Children & Young People's

Emotional Wellbeing, Autism & ADHD Services Framework

1.0. Introduction and Operational Context.

This paper sets the framework for the reform of services for children and young people who require support for emotional, behavioural, and mental health needs, autism and Attention Deficit Hyperactivity Disorder (ADHD) in Northern Ireland. The framework has been informed following a range of discussions with children, young people, their families and the professionals who work with them. The framework has been developed to reflect best practice models and guidance drawn from international, national and local literature. (See reference section).

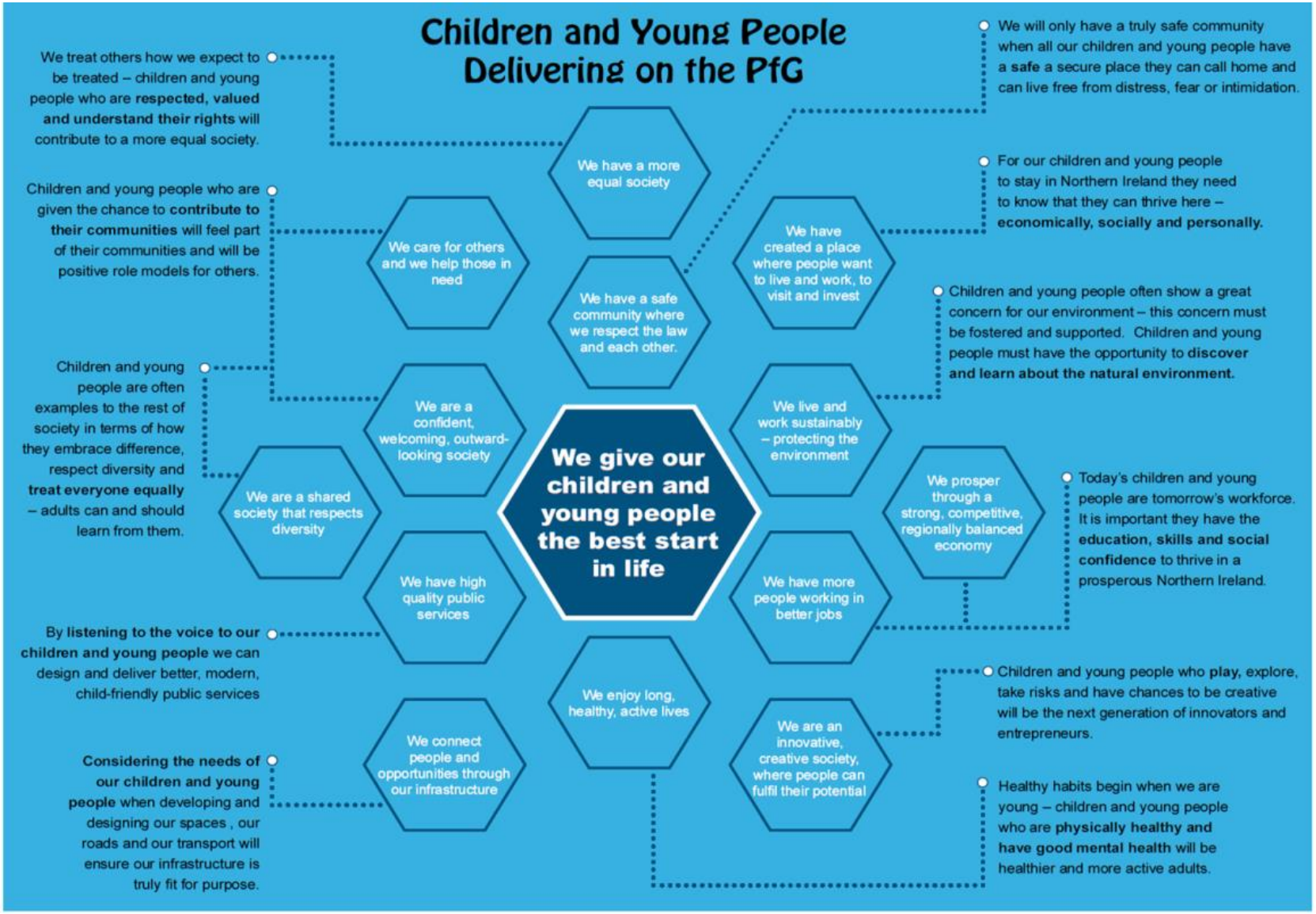
Although this framework aims to strengthen the integration of CAMHS, ADHD and ASD services in the first instance, it also seeks to strengthen greater partnership and better integrated working across universal and early intervention services. This is to recognise the vital importance of effective prevention for developmental and emotional difficulties arising in childhood and the provision of evidence based timely support.

There are many strategies and policies which have an influence on this framework, and they are highlighted in appendix 1. Below are some of the key principles from those which have particular relevance in the effective development and implementation of the framework. Underpinning this framework is the need to determine, develop and embed an Outcomes Based Accountability approach, which captures " How much did we do?", "How well did we do it?" and most importantly "Is anyone better off?"

1. **The Programme for Government**. The Programme for Government 2016 – 2021, NIE, in keeping with the *UN Convention on the Rights of Persons with Disabilities* and the *UN convention of the rights of the child*, (see figure 2) aims to address inequalities, improve life experience and improve mental health and emotional wellbeing. One of the key objectives of the Programme for Government is to create the condition for children and young people to succeed in life, and seeks to achieve this by creating integrated working across the key departments for health, education, the economy and communities and it seeks to achieve this using Outcomes Based Accountability methodology . The recent Children's Services Co-operation Act

(2015) sets out a clear expectation that organisations should work together to deliver the parameters of wellbeing as set out in the Children and Young People's Strategy, 2017 – 2027, DoE NI, and outcomes which are broader than what is delivered solely by Health and Social Care. This requires an integrated framework to improve the well-being of children and young people.

Figure 2



1.2 Health and Wellbeing 2026: Delivering Together outlines the need for services to be reconfigured to deliver better health and wellbeing outcomes by:-

- Co-designing services with those who require support
- Developing new ways of delivering "person centred" care, by working across primary, community care and specialist services.
- Redesigning services through the development of new integrated care pathways, working across traditional organisational boundaries.
- Utilising innovative technologies
- Improving outcomes by providing earlier intervention and support

1.3 The Strategy for Paediatric Healthcare Services Provided in Hospitals and in the Community (2016 - 2026), DoH recommends the delivery of services which meet the physical, emotional, social, educational and psychological needs of children and young people. This includes providing information and community support in ways which promote self-management and maximise independence.

1.4 Department of Education policy needs to be referenced

1.5 Graduating for Success April 2012 and Access to Success; an Integrated Regional Strategy for Widening Participation in Higher Education, September 2012 sets out a commitment to create the necessary conditions for young people to contribute to the development of a modern, sustainable knowledge-based economy. These strategies are designed to enable young people, to gain access to right form of higher education irrespective of their personal or social background.

1.6 Operational Context. The development of Autism services in Northern Ireland has been influenced by a number of key factors as outlined in figure 3, below. In developing the framework these factors and have been summarised as follows:-

Figure 3

1.6.1 National Institute of Clinical Evidence (NICE) Guidelines sets out the clinical standards for the assessment and management of autism for children and young people. Although all Health and Social Care Trusts have endorsed these guidelines, there is variation in interpretation and application of the processes outlined and consequential variance between Trusts. Additionally there is variance in the diagnostic rates regionally and a more standardised diagnostic process is required to ensure equitable diagnostic thresholds.. As part of the new framework variation will be minimised through the regional agreement of a autism diagnostic process, supported by robust clinical audit to ensure consistency of diagnostic outcomes across all five Trusts.

1.6.2: Autism Six Step Pathway. The Autism Six Step Model was developed in partnership with parents and the community and voluntary sector aimed to develop a standardised approach for paediatric autism services and to promote integrated working with CAMHS. While elements have been implemented within Autism specific services, the differing service models across Trusts have resulted in variable experience by children, young people and their families.

1.6.3: CAMHS Stepped Care Model framework. This stepped care framework aimed to standardise the provision of CAMHS across all Trusts and while this has substantially been achieved, the integration of specialist Autism and ADHD services is yet to be fully and consistently realised.

1.6.4: Autism Strategy and Action Plan 2013 – 2020, is led by the Department of Health, but has a cross departmental implementation requirement Progress has been made on many aspects of the strategy, but organisational and traditional boundaries often limit the opportunity for pooling resources and delivering an integrated and streamlined service The Children's Cooperation Act 2015.

1.6.5: Rising demand for Autism Services. The number of children and young people being referred for an autism assessment has steadily risen from approximately 1,500 in 2012 to 3,000 referrals in 2016. There are several factors impacting on this increase including increased awareness of autism, changes in diagnostic parameters and shifts in demand from one service area to another. In recognition of the growing demand for specialist Autism services and the consequential unacceptable waiting times for support, an additional £2 million was allocated across the Trusts in 2016, to increase assessment capacity and to promote the development of an early intervention approach.

1.6.6: Children, Young People and Parent Experiences The recent Sense Maker Survey conducted as part of the 10,000 Voices initiative sought to gather the views of children young people, their families and professionals who had recent involvement with either paediatric Autism or CAMH Services. The completed report can be found on http://www.publichealth.hscni.net/publications/10000-voices-regional-report-experience-paediatric-autism-and-camhs-project.

The key themes which emerged from the review included:

- The variance between demand, capacity, skill mix, waiting times and access to services
- The importance of personalisation of support, focusing on hope for the future
- Extending the availability of support, and providing signposting to other services and agencies.
- Maximising the use of resources across agencies – and balancing between diagnostic process and support and intervention
- Collaborating with other agencies and departments - Department of Education, Further Education, communities and local councils to join up services and make best use of resources.

It was evident in the feedback, as outlined in figure 4, that families often experience difficulties navigating their way across paediatric, child development, behavioural, Child and Adolescent Mental Health Services (CAMHS), autism and ADHD services. Children are frequently on more than one waiting list for services and as a result the support they receive is disjointed and not as effective as it could be. It is acknowledged that there is inconsistency and variation across all five Trusts in implementing the guidelines and plans. This framework provides an opportunity to address inequity and improve regional consistency.

Figure 4

2.0. The Review Approach

The review of Autism Services was in response to the growing demand for autism assessments, and subsequent intervention and support, and the significant variation in service delivery across Northern Ireland:-

Phase 1 - To undertake a fundamental review of Autism service and practice models including scoping out referral demand, prevalence rates and the operating models and pathways across all five Health & Social Care Trusts in Northern Ireland.

Phase 2 - Undertake a review of children, young people and parental experiences of autism services. (Sense Maker Survey 10,000 Voices Initiative)

Phase 3 - Develop ***a*** regional standard operating model for the assessment, diagnosis and on-going support for children, young people and their families based on the best available evidence.

The findings from phases 1 and 2 have been used to inform the third phase which is reflected in the framework proposed in this document. A series of workshops were held to share service models and agree on a regional assessment process for autism. This is to be set within a new framework, which aims to fundamentally change the current pathway for CAMHS, Autism and ADHD services through the integration of all these services into a single system of care.

Section 3 – Purpose and Values Underpinning the Design of the New Framework

3. **Purpose: -** The key aim of this framework is to ensure children and young people who have autism, ADHD, behavioural emotional and/or mental health needs will have their individual needs identified and assessed; that support and interventions will be effectively coordinated by appropriate agencies and services, and delivered consistently across the region. The overarching objective is to support each child and young person with behavioural emotional and/or mental health needs and autism and ADHD to realise their full potential

3.1. **Design Values** There are four design values at the core of the framework

1. Co-produced with children, young people and their families to create a flexible, person-centre, timely service, which is responsive to presenting need.

2. An integrated approach which wraps support around the child/young person and their respective family and making the best use of all available resources from across Departments.

3. Informed by evidence based and characterised by a system which promotes wellbeing through early support and intervention.

4. Outcome Based Accountability approach in line with cross departmental Programme for Government population outcome Indicators.

3.2. **What the new framework will mean for Children, Young People and Families?** (See figure 6).

Figure 6

The development of the new framework anticipates a number of key benefits as follows:-

3.2.1 A single centre in each Trust which processes all referrals for all children with social, emotional and mental health issues, including ASD and ADHD.

3.2.2 A range of professionals and agencies will be involved in determining the most appropriate services and professionals to be involved, based on the information provided at referral. This will provide a holistic approach to service delivery.

3.2.3 The active participation of children, young people, and their families in the formulation of their own needs.

3.2.4 Each child or young person following consultation will have a key worker, who will co-ordinate care, support and transition

3.2.5 Provide each child, young person and family with an initial consultation appointment within 6 weeks of referral. This consultation appointment will provide an opportunity for the child, young person and their families to discuss their respective needs and to make decisions about next steps.

3.2.6 Provide appropriate support and intervention based on assessed need, and not dependant on a confirmed diagnosis.

3.2.7 When a diagnostic outcome is required it will be completed within 26 weeks. If a diagnostic assessment is required, the child, young person and their family will be informed and involved in the process. This will not stop their access to support and intervention services, as required.

All supporting services and agencies should contribute to an integrated action plan, which is co-produced with the child, young person and their family, and has agreed and coordinated aims and desired outcomes. The plan should also include details and arrangements for review and updating of the plan which will depend on the specific needs identified following assessment. The key worker will be responsible for implementation of the agreed review arrangements

Section 4 – What Children, Young People and their Families Want; Evidence of What Works; Expected Outcomes

4. **What children, young people and their families want: -** feedback on the experiences of children, young people and their families who required support from CAMHS and paediatric Autism Services was gathered at three workshops held to review autism services and four workshops were held as part of the 10 000 voices initiative (figure 7). The views of professionals within these services were also captured. Parents of children and young people had the opportunity to share their experiences and be involved with the Trusts, HSCB, PHA and DOH staff to review current systems and commence the process of agreeing a new service model thereby improving experience and reducing regional variance:

4.1 Feedback from the review of autism services highlighted a range of specific issues and problems:

4.1.1 Experiences of disjointed services - both health and social care and education systems

4.1.2 Difficulties experienced at transition stages.

4.1.3 Lack of support for over 18s

4.1.4 Difficulties in getting access to support and intervention during the assessment process.

4.1.5 Variation in the availability of services across Northern Ireland

Figure 7

4.1.6 Families stated they would welcome a central point to access good quality information about services and self-help/community resources

4.1.7 Lack of availability of contact point for outside regular working hours.

4.1.8 A lack of holistic and personalised support in a way which helps young people realise their goals, hopes, and ambitions

4.2 **A summary of the key areas identified for improving experience as reported by parents and young people who completed the 10 000 Voices Survey is summarised in figure 8.** This "whole system" approach builds up the developments which are in place and include 'Families Matter: supporting Families in Northern Ireland – Regional Family and Parenting Strategy March 2009'. This strategy is currently under review.

Key Area For Improving Child Young Person and Family Experience.

1. Improve Information and Communication across services and agencies.
2. Ensure access to similar supports regardless where you live.
3. Create a single point of contact and appoint a dedicated Key Worker to coordinate supports.
4. Design services around supporting the assessed needs of children and their families which a not determined by a confirmed diagnosis's
5. Provide an Integrated Child Young Person Family Support Plan.
6. Create opportunities for parent and peer mentoring services
7. Make better use of technology to improve access to information communication and engagement with services.
8. Enhance collaboration across agencies and departments to enhance education and employment opportunities specially target to children and young people with emotional and mental needs
9. Support should be personalised and flexible.
10. Proactively plan and support young people to transition between services and through key life stages.

Figure 8

4.3 **The feedback received is consistent with current strategic developments across the UK and Ireland which emphasise the need for greater joint working and integration and creating the conditions to address what matters most to children and young people and their families. These themes are summarised in figure 9, as follows:**

- Effective And across life events
- Transitions across life events.
- Education, learning, and employment.
- Community Life.
- Social Inclusion.
- Support for families.

Figure 9

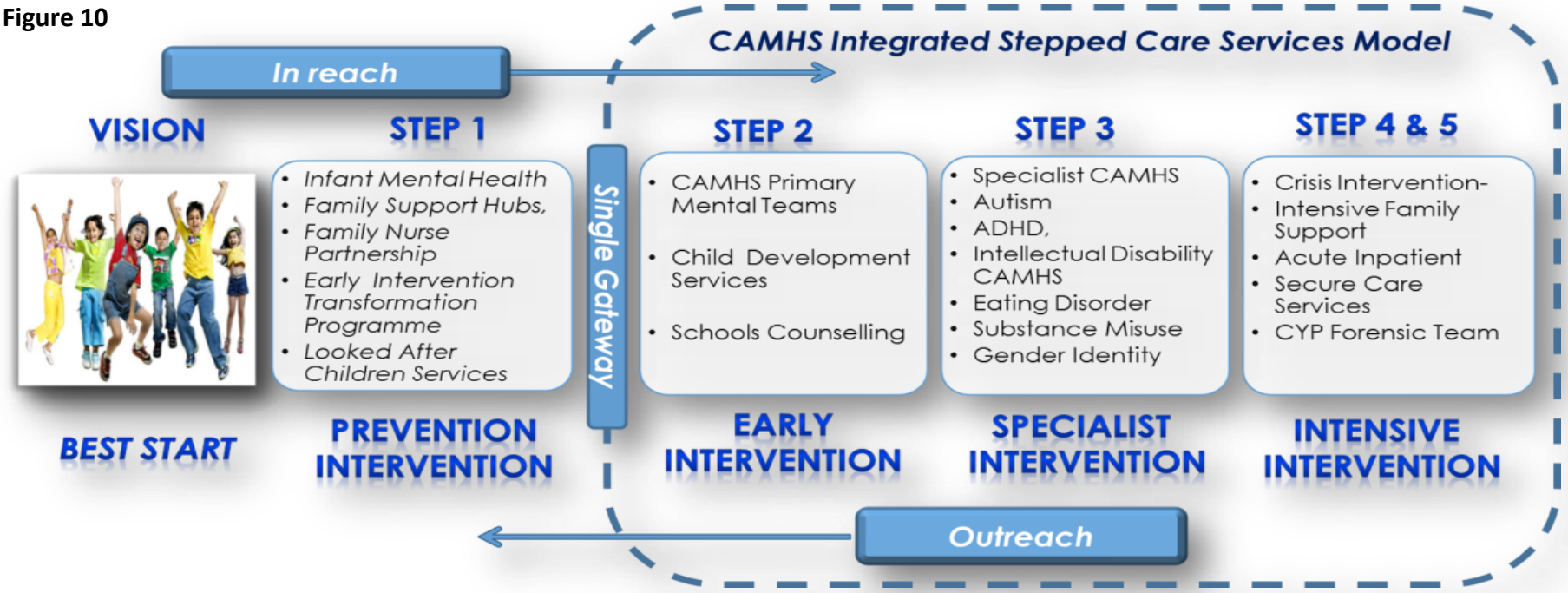
4.4 **Expected Outcomes of New Framework -** The framework recognises that at different stages of life there are different services and agencies which need to be involved. There are known key transition points around which services should be proactive and collaborative in their planning, e.g. commencing school, moving from primary to secondary school and leaving secondary education. The table below outlines outcomes which the model seeks to deliver across the key transitions of pre-school, primary, secondary and post-secondary living. These outcomes are shared across a number of Departments and their agencies.

	Infant 0-4	Childhood 5 -11	Adolescence 12 -16	Young Adulthood 16-25
Children & Young People	Early intervention supports the child in preparing for school and enhances potential to develop in line with expected developmental milestones.	Through the provision of a co-produced personalised plan the child is supported to develop their educational, emotional regulation, social and communication skills. The child is proactively supported to transition to secondary education.	The young person is supported to develop the necessary life skills and is prepared for adolescence. The young person is supported to make choices about their personal goals and in accordance with their needs with is supported through the provision of evidence based or informed programmes, social occupational, and life coaching interventions. Provided with appropriate integrated support for each of the relevant agencies.	The young adult is supported to identify, review and achieve their personal and occupational goals, as they transition to adulthood. Support is provided to strengthening personal independence and to enhance life skills including (social connections, relationship skills, financial management, managing work etc.)
Families	Families and parents provide support to their children and young people at each life stage. Services should be developed, strengthened made easily accessible to support families in this role with a focus on developing their supportive skills and providing additional support at times of need, in collaboration with appropriate agencies as required			
	As a result of parental involvement and family support the parent is better equipped to enhance their child's early learning and development.	Integrated family support is tailored to the needs of the entire family. The family work in partnership with health and education professionals in the development of their child/s personalised plan. Parents and sibling needs are assessed and supported to strengthen the family's resilience.	Parents are offered support through the adolescent period and involved in the commencement of the transition process to manage adolescence, prepare for relationships and to make continuing education or occupational choices.	Support is provided to help maximise personal independence and ensure post transition needs are addressed.
Professionals	Health & Educational Professionals work together with the child and their parents to develop an integrated plan which helps prepare and support the child's transition into primary school.	The Integrated Health & Educational Teams work together to wrap support around the child and family and prepare the child and family to manage the transition from primary to secondary education. The Team should signpost the child and family to a wide range of support networks.	Health & Educational Teams support the young person to choose well and provide tailored intervention which supports the young person's physical psychological and social wellbeing. The team support the development of the young person's personalised life plan and support the young person to make the necessary transitional adjustments. The team signposts, advocates and networks with other agencies to maximise the young person's opportunities including with higher education providers and employers.	Health and social care, Education, employers and communities work together to support self-determination and independent living and provide post-transition support.

Section 5 – The New Framework- Integrating Child Developmental, Emotional and Mental Health Wellbeing Services

5 The views of children, young people and their families, the evidence of what works and the requirements of policy, all support the need for integrated service delivery, both within Health and Social Care, and across appropriate agencies and government departments. There is clear evidence that an earlier intervention and prevention approach supports improved outcomes

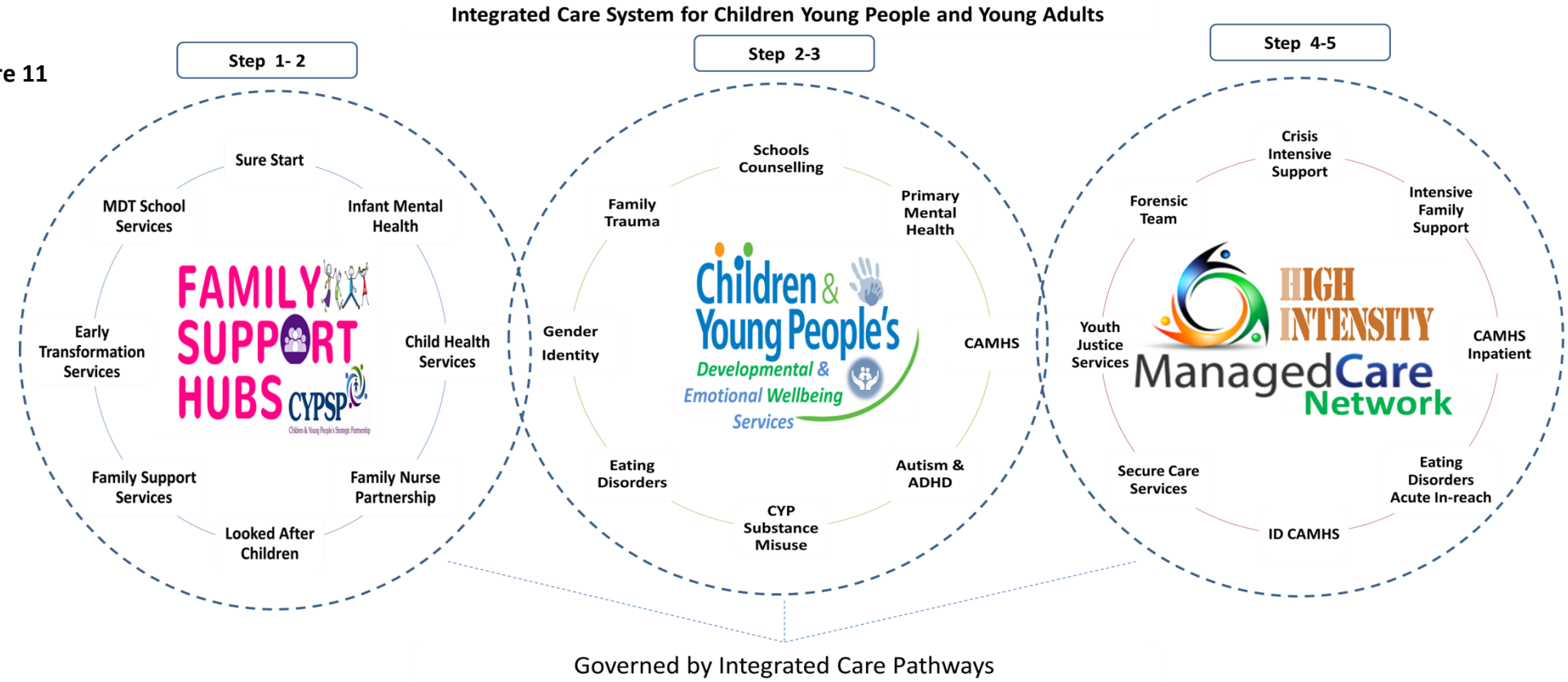
Figure 10



across many life areas. The stepped care framework for CAMHS (2012) outlined in figure 10 assumed the integration and consolidation of CAMHS Services across Northern Ireland. The next stage of implementation of the model is strengthening integration and to simplify the system of support for children young people and their families by embedding ADHD and autism

services with in step 3 of this framework as illustrated in figure 11. The framework proposes consolidating provision around three centres of support recognising that there are important links between early intervention, specialist support and high intensity intervention. The services within each of these three centres should be capable of being delivered simultaneously or as stand-alone services but still within an integrated framework that maintains a flexible service response to needs at any given time. This framework also facilitated the whole systems understanding of population needs, the operational response to that need and the outcomes being achieved which is in line with Health and Wellbeing delivering Together 2026 strategy.

Figure 11



5.1 **Family Support Hubs**: Family Support Hubs are a multi-agency network of statutory, community and voluntary organizations that either provide early intervention services or work with families who need early intervention services. The Hub does not provide services, but receives referrals and uses their knowledge of local service providers and the Family Support Database to signpost families with specific needs to appropriate services. In the context of this framework, the primary objective of these services is to reduce the impact of mental health and emotional problems and prevent escalation to more significant difficulties. Information about Hubs can be found on http://cypsp.org.family-support-hubs/

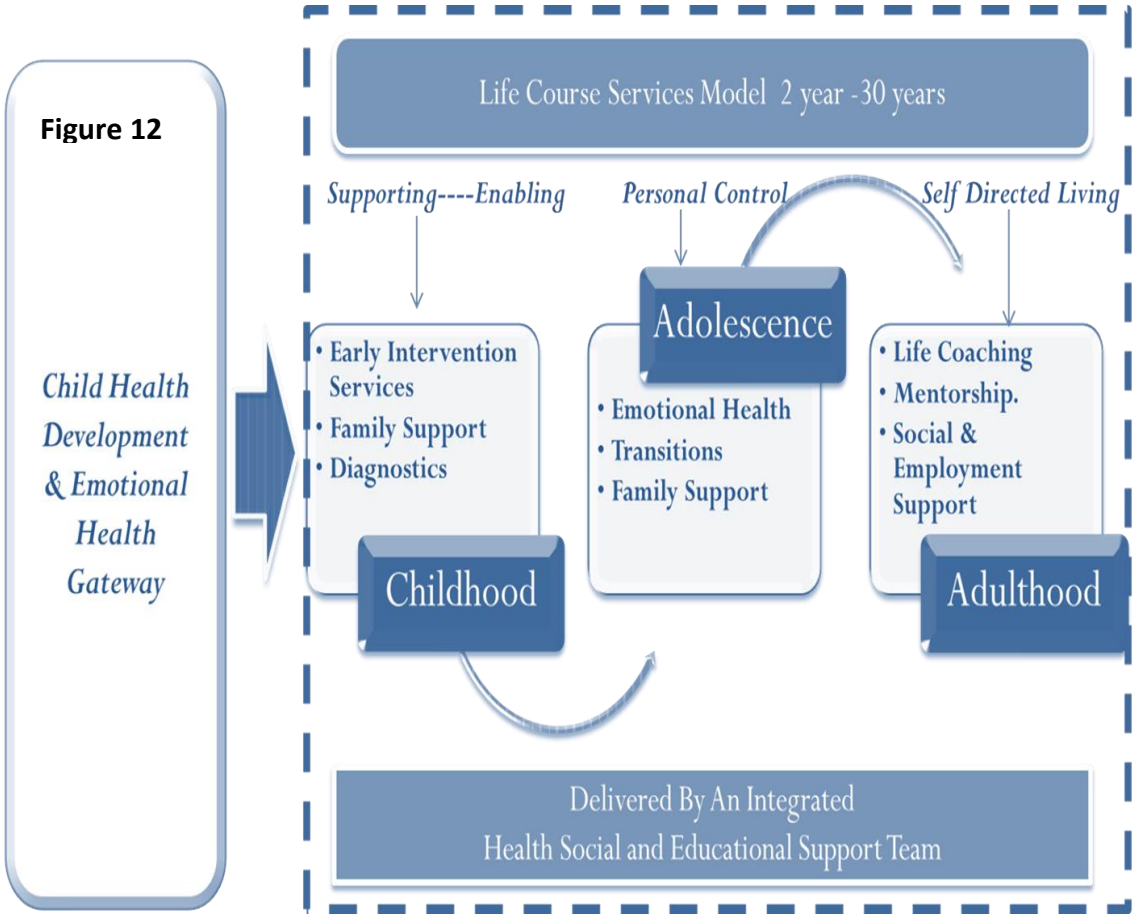
5.2 **Child Young Person Autism and ADHD, Emotional and Mental Health Services.** This involves the provision of specialist diagnostic assessment and the provision of psychological, systemic and/or pharmacological therapy. Intervention is provided to children and young people who are experiencing moderate mental health and emotional difficulties which are having a significant impact on daily psychological /social/ educational functioning. Intervention and support is normally provided through specialised/specific multidisciplinary teams - CAMHS Autism and ADHD services it is the consolidation of these services that main focus of this framework in order to strengthen the model of provision as part of whole integrated systems from early intervention to high intensity provision.

5.3 **High Intensity Child and Young People Managed Care Network:-**The network is designed to consolidate support for children and a young person who's developmental, emotional, social and psychological needs place them at high risk. The network seeks to integrate Secure Care, Youth Justice, Forensic CAMHS and Acute CAMHS (Inpatient and Crisis Services) into a single system of care. In support of this work the Health and Social Care Board in partnership with the Youth Justice Agencies is undertaking a review of the role and function of these services. This review will support practice integration with a view to achieving better outcomes for children and young people who are vulnerable and at risk.

Section 6 – Outline Model; Outline Pathway; System Characteristics

6.1 Support for children and young people who experience, Autism ADHD and/or other mental health needs is often required across the life span, Consequently implementation of any new model crucially needs to take account of the interfaces between young people and adult's service. The reconfiguration of services as proposed by the framework as illustrated by figure 12 aims to bring together services so that young people with continuing care needs are seamlessly supported in adult life. There is already evidence from Looked after Children (LAC) Learning Disability Services and Mental Health (Early Intervention Teams) services which demonstrate the benefits of proactively planning and supporting young people from adolescence into young adulthood. This model seeks to replicate this learning, and by definition will require the realignment of adult services resources to make integrated working a reality

Figure 12



The development of an integrated approach that assimilates autism and ADHD, behavioural emotional and mental health into a single system is an ambitious aim and will require significant leadership and

ownership across Paediatric, Child Developmental Autism ADHD, CAMHS and Educational support services. The model also recognises the need for closer integration of third level education, employment and benefits support services in addressing the needs of young adults. It is within this context the framework has been developed around the following six core principles.

6.2 Core Design Principles

Principle 1: To improve access for children, young people and families and to provide high quality, evidence based care, advice, assessment and intervention: - This means all five H&SC Trusts in line with this regional framework will co-produce a local integrated care pathway which reflects the needs, views and expectations of children and their families.

Principle 2: A system geared towards early intervention: This means that each Health and Social Trusts will provide early tailored intervention, pre and post diagnosis and service models 'geared' towards promoting health & well-being regardless of level of need. This involves utilising best evidence of what works, adopting a 'strengths' based approach which utilises the child and young person's abilities and maximises the capacity of their family, educational and social networks. Early intervention also means developing an anticipatory approach across the lifespan by providing supportive interventions to improve social and emotional outcomes, particularly at critical transitional points of the young person's life, in order to promote resilience and mitigate the risks of developing emotional and mental health difficulties.

Principle 3: **A system which provides child and family centred information**:-This means H&SC Trusts will work with children, young people and parents to develop information in accessible and varied formats, making best and innovative use of technology about services that are available and how to access them including signposting to other supportive services.

Principle 4: A system which integrates and wraps support around families: - Integrated care means that children and their families will be provided with seamless support across Health, Social Education Employment and Community Services who work together for the benefit of children young people and their families. This requires a consistent approach from all the professionals

involved and all support interventions brought together into a single child, young person and family support plan. The development of a whole system integrated pathway will reduce the unnecessary transfers and transactions between and across services.

A single system of care provides greater opportunities to wrap support around children and young people and strengthen partnership working with parents and achieve better outcomes. Re-orientating the system of support reduces the anxiety which may be experienced by families; by providing the right support, at the right time(s) during the life course enables children young people and their families to self-manage and to remain in control of the direction of their lives.

Principle 5: Children, young people and their families are fully involved in their care:-. Children, young people and parents are supported to develop their knowledge and skills in relation to appropriate interventions that enable them to make informed choices. This approach also means young children and their families will be proactively involved in all care and life decisions and will involve:-

- Working with the child, young person and the family unit to ensure the safety and well-being of the entire family.
- Strengthening the capacity of families to manage their needs and function more effectively
- Developing a partnership between parents and services which is characterised by mutual trust, respect, honesty, and open communication.
- Providing personalised, flexible responsive and relevant services for each family.
- Linking families with supportive community-based networks and services.

Principle 6:- Services supported by well-trained competent staff. The framework requires professionals from Autism, ADHD, Behavioural and Child and Adolescent Mental Health Service and, as appropriate, educational professionals, to work together and share their respective knowledge and expertise. This will require the development of a workforce plan to ensure the delivery of a range of evidenced based therapeutic interventions in an integrated approach with appropriate professional skill mix.

6.3 Children and Young People's Developmental Emotional Wellbeing Service Pathway at Glance The proposed pathway, figure 13, seeks to create a single system characterised by a single entry point, directed conversation model and the integration of Child Development Clinics capable of providing seamless access to specialist Autism, ADHD and CAMHS services where these are required. It is proposed that the pathway will be underpinned by the ECHO model which is an approach that creates the conditions for clinicians to consult and share knowledge and have better access to experts working with children and young people.

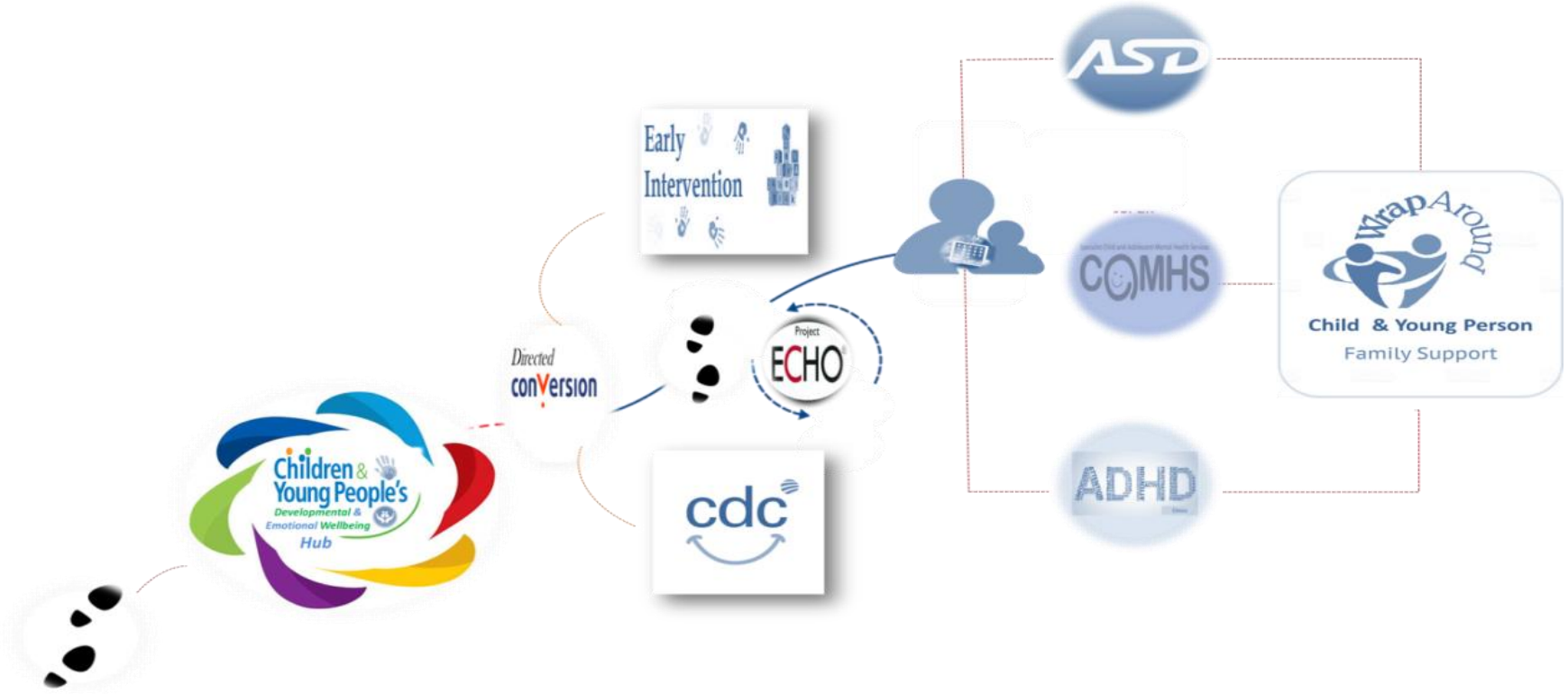


Figure 13

6.4 New Framework Operational Characteristics:- As indicated the following system characteristic outlined in figure 14 reflects a wide range of evidence drawn from international, national and local research, young people/parental perspectives and from those professionals involved in delivering Autism and Child and Adolescent Mental Health Services. The four core domains of the new frameworks as illustrated in figure 14 outline the underpinning characteristics of the integrated service model and will guide the implementation of the model across each local Health and Social Care systems in Northern Ireland.

Figure 14

6.4.1 Single System Operational Characteristics - Health and Social Care Trusts will bring their existing Autism, ADHD and CAMHS into a single system of care. The single system will standardise referrals pathways for all these services into a single integrated care pathway.

This should:-

- Include the criteria for the prioritisation and management of referrals.
- Enable the development of arrangements for pre-referral consultation, advice and support for all referral agents
- Simplify and improve access to the right level of help including signposting to other interventions which can assist with the child, young person and family's needs.

Establishing a single integrated Autism ADHD and CAMH services model will require the following four core operational components to be implemented.

i. **Single Point of Entry:** - A single point of entry for all appropriate services is a crucial component for creating an integrated system of care. It aims to reduce duplication, improve decision-making and most importantly improve people's experience of care. It means that children, young people and their families will not have to find their way to services and/or around the services they need. Crucially this will require the realignment of teams, professional functions and services so that support is wrapped around the child, young person and their family. A single point of entry requires the establishment of a core multi-agency team for the co-ordination and management of referrals This team will triage referrals, provide consultation, advice and support to all referral agents.

ii. **Information Communication & Understanding Population Need**. Each system will also need to develop an informatics and communication plan to support referral pathways. It will also require the integration of all health and social care information into a single electronic record (and as appropriate educational information). The combined information should be

used to assess the needs of the child, young person and to determine the most appropriate support pathway for the child, young person and their families. Each system will also be required:-

- To gather data about the presenting needs.
- The interventions provided.
- Be capable of anticipating need particularly at known transition points.
- Monitor and evaluate outcomes and experience of children, young people and their families.

This information will enable each system to understand its population needs and continue to improve the impact of services provided. Further work will also be required to have a better understanding and details of the needs of the population in regard to identifying groups that may be at risk but who are not benefiting or getting access to services, the prevalence and impact of mental illness and developmental needs in children and young people that enables better identification of service need so in order to inform service planning and development across the region.

iii. **Proactive Involvement of Children Young People and their Families**: - The framework requires each system to engage with and involve children, young people and their parents as active partners in the formulation of their needs. The framework promotes a co-production approach which involves sharing expert knowledge and therapeutic tools which crucially assists children, young people and their parents to develop their own expertise and facilitates their effective engagement in the formulation and diagnostic process. Beyond personal participation in the assessment and care process, systems are also required to develop arrangements for children, young people and their families (advocates) to become equal partners in the development and design of services. Each system will therefore be required to establish reference groups or forums and develop peer mentoring services, so that young people with lived experience can support their peers across the pathway.

iv. **Directed Conversation (Choice appointment): -** Each system will be required to implement the 'Choice and Partnership Approach' (CAPA). CAPA promotes collaborative practice and shared decision-making. Shared decision-making is about sharing expert knowledge, empowering child, young and their families to make health and wellbeing choices. A 'Choice Appointment' is a 30-45 minute structured conversation (Directed Conversation) with children young people and/or their parents, designed to build relationships and establish early on what children, young people and/or their parents want and need. The 'Choice Appointment' is designed to feel like a conversation, rather than a passive assessment interview. The combination of personal and professional knowledge facilities joint understanding and enables shared decision making about next steps which may include watchful waiting, advise, signposting to support services, further specialist assessment, early interventions support or specialist intensive intervention. The Directed Conversation also ensures all professionals already involved (including education) are active participants in determining the next steps in care.

6.4.2 Early Interventions Operational Characteristics

Early intervention means intervening at a young age or early on in a problem and/or reducing its impact on the life of the child or young person.

The CYPSP uses the following definition to describe early intervention: "*Early intervention is intervening early and as soon as possible to tackle problems emerging for children, young people and their families or with a population at risk of developing problems. Early intervention may occur at any point of a child or young person's life*".

Figure 15

'The foundation for virtually every aspect of human development – physical, intellectual and emotional, are laid in early childhood. What happens in these early years has lifelong effects on many aspects of health and wellbeing.' – Marmot Health Inequalities Review (2010)

It is universally recognised that early intervention is the best form of prevention. Early intervention is widely recognised as essential to improving population health and well-being. It is especially critical in the first years of life as this sets the foundation for health and wellbeing in later life, improves individual life chances and can help in breaking the cycle of health and social disadvantage across the generations. Studies about the onset rates of illnesses of all types across the lifespan highlight that mental disorders represent the single largest category of burden of ill health in children, adolescents and young adults, hugely outweighing all other health care related problems. It also known that approximately 50% of people with complex mental health needs will have symptoms by the time they are 14yrs old and many at a much younger age.

In recognition of these factors, promoting social and emotional wellbeing in children:-

- Creates the foundations for healthy lifestyle behaviours.
- Improves educational attainment
- Enables better outcomes across the lifespan.

At the heart of early intervention work is the recognition that a child's early years are critical in terms of their brain development, which can have a major impact on their development and future life outcomes. Research evidence repeatedly demonstrates that an early intervention approach is crucial throughout childhood and adolescence in enabling key developmental milestones to be achieved.

Parents play a crucial role in influencing their children's development. International evidence demonstrates that the parent–child relationship is more important for children's development than family income or structure. The framework aims to proactively assist parents through support and access to parenting programmes, which is not intended to tell parents how to care for their children, rather empowers them in their parenting role. Examples of effective evidence based early intervention programme currently

provided are Solihull, Incredible Years, Life Start, and Family Nurse Partnership etc. What these programmes and many other such programmes highlight is that effective early intervention is dependent on:-

1 Supporting parents from an early stage and supporting child development in the first three years of life
2 Proactively planning for key life transitions
3 Enabling and supporting children's learning
4 Training and developing professionals in evidence based models
5 Developing a consistent model and improving joint working between early years interagency

Early intervention initiatives are already established features within health, social care and education. Each system is therefore required to scope current early intervention provision across agencies and establish integrated provision for children, young people and their families who present with neurodevelopmental, emotional behavioural and mental health needs into a single model of support. It is anticipated that the 'Early Intervention Teams' will deliver a range of interventions as outline in figure 16. This list is not exhaustive but highlights the main features which should be developed or strengthened. It is expected each child and family will be allocated a key worker from the lead agency that will provide support and co-ordinate early intervention support.

The approach should encompass a cohesive, holistic, family-based model. Adopting a whole family approach will also require the

development of a multi-agency partnership which seeks to align and match community and third sectors services together in the delivery of early intervention services to children young people and their families. This should also involve measuring outcomes in line with Families Matter: Supporting Families in Northern Ireland – Regional Family and Parenting Strategy -March 2009.

6.4.3 Specialist Assessment, Formulation and Diagnosis: - Operational Characteristics:

Assessment, formulation and diagnosis is the process by which all the information about the child, young person's and families' health, psychological, and social need is brought together to make a diagnosis, to enable understanding of the underpinning reason for identified needs/symptoms and how these can be effectively managed.

Children & Young People NICE Guidelines

1. Eating Disorders CG 9
2. Self Harm CG 16 & 133
3. PTSD CG 26
4. Depression CYP 28
5. OCD CG 31
6. Bipolar CG 38
7. Antenatal and Post Natal CG 45
8. Alcohol-use disorders -Intervention to Reduce Substance misuse in YP PH4 PH24
9. ADHD TA 98 & QS 39
10. Psychosis and schizophrenia in children and young people CG 115
11. Social and Emotional Wellbeing Early Y
12. Child maltreatment CG 89
13. Conduct disorders in children and young people CG 158
14. Autism CG 128 & 170
15. Anxiety & Panic Disorders CG113

Figure 18

Many parents, children and young people discussed how they often had to repeat their history multiple times across a wide range of services, while professionals identified the need for previous information about the needs of the child, young person and their families to be more readily available at the time of assessment. The Integration of CAMHS, Autism and ADHD services and, as appropriate, education support services, creates the conditions for standardising the assessment process and the sharing of crucial information about needs. Pre-referral information along with information gathered through the initial consultation (Directed Conversation) and details of early interventions supports that have been provided will be combined to contribute to the formulation of a diagnostic outcome.

Reflecting on different patterns of demand and the subsequent variation between Trusts in diagnostic outcome, the new framework will standardise the assessment and diagnostic process across all Trusts. This will involve the establishment of a robust

programme of clinical audit across all Trusts. In addition, historically, access to support has been predicated on a diagnosis. However as indicated the framework aims to provide early intervention support from the outset while the assessment and diagnostic process is to get underway. The assessment, formulation and diagnostic process will be managed in line with following NICE Guidelines as outlined in figure 18 and will be undertaken by a multidisciplinary assessment team.

The process will proactively involve children, young people and their parents as core partners demonstrated by the sharing of knowledge and developing innovative practice to support children, young people and their families. The aim is to help children, young people and their families to be more in control of the assessment and formulation process (figure18), to make sense of their needs and develop an understanding of the helpful and unhelpful factors which are impacting on their developmental, emotional and psychological wellbeing. The process also aims to identify existing strengths, talents and capabilities and assist in the development of personalised ways of resolving problems or find new ways of managing.

Figure 18

Following assessment the team will:-

- Share the outcomes and implications
- Provide the information in a timely manner
- signposting to other services and agencies as may be required
- As appropriate provide support to help children, young people and their families to come to terms with the diagnostic outcome.

In recognition that the previous waiting time only measured the time from referral to the commencement of assessment and in response to the frustration experienced by children, young people and parents about the length of time taken to complete assessment and receive a diagnostic outcome, each system will ensure that all assessments have been completed and a diagnostic outcome determined no later than 26 weeks from the commencement of these assessments. Following assessment a multi-agency care plan should be developed in partnership with the child, young person and their family as appropriate.

6.4.4 Children, Young Person and Family Support Operational Characteristics: - Based on the formulation of needs, interventions and supports should be provided in line with the evidence in NICE guidelines, tailored and delivered in a

Figure 19

holistic, personalized and family centered way. Each system will be required as outlined in figure 19 to provide a comprehensive range of evidence based support interventions with the aim of optimising the developmental psychological, social and economic well-being of each child and young person.

This means each system will also be required to develop arrangements which ensure all the supports required to meet the needs of the child, young person and their families are brought together into a single integrated support plan (Personal and Family Wellbeing Plan). Clearly the child, young person and their families should be actively involved in co-producing their Personal and Family Wellbeing Plan. Intervention and support should be accessible, timely flexible, and age appropriate.

The recent Ministerial investment of £2 million in Autism Service was in response to the significant increase in demand for autism assessment. The increased capacity within the assessment teams will improve access to the diagnostic teams and autism specific support. In conjunction with this it is anticipated each Trust will seek to reconfigure resources to deliver the objectives outlined in this paper. Co-existence of services should not be favoured over coordinated care. This means HSC Trusts will be required to develop a resource and workforce plan, and it is within this context that they will re-organise and align the professionals involved in delivering these services into a multi-agency integrated team which should include the following range of practitioners (Fig 20):

- *Autism therapists*
- *Occupational Therapists;*
- *Speech & Language Therapists;*
- *CAMHS practitioners*
- *Primary Mental Health Nurses*
- *Psychologists*
- *Social Workers*
- *Peer Support workers*

Figure 20

Intervention and support should be based on the best evidence available and staff should proactively maintain their skills, sharing learning and training opportunities both locally and regionally in a multi-agency context, where appropriate. Each system will also be required to strengthen and develop a key worker approach that can support the child, young person and families and who can co-ordinate intervention across agencies. The resource and workforce plan should also seek to strengthen partnership working, investing and engaging with the community and voluntary sectors as partners in delivering the framework.

6.4.5-Transition Operational Characteristics:

All children need preparation for adult life; some will face more challenges than others. Children with complex needs will need to overcome additional challenges so children moving through different development stages will require proactive and purposeful planning to ensure personal wellbeing plans and intervention are responsive to their changing needs and changing circumstances. As children and young people grow they experience several key predicable transitions in their lives: transition from home life to pre-school; from pre-school to primary school; from primary to post-primary school; and finally transition to further education/training, workforce and adulthood. This is often a period of great opportunity but for young people who have autism ADHD and mental health needs it can also represent a significant period of risk

The outcome of effective transitioning is one where children and young people feel empowered, feel a sense of security and stability and are looking forward to their future adult lives. This means services will seek to proactively tailor support for children young people and their families in response to these critical key life events. The new framework creates an opportunity to get transition right for young people by sharing accurate data, planning ahead and implementing best practice guidance for transition. It is therefore important that adolescence/young adulthood should be recognised across the health service as an important developmental phase. Each system will be required to ensure:-

- There should be a lead professional to support young people and their families through transition.
- A documented transition plan that includes their health social education and life skills needs should be proactively developed in response to key developmental milestones.

- A communication or ‘health passport’ to ensure relevant professionals have access to essential information about the young person.
- Health services provided in an appropriate environment that takes account of their needs without gaps in provision between. Children’s and adult services.
- Training and advice to prepare them and their parents for the transition to adult care, including consent and advocacy.
- Health care settings and services should be responsive to the needs of young people and their families when transferring to adult services.
- The needs of parents as carers should be assessed and addressed

Each system will need to adopt an anticipatory care approach which pre-empts needs and proactively plans and personalizes the transitional supports for each child, young persons and their families across the life span.

Transitions should be in line with NICE guidelines and the arrangements for supporting transition should be clearly identified within a supportive multi-agency network. The key worker should oversee the transition and help co-ordinate intervention from other professionals and agencies to the needs of the young person including with education and employers.

Each system should develop a coaching and peer mentoring model which can facilitate young people and young adults in their personal, social and educational development. Working with Recovery Colleges which have been established in each Trust, bespoke co-produced programmes should be developed which can enable young people with neuro-developmental and mental health needs to develop the necessary life skills, (including: emotional wellbeing, sexual health, food and fitness, relationships, physical health and addressing smoking, alcohol and drugs issues) as well as create opportunities for young people to develop skills for life and work.

Each system will also be required to review the interfaces with Adult Services and remodel services to ensure the arrangements for transitioning from children to adult services are integrated and effective. This should include face to face handover from one professional/service to another. Any transition plans and arrangements should be sensitive to needs of the young person and provided in a way that promotes self-determination and independence while acknowledging the need for on-going support as the young person progresses into adult life.

Smooth transitions will depend on different organisations having a shared understanding of how the support they provide contributes to the overall well-being of the young person. In order for transitions to be effectively managed each system will be required to develop a transitional service plan. The plan should be population needs based and should be developed in partnership between health, social care education, higher education employers and communities.

Section 7 – Implementation Framework

The following tables outline the key organisational actions which are required to deliver the key outcomes outlined of the framework. Subject to consultation with other key Departments and each system will be required to develop a local area action and implementation plan.

Domain 1	**Health and Social Care Each Health and Care Trust Will:-**	***Education Support Service Will:-**	***Department of the Economy Will:-**	***Community & Living Department For Communities Will:-**
Single System of Support Child and Young People and their families will have timely access to intervention and support which meets their health developmental psychological social education and economic needs	• Establish a Local integrated Improvement and Leadership Team (LIT) to drive reform. (This will involve integrating CAMHS LIT and Autism Strategy Groups into a single process.) • Profile the needs of their local child, young person population and respective pathways across Autism ADHD and CAMHS Services • Scope the Resources (funding staff skills etc.)and assets available within each local system and reconfigure in line with the new model • Create a Single Point of Entry For All Autism ADHD Behavioural and CAMH Services • Offer a Directed conversation, Choice Appointment))within six weeks of referral • Provide Pre Referral consultation services and implement ECHO to support across professional and across sector learning development and co-working • Develop workforce plan aimed at upskilling CAMHS teams in Neurodevelopmental (ADHD Autism) Assessment and Management			

Domain 2	Health and Social Care Each Health and Care Trust Will:-	*Education Support Service Will	*Department of the Economy Will	*Community & Living (DFC) Will
Early intervention Children and Young People and their families have access to advice and preventive supports which meets promotes personal family and community wellbeing (physical, psychological social and economic)	• Scope the role and functions of all early intervention services which respond to Children Young People and Families with Developmental Emotional Behavioural and Mental Health Needs. • Establish an Integrated Early intervention Team combining Infant Mental Health CAMHS Primary Mental Health Teams and Autism Early intervention services into a single Multi-disciplinary team. • Ensure Early intervention Teams provide the full range of evidence based programme and interventions (Parenting & Family Support Behavioural Management, Social and Communication Skills, Low Intensity Psychological Therapy Interventions Health Reliance training and occupational therapies) • Align the development of services with Family Support Hubs. • Engage all Third sector partners in the design/development/provisions of early intervention Support Services. • Adopt a standardised matrix of outcome measures which demonstrates impact in line with Programme of Government Indicators.	Interface with Pre-School Support services and School Multidisciplinary Teams and Middletown etc.	Interface with Third Level Education Providers Employment Support Services	Interface with Community Planning

Domain 3	Health and Social Care Each Health and Care Trust Will:-	*Education Will	*Department of the Economy	*Community & Living (DFC)
Assessment Formulation and Diagnosis Children Young People and their families are active partners in the assessment in the diagnostic formulation of their needs.	• Scope and align (standardise) all assessment and diagnostic pathways across ADHD Autism and CAMHs Services. • Integrated all Neurodevelopmental ADHD Autism and CAMHS into a single care pathway. • Reduce duplication by harnessing information about the children, young person and their families into a single electronic record. • Establish a rapid assessment pathway, which makes use of previous assessment information in the formulation of needs. • Implement all the NICE Guidelines pertaining to the assessment of Neurodevelopment Emotional Behavioural and Mental Health needs of Children and Young People. • Remodel assessment process to ensure children young people & their families are active partners in their own assessment and in the formulation of their own needs. • Provide children young people & their families with a diagnostic outcome within 26 weeks of their referral and provide post diagnostic counselling and support for the entire family •	Integrate Assessment Diagnostic and Intervention Teams		

Domain 4	Health and Social Care Each Health and Care Trust Will:-	*Education Support Service Will	*Department of the Economy	*Community & Living (DFC)
Integrated Child Young Person Family Support Planning Children and Young people and their families will receive evidence based interventions services which will be brought together into a single integrated personal, family and wellbeing plan.	• In partnership with the child, young person and their family co-produce an integrated single system support plan. This plan brings together all interventions into a single plan required to address their developmental psychological, educational, family and social needs. • Ensure each child, young person and their families have an allocated a key worker who will co-ordinate support across services. • Establish an integrated Multi-disciplinary team across ADHD Autism and CAMHS Services. • Implement all the NICE Guidelines in management of Neurodevelopment Emotional Behavioural and Mental Health needs. • In meeting the needs of children, young people and their families provide the full range of evidenced based developmental, family, psychological, behavioural occupational and social skills therapies. • Adopt a standardised matrix of outcome measures which demonstrates impact in line with Programme of Government Indicators.			

Domain 5	Health and Social Care Each Health and Care Trust Will:-	*Education Support Service Will	*Department of the Economy Will	*Community & Living (DFC) Will
Transition and Independent Living **Children, young people and their families will be proactively supported to live independently and provided support tailored to assist at crucial transitional points across their life span.**	• Adopted an anticipatory care approach which plans and outreaches to children young people and their families. • Provide a range of life skills and mentoring services to enable independent living. • Develop an implementation plan which extends the provision for young adults up to age of 25 within 2 years. This will involve realigning Adult ASD and other adult service resources to create an integrated multidisciplinary Young Adult Support and Transition Team. • Develop and extend the role of Recovery Colleges to include support for young adults with neurodevelopmental needs.(ADHD Autism) • Develop peer led support services (peer mentoring services) • Proactively support family and friends	Interface Youth Counselling Services	Interface with Third Level Education and Employers	Interface with Community planning

References:

1. VIII International Congress Autism-Europe, 2007; “Autism Model Position Paper on Care For Persons With Autism Spectrum Disorders - a rights-based, evidence-based approach”
2. Missouri Autism Guidelines initiative, 2012: Guide to Evidence-based Interventions
3. A Public Policy Exchange Symposium, Sept 2016; Developing Community Services to Deliver Better Outcomes for People with Autism
4. Leicester Partnership NHS Trust; Service pathways
5. New Zealand Autism Spectrum Disorder Guideline, 2008
6. Team Around the Child for the 21st Century: A unifying theory about children who have a multifaceted condition; Peter Limbrick 2010
7. The Westminster Commission on Autism A spectrum of obstacles; July 2016
8. Engaging families in the early childhood development story; Neuroscience and early childhood development; Education Services Australia, 2010
9. Generic Service Interventions Pathway; A competency framework to support development of the learning disabilities workforce – NHS Health Education England
10. Trust Testing in Care Pathways for Neurodevelopmental Disorders: A Grounded Theory Study: posted on Jun 19, 2016 in Current issue, Issue 1, June 2016, Volume 15, Gustaf Waxegard, Linnaeus University, Sweden, Hans Thulesius, Lund University, Sweden
11. Scottish Autism Strategy
12. NICE CG128 NICE CG 149 NICE NG 43 - published Feb 2016: Transition from children’s to adults’ services for young people using health or social care services
13. No decision about me without me 10 000 voices review of CAMHS and paediatric autism services
14. Early intervention: The Next Steps - An Independent Report to Her Majesty’s Government, Graham Allen MP, January 2011
15. Early intervention: Smart Investment, Massive Savings The Second Independent Report to Her Majesty’s Government Graham Allen MP June 2011

16. Parent-mediated social communication therapy for young children with Autism (PACT): long-term follow-up of a randomised controlled trial - www.thelancet.com Published online October 25 2016 http://dx.doi.org
17. Incredible Years in Northern Ireland: Mapping & Fidelity Report: 2013-15, PHA & Northern Ireland Executive
18. Spectrum Star™ - The Outcomes Star™ for people on the Autistic spectrum
19. Quality 2020 Strategy', published in November 2011 DHSSPSNI
20. Programme for Government 2016-20216 framework
21. Allied Health Professions 2012-2017 Improving Health and Well-being Through Positive Partnerships
22. A Strategy for Paediatric Healthcare Services Provided in Hospitals and in the Community (2016 – 2026)
23. Health And Wellbeing 2026: Delivering Together DOH Oct 2016
24. Systems, Not Structures: Changing Health & Social Care Expert Panel Report Oct 2016
25. Families Matter: Supporting Families in Northern Ireland – Regional Family and Parenting Strategy March 2009
26. Ten Years of Learning Prevention and Early intervention in Children and Young People Services Centre for Effective Services.
27. On the Right Tract Child Behaviour Centre for Effective Services
28. On the Right Tract Parenting Centre for Effective Services
29. On the Right Tract Children's Learning Centre for Effective Services
30. On the Right Tract Child Health Centre for Effective Services
31. Department of education England Supporting young people with autism to move from school to college
32. Early intervention: The Next Steps An Independent Report to Her Majesty's Government Graham Allen MP
33. The Young Foundation 2012 A framework of outcomes for young people Bethia McNeil, Neil Reeder and Julia Rich
34. Quality Care Commission 2104 From the pond into the sea Children's transition to adult health services

Appendix 1

Policy and Guidelines

- Autism Act NI 2011
- Autism Strategy and Action Plan 2012 – 2018
- Autism Six Step Care Pathway
- Programme for Government 2016 – 2026 Framework
- Systems, not Structures: Changing Health and Social Care Expert Panel Report October 2016
- Health and well Being 2026: Delivering Together DOH, Oct 2016
- Quality 2020 Strategy DHSSPSNI Nov 2011
- A Strategy for paediatric Healthcare Services provided in Hospitals and in the Community (2016 – 2026)
- Making Life Better. A Whole System Strategic Framework Public Health 2014
- DOH CAMHS Services Framework 2011
- Families matter: Supporting families in Northern Ireland. Regional family and parenting strategy - March 2009, DHSSPSNI
- A Strategy for Paediatric Healthcare Services Provided in Hospitals and in the Community (2016 - 2026), DoH
- Children and Young People's Strategy 2017 – 2027 DoE NI
- Improving health and well-being through positive partnerships - A strategy for the allied health professionals in Northern Ireland 2012 – 2017 , DHSSPSNI
- NICE guidelines:
    - CG128: Autism spectrum disorder in under 19s: recognition, referral and diagnosis
    - CG 170: Autism spectrum disorder in under 19s: support and management
- Six Steps of Autism Care: a guide for families
- Graduating for Success April 2012 and Access to Success; an Integrated Regional Strategy for Widening Participation in Higher Education, September 2012
- Children’s Services Co-operation Act (Northern Ireland) 2015
- NICE guideline NG43: Transition from children’s to adults’ services for young people using health or social care services