

Mencap NI Briefing Paper **No.1**

Creating brighter futures: early intervention for young children with a learning disability

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“The amount of friends
and support groups we
have made has been
great. It makes you realise
that you are not alone.”

Parent, Mencap

Introduction

For all children, what happens in early childhood during the first five years can make a significant difference in terms of their overall life chances. This is when key foundations are laid for future health, well-being, relationships, educational attainment and employment.

The importance of early intervention in supporting children's development is well established in evidence and practice, especially for those deemed to be at risk. Children with a learning disability are at greater risk of many health and social inequalities, however they are generally under-represented in early intervention policy. In our experience, access to high quality, early support is also limited for children with a learning disability and their families.

As part of Mencap's early intervention strategic priority, our aim is to ensure that children with a learning disability have the best start in life; and that more children with a learning disability aged 0-7 have better health and development, improved cognitive skills, and stronger social and interpersonal skills. We want every family to get the support they need to help them meet the individual needs of their child, as early as possible.

In doing so, and in order to find out what works best for children with a learning disability, everything we progress related to early intervention is being informed by robust evidence and good practice. To help us achieve this, we are collaborating with leading experts in the field of learning disability - in particular, the University of Kent's Tizard Centre,⁴ and the Centre for Educational Development Appraisal and Research (CEDAR)⁵ at the University of Warwick.

About this paper

This briefing paper highlights why early intervention is important for young children with a learning disability and their families; and what Mencap is doing in Northern Ireland to improve their outcomes. In doing so it provides an overview of Mencap NI's developing, evidence-informed early intervention framework, and makes recommendations for wider policy and practice.

A learning disability is a reduced intellectual ability and difficulty with everyday activities which affects someone for their whole life. The level of support someone needs depends on the individual person and the extent of their learning disability. With the right support, most people with a learning disability in the UK can lead independent lives.¹

The term 'developmental delay' or 'global development delay' is used when a child takes longer to reach certain development milestones than other children their age. This might include learning to walk or talk, movement skills, learning new things and interacting with others socially and emotionally.²

Key statistics³

In the UK, there are approximately:

1.4 million people with a learning disability

19,000 children born every year who have, or will have, a learning disability.

In Northern Ireland, there are approximately:

42,000 people with a learning disability

11,000 children aged 0-17 years old with a learning disability

5,000 children aged 0-7 years old with a learning disability.

¹ Mencap (2017) www.mencap.org.uk/learning-disability-explained/what-learning-disability

² Mencap (2017) www.mencap.org.uk/learning-disability-explained/conditions/global-development-delay

³ These approximate figures have been calculated using learning disability prevalence rates from Public Health England (2016) and population data from the Office for National Statistics (2017). Approximately 2.16% of adults and 2.5% of children in the UK are believed to have a learning disability.

⁴ The Tizard Centre is the leading UK academic group working in learning disability and community care, is widely known world-wide and has an international reputation.

⁵ CEDAR is an internationally acknowledged research centre whose research includes special educational needs and inclusion, and disability across the lifespan (especially intellectual disability and autism).

Policy context

Early intervention is a widely accepted public policy approach across the UK. It focuses on tackling problems experienced by families before they become more difficult to reverse. Associated services are universal in scope and also targeted towards children at higher risk of poor outcomes, particularly within disadvantaged communities. They increasingly include evidence-based family support interventions focused on children’s development and well-being, and supporting families with multiple and complex needs.

In Northern Ireland, a number of initiatives have also helped drive forward an agenda more focused

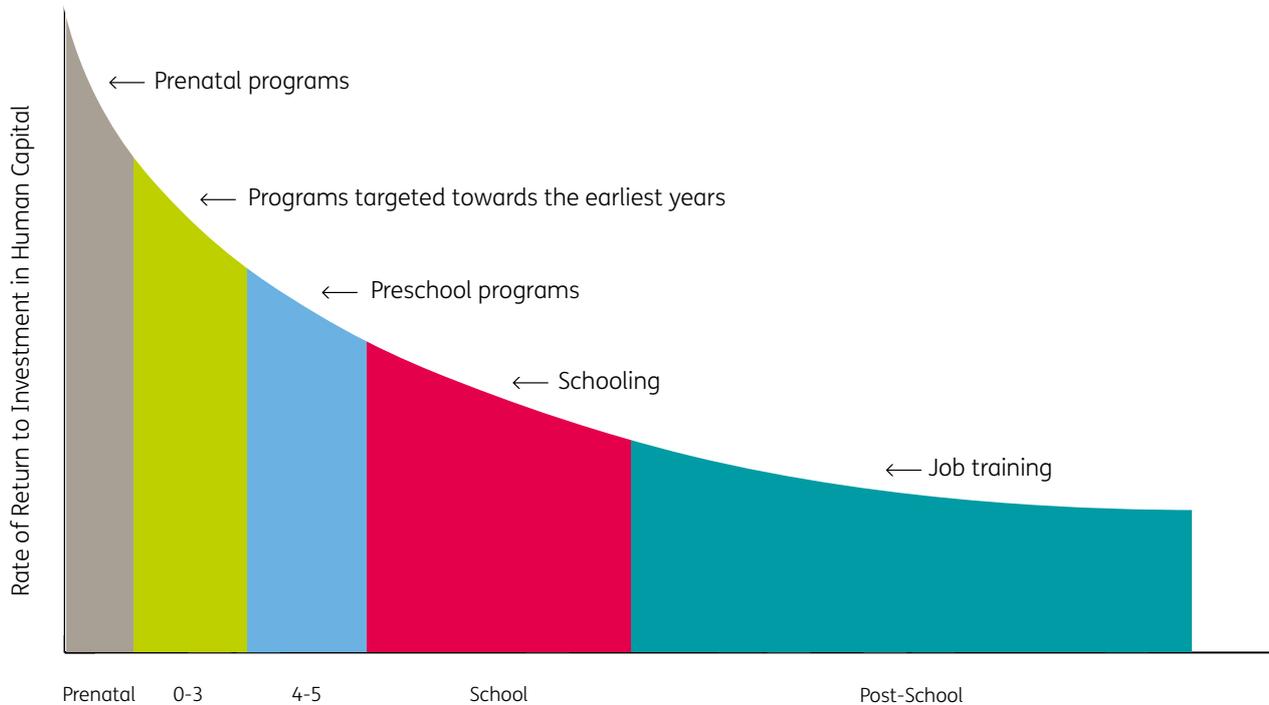
on early intervention, prevention and integrated service provision. These include the creation of Children’s Services Planning, which is supported by the Children and Young People’s Strategic Partnership (CYPSP);⁶ Family Support Hubs;⁷ a dedicated early intervention service; and evidence-based parenting programmes. There are also different funding strands; for example, as part of the Delivering Social Change (DSC) framework set up by the NI Executive to tackle poverty and social exclusion, the Early Intervention Transformation Programme (EITP) is jointly funded by the DSC fund, five Government Departments and private philanthropy. It aims to improve outcomes for children and young people across NI through embedding early intervention approaches.

Why intervene early?

Early intervention represents an ‘intelligent approach’ to public spending.⁸ As a system of coordinating services responding holistically to the needs of families, it is essential for improving child outcomes (Britto et al, 2017). An extensive

body of research shows that intervening early is effective in helping boost brain development and overall child development; increasing the protective factors in children’s environments; and delivering considerable individual, economic and social benefits over time.⁹ Wide-ranging in nature, programmes typically focus on reducing risks for children and families by:

Figure 1: The ‘Heckman Curve’ – the earlier the investment, the greater the return



Source: James Heckman, Nobel Laureate of Economics

⁶ The CYPSP is comprised of leaders from key organisations across the statutory, voluntary and community sector with responsibility for improving children’s outcomes.

⁷ A Family Support Hub is a multi-agency network of organisations that either provide early intervention services or work with families who need early intervention services.

⁸ Early Intervention Foundation www.eif.org.uk/what-is-early-intervention/

⁹ See, for example, Early Intervention Foundation www.eif.org.uk/how-do-we-know-early-intervention-works/; Center on the Developing Child, Harvard University <https://developingchild.harvard.edu/resources/>; and The Heckman Equation www.heckmanequation.org/

- supporting personal development
- improving resilience
- promoting social inclusion
- strengthening parenting skills; and
- supporting children's learning.

Why early intervention matters for children with a learning disability

Unless provided with timely and appropriate early intervention, support and protection, the consequences for children with a disability and their families can be severe, and often lifelong (WHO, 2012). Well-targeted interventions for children with a learning disability are vital when considering their particular risk factors. These include:

Challenging behaviour

Often due to difficulties expressing themselves, and sometimes combined with other adverse family / social factors, children with learning disabilities are at increased risk of displaying behaviour described as 'challenging' (Challenging Behaviour Foundation (CBF), 2014). Typical behaviours include aggression, self-injury, repetitive movements, withdrawal, and disruptive or destructive behaviour (NICE, 2015).

Challenging behaviour often starts at a young age and without intervention can endure into adulthood. Evidence suggests that children with developmental delay, aged 2-3 years, have significantly higher rates of emotional and behavioural difficulties than their typically developing peers (Emerson & Enfield, 2010). When a child is 3-years-old, poor maternal physical and mental health, and lower life satisfaction, are also risk factors for child behaviour problems by the age of 5 (Totsika et al, 2013).

Poor outcomes

Compared to their peers, children with a learning disability are more likely to be exposed to adverse

life events (Emerson, 2013). As shown in Figure 2, they are at greater risk of experiencing less favourable outcomes. Poor outcomes are even more likely for those with challenging behaviours (CBF, 2014).

Children with a learning disability will likely experience more difficulties with sleep and feeding (Gal et al, 2011), and learning basic reading skills which impacts on their ability to achieve in school (Tyler et al, 2015). Growing up, they are also a potentially high risk group in terms of alcohol misuse (Emerson et al, 2016), and poor mental health is a significant issue. For example, children with a learning disability constitute one in seven of all children with diagnosable mental health problems in the UK (Emerson & Hatton, 2007). Notably, children with a disability, particularly a learning disability, are more likely to be 'looked after' than the general population (DoH, 2016).

Lower quality of life and poor outcomes can also be experienced by the families of children with a learning disability. They are at greater risk of poverty, social exclusion, physical and mental-ill health (IASSIDD, 2014), and divorce and separation amongst parents (Hatton et al, 2010).

Barriers to service provision

The key barriers for children with a learning disability and their families accessing early intervention services include:

Under-represented in policy: Despite being at risk of poorer outcomes, early intervention policy and practice in the UK is often not inclusive or specific to children with a learning disability (CBF, 2014). It is unclear how well current early intervention services across the four nations are meeting the needs of children with a learning disability and their families; where the gaps are; and what impact current services are having on children's outcomes.

Article 23 of the United Nations Convention on the Rights of the Child provides that children with a learning disability have a right to support during their early years that will enable them to live fulfilling independent lives in the future.

Figure 2: Outcomes for children with a learning disability

Children with a learning disability are more likely to:



Limited provision: Early intervention services for children with a learning disability and their families are frequently lacking (Gore, Hastings & Brady, 2014). Reflecting the experience of many parents that Mencap works with across the UK, levels of access to mainstream, targeted and specialist early intervention services often do not correspond to levels of need. Many mainstream parenting programmes and services relating to child development are focused on the needs of typically developing children.

Gaps in provision: Parents we work with also highlight a number of notable gaps in service provision for children with a learning disability and their families,¹⁷ including:

- Specialist services usually tend to cater for children requiring a higher level of support, while mainstream settings often cannot meet mid-level needs.
- Children with specific additional needs are particularly poorly catered for in the early years. This is especially relevant for children aged under 2 years, and also 3-5 year olds if they are not accessing early education.

- Children displaying challenging behaviours are also at greater risk of being unable to access evidence-based interventions (CBF, 2014; Gore, Hastings & Brady, 2014). While there are some well-evidenced programmes for family carers of young children with a learning disability, there is a notable gap in parenting support before challenging behaviour and other problems have developed. Support when families are at crisis point is often adapted from mainstream provision.

Lack of specialist skills: Where mainstream support is received, professionals may not have the specific knowledge and skills relating to the needs of children with a learning disability. This includes an understanding of the barriers faced by children and families in accessing early intervention services, and associated adjustments that might be made.

Delayed diagnosis: Without consistent timescales for diagnosing learning disabilities, many families struggle to get their child’s needs identified in the early years once they suspect a problem. In the experience of many parents we work with, support before and after diagnosis is

¹⁰ Public Health England, 2015; Shahtahmasebi, Emerson, Berridge & Lancaster, 2011.

¹¹ Public Health England, 2015.

¹² Tunnard, Barnes & Flood, 2008.

¹³ Fink, Deighton, Humphrey & Wolpert, 2015; Rose, Monda-Amaya & Espelage, 2011.

¹⁴ Jahoda & Pownall, 2014; Tipton, Christensen & Blacher, 2013; Solish, Perry & Minnes, 2010.

¹⁵ Kiddle & Dagnan, 2011; Emerson, Baines, Allerton & Welch, 2011; Emerson, Enfield & Stancliffe, 2010; Emerson & Hatton, 2007.

¹⁶ Emerson, Baines, Allerton & Welch, 2011.

¹⁷ Drawn from a range of sources including Mencap Early Years Vision Statement, and internal family support consultations / surveys.

“The only support we received between diagnosis and age of two was medical support”

“Getting a diagnosis is a very emotional process...we would have found it useful to meet other parents and other children”

“I would have appreciated someone explaining the importance of sensory play, intensive interaction, early intervention and Makaton”

“I would have really liked more support for us as parents and maybe a chance to meet with other parents in similar situations”

generally poor, including access to vital peer-to-peer support.

Lack of information: There is generally very limited high quality information for parents about their child’s needs and what early support is available to them. Information provided often focuses on what a child might not be able to do, rather than what they could achieve.

What Works?

Mencap NI is committed to ensuring children with a learning disability and their families have access to effective early intervention services and approaches. Building on existing work, we are developing an evidence-informed framework of interventions and activities based around the following three themes:

1) Supporting the child

Early Development Support

In partnership with the Belfast Health and Social Care Trust (BHSCT) we provide an Early Development Support programme¹⁸ in the Mencap Centre for 52 children aged 2.



Early Development Support: Key Features

- An onsite team of BHSCT allied health professionals provide specialist and tailored support which is critical for children’s development, and laying the foundations for future attainment.
- The high staff to child ratio (a minimum of one key worker to three children) is important for quality care and better developmental outcomes for children. This is especially relevant for very young children, and also children with a learning disability / complex needs who require additional time and support.
- Individual learning plans give children the opportunity to develop skills and work towards achieving their goals.
- Three play-zone areas are organised to cater for different support requirements, and to incorporate both structured activities and active learning.
- Using the HighScope approach as a framework, the broad and balanced programme has been designed to include child-led activities and choice.
- The evidence-based HighScope COR Advantage tool is used to measure children’s developmental progress across the year in terms of their cognitive, physical and social abilities. Staff are then able to adapt activities accordingly to the interests, abilities and needs of each child.

¹⁸ For children in the BHSCT & SEHSCT.

Mencap NI Early Intervention Framework

Theme 1. Supporting the child	Theme 2. Supporting the family	Theme 3. Influencing systems change
Interventions/activities	Interventions/activities	Interventions/activities
<p>Programmes:</p> <ul style="list-style-type: none"> • Early development support • Early education and reading skills <p>Summer schemes:</p> <ul style="list-style-type: none"> • Including early development support 	<p>Parent and family support:</p> <ul style="list-style-type: none"> • One-to-one • Group-based • Service / home-based • Workshops • Courses (including online) • Peer-to-peer support • Advice and information 	<ul style="list-style-type: none"> • Research projects • Programme evaluation • Mapping local systems and services • Identifying policy and legislative barriers to accessing support; and campaigning for change
Outcomes	Outcomes	Outcomes
<p>Children aged 0-7 will:</p> <ul style="list-style-type: none"> • Meet more of their developmental milestones • Have opportunities to grow and develop through play in an inclusive environment 	<p>Families of children with a learning disability will:</p> <ul style="list-style-type: none"> • Have the emotional and practical skills to best support their child • Be supported to promote their child’s development and their family well-being • Be better connected and understand how to access services 	<ul style="list-style-type: none"> • Policy and legislation recognises and supports families with young children with a learning disability • Services will be evidence-informed and of higher quality • Parents will have increased information and clarity on how and where to access services

We introduced HighScope COR Advantage in September 2016 to measure children’s developmental progress. Results from our first year were generally positive, for example, we were able to demonstrate that:

- **All of the children (100%)** improved in at least one measure in any development area.
- **Nearly two thirds of children (62%)** showed improvements in their ability to resolve social conflicts.
- **Over two thirds of children (68%)** progressed in demonstrating dexterity and hand-eye coordination in using their small muscles (fine motor skills)
- **58% of children** showed improvements in demonstrating strength, flexibility, balance, and timing in using their large muscles (gross motor skills).
- **58% of children** demonstrated progress in understanding language; and 42% showed improvements in expressing themselves using language.

- **Over two thirds of children (68%)** improved in both identifying, naming and describing shapes; and in recognising spatial relationships among people and objects.

What is HighScope?

Based on more than forty years of evidence, including the most up to date brain research, the HighScope approach to teaching and learning is called ‘**active participatory learning.**’ This means that children have direct, hands-on experiences with people, objects, events, and ideas.

HighScope helps support children to become confident, independent and ready for school and life. It is universal and suitable for children from diverse backgrounds and those with special needs. The model utilises 36 Key Developmental Indicators (childhood milestones) within nine themed content areas to measure children’s learning and development.¹⁹

¹⁹ For more information about HighScope, see <https://highscope.org/faq>

2) Supporting the family

Mencap NI is expanding our family support services to include a wider range of evidence-informed interventions, for delivery in both a service and home setting. We intend to offer programmes related to peer-to-peer support; parental optimism; speech and language development; early reading skills; and tackling sleep problems. Interventions will also be tailored to the individual needs of children and parents. Work already underway includes:

E-PAtS (Early Positive Approaches to Support)

Mencap NI is delivering the E-PAtS programme which was developed in the Tizard Centre, University of Kent. E-PAtS comprises 8 x 2.5-hour sessions²⁰ for family caregivers of children (0-5 years) with a learning disability or developmental delay. Its main aim is to meet the needs of families at an early stage, prior to or just after the development of early behaviour difficulties. The programme provides parents with information and practical skills to minimise risks associated with challenging behaviour, and support their child's development and life chances.

E-PAtS: Key Features

- Has been co-produced over a period of 5 years by professionals in the learning disabilities field and family caregivers.
- Is routinely co-facilitated by trained family caregivers and professionals working in partnership.
- Provides an emotionally supportive and sensitive group process that attends closely to care-givers' emotional needs.
- Utilises high quality, evidence-based information and strategies specific to the needs of families raising a child with learning disabilities.
- Can be implemented in a range of settings, is fully manualised and free to use for all organisations who have trained facilitators.²¹

Functional Communication Training

Functional Communication Training (FCT) is an intervention based on Positive Behaviour Support. It aims to teach the child an alternative communicative response to replace behaviours such as self-harm, hitting other people or throwing tantrums (Durand & Moskowitz, 2015). The replacement behaviours generally involve speech or some other type of appropriate communication, such as gestures, signs or pictures. It can be used effectively to address communication, behaviour, school-readiness, and academic and adaptive skills.

The strong evidence-base for the effectiveness of FCT has not previously included studies with children who have a learning disability or developmental delay in the UK. Mencap NI will be piloting FCT as part of a unique study being conducted by the University of Kent to assess the feasibility of implementing the intervention with young children who have a learning disability. The study is also considering the effectiveness of training family carers to implement FCT with their child.

Skills-based workshops

Workshops are available for parents to support their children's learning and development, some of which are delivered by allied health professionals from the BHSCT. Topic areas typically include structured play development, sensory processing, fine motor skills, life skills, and Makaton (a language programme using signs and symbols to help people to communicate).

Practical support

Mencap NI has been consulting with parents about additional interventions they would find most beneficial. Following this, we are co-producing with parents a range of short courses focused on offering practical support. These include areas such as baby massage and parental stress management.

²⁰ Core sessions include: Accessing services and supports; Emotional wellbeing and resilience for caregivers; Supporting sleep for children; Supporting communication; Supporting skills development; Positive approaches to behaviours that challenge.

²¹ Reproduced with permission by Dr Nick Gore, Tizard Centre, University of Kent.

Advice and information

On a one-to-one basis, parents can access advice and information about their rights and how to navigate statutory systems and processes. Key issues include finance, statements of special educational needs, and transition into pre-school education.

Positive Behaviour Support (PBS) will be an underpinning feature across a number of programmes being delivered by Mencap NI. With a strong evidence base for its use, PBS has been identified as the most effective framework for supporting individuals who display challenging behaviour, including children with learning disabilities (CBF, 2014).

The principles of **Applied Behaviour Analysis (ABA)** will support some of our interventions, particularly with children on the autism spectrum. As well as challenging behaviour, ABA techniques target social, motor, and verbal behaviours and reasoning skills. Using an ABA approach can also lead to positive learning outcomes (Grindle, 2013).

3) Influencing systems change

The focus on service evaluation, feasibility studies, continuous improvement and reflective practice across all our programme delivery is key to ensuring we develop programmes and services that work for children and families. A shared learning approach will be further used to influence wider policy and practice in order to improve outcomes for children with a learning disability. We are also committed to extending the evidence base through a new research programme, which currently includes:

- **Early intervention and early years support for young children with intellectual disability and / or autism: Facilitating access**

Funded through the Warwick Collaborative Postgraduate Research Scholarship scheme, this three year UK-wide research project is a partnership between Mencap and Warwick University, Cerebra, and Ambitious about Autism. The project aims to find out what

factors are associated with access to early intervention services in families of children with developmental delay; and how access can be improved.

- **Mapping systems and services**

Mencap NI is developing an exploratory study aimed at mapping the range and scope of early intervention services supporting young children with a learning disability and their families across Northern Ireland. The study will include a review of the policy framework and funding sources, and present a series of case studies demonstrating children's pathways through the system.

Mencap NI's Early Intervention Framework: Key Features

- High quality, evidence-informed interventions and measurable outcomes
- Open to parents of a child aged 0-7 with a learning disability or developmental delay
- A unique specialist learning environment for 52 children with a learning disability or developmental delay
- Support for parents on an individual and group basis
- Service and home-based interventions
- An onsite multi-disciplinary team
- Supported by research and evaluation
- Shared learning with practitioners and policy makers



Recommendations

- 1** Every child with a learning disability should have access to early intervention services that support their development from birth.
- 2** Families of children with a learning disability should have access to family support services in every Health and Social Care Trust.
- 3** An indicator should be added to the draft NI Programme for Government that specifically focuses on the needs of children with a disability and their families; and within this, children with a learning disability should be clearly identified.
- 4** Implementation of the Children and Young People's Strategy 2017-2027 should include a specific focus on achieving outcomes for children and young people with a learning disability.
- 5** Young children with a learning disability and their families should be identified as a priority group in key policy areas relating to adverse childhood experiences, infant mental health, child poverty, and family support.
- 6** A review should be undertaken of how well services are meeting the needs of children with a learning disability and their families. It should identify where the gaps are, what impact current provision is having on children's outcomes, and which interventions are most effective.
- 7** Staff across early years services should have the support, training and supervision needed to ensure they are equipped with the necessary skills and competencies to work with children who have a learning disability; including those with challenging behaviours.

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