



Progressing
Disability
Services
for Children
& Young People

Working together to support children and families

Outcomes for Children and their Families

**Report on an Outcomes-Focused Performance Management
and Accountability Framework for
Early Intervention and School Age Disability Network Teams**

Prepared by the
Standards and Performance Reporting Working Group
for
'Progressing Disability Services for Children and Young People'
programme

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The Outcomes Focused Performance Management and Accountability Framework

Executive Summary

Context

The National Progressing Disability Services for Children and Young People programme was established in 2010. The vision of the programme is that each and every child or young person with a disability will be supported to achieve their full potential through the implementation of an integrated service model that will allow children, whatever the nature of their disability, to be seen and supported as locally to their home and school as possible based on their needs.

The Department of Health tasked the National Co-ordinating Group of the Progressing Disability Services for Children & Young People programme to develop a performance reporting system for programme accountability of multi-disciplinary (and often, multi-agency) children's disability teams, which is focused on outcomes for children with disabilities and their families. The proposed system is called the *Outcomes Focused Performance Management and Accountability Framework*¹ and is based on international best practice and evidence, and extensive consultation with service users, their families and staff, along with key national and international researchers. The call for outcome based performance measurement has since been strengthened in the *Value for Money and Policy Review* (DOH 2012) and *Future Health – A Strategic Framework for Reform of the Health Services 2012-2015* (DOH 2012). This Outcomes for Children and their Families Framework requires each team's work and practice to be underpinned by a child and family centre philosophy. It demands that we translate the core values of respect and dignity; equity; empowerment; accountability; and excellence into practice. It means that as teams we will now need to work and evidence our work differently and measure the impact of our work with families, children and young people in terms of outcome/s achievement and to account for this locally, regionally and nationally.

About the Outcomes for Children and their Families Framework

The Outcomes for Children and their Families Framework sets out 11 outcome statements, the culmination of an extensive national consultation process with children, young people, families and team members providing multi-disciplinary services and

¹ This title is abbreviated to Outcomes for Children and their Families Framework in the remainder of the report

supports. It was also externally reviewed by internationally regarded researchers in the area. It has the potential to replace some of the current output based statistics gathered by uni-disciplinary team members moving towards a much more meaningful outcomes based approach to measure actual added value of services and supports provided for children, young people and their families by multidisciplinary teams.

The 6 outcome statements for children and young people are:

1. Children and young people have a voice in matters which affect them and their views will be given due weight in accordance with their age and maturity
2. Children and young people enjoy the best possible health*
3. Children and young people are safe
4. Children and young people have friends and get on well with other people in their lives
5. Children and young people learn skills to help them to be independent
6. Children and young people take part in home life, school life and community life

The 5 outcomes statements for families are:

1. Families understand their child or young person's needs, what they are able to do well and what they find difficult as they are growing up
2. Families look after, take care of and support their child or young person
3. Families are supported to ensure that their rights and the rights of their child or young person are respected
4. Families take part in community services and supports
5. Families feel supported by family, friends and neighbours in their local community

The outcome statements, which align closely with those identified in the Agenda for Children's Services (DOHC 2007), apply to all children and their families and describe the desired result of our interventions and support of the child, young person and their family – so we are starting with the end in mind. Each outcome statement has a set of goals to define it clearly. In addition, each outcome statement has process indicators and outcome indicators which collectively measure the degree of success we have in reaching the desired outcome for the child, young person and their family.

What you can expect from this reconfigured service and system?

As a child, young person or family member using the services, what you can expect from this change is that;

- Services and supports will provide you and your family with the opportunity to achieve the best possible outcome, regardless of your disability

- The team providing your service and support is accountable for evidencing improvements in outcomes for you and your family
- There will be equity and standardisation in how you receive and experience services and supports no matter where you live in Ireland
- Regardless of the type of disability you have, we will make every effort to support you
- The team will listen to and respond actively to feedback from you on your experience
- You will have an Individual Child and Family Support plan which is developed in collaboration with you and sets out your priorities

As a team member, what you can expect from this change is that:

- Our work will be measured from a team perspective, not from a uni-disciplinary perspective alone
- Our work will be measured and reported on based on the change in outcomes for children, young people and their families. This will be a progression from current measurement solely on throughput and output
- Our team will be required to work differently because an outcomes based approach requires that child and family centred practice is embedded in the culture and practice of all team members
- Our work will be subject to feedback from the families and children who use the services and we will be asked to rate our own practice and to actively listen to this feedback
- We will be facilitated in changing through team development, training and support as part of a national change management programme

Recommendations

The Working Group acknowledges from its learning over the past eighteen months that dedicated, coordinated project management at national/regional level is essential to ensure the safe and effective implementation of the Framework, due to the sizable cultural shift for all involved. This is evident from international research, discussion with those researchers and experienced children’s disability network teams striving to work towards this outcomes focused model (see Appendix 4 Focus Group Notes). Without dedicated project management, risks include existing practices being undermined, and further development and implementation of outcome focused performance management in Disability Services, as mandated by Value for Money and Policy Review (DOH 2012), being compromised.

The Working Group recommends that the Outcomes for Children and their Families Framework is phased in over three years, commencing in Q1 2014 with a number of demonstration sites geographically spread across the fifty-six already reconfigured teams. Project Lead(s) at national or regional level will require the necessary authority and mandate from the Social Care Division to lead on and implement the change programme (See Appendix 2 Project Management for Implementation).

Further recommendations, developed from research, the online survey with service users, families, staff and focus groups with children's disability network teams include:

- **Standardised training and development** in team based outcome measurement for early intervention and school age teams
- **Standardised 'communication kit'** for staff to assist with coaching, hearing and empowering parents from day one
- **One standardised template** with local flexibility merging the Outcomes for Children and their Families Framework, service user/family goals and interdisciplinary strategies to support goal achievement
- **Support for demonstration sites** to include ongoing evaluation, parental and staff experience, acknowledging geographical and resource variances between teams
- **Stronger link between Children's Disability Teams and the National Social Care Division** to ensure ongoing clarity and awareness at the frontline of the national context, including the outcome focused drivers mandated in *Value for Money and Policy Review* (DOH 2012), *Future Health – A Strategic Framework for Reform of the Health Service 2012-2015* (DOH 2012) and the National Service and Operation Plans
- **Information management system** to support team based performance management and the gathering, collation and analysis of data, and aggregation upwards of KPI returns for this and all Disability Information requirements
- **Feedback, support and direction from the National Social Care Division** on KPI returns and outcomes focused, team based, performance management for Children's Disability Teams.

Conclusion

Early in the development of the Outcomes for Children and their Families Framework, it was clear that whilst there is extensive international research and many academic resources dedicated to this work, a complete model including standardised measurement has not been developed yet anywhere in the world. During consultation on the first draft, national and international researchers commended the Working Group on the draft Framework and advised strongly to move ahead with implementation of its final draft presented in this report. The Working Group is cognisant that as national and international progress is made, along with local experience of implementing the Framework, the Framework will require revision in line with best practice. In conjunction with this is the work commenced by the National Disability Authority and mandated by the DOH on the development of a draft framework for outcome measurement of HSE funded Disability Services which will also influence future development of the Outcomes for Children and their Families Framework.

This report contains the Working Group's proposed Outcomes for Children and their Families Framework, based on literature review and consultation with children, young people and their families, former service users and staff. It has identified the challenges of implementing this model of working across Children's Disability Network Teams and a number of recommendations essential for a safe and effective transition to this model of working which included dedicated national/regional project management. It has prepared a draft Project Management Role (Appendix 2) and a draft Implementation Plan (Appendix 3) to guide the work of the Project Manager(s). Finally, the Working Group acknowledges the steep learning curve for its members during eighteen months developing the Framework, which has led to our understanding of the deep cultural shift required of individuals and teams, often multi-agency, to implement it. We are committed to the foundation this Framework provides for the introduction of outcome focused performance management and will provide what assistance, advice and support possible to the Project Manager(s) tasked with its implementation and review.

Section 1: Introduction

1.1 The Vision for Children's Disability Services

The Outcome Focused Performance Management and Accountability Framework is the result of much review of literature, discussion, reflection, consultation and a great deal of commitment by those involved in the working group. The outcomes statements for children, young people and families contained in this Framework and the accompanying goals, process and outcome indicators and recommended measurement tools provide a workable framework for professionals, families, researchers, policy makers and planners in the introduction of outcome focused performance management to Disability Services. This in itself begs a question – a workable framework towards what purpose? What is our vision for children and young people with disabilities in Ireland and their families? Does our vision align with the vision of children and young people themselves and their families? This common vision must underpin the Outcomes Focused Performance Management and Accountability Framework.

It is important to note that the outcome statements refer to universal outcomes. That is, outcomes which are relevant and meaningful in real-world daily life for *all* children and *all* families. They are not 'special' outcomes. Universal outcomes in this sense refer to children, young people and their families inhabiting, fully participating in and contributing to the same physical, social and environmental spaces as all children, young people and families.

The National Implementation Framework for 'Value for Money and Policy Review of Disability Services in Ireland' (2012) refers to two overarching goals supporting a vision for the Disability Services Programme. Goal 1 refers to the '*full inclusion and self – determination for people with disabilities through access to the individualised personal social supports and services needed to live a fully included life in the community.*' Goal 2 refers to '*the creation of a cost – effective, responsive and accountable system which will support the full inclusion and self – determination of people with disabilities.*' (p. 5). The goal of full inclusion and self-determination is also echoed in the 'Vision Statement for Intellectual Disability in Ireland for the 21st Century' (National Federation of Voluntary Bodies Discussion Document 2009). It states that '*above all people have a deep rooted desire to belong, to be in relationships, to live within the intimacy and security of their family and friends, to be included in the greater life around them with all its attendant possibilities for hope and fulfilment and to do so, to the greatest extent possible, on their*

own terms. The implications of this simple truth will determine our actions on behalf of all citizens with intellectual disabilities.'

Full participation, belonging, relationships, inclusion and self-determination for people with disabilities is then the end in mind. This should be the purpose underpinning all service activities from the beginning of service involvement with families and their children. This vision should also provide guidance in day-to-day decision-making and planning about assessments that are authentic and interventions and supports that are designed for children's daily environments where they grow, develop and learn.

Without such a vision there is a real danger that the implementation gap between policy and practice will remain considerable. Family-centred and person-centred practices are essential guiding factors for service professionals in keeping this vision in mind at all times. Service professionals need to be equipped with a strong theoretical base and robust principles in working towards effective family support practice (Dolan et al. 2006). The family-centred and person-centred perspective requires that service professionals, researchers, planners and policy makers recognise, support and strengthen the primacy of the family in their primary role and responsibility for their child and relate with families from this perspective from the initial contact.

The traditional medical service delivery model of disability services for children and young people has been a disempowering model for children, adolescents, young people and their families. This model has encouraged families to regard adding more and more discipline inputs into their children's lives as a solution. The traditional medical model has been too focused on what is 'wrong' with children, their deficits and shortcomings. The traditional medical model has disempowered families and blocked out the reality of parents needs to feel confident and competent in their parenting of all their children.

The outcomes focus offers a unique opportunity for disability service providers for both children and adults to be realigned in ways that are more family and person-centred as a continuing process that begins intentionally at the moment of initial contact with families. It is at this moment that some fundamental principles and practices must be active and alive in the minds of service professionals as they have the initial conversation with families about young children. These principles and practices must then continue to be active and alive as the young child and family grows through the lifespan, towards the fullest possible participation and inclusion in community life and appreciating the fundamental need to experience belonging and relationships in home, school and community life.

1.2 Progressing Disability Services for Children & Young People Programme

Background and context

In Ireland, children's disability services, delivered by the Health Service Executive (HSE) and non-statutory organisations, have developed independently over time. As a result, there is wide variation in the services available in different parts of the country and for different types of disability. Consequently, some children and their families have little or no access to services.

The National Progressing Disability Services for Children and Young People' programme was established in 2010 to change the way services are provided across the country. The objectives of the programme, which is based on the recommendations of the *Report of the National Reference Group on Multidisciplinary Services for Children aged 5-18 Years*, are to ensure:

- A single, unified system of disability services for children and young people;
- Equity in access to services across the country;
- Effective teams working in partnership with parent/carers;
- Resources are used optimally in a challenging fiscal environment.

The programme is implementing an integrated service model that will allow children, whatever the nature of their disability, to be seen as locally to their home and school as possible:

- At primary care level when their needs can be met there;
- Network early intervention and school age teams for children with more complex needs;
- Specialist services with a high level of expertise in particular fields to support primary care and disability network teams.

Local Implementation Groups are planning implementation of this programme so that, in due course, there will be network teams operating in all parts of the country.

Teams are being developed from within existing resources and will comprise of clinicians and other healthcare professionals from the HSE and voluntary organisations, in some cases on a multi-agency partnership basis. Consideration is currently being given to appropriate multi-agency governance arrangements for these new structures.

Vision and Philosophy for Progressing Disability Services for Children & Young People Programme

The vision of the 'Progressing Disability Services for Children and Young People' programme is that each and every child or young person with a disability will be supported to achieve their full potential.

Children, young people and their families availing of early intervention and school age disability services will benefit from a needs-led child and family-centred service informed by a human rights based approach². They will receive the highest quality information, supports, training and education, assessment, treatment and intervention, as appropriate and in accordance with their needs.

This vision is underpinned by a child and family-centred philosophy, which is grounded in the following concepts:

1. Families and services listen to the child, taking into account the child's age and maturity, and strive to achieve the best possible outcomes for that child or young person
2. Families are, in the main, fully capable of making informed choices and acting on their choices. Parent/carers have the ultimate responsibility for the care of their children and for all decisions made about them
3. Services exist to support children and families to attain the best possible outcomes
4. Interventions are appropriate to the needs of the child and family, and emphasise capacity-building, strengthening existing skill sets, promoting the acquisition of new skills, medical care and other supports
5. Children, families and service providers all benefit most when services are based on true collaborative partnerships between families and professionals

Reference to the 'family' in this document should be understood to include all members of the family (parent/carers, siblings, grandparents etc.) and all variations in composition.

This philosophy is put into operation through the values, principles and practices set out in the Outcomes for Children and their Families Framework for early intervention and

² A Human Rights Based Approach (HRBA) is an established framework and set of guiding principles for ensuring that human rights are upheld in organisations or services that adopt this approach. The five guiding principles are: (a) Express link to rights (b) Participation (c) Empowerment (e) Non-discrimination (f) Accountability

school-age disability teams. It is grounded in a humanistic approach to service delivery in accordance with the UN Convention of the Rights of the Child and UN Convention on the Rights of Persons with Disabilities.

A life-span perspective, which recognises the growing independence of the child or young person, informed the development of the Framework. Building the capacity of children, young people and their families is critical to child and family resilience and, in this context, it is anticipated that services will support a continuum from family-centred to person-centred services, through the transition stages of a child's life from early intervention to school age and on to adult services.

Services are moving away from the medical model of impairment to the bio-psycho-social model through the World Health Organisation's International Classification of Functioning, Disability and Health which assesses needs in the context of the impairment and the environment.

1.3 Reframing Disability Services in Ireland for the Future

The Value for Money (VFM) and Policy Review of Disability Services in Ireland (DoH, 2012) published in June 2012 proposes *'a fundamental change in approach to the governance, funding and focus of the Disability Services Programme, with the migration from an approach that is predominantly centred on group-based service delivery towards a model of person-centred ... supports'*.

A core principle that guided the Review is *'that agencies which receive funding from the State for the delivery of services and supports to people with disabilities are accountable for that funding, and the necessary systems and protocols should be put in place to ensure full accountability and transparency on a standardised basis'*.

It is against this backdrop that the Standards and Performance Reporting Working Group of the HSE 'Progressing Disability Services for Children and Young People' programme has developed the Outcomes for Children and their Families Framework for Early Intervention and School Age Disability Network Teams.

The report of the Expert Reference Group on Disability Policy (DOH 2011), which was an input into the VFM process, also emphasises the need to *'to create a high quality, cost effective, responsive and accountable system which will support the inclusion and self determination of people with disabilities'* underpinned by a strong governance framework

(p.120). In this context, the Expert Group identified a number of values and principles that should underpin services and translated these into practice through the use of governance structures and processes.

Table 1.1: Translation of values and principles into practice through the use of governance structures and processes (Source: *Report of Disability Policy Review, Expert Reference Group on Disability Policy, Department of Health, 2011: p.121*)

Values and principles	...into practice	Governance structures/processes
Fair and equitable	Provision based on needs	Needs assessment process
	Universal access for people with disabilities to local services depending on needs	Structure of delivery system based on catchment areas/integrated service areas
Person-centred	Service user centrally involved in the needs assessment process and in defining outcomes	Needs assessment process Outcomes-focused delivery
	Service user consulted on formulation of standards	Part of process of formulating standards
	Service user aware of the funding available to meet their needs	Part of process of allocating funds
Efficient and effective	Focused on outcomes	Outcomes-focused processes
	Funding allocated on the basis of identified need	Individualised funding model
	Variety of providers	Commissioning model with equal emphasis on cost and quality
High quality	Creation of agreed standards	Inspection, monitoring and review processes based on standards and outcomes to be conducted regularly and results fed back to the system to continually improve practice
	Creation of service-provider and system-wide outcomes, as well as service user-defined outcomes	Information systems are required to capture relevant information to measure and review outcomes
Accountable and transparent	Regular review and monitoring	Inspection, monitoring and review processes based on standards and outcomes to be conducted regularly and results fed back to the system to continually improve practice
	Right of appeal and redress	Develop effective complaints and appeals procedures

Clearly, the measurement of service quality and accountability is shifting from a more traditional focus on *only* compliance with organisational processes and standards, to a broader focus on continuous quality improvement and responsiveness through outcomes statements and outcomes measurement, framed in the context of the child and their family.

This new, broader focus has informed the development of the Outcomes for Children and their Families Framework for Early Intervention and School Age Disability Network Teams.

1.4: An Outcomes-Focused Performance Management and Accountability Framework for Early Intervention and School Age Disability Network Teams

The Outcomes for Children and their Families Framework will apply to all staff in early intervention and school age disability network teams in terms of what they can be held accountable for and its purpose is:

- To maintain a focus on desired outcomes for the individual child and the family through a process of clarifying expectations (clinical outcomes, functional outcomes and personal outcomes) as appropriate.
- To ensure a standardised outcomes-focused approach to the delivery of services and supports for each child and their family in accordance with their needs and priorities;
- To provide a framework for the governance, including the clinical governance, and accountability of early intervention and school age disability network teams.
- While the Framework applies to interdisciplinary early intervention and school age disability network teams, they may be relevant to other care group settings.
- The Framework will be integrated with the Framework for Collaborative Working between Education and Health Professionals

For the purpose of this document, an outcome is defined as a benefit experienced by a child, their family or the wider community as a result of the services and supports provided.

Section 2: Values and Principles

*Values are what people prize; not just ideals, but also a set of practical criteria for making decisions and as such are the drivers of behaviour*³

2.1: Introduction

All efforts to support children and their families depend on our ability to build rapport and relationships with one another. However, the idea that there is one kind of perfect relationship that fits for everybody is a myth. Different children and different families have different needs, strengths, resources, perceptions, experiences and ideas. Effective support involves a mix of styles, skills, and strategies tailored to the kind of relationship that is right for each person.

While there is no one right way to build a relationship, there are underlying key values which have been found through experience and research to be both fundamental and necessary in all efforts to support children and families in skilled ways. So, one of the best ways to characterise a supportive relationship is through the values that permeate and drive it. The relationship is the vehicle through which the values come alive. These values are expressed concretely through supportive behaviours and should be intrinsic to the child and family's experience of relationship with service professionals, e.g. respect and dignity, equity, empowerment, accountability and excellence.

When reflecting on our values, in addition to the importance of building relationships with children and families, we must also factor in the types of child and family supports and services that professionals working in services should be competent to offer and that services have the resources to provide. Just as there is no one right way to build a relationship, there is no one right way to deliver a specific type of support or service. Each must be individualised as much as is possible. However, each and every type of support and service should be delivered based on underlying key values e.g. respect and dignity, equity, empowerment, accountability and excellence.

These values - respect and dignity, equity, empowerment, accountability and excellence - are not just ideals. They are also a set of practical criteria for making decisions. As such, they are the drivers of behaviour. Services without a set of working values are adrift. At the same time, values which underpin our services cannot be handed out on a

³ Egan, G. *The Skilled Helper*; 8th Edition; 2000, Brookes/Cole

plate. In the final analysis, only those values that we have made our own will make a difference in our supportive behaviours with children and families. However, there is a rich tradition of values in human services and the values identified in this document come from that tradition. These values are also especially relevant and important as we seek to change service culture from the current exclusive emphasis on inputs/outputs and compliance with organisational processes to an outcomes – focussed culture where services and families begin their work together with the end in mind, asking what is really important to both child and family, what will be of greatest benefit?

To deliver this vision of each and every child or young person with a disability being supported to achieve their full potential, service practices and interventions will be grounded in the following values and principles:

- respect and dignity;
- equity;
- empowerment;
- accountability;
- excellence.

2.2 Values and Principles

Respect and dignity

- Respect is the central value in which all relationships, actions and behaviours in disability services are grounded.
- Children and families are accorded respect and dignity at all times. This includes recognising that every family is unique, and has its own roles and structures, values and beliefs, and abilities, strengths and capacities.
- Parent/carers understand their children best and are fully respected as equal members of the team, bringing expertise by virtue of their knowledge of their child.
- Cultural, ethnic and socioeconomic diversity is respected.
- High standards of confidentiality ensure that privacy is respected.
- Good communication is maintained by all possible means.
- All actions and behaviours are transparent.

Equity

- Equity is underpinned by the principles of fairness and equal human rights allowing for flexibility in response to individual needs. Every child is first and foremost a child.
- Every child has the right to:

- Be heard;
 - Belong to and contribute to their family and their community;
 - Have opportunities;
 - Realise his/her full potential;
 - Enjoy the best possible health;
 - Be safe;
 - Access appropriate education and learning;
 - Gain independence;
 - Be self-determining, as appropriate to their age;
 - Participate;
 - Be included;
 - Have good relationships;
 - Enjoy life
- Equity does not mean that all children receive the same services and supports. These are identified according to the needs of child and family through individual plans.

Empowerment

- The family is the primary and most essential support for the child and must be empowered in that role in all possible ways.
- Children's needs are best met when families are supported in making informed decisions about them and in developing competencies to meet their needs.
- Services exist to contribute to the best possible outcomes for children and families. In doing so, they engage with each family's strengths and perspectives, explore the family's desired outcomes and strive to respond to these, in the best interests of the child.
- The primary role of services is to give the benefit of professional skills, experience and knowledge to the family, in ways that enable them to help their child reach his/her full potential.
- Partnership with the child and their family focuses on their expressed concerns, desired outcomes and goals, and strategies are designed to be flexible so that they can be integrated into everyday family activities and routines.

Accountability

- Services are accountable for the outcomes and benefits of interventions.
- Services listen and respond to families' views on the benefits they want and on how services are being delivered.

- Services listen and respond to the child's views taking into account the child's age and maturity.
- Services show integrity by being honest, impartial and trustworthy and making decisions based on values and principles.
- Services have a robust appeals and complaints system.

Excellence

- Services ensure the highest possible quality of service based on current knowledge and evaluated practice by keeping up to date with the latest research.
- Services are regularly monitored and reviewed with the involvement of service users.
- Services include children, young people and families in the structures, design and development of services in line with best practice.
- Services work through partnership with families, with other service providers and with all team members.

Section 3: Outcomes-Focused Performance Management and Accountability Framework

Outcome Statements	GOALS relating to outcomes	Process Indicators	Outcome Indicators Short and long-term impact on the child / family as result of services/support received
CHILDREN			
1. Children and young people have a voice in matters which affect them and their views will be given due weight in accordance with their age and maturity	<ul style="list-style-type: none"> Children and young people are encouraged to express their views Children and young people are confident that their views are taken seriously 	<ul style="list-style-type: none"> % of children and young people with an up to date complete individual plan, including goals which incorporates their views and preferences 	<ul style="list-style-type: none"> % children and young people who report that their voice is heard in matters which are important to them
2. Children and young people enjoy the best possible health*	<ul style="list-style-type: none"> Children and young people have the best possible health. This includes physical, mental, dental and nutritional health. This is not an exhaustive list Children and young people are supported to manage their own health, in so far as possible 	<ul style="list-style-type: none"> % children and young people with an up to date complete individual plan, including goals which addresses their health issues 	<ul style="list-style-type: none"> Attainment of achievable, measurable goals in health through strategies based on outcomes, agreed with children and young people and their families
3. Children and young people are safe	<ul style="list-style-type: none"> Children and young people have a safe physical environment at home, at school and in their community Children and young people are free from abuse and neglect 	<ul style="list-style-type: none"> % children and young people with an up to date complete individual plan, including goals which addresses their safety issues Services are compliant with Children First (2011) 	<ul style="list-style-type: none"> Attainment of achievable, measurable goals in safety through strategies based on outcomes, agreed with children/young people and their families

Outcome Statements	GOALS relating to outcomes	Process Indicators	Outcome Indicators Short and long-term impact on the child / family as result of services/support received
CHILDREN Continued			
<p>4. Children and young people have friends and get on well with other people in their lives</p>	<ul style="list-style-type: none"> • Children and young people feel safe and secure with the main people who are looking after them • Children and young people can make friends with people of their choosing • Children and young people develop socially and emotionally according to their age • Children and young people understand about different relationships, including sexual relationships 	<ul style="list-style-type: none"> • % children and young people with an up to date complete individual plan, including goals which addresses their social and emotional development 	<ul style="list-style-type: none"> • Attainment of achievable, measurable goals in social and emotional development, through strategies based on the outcomes, agreed with children and young people and their families
<p>5. Children and young people learn skills to help them to be independent</p>	<ul style="list-style-type: none"> • Children and young people develop day to day skills that help them live their lives as independently as possible • Children and young people have growing independence in making decisions and choices every day in school, at home and in their community • Children and young take part in and complete education to their fullest potential • Children and young people are supported when they move between services and supports 	<ul style="list-style-type: none"> • % children and young people with an up to date complete individual plan including goals addressing their skills to optimise their independence 	<ul style="list-style-type: none"> • Attainment of achievable, measurable goals in functional skills to optimise independence, through strategies based on outcomes, agreed with children/young people and their families

Outcome Statements	GOALS relating to outcomes	Process Indicators	Outcome Indicators Short and long-term impact on the child / family as result of services/support received
<p>CHILDREN Continued</p> <p>6. Children and young people take part in home life, school life and community life</p>	<ul style="list-style-type: none"> • Children use community services and facilities as they wish • Children and young people live, learn, play and socialise with their peers • Children take part in the everyday life of their community 	<ul style="list-style-type: none"> • % children/young people with an up to date complete individual plan which addresses their information, supports and access needs to optimise their participation in their home, school and community • Services provide information and assistance to schools and communities to facilitate participation of children with disability 	<ul style="list-style-type: none"> • Attainment of achievable, measurable goals of participation in home, school and community through strategies based on outcomes, agreed with children/young people and their families

Outcome Statements	GOALS relating to outcomes	Process Indicators	Outcome Indicators Short and long-term impact on the child / family as result of services/support received
<p>Families</p> <p>1. Families understand their child or young person's needs, what they are able to do well and what they find difficult as they are growing up</p>	<ul style="list-style-type: none"> Families have easy to understand information about their child or young person's needs as they are growing up Families and services work together so that they can understand what the child or young person is able to do well and what they find difficult 	<ul style="list-style-type: none"> % families who as part of their individual family plan process shared their experiences and opinions through the family questionnaire MPOC 20 	<ul style="list-style-type: none"> Aggregated scored results from the parent/carer questionnaires MPOC-20 and service provider questionnaire MPOC-SP in the area of information about the child
<p>2. Families look after, take care of and support their child or young person</p>	<ul style="list-style-type: none"> Parent/carers are confident in their parenting skills Families make sure they have a safe and caring home for their child or young person to grow up in and learn new things Families support their child/young person in learning new life skills and how to become more independent 	<ul style="list-style-type: none"> % families who as part of their individual family plan process shared their experiences and opinions through the family questionnaire MPOC 20 	<ul style="list-style-type: none"> Aggregated scored results from parent/carer questionnaires MPOC-20 and service provider questionnaire MPOC-SP in the area of support for parenting

Outcome Statements	GOALS relating to outcomes	Process Indicators	Outcome Indicators Short and long-term impact on the child / family as result of services/support received
Families Continued			
3. Families are supported to ensure that their rights and the rights of their child or young person are respected	<ul style="list-style-type: none"> Families know how to get the information and supports that they need Families know their own rights and the rights of their child Families know about the different kinds of services and supports available and how to access those of their choosing Families are comfortable telling staff if they have a problem with the service and giving their ideas on how to improve services 	<ul style="list-style-type: none"> % of families who as part of their individual family plan process expressed their concerns and suggestions through the family questionnaire MPOC 20 	<ul style="list-style-type: none"> Aggregated scored results from the parent/carer questionnaires MPOC-20 and service provider questionnaire MPOC-SP in the area of feedback about the services received
4. Families take part in community services and supports	<ul style="list-style-type: none"> Families have access to childcare services as they choose Families use community services and facilities as they choose Families take part in community activities such as social and leisure as they choose Families take part in parent/carer support groups as they choose 	<ul style="list-style-type: none"> % of families who as part of their individual family plan process shared their experiences and expressed their opinions through the family questionnaire MPOC 20 	<ul style="list-style-type: none"> Aggregated scored results from the parent/carer questionnaire MPOC-20 and service provider questionnaire MPOC-SP in the area of information about community services and supports
5. Families feel supported by family, friends and neighbours in their local community	<ul style="list-style-type: none"> Families have support from extended family, friends and neighbours as they choose Families meet and get to know other families 	<ul style="list-style-type: none"> % of families who as part of their individual family plan process shared their experiences and opinions through the family questionnaire MPOC 20 	<ul style="list-style-type: none"> Aggregated scored results from the parent/carer questionnaire MPOC-20 and service provider questionnaire MPOC-SP in the area of information and encouragement to draw on family and community supports

Section 4: Guidance for Early Intervention and School Age Disability Teams

This section is a tool kit to provide practical guidance for services in their work towards delivering on the outcome statements for children and young people. It builds on previous work⁴ undertaken to support teams and creates a bridge between the operation of services and the high level values and principles. The purpose is to provide teams with a method of tracking their progress in the key elements of service delivery. There may be wide differences between teams on their stronger and weaker areas. The fact that all the following elements may not be currently in place should not prevent teams from implementing the Outcomes for Children and their Families Framework.

The guidance is grouped under 16 aspects of service delivery and these are related to the values and principles as set out in Section 2 of this report:

- Respect and dignity
- Equity
- Empowerment
- Accountability
- Excellence

Guidance for the Operation of Services

1. Ethos

- There is a written statement on the child and family centred ethos of the team.
- The team members regularly review their competence and knowledge to respond appropriately to cultural diversity.
- All policies and procedures are written and reviewed to reinforce the centrality of the family.

2. Governance, policies and procedures

- Each team's governance and reporting relationship is clearly outlined and documented.
- Each team is accountable to a designated manager/coordinator with appropriate clinical and management experience.

⁴ Standards Framework for the Delivery of Early Intervention Disability Services. HSE. 2011

- The manager/coordinator has clearly defined roles and responsibilities regarding implementation of service model, clinical management, quality assurance, service planning and accountability.
- The manager undertakes an annual review of the team structure and associated documentation.
- The team has identified a list of policies and procedures relevant to the team.
- There is a documented process for formulating, approving and reviewing policies and procedures.
- All policies and procedures record dates of development; date of approval and proposed review date.
- Written policies and procedures are available and accessible to all stakeholders.
- Policies and procedures are clearly communicated through the induction process.
- The service informs families about the complaints procedures, and consults about its effectiveness.
- There is a documented policy and criteria in relation to provision of services in a variety of settings such as the home, local clinics, pre-school and school.

3. Measurement of Outcomes

- The service has a recognised system in place to measure each child's/young person's outcomes of health and therapy interventions.
- The service implements processes to support people who use their service (children, families, communities) to provide feedback about performance against the Framework and their achievement of outcomes. These processes should be:
 - Documented
 - Planned and co-ordinated
 - Independently facilitated
 - Provide support to fully participate in the process
 - Focus on the effectiveness of supports and improved outcomes
- The service implements processes to measure if their practices support the attainment of outcomes for stakeholders:
 - Documented
 - Outcomes and strategies clarified and planned for upfront
 - Involves service users
 - Identifies the extent to which strategies and interventions have facilitated or detracted from outcomes for service users.
 - Identifies improvement opportunities
- The service use information systems to capture relevant information to measure and review outcomes

4. Team Working

- The team has a written mission and vision statement which is in accord with their service delivery model.
- The model of service delivery is documented and communicated to all team members and line managers
- The model of service delivery is reviewed at agreed regular intervals to ensure it continues to meet the needs of stakeholders.
- All team members work within this model of service delivery
- The team identifies the core members required to meet the needs of the service users within their catchment area.
- Members of the team are in place/ post.
- The roles and responsibilities of team members are clearly documented
- There is evidence that team members have the necessary qualifications and skills to carry out their role.
- The team manager ensures that the team works in a co-ordinated and collaborative fashion e.g. documentary evidence of joint sessions, co-ordination of appointments etc.
- The team has a documented policy on the process of conducting team meetings encompassing operational and clinical discussion and planning.
- The agenda and minutes of team meetings are recorded and circulated. Agreed decisions and actions are identified, documented and followed through.
- Each team member has access to administrative support
- There is a comprehensive induction process for all staff concerning the service, roles and responsibilities of staff.
- All team members including administrative support are based in the same building.
- Team members have access to IT facilities
- Telephone facilities are adequate to meet the needs of all team members
- There is access to confidential space for meetings of families and team members.

5. Evidence Based Practice and Continuous Improvement

- The service can demonstrate that they deliver an evidence based practice
- The service implements processes to support continuous improvement
 - Documented
 - Based on data analysis of self-assessment, consumer assessment and outcomes measurement
 - Informed by other statistical data /events
 - Set priorities, strategies, responsibility and timeframes

- Be monitored and reviewed
- Team members have access to relevant training to develop skills appropriate to the needs of clients and families accessing the service.
- All team members have a structure for clinical supervision which has protected time and is planned, documented, audited and supported within all disciplines.
- All team members have access to evidence based research e.g. journals, online libraries/journals.
- All team members have a professional development plan which is reviewed annually and linked to the team development plan.
- The manager identifies on an annual basis the competencies within the team and those competencies needed to be developed to meet the needs of the children/young people and families within the service.
- There is team development and training scheduled, planned and delivered on an annual basis.
- The training needs identified are incorporated in budget planning.
- There is evidence of the completion, evaluation and review of all training programmes
- There is a regular opportunity for parents/ carers and children/young people to express their opinions and experiences of the services they receive and make comments and suggestions on services (e.g. annual focus group)
- The service encourages families to actively engage in general service planning and development
- The service implements an annual self-assessment process to assess, monitor and improve quality against this Framework:
 - Documented
 - Planned, processed based approach
 - Involve management/team members
 - Involve service users
 - promote continuous improvement
 - support compliance against the standards
 - Identify and prioritise improvement opportunities

6. Information Management, Confidentiality and Consent

- The team has written policies and procedures in relation to information management, record keeping and client file management.
- The team have a written policy on consent in accordance with organisational and legislative guidelines. This includes details of:
 - Consent of parents/guardians

- Consent of service user from age 16 years
 - Consent for assessment and intervention
 - Information recorded
 - Retention of information
 - Sharing of information
 - Specific occasion consent
 - Legal guardianship
- All team members use integrated shared client files.
 - The service has a standardised mechanism in place for collation and return of data in line with governance arrangement at national and local levels.
 - The team has a written policy on confidentiality developed in accordance with organisational guidelines and relevant legislation, including the Data Protection Acts (1988-2003) and the Freedom of Information Acts (1997-2003).
 - There is evidence that each team member understands the team's policy on confidentiality and their duties to keep and maintain child and family information in confidence.
 - All collected data applies legislative and professional best practice standards in terms of client consent and information sharing.
 - Each team member receives FOI and Data Protection training
 - Records are audited for compliance with the Acts.
 - Parents/carers and children/young people as appropriate to their age are informed about their rights under the Acts.

7. Information for Families Children and Young People

- There is an information leaflet for referrers providing information on the service and access to the service.
- There is an information leaflet for parents/carers including information on team members and their roles, access, the assessment process and other service information.
- Professional approved translators/interpreters are provided when appropriate, and there is a clear policy relating provision of translation in place
- Parents/carers receive appropriate information throughout the child's/young person's involvement with the service
- Children and young people receive information throughout their involvement with the service as appropriate to their age and understanding
- Information is available in a range of accessible formats

8. Safety

- The service identifies safety and access issues for all environments in consultation with families (and children/young people) through risk assessments, and supports are put in place
- The service is delivered in a building which is accessible to the child/young person and family.
- The team has a written health and safety policy developed in line with corporate health and safety strategy and reviewed regularly
- The service reports child welfare and protection concerns in accordance with Revised Children First 2011
- The service provides families with information on their child protection and welfare policy, procedures and protocols, in accordance with national policy
- The service offers support to children/ young people and their families in addressing their education needs in sense of self, intimacy, sexuality and relationship appropriate to their age and capacity.

9. Health

- There is an open referral system in place, including referral by parents.
- Clear information is available to parents/carers along each step of the referral process.
- The team has clear and up to date information leaflets, specifying the services they provide and for whom they are provided.
- The team has a documented referral appeals process in place, which is made available to all parents/carers and referrers.
- The service ensures that children/young people are appropriately assessed and receive services in a timely manner
- The team provides information on the assessment purpose and process and team members involved.
- The service has a recognised system in place to measure each child's/young person's outcomes of health and therapy interventions
- The service supports children and their families in transition between health services (e.g. disability and primary care) and, in education (e.g. primary to post primary)
- The service facilitates children/young people and their families to access mainstream health services, as appropriate to their needs,
- The service supports families to modify the home environment or routines to meet their child/young person's needs

10. Assessment and Intervention

- Parents/caregivers are assigned a designated key worker/contact person
- The team has documented evidence of agreed role and responsibilities of key worker/contact person.
- The team provides families with feedback throughout the assessment process, which focuses on the child's/young person's strengths as well as needs in a manner that is clearly understood.
- Team members assessing the child or young person regularly check with the family that they are clear about the assessment and its findings with follow-up appointment if necessary.
- The team is flexible regarding appointment times and venues and these are mutually agreed with the family.
- Clinicians gather information from a variety of contexts as appropriate, in order to contribute to assessment and help determine strengths and needs e.g. home/education setting.
- The assessment identifies goals that are functional, specific, achievable and measurable and contribute to intervention planning
- The team compiles a joint team assessment report with input from all disciplines involved in the assessment, which is conveyed to parents and the child/young person, as appropriate to their age, in person and by written reports.
- There is documented evidence to demonstrate that assessments are in line with best practice and appropriate to the individual client
- The team has a documented framework for measuring intervention outcomes.
- There is documented evidence to demonstrate that intervention plans are in line with best practice and appropriate to the individual client

11. Independence and Participation

- There is a written statement on the child/young person's right to self-determination and choice
- Interventions allow for maximum independence and choice
- The service provides families with a range of interventions empowering them to enable their child/young person reach their potential
- The service is delivered in age-appropriate environments
- The team has a documented system in place to plan, manage and support transitions for the child/young person and family
- Children/young people are involved in planning for all transitions as appropriate for their age

- The service advocates the use of mainstream community services and supports and provides relevant information and links where appropriate.
- The service works collaboratively with families and local community supports to optimise access and participation by children/young people and their families
- The service is delivered in inclusive natural environments wherever possible and appropriate
- There is evidence of a commitment by the service to encouraging maximum independence and inclusion in the community
- The service engages with local community support to enable children/young people to participate in their community life
- The services support families to know about, and help their child use, special adaptive equipment
- The service offers children/young people opportunities to acquire skills and knowledge to enable them determine their own needs for services and supports as adults

12. Parent empowerment and skills development

- Parents/carers are offered a range of interventions to provide them with skills to enhance their child's development, including:
 - Individual counselling
 - Group programmes and courses
 - Opportunities to meet with other parents
 - Relevant literature and information
- Parents/carers are given appropriate strategies to support their child's development while awaiting intervention with the team
- Recommendations and any helpful literature relating to the child's needs are given to parents/carers and the child/young person as appropriate.
- All written material is in clear, concise and easy to understand language and is accompanied by pictures and diagrams where appropriate.
- Translation is made available where appropriate.
- The team have a process in place for skill development needs to be expressed by parents/carers/community providers.
- In each health service area there is an annual calendar of training events for parents/carers accessible to all parents/carers within the health service area
- Team members develop programmes to support other service providers in their community
- The service provides families with information on their child/young person's developmental progress in easy to understand formats

- The service provides and evaluates information, training and education programmes for families which may include 'expert by experience'.
- The service informs families on relevant health services and how to access them

13. Individual Plans

- At all stages parents/carers and children/young people as appropriate to their age, are partners in decision making in relation to the child's/young person's service pathway
- The team has a documented policy and procedure on the implementation and review of the individualised family centred plan.
- All children/young people have an individualised family centred plan (IFCP/IFSP).
- A named person is identified who is responsible for the co-ordination of the individualised family centred plan.
- The individualised family centred plan is developed in collaboration with relevant team members and the family and is kept up to date.
- Parents/carers and children/young people as appropriate to their age are encouraged to be actively involved in the development and delivery of the child's plan
- With parents'/carers' consent and the young person's if he or she is over 16 years, relevant external agencies are invited to participate in the individual plan process
- Goals in the individualised family centred plan are clearly defined outcome based and measurable.
- A written report is compiled and families are given an opportunity to provide feedback on the report.

14. Involvement of families/children/young people in decision making

- There is an agreed system of decision making by the team and family.
- There is evidence of inclusion of families and the child/young person in all decision-making.
- Parents/carers have opportunities to express their priorities for interventions.
- Feedback is sought from the parents/carers regarding their expectations and the outcomes of service delivery on a regular basis.
- The team has practices and protocols for ensuring children and young people are encouraged to take part in decision-making as appropriate to their age and understanding.

- Children and young people have access to information about the services they receive that is appropriate to their age and understanding. This includes verbal and written explanations.
- Children and young people are given opportunities to express their own views about the services they receive and their own goals.

15. Advocacy

- The service informs families about their rights and the rights of their child/young person in a range of media, information and education programmes and events (e.g., local parent organizations, the Internet)
- The service encourages families to express their opinions, concerns and experiences of the service formally (e.g. focus group) and informally (e.g. active listening in everyday context)
- The service provides children/young people with sufficient information and support to enable them to express their opinions, concerns and experiences re their services and supports
- The service ensures that decisions taken are explained to children/young people, especially when the views of the child cannot be fully taken into account
- The service support families as appropriate in their role to help their children / young people in their social, emotional and behavioural development

16. Co-ordination of services and supports

Children's Disability Services Forum

- There is an interagency children's disability services forum in the health area including primary care, disability and Child and Adolescent Mental Health teams and other relevant stakeholders to implement and support collaboration.
- Within the forum, agreement is reached regarding parameters in terms of geographical area covered, target population, services provided and interagency working.
- The forum agrees practices/ protocols on sharing information across agencies.
- The forum identifies resource needs for the teams within the health service area.
- The forum has written terms of reference and procedures for meetings, decision-making and disseminating information.
- There is an annual review of the operation of the forum.
- The team engages with other agencies to establish working practices to ensure smooth transition between services for the child/young person and family.
- The team identifies any gaps or breaches in continuity of service provision for children/young people and families and informs the inter-agency forum.

Education and Health Services Forum

- An education and health services forum is established in the health service area with representatives of health services and the local education sector, including individual schools and other relevant stakeholders. See 'Framework for Collaborative Working between Education and Health Professionals'.
- Within the forum, agreement is reached regarding parameters in terms of co-operation between health services and schools, including roles and responsibilities.
- The forum agrees practices/ protocols on sharing information across agencies and joint working.
- The forum promotes opportunities for relevant training including joint working for health and education professionals.
- The forum has written terms of reference and procedures for meetings, decision-making and disseminating information.
- There is an annual review of the operation of the forum.

Section 5: Recommendations for Implementation and Conclusion

5.1 Introduction

The mindset and culture that has traditionally underpinned service policy, planning and funding in Ireland will be significantly challenged by the changes envisaged in the implementation of this outcome focused approach, a first in Disability Services in Ireland. For services, the ultimate challenge in implementing an outcomes-based approach is how they will adapt their role to complement, assist and strengthen families and others in their primary roles of enabling children's holistic development and learning in natural environments.

Extensive consultation with service users, families, staff, international researchers and focus groups with children's disability teams has confirmed the significant cultural shift required for each team to transition to measuring their *team's* performance on assisting children and their families to reach their desired outcomes. To date, national statistic requirements for children's disability teams are solely unidisciplinary in manner and not conducive towards nurturing or measuring team based performance or added value for the service user, their family and ultimately their community and society. Many teams comprising of staff from different organisations will have the additional challenge of merging their individual organisations' cultures, including their approaches to measuring the effectiveness of their services and supports.

5.2 Recommendations

The Working group acknowledges from its learning over the past eighteen months that dedicated, coordinated project management at national/regional level is essential to ensure the safe and effective implementation of the Framework, due to the sizable cultural shift for all involved. This is evident from international research, discussion with those researchers and children's disability network teams striving to work towards this outcomes focused model (see Appendix 5 Focus Group Notes). Without dedicated project management, risks include existing practices being undermined, and further development and implementation of outcome focused performance management in Disability Services, as mandated by Value for Money and Policy Review (DOH 2012), being compromised.

The Working Group recommends that the Outcomes for Children and their Families Framework is phased in over three years, commencing Q1 2014 with demonstration sites geographically spread across the fifty-six already reconfigured teams. Project Lead(s) at national or regional level will require the necessary authority and mandate from the Social Care Division to lead on and implement the change programme.

The Project Manager(s)' role (appendix 2) requires:

- a full understanding of the Outcomes for Children and their Families Framework and its component elements
- expertise in change management at senior level
- ability to foster on-going cultural change
- continuous consultation with service providers and service users, communicating a clear sense of purpose and direction
- ongoing training relevant to service providers, service users and their families
- provision of support to local leaders
- further development of the draft project plan with targets for the key stages of:
 - Initiation
 - Planning
 - Implementation
 - Mainstreaming
- identification of IT requirements to facilitate national reporting
- initiation and co-ordination of reporting and monitoring systems
- ensure the collection, provision and reporting of relevant data and information
- review and evaluation of systems until they become mainstream
- collaboration with the DOH/NDA on development of Outcome Measurement Tools Suite

Further recommendations, developed from research, the online survey with service users, families, staff and focus groups with children's disability network teams include:

- **Standardised training and development** in team based outcome measurement for early intervention and school age teams
- **Standardised 'communication kit'** for staff to assist with coaching, hearing and empowering parents from day one
- **One standardised template** with local flexibility merging the Outcomes for Children and their Families Framework, service user/family goals and interdisciplinary strategies to support goal achievement

- **Support for demonstration sites** to include ongoing evaluation, parental and staff experience, acknowledging geographical and resource variances between teams
- **Stronger link between Children’s Disability Network Teams and the National Social Care Division** to ensure ongoing clarity and awareness at the frontline of the national context, including the outcome focused drivers mandated in *Value for Money and Policy Review* (DOH 2012), *Future Health – A Strategic Framework for Reform of the Health Service 2012-2015* (DOH 2012) and the *National Service and Operation Plans*
- **Information management system** to support team based performance management and the gathering, collation and analysis of data, and aggregation upwards of KPI returns for this and all Disability Information requirements
- **Feedback, support and direction from the National Social Care Division** on KPI returns and outcomes focused, team based, performance management for Children’s Disability Teams.

5.3 Conclusion

The National Coordinating Group for “Progressing Disability Services for Children and Young People” was mandated by the DOH to develop a draft Outcomes Focused Performance Management and Accountability Framework. The Working Group, established in January 2012 planned to complete the draft in six months but early in the project, it was clear that whilst there is extensive research on the topic, particularly in the New World, Canada and the U.S. and many academic resources dedicated to this work, a complete model including standardised measurement has not been developed yet anywhere in the world. During consultation on the first draft, national and international researchers commended the Working Group on the draft Framework and advised strongly to move ahead with implementation of its final draft presented in this report. The Working Group is cognisant that as national and international progress is made, along with local experience of implementing the Framework, the Framework will require revision in line with best practice. In conjunction with this is the work commenced by the National Disability Authority and mandated by the DOH on the development of a draft framework for outcome measurement of HSE funded Disability Services which will also influence future development of the Outcomes for Children and their Families Framework.

This report contains the Working Group's proposed Outcomes for Children and their Families Framework, based on literature review and consultation with children, young people and their families, former service users and staff. It has identified the challenges of implementing this model of working across Children's Disability Network Teams and a number of recommendations essential for a safe and effective transition to this model of working which included dedicated national/regional project management. It has prepared a draft Project Management Role (Appendix 2) and a draft Implementation Plan (Appendix 3) to guide the work of the Project Manager(s).

Finally, the Working Group acknowledges the steep learning curve for its members during eighteen months developing the Framework, which has led to our understanding of the deep cultural shift required of individuals and (often multi-agency) teams to implement it. We are committed to the foundation this Framework provides for the introduction of outcome focused performance management in Children's Disability Network Teams and will provide what assistance, advice and support possible to the Project Manager(s) tasked with its implementation and review.

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Appendix 1

Relevant Conventions, Legislation, National Policies and Guidelines

The Outcomes for Children and their Families Framework has been developed in the context of the following:

- UN Convention on the Rights of Persons with Disabilities
- UN Convention on the Rights of the Child
- National Disability Strategy 2005
- Education for Persons with Special Education Needs (EPSEN) Act 2004
- Disability Act 2005
- *Health Strategy – Quality and Fairness A Health System for You. Department of Health and Children (2001)*
- *National Children’s Strategy – Our Children Their Lives. Department of Health and Children (2000)*
- *The Agenda for Children’s Services: A Policy Handbook. Office for the Minister for Children. Department of Health and Children (2007)*
- *Children First: National Guidelines for the Protection and Welfare of Children. Department of Children and Youth Affairs (2011)*
- *Síolta, The National Quality Framework for Early Childhood Education*

Appendix 2

Project Management for Implementation of Outcomes Focused Performance Management and Accountability Framework

The Standards and Performance Reporting Working Group of “Progressing Disability Services for Children and Young People” recommends dedicated national/regional project management to lead on the implementation of the Outcomes Focused Performance Management and Accountability Framework for Children’s Disability Teams (See Recommendations pages 36-39 and draft Implementation Plan Appendix 4.

The introduction of an Outcomes Focused Performance Management and Accountability Framework for children’s disability teams, a first for Disability Services in this country, will encompass a far reaching change, much deeper than only putting a new reporting and accountability system into operation.

- What do we want for children with disabilities?
- What do we want for children?
- Why is it frequently assumed these two questions have different answers?

‘Above all people have a deep rooted desire to belong, to be in relationship, to live within the intimacy and security of their family and friends, to be included in the greater life around them with all its attendant possibilities for hope and fulfilment and to do so, to the greatest extent possible, on their own terms.’(National Federation of Voluntary Bodies 2009)

An outcome is a benefit experienced by a child, family or the wider community as a result of services and supports provided

The outcomes focused performance management and reporting system is based on universal outcomes, setting the role of disability services within the assumption that children with disabilities should live their lives as all children do in the real world. Full participation, belonging, relationship, inclusion and self-determination for people with disabilities is the end in mind. This should be the purpose underpinning all service activities from the beginning of service involvement with families and their children.

This means we need a steady move in services away from a role of providing a menu of professional inputs to one of complementing, assisting and strengthening families and others in their primary role. Change is often daunting and even painful, and mindset and service cultures do not change overnight, but it can also be an opportunity to shift long accepted thought patterns.

Professional staff and families need to be engaged, so as to enable them to feel they are valued stakeholders in the process. Without serious reflection and planning it is likely that the proposed changes will be aspirational, resulting in frustration and anger from both service professionals and families as a lost opportunity.

Now is an opportunity to reframe and realign all services with a shared and common vision, inspiring creative and respectful ways of providing services and supports towards the fullest possible participation and inclusion in community life and appreciating the fundamental need to experience a sense of belonging and relationship.

The National Project Manager role is critical to the full realisation of the project, by bringing the responsibility and authority to drive the implementation of this new national reporting system in the context of the major cultural and operational changes required.

This Outcomes for Children and their Families Framework for Children's Disability teams, commissioned by the DOH in January 2012 has its roots firmly based in the current disability legislation, Value for Money and Policy Review (DOH 2012) and Future Health – A Strategic Framework for Reform of the Health Service 2012-2015 (DOH 2012), and its full implementation now requires a Senior Project Manager with an explicit mandate. The experience of the national group in this programme is that having a dedicated resource person with responsibility and authority to drive the project forward is a key reason for its success to date.

The Project Manager role requires:

- a full understanding of the Outcomes for Children and their Families Framework and its component elements
- expertise in change management at senior level
- ability to foster on-going cultural change
- continuous consultation with service providers and service users, communicating a clear sense of purpose and direction
- ongoing training relevant to service providers, service users and their families

- provision of support to local leaders
- further development of the draft project plan with targets for the key stages of:
 - Initiation
 - Planning
 - Implementation
 - Mainstreaming
- identification of IT requirements to facilitate national reporting
- initiation and co-ordination of reporting and monitoring systems
- ensure the collection, provision and reporting of relevant data and information
- review and evaluation of systems until they become mainstream

Appendix 3

Draft Implementation Plan of Outcomes Focused Performance Management and Accountability Framework for Children's Disability Network Teams

Abbreviations

NDGG = National Disability Governance Group

PM = Project Manager

CPCP = HSE Corporate Planning and Corporate Performance

SPRG= Standards and Performance Reporting Group

Phase 1: Initiation

Action	Who	Start	Finish
1. Approval for project and project mandate signed off by HSE NDGG	HSE NDGG	2013	
2. Establish Governance Structures for the project			
3. Assign project manager with relevant competencies and autonomy	HSE NDGG	Q3 2013	
4. Resources and supports identified for admin support, NDU office space and other implementation resources	HSE NDGG	Q3 2013	
5. Full induction of Project Manager into role and clarify roles, responsibilities and thorough briefing for rationale and vision for the Outcomes for Children and their Families Framework	HSE NDGG/ Progressing Disability Services for Children & Young People National Co-Ordinator/SPRG	Q4 2013	

6. Conduct in depth analysis of culture, philosophy and ethos of relevant stakeholders organisations and compare with Outcomes Accountability project vision, to assist with determining level of change			
7. Project manager to develop need, purpose and vision for change and identify champions at national, regional and local level	PM		Q4 2013
8. Health Areas identify named manager with responsibility and authority for co-ordinating implementation	PM		Q4 2013
9. Gain project commitment through embedding the project vision with Progressing Disability Services for Children & Young People programme and other relevant national policies	PM		Q1 2014
10. Establish timelines for major project milestones Confirm timing estimates with relevant stakeholders for major project milestones	PM		Q1 2014
11. Identify all key stakeholders through stakeholder analysis including service users and their families, health service providers and the education sector	PM		Q1 2014
12. Identify critical success factors in line with analysis	PM		Q1 2014
13. Identify readiness and capacity to change for all key stakeholders	PM		Q1 2014
14. Develop risk register	PM		Q1 2014
15. Develop agreed national KPIs for implementation of the Outcomes for Children and their Families Framework	PM		Q1 2014
16. Identify stages of phased implementation for each team based on their state of readiness with local leads as areas form Network teams	PM		Q1 2014
17. Design pre- and post evaluation with all key stakeholders	PM		Q1 2014
18. Agree arrangements with relevant stakeholders for monitoring / reporting	PM		Q2 2014

mechanism for the project				
19. Communication Plan for all stakeholders prepared in conjunction with HSE Communications to assist with embedding project vision with Progressing Disability Services for Children & Young People programme and other relevant national policies	PM		Q2 2014	
20. Establish governance arrangements with local managers who will take lead responsibility in local implementation	PM		Q2 2014	
Phase 2 Planning and Negotiation				
Action	Who	Start	Finish	
1. Dissemination of information about project and phased implementation process to all stakeholders	PM/ Local Leads	Q1 2014		
2. Detailed specification of the following elements: <ul style="list-style-type: none"> • Detailed timelines • Cost • Quality Outcomes • Risk • HR – Detailed roles and responsibilities of all project players • Procurement • Integration 	PM	Q1 2014		
3. Design the detail of the reporting system	PM/ Local Leads	Q2 2014		
4. Planning for training of future system with regional and local children's disability governance/management groups; clarification of roles and responsibilities	PM/ Local Leads	Q2 2014		
5. Develop an IT Spec for Outcomes Reporting system		Q2 2014		
6. Specify training and support requirements for staff on cultural change to an outcomes based service as well as procedural		Q2 2014		

7. Plan communications strategy of changes for service users and families to include: <ul style="list-style-type: none"> • accessible language • empowerment of service users and families 		Q2 2014	
8. Plans for migration from one system to another	PM/ Local Leads	Q2 2014	
9. Plans for testing the system and the procedures		Q2 2014	
10. Plan demonstration sites and implementation		Q2 2014	

Phase 3 Implementation

Action	Who	Start	Finish
1. Implement demonstration sites in chosen areas and review		Q2 2014	Q3 2014
2. Develop processes and procedures for the operationalisation of the new Outcomes for Children and their Families Framework based on demonstration sites		Q4 2014	
3. Develop national guidelines in conjunction with key stakeholders* informed by experience from demonstration sites	PM	Q2 2014	Q4 2014
4. Organise meetings in areas as they adopt the system with service providers, staff and service users and families at local level to inform, engage and guide them in changes, with support from national level	PM/ Local Leads	Q2 2014	
5. Roll out communication sessions for staff on vision, rationale, ethos	PM/ Local Leads	Q2 2014	
6. Address ongoing communication needs as appropriate in line with communications strategy	PM/ Local Leads	Q2 2014	
7. Implement Reporting system including IT system nationally	PM/ Local Leads	Q2 2014	

Phase 4 Mainstreaming

Action	Who	Start	Finish
1. Continue to provide support to staff and service users through period of transition	PM/ Local Leads	2014	
2. Acknowledge successes and achievements and areas for improvement in terms of KPIs on regular basis	PM/ Local Leads	2015	
3. Support integration of change through evaluation of progress in achieving project milestones at all levels and with all key stakeholders including service users	NDGG & CPCP	2015/2016	
4. Evaluate the efficacy of new business processes (for example service planning and review, reinforce and support the embedded changed reporting system)	PM/CPCP	2015/2016	
5. Develop system for continuously monitoring developments and improvements at organisational and service level in line with best practice	NDGG & CPCP	2015/2016	
6. Monitor developments monthly (or as appropriate) in each Health Area for consistency with the Outcomes for Children and their Families Framework and troubleshoot where necessary in line with shared project learning	Regional Leads/ Specialists		
7. Evaluate Outcome Reports for consistency and quality and review/amend system accordingly	PM/NDGG	2015/2016	
8. Close project and amend the role and responsibilities of project managers at local and national level as appropriate	PM/NDGG	2016	
9. Sign off on change project as completed with KPIs and milestones achieved	PM/NDGG	2016	

Appendix 4

Notes collated and themed from three focus groups with staff from early intervention and school age teams

1. How to implement the Outcomes for Children and their Families Framework into existing multidisciplinary structures processes and services?

Measurement of outcomes

- Starting with the 11 outcome statements, identify goals with the child and their family and prioritize those goals with the family. Work backwards from there to individual therapy goals. These goals must be realistic. Review with family which goals were met, which were not and why. Some C&F goals identified could address several outcome statements
- MPOC annually? Can be used to drive team performance
- Random sample or all children? – all children as it is about improving processes and not about research. Parents completing the MPOC every year will get used to it and learn its value. All opinions count.
- Fit G.A.S. into Outcomes for Children and their Families Framework outcomes. Justify in IDP why certain goals were prioritized to meet child and family needs and document
- Need to marry uni-disciplinary and interdisciplinary goals into the 11 outcome statements. Parents informed on the goals and big picture. It grounds them. Start with the end in mind
- Link outcome measures to skills needed in the real world

IFSP/Annual Review

- Use our Annual Review which covers areas in the Framework and a lot more
- Need to go the IDP route because parents don't connect independent mobility or achieving the 's' sound goal to what they want
- Via the Individual Child and Family Service Plan- however, it doesn't measure how far the team has achieved the goals.
- Need to factor in IFSP for all children with outcomes into this national outcome set
- Must move away from the "IDP process" to the IDP as a concept, a live document constantly evolving on dialogue with parents as more information on the child and their needs comes in, what their key priorities are, what will get them most bang

for their buck. Ongoing intervention/evaluation so information going into IDP must be constantly evolving as more information, preferences/changes become known

- Regular review to see progress with the child and family
 - What helped you?
 - What benefits did you enjoy as a result of.....?
- Must be qualitative to problem solve, helps to continuously question why we are doing certain things and to prioritize e.g. if we do a) he will ... but if we do b) now, he may achieve more outcomes which are a priority for him (not necessarily for us). Help to move away from focus on 'more therapy'. Helps parents and teams to recognize and celebrate their achievements
- Outcome based approach: ask the right questions to identify what is important for the child and his family vs. therapist forcing the goal or what therapy does the child need?

Parent Involvement and understanding

- Language with parents is crucial to ensure their ownership and involvement in the design of their child's programme (pending resources) to whatever level they can/want to be involved
- Parent workshops to explain the rationale, MPOC, how to complete and its value
- Parent difficulty understanding all the information coming out to them
- Need to consider language, voluntary induction meetings with parents after intake meeting both for EI and SA
- Look at why parents are not responding accurately to information requests e.g. NIDD even when clear explanations are given
- Finite resources We should be frank with parents from beginning – they will get an average amount of therapy input/year, inform parents on different roles of team members/what we do and based on their child's needs, help them prioritize rather than prioritizing for them how they will use their hours with us to get the best bang for their buck
- Shared folder for parent, teacher and therapist to facilitate information sharing

Key worker

Nominate a Key Worker who represents each child and their family at the table. Key worker essential in building relationship with the child and family and will know their desired outcomes. Lot more going on in many families than therapy, which impacts on their ability to participate and follow programmes etc. Currently, Key worker contacts family before case review to update the plan. We are changing our process to more robust structures for family involvement in the meeting.

External influences on outcomes

- Other external influences impacting on level of outcome achievements which requires team strategising on best approach to meet family's needs.
- Some situations, on review, where there was a lot of team intervention but family did not achieve their outcomes, due to myriad of factors external to team influence. We need to focus for example on 'how we kept that family safe'

Team working

- Co-location crucial to facilitate cross organisational cultural merge to focus on Child and family outcomes, this is not normal practice for HSE staff.
- Facilitates informal as well as formal communication and relationship building

Operational issues

- EIT and SAT must work together to standardize assessment forms and help prepare family gradually for transition to SAT. Could this be standardized across the country?
- Need to build the Framework into your information management systems. Align existing IT systems to support this
- Ensure no duplication between these questions and those of NIDD
- How can this process be streamlined? Time consuming – lot of service development, parent meetings etc going on
- Replace current information demands (HealthStats, KPIs) in order to gather these measurements

Draft Framework suggested to marry Outcomes for Children and their Families Framework with Team Strategies and Goals

Outcome Statements	Goals relating to outcome statements	Process Indicators	Outcome Indicators	Goals agreed with and prioritized by John and his family....	Team Strategies to enable John and family achieve their goals
1. Children and young people have a voice...					
2. Children and young people have the best possible health ...					
3. Children and young people are safe					
4. Etc					
5. Etc					
6. Etc					
1. Families ...					
2. Families ...					
3. Etc					
4. Etc					
5. Etc					

2. What are the challenges for a team implementing the Outcomes for Children and their Families framework?

Changing the way we work

- Move from unidisciplinary goal setting to interdisciplinary which this Framework will help
- How to integrate individual discipline specific goals with family goals – this (Framework) will be a driver. We need to move to that way of working anyway
- Challenge for services to change how we work: from taking children with needs out of real world to specialist services to focusing on what we can do to enable children to be truly part of their community
- Decrease emphasis on diagnosis and discipline
- Increase emphasis on skill sets needed for most benefit for families
- Harness supports outside of therapy i.e. Granny, community

Involving family in process

- How to instil sense of ownership in parents of process, planning from day one/initial interview that this is how you will evaluate our services

- Working with the child's siblings for holistic approach to support them in understanding and in supporting their brother/sister
- Get parents feedback regularly on how their child is doing as a result of services e.g. in EIT, they tell us how they fear moving to school age where supports may not be the same but the goals may be
- Transition phases – planning with parents must be outcome focused.

Measuring goals

- Family perception vs. team perception on achievement of outcome
- Goals have to be realistic
- How to build in evidence based practice – address areas where team is not achieving due to external factors with system e.g. for autism, EBP shows intensive early intervention but resources not there to provide this
- MPOC – consider:
 - literacy level
 - rural settings, challenge to meet parents to complete
 - method of delivering to parents e.g. email, drop box, social media
- MPOC measuring general, not specific
- Role of SNA and Resource Teacher

Resource issues and additional work

- Responsibility to measure outcomes for the child and family from EIT through school, particularly where SAT staff resources may be less
- Posts shared over EIT/SAT and Primary Care
- D.O.E.S. need for diagnosis for supports
- Form filling – bureaucratic
- Actually recording what parents prioritized
- Recording goals
- Moving from individual (discipline specific) to team based goals
- Appropriate time for 'assessment for measurement' which is a point in time whilst in practice, assessment and intervention are ongoing and interchangeable, pulling information for IDP out as needed

3. What supports will a team require to implement the Outcomes for Children and their Families Framework?

Guidelines

- Provide national guidelines for teams on how to implement and measure – piggyback on teams experienced in measuring outcomes

- Need national template with local flexibility, main headings aligned with outcome statements
- Context setting for introduction of outcome measurement, including bigger picture

Training

- Training manual for staff on preparing parents and national parent briefing leaflet
- Training for staff on:
 - Actual form
 - Communication with parents
 - National context for this work
 - Coaching parents
 - Empowering parents
 - Hearing parents
 - Goal setting

Implementation and Demonstration sites

- Support for demonstration sites
 - Evaluate thoroughly throughout the demo
 - Parents to experience
 - See what works, disregard what doesn't
 - Be aware of differences between Dublin and Ennis etc
- Time needed to morph gradually
- Clear markers and milestones

Operational suggestions

- External lead for MPOC administration for anonymity – consider neighbouring team - opportunity to share learning
- Co-ordinator across all teams in the region
- Software to support collection, collation and aggregation
- DOH direction and support to move from duplicating paper and electronic base to solo electronic files (electronic signature current block)
- Move Home Tuition funding to therapists who will support children to participate in school – flexibility to support the 11 outcome statements

Appendix 5

Glossary of Terms

Key worker

Excerpt from Reference Group Report:

The Reference Group considered the different current interpretations of key working:

1. A named professional from among the child's team who oversees the coordination of a child's care, provides a single point of contact for the family and organises reviews.

2. A lead professional in a transdisciplinary team who in addition to the above role delivers much of the child's programme under guidance and advice from the other professionals involved.

3. A post of key worker with this specific assigned role within a team, to coordinate each child's care on their caseload, act as advocate and provide emotional and practical support to the family. International experience has shown that this specific role is very effective for children with very complex needs and their families and is less costly than the named professional option as it is a more efficient use of expertise.¹⁰

4. An independent service as is developing in the UK, which employs key workers to work with two or more agencies co-ordinating the delivery of multi-agency services and improving access to services and information for parent/carers.

The Group concluded that in line with international experience the preferred option for children with exceptionally complex needs and their families is the third option above - a key worker post within the network team with the sole role of co-ordinating services and providing support for this minority of children who require this service and their families.

This role is essential when a child is receiving intervention from a number of agencies including the sub-specialist services, and would increase the efficiency of the team by ensuring that clinical/therapy time is focused to the maximum benefit of the child.

Consideration may be given to amalgamating this role with that of Liaison Officer/Case Manager. For other children and families, whose needs are less complex, a social worker or a therapist could take on the function of key worker as appropriate. Not all families need or want a key worker but it should be an option.

Team

Excerpt from Report of Reference Group:

An interdisciplinary team is a number of professionals from different disciplines who work with the child and family, sharing information, decision-making and goal-setting. They have common procedures and policies and frequent opportunities for communication.

They work collaboratively to meet the identified needs of the child with a joint service plan, and see the child separately or together as appropriate.

Children's Disability Network Teams

Excerpt from Draft National Access Criteria Policy:

Disability Network Teams will be established within defined geographic areas i.e. Health and Social Care Networks. They will be formed to address the needs of children with a wide range of disabilities including but not limited to, intellectual disability, physical disability, sensory disability and autism. The team members should work within an interdisciplinary team model, contributing to a joint integrated plan for each child, young person & family. The family will always be seen as part of the network disability team.

Specialist team/service

Excerpt from Draft National Access Criteria Policy:

Children's Specialist Disability Services may operate at Health Area, national and/or regional service level and will provide the specialised expertise that some children, young people and their families require.

- *The role of Children's Specialist Disability Services is to provide support to the Children's Disability Network Teams and Primary Care Teams, who will remain the main service provider for the child with disability and their family.*
- *Specialist services may involve addressing physical, social, emotional, communication and behavioural needs which in many cases require linkages with ISA/Regional and/or national medical specialties.*
- *Individual plans will be required for children who require access to Specialist Disability Services.*
- *It should be clearly demonstrable that these needs can not be met solely within a uni-disciplinary basis or multidisciplinary framework of a primary care team or solely by a Network level team.*