor which supports are needed but not met.

# Appendix 5: Forecast change in child population

The following tables present CSO population projections between 2011 to 2021, in the age groups 0-4 and 5-19, roughly corresponding to the age groups covered by early intervention and by school age teams.

Table 31 Projected % change in no. of children aged 0-4, 2011-2021

	2011 to 2021
MIFI	-3.1
MIF2	-9.2
M2FI	-5.0
M2F2	-11.0
M3FI	-7.4
M3F2	-13.2

Note: F1: fertility to stay at 2.1, F2 fertility to fall to 1.8. M1 net inward migration to recover by 2016, M2 net inward migration to recover by 2018, and M3 migration is outwards for whole time. <a href="https://www.cso.ie/en/media/csoie/releasespublications/documents/population/2013/poplabfor2016">www.cso.ie/en/media/csoie/releasespublications/documents/population/2013/poplabfor2016</a> 2046.pdf)

Table 32 Projected % change in no. of children aged 5-19, 2011-2021

	2011 to 2021
MIFI	18.7
MIF2	18.1
M2FI	17.8
M2F2	17.3
M3FI	16.8
M3F2	16.3

Note: 19 year olds are included as this is how the CSO data is broken down. . www.cso.ie/en/media/csoie/releasespublications/documents/population/2013/poplabfor2016 2046.pdf)

# Appendix 6: Submission from Faculty of Paediatrics on Disability Team Composition by a consultant paediatrics

Background – Faculty of Paediatrics:

The Faculty of Paediatrics of the Royal College of Physicians of Ireland is responsible for promoting excellence in the areas of patient care, professional standards, education and training in paediatrics. The Faculty is the training body for paediatrics in Ireland and represents the specialty of paediatrics on international, national and regional councils and committees concerned with paediatrics and paediatric education and training. Each consultant paediatrician is a fellow of the Faculty. Fellows form the nucleus of the Faculty and help the Faculty fulfil a wide range of functions including:

- Acting in an advisory capacity to governmental & statutory bodies in all matters pertaining to paediatrics
- Developing and administering all postgraduate training programmes for paediatrics
- Responsibility for setting and maintaining standards in the MRCPI (Medicine of Childhood)
- Developing and administering the Professional Competence Scheme for Paediatrics
- Acting as a vital source of information for individuals practicing in paediatrics.

#### Background - The task:

Determining the quantity of time and therefore the number of medical doctors required to provide this necessary service to a disability team is complex. The exercise demands more in-depth research that covers a full needs analysis to be accurate and standardised across the country. For the purposes of this report I will outline the information that can be deducted from the current service as they exist and available research. To form an opinion, all consultant paediatricians in Community Child Health have been contacted for information regarding their current practise and posts. Current work practises and research allows us to best guess the whole-time-equivalent (WTE) consultant paediatricians in Community Child Health (CCH) required to provide a medical service to the entire disability group per entire population (and therefore health region). It is a lot more complex to estimate the WTE of consultant paediatrician in CCH required to provide the service for 100 children enlisted in a disability team as team work is only a component of the disability work of a consultant. It would

depend on the age, complexity, severity, and co-morbidities of the children's diagnoses as well as the criteria for enlisting to the team. For example, criteria for enlisting to EIT are not standardised across the country leading to a different mix of children in the teams. In addition the mix of children in the teams often depends on the services available in the region i.e. specialist public health nursing for Child Health, CAMHS, community psychology, the availability of direct access parenting supports, NEPS, school supports, tertiary care such as CRC and primary care teams.

# The true proportion WTE consultant paediatrician CCH time required to provide a service to a disability team of 100 clients would also have to take in the following variables:

- The severity and complexity of disability among the children
- The age range, i.e. EIT or school-age team (SAT)
- The organisation of the disability team including team manager, administration support, key worker and social work
- Professionals on the team including specialist public health nursing, public health doctors (primary and/or senior medical officers)
- Prevalence of disadvantaged population groups within the region, taking into account poverty and ethnic minorities, particularly when English is not the first language
- Whether the service required is secondary or tertiary e.g. in a specialised centre such as Enable Ireland or CRC
- Central based or peripheral based clinics with travel time taken into account
- The impact of team working versus the consultant seeing the child independently
- The need for palliative care in addition to the expected medical needs
- Whether the doctor's responsibilities are covered during long or short-term leave.

The Report of the National Reference Group on Multidisciplinary Disability Services for Children aged 5-18, December 2009, summarises the role of consultant paediatrician in the care of children with disability.

"The consultant paediatrician will attend Network services on a regular sessional basis to see children individually and to provide consultation for the other team members

- Investigation, assessment, and diagnosis of children presenting with significant disorders of development
- Surveillance and management of children with identified disability in partnership with other team members and the primary care team
- Liaison with multidisciplinary teams at all levels to provide medical expertise, information and training to families, team members and frontline staff where necessary
- Ensure regular monitoring of children and adaptation of programmes in line with changing need
- Provide secondary and specialist medical expertise to educational and community services in the catchment area
- Provide consultant secondary/tertiary level care to children with chronic medical conditions especially those with epilepsy, cerebral palsy, Down Syndrome and other physical and learning disabilities
- Child protection consultation for colleagues and CSA medical and liaison work
- Liaison with other services such as acute hospital services, mental health services, specialist medical services (neurology, cardiology, endocrinology)."

#### **Core principles:**

- Each child with a significant developmental delay should have a medical assessment to determine the diagnosis, identify co-morbidities and institute treatment
- This assessment should only be carried out by a doctor trained to do so
- Children with disability or significant developmental delay require on-going management of the condition by a doctor qualified to do so.

#### **Current Practise and Consultant Workforce**

This service is currently led and provided for by consultant paediatricians with a special interest in community child health in many geographical regions. Each of these consultants has a 0.5 commitment to hospital services and 0.5 to community (predominantly disability) service. The care of children with disability by the consultant paediatrician is continued, usually, until the child completes secondary or special school at 18-19 years. In some areas, community and public health doctors provide part of the service, either under supervision of consultant colleagues or on their own. There are still areas of the country where the

disability teams have no medical liaison or service which is very worrying. In many other areas there are insufficient consultant paediatricians appointed to cover all aspects of the service required. So there are many gaps in the service and this is particularly true of Dublin-Mid-Leinster and Dublin-North-East regions. In some areas, the early intervention team has a designated paediatrician but the schoolaged children do not and vice versa. In Dublin, the consultant paediatrician is based in the hospitals or within the voluntary agencies service. Generic teams are not covered by a consultant.

#### **Available Workforce Recommendations**

The Report of the National Reference Group on Multidisciplinary Disability Services for Children aged 5-18 recommended that there should be a whole time equivalent community paediatrician post in each Local Health Office (150,000 pop) area whose role would include providing sessional input to all Network teams. This equates to 28 WTE consultants to provide the disability component of the CCH consultants role (56 consultants with 0.5 hospital commitment ). There are currently only 12.75 WTE consultants in CCH in the country. This estimation pertains to the disability (secondary level) component of the work of a consultant community paediatrician and does not take into account the other duties of this role, which are tertiary level disability (e.g. spasticity management), consultative role in Child Protection, teaching, and public health.

The British Association for Community Child Health (BACCH) analysed the community paediatrician workforce requirements to meet the needs of children in the 21st century in 1999 and 2002. (Paediatric Workforce Requirements to Meet the Needs of Children in the 21st Century). The report concluded that a geographical area of 100,000 population with average health needs requires 4.5 WTE community paediatricians to provide "good enough care". The community paediatrician in the UK includes the consultant, associate- grade and staff-grade paediatrician. There are no associate-grade or staff-grade paediatricians in Ireland. An equivalent role to this in Ireland would be the Child Health component of the work of community or public health doctors. There is a large variation in the existence of community doctors (senior and area medical officers) in the country. In some areas there are no S/AMO's and in many areas the Child Health component of their post is small. In other areas, however (e.g. Longford/Westmeath) the S/AMO is an integral part of the EIT team and works under supervision of the consultant paediatrician in CCH. Given the Irish population in 2011 the BACCH guideline would recommend 189 WTE doctors working in community child health, 63 WTE of whom to be consultants.

The contribution of the consultant paediatrician to the disability teams is best provided where disability teams are well resourced and managed and there are

good examples of this in the country. In a minority of regions there is one WTE consultant in CCH providing a service to a typical region with 150,000 general population. Consultants there feel that the current organisation of the disability teams and the nature of the liaison between the consultant and the teams works well and is manageable.

#### **Summary**

Each child with a disability or developmental delay requires assessment and management by a suitably trained doctor, either by or under the supervision of a consultant paediatrician in CCH.

There is a lack of doctors throughout the country to provide this service.

Children with disability or developmental delay may or may not require multidisciplinary care and therapy. Those requiring multidisciplinary input are best cared for within a multidisciplinary team.

To best provide a medical service to children with disability in a "joined up" way, the consultant paediatrician in CCH liaises closely with the MDT team.

The medical service to a disability team is most efficient and effective when the team is well resourced and managed.

There are children with disability requiring medical management who are not receiving MDT care (e.g. child with physical disability without intellectual disability or with specific language disorder) and the consultant paediatrician in CCH continues to see these children independently of a team.

The estimate of I WTE consultant paediatrician in CCH per I50,000 of the general population to provide the disability component of the consultants post is a current working guide. This equates to 28WTE consultants throughout the country.

To provide the full range of consultant services to community child health, including child protection, more than this number of consultants is necessary.

To accurately determine the WTE requirement to provide the medical service to a team serving a population of children requires more research. There are good examples of service provision in the country on which to base research.

## **Appendix 7: Reconfiguring Disability Services in Ireland**

### I. Reconfiguring health services

The creation of a governance system in Ireland that will deliver individualized services and supports requires the reconfiguration of existing processes. Table 2 outlines the system changes planned by the Department of Health

Figure 1: Characteristics of current system and its reshaping<sup>254</sup>

Current System	How it is being reshaped
Current disability provision	Toindividualised supports and mainstream services
Fromservice defined by agency	Toservice jointly defined by service user and family, commissioning authority (e.g. HSE) and Government
Fromservice deliverer accountable for inputs and compliance	Toservice deliverer accountable for outputs and quality
Fromcompliance with rules	Toattainment of outcome-based standards and demonstrated commitment to continuous quality improvement
Fromprovides categorical services	Toprovides integrated services
Fromservice delivered through credentialed professionals	Toservices and supports delivered through professionals, non-professionals and service user representatives
Fromfunds isolated projects	Tolevers local innovations into improvements in mainstream services
Fromone size fits all	Toassumption of need for diversity

Source: adapted from National Economic and Social Council (2005) The Developmental Welfare State Accessible at http://files.nesc.ie/nesc\_reports/en/NESC\_I13.pdf

 $<sup>^{254}\</sup> www.dohc.ie/consultations/closed/disability\_policy\_review/key\_themes.html$ 

#### 2. Reconfiguring children's disability services

To address the development of nationally consistent children's disability services, the HSE has undertaken a programme of progressing services for children with disabilities. In 2008, a National Reference Group (NRG) was set up to develop interdisciplinary disability services for children aged 5 to 18 years. The NRG assumed population figures of 8,000 -10,000 per primary care team, 30,000-40,000 per network, 150,000 per Local Health Office (LHO) and sub-regions of 450,000, comprised of 3 LHOs. The NRG met between March 2008 and June 2009 and published a report in Dec 2009. The HSE approved the report in 2010.

The HSE established a National Coordinating Group (NCG) to implement the recommendations of the 2009 NRG report and to plan the reconfiguration of children's services. This national program is called "Progressing Disability Services for Children and Young People," and involves a partnership between the HSE, nongovernmental agencies, the Department of Health and the Department of Education and Skills. The NCG oversees and monitors the programme. This group has representatives of the HSE, disability organisations, parents, the Department of Health, the Department of Children and Youth Affairs and the Department of Education and Skills.

The NCG formed a project plan, so that in each local area, representatives from services and parents, together with local leads for the programme, study how current services can be reorganised within the framework laid out in the National Reference Groups 2009 Report. There are Regional Co-ordinating Groups in each of the HSE Regions. Regional leads head the local implementation groups and have a co-ordinating and monitoring role for the groups. Local Implementation Groups include representatives of service providers, parents and education services. Their task includes agreeing the principles, which should underpin local disability services, mapping services and gaps, consideration of the changes needed and a detailed plan of how to advance. Guidance from the national group is available, as are the objectives under the HSE National Service Plans.

The aim of the national Progressing Disability Services programme, is to provide high quality, local, inter-disciplinary, child and family centred disability services

Disabilities, that the focus of the NRG work and NRG report would be the development of a framework for the future delivery of services for the 5-18 years age cohort

<sup>&</sup>lt;sup>255</sup> The NRG comprised representatives of the professions and management involved in delivering multi-disciplinary services to children. Due to the economic downturn, the implementation of the EPSEN Act and of the Disability Act for children over five was deferred. A decision was made by the NRG, in consultation with the HSE Lead Local Health Manager for

integrated with Primary Care, Child and Adolescent Mental Health Services (CAMHS) and other children's services. The programme includes:

- Formation of partnerships between statutory and non statutory health and social services, to guide the development of community based early intervention and school based disability services
- Development of geographically based network (Health and Social Care Network Level) early intervention and school age disability services across Ireland, that eliminate inconsistencies in service provision
- Integration and coordination between early intervention and school age development teams
- Development of team work between the various therapy and other disciplines working within the new interdisciplinary disability services
- Promotion of collaboration and cooperation between Disability Services,
   Primary Care Services, Community and Hospital Paediatric Services, Child
   Protection and Welfare Services and CAMHS
- Joint working with the HSE officers who administer the Assessment of Need process under Part 2 of the Disability Act, 2005.

The Mid West Region, for example, has developed joint working protocols between Children's Disability Services and CAMHS, CAMHS Intellectual Disability and Child and Family Psychology Services. The Children's Disability Services have developed Clinical Consensus Guidelines for improved integration of Primary Care and Disability Services School Age Child Development Teams. These structures are essential to ensure collaboration and cooperation between therapists within disability services and Primary Care Teams (PCT) under new access criteria for children with disabilities, Primary Care has responsibility for all children with disabilities who have non-complex needs.<sup>256</sup>

Figure I outlines the Framework on Access to service for children and young people to meet their needs

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<sup>&</sup>lt;sup>256</sup> Needs are to be classified according to the International Classification

Figure 1 Access to services for children & young people to meet their needs

