Working Together to Support Children & Young People with a Disability and their Families

Inaugural Conference Report

Progressing
Disability Services for
Children & Young People

The not for profit ASSOCIATION

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NATIONAL FEDERATION OF VOLUNTARY BODIES
Providing Services to People with Intellectual Disability

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MARY IMMACULATE COLLEGE
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PRISEM
INSTITUTE FOR EDUCATIONAL & SOCIAL POLICY STUDIES

Working Together to Support Children & Young People with a Disability and their Families

National Conference Report

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Table of Contents

List of Acronyms

ADHD	Attention Deficit Hyperactivity Disorder
ADI-R	The Autism Diagnostic Interview - Revised
ADOS	Autism Diagnostic Observation Schedule
AIM	Access and Inclusion Model
ANP	Advanced Nurse Practitioner
AON	Assessment of Need
APA	American Psychological Association
ASD	Autistic Spectrum Disorder
BS	Better Start
CAMHS	Child & Adolescent Mental Health Service
CBC	Child Behaviour Checklist
CBCL	Child Behaviour Checklist
CBT	Cognitive Behaviour Therapy
CCC	City/County Childcare Committee
CDNTs	Children's Disability Network Teams
CLC	Children's Law Centre
CPD	Continuing Professional Development
CPIP	Cerebral Palsy Integrated Pathway
CPUP	Surveillance Programme for People with Cerebral Palsy
CSIG	Cross-Sectoral Implementation Group
DCD	Developmental Coordination Disorder
DCYA	Department of Children and Youth Affairs
DECPsy	Doctorate in Educational and Child Psychology
DES	Department of Education and Skills
DIMS	Disorders of Initiating and Maintaining Sleep
DoH	Department of Health
DSM-V	Diagnostic and Statistical Manual of Mental Disorders
EASNIE	European Agency for Special Needs and Inclusive Education
ECCE	Early Childhood Care and Education
EIS	Early Intervention Service
EIT	Early Intervention Team
EPSEN	Education for Persons with Special Educational Needs
EYS	Early Years Specialist
EYSS	Early Years Specialist Service
HFASD	High functioning autism spectrum disorder
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
IAN	Interactive Autism Network
ICTA	Infant Toddler Coordinators Association
ID	Intellectual Disability
IDEA	(The) Individuals with Disabilities Education Act
IDG	Inter-Departmental Group
IFSP	Individual Family Service Plan
IEP	Individualised Education Programme
IMH-NG	Infant Mental Health Network Groups
IT	Information Technology
KIDS	Kerry Intervention and Disability Services
KPI	Key Performance Indicators
LIG	Local Implementation Group
LOCE	Ley Orgánica de Calidad de la Educación

LOE	Ley Orgánica de Educación
LRE	Least Restrictive Environment
LSA	Learning Support Assessment
MDT	Multi-Disciplinary Team
MIC	Mary Immaculate College
NABMSE	National Association of Boards of Management in Special Education
NALA	National Adult Literacy Agency
NCMT	National Coordination and Management Team
NCSE	National Council for Special Education
NDA	National Disability Authority
NDT	(Children's) Network Disability Team
NEPS	National Educational Psychological Service
NEYAI	National Early Years Access Initiative
NEYQDS	National Early Years Quality Development Service
NI	Northern Ireland
NICE	National Institute for Health and Care Excellence
NQF	National Qualifications Framework
NUIG	National University of Ireland, Galway
OMCYA	Office of the Minister for Children and Youth Affairs
OT	Occupational Therapy
PA	Personal Assistant
PARS	Pediatric Anxiety Rating Scale
PCCC	Primary Community and Continuing Care
PDS	Progressing Disability Services
PDSCYP	Progressing Disability Services for Children and Young People
PHN	Public Health Nursing
PIP	Programme Implementations Platform
PSI	Psychological Society of Ireland
RCI	Reliable Change Index
SADT	School-Age Disability Team
SEIS	Springtime Early Intervention Service
SEN	Special Educational Needs
SENO	Special Education Needs Organiser / Special Education Needs Officer
SNA	Special Needs Assistant
SLT	Speech and Language Therapy
SpLD	Specific Learning Difficulty
TEP	Trainee educational psychologist
UN	United Nations
UNCRC	United Nations Convention on the rights of the
UNCPRD	United Nations Convention on the Rights of Persons with a Disability
UNESCO	United Nations Educational, Scientific and Cultural Organization
USAID	United States Agency for International Development
VCO	Voluntary Childcare Organisation
WCCDS	West Cork Child Development Services
WHO	World Health Organisation
WS	Williams syndrome
WSAI	Williams Syndrome Association of Ireland
WTE	Whole Time Equivalent

Editor's Note

This report captures the proceedings, presentations and deliberations of the inaugural conference on *Progressing Disability Services for Children and Young People*. However, it is much more than a conference report. It also presents material that seeks to contextualise, ground, support, showcase and allow for reflection on, and evaluation of many of the practices – including innovations and collaborations – and the challenges faced by all stakeholders. The Conference Organising Committee unanimously decided to invest members' time and efforts in compiling this report, as they were keenly aware of the widespread interest in this conference and above all, of the need to have a tangible record and set of signposts on which to further promote progress in enhancing services.

This report begins with a foreword by Minister Finian McGrath TD, Minister of State with Special Responsibility for Disabilities. Minister McGrath also opened the conference. The co-chairs of the Organising Committee, Ann Bourke and Anne O'Byrne, in their introduction, sit *Progressing Disability Services* (PDS) in the context of a wider framework of actions that are required to enhance the lives of children with disabilities and their families. Their sentiments reflect the spirit and resolve of conference delegates. Dr Cathal Morgan's overview of PDS underscores the importance of due investment and forward planning. The Concluding Remarks (Section Ten), provided by Lorraine Dempsey (Parent Representative), effectively identify the learnings upon which we can draw and the trajectories we can follow in ensuring a truly child and family-centred approach.

This report provides summaries of all plenary papers. These accounts are presented in Section Three. They cover a wide range of themes and showcase current and emerging practices. Section Four focuses very strongly on the experiences of practitioners. It presents ten case studies, in which practitioners document particular experiences, and highlight specific issues. These case studies provide the backdrop against which delegates' views and recommendations are presented in Section Five. These are followed, in Section Six, by a listing of the posters elaborated by researchers, and displayed during the conference. Section Seven provides two important insights from Northern Ireland, outlining practices, principles and the issues associated with pursuing a rights-based approach. Section Eight seeks to set the Irish experience in a wider international context, and it presents three papers from overseas' contributors. The report concludes by showcasing some of the research currently being undertaken by Mary Immaculate College staff in the field of disability services. Three sample papers are included in Section Nine. Peppered throughout this report are several illustrations – <u>in no particular order</u>, each thoughtfully drawn, by Fintan Taite, during the conference.

Those who attended the conference can attest to its many successes. This report seeks to rekindle the conference energies and to extend them to those who were unable to attend. In addition, it seeks to add value to the conference inputs and achievements, and we are particularly glad to include the contributions of external experts, and are most grateful to each and every one of them for voluntarily sharing their expertise. Above all, this report has been compiled with the objectives of ensuring enhanced services, conducive policies, constructive and collaborative working, stronger partnerships and a renewed focus on children and their families.

Dr Brendan O'Keeffe
Director, The Institute for Action Research

Foreword

by Minister Finian McGrath TD,
Minister of State with Special Responsibility for Disabilities

I am delighted to have been able to attend the opening of the exciting and very significant conference, the first in Children's Disability Services. I wish to thank the National Children's Programme Oversight Group, Mary Immaculate College and the Conference Committee for the immense work gone into the planning of this conference and preparing this report.

Progressing Disability Services for Children and Young People is one of the three significant reform programmes being implemented under *Transforming Lives,* which cross the life cycle of the individual with a disability.   The reconfiguration of children's disability services is a key priority for the Government, the Department of Health and for me as the Minister for Disabilities. I have met many families and carers on a daily basis, who are navigating their way through services together with their loved ones. Many speak of the excellent care and services that they receive; and the credit for that goes to you, as HSE staff who provide vital supports to children and young people in your different areas. Your roles are immensely important, and it is my job and my wish to support you in that work by providing robust policies and a framework for how children's services should look.   We know that services can vary a lot across the country, and it is against that background that we have embarked on an era of unprecedented change in services for people with disabilities.

As many of you will know, the programme *Progressing Disability Services for Children and Young People with a Disability Programme (PDS)* was established in 2011. Its aim is to bring about equity of access to disability services as well as consistency of service delivery, with a clear pathway for children and their families to disability services, regardless of where they live, what school the child attends or the nature of the individual child's difficulties. While some areas have made great progress, there have also been significant challenges in implementing this programme since its launch. However, the Government remains resolutely committed to its implementation, and there is immense work going on across the HSE to overcome these challenges and to further progress the establishment of the teams. First class early- intervention services and services for school-aged children with disabilities are paramount, and they need to be improved and organised more effectively. I am delighted to note this process is well under way nationwide.

Children, young people and adults with a disability have the same right as anyone else to live satisfying and valued lives. They should be treated with dignity and respect, and receive the supports they need to achieve their goals in order to live healthy, safe and rewarding lives. In order to facilitate this, it is essential that we, as legislators, care providers and society as a whole provide these supports. Many have been frustrated with the slow pace of change in disability services. I share those frustrations, but I know that when we get it right for children's services, we will provide a better stepping-stone into Adult Day Supports and, where required, into supported living. There is more work to be done, and I believe that this can be best achieved by adopting a collaborative approach, harnessing resources, swapping ideas and bringing out the best in each other through a process of rigorous debate. It is a challenge to which we must all rise.

1. Introduction and Overview - Working Together to Support Children and Young People with a Disability and their Families - Conference, 2017

On December 1st, 2017, we were delighted to welcome over three hundred delegates in person and a further five hundred, via Webinar, to the inaugural conference for Children's Disability Services, entitled *Working Together to Support Children and Young People with a Disability and their Families.* The conference was held in Mary Immaculate College (MIC), Limerick, and was organised in partnership by the HSE, HSE-funded voluntary organisations and MIC's Policy Research Institute for Social and Educational Matters (PRISM). This partnership is an example of joint working between the health and education sectors, which is one of the aims of the HSE's *National Progressing Disability Services for Children and Young People programme* (PDS).

The key objective of the conference was to showcase and promote good practice models in reconfigured Children's Disability Network Teams (CDNTs) and in services which have yet to reconfigure, but whose programmes are directly transferable, in line with PDS, into the new teams. The quality of submissions received was truly inspiring, reflecting excellent, innovative practices, most interdisciplinary, and many also incorporating young person and parent feedback, which is absolutely essential for our journey of continuous progress towards 'getting it right for service users'. The presentations, workshops and posters cover the entire gamut of change programmes under children's disability services at this time. Academic staff from MIC facilitated the breakout workshops, and MIC postgraduate students from the Doctorate in Educational and Child Psychology Programme acted as rapporteurs for each session. This participatory element allowed for the voice of the delegates attending the conference to be heard, not only on the day, but also as part of this report. The conference also allowed for the dissemination of evidence-based practices through networking opportunities and sharing of human capital and experiences.

The *Progressing Disability Services for Children and Young People with a Disability Programme* (PDS), based on the Report of the National Reference Group on Multidisciplinary Disability Services for Children aged 5-18 (2009), was launched in April 2011. This programme aims to achieve a national unified approach to the delivery of disability health services for all children, regardless of where they live, what school they attend or the nature of their disability or delay. Fifty-six Children's Disability Network Teams (CDNTs) are in place, with a further eighty-two to be established.

The HSE's *National Policy on Access to Services for Children and Young People with Disability & Developmental Delay*, developed by Disability Services and Primary Care, provides clear signposting and equity of access for children and their families to the most appropriate service, be those Primary Care or Disability Services. The *Joint Protocol for Interagency Collaboration between the HSE and Tusla* (2017) and HSE's *Joint Working Protocol - Primary Care, Disabilities, Child and Adolescent*

Health Services (CAMHS) (2017) will drive integrated working and shared care with our partners in Tusla, Primary Care and CAMHS, where appropriate.

Experience of CDNTs providing a child and family-centred, interdisciplinary model of service shows us clearly that it is not a 'cheaper' model, but a more effective one, based on what the child/young person and their family wants and needs to enable them to realize their optimal potential. ***Outcomes for Children and their Families, a Performance Management and Accountability Framework for Children's Disability Network Teams*** (2013), to commence implementation in 2018, will enable teams to measure the benefit of everything they do with the child and family to ensure best value for them, and ultimately, the tax payer and society as a whole.

Disability Services have been involved in the DCYA-led, interagency programme, *AIM: Supporting Access to Early Childhood Care and Education for Children with a Disability* (2016), since its inception. This model nurtures collaborative working between the early years' educator, early years' specialist and healthcare staff to support the child with a disability to participate meaningfully with his / her peers.

The Conference itself was a wonderful example of partnership between health and education, and this Conference Report captures a flavour of all that was covered on the day, including presentations, delegates' feedback in the breakout workshops, poster presentations and relevant national and international research. We are incredibly grateful to all who have contributed to the conference and this report, especially our colleagues on the Conference Organising Committee and our national and international contributors, who gave so generously of their time, pro-bono, and within a very tight timeframe.

Conference presentations are available at:

https://msite-web.mic.ul.ie/Mediasite/Login/Register?ReturnUrl=%2FMediasite%2FCatalog%2FFull%2F163305782881452fa16eee7317d07f1721
using the password: 1234, until December 31st 2019.

Our intention is to run a biannual conference so get your thinking caps on for the 2019 Conference!

Ann Bourke

National Disability Specialist
HSE Social Care – Disabilities

Anne O'Byrne

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2. Children's Disability Services Reform Programme

Disability Services are going through unprecedented change. *Transforming Lives*, published in 2012, outlines three programmes of change. These are now well underway, and will fundamentally change how we support individuals with disabilities and their families, to live ordinary lives in ordinary places.

Time to Move On from Congregated Settings: *A Strategy for Community Inclusion* is focused on supporting people to transition from institutional settings, where they are living with ten or more others in a single unit or on a campus, into homes in the community. The programme is not just about moving to new homes, but is about delivering person-centred care that enables each person to have choice and control over with whom they live, where they live, how they spend their time and how they wish to be supported.

New Directions *- Personal Support Services for Adults with Disabilities* on the provision of day services for adults with disabilities envisages that all supports available in communities be mobilised, so that people have the widest choice and options about how they live their lives and spend their time. The guiding principle for the future is that supports will be tailored to individual need, and will be flexible, responsive and person centred. Within *New Directions*, the range of supports to which the individual has access should equip him/her to: 1) make choices and plans to support personal goals; 2) have influence over decisions that affect his/her life; 3) achieve personal goals and aspirations; and 4) be an active, independent member of his/ her community and society.

Progressing Disability Services for Children and Young People: involves the reconfiguration of existing, varied and inconsistent disability services for children and young people into Children's Disability Network Teams, to provide for all children with complex disability, based on individual need and regardless of their diagnosis, where they live or go to school.

These change programmes are not without their challenges. They each commenced implementation while Ireland was in deep recession and experiencing a significantly-reduced health budget. Emerging and growing pressure areas within Disabilities include: increasing demand for flexible models of respite; emergency residential placements; appropriate, safe housing; support for school leavers and young people leaving care; and transport. We have an ageing population, with greater and more diverse needs, and we also have the highest birth rate in Europe. As the population ages, there is likely to be an increase in the prevalence of disability (Watson *et al.*, 2011). Demand for disability services continues to grow with over one-in-eight (13.5%) of the population declaring a disability in the 2016 Census of Population. This is up by over five percentage points on the 2006 Census of Population and National Disability Survey.

Each of the programmes involves a significant and essential change in practice and culture for service providers, staff, service users and their families. Bedding down of new ways of working under these three policies will take considerable focus and effort in the coming years. Implementation of the *Sláintecare Report* (2017) - a key programme for government priority, will support this, driving a re-orientation from today's hospital-centric model to an integrated model of primary and community based care, health promotion and public health. Sláintecare identifies the need for significant investment to deliver universal healthcare, expanded primary care, disabilities and older persons care, palliative care and mental health. I am confident that implementation of all three policies will provide greater access to person-centred and sustainable supports and services for people with disabilities.

Dr Cathal Morgan *Head of Operations, HSE Social Care – Disabilities*

3. Plenary Papers

The Conference included ten plenary papers. These were all practitioner-led, and they serve to showcase, review, analyse and critique practices and experience across a wide range of fields.

3.1 Progressing Disability Services in Action – Kerry Intervention and Disability Services (KIDS)

Julie O'Neill, Team Manager; Caroline O'Sullivan, Physiotherapy Manager; Fionola Hogan, Senior Clinical Psychologist and Michelle Foley, Senior Speech and Language Therapist, Kerry Intervention and Disability Services (KIDS).

In this paper, members of the Kerry Intervention and Disability Services (KIDS) teams aim to give an account of their journey through reconfiguration. They also identify learnings from this experience, which ought to benefit other teams. This paper highlights the complex change process that Children's Disability Services in Kerry has gone through. Through it, the authors will share reflections on current ways of working and they make recommendations for future service provision, based on the PDS model.

Background and Context

Prior to the reconfiguration of disability services in Kerry in October 2013, children's disability services were primarily provided through the voluntary services, which comprised of Brothers of Charity, Enable Ireland, St John of God and one HSE-funded Early Intervention Team. These agencies were providing specific specialist services to children and their families within defined categories of disabilities up to school leaving age. They identified gaps in service provision for children, including children with intellectual disability over 6 years of age, who did not meet the team's criteria. In January 2011, a management governance group (MGG) and a local implementation group (LIG) were established to progress the national project PDS for Kerry. This paper highlights the challenges faced during this process and the deficits observed. In conclusion, we will outline the changes to this process which have now been made and we proffer recommendations for future development.

In October 2013, children's disability services in Kerry were reconfigured into to four geographically-based teams for children and young children (0-18 years). The system for the allocation of clients to the new team was based on their home address, and for school age children, on school address. The challenges faced by these teams in the management of this process and the caseload will be discussed. These include the process of gaining an understanding of the child's therapeutic needs, the allocation of clinicians to their new team, allocation of managers to each team, as well as issues such as clinical supervision, clinical governance and clinical pathways, including specialist clinical pathways. This change resulted in a protracted period of upheaval and adjustment for service users and staff. It continues to take time for the teams to become fully operational. We now recognise that there was a need at this early stage for involvement from human resources and from clinical leads, to ensure that these issues are resolved prior to reconfiguration of future teams. We understand that work is ongoing to address these issues nationally, and that areas that are preparing for PDS have clinical leads and HR support at the initial planning stage. This, in our opinion, will lead to clarity around reporting structures and supervision and will bring greater clarity for team members and families around clinical pathways. We also understand that all new teams will be given a much longer phased lead, prior to reconfiguration.

The Journey

Our journey, from a team perspective, and the knock on effect on service delivery will be described using Tuckman's (1965) four stages of group development, including forming, storming, norming, and performing.

Forming: Mullins (2013: 312) refers to Tuckman's forming stage as "the initial formation and bringing together of a number of individuals who identify, tentatively, the purpose of the group, its composition and terms of reference….there is likely to be considerable anxiety as members attempt to create an impression, to test each other and to establish their personal identity within the group." Our experience of this initial stage was one of significant anxiety, as teams were not fully prepared for the changeover. There was no clear team identity; teams struggled with understanding the model and new caseloads. As a result, there was conflict, which was followed by staff changeover, thus impeding the progression of change and team formation. Our learning from this experience is that there is a need for preparation of staff, both individually and within teams, pre and post reconfiguration. There is a need to give recognition to the individual therapists' previous experience and expertise, team identities, clinical supervision, leadership, conflict management and confidence of team members. This process needs to be fully supported by HR (Human Resources).

Storming: According to Mullins (2013: 312) "as the members of the group get to know each other better they will put forward their views more openly and forcefully. Disagreements will be expressed and challenges offered….this may lead to conflict and hostility….The storming stage is important because, if successful, there will be discussions on reforming arrangements for the working and operation of the group, and agreement on more meaningful structures and procedures". Our experience of the storming stage was that it took a long period of time because the framework was not clearly established. As a consequence, staff members continued to work as they had previously worked. Insufficient development of pathways and the absence of a clear definition of the term 'complexity,' without national direction on access scoring maintained clinicians in a heightened state of uncertainty, and resulted in staff conflict.

Other challenges that kept us in the storming stage included a lack of clear communication, a lack of clinical supervision for all staff and a lack of established clear clinical governance structures. These resulted in some team members feeling unequipped in supporting children with disabilities not familiar to them. This led to staff feeling clinically at risk, due to deficits in core competencies. Staff members lacked confidence in their clinical ability, and experienced feelings of loss for the skills which they were no longer using, i.e. reduced need for certain specialist skills and a lack of skills for other specialist areas. Our learning from this is the clear need for a standardised communication kit for team/parents and an ongoing commitment to team development and staff development, together with a commitment to ensuring job satisfaction and ongoing training.

Norming: Mullins (2013: 313) describes the norming stage as "As conflict and hostility start to be controlled, members of the group will establish guidelines and standards and develop their own norms of acceptable behaviour. The norming stage is important in establishing the need for members to co-operate in order to plan, agree standards of performance and fulfil the purpose of the group."   We are now four years in this process. We have achieved more effective team functioning, we have established pathways around team initial assessments, pathways for planned team interventions which are interdisciplinary and family centred. We are also in the process of developing discharge pathways. We will describe our pathways for inter-agency working with both health and education, and the new support and respite services that have been established.

Performing: Mullins (2013: 313) explains that, "when the group has progressed successfully through the three earlier stages of development it will have created structure and cohesiveness to work effectively as a team. At this stage the group can concentrate on the attainment of its purpose and performance of the common task and is likely to be at its most effective". This remains our aspiration, and is a work in progress.

The Current National Access Policy

At the time of service reconfiguration in Kerry, the *National Policy on Access to Services for Children & Young People* was still in development, and was not released for a further three years.

This resulted in:
- Children with non-complex needs reconfiguring into newly reconfigured CDNTs who would not now meet the access criteria for CDNTs under the 2016 National Policy, particularly children from HSE EI Teams.
- Much clinical time post reconfiguration was spent on assessment, interventions and transfer of children with non-complex needs. On each team we would still continue to have a number of children with non-complex needs on our caseloads who have yet not transferred to PC services due to resource issues and primary care teams not being fully resourced.

If a more defined set of access criteria had been available at the outset it would have enabled services to be more guided on where children with complex and non-complex needs would be accessing their interventions. Those children and families not being reconfigured to the new teams could have been supported by the teams they had a relationship in transferring to primary care services.

We recommend the re-establishment of an intake forum and new referral process, with strict compliance and with access criteria, in order to protect the services and to ensure balance between assessment and intervention, so as to best deliver services to those who need them most. The key learning is the need for dissemination of information around levels of complexity to referrers/ families. We are developing this now; for example we are beginning to have 'An Introduction to Services' presentation as a standalone presentation, or at the beginning of parent groups, we are detailing the service model for families at feedback meetings, and we continue to maintain our relationships with Primary Care.

We also stress the need for a comprehensive assessment and report at intake stage. Families contribute to and learn from the assessment process, and we endeavour to make it a consultative process. Thus, an effective intervention, building on family-centred planning – and avoiding the shortcuts that were taken in the past four years – is an important target for each child. We have also endeavoured to adopt best practice guidelines of informing families - again a key element to building partnership with families.

Intervention

This presentation summarises the current model of intervention employed across the four network teams. The model supports the tiered approach to intervention. It describes how we deliver our 'universal interventions', our 'targeted interventions' and our 'direct interventions' to the child and family. Research supports the effectiveness of these tiered interventions; however, without the input of universal and targeted interventions, direct intervention may not be as effective. The inverted triangle assumes that most of the interventions are provided at this level; however, we have found that this is not the case in reality – the majority of interventions are provided at the targeted and direct levels. It is also worth noting that these are the most resource-heavy interventions.

It also considers the associated challenges. Intervention is delivered in a child and family-centred way. We know that best outcomes occur when interventions are incorporated into the child's everyday routines, at home, school and in the community. Our focus is on the enhancement and the optimisation of competence and the promotion of positive functioning across all settings for the child. Our aim is also to enhance parent competencies to enable and support their child to reach their full potential in their own communities. We also strive to support inclusion and to strengthen stress-coping and family wellbeing. However, achieving these goals continues to be challenging for clinicians and families. The learning for us is that delivery requires a change in the traditional perceived role of the team member, which is an even bigger change for some families. Families and team members share responsibility to jointly develop agreed outcomes and work collaboratively to achieve them.

There is a constant struggle between balancing the values and principles of PDS with the challenges the teams and families face. All of the issues summarised below combine to significantly challenge the principles of the model primarily that we are child and family centred and that the service is equitable and accessible to all the families and children.

- Communication - there needs to be a commitment by all to encourage the wider understanding of the model of services to all stakeholders –we have explained earlier how we have been communicating the model to families for example at Initial Assessment stage, during IFSP's and information meetings. Some families will continue to look for a traditional/ medical model of service. Again we cannot emphasise more that in order to successfully implement this model everyone needs to understand it clearly – this also includes our colleagues in education, PC and mental health, whom with we have been steadily building relationships with.
- Resource challenges – To put it simply there is no denying that the teams are under-resourced for the size of the caseloads and the four teams are unequally resourced. There are many part-time positions on the teams, which make it difficult to recruit for and when there is a sick leave/ maternity leave or a vacant post, which is a common occurrence, service delivery is significantly impacted. The team managers and staff are under immense pressure to manage clinical risk and the families do not have a timely service – prioritisation of the caseloads occurs and the most at risk children and families are seen; this again leads to dissatisfaction of our service users and it ultimately impacts on relationships between the team and the family. We strive to share resources where we can, but this has knock on effects in other areas. It is difficult to perform as a team and plan future service delivery when the resources keep changing.
- Geographical challenges – one of the major challenges in Kerry as for all health services in the county is accessibility for families to our team bases. Some families are as far away as a two-hour drive to the team base. This puts added pressure on team members to travel, thus taking away from clinical time.
- Infrastructure – some of our buildings are not adequate for the requirements of the service. During reconfiguration, some teams had to move a number of times resulting in even more disruption.
- Professional expertise and competencies – at the outset of reconfiguration we did not all come to the table with the same expertise/ experience/ competencies, and there was a mismatch across all teams as to levels of experience; for example, some team members had not worked with children over six years of age, others had no experience of children with ASD. We were provided with a training budget to up-skill team members but training courses are only one part of developing competencies, it takes time and lots of experience with a client group to build your clinical skills in this clinical area. As well as team training, there are cross network unidisciplinary C.P.D. meetings, and we need to further develop these in an interdisciplinary way across network teams. Moreover, as there is a focus on service being provided at a universal level, some team members have expressed concern that they are not using their one-

to-one clinical skills, as previously. Team members may be at risk of losing their competencies in their specialist areas; we must recognise that there is still a need within each team to retain specialist competencies in clinical areas.

- As there is a diverse and large caseload, caseload management poses many challenges as follows: prioritisation systems for individual disciplines have been developed but we need to develop clear team prioritisation systems in line with the model. At the moment, given the large number of children on our caseload with or query ASD, team resources are heavily weighted towards ASD, particularly with the numbers of ASD assessments required which takes from the core disciplines of SLT/Psych/OT (Speech and Language Therapy, Psychology and Occupational Therapy).

- Lack of Information management systems; each team has a separate database. They are useful for individual teams but are not linked so there is no system for gathering, collating and analysing data for the county. We also have separate shared drives – again it would be useful for these to be linked, in order to share information across networks whilst recognising there may be a data protection issue.

- Training budget – while we received a substantial training budget, a lot of our training budget has been lost with staff leaving and moving on. There is a continued need for a training budget and a strategic plan for the budget to support the PDS model. Many of our staff were trained in programmes such as *Floortime* and *EarlyBird*. However, given the demands of the caseload not everyone has had the opportunity to use this training.

- IFSPs – we are trying to make this more of a dynamic and responsive document. Again, this is resource heavy, but evidence suggests it is the cornerstone for family-centred practice. The reality is that sometimes we are getting to these when families are in, or close to crisis. We are currently reviewing this process and how it can fit into the realities of service delivery.

- Education – we strive to work closely with the special schools, ASD units and mainstream schools with special classes. We currently have a 'pilot project' in one special school. Schools welcome us into the classroom to work with children the functional environment, as opposed to the 'take out' model. However, some parents still continue to request the latter, despite knowledge of model.

- The final challenge is that of having different staff from different agencies on the same teams. There can be a lack of clarity around policies and procedures and reporting relationships. Therefore, we continue to require support from HR around these issues.

In summary, and given our experience of reconfiguration and working the model we recommend the following for the existing teams and the teams that are soon to be formed:

- The teams will continue to require HR supports and team development training to progress. They also require ongoing commitment to training and supervision;
- We need a shared common language and ethos. Until we have this, we are giving conflicting information to families; and
- Ongoing work is required for specialist cross-network roles, pathways and IT.

Families need to be prepared for reconfiguration by the teams and management. Expectations around what can be achieved/delivered need to be clearly set. We acknowledge that, at this point in time, the model and plan look good in theory, but in practice and in reality, we know that families do not always receive a timely, equitable and effective service. We have outlined the reasons for this, and we understand that the people who are most impacted are the families themselves. PDS is just that, a work in progress.... We know that the success and permanency of PDS will be determined by regular consultation with, and feedback from families, clear pathways for children and timely access to respite for families who require it.

There needs to be continued investment by the HSE and the managing agencies in supporting the CDNTs and the PDS model. We need strong governance and management structures as well as supervision and HR structures. We strongly recommend a dedicated national website for parents and teams to access information on the model, the structures and the pathways. In conclusion, we hope that we have represented the broader view of our service post reconfiguration, whilst acknowledging we could not be completely inclusive of all views and opinions. We would welcome a robust review to inform future service provision and further participation of all stakeholders, including staff and families, in the future rollout of our services.

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3.2   On the PDSCYP Road of Change: Our Journey in Kildare West Wicklow

Anne Hughes-Kazibwe, Network Disability Team Manager & Nicole Dyrssen, Project Manager, Office of Head of Social Care, Community Healthcare Dublin South, Kildare & West Wicklow, HSE.

This paper charts first-hand experience of *Progressing Disability Services for Children and Young People* (PDSCYP) in Kildare and West Wicklow. In addition, it shares the findings of an independent review. Thus, this paper offers practitioner insights and reflections, as well as an objective assessment, all of which focus on how best to deliver services.

Pre-Reconfiguration

In the years leading up to the reconfiguration, the vision and mission served as our road map.   We knew that there would be challenges to the process, but ultimately there was shared belief in the services as children were then receiving inequitable services. The preparation of teams was important and communication was key to ensuring all staff members were on the same journey.

A multi-agency partnership was established between Enable Ireland, HSE, Kare, Muiriosa, and St John of Gods. Consideration was given to establishing five teams on the basis of the primary care networks; however, three teams were established in north, mid, and south Kildare.

Reconfiguration and Beyond

Services in Kildare and West Wicklow reconfigured in May 2014. A steering group was formed with representatives from the partnering agencies. Team managers were appointed to each team. The Network Disability Team (NDT) has expanded since reconfiguration. The teams, with about eighty staff, provide services to more than 1,200 children. Wait times for services vary and range from three months to one year.

As part of the change process, it was important to change the use of language to reflect a needs-led service rather than diagnosis or discipline-led service. It was also important to acknowledge and accept the anxiety that staff and families experienced. Building trust within the team began by remaining focussed on the needs of the children; providing informal support; co-location and open-plan office-sharing in which disciplines mixed. Staff identification, as a team, rather than by employer was encouraged and developed organically because the teams were developed on a multi-agency governance model. The development of competencies through both formal and informal training and support gave a solid base. In particular, caseload management training provided an opportunity for valuable team-based learning. The development of motor management services provides specialised support and further competency development across the teams.

A key service development in the past year includes the move toward *mini-teams* within school-age teams. *Mini-teams* are based on the geographical allocation of school-age teams in an effort to improve communication; caseload management; consistency for families; provide annual *Family Service Plans* and trust within teams. Where it is difficult to provide key contacts for all families, the *mini-teams* ensures that each family has an assigned key contact.

The culture of a family and child-centred service underpins all service developments. Communicating with families about how we work and what can be expected continue to bring challenges. Giving good information in publications, presentations and initial meetings with families is paramount. We focus on providing supports to families in their natural environments including home, school, and local facilities with local supports. The supports have also successfully included *sibling workshops*. Group

learning formats have mixed success with the most successful being those that have a one-on-one element as part of any group interventions (e.g., *Stepping Stones, Hanen*). Staff turnover has been high and training for specific programmes is costly, which impacts on the availability of trained and experienced staff to provide the group interventions.

Parental representation in the service has been an area of need and development. Parental representation on the steering group was achieved in the third quarter of 2017. The links with *Primary Care* and other services continues to develop, and has ensured that services remain inclusive and based on the needs of children rather than any criteria. A joint referral forum between Primary Care and NDT (Network Disability Team) managers was established early on, and continues to grow. Ongoing work is needed to provide for seamless transfer. In addition, the pathways for access to psychiatry are a significant need. The team manager role has been a key component to provide leadership and direction for the teams; support for staff and continued service development. Regular contacts and meetings between team managers have aimed to encourage cohesive messages, as each team develops.

Review

A review was commissioned by the HSE and conducted between June 2016 and May 2017 by Dr Dermot Rush of *The Performance Partnership*, with the bulk of the data collection conducted in mid and late 2016. The objective of the review was to identify what is working and not working in the service; reflect on how the service is evolving and make recommendations for continuous improvement. The review used a multi –method, stakeholder focused evaluation approach, covering six primary strands:

- Timeline Appreciation of Service Development;
- Effectiveness of the Service;
- Organisation & Efficiency of the Service;
- Customer Feedback and Quality;
- Service Capability Development; and
- Governance & Accountability.

Service Development

The review highlighted that progress had been made in integrating staff from five different employer organisations; establishing three team locations; developing a suite of policies and procedures and establishing a family–centred service model in line with the PDS national framework. Although significant resources had been put in place to increase staff numbers within the service, there has been difficulty because of high levels of staff turnover and inability to quickly fill vacancies or provide timely cover for leave. The review stated, "In its relatively short operational history, the service has shown a high degree of responsiveness and flexibility and has demonstrated the capacity to learn and adapt its service configuration to better meet needs within the resources available to it."

Effectiveness

Early Years

The Early Years Programme is generally well regarded by families. Children and families receive a range of intervention and supports underpinned by a regular *Family Service Plan* (FSP). However, families have expressed concern at how well the plans are followed through.

School Age

Feedback regarding the school-age team services is mixed, with schools finding it difficult to organise supports. However, specific supports are positively rated. The collaboration between the NDT and the school system is responsive and based on goodwill, rather than a systematic integrated approach. This is reflected nationally where *Health and Education Fora* are not in place, and are managed by different departments.

School-age teams did not exist for children within mainstream education in the area, until recent years. Although this is a developing area, up to thirty-three percent of families indicate that their needs are not being met by the school-age service. It is identified is that the service tends to deliver services in response to issues that parents raise rather than providing a regular, planned support process.

It is a challenge to meet the demands for the service. Additional staffing has been uneven across the disciplines, leading to substantial waiting times to access the supports of some of the disciplines. For example, due to the rise in complexity of need and the number of school age children, the service is not currently resourced adequately to meet the support needs of all families within the service. In this respect, the review noted, "The service also has considerable room for improvement in terms of facilitating access to the team and improving basic communication protocols. There is no doubt but that the service is under-resourced on the administrative front, as this element has not kept pace with the growth in clinical staff numbers."

Due to greater development of career opportunities in recent years, there has been natural attrition as clinicians have chosen to take new roles. This has led to loss of staff, who have specific training, experience and leadership skills. The review recommended "an enhanced career structure, formal practice development systems and an injection of resources to boost in-service training of staff."

Organisation and Efficiency

Data are not currently systematically collected. The report identified this as a key area of need to evidence how current resources are utilised and linked to service outcomes. It recommended developing an activity-tracking system and completing a resource-modelling exercise that would identify the relationship between child and family-support needs, core service-activity and resourcing needs.

Customer Feedback and Quality

A formal system for collecting regular feedback from families regarding their experience of the service is an identified need.   Family representation should be enhanced at all levels and the addition of representation on the Steering Group was welcomed. The review also calls for the exploration and possible adoption of a quality framework.

Service Capability

The review outlined the importance of systematic staff training, standard induction and practice development, to ensure the skill levels of staff and to uphold the standards within the service.

Governance and Accountability

The report contained more specific recommendations to configure performance management and clinical supervision on a more structured and sustainable basis given the complexity of the reporting and accountability within a multi-agency partnership. It noted "…we found that there is a positive and

cohesive team climate and great credit is due to the Team Managers for their contribution to building and sustaining collaboration and morale."

The final set of recommendations calls for a move toward a single integrated entity with a single lead agency and clearer lines of management. Alongside this, the steering group is asked to accept responsibility for taking a more proactive role in the strategic direction.

Map for the Future
Since October 2017, the steering group is pursuing a work-plan, based on the recommendations in this review. Communication sessions are planned for staff and families. In addition, an executive summary and family-friendly version of the report will be made available. A project leader was assigned to assist the development and implementation of the work plan. Thus, we are progressing the services on a solid footing and a strong evidence base.

3.3 Working in Partnership with Families

Hazel Trudgill, Director of Children's Services and Claire Stokes Occupational Therapist, West Cork Child Development Services.

West Cork Child Development Services (WCCDS) have been in operation since January 2013, when Co-Action West Cork amalgamated with the HSE. The service is comprised of four Children's Disability Network Teams (CDNTs) supporting more than six hundred families in West Cork. The families of children enrolled in the service are key stakeholders in its management.

This paper includes an overview of West Cork Child Development Services, including the history of a family-centred model of practice and parental involvement in the management and planning of WCCDS, illustrating how the service works in partnership with families. It also presents an example of a WCCDS parent-education initiative, which is well established in our service namely, 'Seminars for parents of children with a Developmental Co-ordination Disorder.' Finally, the paper discusses the evidence-based practice supporting this type of intervention and how such an intervention could be rolled-out across CDNTs.

How WCCDS fosters a family centred model of practice

1. Parent representation at management level: There are two parent representatives on the management group. Parents bring a unique and invaluable perspective to all aspects of service-provision and management and parent representation at management level has proved to be very beneficial. An example of parental involvement was when one of the parents contributed to the development of a new information leaflet for parents giving their essential perspective. This made a huge contribution to the content of the leaflet. Other members of the management group, in addition to the two parent representatives, are: the HSE Disability Manager, CEO of Co-Action, Director of Children's Services/Services Manager, a discipline-lead from the HSE and a discipline-lead from Co-Action.

2. Parent Fora: Parent Fora were set up in West Cork since the formation of the West Cork Child Development Services in 2013 and are now well-established and meet three times per year. Attendance ranges from fifteen to thirty parents per forum. Parent fora are led by the parent representatives, with the service manager being present to answer questions during the meeting, as well as being available to meet with parents individually as needed after the meeting. A typical meeting includes a speaker for thirty minutes, fifteen minutes of questions and forty-five minutes of discussion time, including a report on recent service developments from the parent representative and the service manager. Parents report that they find these meetings very informative and supportive, and that they offer a great opportunity to meet other parents.

3. Parent Support Groups: The clinical nurse specialist on each team organises a local parent support-group. This is a smaller group, and it allows parents living in the same community to meet and talk in an informal setting.

4. Keyworker Role: Each family is allocated a keyworker on their child's enrolment with the service. The keyworker is the main contact for the family and the link with the Multi-Disciplinary Team (MDT). He / she works in partnership with the family to support them and provides assistance when needed. In addition, the keyworker is responsible for co-ordinating the Individual *Family Service Plan*.

5. **Individual Family Service Plans**: An individual family service plan meeting takes place at times of transition in the child's life, and is a process of collaboration between the family and the team in order to agree outcomes. There will be a written record of agreed outcomes that focus on the child and family's strengths, needs, goals and plans.

6. **Parent Training**: During the last two years, we have focused increasingly on parental training; types of training include:
- *It takes two to talk*;
- *Early Bird*;
- *More than Words*;
- DCD/Dyspraxia Training for Parents;
- Assistive Technology; and
- Anxiety Management.

7. **Communication:** As the service has developed, we are continually reviewing how we communicate with parents with a view to its improvement. Letters to families have been updated, new leaflets have been designed with parental involvement and a parent waiting-room folder has been introduced with photographs and a profile of each member of the team and their role.

An Example of a WCCDS Parent Education Initiative:
Developmental Coordination Disorder (DCD) parent-education seminars involve all of the multi-disciplinary team and guest speakers. They constitute an example of how such initiatives can be applied to the newly-restructured Children's Disability Network Teams (CDNTs).

Developmental Co-ordination Disorder (DCD) is a neuro-developmental condition characterized by poor motor proficiency that significantly affects an individual's functional performance in daily-living. Research highlights that DCD is a chronic disorder with motor difficulties lasting into adulthood. It indicates that children, who present with a diagnosis of DCD, are at higher risk of obesity, coronary vascular disease and poor physical fitness. Motor difficulties have also been linked to an increased risk for mental health issues, including anxiety and depression (Caçola, 2016).

A child, who is accessing a therapeutic appointment once a week for one hour per week, is spending less than two percent of his or her time in therapy. Research findings call for a sustainable service-delivery model, which increases the awareness, knowledge and capacity among the adults who have a direct influence in the child's daily environment (Missiuna *et al.,* 2012). Indeed, the Health Information and Quality Authority's (HIQA) national standards for safer, better healthcare call for service-delivery models which support service users to have greater responsibility for maintaining and improving their own health (2012). The standards also state that services should be responding to individual needs, but also taking into consideration the collective need. Due to growing caseload demands, clients who score lower on prioritisation matrices are waiting an increasingly longer time for intervention. Currently, there are more than 120 children across the four CDNTs presenting with DCD.

In consideration of WCCDS' resource limitations and evidence supporting a parent-focused intervention, in 2014, we rolled out an education series for parent and caregivers of children with DCD. Following on from the success of the initial seminar and the positive response from parents, the seminars became a yearly event. A database of all children in the service with a known diagnosis of DCD was established, and continues to be updated and monitored. This database is used to track uptake of the seminars and to inform families of upcoming seminars. As it is used by all four network

teams, in excess of one hundred families will be invited to attend, with maximum capacity for thirty-five. The seminars are operated on a first-come first-served basis.

Through trial and error, we found that sessions, each of two hours' duration, weekly, at evenings, over three weeks, during school term are optimal. Uptake in the summer months was poor due to childcare issues. Moreover, the content of the seminars was less relevant for families during that time of year. One day-long seminar was also trialled, and there were similar uptake issues, due to parental work commitments.

In designing the layout of the educational evenings, the first evening was tailored to parents or carers of those children who were recently diagnosed, while the second two evenings covered new topics for all parents to access. A representative of each of the disciplines presented and covered a new topic each evening. An example of a seminar series schedule is included below, for your reference. Guest speakers were also invited each year, one guest per year e.g., The Co-ordinator of Dyspraxia Ireland.

Example of 2016 Schedule
May 5th 2016
- 'What is DCD? The impact of DCD on Daily Living Activities,' Aileen McCarthy (Senior Occupational Therapist);
- 'Practical strategies on how you can help your child in the home,' Fiona O'Connor (Occupational Therapist);
- 'Sensory Processing and DCD,' Claire Stokes (Occupational Therapist);
- 'Linking Speech and Language Difficulties with DCD/Dyspraxia.' Denise Healy (Speech & Language Therapist).

May 12th 2016
- 'Assistive Technology to Enable Students' Success. DCD/Dyspraxia.' Deidre Madden, Disability Support Services, University College Cork.

May 19th 2016
- 'Coping with Anxiety,' Dr Eileen Nitsch (Senior Clinical Psychologist);
- 'Maximising resources in the home,' Riona Hill (Senior Physiotherapist);
- 'How to set SMART goals with your child,' Claire Stokes (Occupational Therapist); and
- Questions & Answers, Feedback, Browsing of Equipment.

Post-outcome measures were administered at each education evening to get parental feedback on the content, accessibility and suggestions for improvements. The outcome measures were comprised of simple, accessible rating scales. Suggestions for future topics were also requested. The findings of the outcome measures and the suggestions given by parents were then presented at in-service training for all staff and used in the planning of the next seminar.

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3.4 Autism Spectrum Disorder Assessment Pathway

Jimmy Burke, Senior Physiotherapist; Mary Lillis, Senior Speech and Language Therapist; Ursula Noonan, Occupational Therapist – HSE Early Intervention Team, Dublin North, CHO Dublin North City and County.

This paper contends that assessment of young children, for whom there is a query of *Autism Spectrum Disorder* (ASD), highlights the need for close collaboration and team working. It draws on first-hand experience of the North Dublin Early Intervention Team (EIT). Here, a refined pathway for assessment has been developed over time, and is continually monitored and reviewed.

The North Dublin EIT ASD Assessment Pathway was created for children and families and is based on best-practice guidelines, parental feedback and team working. The child and family are at the centre of the assessment process and the assessment pathway begins with a developmental interview with the child's parents or carers. The whole-family context is considered to fully inform the clinicians and to reflect on whether or not the timing for assessment is right for the family. The assessment and a possible diagnosis are discussed. These shape the family's expectations and allow them to withdraw, if this is what they prefer.

Family feedback is taken and adopted as part of the pathway. This feedback is collected formally after the assessment and informally throughout the process of involvement with the service. It shapes the structure and content of assessment sessions. In addition to this, each child has an individualised assessment plan, which is tailored to the family's needs.

The pathway was developed by the team and the management group, in the context of National Institute for Health and Care Excellence (NICE) guidelines and the Psychological Society of Ireland guidelines for best practice in autism assessment. Every effort has been made to meet these best-practice criteria, within the context of the other demands on the service and the families involved.

Team-working is critical within the pathway, and as stated above, the pathway is the result of the team working together to define it. Every child sees a clinical psychologist, occupational therapist, physiotherapist and speech & language therapist. A clinical psychologist and one of the other clinicians above-mentioned complete the *Autism Diagnostic Observation Schedule Second Edition* (ADOS-2), which evaluates an individual suspected of having ASD. A social worker also forms part of the team, as required, and school or home-visits form part of the assessment process. The North Dublin EIT works in different combinations of clinicians when completing this assessment pathway, so as to allow every team-member the chance to work with others and to learn from the practices of others.

Our team-working is facilitated by weekly clinical team meetings, where the child's progress through the assessment pathway is reviewed and additional interventions can be planned as required. Complex cases are brought to whole-team discussion to get additional perspectives and ideas on management. The clear structure of the ASD assessment pathway at the North Dublin EIT ensures a comprehensive assessment. In line with best practice guidelines, assessment is carried out in a manner that suits the child and family. Interdisciplinary working is at the core of the ASD assessment pathway, and this dimension strengthens and supports this assessment process.

3.5 Promoting Inclusion and Participation in Preschool: Collaborative working - Families, Preschools, Early Intervention Teams, Access and Inclusion Model (AIM) and Early Years Specialists

Fidelma Loughnane, Preschool Liaison Teacher and Aisling Jones, Galway Early Intervention Services.

It has been a long-standing challenge for communities to support children with additional needs in their local preschool. As a consequence, that access for many children has been limited and on occasion, not possible. Traditionally, these supports were provided by the child's local Disability Service only. This paper presents a Galway-based case study, and it examines how such challenges have been addressed.

In Galway, the Brothers of Charity provided a small yearly grant to parents of children with an Intellectual Disability. This grant was given to parents to employ a preschool assistant for their child in preschool. Enable Ireland employs personal assistants (PAs) for children with a physical disability. These personal assistants were employed, mainly to support children in the preschool setting, significantly affecting their availability to support them at home or in the wider community. Both the preschool assistants employed by parents using the grant and the personal assistants employed by Enable Ireland were supported by their local Early Intervention Team.

These services had limited budgets and often were unable to provide sufficient support to allow a child attend preschool for the number of hours the family had hoped. The introduction of the *Early Childhood and Education Scheme* in January 2010, whilst providing increased opportunities to a large number of children, highlighted the gap in support for children with additional needs in the preschool environment with many children being unable to access this scheme fully due to insufficient resources and poor adaption of the physical space.

In June 2016, The Better Start Access and Inclusion Model (AIM), led by the Department of Children and Youth Affairs and involving the Department of Health, the Department of Education and Skills and others was introduced. Better Start AIM is a model of supports designed to ensure that children with disabilities can access the Early Childhood Care and Education (ECCE) programme. Its goal is to empower service providers to deliver an inclusive pre-school experience, ensuring that every eligible child can fully participate in the ECCE programme and reap the benefits of quality early years care and education. The model is designed to be responsive to the needs of each individual child in the context of their pre-school setting. Springtime Early Intervention Service (SEIS) and Better Start AIM recognised that collaborative working between the teams would greatly enhance the work of both teams and support positive outcomes for children. Collaborative working proved to be essential to ensuring that the experience of working with preschool supports was a good one for families and preschool staff.

From September 2016, a number of discussions took place between Early Intervention Service (EIS) Preschool Liaison Teacher Manager and the National Coordinator (AIM). In EIS, the key worker plays an important role as he/she has established close relationships with the families and the ECCE preschool staff. In Better Start AIM, the Early Years Specialists (EYS) liaise closely with the preschool to ensure the child is included and participating in the preschool day. Structures and fora were explored to see how a relationship between these two key people could be developed. To date, the following collaborative work has taken place.

- Introduction of The National Co-ordinator of Better Start AIM and the early years specialists to the five Early Intervention Teams throughout the city and county where everyone had the opportunity to give an overview of their role;

- Acknowledgment of the importance of collaborative working by both the Early Intervention Teams and Better Start AIM Team and recognition of a shared vision for a coordinated interagency preschool service for families and preschools;
- Meetings between the staff in ECCE settings, Early Year Specialists and Early Intervention Team members to ensure common goals were being addressed for children through review of the Springtime Early Intervention Family Service Plan and the AIM Individual Access and Inclusion Plan;
- Early Years Specialist and EIS Team members scheduled set times for Case Discussions for children with complex needs;
- Functional SMART goals written and strategies to support these goals discussed;
- A clear action plan with who would link with the preschool and who would link with the family agreed;
- The framework of the case discussion allowed for concerns to be identified with how supports by both teams were being implemented and provided a space to discuss these concerns in an atmosphere of trust and mutual respect;
- Where equipment and physical adaptation needs had been identified, applications for Level 5 were completed by relevant EIS team members, and given to the preschool;
- Planning and support for the child's second year of ECCE and their AIM allocation; and
- Meetings in April 2017 to identify new children for the AIM Better Start Programme in September 2018. Families and preschool contacted and supported families with the application process, where required.

Where are we now?

Given that all was so new in 2017, both EIS & AIM team members feel a lot has been achieved and there is a good foundation on which to grow. Dates are currently being organised for case discussions between EIS keyworkers and AIM EYS, for this coming term. It is hoped planning meetings can also be scheduled this term to explore and brainstorm some of the challenges that continue to face us all, as we continue to promote inclusion and participation for all children in the preschool setting. We have identified the following challenges / issues:

- Providing appropriate and sufficient support for children with significant complex needs in a mainstream preschool, so that there is a meaningful experience for the child; and
- The introduction of Better Start (AIM) has heightened awareness of children with additional needs in the preschool setting and the EIS team members are experiencing a real appetite for learning and upskilling among preschool staff.

On a final note, EIS is aware of the need for recording outcome measures and introducing reflective practice, as part of its own working and as part of joint collaborative work with families, Better Start AIM and preschool staff. The EIS Training and Development Group is committed to addressing this gap in the early intervention teams, and it is hoped that it will, in time, be a natural part of all our work. Access and inclusion within the preschool environment, for all children, are priorities for anyone working with children of this age group. Activities can include sitting together, participating in some daily activities enhancing opportunities to develop meaningful peer relationships, to a walk to the local library, which involves community participation at another level. It is our hope that the collaborative working approach of the Early Intervention Team and the Better Start AIM Team, with preschools and families, is one more step in the right direction for these children.

A Parent's View

"Mark had a PA from Enable Ireland supporting him in Preschool. When AIM was introduced, this support was greatly enhanced and it felt like we had found the missing link. The two teams worked well together and with the preschool, and this was very positive for Mark and us a family. We were no

longer concerned that Mark was isolated during the day for specific activities or becoming dependent on his assistant, while still knowing that the activities were appropriate for him and that he was not over or under-challenged in his day. Having the two teams liaise well together and with the preschool took a lot of pressure off us as parents worrying about this."

- Kevin Dolan, Ahascragh, Ballinasloe

A Preschool View

"For some years now, we have been liaising with the local Early Intervention Team and have received supports and guidance from the Preschool Liaison Teachers as well as other members of the Early Intervention multidisciplinary team. This past year saw the introduction of the AIM programme. This was particularly exciting for us as we are extremely interested in being proactive when it comes to supporting children with disabilities to ensure that they have full access to our pre-school programme (ECCE). We have found the AIM Model excellent and found the supports given by the Early Years Specialist invaluable.

As a direct result of our partnership with the Early Intervention Team, AIM and through my training with LINC Course, we have also begun using 'TAC Meeting' (Team around the Child) to support the children with disabilities. We invite the child's parents as well as anyone involved with the child's development across all sectors to come to a meeting. At the meeting we discuss the child's strengths and develop a plan, including goals for the child. We then use an Access and Inclusion Plan to support the child to achieve their goal. We have found these meetings beneficial and it allows us to see the child from a more 'rounded' perspective.   We are delighted to be supported by the Early Intervention Team and the AIM EYS in supporting inclusion in our service."

- Gráinne Holleran, Little Stars, Tuam

QUESTIONS AND ANSWERS:

IDentifing the need for specialist pathways so the child doesn't get lost in the network!

3.6 Joint Working Practices - Supporting the Student with Complex Special Needs

Éilis Dillon Principal St. Cecilia's School, Cregg, Sligo and Lisa Mc Gill Senior Paediatric Occupational Therapist Sligo-Leitrim.

St. Cecilia's School Special School, Sligo, welcomes students from 4-18 years of age with moderate, severe and profound learning / intellectual disability from Sligo, Donegal and Leitrim (CHO 1 Area). Currently, the school runs three curricula: Primary 4-12 years; Level 1 Junior Cycle (pilot); and Level 2 Junior Cycle. There are two classes for children with autism – Junior and Senior. In total, there are eight classes of forty-four students.

At present, Sligo-Leitrim has not yet reconfigured School Age Teams. However, designated team members are in place for school age services, and there are long-established good working relationships in place in Sligo-Leitrim. We are going to give three examples of the work in Sligo, which is directly transferable to the PDS model of inter-disciplinary teams providing services based on the child's needs.

In Sligo, in 2002, a joint working party between health and education was formed. This aimed to discuss services for students with disability, who, at that time, were mainly in special schools. Educational requirements, continuum of needs, post school provision and support services were all on the agenda in those early days. This innovative group was successful because senior management in the HSE and Department of Education and others in positions of influence on policy were participants. At various times, membership included representation from the Department of Education and Skills Inspectorate, HSE learning disability managers and therapists, occupational therapists, parents, principals of special schools, the National Council for Special Education (NCSE) and National Educational Psychological Service (NEPS). This group was in place for five years, but ended with the introduction of new management structures. The working group set the foundation for good working practices and relationships between frontline health and education services.

Three key areas in 2005 included transport, respite and further education. Work continues in two of these areas – transport and respite. Research by Povenmire-Kirka *et al.*, (2015) found the positive characteristics of interagency capacity to include relationship-building within teams, encouraging members from a variety of organizations to participate, a commitment to time for meetings and projects and engendering a sense of cooperative leadership. Collaborative strategies, which affected team working, include mutual training and information sharing across agencies, knowledge of each agency through site visits, and designing and participating in-group projects. The particular areas we are going to focus on are: transport; working for transitions; IEP reviews; and respite.

School transport for special needs is complicated in Ireland. Bus Éireann administers the School Transport Scheme on behalf of the Department of Education and Skills. Many routes are operated by private bus operators, under contract to Bus Éireann. School boards of management employ bus escorts to escort students with complex disability and care needs to and from school. Transport can involve an occupational therapist, whose aim is to work with children and young people to provide them with the most appropriate seating, wheelchairs and positioning equipment to meet their individual needs. The occupational therapists observe the students on the bus, and they advise escorts and bus drivers as appropriate. In a unique way, there is a large group of people working together; to transport students with special educational needs to school.

Working collaboratively with bus escorts, occupational therapists, school inspectors, parents and Bus Éireann (2005-2010) led to the establishment of joint training for bus escorts and bus drivers in the areas of child protection, manual handling, challenging behaviour, epilepsy and other dimensions of child wellbeing. Training has taken place in Sligo Education Centre (DES) over many years. In addition, and following research with key stakeholders – parents, bus escorts and principals, a pilot twenty-hour course was provided by the Centre for Special Educational Needs, Inclusion and Diversity, St Angela's College, Sligo. This was delivered in association with the National Association of Boards of Management in Special Education (NABMSE), and was held in Galway in 2013. It was attended by twenty-three bus escorts from the Galway region. Dr Emer Ring from Mary Immaculate College carried out an independent evaluation, and the findings were extremely positive. We hope to roll out similar training in more venues in the very near future. On a practical level, the Occupational Therapy Department and school have drawn up a transport profile / passport, which travels with the bus escort each day.

Collaborative working for transitions had very good outcomes in the past. Clear pathways are in place for a child beginning school. Transition includes visits to schools with parents and the EIT dedicated key workers, the Community Facilitators for Disability or Autism Therapists. A range of schools is included, and the multidisciplinary team make recommendations, but parental choice is paramount.

Regarding post school placement, the policy 'New Directions' is very positive and welcomed. It has the capacity for self-directed funding and choice for students and their families. However, the practical changes in service provision take time and we do not want to lose any long-standing good practice as local initiatives and local decision-making transfer to national policy. "People with disabilities want a 'joined-up service' that enables them to move easily between HSE services and the services provided by other government agencies" (HSE Working Group, 2012: 15). The concepts and thinking behind *New Directions* are beginning to unfold in practice. The teams are dedicated, but it will take time for the new systems and practices to properly imbed. It is our hope that further education will play a big part in post school placement for all with a disability.

Joint Multidisciplinary / IEP Reviews are held at least twice a year in our school. These meetings are attended by all the members of the MDT who are involved with the student, as well as the parents and teacher. Depending on the student's needs, the team may include paediatrician, physiotherapist, occupational therapist, speech therapist, behaviour therapist, dietician, community facilitator, autism therapist, and the Visiting Teacher Service. The joint meetings are a good example of partnership in the best interest of the student and his/her parents. All progression, strengths and needs are discussed collaboratively, and this holistic approach is in line with best practice.

"Effective individual education plans have key characteristics which are …child centred, inclusive, holistic, collaborative and accessible" (NCSE, 2006: 5). Each meeting is specific to each child. The location of the meeting encourages site visits and the commitment of a range of professionals. It benefits other professionals to see the child in his/her school environment and observe how busy and happy he/she is. This may be in direct contrast to the child seen in clinic, who, in some cases may be stressed and uncooperative. The practice of holding joint meetings is in place in other schools in Sligo. The reality is that as more and more meetings take place in different geographical locations professionals may not be available to attend. This good practice will have to be carefully monitored moving forward. The benefit of everybody working to the same goals must be protected, in the best interest of the child.

Respite is very important for young people with disability and their families. To meet this identified need, a working group set up a Saturday Club every second Saturday from 2-4 pm in St Cecilia's School. The agencies involved include:

- St Cecilia's School, who provide the school building, electricity and heating as well as the use of the school bus;
- Family Carers Ireland, who recruit and coordinate staff;
- the HSE, who organise the administration, correspondence and funding; and
- Sligo Sport and Recreation Partnership, who provide a coach for one hour each Saturday.

The response from parents has been very positive, and there is a waiting list in operation. Further evidence of the success of this project is that it has now been extended to include a summer camp for three weeks in August. The location and facilities at the school meet the needs of children with complex disabilities and medical needs, and the entire setup is inclusive of children from Co. Sligo with moderate – SpLD, who wish to attend the club. For those who participate, it is something to which they look forward and love. For the first time, they are going to club just like their brothers and sisters. It frees up parents to spend time with other children. It is consistent, avails of excellent facilities required by those with complex needs, and it is ongoing all year round. Parents must bring the students each Saturday, as transport is not provided. Social experiences are arranged as part of the club activities, and, moving forward, this working group will continue to look at opportunities to involve the participants in community activities, in line with good practice.

We have discussed some practical examples of joint working, joint planning and on-going collaboration in our area. We anticipate that this ethos will continue through the Local Implementation Groups and governance structures for future planning, based on the needs of the stakeholders with whom we work. Working collaboratively with key stakeholders enables the best service for the student (Griffin and Shevlin, 2007).

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3.7 Managing Referrals and Waitlist for a Children's Disability Network Team

Anélle Marynowski, Former Early Services Manager, Enable Ireland and Anine Willemse, Senior Occupational Therapist, Meath.[1]

When discussing disability services in Ireland inevitably long waiting lists, lack of service provision, delays in assessment, and other shortcomings are regularly mentioned. These are real issues for a Children's Disability Network Team and they have a significant impact on the service users, as their needs are not met sufficiently, if at all, or in a timely fashion. Enable Ireland Meath Early Services serve children under the age of six years of age who have a disability or complex needs or a query of same. Currently, the service has over 650 children attending, and the referral rate has been increasing (see below) with very little increase in the number of staff – two new posts in 2016 (the first posts for a number of years).

Volume of Service Referrals by Type to Enable Ireland Meath Early Services, 2014 - 2017

Year	Total Number of Referrals	Number of AON[2] Referrals	Number of Direct Referrals
2014	232	70	162
2015	310	135	175
2016	270	122	148
2017	291	110	181

Note for 2017 the AON officer has been on extended leave for a period.

An increase in referrals does not just impact on service users, but also on staff. The NDA report on Children's Disability Services in Ireland (2015) highlighted the following strategies to help maximise service provision within limited resources:
- Establishing clear pathways for accessing services ;
- Carrying out initial assessment of needs and prioritising clients; and
- Establishing waiting list procedures, such as review and recall.

This led to the development of an assessment triage process and waiting list management system. This process incorporates all the strategies mentioned above. Two different teams were formed from existing staff to address the clients in the service – an assessment team to assess and prioritise all new referrals in a timely fashion and a team to provide intervention to clients. Post allocation to the assessment team was based on the referral rate at the time and an agreement with the HSE to complete a certain number of AON assessments per month. Clear pathways for assessment and intervention were set out as follows:
- All new referrals will get the same baseline assessment and report, as well as programme or home advice;
- Once assessed, a child is either waitlisted for intervention or referred on to the most appropriate service, based on his/her needs; and
- Intake of children from the waiting list will be done every six months, to align with intervention planning that was done for six-month periods.

The assessment team consists of a speech and language therapist, physiotherapist and occupational therapist. The social workers and psychologists are not dedicated to assessment only, but has time allocated to do initial visits or any assessments required. The initial assessment aims to identify client

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[1] Anélle Marynowski is now Service Manager, Mid-Kildare West Wicklow Network Disability Team, Enable Ireland. Anine Willemse is currently Team Manager in Enable Ireland Dublin South West (Tallaght).

[2] AON (Assessment of Need)

needs and to help to prioritise which services to provide to clients and when. Each child is given the same initial assessment process, regardless of whether or not the child is referred directly or via AON - to prevent all referrals being AON[3].

An initial visit is completed by a social worker to explain the assessment process and also to gather background information. This information is shared with the other team members who will carry out the inter-disciplinary play-based assessment. The focus here is on getting an overall sense of the child.

If appropriate, follow-up assessments are arranged with the family. These include pre-school or school observations. After all assessments are completed, a team-report is written and feedback is given to parents. A session to show parents what they can work on at home and other advice may be provided. Clear explanations about onward or external referrals or waiting-list times are given to parents. If the child does not meet the criteria for the team, he or she is referred to another appropriate service. If the child meets the criteria, his or her name is placed on the waiting list with the relevant intervention team. A handover note and the *Rating Tool* are completed to clarify the child's needs - such as individual or joint sessions, groups or specific therapy programmes. If appropriate, referrals to other disciplines or services outside of the team are also completed.

The leader of the intervention team will monitor the waiting list and *Rating Tool* information. If appropriate groups or programmes have been identified and spaces are available or it has been highlighted as a very high priority, the option will be offered to the child and family, while waiting. The child is automatically scheduled for intervention during the next intervention-planning block and to date, the longest waiting period for intervention has been six months. The *Rating Tool* aims to:

- Identify the urgent and non-urgent needs of children on the waiting list;
- Ensure a child with urgent needs is not left waiting for intervention for same (when the urgent need is addressed they can return to the waiting list);
- Ensure consistency in determining urgent and non-urgent referrals regardless of the assessors;
- Allow for a consistent approach in assessing children wait-listed to measure change in needs; for example, an intervention which was identified as non-urgent following initial assessment may be changed to urgent due to school-start not going well;
- Assist with establishing a place on a waiting list (considering: needs, date of referral and age);
- Assist with intervention planning. The scores need to link with intervention planning i.e., there is a clear link between needs and packages of care;
- Ensure early identification of suitable parent and child groups. A place in a group can be offered while waiting for intervention; and
- Aid in communicating with staff expectations, regarding caseload management, in particular for children with identified urgent need(s). Children with urgent needs will need to be seen by the relevant team members within two to four weeks.

The *Rating Tool* was developed by a working group made up of: a social worker, clinical psychologist, physiotherapist, occupational therapist, speech and language therapist and liaison nurse. It is based on the following policy documents:

- National Policy on Access to Services for Children and Young People with Disability or Developmental Delay (2016);
- National Policy on Prioritisation of Referrals to Children's Disability Network Teams;
- National Policy on Discharge/Closure and Transfer from Children's Disability Network Teams;
- Enable Ireland Code of Practice: Pathways of Service Delivery for Children and Families; and
- Enable Ireland Children's Services Operational Plan 2015-2017.

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[3] Note that babies <12 months with delay or <2 years with a diagnosed disability are accepted into service via a Baby Pathway.

Transfers and re-referrals are currently not included on the tool however, they could be. This whole process has been in place since 2015. The time taken from date of referral until a child's assessment is completed has been significantly reduced. If a diagnostic assessment is required, the process takes a little longer, as the following figures indicate:

Year	11/2015	10/2016	02/2017
Average Time to complete assessment in days	256	164	93

The time taken to complete the process is impacted by school holidays, as school observations have to wait. Other factors include: non-attendance or cancellations by families; screening forms not being completed or returned in a timely fashion and staff absences and changes.

In the main, the process has been found to be very positive for all involved. Families are reporting that they appreciate the level and clarity of information provided; they were surprised to be seen so soon; they felt their child had a thorough assessment and they were given practical advice that they can follow up. Staff members reported less stress as they were not asked to meet shifting goal-posts and can focus on providing as much intervention as possible. Assessment staff members have the time to do comprehensive assessments and write reports that are concise and user-friendly. They also provide the families with some activities to work on while waiting for intervention and serve as a contact-point for families who have questions or concerns.

As the process has developed, fine-tuning was required:
- A leaflet explaining the assessment process for families has been developed;
- The report template has been improved to ensure better flow and readability of the reports;
- The assessment team members are all located in the same office to improve opportunity for case discussion;
- A specific format for handover to the intervention team is being pulled together; and
- The *Rating Tool* scoring is under review.

There is still more that can be done to make the whole system as smooth and efficient as possible, but that requires time and practice. For the moment, we are proud to say we can provide a more efficient and transparent assessment and waiting-list management service than before. We hope that our learning will benefit other teams that may be in the same position.

3.8   Working with Families from a Mother's Perspective

Silvia Segales-Angel, Early Intervention Specialist, St. Michael's House and mother of a boy with autism.

When my son Sebastian was two-and-a-half years old, he was diagnosed with autism. At that stage in my life, I had been working in early intervention, with children with intellectual disabilities, in Ireland, for nine years. Although my experience as a professional could not help me deal with this totally unexpected event in my life on an emotional level, it certainly influenced how I have been able to help Sebastian throughout the years. Through my son, I have had the opportunity to meet many other families of children with special needs. We all share the same journey and we support each other, in any way we can. Although we share a lot in common with other families in the same situation, there is one aspect that is very different. The difference is that I am fortunate to have "information" because of my professional background.

I have more information on autism, child development, types of intervention and therapies, strategies, public services available, private practitioners, and modes of support than other families do. With this information, I can quickly identify what areas we need to work on at each different stage of my son's development. For example, last summer I brought Sebastian on holidays. We were away for a few weeks, and Sebastian struggled because he was out of his normal routine. In preparation, I created daily schedules; established clear routines for those weeks; planned transitions between activities and gave him opportunities for quiet time. I could do all of this because of the knowledge I have gained over the years from my professional career, but also because of the guidance I have received from the great professionals I have encountered along the way. On the other hand, a friend of mine has a five-year-old girl with autism, and she is also non-verbal. My friend told me about her visit to a private speech therapist. This particular therapist advised her to stop using pictures as a method of communication with her daughter, as this would hinder her speech development. In this instance, due to a lack of information, my friend who was paying privately for this therapist, didn't realise that this advice was poor. She didn't have the knowledge or experience to judge if this professional was giving her sound guidance or not.

As professionals, the best way to support families is by empowering them. By focusing on "therapy sessions" and one-on-one intervention with a child, we are limiting the effect of that intervention. During those sessions, if we focus on sharing information and skills with families and teachers instead, children can then be supported by their family and community, all the time. We need to focus on developing people's resourcefulness. Although many parents may think, "I am a parent, not a therapist," the truth is that the more knowledge and expertise a parent has, the more he/she will be able to support their child and make better and more informed choices.

Working together with families: How can we communicate this message to families?
The first weeks and months following diagnosis, when families start linking with services is a very important time. It is the most effective time to speak with these families about working co-operatively. Families know their own child more than anyone else, does and professionals know very specific information related to their child´s diagnosis. Families need to be reassured that they are the main and most important educators for their children. The services available will help by supporting them with information and input that is specific to their child's needs. Parents know their children, and they really hold a very important and unique role in assisting their child to develop. We must try as professionals, not to disempower parents. When our son, Sebastian, was first diagnosed with autism, we met so many "experts" offering advice about how to parent him. We started to feel inadequate and overwhelmed, almost doubting our own parenting abilities.

It is true that professionals have crucial information that will help children with additional needs, but we parents know our children the most. This knowledge and relationship with our children is so important and valuable. We, as families, have our own values and parenting styles. We have the right to choose approaches that feel comfortable and integrate with our personal parenting approach. From the very beginning, professionals need to be clear that they are there to help parents, who are the main supports for their own children. As professionals, we need to make sure that we do not make parents feel inadequate by acting as 'experts'. From my perspective as a mother, I have identified three key points that help services create positive relationships with parents, even when time and resources might be less than required:

- Correctly identify family priorities;
- Develop parent's resourcefulness; and
- Give families actionable steps that they can easily implement.

Correctly identify family priorities
Quite often, professionals base their intervention, with my son Sebastian, on the results of tests and checklists that may or may not be relevant to our family. As a mother, I can identify areas of my everyday life with which I struggle. For example, the teachers in Sebastian's pre-school were, despite their best efforts, overwhelmed by him; so I had to take him out of the school. I also had to stop meeting with family and friends because Sebastian was very uncomfortable in a room full of people. At this stage, he had no methods of communication - other than tantrums.

Let us bring families back to their everyday life. What are they struggling with on a day-to-day basis? Professionals need to listen to the goals on which families want to work. Then professionals will have the knowledge to break down that goal and design a process with little achievable steps. A family that wants their child to walk might be guided through exercises to work on to help the child to stand unsupported for a few seconds at first. Similarly, a family that wants their child to talk might be introduced to the Lámh hand-sign system. Families establish their priorities and professionals guide them by planning small steps in that direction. Base your intervention on the unique difficulties that a family is experiencing in day-to-day life.

Developing parents' resourcefulness
As professionals, we need to become teachers to the parents that we meet. We should aim to "work ourselves out of our jobs." By saying this, I mean that over time, we should aim for parents to know as much as possible about their child's condition. Share with them what you are doing, but most importantly, <u>why</u> you are doing it; so that families, just like mine, will be able to continue to support our children when you are not there. If you establish a good foundation, we will be skilled years down the line when you are no longer working with us.

In my experience, effective and successful professionals combine practice and theory together. When Sebastian was younger, his speech therapist used to come to our house. Many times, we played in the garden while she was coaching us on how we could interact with Sebastian so that he would engage and communicate more with us. The fact that the speech therapist combined practical examples that we could easily copy, and patiently explained the rationale behind them, gave us tools to help Sebastian on a daily basis.

When Sebastian was younger, I was hoping to find someone who would do all the interventions for me. Having to deal with everyday life with an autistic boy, plus having to work on interventions felt like a burden that I did not want to carry. Now looking back, I see how much my husband John and I

have been able to help Sebastian, and how much we help him still today. Although we did not ask for or plan for this, it is a job that LIFE gave US. Our hard work over the years has had a huge impact on Sebastian´s quality of life. It is a very big responsibility for us as parents, and it is something that no-one else can do for us. However, professionals can help us to develop our own resourcefulness, and that needs to be the focus of any intervention.

Giving families actionable steps that they can easily implement
As an early intervention specialist, I create lengthy reports about the children with whom I work. These reports consist of four to five pages of goals and activities to help children in all areas of their development. It certainly helps me to monitor children's progress and to plan for specific goals, but how do they help families?

For my son Sebastian, I work in a very different way. My 'Home Programme' is a collage of pictures on our fridge door. It normally starts with one or two affirmations that motivate my husband and me to stay patient and persistent in our work, because living with autism at home is not easy. Then we usually select one new goal on which to focus. From that one goal, we might list a few steps on how to get there. Any more than that would be very unrealistic for us. We also have a weekly calendar for Sebastian to look at, since he likes knowing what is happening every day. Our collage and calendar have been designed with fun and colourful images and shapes that are easy and enjoyable to read. We keep it all very simple, with easy wording and images. We also plan activities that we can do at home as part of our normal routines. With these small simple goals and achievable tasks and working together as a family we have had great success. We should keep this in mind for the families with whom we work professionally - the simpler the better. The more we plan with them, rather than for them, the more success they will have. I understand that professional documents need to satisfy certain standards, but for families, reading pages of wordy documents might not be very effective. It is a challenge, even for me, to find a balance between these documents that I write as a professional and the *Pinterest* forms that I use at home to set up our own personal goals. It is important that we review this and make sure that we create guidelines and programmes for families that are simple to follow and implement in the home.

Over the years, I have been able to help my son Sebastian, because I had information about autism, due to my professional background. I saw the advantage I had over most families, and the positive impact that this has had on Sebastian's quality of life.   When professionals focus on giving parents practical knowledge and skills, parents will be able to support their children 24/7. If we, as professionals, can create a good strong foundation, parents can support their children in daily life and long into the future.

3.9 Managing Sleep Problems in Children attending the Early Intervention Team

Denise Gillespie, Advanced Nurse Practitioner Child Health and Parenting, Donegal and Joanne Dowds, Social Care Worker, Letterkenny Early Intervention Team (EIT).

Sleep is important for health, well-being and development and has important functions in memory consolidation, growth and development (Mindell and Owens 2015). Sleep problems are common in infants, toddlers and pre-school children and are highly prevalent - occurring in approximately 20-40% of children during the first two to three years of life (Meltzer *et al.*, 2008). The incidence in children with disabilities is much higher, with research identifying prevalence rates of 34-80% (Bartlett *et al.*, 1985; Richdale and Prior, 1995; Quine, 2001). In children with disabilities, the problem is likely to persist, if a sleep intervention is not provided, and poor sleep can affect the child's daytime mood, behaviour and learning (Wiggs and Stores, 1996).

Sleep disturbances in young children can have many forms and can lead to stress and anxiety for the parents and the family. It is important, when the parents seek help, that they are assured that sleep problems are rarely the result of poor parenting and that there are many practical steps which may be taken to address it.

The Advanced Nurse Practitioner (ANP) in Child Health and Parenting (Donegal) runs a behaviour support clinic for pre-school children. It was evident that many of the children referred for behaviour support had sleep problems. Research was carried out on a community sample in Donegal and Kildare of children attending the PHN for routine developmental assessment as well as a sample of children referred with sleep difficulties to the pre-school children's behaviour support clinic. This research identified a prevalence rate of 39-66% of Disorders of Initiating and Maintaining Sleep (DIMS) in the community sample of children aged 6-48 months and 96% in the clinic sample (Gillespie *et al.,* 2017).

In response to this research, The Donegal Public Health Nursing service developed PHN-led sleep clinics for children with behavioural sleep difficulties, throughout the county. The Advanced Nurse Practitioner (ANP) in Child Health and Parenting provided training and mentorship to the nurses in establishing the clinics. These clinics deal with straightforward sleep difficulties, with more complex cases being referred back to the ANP.

Research was undertaken in the United Kingdom on managing sleep problems in disabled children and implications for practice. It found that interventions which use a family partnership approach "which empowers parents to generate and implement their own solutions whilst being guided by the knowledge and experience of appropriately-skilled facilitators was a key factor in the on-going engagement of the parents and positive outcomes particularly an increased sense of competence" (Beresford *et al.,* 2012: 13).

The Early Intervention Team (EIT) identified children within their service with sleep difficulties. As a way of developing the service available to these parents, the ANP provided a one-day training programme in behavioural sleep difficulties to the Early Intervention Team in Donegal. Following on from the training, sleep clinics have been established by the Early Intervention Team in collaboration with the ANP to support parents by providing information on sleep hygiene and also on establishing good sleep structures and routines. The clinic runs weekly and the Social Care Worker from the Early Intervention Team and the ANP run the clinic together. Most of the children attending the clinic are three years and older, and may have had a poor sleep pattern since birth. Parents of children with special needs may not seek support for sleep difficulties, as their expectation is that children with

special needs do not sleep well (Beresford *et al.,* 2012). Many parents, at the time of their child's diagnosis, may not be ready to implement a sleep plan, but it is important that they are aware that support is available when they are ready to deal with the sleep problems.

Parents attend the clinic with their child and the initial visit involves a full sleep assessment. Sleep problems can have many forms including problems with sleep associations, bed time routines, feeding during the night, night time fears, bedtime fears, night time waking, daytime napping, partial waking, nightmares or night terrors. In order to address them, it is important that the clinician and the parents, together, learn all they can about the sleep problem. This involves a detailed exploration of the nature of the problem; how often it occurs; how long it lasts; what the episodes are like; how the parents handle the child at bedtime and during the waking period. It is also important to take a holistic view of the family and explore social circumstances that may affect the child's sleeping as well as identifying if there is a family history of sleep disturbances (Ferber, 2006). Sleep problems are not diagnoses any more than 'pain' or 'breathlessness'. To give the correct advice, we must identify the cause of the problem.

Common Sleep Problems
The American Academy of Sleep Medicine has classified over eighty different types of sleep disorders; these have been sub-divided into groups[4]:
1. Insomnias;
2. Sleep Related Breathing Disorders;
3. Hypersomnias;
4. Circadian Rhythm Disorder;
5. Parasomnias;
6. Sleep related movement disorders;
7. Isolated Symptoms; and
8. Other sleep disorders.

In the clinic, we are dealing with behavioural sleep problems. Behavioural sleep problems usually involve:
• Difficulty getting to sleep (insomnias);
• Difficulty staying asleep (sleep rhythm disturbance); and
• Unusual activity/episodes whilst asleep (parasomnias).

Difficulty getting to sleep (insomnias)
Many children have difficulty getting to sleep and rely on their parents or 'props' to get to sleep. These children have not learned to self-soothe. If a child requires parental intervention to settle to sleep they usually have frequent wakenings as they transition through the different stages of sleep. In the lightest stage of sleep, they try to re-create the conditions they had initially falling asleep. Common sleep associations include: rocking; rubbing; stroking or holding by a parent until the child is asleep. The bottle is another common sleep association. In order to address these sleep associations, it is important that the clinician and the parents together, identify the sleep association and plan a sleep intervention to deal with the association.

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[4] *Sleep disorder categories. International Classification of Sleep Disorders* (ICSD) 2014, American Academy of Sleep Medicine.

Difficulty staying asleep (Sleep Rhythm Disturbance)

The circadian rhythm may be 'out of sync,' and this leads to the child going to sleep and getting up at inappropriate times.

Unusual activity/episodes whilst asleep (parasomnias)

"Parasomnias are defined as episodic, often undesirable behaviours that accompany sleep" (Mindell and Owens, 2015). The most common partial arousal parasomnias occur during non- REM sleep (deep sleep) and includes sleepwalking, sleep terrors and confusional arousal.

Designing a sleep intervention:

Once we have carried out a holistic family assessment, including a review of sleep history, we can then identify the nature of the sleep problem. Consequently,

- A sleep intervention plan is agreed with the parents with specified goals;
- The sleep literature and a sleep diary is given to the family; and
- A follow up appointment is scheduled, usually within a week, with telephone support available.

The family returns to the clinic for weekly review appointments to evaluate progress made and to update the sleep plan for the week. Visual schedules and social stories are useful tools to support the implementation of the sleep plan.

Feedback from the parents attending the clinic has been good. A mother of twins with Autism Spectrum Disorder (ASD) states, "My sons are now in a set routine when it comes to bedtime, and are sleeping right through until morning." Another parent commented, "I never thought I would be able to do it but the support I got from the sleep clinic and the encouragement was fantastic. I now have some me time at night and both my kids are in a great routine, which will be really helpful when the new baby arrives."

In the first instance, the clinics are focusing on providing solutions to behavioural sleep difficulties. However, the expertise of the multi-disciplinary team is often utilised when other interventions are exhausted and progress is slow. Paediatricians, psychologists and general practitioners can offer additional interventions and medications, if deemed appropriate, to help family deal with the sleep challenges they face.

The sleep clinic is an example of collaborative working between services to meet the identified needs of the child and family in dealing with sleep problems. The clinic uses evidence-based interventions, to empower parents with the knowledge and understanding, to have confidence to implement a sleep intervention for their child. The children are followed up six months following discharge from the clinic, to assess if progress made whilst attending the clinic has been maintained. Following discharge, the parents can contact the clinic for a review appointment, if needed.

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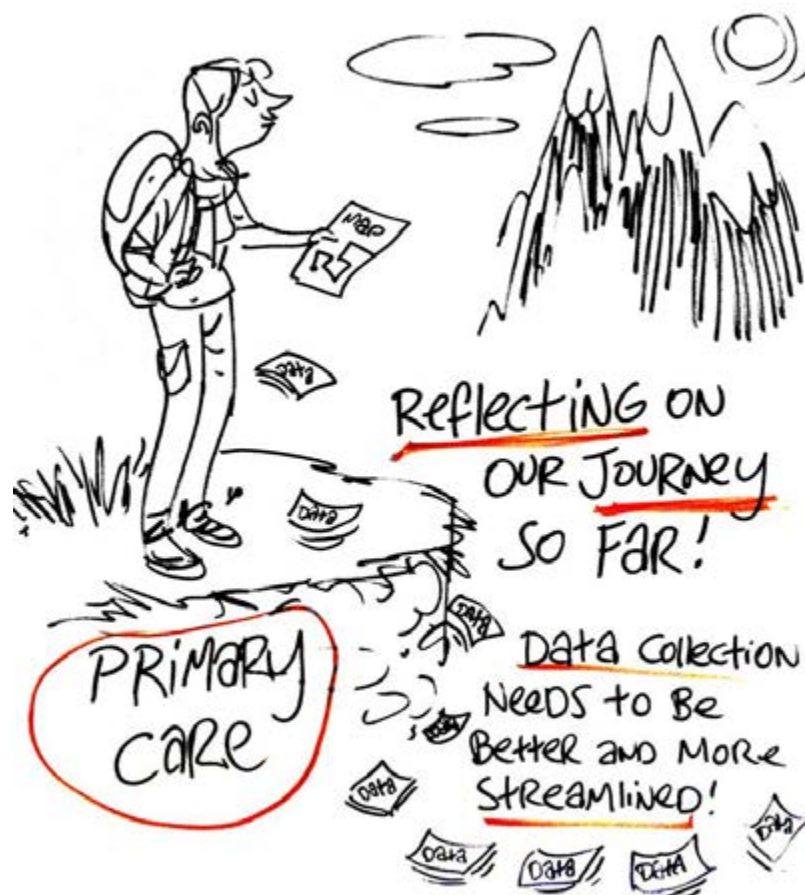
3.10 Standardised Assessment for Children with Physical and Neurodisability to Enable Collaboration between Network Teams and Specialist Supports

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Co-authors: *Dr Ray Barry and Dr Frances Enright, Consultant Paediatricians;*
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Objective measures, used to assess spasticity and need for medical or orthopaedic management or intervention, are not standardised between paediatricians, orthopaedic surgeons, physiotherapists and others working with children with physical and neurodisability. Standardised measurement improves decision-making and facilitates access through a structured, integrated management pathway. The purpose of this project is to highlight the benefits of standardised physical assessment to improve inter-disciplinary communication and decision-making.

An Orthopaedic Care Pathway was developed in collaboration with local hospitals. For any child (0-18 years) with complex physical and neuro-disability, to access this pathway, a standardised physical assessment and 2D-video analysis must be completed. A standardised, individualised service plan is completed which highlights: primary findings from assessment; subsequent Orthopaedic Care Pathway Team recommendations; and which care pathway services need to be accessed. This approach enables inter-disciplinary team to take decisions in a timely manner through Orthopaedic Care Pathway; and is a cost-neutral initiative. The key ingredient is in upskilling network therapists in standardised assessment for the identification of secondary impairments and functional limitations. This includes providing upskilling from physiotherapists, with particular specialist skills experience and critical mass, working as part of network teams at designated times facilitating training and education in standardised assessment for Children's Disability Network Teams and/or Primary Care Services. Early surveillance is important.

Over six-hundred children from counties Cork and Kerry have accessed, and are triaged through the Orthopaedic Care Pathway since 2013. This has resulted in increased collaboration between the child/family, therapy teams, specialist support clinicians on the network teams and consultants (paediatric, neurology, and orthopaedic). This early surveillance and subsequent intervention has enabled timely detection and management of secondary musculo-skeletal complications in this population.

There are plans in place to upskill regional teams in the HSE South Area in standardised assessment. A National Database for all children with cerebral palsy, in line with international best practice (CPIP/CPUP), would be beneficial. Information should be provided on the Orthopaedic Care Pathway system for parents and families, to enable a better understanding of how the services can be accessed through Network Teams and Primary Care.

4.   Good Practices and Practitioner Insights

The conference provided for ten workshops in which practitioners spoke about their experiences, illustrated recent innovations and provided reflective analysis.   This section presents eleven practitioner case studies and sets of insights.

4.1   Cygnet Parent Support Programme - An Evaluation as Facilitators

Aideen Shinnors, Marieta Mullane, Sarah O Sullivan and Angela Murphy,
West Limerick School Age Team.

After a diagnosis, parents and carers can have many questions and may feel isolated in managing their child's needs. Children and young people's needs change and information and advice may need to be updated to be relevant for the child, as (s)he gets older. We have adopted and used the Cygnet Parent Support Programme, which was developed by Barnardos, over the past year and have now delivered three full training programmes to families, in the service. The Cygnet Programme has been delivered by all of the school-age team members and is non-discipline specific. Cygnet is a parent intervention that aims to improve understanding of: autism; communication; sensory needs; behaviour and managing these behaviours. There are also elective topics for the final session including: supporting siblings; puberty; sexual wellbeing; and relationships.

Training evaluations have been completed by parents both pre- and post- completion of the Cygnet programme and at the end of each training session. This feedback has been analysed qualitatively over the course of the three programmes, we have delivered. We have adapted our delivery from week-to-week and from programme-to-programme. We aim to further elaborate on this information in our presentation and outline the feedback received from parents who have completed the Cygnet Parent Training Programme.

West Limerick Children's Services operate a family-centred service and the Cygnet Programme integrates very well into this service delivery model, as follows:
- Cygnet acknowledges parents as the experts when it comes to their own children;
- Cygnet builds on parents' knowledge and experiences;
- It is a supportive process, led by parents and facilitated by team members;
- It provides opportunities for exploring possible difficulties;
- It facilitates joint problem solving; and
- Parents collaboratively choose an elective for the final session based on the group and family needs.

The programme has also been delivered in a very flexible manner; for example, it has been delivered at different times of the day. We have taken breaks for school holidays, and parents are empowered to make these decisions and provide feedback on changes needed. Some of our parents attending the Cygnet Programme have taken the initiative of establishing further means of continuing parent supports following the programme such as a local 'Whats App' group for parents of children with autism as well as a local parent support Facebook page.

As a team, we conclude that Cygnet is a promising intervention for parents of children with autism, in terms of understanding autism as their child gets older; developing and implementing strategies to help the child and family throughout their daily lives and facilitating parent networking.

4.2   Supporting Grandparents in Understanding their Autistic Grandchildren

Sarah O'Sullivan Senior Occupational Therapist and
Caroline Lawson Social Work Team Leader, HSE Early Intervention Team, North Dublin.

In Ireland, grandparents play a large relational role in the lives of their grandchildren and in meeting their adult children's regular and sporadic childcare needs. The vast majority (89%) of parents in the 'Growing up in Ireland Study' (2013) reported that they have regular contact with the study child's grandparents. Ireland's 2005 Quarterly National Household Survey, recorded that while parents/guardians are the main carers during working days for families with pre-school children (59.7%), unpaid relatives (11.5%) considered to comprise largely of grandparents are also an important source of non-parental childcare for preschool children. Research undertaken by the Interactive Autism Network, in the USA, has shown that just under one-third (30%) of grandparents are the first to notice an initial delay in their grandchild's development, and almost all (90%) grandparents reported that facing the diagnosis together with their adult child brought them closer together as a family (Anderson, 2010).

There has been a fundamental shift to family-centred practice within disability services in Ireland, in recent years. Extensive national consultation with children and families attending disability services, conducted in 2013, illuminated that families feeling supported and resourced by their own family system, friends and community is a desired outcome of intervention (Standards & Performance Reporting Working Group, 2013). Current service provision should seek to support this goal, by working with the child within the context of their immediate and wider support systems, (Bronfenbrenner, 1979). Resourcing and supporting the extended family is contributory to enhancing the child's outcomes. Canary (2008) emphasised that grandparents tend to provide higher levels of support to their families where the quality of familial relationships is strong and they have a good understanding of the child's disability. Furthermore, a positive correlation is recognised between perceived emotional support by grandparents and parental well-being (Heller *et al*., 2000; Seligman *et al*., 1997).

Objective: To provide a therapeutic space for grandparents to explore their understanding of autism, behaviour and communication in relation to their grandchild.

Method: Grandparents (three different groups, n= 9, 10, 11) of newly-diagnosed grandchildren within this EIT were invited to a facilitated seminar. Topics explored included: common misconceptions in relation to the cause of autism; exploration of stigma around autism; sharing of strategies to support communication, play and social interaction; understanding behaviour; and practical day-to-day suggestions around enhancing relationships with their grandchild.

Evaluation: 100% of participants reported that they found the workshop useful. Four out of five (80%) participants indicated that they would be interested in attending further facilitated seminars.

The following themes were identified by participants as being of value:
- the facilitated experience of meeting and hearing other grandparents' stories;
- the importance of enhancing their understanding of ASD and how it might impact their grandchild; and
- the benefits of learning about strategies to engage with their grandchild.

The helpful strategies identified comprised communication and interaction approaches such as waiting, slowing things down, breaking down instructions, simplifying language, using 'First and Then'. It also manifests service implications as follows:

- Devise a tip sheet for grandparents to be included in welcome packs for all new families into the EIT Service;
- Devise EIT Policy around co-facilitating with grandparent(s) volunteers at future seminars; and
- Extend facilitated workshops to wider family support system including aunts, uncles and friends.

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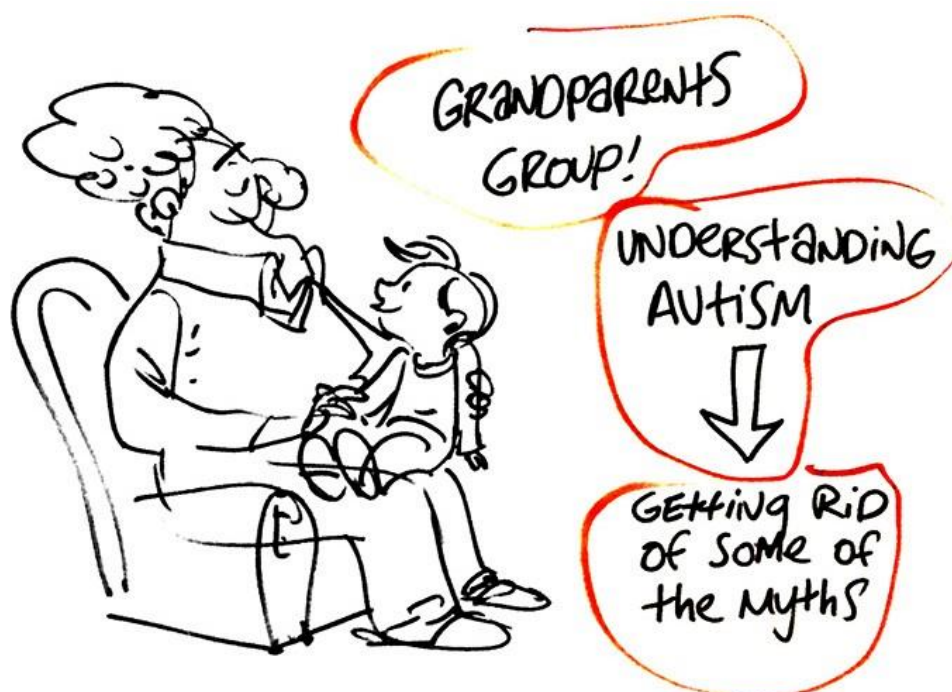
4.3 Assessing and Diagnosing Children and Adolescents for Autism Spectrum Disorder (ASD) - the Dynamic Team Approach

Maria Gomes, Senior Clinical Psychologist; Patrick Hynes, Senior Occupational Therapist and Fiona Woods, Senior Speech and Language Therapist, St. Gabriel's Children's Service, Limerick.

The aim of this paper is to outline the various factors associated with working as a team, when diagnosing and assessing children for Autism Spectrum Disorder (ASD), including the different assessment tools utilised. This paper presents how the team members work collaboratively through the entire assessment process to identify challenges and strengths. It highlights the strengths of working on team-based assessments, which include assessing complex needs within a holistic approach to children's play and development skills, and it also highlights the challenges that it poses, such as overcoming the risk of over-assessing.

Contemporary discourses on the assessment and diagnosis of ASD indicate that a team-based assessment approach is best practice when assessing children for ASD. Best practice guidelines, such as the PSI guidelines in Ireland (2010) and the NICE guidelines in the UK (2011) recommend a team assessment. Thus, ASD diagnosis should be completed by paediatricians, child psychiatrists, or psychologists, and other professionals, often working in multidisciplinary teams, including psychologists, speech and language therapists, occupational therapists, physiotherapists and social workers. It is essential that these multidisciplinary teams have specific training in the diagnosis and intervention of people with ASD. Furthermore, the shifting paradigms that have resulted from the introduction of the Diagnostic and Statistical Manual of Mental Disorders (DSM – V) (American Psychiatric Association, 2013), regarding the diagnosis of ASD, encapsulate the need for a multi-faceted team approach to assessment.

It can be concluded that no single assessment type is perfect. Careful consideration has to be given to ASD-specific diagnostic tools and observation measures that are accurate, reliable and valid instruments to determine a diagnosis of ASD, such as the ADOS and the ADI-R. However, they have to be used in conjunction with other standardised tests and clinical observations (Gardner *et al*., 2016). A critical challenge for the different team members is the integration of diverse test data and information from clinical observations into a comprehensive evaluation and final report. Time pressure and different backgrounds of team members can also pose a challenge (Tang and Hsiao, 2013).

The benefits of a multidisciplinary team approach appear to overcome the disadvantages. An integrated team approach to the assessment and diagnosis of ASD facilitates a greater understanding of the child's or adolescent's experience, behaviour, capacities and needs. This contributes to an improved picture of a child with a diagnosis of ASD and to a more accurate and reliable diagnosis of ASD, which is differentiated from other developmental disorders, such as language and sensory impairments, attention and hyperactivity disorders, anxiety disorders, behavioural issues, among others, that can mimic ASD features or can co-occur with ASD (PSI, 2010). Parents are also more likely to trust a team of professionals who have used an integrated approach to determine a diagnosis of ASD, rather than an approach that presents them with disintegrated discipline-specific individualised assessments and reports. An integrated team approach also facilitates future collaborative goal-setting for intervention and monitoring progress. Positive relationships, based on trust and understanding amongst team members, are crucial.

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4.4 Training Programme for Parents of Children with ASD - A Way to Empower Parents and Target Goals in the Natural Learning Environment

Patrick Hynes, Senior Occupational Therapist; Maria Gomes, Senior Clinical Psychologist and Fiona Woods, Senior Speech and Language Therapist, St. Gabriel's Children's Service, Limerick.

The aim of this paper was to explore literature regarding training programmes for parents of children who have a disability, with a particular emphasis on Autism Spectrum Disorder (ASD). This formed part of the development of the training programmes for parents of children who have ASD. It also presents the outline of the training programme content implemented by the authors - as delivered to parents of children who have ASD.

There are many challenges faced by disability services and families, due to large caseloads and limited resources. Members of multidisciplinary teams need to consider service delivery when working with children who have Autism Spectrum Disorder (ASD) and their families. In some instances, there is a need for a shift in service delivery from direct therapy, to a more indirect consultation/empowering model that considers the child's specific needs, such as level of functioning and age, within the natural learning environment.

Research indicates that a diagnosis of cognitive and behavioural impairments places additional strains on families (Baker *et al*., 2003; McIntyre, Blacher and Baker, 2006), with the case being similar for children with ASD, including elevated levels of parenting-related stress (Estes *et al*., 2009). Additionally, research (e.g., Hinshaw, 2002; Sameroff and Fiese, 2000) indicates that a link exists between parenting skills and practices, and the behaviour of children. One treatment option that is utilised with children without developmental disabilities is parent training, with less research available on evaluating parent training for children with developmental disabilities and their families. However, some of the research reports on parent training can be based on social learning theory, with principles of operant theory and behaviour modification, accompanied by aspects of psychopathology (McIntyre, 2008). Parent coaching, which is embedded in family-centred practice discourse, offers a basis for determining the approach to take when devising parent-training workshops. Positive findings on coaching are reported by Estes *et al.* (2014), including lower levels of parent stress following parent coaching. This paper deals with:

- the theory and practice of delivering training programmes for parents of children with ASD;
- how to empower parents to develop their child's independence and functional skills through their interactions in the natural learning environment;
- how to provide parents with the opportunity to form peer networks and problem solve together; and
- shifting from a multidisciplinary team approach to an interdisciplinary team approach by using multiple domains of knowledge to address skills relevant to supporting children with ASD.

The different training programmes delivered, using an interdisciplinary model, addressed: emotional regulation and anxiety management; sensory integration; behaviour challenges; social communication; understanding language; structuring the environment and long-term planning. Through these training programmes, parents develop their sense of self-confidence, independence and autonomy, and subsequently their ability to support their children and themselves in the different developmental phases. The training programmes support parents to implement goals in their child's natural learning environments. The application of natural learning environment practices supports parents with their child's learning and development. Further research would be useful to gain a greater insight into this area of practice.

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4.5 Cultural Competency: Responding to the Needs of Migrant Parents

Erica Calder, Senior Social Worker Enable Ireland, Dublin South West Services.

Ireland is becoming an increasingly diverse society with families coming from many parts of the world to live in Ireland. One in eight (12%) of the population is now made up of people from almost two hundred other countries. In working in partnership with parents from new communities who have a child with a disability, service providers need to understand parent and children's needs, beliefs, hopes and expectations; how they understand their world. Cultural competence is at the heart of engaging appropriately with both parents and children from new communities. It promotes inclusion and is essential to ensuring a team works in a culturally-sensitive way. Cultural competence is important for individual practitioners, as well as for services and organisations, and this workshops looks at ways to begin developing this competence.

The workshop will include:
- Irish and UK research findings on the needs, outcomes and experiences of migrants and migrants with children with disabilities;
- The voice of migrant parents. Migrant parents speaking on video about their experience of their child having extra needs and being referred to a disability service. They will talk about challenges they face in understanding their child's needs, the isolation and shame that may be felt as they can be excluded from family and community supports and ways to be supported by services;
- A communication exercise to sensitise therapists to cultural difference by understanding more about their own cultural inheritance, different communication styles and the cultural lens through which each of us views the world;
- An introduction to two tools useful in helping to build a picture of migrant parents' experiences and understanding of disability are the Culturagram and Explanatory Model. A culturagram is a family assessment tool that provides a graphical representation of various aspects of an individual and family's culture. It gives workers an opportunity to understand a family's culture on an individual basis rather than generalizing them to the cultural group. Kleinman's Explanatory Model (1980) gives structure to clinicians seeking the how, why, what, when, where, and what next of illness and health experiences, and is useful in sensitively gaining an understanding of parents beliefs and thinking about their child's disability; and
- Opportunity to think about the next steps i.e., what can be done to develop cultural competence, both individually and as a service.

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4.6 Translating the Principles of Parental and Infant Mental Health into Real-World Practice within a Children's Disability Network Team (CDNT)

Dr Aoife Menton, Senior Clinical Psychologist, Enable Ireland, Dublin South West.

The aim of this workshop is to present the concepts and principles of parental and infant mental health and explore how they are integrated in the real-world setting of a multidisciplinary CDNT with real-world examples and group discussion.

We know from extensive research that parents of children who present with developmental delay and additional needs experience increased stress and are more at-risk of developing mental health difficulties, as a result. There is also a growing recognition both globally and here in Ireland that children, from the beginning of their lives, can experience mental health difficulties. In recognition of the additional complexities that come with living with developmental delay and/or a lifelong disability, the need to recognise and address infant and child mental health is of paramount importance. We also know from extensive and robust research that the relationship between a parent and child is critical in determining a child's developmental trajectory, and when that relationship is compromised, the outcome can have a significant bearing on a child's physical, social, emotional and cognitive development.

The term 'infant mental health' was first coined by Selma Freiberg in 1980, with 'infant' referring to children under the age of three years, 'mental' referring to their social, emotional and cognitive development, and 'health' indicating wellbeing of the child and family (IMH-NG, 2015). In 2001, the National Center for Infants, Toddlers and Families published the following definition: "'infant mental health' refers to the capacity of children from birth to age three to experience, regulate, and express emotions; form close, secure interpersonal relationships; and explore the environment and learn – all in the context of family, community, and cultural expectations for young children. Infant mental health is synonymous with healthy social and emotional development" (Infant Mental Health Task Force, 2002: 1; cited in Nelson and Mann, 2011). Therefore, infant mental health describes the state of social and emotional wellbeing of the child whilst also describing a field of practice and research, involving the child, their family context and wider community (ICTA, 2000).

Infant mental health is considered an area of practice that is interdisciplinary in nature and does not fall within the remit of one professional group. Therefore, incorporating the principles of such a dynamic approach promotes team working and collaboration amongst clinicians but, most importantly, with families.

Our experience demonstrates how these concepts and principles have been incorporated into daily clinical practice with families, with the aim of working in partnership with parents, families and young children by accounting for their current levels of resilience and psychological and emotional wellbeing, and how these factors influence engagement with the service.

In summary, the principles of parental and infant mental health acknowledge the psychological and emotional wellbeing of both parents and infants within a CDNT. Actively working to promote and improve mental health and wellbeing is crucial in viewing the child holistically and within the context of their family and broader ecosystem.

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4.7 Siblings and Young Carers Support Groups

Christina Egan, Community Facilitator for Disability Services, Sligo/Leitrim, West Cavan.

Living with a sibling with special needs is a reality into which many children are born. Given that siblings of children with special needs are intricately engaged within the family framework, the demands on parents may have a negative impact on the allocation of time and resources to their other children and on their expectations of the healthy siblings in terms of achievement and responsibility (Meyer and Vadasy 2008). Siblings have a unique relationship with their brother /sister with special needs, and while this relationship may offer unique opportunities to develop a range of positive qualities, it can also pose significant challenges. This may lead a child to refrain from expressing their emotions or seeking parental support when needed. A range of negative emotions has been reported by siblings such as anger, resentment, embarrassment, fear and grief (Meyer and Vadasy 2008).

In 2009, the Community Facilitators for Disability Service participated in a research project with the National University of Ireland, Galway (NUIG) entitled *'Study of Young Carers in the Irish Population'* (Fives *et al.,* 2010). This led on to the development of Sibling/Young Carers Support groups, one for the younger children (8-13 year olds), and a teenage group (13-17 year olds). The groups were co-ordinated by the Community Facilitators for Disability Service, and facilitated by the Director of Adult Education in Sligo IT (Institute of Technology) and a psychologist from the HSE. The objectives and rationale of these groups were to ensure that service providers offer this group of people a way of accessing support, an outlet for their emotions, validation of their feelings and a place where they can garner support from peers in a similar situation and learn alternative ways of coping with their situation where necessary. The methods used in all the groups are outlined as follows:

1. **Information evening for parents**
   • Rationale of programme;
   • Content overview; and
   • Confidentiality.

2. **Workshop across four weeks for both groups**
   • Four consecutive weeks of ninety minutes' duration; and
   • Themes each week: Feelings communication, problem solving, knowledge and understanding of siblings' needs.

3. **Evaluation**
   • Weekly from participants;
   • Parents' evaluation on completion of course; and
   • Weekly discussion and evaluation meetings between facilitators and project coordinator.

4. **Feedback session for parents**
   • Rationale for each activity ;
   • Themes worked on - the learning and challenges; and
   • Snapshot of what participants expressed in general terms

5. **Check in sessions**
   • Parents and participants identified the need for the support group to continue; and
   • Planned check in sessions arranged for the group.

Following evaluation of the groups, multiple outcomes were identified. These were taken into consideration in the planning of the subsequent groups. The demonstrable impacts of the project on service provision include:

- Providing a wider support network to parents;
- Offering support and individual time to siblings;
- Raising awareness of issues for siblings in service delivery which 'gives them a voice';
- Fast-tracking children who require more intensive level of psychological support; and
- Delivering a more inclusive family-centred model of service delivery.

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4.8 Working Together: An integrated Multi-agency Approach to Psychology Services to schools for all children

Dr Toby Sachsenmaier, Senior Clinical Psychologist, Clare Children's Services School Age Team and Christine O'Sullivan, Senior Educational Psychologist, NEPS.

A cross-agency initiative to help schools across County Clare access psychological support at school for children and young people has been developed. To support this new development, a booklet was published to guide school principals and teachers toward the most effective help when concerns arise about children's learning, social and emotional development, or behaviour in school. This development is the first initiative of its kind in Ireland.

The National Educational Psychological Service (NEPS) provides an integrated service to all primary and secondary schools in Clare through a tiered system known as the Continuum of Support. School principals who are concerned about how a child is doing in school academically, socially, emotionally, or behaviourally can easily contact the school's NEPS psychologist to discuss the concerns and get advice from psychology professionals.

Psychologists in NEPS work closely with their psychology colleagues in the health services to identify and access the range of supports that are available for children who have difficulty at home or in the community, as well as at school. Depending on the needs of the child, the NEPS psychologist may work together with psychologists from three health services in Clare. These are the Clinical Psychology Service, the Child and Adolescent Mental Health Service (CAMHS), and the School Age Disability Team (SADT). The new booklet provides guidelines on how to decide which community-based supports would be most helpful for the child who needs this kind of professional support.

The Clinical Psychology Service provides a broad range of psychological supports for children and adolescents and their families, including children who have social, emotional, and behavioural difficulties at home or in the community. If more specialised psychological support is required, there are also clinical psychologists working as part of multi-disciplinary teams in the specialist services. CAMHS provides assessment and intervention for children presenting with mental health issues, such as significant depression, anxiety, self-harm, eating disorders, or Attention Deficit Hyperactivity Disorder (ADHD). The School Age Disability Team provides support for children and young people with a range of moderate-to-severe diagnosed disabilities, including intellectual disability, physical disability, and Autism Spectrum Disorder (ASD) when their needs are complex and cannot be met by their local primary care services. When it is beneficial, psychologists in NEPS may work together with clinical psychologists in these services to help children in school.

In Clare, psychologists who work with children and young people have been working together to develop a clearer pathway to access appropriate psychology services. This collaborative approach was the first initiative of its kind nationally, and is seen as a promising innovation in multi-agency working. The new booklet summarizes the psychological supports available through the school, the community, and the specialist services, and gives a clearer picture of the way psychologists work together to support children who struggle in the school setting. Through good communication, joined up thinking, and mutual goals, the psychologists in four different services aim to provide the most effective support to children and young people who seem to have difficulty in school.

4.9 Cultivating a Learning Environment for Children with Special Educational Needs (SEN): Multidisciplinary Strategies

Grace Heraty, Senior SLT, SAT and David McGrath, Senior Paediatric Physiotherapist, Primary Care (HSE) Castlebar.

Since the implementation of the Education for Persons with Special Education Needs (EPSEN) Act in 2004, increasing numbers of children with learning, communication, sensory, emotional and movement difficulties are being identified within the primary school population. In addition, children with complex disabilities are opting to attend their local primary school instead of special schools. Teachers require supports from local therapeutic services to help these children transition to school and access the curriculum. In response, speech and language therapy, occupational therapy, physiotherapy and psychological services from the HSE have devised a solution-focused and practical twenty-hour course for teachers, in collaboration with the local expertise of Western Care Association and Enable Ireland with the local SEN expertise of the Department of Education and Skills, which has been delivered to seventy-four teachers since 2016.

This training supports schools with the transition and placement of children with SEN, in both local national schools (promoting community inclusion) and in special schools. Bringing multidisciplinary staff together from Health and Education has developed a shared understanding and responsibility. Teachers are more empowered and confident in setting and achieving goals for children in their classrooms and have a more holistic understanding of the children. The primary goal of this course is to up-skill staff to integrate the health and educational needs of children with disabilities.

Following the success of other teacher-training initiatives within the Speech and Language Therapy Department (HSE[5]), a group of speech and language therapists met to discuss the feasibility of teacher training for children receiving therapeutic services from the disability team. We quickly realised that, input from every discipline was required to support these children in mainstream schools, and other relevant disciplines were approached. With agreement from all parties, the application for a face-to-face summer course was submitted to, and approved by the Department of Education and Skills, for a three-year period.

The multidisciplinary team met, and a schedule of training was drafted to run in summer 2016. Each discipline took responsibility for the content of its presentation, while trying to ensure a common thread ran through all presentations. The training was reviewed and expanded in 2017 to include behaviour support services and NEPS. The stakeholders included:
- Department of Education – Special Education Needs Organiser (SENO), Mayo Education Centre, National Educational Psychological Service (NEPS) and a local special school teacher;
- Enable Ireland – Assistive Technology;
- Western Care Association (voluntary body) – Behaviour Support Services and Occupational Therapy;
- Education DESTY (Private) – Social and Emotional Wellbeing Specialists;
- Educational Technologist (Private); and
- Parents of children with Special Educational Needs

The project operates on the core values of care, compassion and trust. Pre and post evaluation forms asking teachers to score self-efficacy relating to that day's topics, were distributed daily. Combining

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[5] Early Intervention SLT services in Mayo are provided by both Western Care & HSE staff following amalgamation into a team a few years. School Age SLT services are provided by the HSE solely in Mayo.

pre-course rating with post-course ratings, there was an average increase of forty percent across all topics covered. The assessment notes that:

- There was full engagement between the Department of Health and the Department of Education;
- This training supports schools with the transition and placement of children with SEN in both local national schools and (promoting community inclusion) and special schools;
- This multi-agency training is bringing staff from Education and Health together to support children with SEN throughout Mayo;
- This project required staff across disciplines, not just within the HSE, but also across agencies and across the Departments of Health and Education to work together to support the integration of children with SEN into the mainstream setting;
- All stakeholders involved in school age disability services were involved in the project;
- Planning and delivery of the course have been achieved, despite significant pressure on all departments involved; and
- Exceptional feedback has been obtained from teachers.

The particular merits include:
- Direct impact on children with SEN accessing the curriculum through a holistic approach;
- Strengthened relationships between disciplines, agencies and across the Departments of Health and Education;
- Being cost neutral; the programme used existing human resources (e.g., therapists, SENOs, teachers and parents), time, local education structures and facilities;
- Being therapist-led from the 'ground up' in the absence of a formal school age disability team;
- Enabling 'buy-in' from teachers who opted to attend this new course over other established courses; and
- Ensuring that the child and family were central to this training, parents spoke of their experiences in terms of selecting a school, the transition to school and the barriers and opportunities encountered.

AUTISM ME – AUTISM MY CHILD

4.10 Working together for Better Outcomes – An Overview of a Barnardos – HSE Integrated Service Model

Miriam O'Donohue, Senior Psychologist, HSE Dublin South West Early Intervention Team & Patricia McDonnell Coordinator Barnardos.

This presentation aims to demonstrate an innovative partnership between the HSE Dublin South West Early Intervention Team and Barnardos Special Needs Service Tallaght. The two agencies operate an integrated working model of service delivery for children with complex developmental needs and their families. The model aims to give the child and family in the catchment area access to a unified, holistic continuum of service delivery. Our vision for the service is that children and families have the opportunity to grow and fulfil their potential.

In 2011, a collaborative process began to develop an integrated model of service for Dublin South West. From this process, the procedure for working together was developed to guide this joint working agreement. The service came into operation in February 2012 when the two agencies co-located in the HSE building Chamber House Tallaght. This integrated model of service is a family-centred, social model that is community based providing a specialist early intervention service for children under 6 years with complex needs. Once referrals are accepted by the Early Intervention Team, families go through the intake process and a family action plan is completed. Following this, where appropriate, referrals are then made to Barnardos Special Needs Service. The children once, accepted into Barnardos, go through its assessment framework, which guides the interventions provided.

The working model involves a joined-up process from referral to intervention and discharge between the two agencies. This involves a seamless mechanism for communication, which supports the child and families' journey through the integrated service. This includes a shared approach to assessment, goals-setting, interventions, review and closing. The children referred to Barnardos attend for two sessions per week for blocks of twelve weeks. The Barnardos Special Needs Service is responsible for the delivery of specific therapeutic interventions to children and families based on their assessed needs. These can include:
- 1:1 and small group development interventions with children;
- Parental support, advice and advocacy;
- Supporting access to every day setting and community activities;
- Family support services;
- Preschool support and supporting a child's access to follow on educational placements; and
- Delivery of targeted interventions recommended by the early intervention team.

This service has had very favourable outcomes for children and their families who have attended. This includes:
- Increased parental understanding and adjustment to their child's developmental needs;
- Improved family access to mainstream education and community settings; and
- Attainment of targeted developmental goals for children.

The presentation shares the perspectives of service users and staff in relation to the benefits, strengths and challenges of a joint integrated working model. In the future, as part of progressing disability this potentially could be a model, which would benefit other Early Intervention Teams. In conclusion, the collaborative approach ensures that the child's needs, within their family and community, are better met, and that services are holistic, integrated and family centred.

4.11 Strengths-based Report Writing - It's all in the language you use

Mary Lillis, Senior Speech and Language Therapist; Elizabeth O'Shee, Senior Speech and Language Therapist – HSE Early Intervention Team, Dublin North, CHO Dublin North City & County and Suzanne Kirwan, Speech and Language Therapist.

When working with young people and their families, a strengths-based approach to family-centred service delivery is strongly recommended. Strengths-based approaches are a guiding principle in national strategy in the areas of health, welfare and education for young people. These concepts are rarely translated into genuine practice. In written reports by allied health professionals, the language used tends to be deficit-focussed.

We aimed to develop clear guidelines for writing strengths-based reports for allied health professionals. A guideline document was created which suggested ways of rewording language and highlighted the words and phrases to use and avoid when writing strengths-based reports. The guideline document and rationale was shared with the Primary Community and Continuing Care (PCCC) Speech and Language Therapy (SLT) Team and the local EIT in North Dublin. The team members were asked to complete a questionnaire once they had compiled a report using these strengths-based principles.

Team members reported the guideline document was 'extremely useful' for aiding changes to the language they used in reports. Some team members reported that changing how they wrote reports also supported their verbal feedback to families. Concerns about writing strengths-based reports were also shared.

Team members have reported that they are more comfortable sharing these reports with families and teachers. Initial feedback from parents and teachers has been extremely positive. Concerns and limitations to strengths-based report writing are also discussed.

Providing guidelines for writing strengths-based reports can support therapists to produce reports that are accurate and useful, as well as positively framing the child's presentation. By moving away from the use of deficit-focussed language, perhaps we can change how we view young people, their families and how we support a child to achieve their potential.

Further investigation is required to compare families' (and children's) perceptions of reports written with, and without, strengths-based language, and to explore the limitations to this approach.

5. Delegates' Experiences, Observations, Feedback and Recommendations

Conference delegates attended one of eight workshops. Each workshop dealt with one or two specific themes as presented in Section Four of this report. The workshops allowed for learning and discussion in respect of current practices and innovations, with all of the workshop presenters brining their expertise to the table. Moreover, the workshops, which were independently facilitated by Mary Immaculate College staff members, allowed delegates to have a say on the issues and to advance proposals and recommendations.

Workshops lasted over an hour, and all followed the same format. Having listened to a focused presentation (all of which have been synthesised in Section Four), delegates were then facilitated to respond to a series of questions as follows:

1. What considerations (specific issues) arise from this presentation?
2. What needs to be done?
3. Who should do this?
4. When should they do it?
5. What resources (e.g., physical, human, policy) are needed?

The ensuing deliberations provided some reflections on current processes and experiences from multiple perspectives. In addition, they provide some signposts as to where and how the PDS agenda needs to advance.

In the interest of consistency, all workshop proceedings have been recorded by synthesising delegates' responses to the five questions posed by the facilitators. The proceedings were recorded by students of the Doctorate in Educational and Child Psychology (DECPsy) programme at Mary Immaculate College.
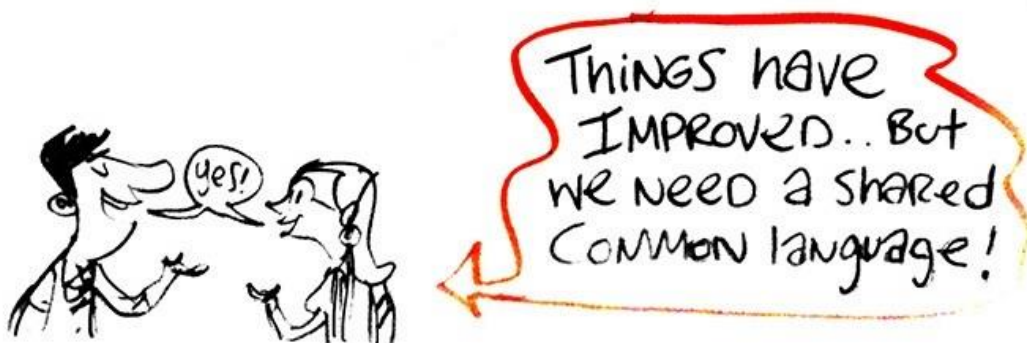
Workshop 1: Cygnet Parent Support Programme - An Evaluation as Facilitators *and* Supporting Grandparents in Understanding their Autistic Grandchildren

Presenters: Aideen Shinnors, Marieta Mullane, Sarah O Sullivan, Caroline Lawson and Angela Murphy

Facilitator: Dr Margaret Nohilly

Rapporteurs: Orla Murphy and Maura Moriarty

Note: This workshop dealt with the two themes listed above.

1. What considerations (specific issues) arise from this presentation?

Grandparents'-support programmes like Cygnet, should be rolled out nationally. Explaining the diagnosis by the parent to the grandparent, or vice-versa, can be difficult. Understanding aspects of the child's specific needs and contexts around the family is important too, as addressed by this programme.

2. What needs to be done?

There is a need to move beyond assessment and diagnosis to intervention. Multidisciplinary work is just as important as a uni-disciplinary focus. Public access (e.g., through libraries) to such programmes to increase access is important, as is cross-agency work. Barnardos has been approached to update materials (videos, STAR). If one team could share the content of "good evidence-based programmes" nationally, this would help.

3. Who should do this?

Grandparents and Cygnet support groups should be incorporated into pathways for Child Disability Network teams. Foster parent knowledge and support within the Cygnet programme – so that when parents have completed the programme, they could be trained as facilitators to deliver it to others. Grandparents supporting grandparents have an important role to play.

4. When should they do it?

Consideration of needs within service and teams takes precedence. Groundwork and research need to be done, and then the human cost needs to be considered. This work needs to be completed now, but individual grandparents need to undergo the programme relative to their grandchild's given stage of development with the autism diagnosis.

5. What resources are needed?

For a service to buy the Cygnet programme package, it may be more cost effective than the *EarlyBird.* We need to invest in, and enable staff sharing the evaluation of the programme, rather than "having it saved on an excel database." An expensive but worthwhile resource are interpreters for foreign nationals. There is also a need for organisation and flexibility around facilitating such programmes during the evening time.

Workshop 2: **Assessing and Diagnosing Children and Adolescents for ASD - the Dynamic Team Approach** *and*

Training Programme for Parents of Children with ASD - A Way to Empower Parents and Target Goals in the Natural Learning Environment

Presenters: Dr Maria Gomes, Fiona Woods and Patrick Hynes
Facilitator: Dr Emer Ring
Rapporteurs: Charlotte Carey and Elaine McCarthy

Note: This workshop dealt with the two themes listed above.

1. What considerations (specific issues) arise from this presentation?
Sufficient time is required for discussion and clinical formulation for all assessments. Some diagnoses also require additional time. Geography and caseload priorities are factors. Human resources and staff training are considerations.

2. What needs to be done?
There is a need for training in respect of the new ASD assessments. Highlight the transdisciplinary nature of the work to improve the team-working model. Realistic and flexible timeframes for assessment should be developed, and caseloads should be reduced. Training and other supports for parents may be helpful.

3. Who should do this?
Professional clinicians can empower parents; provide them with information and support the establishment of parent-support groups. Interventions should be delivered by teams, in partnership with parents. Employers and professional bodies should support clinicians to upskill.

4. When should they do it?
They should do it immediately, contingent on resource allocations.

5. What resources are needed?
Financial resources are required. Some professionals may need training and support to work beyond the scope of their own disciplines.

Workshop 3: Cultural Competency: Responding to the Needs of Migrant Families

Presenter: Erica Calder
Facilitator: Dr Margaret Egan
Rapporteur: Roisín Hogan

1. What considerations (specific issues) arise from this presentation?

It raises the issue of acculturation, and describes the need for understanding and empathy with people of other cultures. Professionals need to prepare and ensure that they are sufficiently skilled, through training and teamwork. Communication is key, and a quality interpretation or translation service - with a knowledge of the services, may be useful. Informed consent should be supported. Family structures, dynamics and living conditions are considerations.

2. What needs to be done?
The principles outlined in PDS should be put into practice. A national programme of diversity training should be provided for frontline staff. Agencies should share information to improve person-centred supports. There is a need to mainstream the training programme for people in *Direct Provision* in Kilkenny and link people to supports in their own community. Interpreting services should be improved; the HSE should recruit its own interpreters and translate letters into the service user's language.

3. Who should do this?
Management should resource the process. This includes identifying a leader in each team. All staff should be provided with relevant training and should share knowledge.

4. When should they do it?
It should be started as soon as possible, and should be an on-going process.

5. What resources are needed?
Additional policy guidelines, induction packs and training materials are needed. Finance is required to employ interpreters. Staff require additional time, support and flexibility for the process.

Translating the Principles of Parental and Infant Mental Health into Real-World Practice within a CDNT *and*

Siblings and Young Carers Support Groups

Presenters: Dr Aoife Menton and Christina Egan
Facilitator: Dr Fionnaula Tynan
Rapporteurs: Lainey Keane and Emma Hilliard

Note: This workshop dealt with the two themes listed above.

1. What considerations arise from the presentation?

There are inconsistencies in disability services across the country and clinical resources and time should be prioritised to provide support structures and advocacy for children, siblings, parents and families. Attachment and infant mental health are key issues. These impact on development, and may require early intervention.

2. What needs to be done?

Address the gap between CAMHS and PDS services and inconsistencies across the country. Improve awareness of parental mental health issues and their impact on the child and family, among team members. Long waiting lists must be addressed. Time needs to be ring-fenced for these supports and it may be useful to include infant mental health interventions in initial intake assessment.

3. Who should do this?

This should be led by government departments, including health and education. Primary care functions and CAMHS should be involved. Multi-agency and inter-agency involvement is required. It may be appropriate to designate personnel to run groups.

4. When should they do it?

This should be carried out at all points of engagement with the family.

5. What resources are required?

The process requires an inter-governmental policy (i.e., health and education), staff and training and financial resources. Time, suitable accommodation and respite care are required.

Workshop 5: Working Together: An integrated Multi-agency Approach to Psychology Services to schools for all children

Presenters: Dr Toby Sachsenmaier and Christine O'Sullivan
Facilitator: Siobhán O'Sullivan
Rapporteurs: Deirdre Egan and Katie Curtain

1. What consideration (specific issues) arise from this presentation?

The presentation raises issues of multi-agency working for all disciplines and the potential for replication. The process is innovative and long. The booklet assists with communication and clarification.

2. What needs to be done?

Consider a national approach to care pathways. Share the booklet and adopt it nationally. Appoint a clinical lead in each area and organisation. Build on existing relationships and work with existing resources and knowledge. Protect time and support all disciplines to share knowledge, CPD support and pathway development. The process should be included in service-level agreements.

3. Who should do this?

The N.C.S.E., Department of Education and Skills, Department of Health and H.S.E. should lead change at national level. NEPS, schools and agency HR functions should also be involved. Psychologists, in various services, should be involved.

4. When should they do it?

Joined-up thinking at a national level should start immediately.

5. What resources (physical, human, policy etc.) are needed?

Policy guidelines and a collaborative agreement are required. An information booklet for schools on services would be useful. More trainee psychology places are required. Accessible premises and professional supports are required.

Workshop 6: Cultivating a Learning Environment for Children with SEN: Multidisciplinary Strategies

Presenters: Grace Heraty and David McGrath

Facilitator: Dr Kathleen Horgan

Rapporteurs: Billy O'Meara, Aoife Olsthoorn

1. What considerations (specific issues) arise from this presentation?

The presentation highlights the importance of planning and the benefits of collaborative working. The provision of external training for teachers is considered, and there is potential for replication and modification to meet children's needs and for use in special schools.

2. What needs to be done?

The model and resources should be shared. It should be piloted in other areas and possibly rolled out nationally. It may be appropriate the refine the approach and to make modifications. Link the model with third-level courses and involve the Department of Education. Parental involvement would be beneficial and consideration should be given to mandatory implementation at pre-school level.

3. Who should do this?

The pilot project and members should be involved. School staff including teachers, SNAs, resource teachers and principals should be included. MDTs involved with school-aged and early-intervention teams and the Departments of Health and Education should do this.

4. When should they do it?

It should be timed to suit local demand. It may be appropriate to do it for pre-schools in September and during July and August for primary schools.

5. What resources (physical, human, policy etc.) are needed?

The model requires multi-disciplinary human resources from the local Department of Education group or the education centre and SENO, amongst others.

Workshop 7: Working together for Better Outcomes – An Overview of a Barnardos – HSE Integrated Service Model

Presenters: Miriam O'Donohue and Patricia McDonnell
Facilitator: Dr Orla Slattery
Rapporteurs: Carol Slattery and Alison O'Keeffe

1. What considerations arise from this presentation?

The criteria to select children for the service is a consideration. It may be based on the extent to which it is considered the child and family is vulnerable. The frequency of intake, length of process and number of children should be decided. Educational placements are an element of the model. The family support work is flexible and responds to the needs of the families on a case-by-case basis.

2. What needs to be done?

Include parents and children in service planning from the initial stages. The management structure needs to support a collaborative approach. The staff structure should include early years' practitioners and psychologists. Communication mechanisms should support a partnership approach.

3. Who should do this?

The onus is on clinicians to support access to services and to form communities to support implementation of integrated models. Support is also required from government departments including: Department of Children and Youth Affairs and Department of Education and Skills.

4. When should they do it?

Parents and families should be supported at a community level, all of the time.

5. What resources are needed?

Operating procedures which delineate roles, are required. Premises which allow partners to co-locate are beneficial. Sufficient staffing, including substitute staff from the required disciplines, is needed.
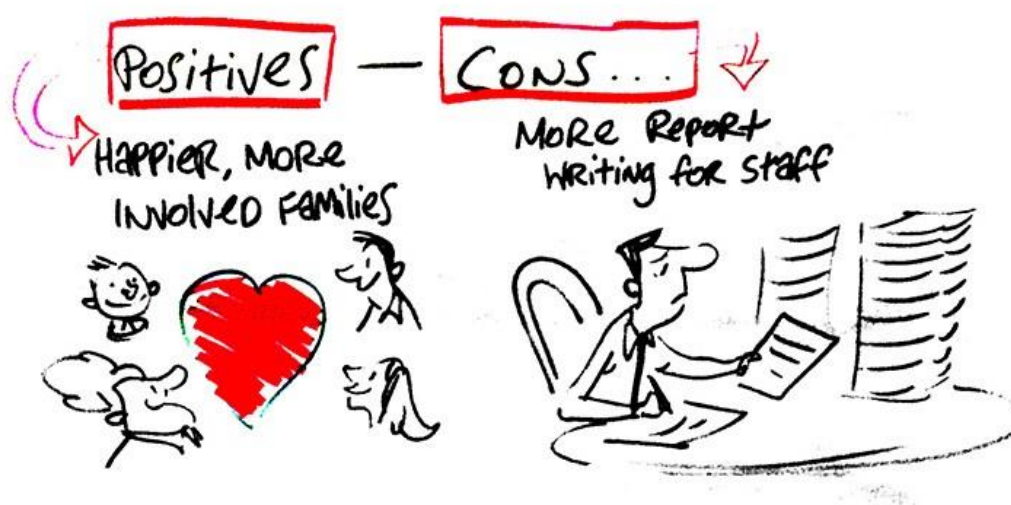
Workshop 8: Strengths-Based Report Writing - It's all in the Language you use

Presenters: Mary Lillis, Elizabeth O'Shee and Suzanne Kirwan
Facilitator: Dr Therese Brophy
Rapporteur: Eoin Harte

1. What considerations (specific issues) arise from this presentation?

It is questioned if a change to the style of report writing, to reflect a strengths-based approach, would affect the access to resources, afforded by reports. Time constraints, current workloads and the deficit-based approach are considerations. An increased awareness of the language used in reports is needed across all the professions. Practitioners need to be more considerate of the reader and of parents.

2. What needs to be done?

There is a need for additional investigation and research, including a national audit of existing reports. Learning and information on the issue should be shared with colleagues with a view to fostering self-awareness and encouraging reflective practice. These should also be included in professional training courses. Parents need to be consulted and empowered in the process. There needs to be changes to DES and agency requirements for reports to move away from a deficit-based model.

3. Who should do this?

Policy-makers, DES, HSE and management can influence change. Universities and training providers can provide support and training. Clinicians will make on-the-ground changes.

4. When should they do it?

It should start immediately and be reviewed as part of the overall service plan during the year. It should be include in professional training, staff induction processes, team-planning, in-service sessions, CPD and clinical supervision periods.

5. What resources are needed?

A policy on writing styles is required. Training and education resources are needed. Human resources, such as clinical, professional and peer supervision resources would be useful. Administrative support and an appropriate IT system and database would support the change. Time and financial resources may be required.
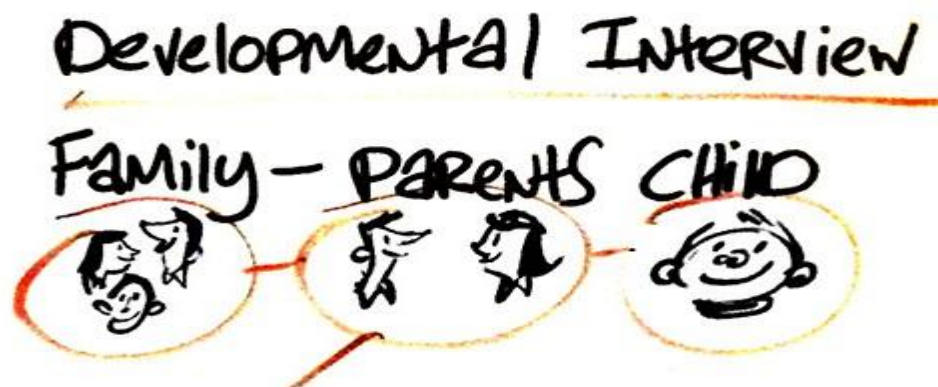
6.   Poster Presentation Catalogue

The following is a list of the posters that were displayed during the conference. The posters themselves can be viewed on line and downloaded.   The link is: https://www.hse.ie/eng/services/list/4/disability/progressing-disability/national-conference/poster-catalogue.pdf
The following entries provide summaries of the posters.

6.1   Rethinking Intervention Services in Line with Best Practice Guidelines North Kildare NDT (Network Disability Team)

Eimear Greene, North Kildare Network Disability Team. Eimear.greene@hse.ie

Kildare West Wicklow disability services progressed in May 2014. The poster outlines a snapshot of some of the interventions currently being provided, three years post reconfiguration. The team provides a range of interventions at the targeted, focused and universal levels. These interventions are reviewed, and have evolved to meet the diverse complex needs of the children in the service. The team works closely with caregivers, to provide the child with experiences and opportunities that promote their acquisition and use of competencies which will enable them to participate meaningfully in the key environments in their lives (Moore, 2012).

The Individual Family Service Plan (IFSP) meeting with children and their families is the starting point for goal setting, and this outlines an individual roadmap of appropriate interventions for that child. The clinicians work in collaboration with the children, their parents, education providers and other staff to ensure that all are provided with the knowledge, skills and support to meet the needs of each child, optimise the child's development and enable him /her to participate meaningfully in family and community life. Many challenges have been overcome since the services progressed in 2014, but some challenges remain in merging best practice guidelines with service delivery.

6.2   Autistic Spectrum Disorder (ASD) Care Pathway

Aisling Finucane, Clinical Manager, West Limerick Children's Disability Network Team. Aisling.finucane@hse.ie

As parents and children journey with the team, there are times when parents do not feel confident or knowledgeable about their child's needs and how to support them to ensure the best outcomes. It is at times like these when parents can feel a lot of anxiety. In the past, families have not felt supported during these times. The team listened to parents and a universal theme was "not knowing what was next and when to expect it" was the most difficult part. This was particularly difficult for families going through ASD diagnosis. Thus, an ASD Care Pathway was developed.

The ASD Care Pathway sets out steps that are taken by the multidisciplinary team in the lead up to and post diagnostic assessment. The Team give parents time frames for each step of the Care Pathway ensuring families have information as to when and what to expect next.

There are pathways for Early Intervention Team and School Age Team, which differ slightly. Parents are equal partners on the team, and are encouraged to give feedback to the team on their experiences of any aspect of the service they are receiving. Pathways will be modified over time, based on parent and team feedback.

6.3 Autism Support Group

Mary Durcan, Autism Service Sligo. Mary.Durcan1@hse.ie

The Autism Service in Sligo/Leitrim is based on an interdisciplinary team model of service delivery for children and young Adults in Disability Services. Those on the Autism Service Team are members of the early intervention teams and school age services, and have a key worker role within the teams.

The service provides practical application of recommended strategies, based on a team model in the home, school, community placement, which is based on an eclectic model, inclusive for example of TEACCH, PECS, social stories™ and the low-arousal approach and positive behaviour support. Role of the Autism team:

- Provides parent support;
- Assess as core team members the needs of the child and their family;
- Provide and supports interventions based on an interdisciplinary team model;
- Provides in-home support with a Family Support Assistance model 3;
- Reviews respite and out of home support needs including after school clubs and summer camps
- Coordinates multi-disciplinary team reviews;
- Transition support – preschools, primary school and secondary (mainstream, special schools and Autism specific classes)adult and training services; and
- Training and Autism awareness for parents, preschool and educational services, afterschool services, community groups and adult services.

The autism service provides supports to children and young people with autism, as a member of the interdisciplinary teams, and in consultation with CAMHS.

6.4 Exploring the effects of a Parent-delivered Intervention for Young Children with a Query of Autism: A Waitlist Initiative.

Dr Margaret Farrelly, Principal Clinical Psychologist, St. Joseph's Foundation Charleville Co. Cork and Alison O'Keeffe, Educational Psychologist in Training Mary Immaculate College, Limerick. mfarrelly@stjosephsfoundation.ie

Early intervention has been demonstrated to reduce the disabling effects of Autistic Spectrum Disorder (ASD), due to greater plasticity of the younger brain and the prevention of the secondary effects of environmental alterations made in response to ASD symptoms and outcome. Successive studies have demonstrated that some children may move off the ASD spectrum following intensive early intervention.

The aim of the present project was to (1) assess the effectiveness of a manualised, home-based, parent-delivered intervention in reducing specified target symptoms and developmental patterns of early ASD in children under three years of age and (2) by screening, to provide a more efficient pathway to a diagnostic assessment. Participants consisted of ten children, who had been referred to the ASD team and were awaiting a diagnostic assessment. Children were aged between 22 and 36 months. During a structured play session, observation of social communicative behaviours i.e., eye contact, joint attention, index pointing, response to name, speech, ability to sit and attend and play skills was conducted. Teaching methodology was discussed and role played, and following the screening sessions, a written programme of instructions and an information pack were forwarded.

Preliminary data indicate that some improvement in presentation of ASD symptoms can be demonstrated quite quickly.

6.5 Together Everyone Achieves More: A partnership model to promote inclusion in preschools

Ursula Murphy, Early Years Advisor/Preschool Support Manager, Mayo Early Intervention Team, umurphy@westerncare.com

'Inclusion' refers to a process involving a programme, curriculum or educational environment where every child is welcomed and included on equal terms, can feel they belong and can progress to his/her full potential in all areas of development (*National Childcare Strategy*, 2006-2010).

In Mayo, there are no special preschools. All children attend their local preschool. This requires meaningful collaboration with parents, preschool educators, the early intervention service and other early childhood services - to share knowledge and expertise, to ensure successful placements for all children.

The introduction of the new national programme AIM has changed the way we support children with disabilities in their local preschool. We recognise the need to support preschool educators with this change. Building on existing partnerships with the Better Start Team and Mayo County Childcare Committee gives us the opportunity to jointly provide accurate and consistent information, coach and mentor, identify learning needs and provide ongoing training through a range of different and unique approaches.

6.6 Access and Inclusion Model (AIM) Supporting children with additional needs to access mainstream preschool: frontline experiences and reflections on collaborative working

Melissa Murtagh, Speech and Language Therapist West Limerick Children's Services. Melissa.murtagh@hse.ie

The emergence of the Access and Inclusion Model (AIM) has complemented the vision of the Progressing Disability Services for Children and Young People (PDSCYP) programme to achieve a unified approach to delivering disability health services. Much research has been conducted which identifies the organisational difficulties of inter-service collaboration. However, the literature also highlights the need for services to be integrated as a clear component of service delivery models so as to meet the needs of children and their parents effectively.

The collaborative working of West Limerick Children's Services with Better Start Early Years Specialists and pre-school services in general has fostered holistic goal setting for children with additional needs within our service. This has yielded a more efficient way of targeting the needs of preschool aged children as all professionals in the child's life are focussed on achieving specific collaborative goals in partnership with families.

The poster depicts a reflection on frontline experiences of collaborative working in relation to the Access and Inclusion Model since the commencement of the programme in September 2016.

6.7 Lego Therapy

Annemarie Rynne and Aisling Noonan, Speech and Language Therapists, Clare School Age Disability Team. Annemarie.rynne@hse.ie

There was a challenge in being able to provide effective intervention to children with Autism Spectrum Disorder (ASD) in our service, whose chief difficulties were with social communication and pragmatic language. The evidence base suggests that teaching social skills, out of context, was an ineffective

intervention for achieving generalisation and improving social skills in children. Thus, to manage the large numbers requiring intervention and provide a more effective service, an innovative approach, which takes into account the importance of context was required. We became aware of an evidence based relatively new social communication intervention in a social context: Lego Therapy.

Positive social skills are promoted incidentally by the facilitator rather than taught explicitly. The focus is on pro-social behaviour – praise of positive behaviour rather than criticism of negative behaviour. In addition to being an appropriate intervention, it also evolved into an assessment tool for our team. Children who were being assessed for ASD could be invited to sessions and observed in social interactions with their peers. The practice has been well received by parents, children and therapists alike and the team will endeavour to continue to offer this therapy to better meet the needs of children with social communication difficulties.

6.8.   'F' Words in Action - Clare DCD Sports Group

Deirdre Talty, Senior Occupational Therapist Clare Children's Services. Deirdre.Talty@hse.ie

The "F-words" in childhood disability - **f**unction, **f**amily, **f**itness, **f**un, **f**riends and **f**uture- is a new way of thinking about children's health and disability in everyday life. It is based on the World Health Organisation (WHO, 2001) International Classification of Functioning, Disability & Health (ICF) Framework. These new ideas are inspiring us to implement a more family/child centred approach in our work practices.

Children with Developmental Co-ordination Disorder (DCD) often participate less in social activities and have low self-esteem, which can cause isolation and emotional problems (Engel-Yeger and Kasis, 2010) and lead to negative long-term consequences. The need for a sports group for children with DCD in Clare was identified, in late 2014, by a parent, because her child's attempts to participate in established local sports activities groups were unsuccessful. The parent, an Occupational Therapist (Clare Children's Services) and Disability Officer (Clare Sports Partnership) worked together to establish this group.

The formation and functioning of this group are in line with current best-practice guidelines (Camden *et al*., 2015) which highlight the need to focus on the wide-ranging challenges for children with DCD and their families. These guidelines also emphasises the benefits of families and services collaborating together to offer evidence-based services promoting function, inspiring participation and preventing secondary issues.

6.9   Domain Youth Club

Aisling Finucane and John Fitzgerald, West Limerick Children's Disability Network Team. Johng.fitzgerald@hse.ie

Parents would often report that their teenage son or daughter with a disability had joined the local youth club and was overwhelmed by the experience. Too many people, too much noise, could not join in with the activities or conversations. Many parents had reported that this experience had a negative impact on the teenager, and has set them back, as they felt excluded and isolated. When reviewing this information and considering research in this area and looking at ways to promote inclusion and partnership with the community, it was evident that there was an opportunity to bridge this gap.

The Domain Youth Club was established to cater for teenagers from 13-18 years of age with additional needs. Club members include teenagers on the Autistic Spectrum, teenagers with mild and moderate

I.d. and Down's syndrome. Club activities include playing pool, table tennis, board games, drawing, painting, group discussions and a drama group. Parent testimonials report an increase in self-esteem, a greater degree of confidence and chattier young people at home.

6.10 The Establishment of Waterford SportsAbility Forum

Rose Bradley Senior Social Worker CRC Services for Children Waterford
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Waterford's SportsAbility Forum was established in 2016, with representatives from various disability organisations, voluntary and statutory organisations and national governing bodies. The aim of the Forum is for organisations to meet quarterly and share information on what physical activity opportunities are available for people with a disability in Waterford. The Forum has been successful in bringing together a diverse range of disability services and organisations all working in partnership to benefit people with a disability in across the City and County. This willingness and commitment of the Forum partners to work together collaboratively has led to the successful establishment of Déise Dragons' Multi Sport Club for Children with a physical disability.

6.11 Independent Gym Group for Children with Physical Disabilities

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The school-age team in Enable Ireland, supports children with physical disabilities in their local community environments. The ethos of Enable Ireland aims to support the empowerment, inclusion and enablement of children and families within their communities.

Following clinical reviews and goal setting with teenage service users and their families, it was noted that a considerable number of service users identified a goal around breaking down barriers to access their local gym. Further research on this indicates that barriers that contribute to low levels of participation in physical activity and sport by people with disabilities in Ireland include the following;
- Lack of knowledge and information of what services are available.
- Lack of experience of the benefits of physical activity.
- Lack of staff skilled to work with people with physical disability
- Lack of accessibility of facilities.

This poster outlines an inter-disciplinary project to promote the participation of teenage service users with a physical disability in accessing a community gym, and furthermore to increase teenager's confidence in sourcing and engaging with a local gym.

6.12   Community Dance Intervention Programme

Áine O'Dea, University of Limerick. Aine.odea@ul.ie

What are the perceptions of parents and youth with a disability regarding a community-based dance intervention that targeted participation outcomes?

Introduction: Participation in life situations has become the outcome of utmost importance for rehabilitation. This study explored perspectives of a community-based dance (hip-hop) intervention to target participation outcomes.

Methods: The intervention a 1-hour dance intervention for seven weeks attended by thirteen participants with a neurodevelopmental condition(s), mild to normal intellectual range, 8-18 years, facilitated by three dance instructors and three health professionals. Interviews data was collected from twelve parents and three youths (14, 15, 16 years). Deductive thematic analysis was completed using the family of Participation Related Constructs framework (fPRC).

Results: Four themes emerged from the data. Two themes: attendance and involvement, described the positive experiences of participating in the intervention. The third theme highlighted improved person related outcomes - activity competency, confidence and preference. Involvement was linked to intrinsic person-related outcomes. The fourth theme, namely 'context,' supported participants' attendance and involvement in the intervention.

Conclusion: The elements of involvement – fun, enjoyment, motivation, choice, social connection were important perspectives that linked to improved participation outcomes. Context as a component of the design and implementation was linked to improved participation outcomes.

6.13   School Leavers' Programme: A team-based approach to supporting adolescents with a disability to prepare for leaving secondary school

Grace O'Hanlon Speech and Language Therapist & Gemma Lehane Occupational Therapist, 6-18 Disability Team Dublin West. Gemma.lehane@hse.ie; grace.ohanlon@hse.ie

With a growing number of adolescents on the 6-18 Disability Team Dublin West caseload, the team identified a need to support students and families who were due to leave the service and finish secondary school. The team recognised the importance of helping these families to prepare and plan for the next stage of their lives.

The School Leavers' Programme is run by occupational therapists, speech and language therapists and psychologists. The Programme's objective is to promote and develop independent life skills. At the end of the programme, parents are offered an opportunity to provide feedback in order to inform planning and improvements for future programmes.

6.14   Supporting the journey to School!

Damhnait Ní Mhurchú, Senior Speech and Language Therapist CRC Waterford. dnimhurchu@crc.ie

This poster presents the complex journey to mainstream school for a child with a significant physical disability and high needs illustrated by a single case. All five disciplines in the core treating team, along with specialist aspects of the service, were required to support the child and family in transitioning from a specialist playgroup, through to mainstream preschool and commencing mainstream school this September. The route to school required significant advance planning including engaging with other services such as the nascent AIM (Access and Inclusion Model) for preschool, and the SENO (Special Educational Needs Officer) for school.

To ensure a child and family-centred approach, close liaison was undertaken with the family regarding their preferences, as well as with the staff in the family's chosen educational settings. This included preparatory visits to share information relating to the client's abilities and challenges, to prepare and manage the environment, to advise regarding equipment, including technology, and ultimately to promote his inclusion, and to safely maximise independence and learning opportunities within these environments. However, the journey has not ended, and ongoing support of varying intensity will need to be provided to help to make this an ongoing success.

6.15 Transition to Secondary School

Eleanor Smyth, Occupational Therapist and Sinéad Flynn, Senior Speech and Language Therapist, North Dublin School Age Disability Team. Eleanor.smyth1@hse.ie Sinead.finn@hse.ie

The 'Transition to Secondary School' poster showcases a multi-disciplinary intervention group that prepares children with neurodevelopmental disabilities and their parents when transitioning to secondary school.

Participants from the School Age Disability Team and Primary Care Services who were transitioning into secondary school were invited to partake in group that simulated a secondary school environment. Children were separated into three small class sizes, provided with a school map and timetable. Clinicians introduced children to new skills such as initiating conversations with new people, reading timetables and organising lockers. Simultaneously, parents attended talks from clinicians on the topic of secondary school transitioning. The group received input from professionals in occupational therapy, speech and language therapy and psychology. Qualitative positive outcomes were recorded for this multi- disciplinary and interagency intervention group, and participants deemed the group an effective intervention.

6.16 Ready Set Cycle

Sarah Gately, Physiotherapist School Age Disability Team HSE Dublin North Central. Sarah.gately@hse.ie

The School Age Disability Team has a caseload that consists of children with complex functionally difficulties. Often, these children do not have the gross motor skills to participate in games in school and outside school and so are not included in typical peer interactions therefore they lose an opportunity to develop friendships and social skills. These lost opportunities can be detrimental to these children as they are already finding it difficult to develop and maintain friendships due to a large number of them have difficulties with social communication and interaction.

The aim of the cycling groups was to provide the children with the motor skills to allow them to participate in social interactions suitable for their age in order to give them the opportunity to develop lasting friendships in an appropriate manner.

Following the cycling group, the children gained the skills of cycling independently thus they have more independence and have more opportunity to engage with their peers. A number of the parents reported that the group had a big impact on the children's confidence across all areas, and they reported an improvement in participation.

6.17 Developing a Vocabulary Skills Pathway for School Aged Children – Treasure Hunters

Ciara McGlade and Noreen O'Leary, Senior Speech and Language Therapists Enable Ireland Dublin Children's Services. cmcglade@enableireland.ie

The School Aged Team in Enable Ireland, Sandymount, offers therapy groups across the year as an opportunity for children and parents to develop supportive networks. Within this framework, and with EBP as a guiding principle, the SLTs target vocabulary skills.

In the absence of intervention studies specific to our complex caseload, we sought to amalgamate the best available evidence to develop an intervention pathway. This poster presentation outlines the sources of evidence considered in this process. The format of the intervention, incorporating both parent training and group intervention for children, is described. Formal and informal outcome measures from the initial 'Treasure Hunters' group are discussed. Subsequent developments are described along with the learning to date.

The aspiration is to develop a series of group programmes that will support children and their parents in the development of specific vocabulary skills, and the utilization of these to support oral and written narrative skills, thereby supporting age-appropriate social and academic skills.

6.18 Communication Is Core

Teresa Orlandi, Speech and Language Therapist and Sinéad Healy, Speech and Language Therapist, Enable Ireland Cork. shealy@enableireland.ie; torlandi@enableireland.ie

The Speech and Language Therapy (SLT) Department in Enable Ireland Cork services runs a weekly communication group in a special school. The children in the group all use a form of Augmentative & Alternative (AAC) communication device. This group is facilitated through collaborative work between a class teacher and two SLTs. The six children who participate have limited or no verbal communication, and therefore use various communication devices to interact with each other.

The vocabulary targeted in the group is CORE vocabulary. CORE vocabulary refers to the small number of words that make up approximately 80% of what we say on a daily basis. Research and best practice continues to show us how important it is to give children access to robust AAC systems, complete with CORE words. When we give children access to these words we are providing them with power and flexibility in their communication.

The children in the group practise using these words in fun and meaningful activities. The group's success can be attributed to the collaborative effort between therapists, staff and families. The group strives to maintain best practice by emphasising CORE, applying evidence-based modelling principles, and encouraging participants to communicate everywhere. We are dedicated to continuing to raise awareness of the power of CORE.

6.19 Supporting Functional Hand Use of Children with Cerebral Palsy

Evelyn Bergin, Senior Occupational Therapist Enable Ireland, Tallaght;
Margaret McGrath, Senior Occupational Therapist Enable Ireland, Sandymount;
Adrienne Carolan-Gillan Senior Occupational Therapist Specialised in Upper Limb Motor Management Kildare/West Wicklow Network Disability Team and
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This poster explains the service development strategy which took place within three centres in the East Region. The aim was to develop and standardise the approach to how children with cerebral palsy are enabled to reach their potential to effectively and functionally use their hands. Therapists from Enable Ireland Sandymount, Tallaght and the Network Disability Team in Kildare set up an 'Upper Limb Special Interest Group' with nominated lead occupational therapists being responsible for service development within their own centres. The lead occupational therapists worked collaboratively to further develop pathways for assessment, intervention and follow up for children identified with a neurological need. Within this strategy, there was a strong drive towards the professional development of all therapists working with children with neurological needs, and this included a mentoring and training programme; this continues to evolve with plans for greater national and international links, further work on pathways of care for medical and therapeutic interventions and the development of a competency framework to structure clinician's professional development.

The model of service delivery ensures that children with cerebral palsy receive a high standard, equitable service – enabling them to reach the potential for functional hand use through evidence-based interventions. These include upper limb bimanual training, modified constraint induced movement therapy (mCIMT), strength and goal-directed training and medical support such as botulinum toxin therapy. The preventative paradigm, which includes splinting, casting and medical motor management through botulinum toxin treatment ensures that children will have a lower risk of developing painful and debilitating deformity and contractures as they grow.

6.20 Social Communication Pathway@ Treetops

Sorcha Murphy, Speech and Language Therapist, School Age Team, Treetops Children's Services, Dublin 8. Sorcha.murphy@hse.ie

The SLT team on Dublin South City SAT devised a pathway for children with social communication needs in 2016.
1. Cygnet: This programme is designed for families of children aged 7-18 with ASD. The programme is designed to: increase parents' understanding of ASD and guide parents through practical strategies.
2. TalkAbility™ – The Hanen Program® for Parents of Verbal Children on the Autism Spectrum is implemented once a year by the SLT department.
3. Social skills groups: The aim of these groups is to further develop conversation, non-verbal communication, verbal reasoning and flexible thinking along with friendship making skills and self- awareness.
4. Further parent training: is aimed at refreshing parents' knowledge of ideas and strategies covered in previous interventions and updating their skills to work with their now older child.
5. Annual reviews: The assumptions of Solution-Focused Brief Therapy are applied to these reviews.

6.21 Making Inclusion and Empowerment the Core

Mona Albertini, Social Work Team Leader, Springtime Early Intervention Service, Brothers of Charity Galway. monaalbertini@galway.brothersofcharity.ie

The Brothers of Charity Galway, School Age Service offers inter-disciplinary supports to children with an intellectual disability, aged six to eighteen years, and their families. The disciplines are; psychology, speech and language therapy, physiotherapy, social work, occupational therapy, paediatrics and psychiatry.   We are committed to the principles of Inclusion and Inclusive education and aim to provide a quality service where children, teenagers and young adults are offered a range of supports. This enables and empowers them to participate in the life of their local community to the best of their ability.

The service is delivered in family homes, in local primary and secondary schools, special schools and through our respite service, which includes in home family support and home sharing. We work in partnership with families and a wide range of community agencies in order to ensure collaborative practice and that the children and young people who use our service are valued in their local community, have opportunities to participate in education and leisure time activities, make choices about their lives and be closely connected to family and friends.

Group work, *Parents Plus* training, sibling workshops, parent groups, *Circle of Trust* training, social skills for children, *Studio Three* training for families and Saturday Clubs for young people are offered to families. We have recently launched an annual information fair for young people who are transitioning to adult service, and published an information booklet which details a wide range of resources, community services and further education opportunities.

6.22 Autism and me, Autism and my Child

Suzanne Kirwan and Angela Murphy, North Dublin Early Intervention Team. Suzanne.kirwan2@hse.ie

This study was a qualitative evaluation of the support and psycho-education programme, 'Autism and Me, Autism and My Child' (A & M). This programme was developed for parents of children diagnosed with an Autism Spectrum Disorder (ASD). The programme was developed by senior clinical psychologists, and other team members. It was developed to fill a training gap, as no team members were trained in Early Bird, Ascend, or other such programmes.

It covers topics including understanding autism and its relationship with behaviour, communication, sensation, cognition, emotion etc. The programme is based in an awareness of the journey of getting a diagnosis and the value of parents meeting each other.

Six participants undertook a semi-structured interview. The interview explored participants' experiences of attending A & M, focusing on helpful and unhelpful aspects of content, structure and facilitation. Using a descriptive-interpretive approach to thematic analysis, interviews were analysed. The themes revealed included: the ongoing journey of ASD, benefits of hearing other parents' stories, space to express emotions and relevance of MDT group input. Unhelpful aspects of A&M were also raised, including the need for alternative delivery times. Group matching was seen as a barrier to balancing content and process within the group.

6.23 Group-based Parent Training to reduce the Risk of Problem Behaviour for Children with Developmental Disorders and to support Family Wellbeing and Parent Mental Health

Fionola Hogan, Clinical Psychologist and Aisling O' Dwyer O' Brien, Psychologist in Clinical Training. fhogan@enableireland.ie

Background: Children with a Developmental Disorder (DD) are more likely than typically-developing children to experience behaviour difficulties.

Method: A mixed-method design was employed to evaluate the effectiveness of the integration of an adapted Webster-Stratton Incredible Years Basic Parenting programme for pre-school children with DD (IYPT-DD; McIntyre, 2008a, b) and a Mindfulness-Based Stress Reduction intervention (MBSR; Jon Kabat-Zinn, 1990). Nine families attended for 12 weekly (2.5 h) sessions. A pre and post methodology was used to evaluate the child's social emotional behaviour using the Child Behaviour Checklist (CBCL 1.5-5; Achenbach, 1998). Post intervention, an IYPT Satisfaction Questionnaire (Webster-Stratton; 2013) and a semi-structured interview were conducted with parents.

Results: Results suggest that this approach increases positive parent perceptions of their child with DD, reduces children's problem behaviours, increases parent competency in management of problem behaviours, and decreases parenting stress.

Conclusions: This study provides preliminary evidence for the efficacy of the integration of an IYPT-DD and MBSR intervention for pre-school children with DD experiencing behavioural difficulties. Although this approach is promising, future research should investigate this integrated intervention using a randomised controlled trial design and to ascertain if outcomes are maintained and generalised over time.

6.24 Circle of Security Parenting Tool

Dr Michelle Keavey, Clinical Psychologist Clare Children's Services and Berry Guthrie, Social Work Team Leader, Clare Children's Services. Michelle.keavey@hse.ie; Berry.guthrie@hse.ie

Circle of Security (COS) is a relationship-based parenting tool which implements decades of attachment research in an accessible step-by-step way that can be used in a variety of settings. It is designed to transfer research knowledge to parents in a user-friendly way using a video-based programme and to provide understanding to parents of their own attachment history as it relates to their parenting.

This programme is offered to parents of children in Clare Children's Service across the Early Intervention Service and the School Age Disability Team. It has been found to be incredibly useful as a conceptual and therapeutic framework for working with families. Feedback from parents has been positive in terms of how they now view and interact with their children. It is innovative and novel in a disability service as traditional interventions often focus on supporting parents to develop specific skills whereas COS focuses on the relationship between children and parents from which change occurs. The aim, therefore, is to help parents to look beneath their children's behaviour to discover the relationship needs and to support these needs with both confidence and empathy, which promotes a positive parenting approach which is effective in making long-term gains.

6.25 Using Parents' Experience in Designing Service Changes – listening sessions for parents of children in early intervention speech & language therapy services

Breda Flynn Murphy, Speech and Language Therapy Manager and Fiona Murphy, Senior Speech and Language Therapist HSE Laois Offaly. bredaflynnmurphy@hse.ie and fionaE.kelly@hse.ie

The *Parents' Experience of Service in Early Intervention* SLT Laois/Offaly poster was developed by conducting 'Listening Sessions' with parents whose children were awaiting SLT Early Intervention Services (both pre and post multi-disciplinary team assessment. Parents' perceptions, views and comments were collected and considered in conjunction with SLT knowledge of current best practice to advise quality improvement plans (QIPs).

The following themes were identified by the parents; Communication between the SLT Department and the parents: model of service delivery for their children; level of service received; access to the service; support in transitioning to school; support for parents and accommodation. The SLT team then established this new practice in Laois/Offaly, to work more collaboratively with parents in a manner promoting inclusion and partnership and to advise changes in service design.

6.26 Working Together: Learning from Teachers' Experiences of Teaching Children with Sensory Processing Difficulties (SPD)

Áine Henry, St. Michael's House Dublin and Dr Iseult Wilson, Ulster University. aine.henry@smh.ie

Sensory processing difficulties (SPD) can impact children's school participation and the researcher, while working as an occupational therapist (OT), found that teachers often struggled to deal with SPD in the classroom, and she sought to understand their perspective.

OTs frequently collaborate with teachers to address SPD and interventions can be used to impact behaviour within school environments (Worthen, 2010). In Ireland the OT role in schools is not clearly defined, which obstructs collaborative working (Quinn and Mullally, 2008). OT-teacher collaboration occurs within complex health and education systems, with structural barriers to inter-agency working (Villeneuve & Shulha 2012). This study explored the experiences of seven recently-qualified Irish primary school teachers of teaching children with sensory processing difficulties and autism. It aimed to gain insight into their perspective in order to improve intervention and collaborative practice.

Findings were discussed from an ecological systems perspective and highlight the need for changes in initial teacher education and the organisation and delivery of clinical services to schools. The need to improve collaborative practice and develop better systems of communication between parents, school staff and clinicians emerged as key findings.

6.27 'Snax, Popcorn, Ketchup & Bread Rolls'– Diet of a Child on the Autism Spectrum

Anne Marie Clancy Senior Speech and Language Therapist Treetops Children's Service, Dublin 8. annmarie.clancy@hse.ie

Research indicates that 40-60% of children presenting with autism spectrum disorder (ASD) present with Feeding, Eating, Drinking and Swallowing (FEDS) needs, but there is a dearth of information in the literature on the nature of these FEDS needs and how to manage the associated issues.
The objectives of the research were to determine:
- The percentage of children on a disability caseload presenting with FEDS needs,
- The nature of the children's FEDS needs including the range of foods accessed by the children, willingness to try new foods
- The impact of these FEDS needs on the child and on the family

A questionnaire was disseminated to the caseload (parents of 358 children) of a Health Service Executive (HSE) disability caseload – 0-18 years of age. A fifth (21%) of forms (62/358) were returned, outlining the nature of the child's needs. This figure (21%) would appear to be an underestimate of the prevalence of FEDS needs in children with ASD as outlined in the literature. There are similar patterns in the foods accessed by children with ASD. Preferences for carbohydrates/starch and foods high in sugar were observed. High levels of anxiety were reported in relation to food consumption from parents' report of their own experience and that of their children.

6.28 Examining Staff Perspectives on the Nature of Family-Centred Practice in an School Aged Disability Team

Derbhela Farrell & Suzanne Guerin University College Dublin; Nicola Barry, Karina O'Doherty, Stephanie McGrath and Caitríona Lyng, St Michael's House Service. Nicola.barry@smh.ie

Family-centred practice (FCP) is recognised as central to contemporary disability services. However, the literature reflects general paediatric services. Given the centrality of FCP in Progressing Disabilities there is a need for research in Irish settings.

This study examined staff views of FCP within the School Aged Disability Team in St. Michael's House (SMH) Dublin, a new pilot MDT service for those aged 5-18 years and their families. Semi-structured interviews were conducted with eleven participants (clinicians and managers). Data were analysed using thematic analysis and a focus group with the team assisted with interpretation. Topics related to understanding of FCP, implications of FCP, team roles, supports for and barriers to FCP. Key principles included recognising family expertise, working in partnership and empowering parents, and being flexible/mindful to family dynamics. Barriers/supports included staff roles and responsibilities, families' expectations and experiences of FCP, and issues relating to resourcing. The findings highlight complex perspectives on FCP, represented as best practice but difficult to operationalise. Given the potential for FCP in disability services there is a need for further research, in particular exploring child and family perspectives. Further research will allow the concept to advance beyond its theoretical and general health services base.

6.29 National Council for the Blind of Ireland (NCBI) - Working for People with Sight Loss

Caroline Lane, NCBI, Children's Services Lead Co-ordinator. Caroline.lane@ncbi.ie

NCBI is a national organisation providing assessments and interventions for over 1,300 children with sight loss and their families. Through a team of specialist staff operating from centres located throughout Ireland our objective is to support the development of compensatory skills to enable children with sight loss to fully participate in all aspects of daily life within their home, community, education, social and leisure based activities.

Sight loss can impact upon a child's physical, cognitive, social and emotional development as we primarily use vision as the channel for learning. Research has shown that children with severe sight loss can be developmentally delayed by up to two years. In addition to this a significant number of our service users have more than one disability, hence relationships between NCBI and other professionals involved are essential in order to understand and share our knowledge of the impact on overall functioning including vision.

Sight loss is a low incidence disability and requires targeted input from early intervention therapies and specialist workers in the field of vision impairment. Our experience to date has shown that collaborative working practices help to improve outcomes overall for children with sight loss in Ireland.

6.30 The Role of Community Facilitators for Disability Sligo – Leitrim - West Cavan

Christina Egan, Community Facilitator for Disability HSE Sligo/Leitrim/West Cavan. Christina.egan@hse.ie

The Community Facilitator for Disability (CFD) provides support to children with disabilities in the 0-18 year group as a key team member of the Early Intervention and school age teams. The CFD has a designated key worker role within the teams.

The role of the Community Facilitators for Disability:
- The CFD service provides ongoing support to families of children with complex needs;
- The CFD is a key resource person in the planning and provision of services, which meet the child's specific and assessed needs and works within the inter disciplinary team model;
- The service is home and clinic based and aims to assist and offer guidance to parents /carers with the developmental needs of each child at key transition stages;
- The CFD co-ordinates the multi-disciplinary team review process for school age children.
- Referral to support services;
- Guidance on Early Intervention Programmes as part of the Early Intervention Team
- Information on benefits and allowances; and
- Providing information on referral to health professionals and inter agency services as appropriate.

Support services for Parents /carers:
- Support in preschool services;
- Support at various Transition Stages - Pre-school, school and school leavers;
- Carer support at home;
- Respite services in HSE;
- Home-to-Home holidays in HSE;
- Social and Recreation programmes;
- Summer Camps;
- Saturday clubs;
- Sibling Support groups;
- Parent and toddler support group;
- Health and wellbeing groups; and
- Independent living skills.

6.31 The Role of the Early Educator in the Multi-disciplinary Team

Ann Coughlan, Early Intervention Educator Enable Ireland Cork Services and Gino Lerario, Early Intervention Educator North Tipperary Children's Services, HSE. acoughlan@enableireland.ie

Early Childhood Intervention involves medical and pedagogical concerns. In a 'best practice' model, these areas and concerns should not be compartmentalised but rather approached within a holistic framework. Despite the fact that many early childhood intervention centres in Ireland espouse evidence based best practice, a 'clinical' therapeutic ethic is still influential. Many ECI teams maintain elements of the medical model, thus retaining disciplinary boundaries.

If we are to aspire to a social model of service delivery, there needs to be a balance between medical and educational practitioners on any specialist team. Achieving this coalescence is impeded by the lack of a working partnership between the Departments of Health and Education in addressing the needs of young children with disability.

We present the role of the educator as being critical on the multi/inter/ and transdisciplinary teams:
- in shaping a holistic approach to early childhood intervention;
- in supporting children with developmental delay and those with complex needs, with early learning skills;
- in leading transitions into educational mainstream institutions i.e. pre & primary schools; and
- in training and supporting parents/caregivers to develop their own teaching strategies to assist the child.

6.32 Developing Team Culture

Elizabeth O'Shee and Helen O'Connell, HSE Early Intervention Team, North Dublin. Elizabeth.oshee@hse.ie; Helen.oconnell3@hse.ie

The EIT service was redeveloped in 2014 and as part of this; team working was embedded into the structures of the team. Managers and clinicians came together over six months to plan, reconfigure and redesign the service.

From this bottom-up, participatory process, a new way of working in EIT has translated the concept of 'inter-disciplinary working' into genuine practice, whilst supporting ownership by the team. Team working begins with every new client, allocated a different combination of clinicians to work with them. Individual disciplines do not have individual waiting lists, ensuring true inter disciplinary working and shared responsibility.

The Team Coordinator and Administrator work in complementary roles to support the work of the team. Their roles include liaising with parents, management, planning and organising. Compulsory weekly meetings, sharing breaks and important celebrations together support the team in creating an open and supportive culture and supporting self-care. A culture of respect and open communication is worked towards consistently through working together in the same office, team meetings, planning days and daily informal contacts about clients.

Team culture is a dynamic process, which brings frustrations, demands and challenges. Awareness of the need to continuously reflect and adapt as necessary is essential.

6.33 Motor Management

Nicola Sutton, Senior Physiotherapist; Amanda O'Sullivan, Senior Physiotherapist and Adrienne Carolan Gillan, Senior Occupational Therapist, Mid-Kildare Network Disability Team.
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The Motor Management service was established to support local therapists, hospital staff, Area Medical Officers (AMOs) and families to provide a coordinated approach to early detection and service provision for service users who present with difficulties with mild to severe hypertonicity, moderate to severe hypotonicity and neuro-developmental delay. This service involves upper and lower limb assessment of motor function as it impacts on daily living skills, functional performance and quality of life.

The Kildare pathway directly *reflects the vision set out in the HSE Progressing Disabilities Specialist Service* model where there is transferability of knowledge; inclusion of community, hospital and disability service staff whilst ensuring that the primary caregivers are an integral part of the goal setting and decision making process when it comes to treatment implementation and its impact on their lives. Between 2014 and 2017 the pathway has been developed to include all service users accessing services from a network disability team, children on the waitlist for network disability teams, new referrals and service users attending primary care. The numbers reflect the increasing need for such service pathways, and demonstrate how an innovative use of resources to provide training and advice locally and on a wider regional basis can ensure that service users and their families can be supported in the most appropriate setting to meet their overall needs.

7. Experiences in Northern Ireland

This section presents two papers that provide particular insights from Northern Ireland. While the contributors did not attend the conference, they are subject experts, and their insights and experiences bring important added value to bear on progressing disability services.

7.1 Enhancing Services for Children with Disabilities and their Families - A Northern Ireland Perspective

Eamonn McNally, Solicitor, The Children's Law Centre, Belfast.

Access to services for children with a disability and for those who care for them is one of the most common issues upon which the Children's Law Centre is asked to advise. This is unsurprising as Northern Ireland has the highest rate of children with a disability in the UK at 5.5%.

The Children (NI) Order 1995 is the main piece of legislation in Northern Ireland relating to children and it provides the legislative gateway for many young people with disabilities and their families to be assessed for support services.

The Children (NI) Order 1995 deals with a very specific and defined group of children known as "children in need". Once a child has been classified as a 'child in need' for the purposes of the Children (NI) Order 1995, in that the child is unlikely to achieve or maintain a reasonable standard of health or development without the provision of services or that his health or development is likely to be impaired, without the provision for him of such services; or he is disabled, the child's local Health and Social Care Trust should carry out an assessment of need in line with Article 18 of the Children (NI) Order 1995. It is this assessment that outlines the child's needs, and identifies the potential services the child may require.

The notion that their disabled child is a "child in need" can be daunting for parents. When parents contact CLC, they are often unsure what being a child in need actually means for their child, what services may be available to their family or how they can challenge a decision about the type and level of services that are being offered.

There is no particular limitation on the types of services that can be provided to children in need and their families. Some of the most common types of support provided include, but are not limited to, respite care, direct payments to carers so that they can use these to arrange and pay for their own care and support services instead of receiving them directly from their local Health and Social Care Trust, befriending services for children or financial assistance.

The Children (NI) Order 1995 uses the word "families" within the title of Article 18. This inclusion is an extremely important one. Courts have made it abundantly clear that a child's family is the best environment for a child to grow up in and to thrive within, and therefore services may be provided to a child's family if those services will benefit the child. However, when considering the level of services being offered to a child and their family Health and Social Care Trusts in Northern Ireland have a wide discretion open to them regarding the fulfilment of their statutory duties.

An important legislative development in Northern Ireland has been the Children's Service Co-Operation Act (NI) 2015. This places a statutory duty upon the providers of children's services to co-operate to achieve the best outcomes for children.

By virtue of section 2 (1) Every children's authority must, so far as is consistent with the proper exercise of its children functions, co-operate with other children's authorities and with other children's service providers in the exercise of those functions.

Under the 2015 Act the NI Executive must adopt a strategy (the "children and young person's strategy") setting out how it proposes to improve the well-being of children and young persons. Whilst a draft strategy has been consulted upon, the publication of the final strategy is still awaited.

It is essential that those who assess and provide services for children with disabilities and their families adopt rights based approach to the assessment and provision of services. When considering the services required by disabled children and their families, consideration should be given to the overarching principles of the United Nations Convention on the rights of the Child (UNCRC) and the United Nations Convention on the Rights of Persons with disabilities (UNCRPD).

The United Kingdom became a signatory to the UNCRC in 1990 and as a result bound itself to the obligations contained therein. Whilst not directly enforceable in Northern Ireland courts the UNCRC is used as an interpretative tool and should be viewed by service providers as the foundation stone rather than the high bar of achievement. There are thirty-three specific rights for children contained within the UNCRC. In the context of assessment for services, Northern Ireland Health Trusts should comply with Article 3 UNCRC, which provides that in all decisions taken which affect children's lives the child's best interests should be a paramount consideration and Article 12 UNCRC that children have the right to have their voices heard in all matters concerning them. In essence, all reasonable and practical steps to facilitate children's participation and involvement in the assessment process should be taken. Recommendations for services should always be in the child's best interests.

The UN Committee on the Rights of the Child in its fifth periodic report on the UK made recommendations, which are of importance in the assessment of and provision of services for disabled children. With reference to its general comment no. 15 (2013) on the right of the child to the enjoyment of the highest attainable standard of health, the Committee recommends that the State party, the governments of devolved administrations, Overseas Territories and Crown Dependencies develop comprehensive and multi-sectoral strategies on child health:

a. With allocation of the maximum extent of available resources and a robust monitoring mechanism;
b. With a strong focus on eliminating inequalities in health outcome as well as in access to health services;
c. Addressing underlying social determinants of health.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is relatively new in convention terms. The UK ratified the UNCRPD in 2009, and in doing so, bound the State and public authorities to promote, protect and ensure the rights contained within the UNCRPD. In Northern Ireland, the Northern Ireland Human Rights Commission and the Equality Commission hold the role of the Independent Mechanism for the UNCRPD.

The European Union has been a party to the UNCRPD since January 2011. As a party to the Convention, the EU must, and has since 2013, put in place a mechanism to promote, protect and monitor the UNCRPD's implementation on matters of EU competence. The EU becoming a party to the UNCRPD places Northern Ireland in a unique, but as yet untested, position by virtue of Section 6(2) (d) Northern Ireland Act 1998, which prohibits the NI Assembly from legislating contrary to EU law, and thus it is the view of many within the voluntary sector that the UNCRPD has a special status in Northern Ireland.

Whilst the entirety of the convention applies to children with disabilities, Article 7 of the UNCPRD specifically refers to children:

1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.
2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.
3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

This again emphasises the needs for decisions about children to be in their best interests and for children to be fully involved in the process of assessment for services.

Families often feel aggrieved when the services, which are identified as being necessary for their children, are not provided and their children's needs go unmet. The courts have made it clear that Health Trusts have a duty to assess and identify needs but not to provide every need, which is identified for a child.

Whilst the impact of BREXIT is yet to be fully assessed, and specifically what impact it will have on children's rights, one concerning development is the potential loss of the Charter of Fundamental Rights of the European Union, which came into force in 2009 after the Lisbon Treaty took effect. It sets out a series of economic, political and social rights for citizens of the EU by drawing together rights from existing EU primary and secondary law. It has multiple articles which are of use when arguing children's rights in an EU law context. Specifically 'Article 24: The rights of the child,' which echoes other pieces of international law to ensure that children are able to express their views freely, that their views will be taken into consideration on matters which concern them and that in all actions relating to children, whether taken by public authorities or private institutions, the child's best interests must be a primary consideration. It appears that the Charter will be lost from the Northern Ireland (and UK) legal system when the BREXIT negotiations are complete by virtue of section 5(4) of the EU Withdrawal Bill. It is the view of the Children's Law Centre that this loss constitutes a regression in the protection of the rights of children with disabilities in the North of Ireland.

For further information please contact the Children's Law Centre on 02890245704 (NI) 04890245704 (from RoI) or info@chidlrenslawcentre.org or visit www.childrenslawcentre.org

7.2   Progressing Disability Services in Northern Ireland

Dr Fiona McCaffrey, Head of Research and Development Middletown Centre for Autism.

This paper responds to the HSE-MIC Conference by providing relevant reflections on practices and experiences in Northern Ireland, as they relate to the PDS agenda. The broad aims of the conference were to:

- • Promote achievements of Children's Disability Teams;
- • Showcase/spread good work practices within Children's Disability Services;
- • Provide support for parents and staff of children's disability services ; and
- • Promote HSE/Voluntary Organisations partnership working for optimal benefits for children and young people with a disability and their families.

The conference promoted collaborative approaches to supporting children and young people with disabilities and the conference programme was reflective of this, featuring parents, and professionals from across the Health, Education and Voluntary sectors as well as input from third level institutions promoting the transformative impact of research into practice.

The conference programme itself is representative of the philosophy that services need to employ in our work within the disability sector, promoting collaboration between key professionals and parents and this is grounded in the research work conducted by Irish universities on issues that are relevant to Irish service users. This covers the broad strata of collaborative relationships that are required to promote excellent in-service provision within the disability sector. The presentations emphasised the importance of quality assessment, quality practice, quality report writing as well as demonstrating models of practice that are ongoing throughout Ireland. Conferences such as this that allow professionals and parents the time out to consider the strength of current practice and the importance of collaboration are critical touchstones in our professional lives. I have no doubt that the delegates finished the day feeling inspired and ready to take collaborative working to the next level in the pursuit of progressing disability services.

Northern Ireland: Collaboration in Public Health

Current practice in Northern Ireland is reflective of practice in the UK and as such is based on critical policy documents that are underpinned by research. Collaborative working that is child and family centred is the gold standard for working within promotion of public health in Northern Ireland. For example, The Northern Ireland Public Health Strategy Making Lives Better details the following as the core values for improving the health of everyone in Northern Ireland

- • Social justice, equity and inclusion all citizens should have the right to the highest attainable standard of health;
- • Engagement and empowerment: individuals and communities should be fully involved in decision-making on matters relating to health, and empowered to protect and improve their own health, making best use of assets;
- • Collaboration: public policies should contribute to protecting and improving health and wellbeing, and public bodies should work in partnership with local and interest group communities;
- • Actions should be informed by the best available evidence and should be subject to evaluation; and
- • Addressing Local Need: Action should be focused on individuals, families and communities in their social and economic context.

(*Making Lives Better* 2013 Department of Health Northern Ireland)

Collaboration is a cornerstone of public health provision in Northern Ireland and as such this impacts on the provision of children's' services and the services provided for children with a disability.

Models of Practice: The Northern Ireland Autism Strategy and Action Plan

How does collaboration in children's services and services for children with a disability work in Northern Ireland? What follows is a model of practice for supporting children with autism; this model is detailed in the Northern Ireland Autism Strategy and Action Plan. The plan is at its core a model of collaboration; it involves all branches of government in Northern Ireland and is underpinned by advice from a specialist research committee. The Northern Ireland Autism Strategy and Action Plan set out to achieve the following aims through high levels of Governmental collaboration:

Strategic Aim	Sample Outcomes	Responsible Departments
Awareness	All public servants should have access to autism training All staff receive an autism fact-sheet	All Departments
Accessibility	People with autism should have full accessibility to schools, shops, services, transport The provision of clear travel Information provision of travel training clear communication of support services	Department of Infrastructure
Children, young people and families	All Government Departments work together to promote services for children, young people and families	All Government Depts. Department of Health Department of Education
Health and Wellbeing	Promote the need for health and wellbeing amongst people with autism Ensure that pathways to health and wellbeing are clear for people with autism and their families	Public Health Agency Department of Health Department of Education
Education	Ensure that Education is delivering for people with autism and their families Provide more support where needed Ensure best working relationships between Health and Education	Department of Education Department of Health
Moving On	Ensure that provisions and supports are in place to support young people post 16. Ensure that there is information on housing, further and higher education and employment and that Government Departments work together to promote pathways to adult life	Department of Education Dept. of the Economy Department of Infrastructure
Choice, Control and Freedom	Ensure people with autism have a choice in their current and future living and working lives. People with autism have independence and autonomy and have equal access to supports, information and equality of choice in their daily lives	All Government Departments
Justice	Extra support for people with autism in the Justice System Training and information for those working in the Justice system	Department of Justice
Being Part of the Community	Provide opportunities for people with autism to participate in community activities including leisure and arts Raise awareness of autism amongst staff working in community buildings for example museums, libraries and leisure Centres	Dept. of Agriculture, Environment and Rural Affairs Dept. of Infrastructure Department of Economy
Being an Active Citizen	Ensuring that people with autism have a voice in the decisions that have an impact on their lives Increasing participation and representation of people with autism in all aspects of public and civic life	All Departments

A 2015 progress report on the NI Autism Strategy detailed significant progress across the strategic aims and in particular encouraging detail on high level and ground level governmental collaboration. People with autism and their families interface with public services across the scope of their lives and their life spans. A joined up intergovernmental approach seems to be the most comprehensive way of ensuring progress in all aspects of their lives.

Middletown Centre For Autism
A final example of collaboration in Northern Ireland is my own service, Middletown Centre for Autism. The Centre is an example of collaboration across jurisdictions and a transdisciplinary model that is predicated on inter-professional collaboration. Middletown is a unique cross border service, funded by both Departments of Education with the purpose of promoting excellence in services for children with autism.

The Centre has three services that work in collaboration these are:
- Training;
- Research; and
- Learning Support and Assessment (LSA).

The Middletown Team
Collaboration is at the core of the Middletown model. Each service is built on the success and output of the other two services, with the child and family at the centre of the model. The Centre's capacity-building model encourages parents and teachers to become part of the same team with all elements working together to support the child and create an autism competent environment:
- Parents, child and family;
- Autism specialists;
- Teachers;
- Occupational therapists;
- Speech and language therapist;
- Autism intervention specialist;
- Learning support officers;
- Trainer/Advisor;
- Researchers; and
- Administration and business support.

Learning Support and Assessment Service

The LSA Service works on a referral only basis, providing direct intervention, training and capacity-building with the child, family and the school. A tailored Learning Support Plan is developed and agreed and the LSA team collaborates to provide a transdisciplinary intervention to support the child. This intervention lasts up to four school terms. Assessment data are collected before, during and after the intervention and a follow-up interview is conducted. All this data are fed back into both the LSA and the Training Service. The data provides LSA practitioners with direction and opportunities for change and growth. This data are also fed back to the training team who develop and organise programmes based on the needs identified by the service users e.g. training on Selective Mutism in December 2017.

The Training Service

Middletown Centre is one of the main training agencies in Ireland and Northern Ireland. The Centre provides a full programme of training for parents, carers, teachers and other educational professionals. The Centre offers part-day, full-day and multi-day sessions delivered by our multi-disciplinary team of autism specialists. We also have a range of guest speakers and lectures featuring respected researchers and practitioners worldwide. The apex of this is the Centre's two-day International conference that is held every two years. This conference has featured speakers such as Temple Grandin (2017) and Tony Attwood (2015).

In order to deliver this, the Centre works in partnership with local schools who provide their facilities and their local networks for the hosting and publicising of the training in local areas. The Centre also works in partnership with the National Council Special Education (formerly SESS) and provides regular input into the NCSE training calendar. Networks of partnerships at strategic and 'on the ground' levels have allowed the Centre to deliver training to 22,000 parents and 29,000 professionals in Ireland since the Centre's training service commenced in 2007.

The Centre in partnership with Mary Immaculate College Limerick provides a Graduate Certificate in Autism Studies. This demonstrates the Centre's collaborative partnerships, at every level of our work and how, with partnership-working, we can reach more and more people with good practice based on our work in schools and with families.

The Research Service

The Centre conducts a follow-up with every child / young person who is referred to the Centre; this is delivered to the main parent / carer face-to-face or by telephone interview. When appropriate the child / young person themselves are offered the opportunity to feedback on their experience of the intervention either faced-to-face or using telephone or online questionnaires. Questionnaires are sent to the professionals who worked with the children and they are also offered the opportunity to engage in a telephone interview. Training evaluations are entered in a database and evaluated regularly. This enables the training team to review both the content and the practicalities of delivering an Island-wide training service for parents and professionals.

Collaboration

The Middletown model provides examples of collaboration at every level. This collaboration is directed towards progressing the autism services and creating an autism-competent environment, as indicated by the following diagram:
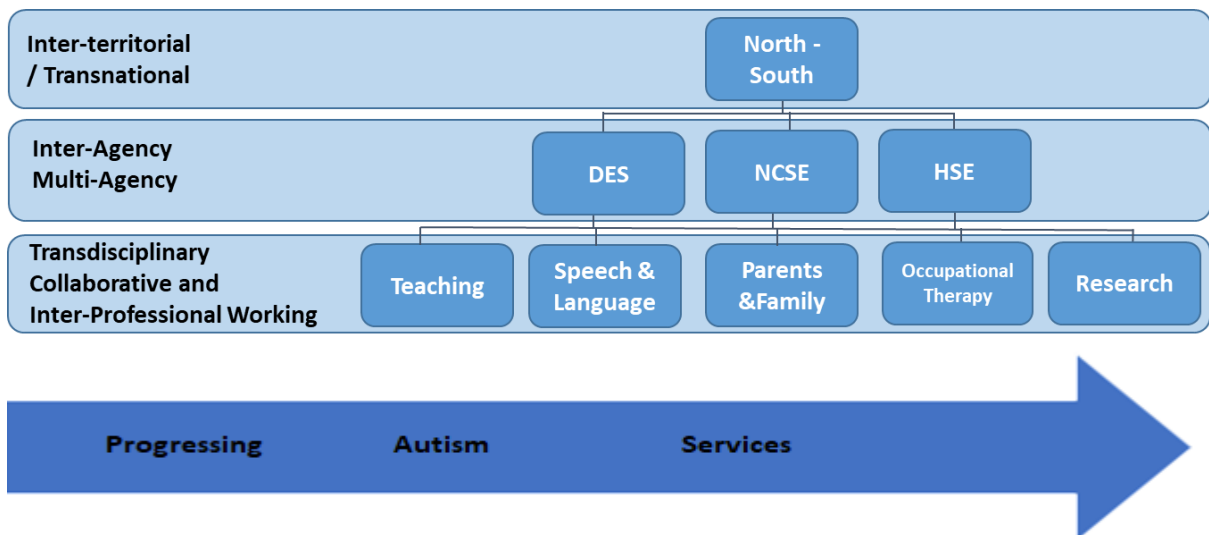
The Middletown model is very much in line with the theme of the conference, where the success of services that foster collaboration was demonstrated. One of the aims of the Centre is to continue to progress services in autism through progressive collaboration and the diversification of existing collaborative relationships. This is even more important in the era of BREXIT, when cross-border services are experiencing a degree of anxiety about the future. While no individual or agency can currently predict what is ahead with BREXIT, it is clear that collaboration is the key in ensuring quality and progressive services.

Further information
Northern Ireland Public Health Strategy
https://www.health-ni.gov.uk/publications/making-life-better-strategy-and-reports

Northern Ireland Autism Strategy and Action Plan
https://www.health-ni.gov.uk/articles/autism-strategy-2013-%E2%80%93-2020-action-plan-2013-%E2%80%93-2016-progress-report-september-2015

Middletown Centre for Autism
www.middletownautism.com

8.   International Perspectives

This section presents three papers that provide an international dimension and help to set the Irish experience in a wider international context. The first paper, by Prof. Séamus Hegarty advocates a right-based approach and argues that our objective should be to make the goal of inclusion irrelevant. The second paper, by Prof. José Manuel, is particularly relevant given the cultural and social similarities between Ireland and Spain. The Spanish experience underscores the relevance of supportive legal frameworks in addition to partnership between schools, service providers and families. The theme of partnership is also to the fore in the third paper in which Dr Mary Houser exposes and analyses practices in the United States of America.

8.1   Inclusion and Beyond

Prof. Séamus Hegarty, Visiting Professor, University of Warwick.

Equal opportunity is a hallmark of civilised societies. Children are not born equal and they grow up in different circumstances. A commitment to equal opportunity requires taking account of these differences, and acting to mitigate their impact. It is for the State to intervene so that genetic endowment, home environment and the tangled links between them do not determine individuals' life chances.

There has been no shortage of rhetoric in favour in equal opportunity, not least in respect of access to education. Seventy years ago, the United Nations Universal Declaration of Human Rights 1948 affirmed that 'Everyone has the right to education' (Article 26). Many countries have promulgated similar commitments at national level, sometimes even enshrining them in legislation. The Millennium Development Goals embodied an undertaking to have all children in school by 2015. Needless to say, it did not happen. According to data from the UNESCO Institute of Statistics, 264 million children and youth were 'out of school' in 2015; these included 61 million children of primary school age[6]. In addition, many children who were nominally 'in school' were not receiving an effective education; their number is unknown, but it is estimated to be at least 300 million. Children with disabilities (and, in some countries, girls) were disproportionately represented among those whose right to education was not being met.

In recent years, there have been significant developments at global and European levels that seek to address this failure and denial of rights. At the global level, a key development has been the adoption, in September 2015, of the Sustainable Development Goals, to supersede the Millennium Development Goals. The Forth Goal is to 'Ensure inclusive and equitable quality education…for all'. Sub-goals call for:
- equitable education leading to relevant and effective learning outcomes for all (4.1);
- equal access across all levels of education and vocational training for all, 'including persons with disabilities, indigenous people and children in vulnerable situations' (4.5); and
- education facilities that are disability-sensitive (4.a).

The Goals build on major disability-oriented initiatives, which have shaped the global agenda in the direction of inclusive developments in recent years. The UN *Convention on the Rights of Persons with Disabilities (CRPD)*, which was adopted by the UN General Assembly in 2006, places an obligation on governments to ensure 'an inclusive education system at all levels' (Article 24). Governments must not only ensure that those with disabilities are not excluded from the general education system, as currently happens all too often, but also that they 'can access an inclusive, quality and free primary

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[6] http://uis.unesco.org/en/topic/out-school-children-and-youth

education and secondary education on an equal basis with others in the communities in which they live'. A subsequent comment specified the broad intention of this requirement: it encompasses 'pre-schools [sic], primary, secondary and tertiary education, vocational training and lifelong learning, extracurricular and social activities' (General Comment No. 4, 2016). The Convention goes beyond aspiration to insist that its 'goal of full inclusion' necessitates targeted support 'provided in environments that maximize academic and social development'.

The Convention has been very widely ratified: as of now, there are 166 signatories, the vast majority of which have also ratified the Convention[7]. Ireland stands out as the only EU country not to have ratified the Convention – on the grounds that the country's laws are not yet sufficiently compliant to ensure that the Convention is legally viable. At the time of writing (February 2018), the Government has affirmed that ratification is imminent.

The World Report on Disability builds on the UN Convention and is an important document in pointing the way ahead at national level. Published by the World Health Organization and the World Bank in 2011, it is the first document to give a comprehensive account of the situation of people with disabilities worldwide, covering health care, rehabilitation, support services, environment, work and employment, in addition to education (WHO/World Bank, 2011). It reaffirms the principles of equal access and entitlement to high-quality education in inclusive settings but it moves the discourse forward in three respects.

Firstly, the Report documents the ongoing failure to deliver on the right to education on the part of children with disabilities. They are less likely to enter school and, when they do, are more likely to leave early and with lower educational outcomes than peers are. It provides data at the global level and for many individual countries; as might be expected, the pattern of exclusion from education and low educational outcomes is more pronounced in poorer countries.
Secondly, the Report makes robust arguments for including children and adults with disabilities in education:

- Education contributes to human capital formation and is thus a key determinant of personal well-being and welfare;

- Excluding children with disabilities from education has high social and economic costs which can be mitigated by investment in inclusive education; and

- Countries cannot achieve the globally agreed goal of universal primary education nor can they fulfil their responsibilities as signatories to the CRPD without ensuring access to high-quality education for children with disabilities.

Thirdly, and crucially, the Report points the way forward. It identifies a range of barriers to inclusive education at system, school and community levels, and outlines interventions that both tackle these barriers and promote the inclusion of children with disabilities. It sets out the general principles that inform inclusive policies in education but also cites numerous examples of dynamic practice from countries around the world. It offers detailed recommendations under four broad headings: clear policies plus improved data and information; strategies to promote inclusion; the provision of specialist services, where necessary; and support for the participation of parents, children, community groups and adults with disabilities.

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[7] http://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/Treaty.aspx?Treaty=CRPD&Lang=en

Initiatives at European level have been led by the European Agency for Special Needs and Inclusive Education (EASNIE), which has, as its name suggests, a major focus on inclusive education. It has coordinated numerous projects and published reports on different aspects of inclusive education in its thirty member countries. Topics covered in relation to inclusive education in current and recent projects include: raising achievement for all learners; implementing policies for inclusive education; classroom practices to support inclusive education; financing for inclusion; organisation of support; information technologies for inclusion; teacher education; early childhood interventions; young people's views; and developing indicators for inclusive education. Full reports are mostly in English, and are available online, but executive summaries are available in more than twenty languages, and there are links to national documents.

As an example of an EASNIE project, *Raising Achievement for all Learners – Quality in Inclusive Settings* set out to identify the key issues that need to be explored and strategies that appear to be successful in raising achievement for all learners in inclusive settings. The project synthesis report (European Agency for Development in Special Needs Education, 2012a)[8] draws together work from project activities – a review of past Agency projects, recent academic research, and the outcomes of a project conference. The report is structured around six themes: collaborative policy and practice; support for school and system leaders; inclusive accountability; personalisation through listening to learners; professional development for inclusive education; and pedagogical approaches for all.

Other relevant activities at European level have been conducted by the European Union, the Council of Europe and, indeed, USAID (the international development agency of the United States). Thus, a joint project under European Union and Council of Europe auspices, *Regional Support for Inclusive Education in South East Europe* focussed explicitly on inclusive education in the Western Balkans. It ran for three years from 2013-15 and included among its outputs a report on teacher education for inclusive education in the region, *Mapping existing quality inclusive education training programmes within the South East Europe Region* (Hollenweger, 2014)[9].

A USAID report, *Best Practices in Inclusive Education for Children with Disabilities: applications for program design in the Europe & Eurasia Region* (Losert, 2010)[10], also included the Balkans as well as other countries. This is based on a study aiming to promote inclusive education in the region by providing an overview of best practice, describing the contextual factors that affect programme implementation, and making recommendations for initiating inclusive education programmes.

A notable feature of contemporary discourse in this area is the extent to which it is couched in terms of inclusion. This is particularly evident in relation to education. There is a long, and contested, discourse around inclusive education. This needs to be seen in the context of societal and professional attitudes toward those with disabilities and other traditionally- excluded or marginalised groups. Over a long history, these attitudes have moved, unevenly, from rejection, through tolerance and charitable support, and so-called integration, to acknowledgement of the right to participate in society's goods as an equal with peers. Major issues in this history include the institutional placement of children and adults with disabilities or developmental delays and, in education, the abiding legacy of two parallel and separate systems. An appreciation of this history is important not only because the history shapes current attitudes and discourse but also because much discourse on inclusive education is confused, if not contradictory.

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[8] https://www.european-agency.org/sites/default/files/RA4AL-synthesis-report.pdf
[9] http://pjp-eu.coe.int/documents/1473702/6691265/140910_Mapping_Report_final_QA.pdf/6cf5367c-5d36-4e5e-8c77-690f92a0d3eb
[10] http://pdf.usaid.gov/pdf_docs/PA00HPH4.pdf

Inclusive education has commonly been seen as simply the opposite of segregated education but this rather misses the point: the focus on just one aspect of good educational provision is misleading, if not indeed unhelpful. It is not segregation *per se* nor even the absence of interaction with a broad range of peers that is fundamentally problematic, but the failure to provide a high quality, appropriate education. Such an education should of course be provided alongside, and among, peers unless there are truly exceptional reasons to the contrary (such as very high care needs or patterns of behaviour that put other children at serious risk of harm), and to that extent is properly termed inclusive. It is unfortunate, however, that this one aspect of a high-quality education is what is constantly foregrounded, as if physical presence is what matters above all else.

It is important, therefore, to bear in mind that inclusive education, if it is to carry the weight of significance commonly attributed to it, is not just about placing children with diverse needs in mainstream settings. It is also, and more importantly, about ensuring they receive stimulating and appropriate learning opportunities in those mainstream settings and are supported, as necessary, in their learning endeavours. To that extent, inclusive education should be at the centre of education policy and a key element of all education reform. The existence of a substantial special education apparatus in many countries cannot be ignored, but it is important to see inclusive education as a powerful driver of change that is located within general education, not as something defined in opposition to special education.

Two key principles of inclusive education are that the neighbourhood, mainstream school is the first option for all children in a locality and that school should provide an appropriate, high-quality education for every child. This calls for major reform in the mainstream sector in most countries so that staff become more receptive to diversity of all sorts, develop the requisite assessment and pedagogical competences, and remove barriers that inhibit or alienate pupils who are different. The goal is to produce schools that are genuinely for **all** pupils, schools in which academic organisation, curriculum offer and pedagogy provide optimal learning experiences for every pupil, regardless of the challenges they present.

Despite the many high-level commitments to inclusive education for all, special schools continue as a significant element of special educational provision in virtually every country in the world. Besides Italy[11], only two other countries in the European Union – Portugal and Spain – segregate fewer than one percent of pupils, and no fewer than eight countries[12] segregate more than four percent of pupils into special schools and segregated special classes (*European Agency for Development in Special Needs Education, 2012b)*.

This creates a significant dilemma for school systems and national authorities that have signed up to inclusive principles. Clearly, special schools and other segregated provision are not inclusive but, equally clearly, special schools represent some children's best chance of receiving an appropriate, high-quality education **under present circumstances**. Given the very large diversity across countries in the percentage of pupils being segregated, it seems self-evident that many pupils are segregated who should not be – and would not be if they lived in a different place. This means that there should

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[11] Italy is a singular exception. Radical policies dating from the 1970s led to the closure of most segregated provision – there are still 71 special schools – and very little segregation. Often offered as a model for other countries, inclusive education in Italy – or *integrazione scholastica* – raises many complex issues. These were examined in detail in a symposium published in the *European Journal of Special Needs Education*, 30, 4, November 2015 and included articles by Anastasiou, Kauffman & Di Nuovo; Ferri; Norwich; Opertti; and Vianello & Lanfranchi.

[12] Belgium (Flemish), Belgium (French), Czech Republic, Denmark, Estonia, Germany, Latvia and Slovakia.

be a gradual, but not unduly protracted, move from segregated to mainstream provision, as mainstream schools develop their capacities to meet the educational needs of all pupils.

Special school numbers should fall as this process develops. Pragmatic considerations must not be ignored, however. There are pupils whose needs are so complex or whose behaviour is so challenging that placement in a mainstream setting would not be viable without extraordinary measures – which could compromise the educational offer made to other pupils. This is an empirical matter: either a school can provide a high-quality, appropriate education for a given pupil or it cannot. If it cannot, alternative provision must be made. *Such segregated provision is not justified on grounds of disability, behaviour or other in-pupil factors but because of the imperative to provide an appropriate education* for that pupil.

Given that segregated provision is likely to continue in the foreseeable future, the prevailing separation in curriculum, organisation and teacher education routes must be addressed. Where they exist, special schools should be an integral part of the general education system and have dynamic links with the mainstream sector. Special schools can provide valuable outreach support to mainstream schools; their staff members have skills and experience they can share with mainstream colleagues, and dual enrolment of pupils can facilitate the transfer of pupils from a special to a mainstream setting. Special schools tend to be well resourced in pedagogical terms and should be able to act as resource centres in respect of learning materials, assistive technology and pedagogical innovations. They are also well placed to provide targeted professional development for their colleagues in the mainstream sector.

The goal of inclusion advocacy should be to become irrelevant! As long as inclusion dominates discourse, there will continue to be individuals and groups who are seen as 'other', and who need special measures to access education and other services to which they are entitled. When individuals' rights to high quality, appropriate education are truly realised, there will be no need to focus on inclusion: it will be taken for granted as an integral element, but not the defining one, of high-quality provision.

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8.2 Inclusive Education and Specific Educational Support Needs in Spain: Foci, Experiences and Progress

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Contemporary inclusive education in Spain has been shaped by years of reforms, cultural changes and struggles for equality. The future is promising, as the current realities exhibit high levels of inclusion. That said however, some shadows remain, and there is scope from improvement. Yet, the general picture is one in which the rights of the individual are safeguarded - regardless of his or her characteristics or educational needs, so that all receive a quality education in an environment that enables participation and promotes equality of opportunity for all. In every part of the country, one can find examples of inclusive practices. A common element across all of them are teachers who demonstrate positive and favourable attitudes to proactive inclusion, and schools that promote positive attitudes towards inclusion among the entire community and in which work is undertaken collaboratively. They deliver the best results and they also engender partnership with families and promote participation of family members as active agents in the teaching – learning partnership. To these ends, pedagogical leadership among the school community is an essential cornerstone.

Inclusive education is a global movement that recognises the right of all persons, regardless of their characteristics and educational needs, to receive a quality education in a context that favours participation and equality of opportunity for all.

The specific approaches in terms of educational support and inclusive education, together with the intervention foci that are deployed in educational settings, centred on students, families and the child's day-to-day surroundings have been evolving, in Spain, over recent years. However, this evolution has been unequal in its form, when one compares the legislative development with that of the practice realities. This issue therefore, highlights a series of barriers, and these need to be addressed over the coming years.

The measures that have been taken in Spain, within the context of our European and western characteristics, have a long evolutionary trajectory that can be traced, at least to the 1970s. These assume the ideological principles manifested by international organisations as well as those in the ambit of 'special education' (Rao, Cardona and Chiner, 2014). Within this framework, there is particular interest in getting to know practices in education, opportunities that arise, and the barriers and challenges that the Spanish school system currently faces, and will face in the next few years. This will permit us to clarify the realities, which schools – as institutions – assume in providing services to citizens and in their person-centred focuses.

The Evolution of the Legislative Framework
Esther Chiner Sanz (2018: 59-61) provides us with a record of the legislative changes that have occurred in Spain relating to special education, integration, attention to diversity, disability and inclusive education. The first changes were ushered in by education reform in 1970 and subsequently by the coming into force of the Spanish Constitution in 1978. Law 14/1970 (LGE, 1970) led to the introduction of special education within the mainstream education system as a type of alternative education. This proved to be a watershed intervention. A key moment in the normative development of the system occurred with the publication of Law 13/1982 (on April 7th of that year) on the Social Integration of Persons with Disabilities (LISMI, 1982). This embraced and reflected principles of

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normalisation, integration, sectorisation[14], as well as the individualisation – a more person-centred approach – as fundamentals in pupil integration[15]. In 1990, Parliament approved the Organic Law 1/1990, on October 3rd, relating to General Organisation of Education (LOGSE, 1990). Informed by the Warnock (1978) Study, this law introduced an important innovation, namely that of 'special education needs.' This law provides for comprehensive education (the same for all), and diversified, that is adapted for the characteristics of every cohort and socio-cultural context, and the individual characteristics of every person.

The LOCE (*Ley Orgánica de Calidad de la Educación*[16], 2002) uses the term 'specific education needs.' The LOE (*Ley Orgánica de Educación*[17], 2006) refers to the pupil with 'specific education support needs,' and also introduces, at the same time, the principles of equality in education and inclusion. The current LOMCE (2013) manifests a concern with the prevention of discrimination and with effective equality, with regard to access as well as retention within the education system. The principal changes it introduced relate to the organisation and responsiveness of the second-level education system, including the re-organisation of cycles[18] and stages and the development of programmes for the improvement of learning and student performance.

Within just over twenty years, four education laws have been enacted in Spain, although one of these (LOCE) has not been implemented. The evidence over this period supports the view expressed by Chiner-Sanz (2018) that without having due regard to the medium or long-term effects, new norms arise, which, in the majority of cases, derive exclusively from the ideology of the governing political party and its desire to leave its footprint in the field of education.

Measures for the Specific Needs Education Supports
At present, the generic term of 'Specific Needs of Educational Support' (SNEC), encompasses the pupil with special education needs, the pupil with high intellectual capacity, the pupil with specific learning difficulties and the pupil requiring compensatory actions.

In the Spanish context, the existence of regions with autonomous governments, each having legislative capacity, ensures the application of Common Framework Provisions in all corners of the country, in addition to variations and adaptations within these regions. We can cite, for example, the most southerly region of Spain – the autonomous region of Andalusia, in which a bespoke set of measures has been developed over the past few years. The specific necessities of educational support make reference to those needs with which any pupil can present, either temporarily or permanently. These then shape complementary supports and individualised curricular adaptations that are pupil-centred and which enable him or her to develop capacities, knowledge, abilities and skills as learning objectives and outcomes. In addition to this, the strategy puts emphasis, not just on the pupil, but, on the wider educational responses, and specifically the means of supports, aids and adaptations in order to achieve the maximum possible development in respect of an inclusive school. In this framework, it is equally important to support the family, both directly and through public agencies.

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[14] The so-called 'Sectorisation Principle' implies that the student belongs to a social environment where he / she lives, educates and relates to others, and in which he / she must find the necessary supports for his /her optimal personal development. Sectorisation means that the subject, with special educational needs, uses the institutions and services of their community sector with the intervention of a plurality of functions and professionals.

[15] Integration proved to be a very important concept, particularly during the 1980s. It implies unification of ordinary and special education, offering a series of services to all children based on individual learning needs.

[16] Education Quality Act, 2002

[17] Education Act, 2006

[18] The term 'cycles' here refers to the set of years in which education is organised in Spain, namely: Infant, Primary or Secondary Education. Each of them has a number of years, and these are, in turn organized (divided) into cycles to better organise the objectives, the contents and the evaluation criteria. For example, the Primary Stage has 3 cycles: from 6 to 8 years, from 8 to 10, and from 10 to 12 years.

Educational Attention for Students with SEN

The framework for the implementation of this attention is perceived as inclusive education; developments within and outside the school dismantle the barriers by means that facilitate and give effect to equity in terms of presence, participation and learning on the parts of all students, without exclusion. This leads to the question: How, in that case, do we deliver inclusive education?

According to Hernández (2016), such a school should place importance on a good learning environment, conducive attitudes and a positive climate in the classroom. This implies fomenting determined values and ethical principles in 'the life of the classrooms,' offering a broad common curriculum that responds to an integral vision of the person and is universally designed, from the outset, so as to respond to the educational needs for the maximum number of pupils and the achievement of essential objectives. It ought to support, in an individualised manner and adapt to the surroundings, while promoting and refining the child's social and inter-personal skills. In addition, it needs to influence teacher formation and understand that shared responsibilities, among agents, is an essential factor; it ought therefore to foment mutual collaboration between families and professionals.

This leads to the following question: Is this generally reflected in the vision and practices that pertain in Spain, inside and outside the school? This would be a difficult question to answer in any country, due to the existence of several realities. In general, the following are among the interventions and practices that pertain, in varying degrees across the country:

- Comprehensive / person-centred care is initiated from the very moment in which the need is identified, and is governed by the principles of normalisation and inclusion;
- Education administrators seek to arrange the requisite means, so that all of the pupil population can reach the maximum in terms of personal, intellectual, social and emotional development;
- Attention to diversity is adopted as a fundamental principle, and this is followed through, in every sense, in the school's educational approach;
- Centres of education can count on the requisite school organisation and give effect to the specific curricular modifications and diversifications, in order to facilitate the entire school population in the attainment of the established objectives; and
- The teaching and learning offered by the education system are adapted to the pupil who presents with particular needs. This adaption guarantees pupil access, retention and progression within the system;

These variables contribute to enabling the elaboration of open models in the structuring and planning of teaching and of didactic materials that attend to pupils' distinctive needs. In addition to the aforementioned general criteria, we need to add other specifics to each of the teachings offered by the education system.

Infant Education (3 to 6 years)

Education interventions ought to apply, from the outset, the principle of attention to the diversity of the cohort, adapting education practices to the personal characteristics, needs, interests, and cognitive style of the children, considering the importance, at this age, of acquiring the rhythm and processes of maturation.

Primary Education (6 to 12 years)

Education interventions ought to apply, from the outset, the principle of attention to the diversity of the cohort and a personalised attention, depending on the needs of each pupil. In this way, schools and teachers establish timely curricular and organisational interventions that ensure adequate pupil progress.

Compulsory Second-Level Education (12 to 16 years)
This ought to be organised in line with the principles of universal education, and with attention to diversity. Measures are oriented to respond to concrete educational needs of pupils / students and to the basic competences and objectives of this educational phase. Measures centred on the pupil / student: flexible groupings, support in mainstream groups / settings, splitting of groups, offering the optimum materials, reinforcement methods, curricular adaptions, integration of applied subjects (and content), curricular diversification programmes and other programmes of personal treatment.

Inclusive Education and Special Education Needs: Barriers & Challenges – Experiences & Progress
The recent study by Chiner Sanz (2018: 61-62) provides clarification about the normative evolution in relation to inclusive education, as well as terminology and concepts. It revitalizes the foci and forms of intervention in 'special education' in Spain. Inter-institutional coordination needs to be understood, in the broadest sense as facilitating the actions of all relevant and implicated agents. Recent research in one of the Spanish regions (Arnaiz Sánchez, Carbajal Frutos and Caballero García, 2017) highlights the elements that underpin best educational practices as follows:
- Teachers show a positive and favourable attitude towards inclusive practices;
- Schools in which a positive attitude towards the inclusion of the whole community is promoted, and in which it is worked in a cooperative way, obtain better results;
- From the schools themselves the participation of the families is encouraged, as active agents of the teaching-learning process; and
- The pedagogical leadership of the school's management teams is vital.

In the same way, examples of good practices are found throughout the country, and there are several instances of progressive innovation. One of them is that of the Special Education Center Francisco Esteve Educational Centre (in Paterna, Valencia). Specifically, in this educational centre the inclusive practices that are developed can be classified as follows:
- In relation to the organization of the Centre:
  - ✓ Acting as a resource centre for the educational community: support, information, advice and intervention are provided to the needs of other schools in the environment in relation to their students;
  - ✓ Arranging / organising groupings flexibly to encourage and enable student interaction; and
  - ✓ Creation of parents' fora, to improve the participation of the families in the school.

- In relation to the educational stages:
    In the basic schooling stage:
  - ✓ Develop 'Educational Work by Environments,' as this is more meaningful for students; and
  - ✓ Make the environment comprehensive for all (e.g., to adapt the signage and modes of communication).

In the transition stage to adult life - in order to achieve real inclusion:
  - ✓ Ensure that the repertoire of learning is as functional as possible for the student's life;
  - ✓ Ensure that learnings and methodologies use the community and the real (external) environments as a resource and place of development;
  - ✓ Seek and promote a structure of collaboration between different educational, social, cultural and / or work services – at all tiers. Joint actions ensures grater effectiveness; and
  - ✓ Work with content and attitudes oriented towards the 'working world,' thereby empowering and assisting learners to manage work options for the future, and teaching them to be active members of a community, and to be better accepted.

This experience, as well as wider research in the field leads to the conclusion, that starting from an apparently positive evolution, marked by notable achievements, inclusive education and interventions in area of special needs and supports require a radical transformation. Such a transformation needs to relate to, and affect the ways in which we understand the objectives of education, its purposes, and consequently and its forms of intervention. Above all, education needs to conceived, formulated, delivered and underpinned by a partnership model, based on collaboration between all stakeholders. It is through such normative, stable frameworks, guided by consensus principles, that one engenders support for intervention strategies, characterised by continuity, and stability, and based on a 'common language' that transcends geographies and, which also can be prolonged and sustained for the delivery of long-term secure goals. In so doing, stakeholders need to pay attention to avoiding the pitfalls identified by Chiner Sanz (2018). Addressing these generally implies dealing with contextual and political factors, so as to create constructive and conducive learning and development environments. The following barriers or pitfalls may be identified:

a. The absence of a genuinely-inclusive framework and insufficient commitment on the part of national, regional and local government in respect of the adoption of methods;
b. An education system based on achievements, that is to say, based on the evolution of education and efficiency with regard to the academic results / grades of the pupils / students. This generates segregated practices in relation to students who do not reach the minimum requirements;
c. The existence of special schools and special classrooms, which perpetrates the segregation of certain pupils / students;
d. Professional specialisation based on the old medical model that centres on the deficits of the pupil / student and on individualised attention on the parts of different professionals. This leads to difficulties in the realisation of fundamental inclusive practices in respect of cooperation, coordination and orientation;
e. Limited teacher involvement;
f. The lack of support to teachers in respect of initial teacher education, continuous professional development and personal human resources, and the absence of the requisite materials for clear foci;
g. The limited or absent participation of the persons with disability, who continue to be put aside in decision-making processes; and
h. The absence of family support.

Promoting the converse, of each of these, enhances and enables the effective delivery of inclusive and person-centred education. Although much has been achieved, in Spain, as in other countries, including Ireland, there is an apparent and residual need to leave the medical model definitively behind, and complete the move towards a social model. At the same time, it is also necessary to develop and improve the skills of all the professionals involved in the educational process, the collaboration between them and the establishment of the principles and strategies of personalised learning (Down and Choules, 2017). All this needs to happen in a framework that is truly promotive of inclusion – in every sense.

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8.3 Service Delivery and Collaboration When Serving Children with Disabilities in the United States

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Abstract

Service delivery for children with disabilities in the United States occurs primarily through the public education system. Current legislation, P.L. 101-476, ensures that all children with disabilities in the United States receive a free, appropriate public education in their least restrictive environment. It is through their public education that children receive necessary disability services such as speech/language therapy, occupational therapy, and physical therapy. All children who qualify for special education services are provided an Individualized Education Program (IEP). The multidisciplinary team is responsible for the creation and implementation of the IEP. Collaboration between the multidisciplinary team members and the family of a child with a disability is critical to the child's development and success. Such collaboration ensures the highest quality of service delivery and subsequent education.

Keywords: Special Education in the United States, service delivery, collaboration, individualized education program (IEP)

Providing disability services to youth with disabilities is an essential endeavour. This process is generally contemplated and carefully executed. Different countries provide disability services to those who are eligible in their own respective manner. Each one considers the needs of its youth and the culture in which they exist. In the United States, individuals with disabilities aged 3-21 are provided the majority of their disability services through the public education system. It is there that they are educated and provided with related therapies to ensure their proper development.

In the U.S., it is almost impossible to separate the concept of disability services and public education. School-aged children in the United States receive comprehensive disability services through the public education system which is governed by their respective state. Implementation of such services is mandated by federal law, P.L.101-476, 'The Individuals with Disabilities Education Act of 1990 (IDEA),' (last amended in 2004). IDEA has several components that guarantee service delivery to those individuals who qualify. To begin, individuals with disabilities are ensured a free, appropriate public education (FAPE). IDEA guarantees that no child, regardless of the severity of his disability, is denied a free, appropriate public education in an educational setting that is as close to the general education setting as would benefit him. This is commonly referred to as educating a child in his least restrictive environment (LRE). IDEA guarantees that every child, suspected of having a disability, receives a non-discriminatory evaluation to determine whether or not a disability is present, and, whether or not it impacts his educational performance. It also ensures procedural safeguards be in place so that special education procedures are correctly followed. A fundamental component of IDEA is including parents as decision-makers in their child's service delivery (Smith, 2003). Special Education in the United States in managed by a national organization referred to as The Council for Exceptional Children. The Council enforces all legislation to fund current programs and mandates that programs contain mechanisms for evaluations. In addition, it requires that evaluation findings be reviewed regularly. Furthermore, The Council for Exceptional Children mandates that both external and internal systems be developed to aid in the evaluation of programs for youth with disabilities (Council for Exceptional Children, 2018).

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Each child in the United States qualifying for special education services is required to have an Individualized Education Program (IEP). The IEP acts as a blueprint outlining all of the child's academic and related disability services. Examples of its components include areas of service delivery eligibility, annual goals and objectives by subject matter, and the amount of time the student will spend in the general education and special education settings. It also specifies additional therapies such as speech/language therapy, occupational therapy, and physical therapy to be provided. The IEP is considered a legal document and teachers are held accountable for its successful implementation. The IEP is created by a group of school professionals, who know the child with a disability, best. These individuals are commonly referred to as the multidisciplinary team. Typical multidisciplinary team members include a general education teacher, a special education teacher, an individual who can interpret assessment results, a representative from the local education agency, an administrator, and most importantly, the parents of a child with a disability. When the individual with a disability turns fourteen, he is invited to attend his IEP meetings as a participant. The multidisciplinary team is considered the central decision-making source for the child's service delivery and whose ability to work together is paramount to the child's success. Effective collaboration between the group members helps to ensure the most effective IEP design and implementation. Multidisciplinary team members must work together to devise an educational program that will ultimately assist the child in making progress throughout his school year. No one individual on the multidisciplinary team makes a decision about the child's disability services in isolation. Such decisions must be made as a group, weighing the pros and cons of the decision's outcome, and making a team decision. This type of collaboration requires each team member to communicate with respect, prioritize goals for the child, and build consensus within the group (Power School, 2017). Such collaboration requires teachers to understand parental perspective, empathize, and build trust with them (Diliberto and Brewer, 2012). Conversely, parents must be patient with teachers responding to their calls and communicative attempts as well as acknowledging them as the expert in the field of special education (The Collaborative IEP: How Parents and Teachers Can Work Together, 2013-2018). Parent-teacher collaboration is central to the productivity of IEP meetings and their outcomes. The more effectively educators and families communicate and work together, the better the outcome will be for the child (Houser & Fontenot, 2015). It is also relevant to note that parents in the U.S. play a major role on the multidisciplinary team as they make the final decisions about the team's suggestions for implementation. Without parental consent, the child with a disability may not receive any special education services.

The need for collaboration between parents and teachers continues outside of the IEP meetings. Parents of children with disabilities often desire a collaborative relationship with their child's teacher. They want to know how their child is doing, if he is able to keep up with assignments, and how he is managing behavioural challenges that might exist. In some cases, the parents are unable to access this information from their child due to the limitations defined by his disability. Typically, parents are willing to implement suggestions made by the teacher at home to benefit their child's progress. This makes the partnership between the parents and the teacher even more critical. Research in the U.S. indicates that collaboration in the area of service delivery of students with disabilities is essential and has resulted in positive outcomes for those with special needs. Examples of its gains include students attaining higher grades, performing better on tests, attending school more regularly, and demonstrating better attitudes toward school themselves and special education personnel (Houser, 2014).

Service delivery and collaboration when serving youth with disabilities in the United States go hand-in-hand. The public education system makes the disability services available to youth who qualify.

Multidisciplinary team members must work together so that the services are implemented with the greatest success. Collaboration is considered a best-practice and one that should be given top priority when serving children with special needs.

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9. Current Academic Research in the Field

The following three articles are indicative of the research being undertaken in Mary Immaculate College in respect of disability issues.

9.1 A review of the effectiveness of Cognitive Behaviour Therapy (CBT) interventions in reducing anxiety levels of children with Autistic Spectrum Disorders aged 4-7 years

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Abstract

There is emerging evidence demonstrating the effectiveness of cognitive behavioural therapy (CBT) approaches to reduce anxiety in children and adolescents with autism spectrum disorder (ASD). However, there is little evidence examining the effectiveness of these approaches with younger children with comorbid anxiety symptoms. A systematic literature search was conducted and four single case research studies were identified for review. The results suggest findings are limited in terms of generalisability but indicate the potential effectiveness of modified CBT interventions in reducing and managing anxiety. Implications for future research and practice are also explored.

Keywords: autism; anxiety; young children aged 4- 7 years; cognitive behaviour therapy; single case participant design.

Introduction

Autism spectrum disorder (ASD) is a complex and pervasive developmental disorder which is characterised by persistent deficits in social communication and interactions across multiple contexts in the presence of restricted, repetitive patterns of behaviour, interests or activities (American Psychological Association [APA], 2013). Symptoms must also be present in the early developmental period either currently or historically; that is, symptoms may become more apparent when social communication demands exceed ability (APA, 2013). A recent report from the National Council for Special Education (NCSE) suggested a prevalence rate of 1.55 per cent or approximately one in every sixty-five students in Ireland (NCSE, 2015). This rate is much higher than previous estimates of 1 per cent of the population (Baird *et al.,* 2006; Baron-Cohen *et al.,* 2009), and is possibly linked to developments in assessment and diagnostic approaches, service availability and greater awareness of autism spectrum disorders (NCSE, 2015).

Anxiety is also common in children and adolescents with ASD. White *et al.* (2009) suggested that between eleven per cent and eight-four percent of children with ASD experience some form of anxiety, which causes impairment. The variability in prevalence is accounted for by differences in approaches used to measure anxiety and differences in defining anxiety and its subtypes (Shaker-Naeeni *et al.,* 2014). The most commonly-reported disorders and symptoms included phobias, separation anxiety disorder, generalised anxiety disorder, obsessive-compulsive disorder and social phobia (White *et al.,* 2009). Specific phobias or fears are more common in younger children with ASD and are thought to contribute to 'acting out' behaviours, while adolescents may experience more obsessive-compulsive symptoms and social phobia (White *et al.,* 2009). White and colleagues recommended that further research should examine developmental changes in anxiety from childhood to adolescents as its effects may inform treatments options.

Cognitive behavioural therapy (CBT) is commonly used as an intervention approach to ameliorate symptoms of anxiety, and has more recently been modified to support children with ASD (Warren *et al.,* 2011). CBT approaches focus on understanding and restructuring unhelpful thoughts and feelings that may be impacting negatively on behaviour. Research suggests that modified CBT approaches to support older children with ASD and who are higher functioning, are developing a promising evidence base (Reaven *et al.,* 2012; Ung *et al.,* 2015; Warren *et al.,* 2011). CBT approaches are normally modified so that they are more agreeable to children with ASD (Warren *et al.,* 2011). Modifications may include greater parent involvement to support generalisation to other contexts, the use of concrete elements and visual aids, structured and predictable sessions and more frequent practice (White *et al.,* 2009). The effectiveness of CBT interventions in younger children with ASD is relatively unknown (Warren *et al.,* 2011).

Given the recognised need for greater understanding of anxiety and ASD in the early years and the paucity of research examining the effectiveness of CBT with young children with ASD, this study, undertaken by a trainee educational psychologist[21] at Mary Immaculate College, sought to systematically examine the effectiveness of CBT interventions in reducing anxiety levels of children with ASD aged 4-7 years.

Methodology
An electronic database search of Academic Search Complete, PsycINFO, Google Scholar and Science Direct databases was conducted in September 2017 using search terms outlined in Table 1. If available, a filter was applied so that only peer reviewed studies and studies written in English would be included.

Table 1: Database Search Items

Databases	Search terms
Academic Search Complete (84 search results), PsycINFO (140 search results)	cognitive behav* therapy AND autism spectrum disorder OR autis* AND anxiety OR anxious
Google Scholar (123 search results)	"cognitive behav* therapy" AND "autism spectrum disorder" OR autis* AND anxiety OR anxious
Science Direct (171 search results)	cognitive behav* therapy AND autism spectrum disorder OR autis* AND anxiety OR anxious

Note: Search refined to articles in the psychology domain and limited to the topics child, autism and anxiety

The initial search yielded 518 results. Seventy duplicate studies were removed by screening article titles. Of the 440 remaining studies, titles were screened against inclusion and exclusion criteria outlined in Table 2, reducing the search to fifty studies for screening abstracts. A total of eighteen articles remained for full text screening against inclusion and exclusion criteria. Fourteen articles were excluded and four articles included for review. See, Table 3 for list of included studies.

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[21] While on placement with disability services, trainee educational psychologists (TEPs) from Mary Immaculate College engage in research and enquiry activities relevant to service requirements. There is an ongoing need to ensure that outcomes and effectiveness of psychologists' work within services is informed by an evidence base in psychology. To support this philosophy, TEPs in Year 2 were asked to consult with their placement supervisor in disability services to identify a research topic related to 'Therapeutic and/or Preventative Evidence Based Interventions Aimed at Promoting Resilience and/or Well-Being'. The critical review papers, produced by trainees, are intended to provide succinct and up-to-date summaries of research relevant to the practice of psychologists working within the service. The TEP who undertook this review was on placement with an Early Intervention team.

Table 2: Inclusion and Exclusion Criteria

Criteria	Inclusion	Exclusion	Rationale
Type of publication	Peer reviewed study	Not a peer reviewed study	Peer reviewed studies have been independently assessed for quality
Language	Study must be written in English	Study is not written in English	In order for the study to be understood, it must be written in English. Translators were not available for the purpose of this systematic review.
Intervention	CBT programme	The intervention is not a CBT programme	Only CBT programmes are being evaluated in the current review
Setting	Intervention must be conducted in a clinical or community setting	Intervention is not conducted in a clinical or community setting	CBT interventions are typically conducted in these settings
Data	The study provides empirical data	The study does not provide empirical date	Empirical data will allow the reviewer to examine the effectiveness of CBT interventions relative to the review question
Participants	Participants must be children with ASD and anxiety, aged between 4-7	Participants are not children with ASD and anxiety, aged between 4-7	This is the age range stipulated by the review question
Measures	Measures must demonstrate changes in subject's anxiety levels	Measures do not demonstrate changes in subject's anxiety levels	This is the primary outcome investigated by the review question

Table 3: List of Articles included in the Review

Included Studies:
Cook, J. M. *et al.,* (2017) 'A parent-mediated, cognitive behavioral therapy group treatment for young children with high-functioning autism spectrum disorder and comorbid anxiety: Development and case illustration of the fun with feelings program', Journal *of Cognitive Psychotherapy, 31*(3), 204-224. doi:10.1891/0889-8391.31.3.204
Nadeau, J. M. *et al.,* (2014) 'A cognitive-behavioral approach for anxiety in a preschool-aged child with autism spectrum disorder', Clinical *Case Studies, 14*(1), 47-60. doi:10.1177/1534650114536028
Neufeld *et al.,* (2014) 'Integrating best practices in positive behavior support and clinical psychology for a child with autism and anxiety-related problem behavior', *Canadian Journal of School Psychology, 29*(3), 258-276. doi:10.1177/0829573514540603
Schleismann, K. D. and Gillis, J. M. (2011) 'The treatment of social phobia in a young boy with Asperger's disorder', *Cognitive and Behavioral Practice, 18*(4), 515-529. doi:10.1016/j.cbpra.2010.08.004

Overview of Studies

The current review sought to examine studies with research designs, that are conducive to measuring the effectiveness of CBT interventions, to support young children aged 4-7 years with a diagnosis of

ASD and elevated anxiety levels. Following a systematic search of the literature, only four studies with a single case design methodology met review criteria as outlined in Table 2. The studies reviewed adhered to the principles of CBT; however, in following recommendations in the literature, the CBT manual or approach may be adapted and modified according to the presentation of ASD. The interventions were facilitated by a clinician individually, in a clinical or community context (e.g. school, home), in collaboration with home and/or school/pre-school. Findings from a critical review of the studies are presented with regard to participants, intervention implementation, data collection and analysis and intervention effectiveness.

Presentation of Findings

Participants: A total of four participants received CBT intervention in the included studies. All participants were male and met the stipulated subject criteria for review but differed in type of diagnosis of ASD and in the presentation of formal diagnosis of anxiety disorder or symptomatic behaviours (see Table 3). Participants were existing clients of the researchers' clinics (Neufeld *et al.*, 2014) or were referred to the researchers for treatment by their parents. All participants lived at home with their parents and siblings, and additional extended family members in one case (Neufeld *et al.*, 2014). Minimal parental characteristics are provided, although one parent is described as having a diagnosis of Asperger's Disorder and experiencing similar anxiety symptoms and fears as his son (Schleismann & Gillis, 2011). Participant ethnicity (Hispanic) and residential area (urban) is reported in one study (Nadeau *et al.*, 2014).

Table 4: Participant Summary

Study	Age	Primary diagnosis and co-morbid symptoms/diagnosis	Anxiety related behaviours
Cook *et al.*, (2017)	5	High functioning autism spectrum disorder (HFASD) and anxious behaviours	Crying, shaking, fleeing and refusing to speak in social situations and in response to change
Nadeau *et al.*, (2014)	4	Autistic disorder and comorbid generalised anxiety disorder and social phobia	Avoiding social situations, significant increase in respiration and heart rate, sweating, trembling when exposed to feared situations
Neufeld *et al.*, (2014)	5	Autism and anxiety-related problem behaviours	Anxiety around unfamiliar situations (e.g. going to new places). Repeated questioning, protesting, screaming, physical resistance to riding escalators.
Schleismann and Gillis (2011)	6	Asperger's disorder and a diagnosis of social phobia	Fear of crowds and unfamiliar people, fear of ridicule and shame, display of avoidant behaviours.

Intervention Implementation. All studies met the inclusion criteria of delivering a CBT intervention to participants. Intervention delivery followed a similar structure in each of the studies, starting with psychoeducation or affective education for parent and child, development of an anxiety hierarchy, exposure sessions and generalisation/maintenance in new settings. These steps are consistent with CBT principles for treating anxiety (Moree and Davis, 2010; Seligman and Ollendick, 2011). Two of the studies adapted a CBT manual for intervention delivery (Cook *et al.,* 2017; Schleismann and Gillis, 2011). Parent(s) were present during intervention delivery in clinical settings and received training in CBT and psychoeducation for maintenance and generalisability of skills. In two of the studies, graded exposure sessions sometimes took place in community settings to further promote generalisability of treatment and skills (Cook *et al.,* 2017; Neufeld *et al.,* 2014).

Participants in each of the four studies are reported to have attended all CBT sessions. Parent commitment and collaboration was highlighted as essential to the success of each intervention programme. No specific attendance measures are described, and homework in between sessions in all studies was often incomplete. All studies lacked the use of integrity checklists and inter-observer reports to ensure programme delivery adhered to intervention goals and aims. Each of the interventions applied were based on CBT principles for treating anxiety. Examples of modifications made to CBT programmes are summarised in Table 5.

Table 5: Modifications to CBT Programmes

Study	Modifications
Cook *et al.,* (2017), Nadeau *et al., (*2014), Neufeld *et al.,* (2014), Schleismann and Gillis (2011)	Adaptations to suit developmental level and communication style e.g. Use of clear, concrete language, visual supports
Nadeau *et al., (*2014), Neufeld *et al.,* (2014), Schleismann and Gillis (2011)	Use of rewards as motivators to complete steps on exposure/anxiety hierarchy
Cook *et al.,* (2017), Schleismann and Gillis (2011)	Emphasis on behavioural, over cognitive strategies
Neufeld *et al.,* (2014), Schleismann and Gillis (2011)	Social stories
Cook *et al.,* (2017), Schleismann and Gillis (2011)	Larger affective education component
Cook *et al.,* (2017)	Highly structured, predictable format of session delivery, short activity duration, use of child activity books, opportunities for repetition and practice, use of puppets, use of creative activities for young children (e.g. drawing, collage).
Neufeld *et al.,* (2014)	Role play

Data Collection and Analysis. The studies applied measures to determine effect of the CBT intervention on participant anxiety levels. However, only two of the studies applied standardised checklist measures at pre and post intervention (Cook *et al.,* 2017; Nadeau *et al.,* 2014). Monitoring of effect during intervention was demonstrated by two of the studies at three or more time points (Neufeld *et al.,* 2014; Schleismann and Gillis, 2011) and three of the studies demonstrated external validity with replication of intervention effects across settings (Nadeau *et al.,* 2014; Neufeld *et al.,* 2014; Schleismann and Gillis 2011). As is the nature of single case design research, the individual participant is considered his own control therefore effectiveness of the intervention is generalizable to the individual participant(s) as opposed to the general population (Horner *et al.,* 2005; Mertens 2015). All four studies documented the social validity of the dependent variable being measured however just one study applied a formal measure (Schleismann and Gillis 2011).

Intervention Effectiveness. All four studies demonstrated changes in anxiety levels following CBT intervention. Visual analysis conducted on observational data and self-reported fear thermometer ratings collected by Schleismann and Gillis (2011), indicated a downward trend in fear and avoidance behaviours, and an increase in approach behaviours in social situations. These gains were also maintained at follow up. Similarly, visual analysis on observation data conducted by Neufeld *et al.,* (2014) demonstrated an increase in child social behaviours consistent with the steps of the anxiety hierarchy and maintenance of these behaviours was maintained at 24-month follow up. Cook *et al.,* (2017) demonstrated a decrease in anxiety subscale t-scores on the Child Behavior Checklist (CBCL;

Achenbach, 2001) from pre-intervention to post-intervention to three-month follow up. The Reliable Change Index (RCI) (Jacobson and Truax, 1991) was applied by the researchers to demonstrate reliability of improvement across the three-time points. Similarly, Nadeau *et al.,* (2014) demonstrated a decrease in parent ratings on the Pediatric Anxiety Rating Scale (PARS) (Research Units of Pediatric Psychopharmacology Group 2002) from 17 at baseline, to 8 at post intervention, to 3 at the four month follow up. CBCL t-scores demonstrated a reduction on the withdrawn/depressed, anxious/ depressed scales, and overall internalising problems.

The studies report anecdotal parental feedback on reduction in anxiety levels at post intervention and a generalisation of skills to other settings, including for example, ordering food at a restaurant and spending the night alone at a friend's house (Schleismann and Gillis, 2011), saying 'hello' to family members without prompting (Cook *et al.,* 2017), increase in verbal responses in new social situations (Nadeau *et al.,* 2014) and riding escalators in different shopping centres accompanied by different people (Neufeld *et al.,* 2014).

Implications and Recommendations for Research and Practice
Considering the single case design of each of the studies included for review, successful treatment response is not statistically representative of all young children presenting with anxiety and ASD. The small sample size and single case design provides preliminary evidence of the effectiveness of CBT interventions in reducing anxiety levels of children with ASD aged 4-7 years. In addition, threats to internal validity, experimental control and reliability of observational methods have implications for strength and reliability of findings. Future research could attempt to exert more stringent methods of experimental control, conduct direct observations across all phases of the study with reliable and valid tools and implement formal measures of inter-observer reliability, intervention fidelity and social validity. Considerations could be given to conducting larger scale experimental studies, before conclusions can be drawn on the effectiveness of CBT interventions in reducing anxiety levels of young children with anxiety and ASD.

The positive findings demonstrated can be considered through the lens of Bronfenbrenner's (1977, 1989) ecological systems' theory. All participants lived at home with their parents and siblings and in one case, additional extended family members (Neufeld *et al.,* 2014). They did not represent diverse family types; therefore, findings may be generalizable to this type of family unit only. Furthermore, the socio-economic status and ethnicity of participants and their families were reported in just one study. Future practice and research could consider contextual factors, including parents' own anxiety levels, as seen in the Schleismann and Gillis (2011) study, and how these may be impacting upon child symptoms of anxiety (Craske and Waters, 2005).

All review studies involved some parental involvement and two studies commented on the high level of parent support and commitment during intervention, which may have contributed to successful outcomes (Nadeau *et al.,* 2014; Neufeld *et al.,* 2014). The benefits of including parents in intervention delivery have been recognised in the literature (Cobham *et al.,* 1998) in particular with children with ASD (Chalfant *et al.,* 2007; Wood *et al.,* 2009) and very young children with anxiety. Parental participation may enhance maintenance and generalisation of the skills learned across different settings (Reaven, 2011). Future research may need to consider the level of parental involvement (e.g. CBT instruction/psychoeducation, co-facilitators) in CBT interventions.

Each of the interventions applied were based on CBT principles for treating anxiety e.g. instruction/psychoeducation, (i.e., rational for exposure treatment), development of an anxiety hierarchy, exposure sessions, and generalization/maintenance (Moree and Davis, 2010; Seligman and

Ollendick, 2011). It is recommended that modified CBT programmes for children with ASD reduce cognitive load, increase parental involvement and simplified, affective education for understanding and recognition of basic emotions (Attwood, 2003; Green and Wood, 2013). The studies reviewed used a variety of modifications to support the individual needs of their participants. These modifications are consistent with recommendations in the literature and could be considered when planning CBT interventions with young children with ASD in early intervention teams.

Conclusion

The current review provides preliminary evidence for the effectiveness of CBT interventions in reducing anxiety levels of children with ASD aged 4-7 years. As is the nature of a single case study design, the findings are limited in terms of generalisability but indicate the potential effectiveness of modified CBT interventions in reducing and managing anxiety in young children with ASD. Larger scale experimental studies need to be conducted before conclusions can be drawn on the effectiveness of CBT interventions in reducing anxiety levels of this population cohort. Future research should, in addition to using an experimental research design, conduct direct observations across all phases of the study, implement formal measures of implementation fidelity and inter-observer agreement, and gather formal social validity data (Neufeld *et al.,* 2014). In future research examining effectiveness of CBT interventions targeting anxiety, gathering and examining data from multiple sources (standardised measures, direct observation, and participant feedback) is recommended for a comprehensive evaluation of intervention effect.

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Appendix 1: Summary of CBT Interventions

Study	Interventionist	Setting	Intervention framework	CBT manual	Sessions	Homework
Cook *et al.* (2017)	Primary researchers deliver sessions to parent so parent can mediate to child	Home and community	1: Psychoeducation and goal setting 2-3: Parent skills training (develop anxiety and exposure hierarchy) 4-7: Affective education 8: Emotion regulation strategies 9-10: Review of content	Fun with Friends (Ford, Plows, & Garnett, 2010)	All 10 sessions attended by parent	Completed 85% of homework tasks (intervention delivery to child in between sessions)
Nadeau *et al.* (2014)	Clinician delivers sessions to child, receiving weekly supervision from primary researcher with parent involvement	Clinic	1: Psychoeducation, treatment plan 2-3: Affective education 4: Coping 5: Anxiety/Exposure hierarchy 6-8: In vivo exposure	Manual not specified: Modified CBT protocol for use with young children with ASD	8 weekly sessions ranging 35-70 minutes over 3 month period	Researchers report parents completed all homework tasks with child
Neufeld *et al.* (2014)	Clinicians deliver sessions to child, receiving bi-weekly supervision of primary researchers with parent involvement	Home and community (shopping mall)	1: Conduct a family ecology assessment and functional assessment 2: Develop an anxiety hierarchy 3: Develop gradual exposure plan 4: Clinicians deliver plan in mall 5: Transfer control to parent in mall 6: Maintenance and generalisation in alternative community settings	No manual-researchers designed their intervention based on CBT and PBS best practice components	3 to 9 30 minute sessions per month for 4.5 months	No formal homework tasks assigned, parents became more involved at stage 6 of the intervention framework
Schleismann & Gillis (2011)	Primary researchers with parent presence and involvement	Clinic	1: Assessment and introduce fear thermometer 2: Identifying feelings and physical responses (child) Psychoeducation and hierarchy (parent) 3: Teaching coping skills 4-5: Practice being brave (child) observe exposure session (parent) 6-11: Practice being brave (child) run exposure sessions (parent)	Coping Cat Workbook (Kendall, 1992)	All 11 sessions attended by child and parent	Competed 2 out of 11 homework tasks

9.2 Hear my Voice: Developing strategies for anxiety through self-advocacy in the Williams Syndrome Association of Ireland

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Abstract

The Williams Syndrome Association of Ireland (WSAI) was established in 1987 as a support-group for parents of children with Williams syndrome (WS). It has developed into a family support group, which offers opportunities for parents, siblings, and most importantly, individuals with WS to come together for social, educational and research events. In line with disability research, the association now places a strong emphasis on participant voice and self-advocacy for individuals with WS. WS is associated with high anxiety, which is frequently masked by hyper-sociability and a 'happy' disposition. While many interventions are developed through parent participation, there are very few interventions developed with, or by, individuals with WS. This paper outlines a workshop developed to enable people with WS to discuss their experiences of anxiety and their associated strategies. It led to an intervention being developed by the group, which they felt addressed their needs in a holistic way.

Introduction

Williams syndrome is defined as a neurodevelopment condition of genetic origin (Farran and Karmiloff-Smith, 2012), which produces an atypical cognitive, behavioural and neuroanatomical profile (Martens *et al.,* 2008). It is described as 'one of the field's most intriguing genetic disorders' (Dykens, 2003: 291), characterised by 'peaks and valleys' (Dykens *et al.,* 2000, p. 106), due to disparity between the learning strengths and learning challenges (Semel and Rosner, 2003). The 'peaks' include auditory memory, sociability, musicality and expressive language; the 'valleys' encompass motor performance, visuo-spatial skills, auditory sensitivity, distractibility and anxiety. Almost all individuals with WS have an intellectual disability (ID) in the mild to moderate range (Bellugi *et al.,* 2000).

Individuals with WS are four times more likely to experience anxiety than are other individuals with ID (Royston *et al.,* 2016). A study of parent-reports of anxiety in individuals with WS over a four-year period indicates that high anxiety persists over time and is related to social and executive functioning impairments (Ng-Cordell *et al.,* 2018). Individuals with WS have significantly more fears and a wider range of frequently occurring fears relative to peers (Dykens and Rosner, 1999; Leyfer *et al.,* 2006). Specific phobias are more prevalent in WS than generalised and anticipatory anxiety, with a large majority showing persistent and marked fears (Dykens, 2003). An Irish study of seven pupils with WS of primary-school age found that all parents identified anxiety in their child, while only two teachers reported anxiety in the children, indicating that anxiety is frequently masked by high sociability in WS (Tynan, 2015).

Discourse in disability studies is consistently indicating a need to include the voice of those with a disability in matters, which affect them (Dowse, 2009; Kubiak, 2017). Despite this, the majority of research carried out on Williams syndrome, as a neurodevelopmental condition, tends to overemphasise research **on** individuals or research **about** these individuals as seen through the eyes of their parents or educators. Mencap (2012) has castigated society for the lack of value placed on the life of the individual with ID. Rowe and Nevin (2014) carried out a pilot study to include 'patient voice' of individuals with ID in their psychological interventions. It found that, while all four individuals in the study could contribute to their own programme, those with a mild ID could contribute most fruitfully, largely due to higher levels of receptive and expressive language skills. Considering individuals with

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WS have advanced social and expressive language skills, typically above their overall IQ score (Semel and Rosner, 2003), they tend to be excellent research participants (Tynan, 2015). As parents in the WSAI sought support for their children's high anxiety, it was decided that the individuals with WS would be best placed to discuss anxiety, its causes for them and their strategies.

Methodology

The Williams Syndrome Association of Ireland (WSAI) hosts a family-activity weekend each spring to support families who have an individual with the condition. Research is frequently conducted during this weekend as part of the activities. In April 2015, a workshop was run with individuals with WS to ascertain their awareness of anxiety, its causes and their personal strategies.

Ten individuals with Williams syndrome (WS) aged 12-45 participated in the workshop. Parental consent was sought from all but one participant (who lives independently) and the consent of all participants was also secured. The session was organised as a 'circle time' activity, whereby all participants sat in a circle on the floor with the facilitator and took turns to share their views and respond to the views of others. The rules of circle time were explained and a shared understanding of anxiety was established. A number of open-ended questions were prepared as a stimulus for the workshop with the intention of following the responses of the participants. The focus was on a participant-led workshop responding to the needs of this particular group of people with WS.

Results

There was a very high level of participation and engagement in the workshop. The participants were very interested in information about WS (such as the challenges experienced by others with WS) and in hearing one another's viewpoints. They were an exemplary group in terms of motivation to learn about new strategies!

Participants were invited to answer the question 'what makes you feel most anxious?' This yielded a variety of responses including strict teachers (afraid of getting in trouble), parents dying, people leaving the workplace, arguments with siblings, not being allowed to express emotion (in a work situation), burglars and using lifts, escalators or playground equipment. In almost all cases, the majority of participants agreed that they had anxiety around those voiced by another individual. One participant also spoke of the responsibility of protecting other people from feeling anxious. This indicated that anxiety was a unique experience for each individual, and while similarities existed between individuals, each had their own combination of stressors. Based on the reaction of the group to the anxieties listed above, it was found that the most emotional reactions emerged when talking about arguments or other people getting angry. One participant became very distressed talking about arguments with her sister. Others described distress about people being angry around them, even if the anger was not directed at them.

For each of the aforementioned anxieties the participants were invited to share the strategies they had for dealing with them. This showed, in most cases, a high level of awareness of self and others. Strategies included talking to friends, praying, working through an anxiety with a trusted adult and practising a skill (such as using an escalator). Three strategies stood out as being 'usable' for the workshop: seeing the situation from the other person's perspective, saying stop and being assertive and repeating a script, which their parents would say to them (such as 'you can do it!'). The participants expressed an interest in developing a strategy that could be used in a variety of situations where someone was angry.

A discussion about the feelings behind an angry voice ensued (strategy: seeing things from the other person's perspective) and participants agreed that a person may sound angry due to feeling impatient, worried, afraid or frustrated and that the source of the perceived anger may not be the person with WS! This was followed by using the story of 'Goldilocks and the Three Bears' as a basis for promoting tolerance of angry voices. Participants chose a finger or hand puppet to express their angry voices to say 'Who's been eating my Maltesers!' (as this was more relevant than referring to porridge!). It was important through the workshop to come out of role regularly to show the participants that I, the facilitator, was not angry with them, such was their level of anxiety around angry voices. Building tolerance for angry voices was a valuable strategy in its own right. The participants relaxed more and more over time, even when we moved from puppets to face-to-face interactions.

The facilitator then created scenarios where someone was angry and suggested a development of strategies from participants. The strategy was saying 'Stop!' and holding up both hands to create a distance from the situation. This was also a total body response, which was important for channelling the energy from their anxiety. The use of actions was in response to the strong sense of drama, which emanated from the group; the actions appeared to help them in the role of being assertive.

Individuals with WS tend to find it difficult to express negative emotion, despite their very good verbal skills (Semel and Rosner, 2003); therefore, a script was suggested. One individual suggested the use of identifying the issue: 'When you get angry, I feel anxious'. The use of a script capitalizes on the auditory memory associated with WS. To link in with the total body response, actions were matched to the script as follows: 'When you (point to the person) get angry, I (point to self) feel anxious'. This strategy was practiced several times and done to a rhythm, which linked to their musical intelligence. Different scenarios were presented to promote awareness of the transferability of the strategy.

The participants used the strategy during the weekend, although there was not adequate time to explain the workshop outcomes to parents, a significant shortfall of the workshop. An article about the workshop content and outcomes was published in the newsletter of the WSAI with the photos for the strategy as outlined below. Feedback from parents and from individuals with WS indicated its practicality as a strategy for dealing with anxiety in social situations. However, feedback from one parent indicated her child was using the strategy out of context. She was using it to distance herself from all emotional situations, rather than just those where someone was angry. While the script allowed the child to verbalise that she was in a state of anxiety, it shows that additional scripts need to be created for other situations.

Conclusions

Participants showed high levels of self-perception regarding what makes them anxious and many had effective strategies to help manage anxiety. They responded very well to work with puppets and story as a way to build up resilience for angry voices, a common source of anxiety for participants. A strategy based on a combination of strategies suggested by participants was developed, with a focus on total body response and use of a script. It is essential that the strategies are explained, understood and implemented by parents or carers, to ensure the individual feels empowered to use these strategies in context. This workshop shows that individuals with Williams syndrome, despite having an ID can participate in a highly successful way in discussing their challenges and in suggesting interventions, which may be helpful. Family support groups provide an ideal forum for this type of work where individuals have the support of one another and of their families. It is, however, imperative that any interventions developed with the group are shared with those who can provide ongoing support to the individual.

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9.3 Trans-disciplinary Dissemination of Good Practice: Applying 'Strengths-Based Report Writing' to the Training of Educational Psychologists at Mary Immaculate College

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Keywords: strengths-based, report, assessment, psychological, psycho-educational

Abstract: One of the stated objectives of the Progressing Disabilities Conference was to showcase and disseminate good work practices within children's disability services. A secondary outcome of hosting the conference at Mary Immaculate College (MIC) was the cross-pollination of evidence-based practice across Health and Education sectors. This paper provides an account of the application of 'strengths-based report writing' principles (Towle *et al.,* 2008) to the training of educational psychologists on the Doctorate in Educational and Child Psychology (DECPsy) programme at MIC. It also highlights the potential of sharing good practice across disciplines to enhance outcomes for children and families attending support services in Ireland.

Introduction

The strengths-based philosophy has its roots in the mental health movement of the mid-nineteenth century where a strengths-based approach emerged amid dissatisfaction with an authoritarian and deficit-focused treatment model for individuals with mental health difficulties (Bendtro, 2004). The approach spread to the youth movement of early twentieth century Europe and began to gain traction in fields as diverse as social work, business and psychology. Within the field of psychology, Seligman popularised the strengths-based movement and coined the term 'Positive Psychology' (Seligman & Csikszentmihalyi, 2014.). The following definition provides a comprehensive overview of strengths-based practice and highlights the importance of attitudes, beliefs and values held by practitioners, as well as skills and knowledge.

> '*A strengths-based approach emphasizes an individual's or community's existing strengths, capabilities and resources. Those who embrace a strengths-based perspective believe all individuals and their families have strengths, resources and the ability to recover from adversity. This perspective replaces a primary emphasis on problems, vulnerabilities and deficits. A strengths-based approach is developmental and process-oriented. It identifies and reveals a person's internal strengths and external resources as they emerge in response to specific life challenges. A strength-based paradigm uses a different language to describe a person's challenges and asks different questions to explore struggles. It allows one to see opportunities, hope and solutions rather than barriers, hopelessness and problems*'* (Resiliency Initiatives, 2013: 8).

The deficit-focus identified by Towel *et al.* (2008) in early intervention services is also evident in the field of educational psychology. Mastoras *et al.,* (2011) highlight a range of issues identified in the literature on psycho-educational reports. These include a focus on the client's problems, inadequate links between the referral issue and recommendations, and the use of technical jargon and unexplained acronyms. There are indications that these issues are pervasive across public services in Ireland. Indeed, the National Adult Literacy Agency (NALA, 2009, p.5) contends that much of the written information produced by the Irish public service is perceived to be "formal, wordy and awash with unnecessary or unexplained jargon".

Mastoras *et al.,* (2011) assert that these issues are not new, and that they have featured in the literature on psycho-educational report writing for many decades. These enduring issues are

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paralleled by a growth in the prevalence of a strengths-based philosophy in policy and service statements in the helping professions (Roebuck, 2007). Despite this prevalence, there are few practical resources available to professionals to incorporate such policy statements meaningfully into practice. To address this anomaly, the literature on strengths-based report writing was examined and applied to the training of educational psychologists at MIC. This paper describes the process of incorporating the principles of strengths-based report writing into a three-hour session on feedback and report writing for Year 1 students on the DECPsy programme.

Description of the DECPsy Session
The Professional Doctorate in Educational and Child Psychology (DECPsy) is a three-year full time programme which prepares students for the range of professional roles that are performed by educational psychologists (EPs) in a variety of contexts and with a range of client groups (DECPsy, 2017). The programme espouses a 'connected curriculum' where taught modules have explicit links to professional placement activities and the research strand of the programme (Fung, 2017).

Students in Year 1 of the DECPsy Programme complete a module entitled 'Psychological and Psycho-Educational Assessment'. This module aims to provide students with the skills to conduct a psychological assessment from referral, informed consent, assessment and intervention to feedback and report writing using evidence-based approaches. One of the learning outcomes of the module states that students will 'display skills in providing clear, coherent and relevant feedback, both oral and written, of assessment results' (DECPsy, 2017).

To this end, the feedback and report writing session was comprised of two related strands:
1. Evidence-based approaches to the provision of client and family feedback
2. Evidence-based report writing guidelines

Strand 1: Evidence-based Approaches to Client and Family Feedback
In advance of the session, the 'flip-the-classroom' methodology (Bergman and Sams, 2012) was employed to allow the students to come prepared to practice feedback skills in an experiential way. 'Flip-the-classroom' is an instructional methodology that provides content in advance of a classroom session, typically with a specific task in mind. This format allows students to engage with the material at a deeper level of processing with the support of the teacher in the classroom at a later stage. Students were provided with Tharinger *et al*.'s (2008) paper on evidence-based approaches to parent and child feedback, and an anonymised client profile via Moodle in advance of the session. Students were required to prepare a parent feedback by applying Tharinger *et al*.'s (2008) feedback principles to the profile provided.

A full account of the evidence-based guidelines provided by Tharinger and his colleagues (2008) is beyond the scope of this paper. However, the following summary outlines some key recommendations, which guided the student's preparation for the session:
- Select 3-4 key areas around which to organise feedback;
- Use language sensitively and pay attention to your tone;
- Be aware of cultural factors at play;
- Adopt a collaborative approach to feedback by actively engaging clients and their families through inviting discussion, comments and joint goal development;
- Consider the potential of feedback as a therapeutic intervention;
- Incorporate Finn's (1996) (cited in Tharinger *et al.*, 2008) Levels 1, 2 & 3 when providing feedback;

- o Level 1 - Findings that support a parent's existing view of their child. This level of feedback is likely to be readily accepted by the family.
- o Level 2 - Findings that challenge parents' existing view of their child to some degree, but are unlikely to threaten deeply held beliefs or family esteem. Finn (1996) argues that most of the feedback should be at Level 2.
- o Level 3 - Findings that significantly challenge parents' existing view to the extent that they are likely to be rejected out of hand. Finn contends that Level 3 findings can be anxiety-provoking, and therefore likely to invoke defensive responses from parents. Finn contends that, in the context of a feedback session where parents have experienced support and understanding, Level 3 findings may be accepted.
- Help the client and family to develop a new story;
- Incorporate metaphor and the client's language into feedback; and
- Pay attention to the emotional component of feedback (the psychologist's and client's)

(Tharinger *et. al.,* 2008)

In line with Bandura's social learning theory (1977), the presenter used an anonymised profile to first model a feedback session with a client. This allowed the students to observe a feedback session before engaging in their own role-play of a parental feedback. Students were then assigned the *Informing Families E-learning Module* (www.informingfamilies.ie) as a follow up activity to reinforce good practice in feedback provision. The guiding principles of the *Informing Families* approach to feedback are aligned to a strengths-based philosophy and include:

1. Family-centred disclosure;
2. Respect for child and family;
3. Sensitive and empathic communication;
4. Appropriate, accurate information;
5. Positive realistic messages and hope;
6. Team approach and planning; and
7. Focused and supported implementation of best practice (HSE, 2007).

Strand 2: Evidence-based Approaches to Psycho-educational Report Writing
The students then proceeded to engage with the second strand of the session to inform their approach to report writing. Students were advised to take account of individual service conventions for report-writing and were referred to Sattler's (2014) and Carr's (2015) texts as resources for clinical report writing templates. The following evidence-based elements were also incorporated into session activities:
- Ethical considerations such as respect for the client, the rights of the child and confidentiality as a central guiding principle (PSI, 2011);
- Consideration of the audience for the report (Sattler, 2014);
- The use of person first language (Blaska, 1993; Dunn & Andrews, 2015);
- Readability : 'Plain English' principles were outlined to the students (NALA, 2009);
- Decisions on which information to include. Pameijer (2006) advocates a 'need to know' not 'nice to know' approach;
- Report length - Reports in excess of 5-7 pages (single spacing) may present a challenge for both parents and teachers (Wiener, personal communication in Mastoras, 2011); and
- The strengths-based approach to report writing (Towle *et al.*, 2008).

The strengths-based report-writing component was expanded upon by first examining some of the key guiding principles outlined by Towel *et al.* (2008). These include:

1. Describe what you observed objectively and in the past tense;
2. Lead with strengths;
3. Avoid 'but' and 'however'. Use two separate sentences instead; and
4. Use 'not yet', avoid 'only.'   (Towle *et al.*, 2008)

In order to engage with the strengths-based approach, students were encouraged to provide strengths-based commentary to audio-visual clips using the guidelines outlined above. Students then amended deficit-focused language to complete written feedback for a client report to convey information in a way that focused on the client's strengths, while retaining an accurate portrayal of the client's presentation. For example:

'*Mary has difficulty with age appropriate readers. She can only read books at level 10 in the PM series. She can only answer literal comprehension questions (who, what, when, where questions) based on level 10 texts*'.

This was amended to:
'*Mary was able to read books at level 10 in the PM series and to answer literal comprehension questions relating to the text. Mary had yet to develop interpretive comprehension skills (what if, how and why questions) based on level 10 PM readers*'.

Reflections on the incorporation of strengths-based report writing principles
Student reflections indicated that completing the activities involved a paradigmatic shift away from noticing client deficits to highlighting their abilities and potential, echoing McCashen's (2005) assertion that attitudes, beliefs and values are central to the implementation of the strengths-based philosophy. The students also raised some interesting points for debate, including concerns that the strengths-based approach may result in the client and their family emerging with an unrealistic perspective of the nature and degree of the challenges faced by the client. These concerns are prevalent in the literature on strengths-based report writing. The strengths-based approach has been criticised on the grounds of a failure to deal with problems sufficiently; potentially setting up unrealistic expectations and presenting a picture to clients and families that is not reflective of current and future challenges (Roebuck, 2007). Proponents of a strengths-based philosophy counter that this represents a mis-construal of the approach. They contend that the strengths-based approach is not concerned with the attribution of blame or the identification of failures of the client, their families and their support system. Rather, it is concerned with examining the resources individuals, their families and their support network have at their disposal to address challenges and build capacity in order to prevent or minimise the impact of future challenges (Roebuck, 2007).

McCashen (2005) contends that a move to strengths-based practice requires more than the super-imposition of a strengths-based framework onto existing practice within an organisation. He suggests that an examination of the underlying values and attitudes of the people within a service rather than the skills and knowledge they possess will determine the extent to which strengths-based practice is meaningfully embedded within an organisation. However, there are some indications that the adaptation of a strengths-based framework can act as a catalyst for an organisational shift towards a strengths-based philosophy. Donovan and Nickerson (2007) reported that the addition of strengths-based data to a fictitious client report affected predictions about client outcomes made by the members of a multi-disciplinary team. This study highlights the potential impact of 'bottom-up' approaches to organisational change on the culture within a service. By changing the way that language is used in the workplace, practitioners can promote a different tone to professional conversations about clients, where deficit-focused language is no longer the norm. This has the potential to impact significantly on the experiences of clients and their families when they engage with disability services.

Conclusions

Laursen (2003) observed that clinicians and academics continue to seek the best ways to apply strengths-based practice. Snyder *et al.* (2006) recommend a balanced approach to information gathering and report writing, and emphasise the importance of the retention of hope for clients and their families. They suggest that the practitioner attend to the client's psychological strengths and challenges, as well as strengths and challenges in the client's environment. Snyder et al (2006) assert that goal development is an important component of the report-writing remit and stress the need for awareness of motivational factors that will impact on the likelihood that the client will pursue these goals.

The process of incorporating the strengths-based philosophy into the training of educational psychologists at MIC led to an engaged debate on the relative merits of the strengths-based approach. It was concluded that a nuanced approach to psycho-educational report writing that attends to client, family and environmental strengths and challenges is required. The approach taken in the feedback and report-writing session may be transferable to training in assessment and report writing in other fields, emphasising the additional potential for collaborating across disciplines at an early stage of professional development for the benefit of children and families within disability services in Ireland.

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10. Conclusions and Recommendations

For one day on the 1st of December 2017, we took a step back from all of the planning, negotiations, frustrations and blockages, to create a space to collectively take stock of what is going well, where we came from and what do we have to do to get where we want to be. We also found an opportunity to shine a light on the multitude of interdisciplinary initiatives and collaborations taking place across agencies to positively impact on the lives of children with disabilities and their families. The enthusiasm and facilitation by staff in Mary Immaculate College brought an added dimension to the conference and to this conference report, which sets out to provide a valuable resource to those fortunate to attend and those who missed out on a great opportunity.

Back in 2009, members of the Reference Group on Multidisciplinary Services for Children aged 5-18 had a vision, which set out a roadmap to create clearer pathways for children to access services and to strengthen greater links between health and education. In 2011, that vision was taken further with the launch of *Progressing Disability Services for Children and Young Persons 0-18.* I remember my first thoughts on reading the proposals and the concept of having pathways to accessing services based on needs not diagnosis. These stood out for me because children do not always fit neatly into categories, and too many were falling into, and being lost in the grey areas of the existing service structures.

In his opening remarks at the conference, Minister McGrath spoke of the reconfiguration of children's disability services being a key priority for the Government, for the Department of Health and for himself as the Minister for Disabilities. He said that despite challenges, "The Government remains resolutely committed to its implementation". Minister McGrath also rightly stated that we must ensure that children and young persons have a right to, and can live satisfying and valued lives. This would "be best achieved by adopting a collaborative approach, harnessing resources, swapping ideas and bringing out the best in each other - through a process of rigorous debate". It would be fair to say that all of that was evidenced by the content of the presentations, workshops, posters and discussions between conference attendees - all reflected in this report. However, no one can escape the reality that there is a paucity of resources relative to the needs and numbers of children requiring assessments and interventions. We look forward to realistic and sustained funding packages that will allow the Minister to provide infrastructural investment and additional staffing, to support the complete roll out of Children's Disability Network Teams - almost nine years after the proposal itself was conceived.

What I observed at the conference and through opportunities to make connections with staff and other stakeholders on the day, is that we have many high-calibre professionals working in children's disability services and in ancillary services, who have driven well-planned and effective initiatives in clinical practice, despite many of the challenges posed by the lack of resources. There was in evidence

during the day of a shared passion among professionals to really make a positive contribution to supporting our children's development. Presenters described their respect for and a heavy weighting around the role parents play in their child's ongoing development and working with therapists, as a team, so they all could achieve common goals for the child and family.

There was also an acknowledgement of the role parents have played in the reconfiguration planning process. Hazel Trudgill, Director of Children's Services West Cork spoke of how "Parents bring a unique and invaluable perspective to all aspects of service provision and management, and parent representation at management level has proved to be very beneficial".   During the morning presentations, we heard honest appraisals of the difficulties, challenges and successes of Children's Disability Network Teams in action, which spurred on much of the consequent discussions on pitfalls and avoiding the same in areas that are pre-reconfiguration. We heard of the growing waiting lists for services and warnings of the staggering numbers of children in some areas currently without a service, which has the potential to swamp newly reconfigured teams if they are assessed as having complex needs. It was noted that waiting lists were not a new phenomenon, but managing them in the context of Children's Disability Network Teams required a different approach.

Fidelma Loughnane, Preschool Liaison Teacher and Aisling Jones, both of the Galway Early Intervention Services, demonstrated how cross-agency collaboration with families could promote better inclusion and participation in preschool. The new role of the Early Years Specialists and the supports available to preschools and children with disabilities through AIM (Access and Inclusion Model) were compared to the previous local arrangements. Although a relatively new initiative, parent and preschool providers' feedback, as presented to the conference, was resoundingly positive. In particular, the mention of a rounded approach and finding missing links showed us that parents and preschool providers value a more consolidated and streamlined approach to supporting the needs of children with disabilities.

Among many of the contributions to the conference, the same words were used repeatedly by presenters: child and family centred practice; collaboration; best practice; supporting; and team approach. The most powerful contribution of the day, delivered by Silvia Segales-Angel, a parent and professional, made those words come alive as she shared her real lived experience of what all of those words and phrases mean 'off paper'. Silvia's presentation was structured around three key take-home messages: correctly identify family priorities; develop parents' resourcefulness; and give families actionable steps that they can easily implement. Her delivery of those messages struck a powerful chord with every attendee, including myself as a fellow parent. Part of why her message was so clear and powerful was because during the bulk of her presentation, our eyes were drawn to images of her son Sebastian. You see, this is why we are all here.

Sebastian visually represented all of the thousands of children with disabilities - both known to therapists and on waiting lists. Sebastian is real, not a number. Sebastian showed us that every child has potential waiting to be unlocked, and every parent is striving to find the right set of keys to suit their child's needs. Sebastian's mother, Silvia, emphasised the expertise parents have in respect of their own child(ren), and the professionals' role in developing that. Silvia closed off her presentation by saying that, *"If we as professionals can create a good strong foundation, parents can support their children in daily life and long into the future"*.

I have always described *Progressing Disability Services for Children and Young Persons 0-18 Programme* as a framework, which was more about building strong foundations, a solid house on top and a single clearly-identifiable front door that would be the same, regardless of the street in which the house was built, and easily accessible. However, on entering the house you may not always find someone to greet you, or even have furniture in all of the rooms. Indeed, you may find some internal doors locked. The lack of resources is a most-challenging and ongoing loud conversation. The establishment of Children's Disability Network Teams will not address ever-increasing waiting lists; it will not address the paucity of service provision in some areas and it will not ensure that all children like Sebastian have a better chance in life, unless given the opportunity and resources to do so. If anything, the conference has showcased huge potential and given people an appetite and energy to try and deliver more, in different ways, and demand that the right level of resources is in place to do so. Child and family-centred practice and actual "progressing" disability services for children and young persons can only become a reality when the energy and professionalism of staff working with our children is matched by realistic, proactive and sustained investment by Government.
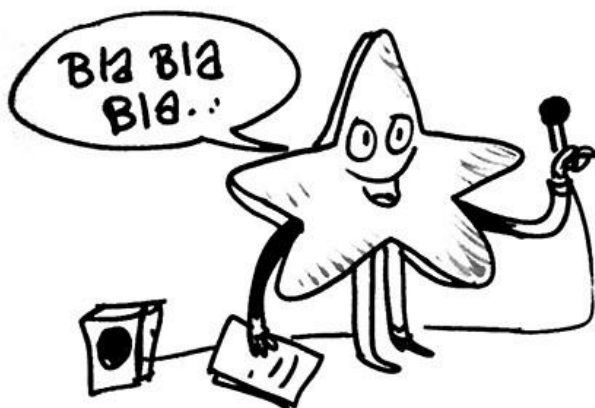
Lorraine Dempsey

Parent Representative, National Children's Programme Oversight Group

① ⇨ GRANDPARENTS Should Be given a Diagnosis with the PARENTS

Supporting Play Between GRANDPARENTS AND CHILDREN!