



Investing in early intervention

Why we should intervene early to support children with learning disabilities and their families, with examples from practice showing how it can be done

May 2022

About

This report has been produced by:



A seminar "Early intervention. Why and how should we intervene early to support children with learning disabilities and their families?" was held in July 2021. The aims were to:

- share learning about why early intervention support focused on children with learning disabilities and their families is important and
- highlight innovation and good practice.

This report was written to share information from the seminar with a wider audience and encourage good practice.

Acknowledgements

We would like to express our gratitude to all the speakers, facilitators and panel members who contributed to the seminar which informed this report. Please see the appendix for further information.

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Foreword

Every child has the same rights to a good quality of life, including to be safe, healthy and to fulfil their potential - and to have the support they need to make that a reality. We know at the Challenging Behaviour Foundation that many families of disabled children struggle to get the right support in the right place at the right time - and this can have significant detrimental and lasting impacts on the whole family.

High quality early support can change someone's life course. When my son was just a year old, he started banging his head. If we had received good information and access to professionals with the right skills and knowledge then, he may not have ended up in a high cost 52-week residential school nearly 300 miles from his family.

This report summarises information from a seminar of families, researchers, practitioners, and voluntary organisations - where we brought together the existing evidence and good practice to help "make the case" for early intervention support for children with learning disabilities and their families.

The benefits of early intervention are recognised; and the principle of early intervention is embedded in policies and best practice guidance. Yet too often it is not happening. This is deeply shocking when we have a multitude of evidence setting out the terrible consequences of failing to do so and adopting a crisis management approach.

The starkest evidence of a crisis management approach is evidenced in the over-reliance on inpatient beds to detain children and young people with learning disabilities and autism due to a lack of appropriate support and services in the community. The Transforming Care (now Building the Right Support) programme was initiated to address this issue following the appalling abuse of people with learning disabilities and autism at Winterbourne View. As yet the progress needed has not been achieved.

The pandemic has exacerbated the issues for children with learning disabilities and their families and therefore it is even more important to ensure we urgently invest wisely and act strategically. We have an opportunity to show that children with a learning disability are valued, and to focus on early intervention as part of a long-term holistic approach that is transformational. It is an opportunity we must take.

Viv Cooper OBE, Chief Executive of the Challenging Behaviour Foundation



What is early intervention?

Definition

The Early Intervention Foundation defines early intervention as follows:

*“Early intervention means identifying and providing effective early support to children and young people who are at risk of poor outcomes. Effective early intervention works to prevent problems occurring, or to tackle them head-on when they do, before problems get worse. It also helps to foster a whole set of personal strengths and skills that prepare a child for adult life. Early intervention can take different forms, from home visiting programmes to support vulnerable parents, to school-based programmes to improve children’s social and emotional skills, to mentoring schemes for young people who are vulnerable to involvement in crime. While some have argued that early intervention may have its strongest impact when offered during the first few years of life, the best evidence shows that effective interventions can improve children’s life chances at any point during childhood and adolescence.”*¹

In line with this definition this report focuses primarily on support offered to children with learning disabilities and their families during the early years. Evidence also suggests that effective interventions can improve children’s life chances at any point during childhood and adolescence. Therefore, this report does include some examples addressing preventative action for older children, particularly where there is a risk of requiring provision that may remove them from their local community such as a placement in a residential school or inpatient bed.

The rights of children and young people with learning disabilities

The right of a child to access early intervention support is set out in the UN Convention on the Rights of the Child² and the SEND Code of Practice³.

The UN Convention on the Rights of the Child Article 23 emphasises the right of disabled children to have effective access to a range of services and support to enable their full participation in society and maximum possible individual development:

A child with a disability has the right to live a “full and decent life in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community”.

Services and support should be in place that ensure a disabled child has access to and receives “education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child’s achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.”

The SEND Code of Practice highlights the need for commissioners to fund early intervention support and work in partnership with other agencies to fill gaps in early intervention support:

“Joint commissioning should be informed by a clear assessment of local needs. Health and Wellbeing Boards are required to develop Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies, to support prevention, identification, assessment and early intervention and a joined-up approach.” (page 39).

In addition, the SEND Code of Practice sets out the legal duty for all providers of early years education in the maintained, private, voluntary and independent sectors that a local authority funds to identify needs and put in place appropriate support:

“Providers must have arrangements in place to support children with SEN or disabilities. These arrangements should include a clear approach to identifying and responding to SEN. The benefits of early identification are widely recognised – identifying need at the earliest point, and then making effective provision, improves long-term outcomes for children.” (page 79).

The SEND Code of Practice also sets out the legal duties towards children with learning disabilities under the Equality Act 2010 including:

A. the requirement to make reasonable adjustments:

“They must make reasonable adjustments, including the provision of auxiliary aids and services, to ensure that disabled children and young people are not at a substantial disadvantage compared with their peers. This duty is anticipatory – it requires thought to be given in advance to what disabled children and young people might require and what adjustments might need to be made to prevent that disadvantage” (page 17).

B. the requirement to eliminate discrimination and promote equality of opportunity:

“Public bodies, including further education institutions, local authorities, maintained schools, maintained nursery schools, academies and free schools are covered by the public sector equality duty and, when carrying out their functions, must have regard to the need to eliminate discrimination, promote equality of opportunity and foster good relations between disabled and non-disabled children and young people.

Public bodies also have specific duties under the public sector equality duty and must publish information to demonstrate their compliance with this general duty and must prepare and publish objectives to achieve the core aims of the general duty. Objectives must be specific and measurable. The general duty also applies to bodies that are not public bodies but that carry out public functions. Such bodies include providers of relevant early years education, non-maintained special schools, independent specialist providers and others making provision that is funded from the public purse.” (page 17).



What policy and guidance is there about early intervention for children and young people with a learning disability?

The importance of early intervention is recognised in a range of policy and guidance around support and services for children and young people with learning disabilities, including:

1

Building the Right Support (Local Government Association, Association of Directors of Adult Social Services & NHS England)⁴:

“Care and support should be person-centred, planned, proactive and coordinated – with early intervention and preventative support based on sophisticated risk stratification of the local population, person-centred care and support plans, and local care and support navigators/keyworkers to coordinate services set out in the care and support plan.” (page 25)

2

Ensuring Quality Services (Local Government Association & NHS England)⁵:

“Everyone, with no exception, deserves a place to call home. Person by person, area by area, the number of people with learning disabilities and autism in secure hospitals or assessment and treatment settings will permanently reduce. At the same time local community-based support and early intervention will improve to the point it will become extremely rare for a person to be excluded from the right to live their life outside of a hospital setting.” (page 30)

3

Service Model (Local Government Association, Association of Directors of Adult Social Services and NHS England)⁶:

“All families or carers who are providing care and support for people who display behaviour that challenges should be offered practical and emotional support and access to early intervention programmes, including evidence-based parent training programmes, and other skills training, in line with NICE guidance and which is targeted to meet their specific strengths, challenges and needs.” (page 17)

4

National Institute for Health and Care Excellence (NICE) guidelines on prevention and interventions for people with learning disabilities and challenging behaviour⁷:

Clarifies that services and professionals should: *“Consider parent-training programmes for parents or carers of children with a learning disability who are aged under 12 years with emerging, or at risk of developing, behaviour that challenges”, and “preschool classroom-based interventions for children aged 3–5 years with emerging, or at risk of developing, behaviour that challenges.” (page 21–22)*

5

NICE guidelines on service design and delivery for people with learning disabilities and behaviour that challenges⁸:

“Local authorities must promote the upbringing of children and young people with a learning disability and behaviour that challenges by their families, in line with section 17 of the Children Act 1989. This should include providing a range of services including education, and general and specialist learning disability support services in the community, as an alternative to residential placements away from home and to reduce the potential need for such placements.” (page 27)

6

NICE guidelines on the prevention, assessment and management of mental health problems in people with learning disabilities⁹

“More reliable [mental health case] identification should help with early intervention and provide better outcomes, and earlier identification could also reduce costs for the NHS and social care”. (page 30)

The gap between policy and practice

Despite the benefits of early intervention being recognised and embedded in policies and best practice guidance, in practice targeted early intervention support is not available to the majority of families. Families describe a postcode lottery of services and support, with many local areas unable to meet the needs of children and young people with the most complex needs locally resulting in out of area residential school placements or inpatient admissions.

Key messages

The policies and guidance emphasise the importance of supporting families with evidence based, targeted support including the provision of early intervention programmes. Policy and guidance highlight the need for services and support to be co-ordinated, joined-up and inclusive.

One key driver to invest in early intervention and local community-based support is the avoidance of costly out of area residential placements and inappropriate inpatient admissions.

Drawing on guidance, Integrated Care Systems must work closely with Health and Wellbeing Boards to identify the needs of babies, children, young people and adults in their area and ensure appropriate services are commissioned locally- including early intervention support for children with learning disabilities and their families.

Despite the benefit of early intervention being clearly recognised in national policy and guidance there is currently no evidence of strategic implementation or monitoring of investment and outcomes.



Policy vs Practice

Policy and key reports say:

“Local community-based support and early intervention will improve to the point it will become extremely rare for a person to be excluded from the right to live their life outside of a hospital setting.”⁵

- 2015 (page 30)

Policy and key reports say:

“Our vision is that LAs and CCGs would offer a range of services, including mental health and social care support, to ensure children and young people could be educated locally as far as possible, and local schools and colleges would ensure these children and young people felt welcome there.”¹⁰

- 2017 (page 5)



Residential school placements

1360

Children with learning disabilities and autism placed in residential schools¹¹

“Many of the children and young people currently in residential special schools and colleges could be educated in their local communities if better support was available.”

(Lenehan, 2017)¹⁰ (page 5)

Inpatient beds

190

Children with learning disabilities and/or autism placed in inpatient units¹² (Feb 2022)

“The detention of those with learning disabilities and/or autism is often inappropriate. It causes suffering and does long term damage.”

(Joint Committee on Human Rights, 2019)¹³ (page 18)

The average cost of a 52-week residential school placement is

£171,176

Per child, per year¹⁴

The average cost of an inpatient bed is

£250,000

Per child, per year¹⁴

10,985

Reported uses of restrictive interventions e.g., physical, chemical, mechanical restraint and being kept in isolation in one year for under 18's¹⁵ (Nov 2020 – Dec 2021)

What does the research evidence tell us about children with learning disabilities and their early development?

Inequalities

Children with disabilities are at **greater risk** than non-disabled children of experiencing both social and health inequalities.

Social inequalities

Children with learning disabilities are **more likely to experience a range of social inequalities** than typically developing children¹⁶. (Figure 1)

Research¹⁶ has identified that children with learning disabilities across childhood and adolescence are, compared to other children:

- 1.6 times more likely to be living in a family in **income poverty**
- 2.1 times more likely to have **no adult in paid work** in the household
- 1.4 times more likely to have a mother with **mental health problems**
- 3.3 times more likely to have a mother with **poor physical health**
- 1.5 times more likely to experience two or more negative life events such as **bereavement and sexual abuse**
- 1.5 times more likely to experience **poor family functioning**, for example, a decreased ability to problem solve or talk through problems as a family
- 1.3 times more likely to live in a **single parent household**
- 1.9 times more likely to have a **primary carer with no educational qualifications**



Figure 1. Graph to show the number of children with learning disabilities experiencing social inequalities compared to children without learning disabilities.

Health inequalities

In addition to increased social inequalities, children with learning disabilities are also **more likely to experience health inequalities from an early age** than other children:

- 1.5 times more likely to be obese by 11 years of age¹⁷
- 4.5 times more likely to have a mental health problem¹⁶

Key message

Children with learning disabilities are at increased risk of experiencing social and health inequalities, and multiple layers of inequality.

When do inequalities in outcomes start to emerge?

Inequalities in outcomes for children with learning disabilities emerge very early in child development. For example, children with learning disabilities are more likely to have behavioural and emotional problems i.e., childhood mental health problems aged 3 years old compared to children without learning disabilities.¹⁸ (Figure 2)

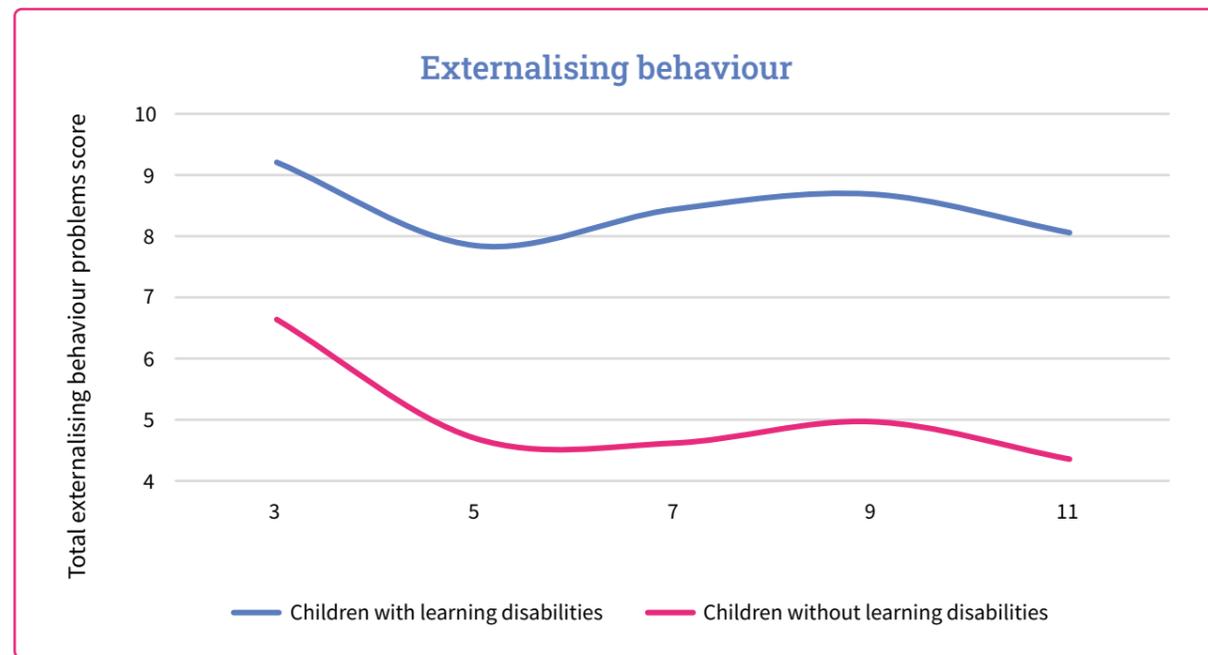


Figure 2. Graph to show the frequency of externalising behaviour problems (conduct problems, hyperactivity etc.) displayed by children with learning disabilities and other children aged 3-11 years.

As shown in Figure 2 above, the inequality in outcomes between children with learning disabilities and other children starts early (by age 3 at latest) and widens over time. Behaviour problems in particular place children at risk of exclusion and social isolation.

Recognising the increased prevalence of emotional problems in children with learning disabilities, a tailored web-based resource has been developed to promote emotional literacy, resilience and wellbeing. This is highlighted in the following case study.



Case study: PELICAN: Promoting Emotional Literacy in Children with Additional Needs

PELICAN: Promoting Emotional Literacy in Children with Additional Needs focuses on supporting children and young people aged 4-18 with learning disabilities to develop emotional literacy skills including noticing and coping with feelings, problem-solving and relaxation.

PELICAN is built from practice-based evidence, evidence-based practice, collaboration and feedback, literature reviews, networking, community of practice and co-production supported by the Foundation for People with Learning Disabilities.

PELICAN's web-based resources include a simple, engaging, visual story showing the PELICAN framework, guidance, resources and session plan examples to equip professionals and parents supporting children and young people with learning disabilities to develop emotional literacy.

The PELICAN framework has 4 'I CAN...' elements which each build on emotional literacy, resilience and wellbeing:

- I CAN Feel: Resources for developing skills in noticing, naming and becoming familiar with feelings,- identifying body signs for these feelings and understanding how they may be connected to situations, and behaviours.
- I CAN Relax: Resources to help notice body signs and situations that induce worry or anger, and different relaxation to calm the body and mind.
- I CAN Think: Resources to help differentiate thoughts and feelings, and helpful and unhelpful thoughts, develop helpful thoughts, and build links between feelings, situations, thoughts and behaviours. This also includes resources to help develop problem solving skills, make goal and coping plans, use flexible thinking and other PELICAN skills.
- I CAN Do: Resources to help the individual to practice, be rewarded for trying, use support and have fun!

Key message

Children with learning disabilities are more likely to display behavioural and emotional problems than other children from an early age. The disparity between children with learning disabilities and other children increases over time.



Figure 3. The four elements of the PELICAN framework from its web-based resources

Feedback and outcomes:

As PELICAN was completed and launched during the pandemic, it has been difficult to systematically measure the impact of implementation.

During the development phase, reported outcomes of PELICAN learning from children and young people with learning disabilities, their families and practitioners included:

“Using new skills when upset with my brother & going to bedroom to cool down”

“Fewer incidents of walking out of lessons”

Feedback from practitioners on the PELICAN story, framework, resources and on activities from the website and some pilot training include:

“Amazing”

“Incredibly useful resources”

What next?

We aim to continue sharing and growing PELICAN practice across a range of settings (including with families), develop some demonstration videos for the web and seek funds for more systematic evaluation.

Further information and copies of the free resources are available [here](#).

Why should we intervene early?

Theory, and to a certain extent research evidence on early intervention, suggests that if you intervene early and support young children with learning disabilities you can change their developmental trajectory and reduce the gap in outcomes between children with learning disabilities and other children.

At an early age, key developmental skills (e.g., communication, language, social skills, motor skills) would be the focus for early intervention. This is because these are bedrock or pivotal skills that contribute to all later developmental outcomes. If we can improve these early on for children with learning disabilities, other later skills are more likely to follow either naturally or with less intensive later support. In addition, these pivotal early skills, if not developed early on, increase the risk of later problems for children with learning disabilities (including challenging behaviour and mental health difficulties). Thus, early intervention focused on pivotal developmental skills is also likely to contribute to prevention of later problems.

“We began to see behaviours that could be described as challenging when Lucy was two or three, but thanks to the skills and knowledge that I’ve been fortunate enough to learn, Lucy rarely needs to use these behaviours to communicate, and our lives have been transformed as a result. My early intervention experience, especially learning about positive behavioural support utterly changed our lives. It has enabled us to expand Lucy’s world in ways I could never have imagined were possible”

- Debbie Austin, mother of Lucy, a child with a severe learning disability, describing her early intervention experience



For these reasons, it is important to start intervening at an early age. If early intervention support commences later in a child’s life (i.e., compulsory school age or later) significantly more input is needed to see benefit. A benefit may still be apparent, but there may be less impact.

Children with learning disabilities will require continued support and services when they are older, but it is important to start intervening in the early years to narrow the gap in outcomes between children with learning disabilities and other children.



Key message

Intervening early to support children with learning disabilities has the potential to change the trajectory of development and decrease the inequality in outcomes between children with learning disabilities and their peers.

Families' experiences of early intervention in the UK

Unmet needs in the early years

Access to support and services for families of pre-school children is usually via health professionals e.g., health visitor, GP, or Paediatrician.

UK research shows that, on average, although families of pre-school children with learning disabilities are typically in contact with a lot of different professionals and services, **this does not necessarily lead to focused early intervention support**¹⁹.

The graph below shows the percentage of parents of children with learning disabilities who accessed support from a range of professionals over a 12-month period and those who wanted to access support but were unable to do so - indicating unmet need.

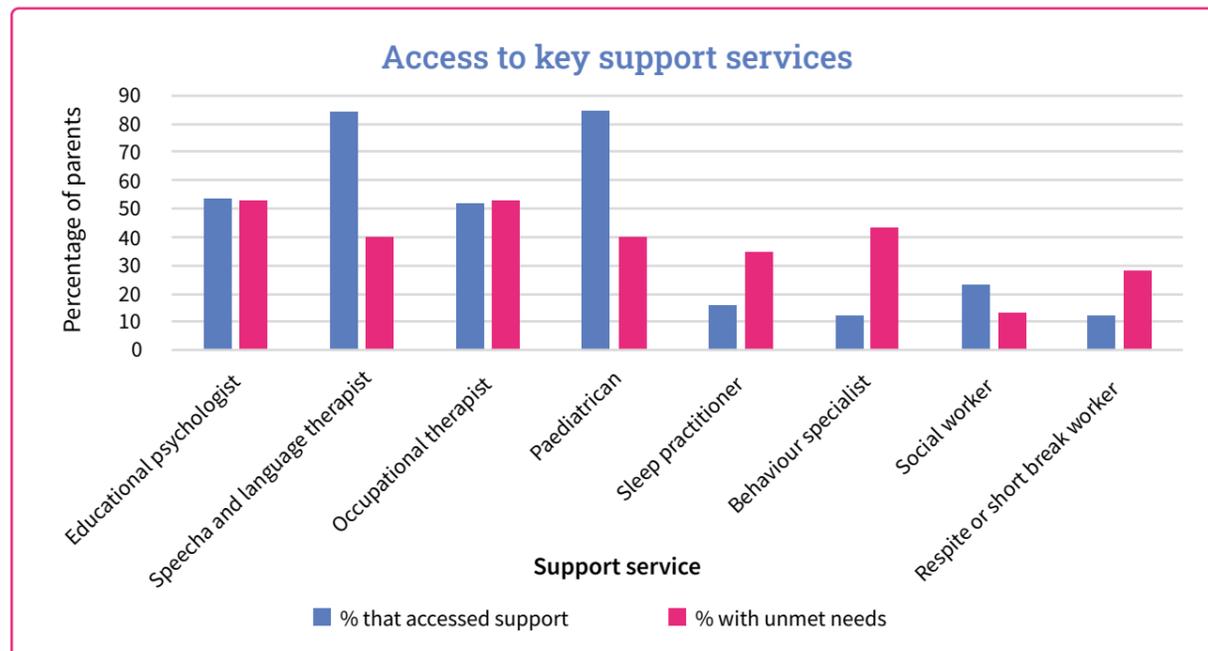


Figure 4. A graph to show the percentage of parents who accessed key support services, compared to those left with unmet needs over a 12-month period

The highest levels of unmet needs were in accessing support from an occupational therapist (52.9%), educational psychologist (52.8%), behaviour specialist (43%), paediatrician (40%) and sleep practitioners (34.8%). Unmet needs were shown to arise due to limited availability or capability of services and demand for support¹⁹ (Figure 4).

This recent UK study of over 600 families found that **less than 30%** of families in the UK who have a child with a learning disability had access to targeted early intervention support in the preceding 12 months¹⁹.

This same study also evidenced significant areas of unmet needs in the early years including:

- Educational support
- Child needs (e.g., communication, behaviour, sleep)
- Family support/short breaks
- Access to some specific health professionals (occupational therapy, dental and paediatrics).

The most frequently mentioned barriers to accessing early intervention support within this study were:

- Barriers for caregivers (limited resources, knowledge, and time)
- Lack of sufficient services (absence of available services, insufficient resources and capacity, lack of continuity, inflexible services)
- Unhelpful professionals (limited knowledge, negative engagement, and actions).

The most commonly reported facilitators of early intervention were:

- Supportive and competent professionals (positive attitudes, proactive engagement, knowledgeable)
- Empowered parental caregivers (access to resources, skills and knowledge, proactive behaviours, support from others)
- Accessible services (features of service delivery, flexibility, provision of resources, availability, continuity)

A key enabler of early support is early identification of needs to ensure that the support that a child requires is provided at the earliest opportunity²⁰

Key messages

More needs to be done to identify when support may need to be put in place for children, based on early indicators that they may need additional provision.

Recent UK based research evidences that only a minority of families (less than 30%) who have a child with a learning disability currently have access to targeted early intervention support and services.

One initiative aiming to address the unmet needs of families is a collaboration between the Institute of Health Visiting and charities. This is detailed in the case study below:

Case study: Changing conversations – understanding behaviour

“Working with families to understand behaviour and reduce restrictive practice”.

In partnership with CBF, Contact, Pathways and The Sleep Charity, this project, funded by the Burdett Trust for Nursing aimed to raise awareness of restrictive practice in the early years. There was a need for awareness raising and support within health visiting as parents reported restrictive practice being used with children aged 1-3 years, and that this continues throughout their life, limiting opportunities and reducing quality of life.

The project was initiated following a survey of parents. This found that restrictive practices are reported to be used with children with SEND and before the age of 2 years old. Parents felt unsupported and didn't know where to find support.

A survey of health visitors identified a lack of understanding around how to support behaviour, what restrictive practice was in early years and what it might look like. The survey identified the need to recognise restrictive interventions and increase awareness of ways to use proportionate restrictions if needed to keep the child safe, particularly within early years.



Co-production

Working alongside parents and practitioners, a training resource for health visitors, and an animation have been created. The animation was created using a compilation of stories to create a powerful story of a young girl and how restrictive practice became a part of her daily life. It shows the impact on both her and her family, as well as what can be done differently to understand behaviour and promote the least restrictive approach.

Training

A series of training sessions were delivered for health visitors which introduced the animation and offered practical advice to support practice.

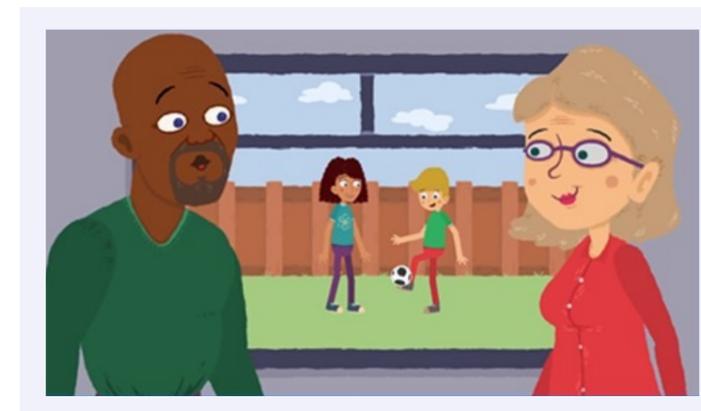


Figure 5. Image from the Changing Conversations animation

The training sessions were delivered to health visitors across the UK.

Feedback

“I have a much better understanding of what constitutes restrictive practice and feel able to support parents to use more positive strategies for long term benefit.”

- health visitor

“This workshop has raised my awareness about something that I had not considered before and that I am aware my colleagues also do not understand.”

- health visitor

The animation is available [here](#).

Early intervention in action

In this report we have highlighted some of the early support that is currently being provided to children, young people and their families.

The case study below describes an early years support programme which is specifically tailored to family carers of children with development disabilities.

Case study: Early Positive Approaches to Support (E-PAtS)

An early years support programme for family carers of children with developmental disabilities was developed by Dr Nick Gore at the University of Kent.

Early Positive Approaches to Support (E-PAtS) is a group support programme delivered to families of children who are aged 5 years and under with additional developmental needs (thought to have an intellectual disability or to be autistic).



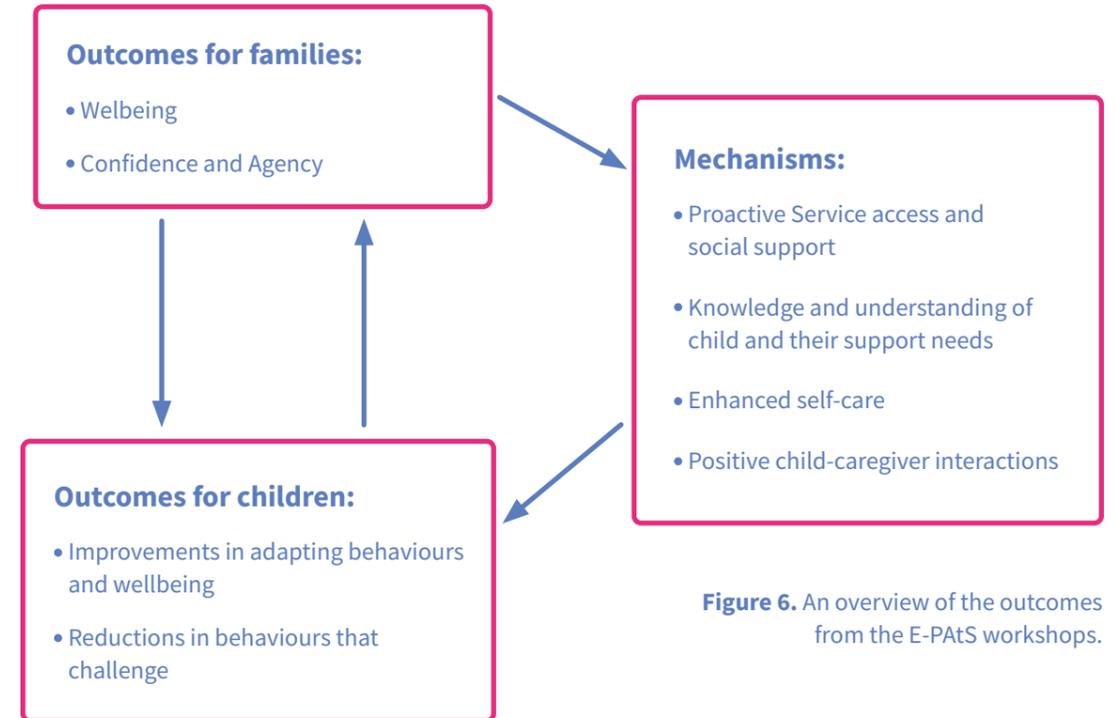
Dr Nick Gore. Copyright ©2012, University of Kent, UK. All rights reserved

There are 8 sessions each lasting for 2.5 hours that cover:

- 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

The sessions are co-produced through ongoing partnership working with family caregivers (starting in 2012). They are routinely co-facilitated by trained family caregivers and a practitioner.

Outcomes



Dr Nick Gore. Copyright ©2012, University of Kent, UK. All rights reserved

Figure 6. An overview of the outcomes from the E-PAtS workshops.

A feasibility trial²¹ found good indications of greater improvements in wellbeing for families who attended E-PAtS relative to those receiving 'treatment as usual'.

What next?

Funding is currently being sought for a full-scale research study to assess the impact and cost effectiveness of E-PAtS.

“After the course I was like you know what, take a deep breath, calm, speak to him in a low voice, get down on his level. And I see the tantrums, they have lessened.”

- Parent

The case study below is an example of delivering E-PAtS in a local area as part of an asset-based community development approach.

Case study: Early intervention in Newham – Asset Based Community Development

A programme of early support has been running since 2019 in Newham with families of children aged 0-7 years in a collaborative project facilitated by Mencap.

What is Asset Based Community Development (ABCD)?

Mencap are taking an asset-based approach. This approach recognises that communities hold the strengths they need to find solutions; they just need to be identified – this is known as Asset Based Community Development (ABCD). The premise of this is that communities can drive their own development by mobilising existing, but often unrecognised assets including individuals, associations, institutions, places, and connections. This means sharing power between families and decision makers so families can co-produce the services they need.

In this context, Mencap are working with the existing systems, networks and structures that currently support families in Newham, and mobilising parents with lived experience to shape and co-deliver a shared vision. Working in partnership to strengthen and enhance the system and develop more opportunities for collaboration and co-creation with families.

Co-production

Co-production is central to the approach in Newham. Support is developed and delivered alongside and in equal partnership with families. Co-production brings people together to connect roles and skills. This develops a culture based on shared understanding, relationship and trust building, and empowerment.

Diversity

There is also a focus on socioeconomic context, and the diverse and transient communities in Newham. People are treated as equals and their skills and gifts are built on. People get good advice and information based on their individual needs.

E-PAtS – Early Positive Approaches to Support

The biggest facilitator of the early intervention approach in Newham is E-PAtS, which has been available since 2018, predominantly delivered within Children’s Centres. Newham now have over 20 facilitators trained to deliver E-PAtS across the borough.

Family connectors

The Family Connector role was launched in April 2021. Parents with lived experience take on this paid role, providing emotional support to parents and walking the journey alongside them. Family connectors have been reaching out, facilitating workshops and peer support, translating for parents delivering E-PAtS and building relationships with community practitioners.

Outcomes

“Parents have really felt valued. They were able to share their experiences and anxieties with other parents that they felt could relate to them.”

- Alberta Ossoulo, Family Connector

“The best thing about working together in this programme for me is to have more understanding and tolerance, acknowledge the expertise of parents. Celebrate differences, make families feel they are part of the community.”

- Ieva Jupe, Family Partner



Figure 7. An overview of the early intervention services and support in Newham

“We are committed to a partnership approach because we can achieve more together. We are seeing changes over time that mean parents are being supported earlier. Parents with lived experience are guiding other parents through the SEND system in Newham and taking them along the path that they have already walked upon themselves which is so powerful.

The biggest facilitator is the E-PAtS programme, it has been absolutely amazing. This is the programme that professionals want to refer parents to. E-PAtS co-facilitators are now part of wider discussions in Newham. It has been so powerful in the borough. Our biggest asset is our

parents: they are making sure that we are developing a SEND community where there is always someone to be there for you if you need them.

We are seeing a reduction in duplication where services are pulling together and working more closely which gives everyone more room and flexibility to do other things.”

- Tracey Schofield, 0-5 Collaborative early years quality improvement manager, London Borough of Newham

What next?

Newham aim to continue developing the approach to further embed the vision by becoming more visible and known to families. This includes building connections through peer support networks, outreach, and collaboration with local organisations.

For more information: [Stories from Newham - Strength, Empower, Nurture - YouTube](#)

While early intervention in the early years has the strongest impact, effective interventions can improve children's life chances at any point during childhood and adolescence. The Intensive Positive Behavioural Support Services (iPBS-LD) detailed on the next page delivers support to avoid costly out of area placements.



“Positive Behaviour Support (PBS) is about working in partnership with people, treating them with dignity and respect and enabling them to have a better life. All behaviours have a meaning. Positive Behaviour Support aims to understand what behaviours that challenge tell us so that the person's needs can be met in better ways. The way the person is supported often has to change to achieve this and this needs to be regularly reviewed by all the people involved. Positive Behaviour Support is an approach that puts the person at the centre to make systems work for the person.” - (BILD)²²

Case study: Intensive Positive Behavioural Support Services (iPBS-LD)²³

About iPBS services

iPBS is provided to children and young people with learning disabilities and/or autism who are at risk of admission to an inpatient service. Most of the young people are male, with an average age of 11, a majority also have a diagnosis of autism. The primary reason for referral is often aggression and the average duration of support is 20 months.

iPBS aims to improve the quality of life for young people and their families, reduce challenging behaviours, and reduce the likelihood of out of area placements.

The key elements of iPBS include being person centered, building positive relationships, being skills focused and working long term. iPBS was first commissioned in Bristol in 2005, extending to South Gloucestershire in 2014. Bristol supports 4 children/young people, and South Gloucestershire supports 8 children/young people. The team consists of clinical psychologists, behaviour analysts, nurses, and assistant psychologists.

Outcomes

The team measure a number of outcomes for each child including aggression towards others and an assessment of functional living skills.



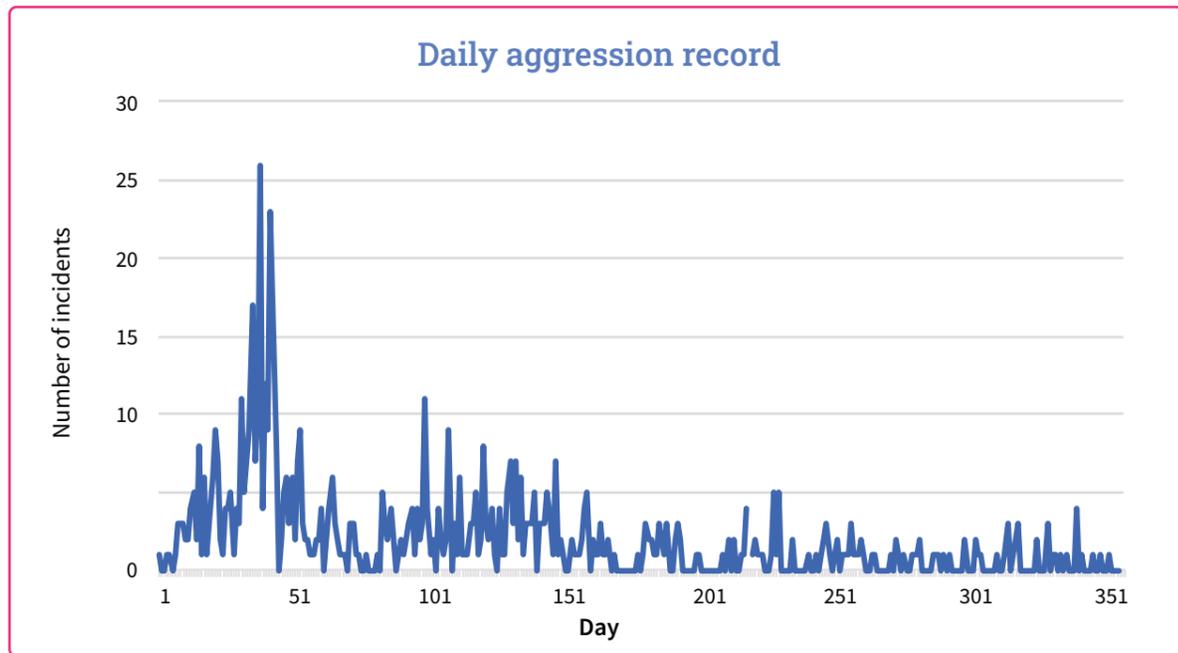


Figure 8. A graph to show the number of incidents of aggression

Figure 8 displays the outcomes for one young person accessing the service. This shows that over time physical aggression was reduced from a peak of twenty-five incidents per day to zero over the course of a year.

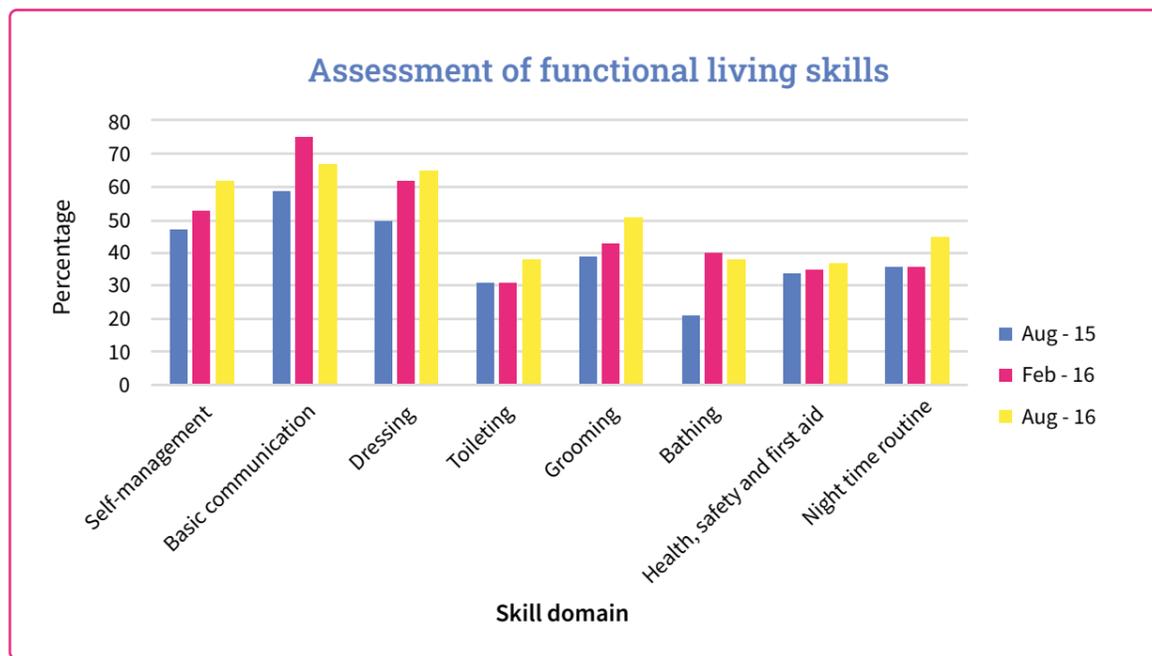


Figure 9. A graph to show the functional living skills of a child at 3 time points

The increase in functional skills and associated reduction in challenging behaviour enabled the young person to remain living with their family and attend a local school (Figure 9).

The iPBS service is provided late on in a child's life in order to avoid costly out of area placements. A financial review of the iPBS in Bristol calculated that, over four years, the iPBS produced savings of **£1.8 million**.

Recommendation to intervene earlier

The iPBS-LD service has identified that the key needs of most children are communication skills. Communication skills can be taught earlier and therefore improving functional skills and communication is key to improving outcomes for children with learning disabilities.



The economic case

Services and support for children and young people in crisis are costly in human and financial terms. There is an economic case for investing in high quality early intervention to deliver better outcomes:

“We know that investing in high-quality, evidence-informed early intervention can lead to better outcomes from public spending... The evidence shows that this investment will lead to large pay-offs, for children and families themselves, for local communities and for the wider economy.”

- Early Intervention Foundation²⁴

Early intervention makes good human sense

Elliot's story illustrates a well-trodden pathway of a failure to provide early support and exclusion from local services in adolescence leading to a high-cost placement and a restricted life in adulthood. It is possible to identify children and young people at risk of exclusion earlier on, such as via a dynamic risk register, and provide support to prevent a pathway of exclusion.



Case study: Elliot

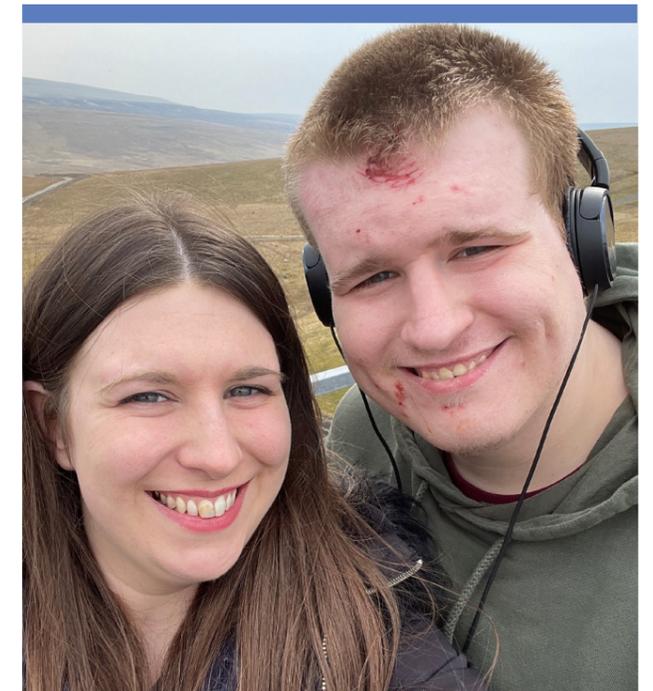
Elliot is 26 years old. He has a wicked sense of humour.

He has a diagnosis of moderate learning disabilities, autism and complex PTSD (Post Traumatic Stress Disorder). Elliot went to a special needs school from the age of 6. Once Elliot reached puberty his behaviours changed. The school excluded him as they were unable to support him. At the age of 16, he was not in education.

He is currently detained under the Mental Health Act and placed in an inpatient unit. He has been an inpatient for 4 years and has spent significant periods of time in isolation. Despite an independent review recommending steps should be taken to formulate a community care package for him he remains detained with no discharge date. Based on an average cost of £3,449 per week for an inpatient bed in 2015²⁵ we estimate the cost of Elliot's placement over 4 years would be in the region of £717,392.

“Elliot was sectioned because the support he needed wasn't available in the community. It is a constant battle to fight for the basic help for his needs and to find professionals who understand and are experts in autism. Elliot's needs are complex, but he does not deserve to be shut away, detained in isolation. I wish the information about how to intervene early was available 20 years ago. Life for Elliot would have been very different and much more positive if we had access to this support.”

- Beckii Davis, sibling



Early intervention makes good economic sense

Across all children there is a clear case for the economic benefit of early intervention. If you intervene early, the gain you achieve is much greater than later interventions.

“Early interventions targeted toward disadvantaged children have much higher returns than later interventions.”²⁶

There is limited direct economic evidence available in relation to early intervention in children with learning disabilities. Investment is needed in research to address this gap. Ethical considerations and the scale and long-term nature of data collection required make it hard to provide evidence on the long-term economic benefit of early intervention support for children with learning disabilities. This issue of difficulties generating long-term evidence for early intervention is not unique to learning disabilities. It relates to the general challenge of gathering data about early intervention in terms of its impact on children’s lives over decades.

There is, however, case study evidence that demonstrates that early intervention approaches deliver good outcomes for children and families and are cost effective.

The following two case studies are examples of services that have been successful in preventing residential placements for young people with learning disabilities. They have been able to evidence cost effectiveness by identifying the savings generated from preventing such residential placements.



Case study: Ealing Intensive Therapeutic and Short Breaks Service (ITSBS) – Preventing residential placements for young people with learning disabilities and challenging behaviours

The Ealing Intensive Therapeutic and Short Breaks Service aims to prevent unnecessary residential care placement for children and young people with learning disabilities enabling them to remain in their family home or local community.

It provides intensive, psychology and social care input to the young person, family and frontline workers, including additional/intensive short breaks as needed.

The service has provided support to children aged 7-17 years with an average age of 12 years old. All the children attend a special needs school except one. Many children accessing the service are from single parent families and families with no adults working in the household.

Out of 47 children who have accessed the service 8 are currently living in a residential placement. Ealing has one of the lowest numbers of children in residential care in the South East. No children accessing the ITSBS have been admitted to an inpatient bed in the last four years.

Outcomes

The children show a significant reduction in challenging behaviour and parental concerns.

“As a result of the work our child is now sleeping at night, she is calmer, happier, and levels of self-injurious behaviour have reduced a lot. The whole family feel happier and less stressed now – it has had a positive effect on all of us.” - Parent

The results achieved by Ealing ITSBS are

“exceptional, with research showing improved outcomes for children and their families, as well as substantial savings for the local authority, by avoiding the need for residential placements.” - (Christine Lenehan)²⁷

Children are more likely to stay in the community when receiving this type of intervention, and families are better able to cope, thus improving the quality for the young person and their family.²⁸

Cost effectiveness

The annual cost of intensive support and follow up for 7 young people was circa £110,000, less than the average cost of just one residential placement. Collaboration with London School of Economics to complete an economic evaluation indicated even when accounting for additional costs of children remaining locally, Ealing ITSBS is significantly cheaper than placing children in residential schools.²⁹

“The Ealing Service shows that a crisis does not have to result in an unplanned admission to hospital or a move to a 52-week school. Crises can be well-managed locally in what look very cost-effective ways using a positive behavioural support approach.” - Professor Martin Knapp, LSE

Case study: Affinity Trust. Intensive support for children and young people with learning disabilities

Jake*, aged seven, always had a smile on his face. He loved swimming, trampolining and playing with his trains.

But at home, he was often challenging, causing severe injuries to his mother and grandparents and serious damage to the family home. In the community, he would lunge at his mother when she was driving and he caused significant damage to the family vehicle.

Following a Functional Analysis a Positive Behaviour Support plan was co-produced with Jake's family and school. This was written for everyone in Jake's care team to use, with one commenting:

"It's amazing to see this much work go into one child's plan."

Among other things the outcomes achieved were:

- Making Jake's daily routines more predictable
- Improved expressive and receptive communication
- Facilitating safe community outings with minimal incidents
- Development of healthy sleep routines and dietary choices

Within six months, Jake was making exceptional progress. Jake is now sleeping in his own room. His diet is healthier and more varied. Jake's mother has reported no aggression or property damage, commenting:

"Jake is like a different child now."

As a result, the Affinity Trust has been able to stop working intensively with Jake and his family. The intensive work has supported Jake to remain living at home with his mum and avoided a costly and unnecessary residential care package.

Over the 10 year lifetime of this contract, the Council involved calculates that the Affinity Trust Positive Behaviour Support service will reduce their costs by at least **£1.9m**.

The average cost per annum of one of the Affinity Trust PBS services is £52,000 per child. The most common range for specialist residential placements was between £2500 and £3499 per week^{25 30}. The Median average of this figure has been selected to be conservative which is £3000 – so a total of £150,000 per year per child.

If the young person remains living with their family there is a saving of £100,000 per annum per young person. The Affinity Trust PBS service average cost is £220,000 per annum working with 4 to 5 young people at any one time. Therefore if 4 young people remain out of specialist residential services due to the Affinity Trust PBS service, an average cost avoidance of £400,000 per year is secured. Even taking into account additional costs such as short breaks for the family the council calculates a six figure saving.

*Child's name has been changed to protect his identity

Shifting the balance to allow greater prevention is likely to reduce costs – both "financial" and "human" on a long-term basis. This is an important challenge that requires a co-ordinated response to develop community based early intervention services and support.

"The challenge facing commissioners is as much about preventing new admissions and reducing the time people spend in inpatient care by providing alternative care and support, as it is about discharging those individuals currently in hospital. The task requires: advocacy, early intervention, prevention, ensuring the right set of services are available in the community."

- Building the Right Support.⁴

It is important to consider the meaning of "effective" and "worth" when evaluating cost effectiveness. A policy or service does not have to be cheaper to be cost effective. It just has to be "worth it" - delivering added value in terms of the outcomes for children, families and society.

Key messages

Early intervention is a key element to improve the health, wellbeing and quality of life of children with learning disabilities. It is also crucial to make a successful shift away from inpatient admissions and residential school placements towards children, young people and adults living in their local communities.

Intervening early not only makes good human sense but makes good economic sense in terms of both potential cost savings and also increasing the societal economic contribution that can be made by families of disabled children.

The impact of the pandemic

Covid-19 and the national restrictions affected all our lives. Children with special educational needs and disabilities (SEND) have been particularly adversely affected by Covid-19. Ofsted found that longstanding issues with the SEND system have been exacerbated by the pandemic:

“We know that many children and young people with SEND, and their families were already experiencing flaws in the services that they were receiving before the first national lockdown began in March 2020. There were also many existing concerns about their outcomes. The effects of the pandemic and the related lockdowns served to exacerbate these issues enormously.”³¹

Children with SEND and their families reported missed and narrowed education, a suspension or reduction in essential services (such as physiotherapy or speech and language therapy) and long waiting times for assessment and treatment. This left many families who were persistently unable to access essential services feeling “exhausted” and some “despairing.”^{32 33 34 35}

Other UK based research also found that children with SEND were particularly affected by the fragmentation of the SEND support system as the result of changes due to Covid-19³⁶. In particular Special Educational Need Co-ordinators highlighted additional barriers when trying to liaise with professionals beyond the early years setting with many external agencies such as occupational therapy,

physiotherapy, speech and language therapy no longer visiting nurseries to complete assessments or update plans.

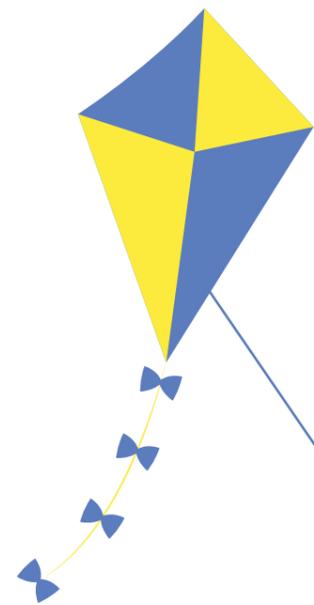
Concern was expressed about children whose communication skills have been negatively impacted by Covid-19. The communication charity ICAN surveyed teachers during the pandemic and found that 62% of primary teachers who have pupils who are behind with their speaking or understanding are worried that these pupils will not be able to catch up³⁷.

Ofsted³² also reported an impact on the development of young children, particularly those with SEND:

“Almost all children felt the impact of COVID-19 and the resulting restrictions to some extent. Many of the youngest children had their development and progress hampered, with some even regressing...Many of those with special educational needs and/or disabilities (SEND) were not able to access the support they rely on.”

Key message

The COVID-19 pandemic has exacerbated existing inequalities. Children and young people with learning disabilities should be prioritised in recovery plans and provided with support targeted to their needs.



Conclusions and key recommendations

All children deserve the best start in life. To make this a reality for children with learning disabilities health, education and social care need to work closely together to deliver targeted early intervention support. Effective local area leadership is key.

We would encourage commissioners to use evidence and examples, such as those included in this report, to inform future decisions.

Due to the number of factors that affect a child’s early years, there is a clear need for a strategic and multi-faceted approach to deliver effective early years policy. Solutions must holistically support the child, the family and their socio-economic context. Working with the child and their family, a whole family approach is central to the success of early intervention.

How should we intervene?

Based on the evidence presented in this report, to improve outcomes for children with learning disabilities we recommend a focus on providing early support in the following areas:

1. Empowering and equipping families to meet the needs of their child

Families caring for a child with a learning disability require targeted early intervention support to empower and equip them to meet their child’s additional needs.

Programmes tailored to the needs of families who have children with developmental delays are needed. These need to focus on empowering parents and carers to build their child’s skills (e.g., communication skills) and equip them to effectively support any difficulties with sleep or behaviours that challenge.

This support helps to prevent behavioural and emotional problems developing, and, where they do develop, enables families to respond to reduce distress and maximise their child’s wellbeing.

2. Investing in the wellbeing of family carers

The family unit is a really important context in child development. To improve outcomes for children with learning disabilities it is essential to take a whole family approach and invest in providing support to parents of children with learning disabilities. Services and professionals need to work effectively to reduce family stressors, family adversity and parents’ emotional

distress³⁸. Parents then stand a better chance of maintaining good physical and mental health, also increasing their capacity to effectively support their child.

Family carer wellbeing can be supported in a number of ways including by providing a variety of short breaks³⁹, access to affordable childcare, emotional support, peer to peer support and empowering family carers with information.

Integrated Care Systems should co-design and commission programmes of support addressing parental mental and physical health, tailored to the needs of families of children with learning disabilities. A full range of services with flexibility to meet individual families’ circumstances should be available.

3. Workforce development

To reduce inequalities, it is necessary to intervene early and increase the range and availability of early years support with a particular focus on support that is targeted to meet the needs of families who have a child with a learning disability. To achieve this, workforce development is required to ensure frontline staff are equipped with the right skills and expertise to deliver evidence based early intervention support. It should have a particular focus on the development of key skills such as communication, social and emotional and motor skills.

4. Timely access to specialist support

Every local area should provide timely access to a range of specialist local services for both children and their families that support the implementation of early intervention such as speech and language therapy. Local teams require a multi-disciplinary approach to enable an effective response to children’s and families’ needs.

In addition, as outlined earlier in this report, when difficulties arise in later childhood or adolescence timely access to specialist services can improve outcomes and prevent costly residential care and inpatient placements. Key features of these services are set out in the NHS Long Term Plan⁴⁰, within NICE guidance⁸ and Building the Right Support⁴. In addition to their preventive role, these services should be available 24 hours a day seven days a week to respond effectively to crisis situations.

Opportunities to improve early intervention support

Proposed systems changes (e.g. the introduction of Integrated Care Systems and Family Hubs as well as proposals to reform the SEND system⁴¹) present opportunities to improve early intervention support. The following recommendations identify how these opportunities could be used to improve early intervention support for children and young people with learning disabilities and their families:

- 1.** The new Family Hubs provide an opportunity to enable families to access support, information and advice and the wider peer-to-peer support that is required. We recommend that they are developed with the needs of children with SEND in mind and have appropriately trained specialist staff.
- 2.** There are proposals in the SEND Review for national standards for provision for children with different types of need. If such standards are developed, they must include standards for early intervention services and support for children with learning disabilities and their families.
- 3.** Integrated Care Systems (ICSs) should ensure better join up between health and social care to enable both sectors to intervene in a more timely way. Integrated Care Boards (ICBs) within ICSs have a key role in ensuring implementation and holding system partners to account. Learning disability and autism expertise is required on each ICB to ensure an effective strategic plan is developed and delivered and outcomes are monitored. The learning disability and autism lead on the ICB should provide leadership and ensure that early intervention is encouraged in the new systems' strategic approaches to meeting the needs of their local population, including children and young people with a learning disability.

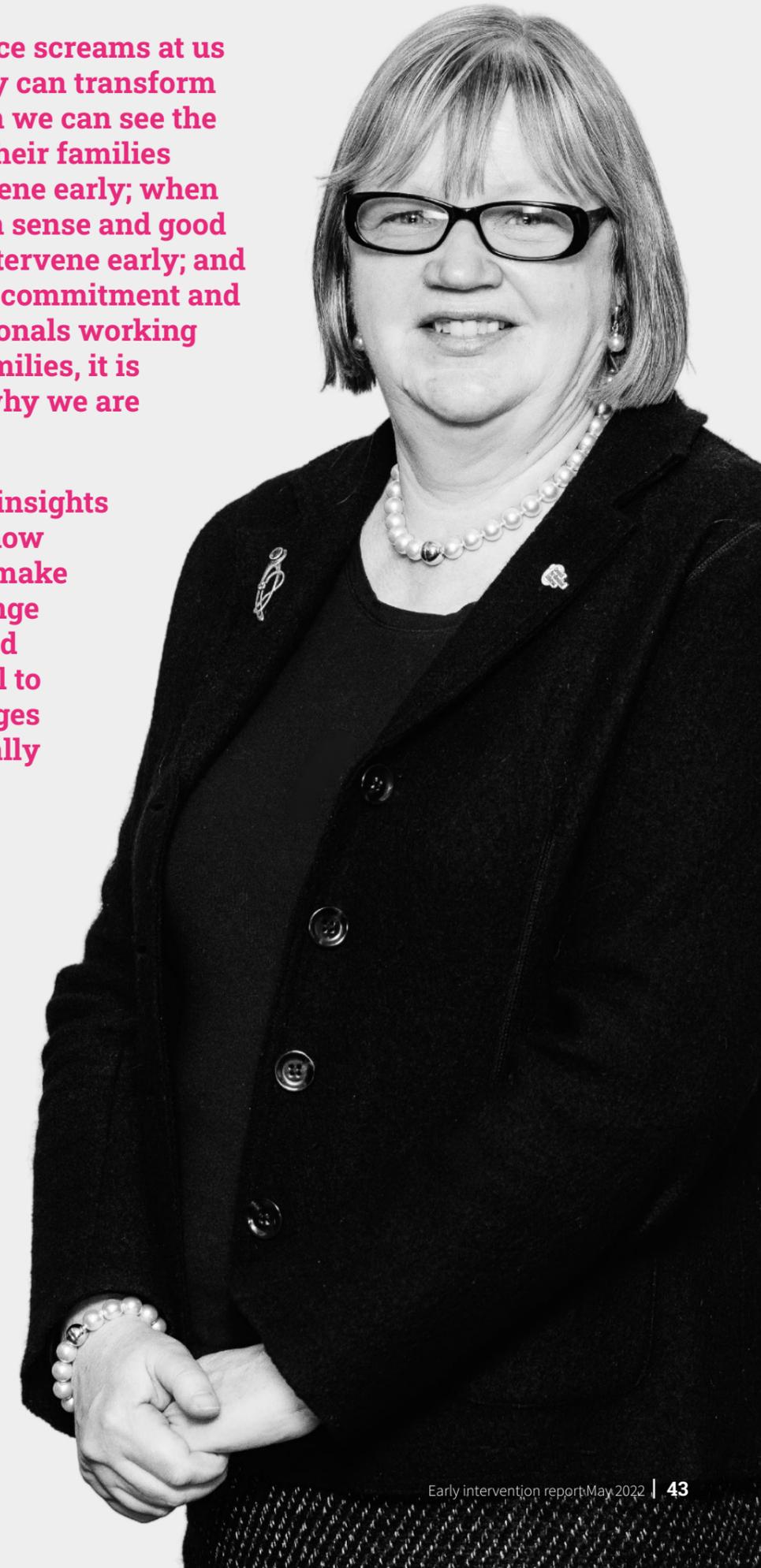
- 4.** Investment in early intervention. Allocating specific and adequate resources to early intervention for children and young people with learning disabilities is required to turn the vision of early intervention set out in national policy into reality on the ground. For example, the Disability Access Fund should be reviewed to assess whether additional approaches and funding is required to enable families of disabled children to access high quality childcare.

As outlined in detail earlier in this report underlying the work on early intervention, there are social and health inequalities that disproportionately affect children with learning disabilities. Social inequalities and health inequalities represent differences in experiences that we **can** do something about at a societal and public health prevention level. As part of a holistic approach, these need to be addressed if we are to reduce early adversity and associated negative outcomes.

“When all the evidence screams at us that intervening early can transform children’s lives; when we can see the toll on children and their families when we don’t intervene early; when it makes good human sense and good economic sense to intervene early; and when we can see the commitment and creativity of professionals working with children and families, it is hard to understand why we are not doing more.”

This report provides insights and examples that show the difference it can make and how we can change for the better. We need to use this report well to bring about the changes that we need, nationally and locally, to ensure children and young people secure better outcomes, realise their ambitions and live full lives with their family and in their community. There is no more important indicator of our national wellbeing and of our fundamental humanity.”

- Dame Christine Lenehan,
Director, Council for Disabled Children



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