



## **Disability Matters in Britain 2016:**

Enablers and challenges to inclusion for disabled children, young people and their families

[www.disabilitymatters.org.uk](http://www.disabilitymatters.org.uk)

"Progress is impossible without change, and those who cannot change their minds cannot change anything."

**George Bernard Shaw**  
Nobel Prize-winning playwright



## Overview

<b>Foreword</b> .....	<b>4</b>
<b>Introduction</b> .....	<b>6</b>
<b>Executive Summary</b> .....	<b>8</b>
<b>1. From Infancy</b>	
Ensuring the Best Start in Life.....	14
Equal Access in Action .....	16
Diagnostic Overshadowing .....	18
Attitudes in Healthcare .....	20
Empowering Parent Carers.....	22
Building Inclusive Communities.....	23
<b>2. Childhood</b>	
Having Fun .....	30
Why Can't I Join In?.....	32
Behaviour that Challenges .....	34
Creating Welcoming Environments .....	36
Primary School .....	40
What Inclusion Means to Us.....	44
<b>3. Teenage Years</b>	
Growing Up.....	48
Socialising and Friendship .....	50
Multimedia Advocacy .....	56
Teen Health and Wellbeing.....	58
Vital Role of School Nursing.....	62
Senior School.....	65
Signposting and Information .....	72
<b>4. Young Adulthood</b>	
Transition from Child to Adult Services .....	76
Further Education .....	78
Employment .....	80
<b>5. Summary</b>	
What You Can Do .....	88
Acknowledgements .....	90
Useful Links .....	91

## Foreword

**Childhood disability is an area that evokes great sympathy and interest, but where the obstacles to inclusion remain considerable, despite decades of attention having been paid to the issue.**

Healthcare is able to do more than ever to enable children with illnesses and impairment to survive – and many more children with rare conditions are surviving into adulthood, where previously they would have died. But services are not always coordinated, transitions are difficult, and families still do not get the support they need.

One of the difficulties in the field of childhood disability is that there remains a lack of research. For example, even on the most contentious question, of whether inclusive or special schools have the best educational and social outcomes for disabled children, there is no conclusive evidence either way. In particular, there is still not enough research that listens to disabled children themselves.

But, nevertheless, there are many examples of good practice, and many simple changes that can enable children and families to flourish better. It is heartening to see so many tips and testimonies in this report, which I am certain will be of benefit to many practitioners and families. I can imagine sharing this document with my medical students at Norwich Medical School, for example, as well as with my child psychology colleagues.

**One of the difficulties in the field of childhood disability is that there remains a lack of research.**

Above all, a shift in thinking is needed, away from the traditional, medicalised, individual mindset, to the human rights approach, which pays equal attention to environments and attitudes, as well as to health conditions. Children with disabilities are doubly protected – by the Convention on the Rights of the Child, and by the Convention on the Rights of Persons with Disabilities. What comes through clearly from these global treaties is the right to participation on an equal basis with others; the right to be heard; and the principle of the welfare of the child. These principles are very relevant at the local level, not just at the UN headquarters.

Children do not want to be defined as special or to stand out as different. More than anything, they want to be accepted and included by their peers. Our challenge is to deliver the support that may be needed, in ways that do not further stigmatise young people. Parents have to learn this, as do professionals. Partnership, between different professionals, and with parents as equals, and always with the young person at the centre, has to be the way forward.

**Tom Shakespeare**

**Tom Shakespeare**

Professor of Disability Research, Norwich Medical School, University of East Anglia



## Introduction

**On 3 December 2015, the UN issued a global blueprint for disability action that called on society to “leave no one behind”.<sup>1</sup>**

Inspired by this challenge, Disability Matters launched a **Call for Evidence on Inclusion** in February 2016.

We asked disabled young people and their parent carers about their experiences (positive and negative) of inclusion, and how easy they had found it to access education, leisure and social activities, health providers, community services, and further training or work during 2015.

We also invited educators, health professionals, community workers, volunteers, training providers and employers to tell us about the different ways they ensure that disabled people are included in their service or community, the challenges they’ve overcome and how their actions have benefited the people they engage with.<sup>2</sup>

We heard inspirational stories from young people and parent carers, as well as from professionals and volunteers who are delivering truly inclusive services, working together with families to achieve incredible results.

We also received heartbreaking testimony from parent carers who are tired of struggling, who feel alone and abandoned

by society, and who see their disabled children, young people and adults excluded from the community, discriminated against by successive cuts in government funding and denied access to the very services that are meant to help them. They told us in no uncertain terms that there is so much more we could all be doing: as individuals, as communities, as providers and as commissioners of vital services.

This report highlights the organisations whose approach to inclusion stood out from the crowd, and celebrates the flexibility, ingenuity and willingness of the individuals and teams who deliver their services. We also explore the frustrations and barriers faced by families in their own communities, their struggle to access services, and their ongoing fight to ensure their disabled child, young person or adult has the same opportunities for education, fun, friendship and independence as everyone else.

In mapping the collective experience of our families from infancy to adulthood, it becomes apparent what a huge difference even small changes in our own and others’ attitudes towards disability and disabled people can make. This report reveals how vitally important it is for all of us to continually reflect on our own attitudes and behaviours, making sure we are being genuinely inclusive and are able to make the adjustments needed to meet each individual’s needs.

A welcoming smile, open mind, flexible attitude, willingness to listen to what the

person and those who know them best have to say about their needs, and an ability to creatively problem-solve can all positively transform the experience of disabled people, with benefits for their health and wellbeing.

The report offers practical, inspiring and down-to-earth examples of inclusion and a comprehensive guide to making the most of our free Disability Matters resources. There are also a range of suggestions on how to ensure disabled children and young people are meaningfully included in the health and education services, leisure opportunities, sports and everyday activities that we all take so much for granted.

From the simplest of adjustments to comprehensive approaches involving policy change and service redesign, the organisations profiled here develop and deliver their commitment to inclusion in many different ways.

They show us that inclusion is not a static two-dimensional concept, but a multifaceted, dynamic and ever-changing landscape shaped in constant partnership with disabled people and their families.

In the face of austerity, funding cuts and diminishing statutory services, there has never been a more important time for us to think creatively about inclusion and develop innovative solutions to improve access for everyone in our society.

We must move forward together, constantly challenging our behaviours, our attitudes and the actions that underpin the services we provide.

We must make the commitment to do our very best, however we can, for all disabled people.

Above all, we must ensure that we leave no one behind.

### Layla Brokenbrow

**Layla Brokenbrow**

Disability Matters Programme Manager  
Royal College of Paediatrics and Child Health

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**We must make the commitment to do our very best, however we can, for all disabled people.**

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## Executive Summary

**This report reflects the views of the 10 young people, 123 parent carers of disabled children, young people and adults, and 128 professionals and volunteers from across the UK who responded to the Disability Matters' Call for Evidence in early 2016.**

**Positive, can-do attitudes cost nothing, but can make the world of difference.**

All responses were carefully considered by the Disability Matters team and analysed to identify the key themes.

A lot of good and inclusive practice was celebrated by those who responded. Frustration and disillusionment at the increasing barriers to meaningful inclusion brought about by austerity cuts in services were lamented, as was the 'shocking lack of can-do attitudes'.

There were a number of cross-cutting themes that young people, parent carers, professionals and volunteers all reported as **enablers of a warm and meaningfully inclusive welcome**. These included:

### 1. People with positive, can-do attitudes who:

- Are **respectful**, supportive, encouraging, enthusiastic, motivated and understanding
- **Value diversity** and see the person (not just their disability)
- Take the time to **listen** to what the person and those who know them best say that they need, with the patience to understand that some barriers to inclusion may be hidden
- **Communicate** well, keeping everyone informed and inspiring confidence
- Are **well trained**, knowledgeable, understand individual needs and can put in place any adjustments that are needed, ensuring everyone is safe and happy
- Can think out of the box, problem-solve, and be **flexible** and **creative**
- Empower disabled people, their families and other carers to be **resilient**, able to advocate for themselves, have their voices heard and be good at problem-solving independently
- Are **friendly**, treat them like everyone else, don't judge them or make them stand out or feel different, don't pity or patronise them, or put them on a pedestal

- **Celebrate** every achievement, have **high aspirations** for everyone, encouraging goals and dreams
- Don't draw excessive attention to a person's disability or make it obvious to others that they need extra help
- Don't make assumptions about what somebody can or can't do without checking with them and those who know them best

### 2. Physical accessibility

Including accessible lifts, doors, changing places and toilets, transport, parking, shops, play and leisure facilities, venues and safe places to cross roads.

### 3. A quiet place

To go to have a bit of space to chill out if things become too much or get overwhelming.

### 4. High-quality services

High-quality, adequately funded, flexible universal and disability specialist services appropriate for a range of needs, which involve disabled people in their design and testing and can be accessed in a timely way as and when needed. There were some positive examples, most and increasingly involving specialist services delivered by the voluntary sector (e.g. charities) or organised by other parent carers. These were generally experienced as better and more inclusive than statutory or universal services.

**"How can it be so easy to take my son to a festival in a field yet struggle at the hospital?"**

There were many more examples of funding cuts, service cuts or closures and a sense of responsibility shifting solely onto families. One parent carer summed up the reported views of many others: "It's all about limited funds, limited resources. Everything lies with the carer but sadly carers will and are, slowly falling apart".



## 5. Risk assessments

Adequate arrangements across settings and lifespan for appropriate **risk assessments for health and safety** (not risk averseness), **manual handling** and **personal care**.

## 6. Information and support

Easily accessible, timely **information** and **support**.

This report has the potential to make a positive difference. If everyone who reads it reflects on their own attitudes and practices and uses the Disability Matters resources to help them positively change, that would be a good outcome.

Ministers, commissioners and providers of services across sectors should reflect on the key messages in this report, particularly what CAN be achieved and what they can help to deliver.

We must also all hear and respond positively to the messages of despair from those disabled young people and parent carers who have taken the time to respond to our Call for Evidence. We must expose the relentless challenges that they report, hampered by austerity cuts to the services that they rely on to achieve their basic rights and have their needs met. Many report being worn out, feeling hopeless and abandoned. This is NOT good enough. If those in positions of power were measured by the same

standards as parents, they would stand accused of neglect and of causing avoidable harm.

It is up to each and every one of us at every level in our society, disabled and not disabled, friends and families, professionals, service providers and volunteers, to take responsibility. We must rise to the challenge to be better informed and to examine and improve our own attitudes towards disability and disabled people, so that everyone can enjoy a meaningful, inclusive welcome wherever they choose to go and whatever they choose to do in our communities.

Positive, can-do attitudes cost nothing, but can make the world of difference.

*Karen A. Horridge*

**Dr Karen Horridge**

Paediatrician (Disability), Sunderland Chair, British Academy of Childhood Disability Clinical Lead, Disability Matters

"This report has the potential to make a positive difference."





# 1. From Infancy

## Ensuring the Best Start in Life

**For the families of disabled children, easy and timely access to the right health services, the provision of safe, appropriate childcare and a positive, empowering attitude from the professionals they engage with are vital components in ensuring their child has the best start in life.**

Yet accessing these basic services can be fraught with difficulties. Services can be sited in out-of-the way locations in inaccessible buildings with limited facilities (such as accessible changing places and toilets for the disabled) with few or expensive parking options. Multiple appointments with different services are logistically difficult for parent carers to manage, while noisy or chaotic environments can be stressful for their child and may trigger behavioural responses that others do not respond to well.

The attitudes of staff and volunteers in these situations assume an importance that many of us fail to realise. Attitudes may make the difference between a family receiving the healthcare, social interaction and support their child needs and being left unsupported, to fight a long battle alone.

This report explores all these issues, and the different challenges they pose throughout the journey from infancy to adulthood. We will also look at the different ways that health, childcare, social care, education and community providers can respond and adapt in small ways that make a real difference to children, young people and their parent carers from the very start of their lives.

The experience of infants, young children and their families in these early years sets the foundations (and expectations) for the future, and has the power to shape their physical health and emotional wellbeing for many years to come.

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**It is crucial that, as individuals and service providers, we do everything we can to get things right.**

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### How easily can families connect with services?

In our survey, we asked parents which (if any) services they had found it difficult to access for their child in the last 12 months.

We received **72 examples from 123 parent carers** relating to difficulties in access for disabled children, young people and adults:

**30** mentioned experiencing **negative or unhelpful attitudes** from others, including from other parents

**22** said they had found it **difficult to access healthcare services**

**20** reported **trouble in finding opportunities** for their child or young person to socialise with others

### Parent carers attributed their difficulties to:

- Inflexible systems
- A lack of joined-up care, resulting in too many or too few appointments
- A lack of understanding and empathy from health professionals and care workers
- Negative attitudes from others





## Equal Access in Action

**Professionals can help to reduce health inequalities by ensuring that the services they deliver are accessible, responsive and respect the needs of disabled people of all ages and their families.**

Developing and delivering responsive, accessible services does not need to involve long, difficult processes: often the simplest ideas or changes are the most effective.

As the good practice examples submitted to our Call for Evidence show, all that is required is the time to listen, a positive attitude, flexibility and some lateral thinking.

### Neurology services (Location of service not specified)

This neurology doctor describes how small changes to the accessibility of their clinics have had a big impact on outcomes:

"We reorganised the neuromuscular clinic to be on B (ground) floor of the main hospital so that the patients, often wheelchair bound, did not need to travel so far for their appointment. We also incorporated meetings with the MDT (multidisciplinary team) within the appointment slot. Our muscle patients now find it easier to attend clinic."



### Community paediatrics (England)

This consultant community paediatrician explains the importance of joint clinics:

"I look after a large number of children with a variety of disabilities, many of whom have multiple complex medical problems. Over the last year, I have worked closely with colleagues in different medical specialties to try to establish joint clinics. By seeing children in joint clinics, families have fewer appointments in the hospital... the children miss less school and the parents miss less work. Hopefully it also ensures that more of their issues are dealt with at each appointment; I would hope this leads to reduced suffering and improved health."



### Early support key worker (Kent Community Health Foundation Trust)

This team adopts a flexible approach to help families manage the burden of multiple appointments:

"Where possible, children and their carers are asked where it is best to meet up with them, in their home, local children centre, etc. This supports their attendance and helps the young person by causing as little distress as possible."



### Complex needs 0–19 years service (Wirral Community NHS Trust)

This complex needs lead takes a multi-pronged approach to helping families access services:

"We have improved the presence of health visitors within our local neonatal unit to ensure that babies and their families have a smoother transition from an acute setting to home. This eases the very start of their journey, and helps to build the positive relationships that ensure families are supported. We have also placed a stronger emphasis on signposting to help families of disabled children gain access to appropriate services from social care, education and the voluntary sector more swiftly."



## Learning Zone



Small changes can make a big difference. Visit our free Disability Matters e-learning sessions to learn more about:

[What is Disability?](#)

[Working Together Matters](#)

[How Information is Shared Matters](#)

[See the Person \(Celebrate Abilities\)](#)

[Environmental Challenges Matter](#)

[Reflection Matters](#)

## Diagnostic Overshadowing

We received many submissions from parent carers whose disabled children and young people have experienced poor general healthcare services, because those assessing or treating them get stuck on their disability and do not apply the same rigorous approach that they would with a person who is not disabled.

### This is diagnostic overshadowing.

Simply defined, diagnostic overshadowing is the tendency by a clinician or health professional to **“attribute all other problems to an original diagnosis (often linked to mental health or disability), resulting in the failure to properly investigate new symptoms, or to leave them undiagnosed”**.<sup>3</sup>

The General Medical Council states that health providers **“must not unfairly discriminate against patients by allowing personal views about their disability to affect [your] professional relationships or the treatment you provide or arrange”**.<sup>4</sup>

### As this parent of a three-year-old boy with Down syndrome reported:

“My son is in a special nursery with 50% mainstream children. I feel he is included very well at nursery. I do not feel at this stage in his life that my son is discriminated against. The only thing I have noticed is that when I take him to the GP the sentence I often get is ‘it’s because he has Down syndrome’. This in a way is pigeon-holing my son and not treating what is actually wrong with him.”



Disability Matters encourages all clinicians and healthcare providers to remain vigilant in ensuring that they do not let their unconscious biases or assumptions impact on their care of disabled people of any age. It is vital that all nurses, doctors and allied health professionals listen to, assess, investigate and treat a disabled person of any age in just the same way as they would a non-disabled person presenting with the same symptoms (regardless of existing diagnoses).



### Top tips for...

#### Avoiding diagnostic overshadowing

- Adopt an open-minded approach during consultations
- Follow a rigorous, structured approach to assessment and examination
- Challenge other colleagues if you suspect a disabled person’s symptoms are not being taken seriously or are being left unexplored
- Check with parent carers and those who know the person best about what the person is like when well and how they might show pain or distress
- Learn to use simple tools like pictures, photos, online videos, talking mats etc. to better communicate with learning disabled people of all ages and build trust with their parent carers and other familiar carers

## Attitudes in Healthcare

### Positive attitudes improve outcomes.

Previous research by Contact a Family has shown that a health professional's attitude towards disability and the language they use to discuss a child's potential during their crucial early-years appointments can have a profound effect on a parent's own understanding and acceptance of their child's differences.<sup>5</sup>

Negative attitudes, even subtly expressed, have a lasting impact on the way a parent thinks about their son or daughter's future, even encouraging the formation of life-long negative beliefs and low expectations that directly impact their child's development. Such early parental belief systems are further shaped by the attitudes and behaviours of professionals, such as nursery staff, child minders, GPs, receptionists, staff at the local stay and play or leisure centre, as well as the parents of non-disabled children.

### Everyone working in the health service has their part to play

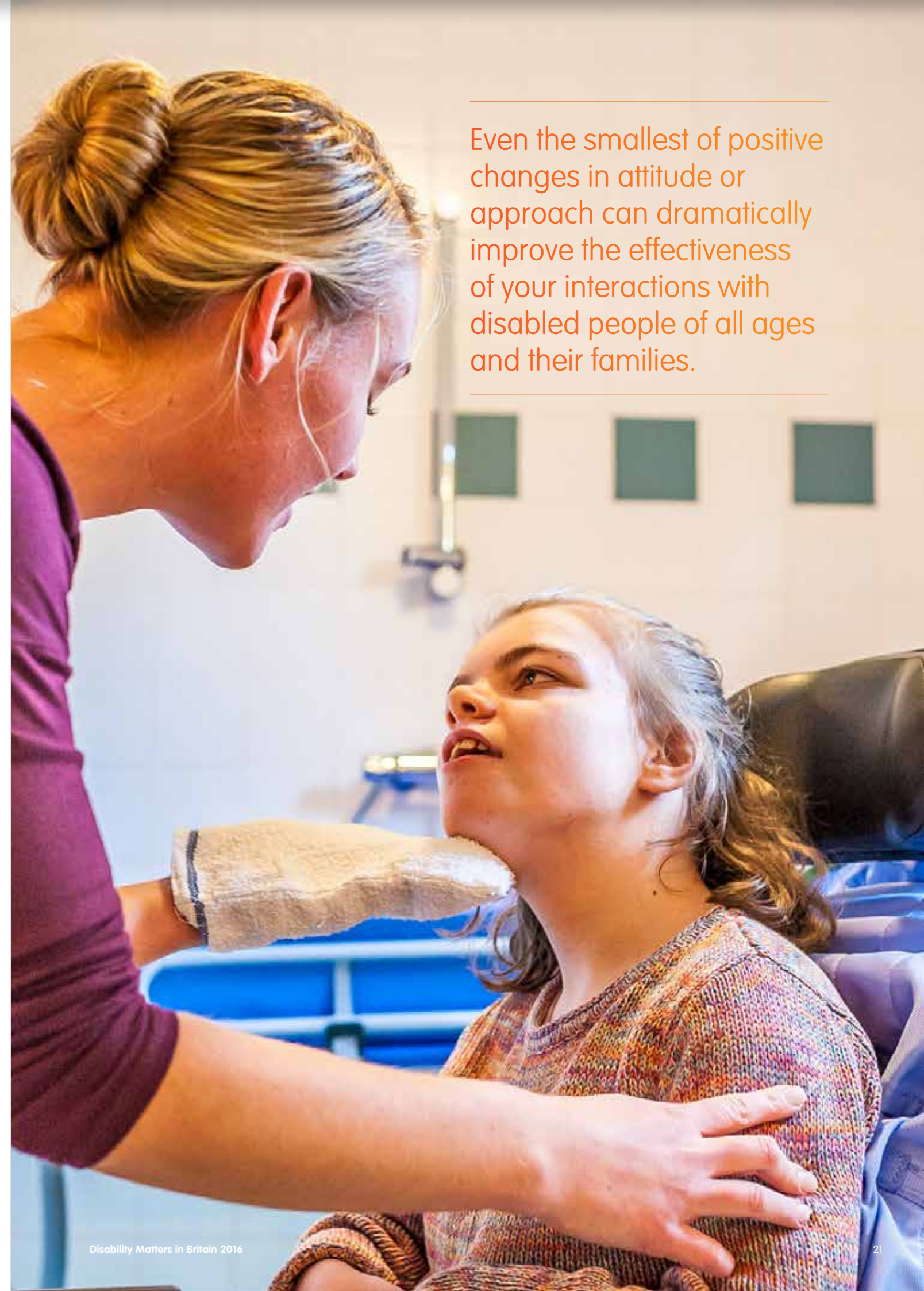
Equal access to healthcare is absolutely vital to the health and wellbeing of all disabled people. When services are designed and delivered by compassionate, caring staff with a flexible approach to access, communication and outcomes are improved.

No matter what your role, or where you work, there are a number of powerful things you can do to support a disabled child's health and wellbeing during the early years of their life:

- Adopt a positive attitude when communicating with parent carers and family members
- Encourage parent carers to celebrate their child's early achievements
- Empower parent carers to think positively about the future
- Reflect on and challenge your personal beliefs about what disabled children "can" and "can't" do
- Be aware of your personal bias and how it impacts your interactions with others

Building trust and rapport during the early stages of a disabled child's life will help with communication later on, including when big decisions may need to be made about interventions or treatments.

Even the smallest of positive changes in attitude or approach can dramatically improve the effectiveness of your interactions with disabled people of all ages and their families.



## Empowering Parent Carers

**A parent carer’s own beliefs about disability will have a powerful impact on their child’s social and emotional development.**

By acknowledging the role of parent carers as champions for their child, adopting a positive approach and focusing on what their disabled child CAN do, professionals can empower parent carers to believe in their child’s future and actively support the development of their independence from an early age, where achieving independence is a realistic goal.

### Continence team

(Location of service not specified)

This children’s continence team places a big emphasis on supporting, reassuring and empowering parent carers to believe that their children can achieve independence:

“We have found that if you give parents and children the right information and support, it can really change their lives. With the right support, you can empower parents to try new things they would never previously have done. For most parents just to know we are there when they need us has changed their attitudes to trying to toilet their children – many thought it wouldn’t be possible. Some of the children we see are in wheelchairs and for them to be free of nappies and not sore or smelly is a huge thing and gives them much more confidence.”



## Learning Zone

To improve your communication skills and learn more about health equality, when working with families, take our free Disability Matters e-learning sessions:

[Communication Basics](#)

[Communication Matters in Health](#)

[Communication Support Tools](#)

[Rights Matter](#)

[Caring for Parent Carers Matters](#)

[Continence Matters](#)

[Understanding Matters for Effective Communication](#)

[Three-way Communication Matters](#)

[Diagnosis Matters](#)

[Equal Access to the Best Health Outcomes Matters](#)

[See the Person \(Celebrate Abilities\)](#)

[Personal Care Matters](#)

## Building Inclusive Communities

**The beliefs and attitudes of professionals, volunteers and parents of non-disabled children are extremely powerful and can have a huge emotional and psychological impact on the wellbeing of disabled children, young people, adults and their families.**

Feeling and being included in a meaningful way is not just about the things that people do, but about what they don’t do, what they do and don’t say, and the body language and gestures that they use. Whether we work in health, education, social care or the community, we all have a responsibility to ensure that our words, actions and behaviours make a positive impact on the everyday lives of disabled people of all ages and their families.

They responded to our survey with a frank view on Britain’s attitude to inclusion that captured the range of environmental, financial and attitudinal challenges faced by the families of disabled children and young people:

“It is an absolute privilege to work with children with disabilities and their families; sadly, our experiences over the last 12 months have seen families struggling with less and less support as a result of the lack of availability of services such as respite and buddying. There are extremely limited opportunities for children like ours (between the ages of 2–11) to access local facilities or activities, despite the fact that everything is now supposed to be inclusive. Our children deserve as many opportunities as anyone else, but their opportunities are extremely restricted and also very expensive to access.”

### Blackmarston School

Blackmarston School (in Hereford) is a specialist school that provides education for children (aged 2–11) with severe and complex needs, learning difficulties, autism and challenging behaviour. They work inclusively with all children, utilising a range of bespoke communication methods and devices.



## The physical environment and reasonable adjustments

Many people submitted examples to our Call for Evidence outlining their efforts to improve the accessibility of the external/physical environments where their services are delivered by making 'reasonable adjustments'.



"We have improved the equipment we use to complete health assessments – we now record the weight of wheelchairs in the notes and have installed a set of scales that means we can weigh the child without removing or disturbing them in their chair. This has help parents and patients to feel more relaxed and reduced their stress."

**Nurse, England**

"We now have a hoist and a lift and low barriers/writing surfaces for patients coming to reception. This has made it easier for families with disabled children to physically get into the building without needing to ask staff to move things."

**Dentist, Shropshire Community NHS Trust**

"In the past year the Civil Aviation Authority (CAA) has focused on providing access to people with a hidden disability and has initiated a project, ensure airports provide appropriate assistance to children with autism. To help drive up good practice, the CAA now sets performance targets for UK airports on providing assistance to disabled people and airports must publish results against these targets."

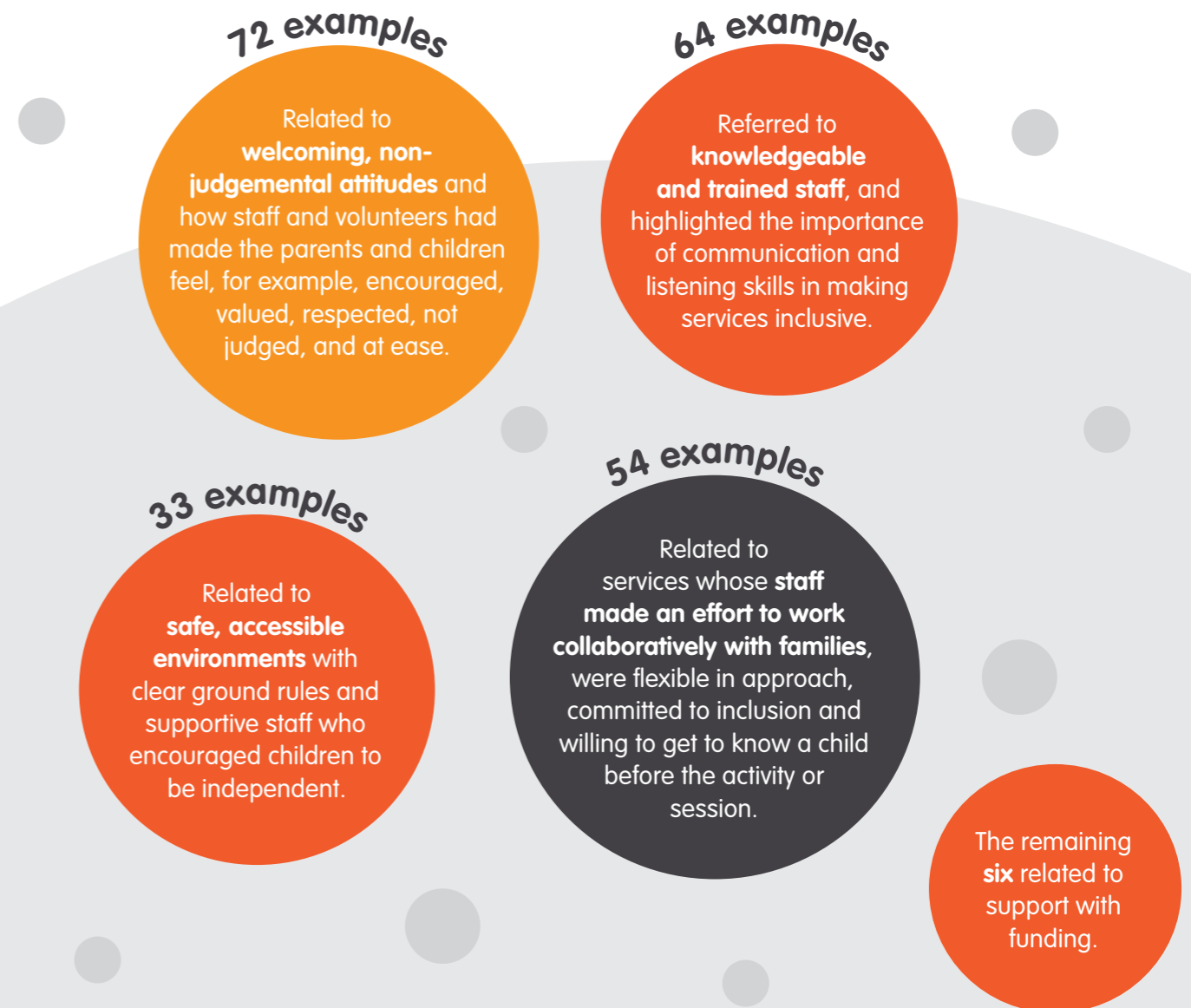
**Civil Aviation Authority, National**

## The cultural environment and attitudinal adjustments

The physical environment is only one part of a person's experience of inclusion. It is just as important for teams to reflect on and positively change their cultural environments, behaviours, language and attitudes.

**We asked parent carers to describe what others had done to make them feel included.**

**We received 229 examples from 123 parent carers:**



## Impact of others' attitudes

"The reaction from other parents is often upsetting. Children are fine and very accepting whereas parents avoid what they don't understand. This has resulted in some exclusion from out-of-school gatherings. We need more education of the parents of non-disabled children!"

Mother of a four-year-old girl

She believes it wouldn't take much effort to make spaces more accessible and caring. There are many things that staff and volunteers can do to improve their organisational culture and adopt or demonstrate an inclusive attitude, no matter what service they provide. All it takes is an open mind and the willingness to do things a little bit differently. Rachael describes how the positive attitudes of some local supermarket workers and their willingness to make small adaptations have meant the difference between joy and disappointment for her family:

## Out and about... In Chesterfield

Although her four-year-old son Oscar's behaviour is often perceived by others as challenging, his mum Rachael makes every effort to find ways for the two of them to spend time together doing the 'normal' things that other families take for granted.

**However, it is not always easy and physical access can be a problem:**

"My local public swimming baths are terrible – they only have places to put babies (like a play pen). My son is too big for this; however, he will run off if not contained. Staff always rush us and frown upon the noises he makes."

"Tesco in Clay Cross have been wonderful. It is my son's favourite place. He struggled at Christmas as he does not like trees. So they switched all the Christmas tree lights off and moved them away from the entrance so that he could enter. The staff are helpful and kind and never phased by anything he does."



Rachael also praises Fairplay in Chesterfield and Yorkshire Wildlife Park for their positive and supportive attitudes:



### Fairplay

"We have found it easy to access Fairplay, which is the only provision in Chesterfield that offers a stay and play group. It is easy to access as the building itself is central and physically accessible. It is always at the same place, meaning that my son knows what to expect and who will be there. Fairplay understand the importance of inclusion and communicating with my son on his level. They use Makaton and find him quiet spaces if he's feeling overwhelmed."

[Fairplay website](#)



### Yorkshire Wildlife Park

Rachael and her son enjoy visits to Yorkshire Wildlife Park, who she says are always very accepting and helpful. Yorkshire Wildlife Park says: "Pre-booking, discounted entry prices and the provision of facilities for visitors with disabilities all help towards our mission, and staff are always prepared to assist where possible."

[Yorkshire Wildlife Park Website](#)





## 2. Childhood

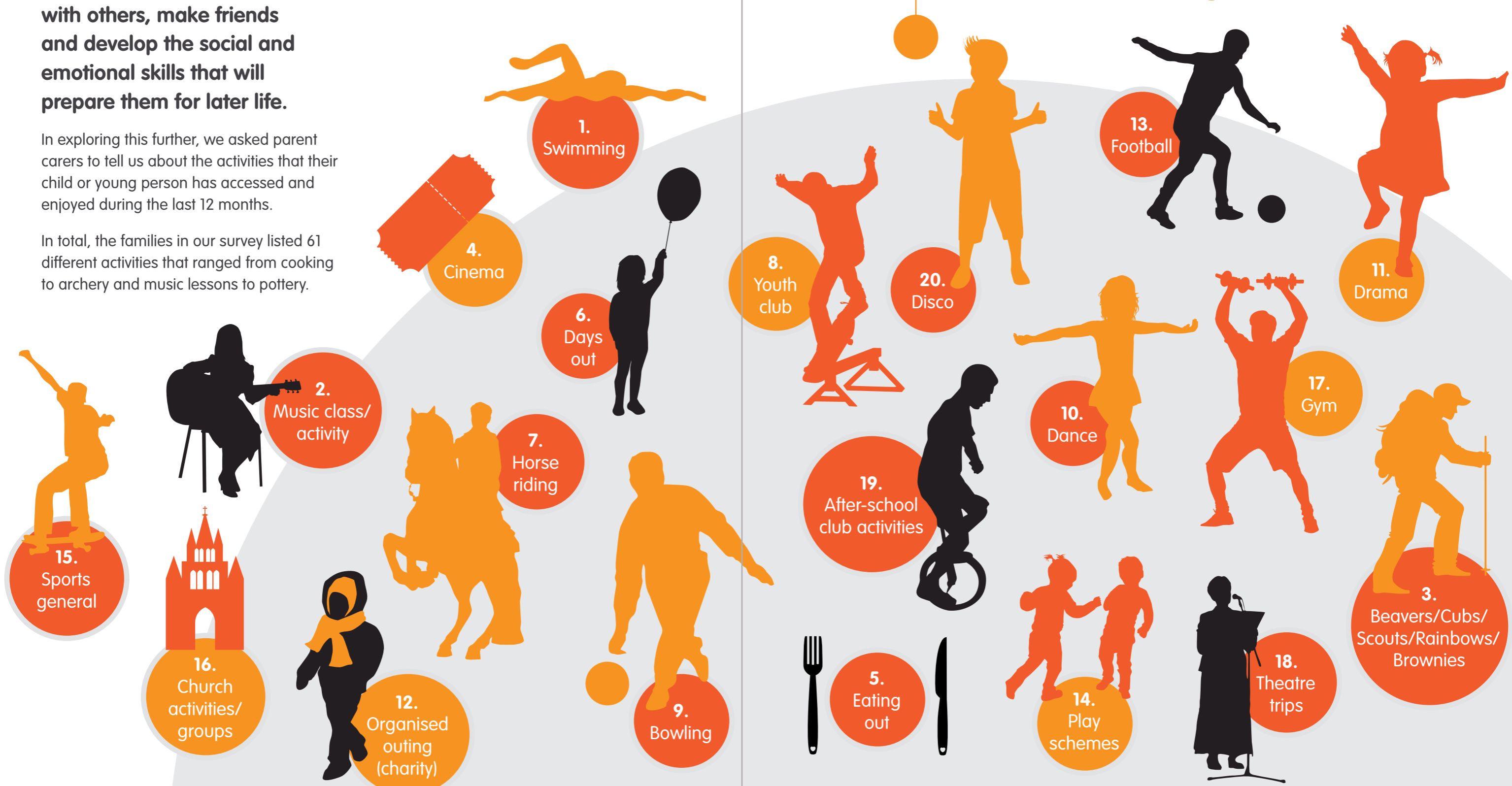
## Having Fun

Childhood is a time for children to learn and explore, play with others, make friends and develop the social and emotional skills that will prepare them for later life.

In exploring this further, we asked parent carers to tell us about the activities that their child or young person has accessed and enjoyed during the last 12 months.

In total, the families in our survey listed 61 different activities that ranged from cooking to archery and music lessons to pottery.

# Here are the top 20 most accessed social or leisure activities during 2015:





## Why Can't I Join In?

### However, it was not all good news.

Nineteen of the 123 parent carers (15%) told us their child or young person **had accessed no social activities** in the past 12 months due to poor attitudes, inexperienced staff or inaccessible buildings and services.

For many other respondents, the opportunities for their children and young people to engage in social and leisure activities were severely restricted. They identified a number of barriers that had prevented their son or daughter experiencing a full and positive childhood. These included:

- Cuts in funding meaning the removal or reduction in support services
- Issues with accessibility
- Unwelcoming attitudes
- Others' negative perceptions of their child or young person based on their disability or behaviour

**15%** of parents told us their child or young person **had accessed no social activities** in the past 12 months



### These parent carers told us:

"It's easier when your child is small and cute. As soon as practicalities get in the way, the world shrinks dramatically. It's not a good place to be."

"My daughter (seven years) is always excluded from everything... there's little understanding of any of her needs by any professionals because she is trache (tracheostomy) ventilated, non-verbal, deaf/blind and has epilepsy and many other things."

"My son (six years) has tried different activities such as gymnastics and holiday clubs."

"Reasonable adjustments have not been made for the most part and we have made the decision to withdraw from these activities after a few attempts."

"The gates to get in and out of most of our local parks are really tricky with a wheelchair. Once you are in, there is normally only one accessible piece of play equipment – you show me any child who just plays on one thing?!"

"I find most services difficult to access as I have to provide 1:1 support... my son had his funding cut so that instead of eight hours per week for short breaks he only received four hours. Then the provider lost funding for children and the new provider would not match what we had before due to further funding cuts, so discontinued the service."

"They did offer my son a male carer, but he is slightly too old at 59 and is not able to run, chase, jump on a trampoline etc., which is what 10-year-old boys want to do!"

**16%** of parents have had **trouble finding opportunities** for their child to socialise with others

**20%** of parents have **experienced negative or unhelpful attitudes** from others in relation to their disabled child

It is hugely important that commissioners, providers, staff and volunteers recognise, support and actively enable disabled children and young people to access and participate in a range of 'normal' childhood activities.

## Behaviour that Challenges

**For many families, it is others' perceptions of, and responses to, their disabled child's or young person's behaviour that create the biggest barriers to inclusion.**

Caring for a child or young person whose behaviour is described by others as 'challenging' can place families under huge strain. It can also leave parent carers with high levels of stress and at risk of emotional or physical health problems of their own.

**When left unsupported, a child's or young person's behaviour can:**

- Put themselves, and others at risk
- Disrupt their home life and affect other siblings
- Result in them being prevented from taking part in ordinary social, educational and leisure activities
- Affect their development and their ability to learn<sup>6</sup>

However, many of these problems are caused by the way that the children and young people are supported – or not supported. In our Call for Evidence, parent carers reported that many services are only available to children, young people or families who fit specific criteria set by local councils and that accessing professional support is often extremely difficult:

"Ultimately, if a disability leads to challenging behaviour because someone is not coping, very few people are prepared to modify their behaviour to meet that child's needs. Challenging behaviour is automatically seen as something to exclude. There does not seem to be any service available to offer support, education or strategies to support behaviour unless you go privately. I am a very experienced clinician who has used all my professional contacts. If I am unable to access services for my child, I honestly don't know who can."

**Mother of a six-year-old with autism and behaviour that challenges**

"There does not seem to be any service available to offer support, education or strategies to support behaviour unless you go privately."

### How can you make disabled children, young people and their families feel included?

The parent carers who responded to our survey told us there are a number of simple, powerful ways that staff and volunteers can make them and their child or young person feel included:

- ✓ Developing good communication skills
- ✓ Being willing and able to communicate with their child/young person/family in different ways
- ✓ Being flexible in their approach
- ✓ Being willing to work with parent carers to make adjustments that enable their child or young person to join in
- ✓ Greeting children, young people and families with a smile and warm welcome
- ✓ Attending training to improve their own confidence, knowledge and understanding of disability
- ✓ Being committed to inclusion across the team, even when it gets difficult



25%

of parents mentioned negative attitudes of staff and volunteers



50%

of them linked this to a lack of awareness of conditions and additional needs, with professionals too quick to perceive their child as 'difficult'

## Creating Welcoming Environments

### Challengers

[Challengers website](#) 

Challengers is a registered children's charity that provides joint play and leisure opportunities for disabled children and young people (aged 2–25) in Surrey and the surrounding areas. It has a true non-exclusion policy, so every child can attend Challengers if they want, regardless of their disability or however challenging their behaviours may appear.

Challengers proactively look for ways to ensure that all children can access their numerous play schemes in a safe way, e.g. staff are trained in administering medication and moving children in wheelchairs.

If a child's behaviour has been used by others as a reason for exclusion in the past, staff put plans in place that are agreed with the parents to ensure volunteers use a consistent approach that is known to work with/for the child.



Image gallery (Click on numbers to view)

### Challengers – More than just play

A short film about the impact that Challengers schemes have had on the lives of five parents of disabled children.

Parents and staff provided the following testimony in response to our Call for Evidence:

“Working at Challengers has been absolutely amazing, and it's really opened my eyes to the world of disabilities. The children I work with are complete gems, cheeky monkeys and absolutely endearing in their own ways. I think everyone should do this sort of work or volunteering placement at least once in their lives.”

**Staff member**

“The only service we have found easy to access is Challengers. Everything else is impossible. If you have more than one child, it's hard to drag a non-disabled sibling to sit at a club for hours. There are no drop-off activities the way you get with NT (neurotypical) kids. In my experience you can't force people to welcome an ASD/ADHD child.”

**Parent of a 10-year-old**

“My child mainly accesses locally funded specialist services for young people with disabilities, e.g. local Mencap, Challengers and our church's special needs youth club. We also attend a non-special needs dance club where the attitude of the teachers is truly inclusive; they are kind, accepting and have clear boundaries. We have stopped going to activities that are not welcoming.”

**Parent of a 17-year-old**



## Top tips for...

### creating a welcoming play environment

✓ **Put on your happy face**

Disabled children are routinely excluded from play settings – recent research by SENSE (2015) identified that 51% of disabled children are intentionally excluded from play in the UK. This means that they and their families are expecting it to happen again. They, more than any other participant, need to receive a positive welcome to reassure them that this is not going to happen in your setting.

✓ **Understand the child – not the label**

The social model of disability underpins this approach, which says that each child has their own unique personality and strengths and weaknesses. It is important to focus on the individual and not to try and cater for general labels, e.g. while Jane and Jim may both have autism, each of them will need and want different things from their daily lives. Instead of trying to understand what a child with the label of autism might need or want, try and focus on what Jane needs to be happy when she is with you.

✓ **Stay up to date**

Remember that children change and develop – and what you do needs to adjust to that.

✓ **Handover**

It is so very important to have a good handover at the start and end of each day. This gives staff and volunteers the chance to collate any information they have gleaned about a child and capture it in central records for use in briefings at the start of the next day. Critical things like triggers for behaviour can be gathered during this process – sharing this information with others will make a real difference to the child's next interaction or day of play with you.

✓ **Child-led play**

Play schemes and other social activities offer a time when the child has the opportunity to spread their wings in a place that they can call their own. This means that there is a real opportunity for learning and development that simply might not exist anywhere else. It is important that the child is able to lead the play and make decisions around what they want to do from all that is on offer. Allow them to play the way they want to, and don't be beholden to traditional 'ways' or ideas about play.



✓ **Training**

Working/engaging with disabled children can be challenging, and staff need to feel confident that they can support the children they work with. Lack of training should not be a reason for not being able to accept a child, and so this means that a comprehensive and regular training package needs to be a requirement for every member of the team. Medical procedures such as medication administration and gastrostomies can be managed by non-medical staff as long as they have the right training.

# Primary School

Image gallery (Click on numbers to view)

## You don't have to make it a big difference to make a big difference to a child!

Feeling welcomed and included at school can have a huge impact on a disabled child's experience and enjoyment of school life.

Submissions to our Call for Evidence revealed that small, low-cost changes to the school environment, a positive attitudinal culture, staff training and working closely with parents makes a huge difference to how welcome and included a child feels, and is vital for creating a supportive culture in which they can flourish.

### East Stour Primary School

Ashford, Kent

East Stour is a mainstream primary school in Ashford, Kent. Through a combination of small physical changes, a positive attitudinal culture, staff training and working closely with the families of pupils, they have created an environment where disabled children are fully welcomed and included in the school, and can participate fully in class, sports and extracurricular activities, like every other child.

"We just have a completely holistic approach to the child. We adapt our environment to their needs. Simple as that."

### Simple physical adjustments

The physical changes that East Stour have put in place to create an inclusive environment are extensive, and include:

- Painting the walls a different colour to the grab rail in the disabled bathroom
- Fitting different coloured plates on the doors to differentiate between push and pull
- Adjusting the hand driers to ensure they are at an appropriate height for children in wheelchairs

While relatively small changes, these accumulate to create an environment where every child has their needs met and feels at ease.

"It doesn't have to be an extreme, expensive change: just making sure the door is painted a different colour to the floor. It looks very nice when everything is colour coordinated but it doesn't help that child who can't see it."

### Adapting the curriculum

The creative and inclusive attitude at East Stour has extended to include adapting activities in the curriculum, such as sports. This not only allows every child to join in, but exposes the other children to disability, which normalises it and can create more inclusive, welcoming and accepting attitudes.<sup>7</sup>

"It was how we could include those children in the PE activities rather than exclude them from the activities. We looked at how we could adapt the activity so all the children could experience everything and that would include the footballs that had bells in them for those children with hearing impairment, we used brightly coloured equipment for visually impaired children... and some games included all children wearing blindfolds."

"The more access and more exposure non-disabled children have to children with a disability, the more normal it becomes and the children don't actually notice the disability."

### Tailored staff training

In addition to making physical changes, all staff at East Stour are provided with ongoing training to equip them with the skills to provide appropriate support for every child, whatever their needs.

"We had a young man with visual impairment and part of the training for the staff was to be given glasses that enabled us to see what he could see or couldn't see, as the case may be. We had a range of visual impairment glasses that we tried out and we looked at how we could adapt the environment, and the children themselves were allowed to try them on to see what the challenges were for their classmates. It had such a profound effect on us – we understood how scary it was walking into an unfamiliar room without being able to see clearly. It made us realise the importance of 'walk-throughs' for a visually impaired child. The walk-throughs are a must!"

Parents are also heavily involved in their child's integration into school, and have given feedback citing the positive impact that attending East Stour Primary School has had on their disabled child: "Self-confidence and academic progress were boosted."

"The families were extremely pleased with their children's attitude to school and learning, and this new confidence was reflected in positive behaviour both in school and at home."

Overall, the proactive and inclusive attitude of East Stour Primary School has created an environment where every child is welcomed, valued, and encouraged to enjoy school and reach their full potential.

"It is something that has evolved, to us it is the norm. It is what we do."



## East Stour Primary School's

### four-step approach to meaningful inclusion

#### 1. Develop an empathic understanding of a child's wants and needs

We took the time to talk to a young visually impaired boy about what HE wanted, and what was important to HIM. He told me the biggest problem he had was on the playground. When he was playing with his friends and they were running or playing a running game, the boy couldn't distinguish his friends from all the other children on the playground.

#### 2. Problem-solve with the young person and others to meet these

We chatted about different ways to solve this problem and came up with a solution. His friends were given two hi-viz jackets, which were adjusted to fit children. The children themselves decided the best way to wear them and where to store them (incidentally, it was next to the playground door – a very visible spot for them).

#### 3. Adapt the environment to the child, not the child to the environment

First, we experimented with which colour was better – orange or yellow. The young lad chose the yellow and it was brighter for him. Then his friends were asked to wear them at break times. We had to write a rota as so many of his classmates wanted to be his playground buddies. The children knew there was a responsibility involved with the jackets – no hiding behind corners or taking them off to hide, etc. It was a simple solution, which enabled a child to carry on running and playing football with his friends, brought about by just asking what was important to him.

#### 4. Keep looking, keep improving

The support process is ongoing. As individuals grow, their needs will change, so keep asking the child/young person about their wants and needs. What is important to them will also change. Keep asking – how can I make this better? e.g. Just because you have made doorways wider or painted the walls different colours, don't become complacent. There is always more to do.

## Rushcroft Primary School

Oldham, Greater Manchester

Rushcroft Primary School is a mainstream primary school in Oldham. Their ethos is: **'If we can't help a child, no one in mainstream can.'**

Rushcroft Primary School has a higher than average proportion of special educational needs and disabilities (SEND) students. Through a combination of positive and inclusive attitudes, a variety of reasonable adjustments, extra support and tailored staff training, the dedicated staff have created an environment where disability is not a barrier to learning. Some of the strategies that Rushcroft Primary School has implemented to create an inclusive and welcoming environment for disabled children include:

- Staff training in diabetes to support children who need a daily injection
- Reallocation of staff and development of personalised learning outside the classroom for children with autism who struggle in mainstream school
- Provision of physiotherapy in school
- Training in relaxation and stress management
- Pastoral manager who works with parents to ensure they have access to early help and outside interventions

The result of these extra efforts is a school environment where any disabled child is welcomed, accommodated and has their learning facilitated.

"We have a very good reputation in the local community for being an inclusive (mainstream) school where the child is the most important element. The staff are totally committed to the children and do not see disability as a barrier to learning, whether physical or mental."



## Learning Zone

Check out the following free Disability Matters e-learning sessions and learn more about autism, what challenging behaviours may mean, and how to better support people with autism and/or behaviours that are seen as challenging:

[Communication Basics](#)

[The Different Meanings of Behaviours](#)

[Learning Disability Matters](#)

[Responding Positively When Behaviours are Seen as Challenging](#)

[Communication Matters in Learning](#)

[Worry and Anxiety Matter](#)

[Self-injury Matters](#)

[Autism Spectrum Matters](#)

## What Inclusion Means to Us

Here is what some of the parents, carers and disabled young people who responded to the call for evidence had to say about inclusion:

"That regardless of any disability, diversity or difference, everybody should be able to explore the same opportunities as everybody else and be supported in that process so that they can achieve their full potential."

"Treat me like a normal person – I don't like being singled out as different, I want to be treated the same as everyone else."

"Despite his problems he wants to be treated and perceived as normally as possible, to get the same opportunities as his friends and be able to do some of the things that they do, although he knows he has some limitations."

"With reasonable adjustments and my support my son was fully included. It's about working together and having a positive attitude that makes things happen in my opinion."

"Speak to us like humans, speak to my son, get down to his level, sign to him, smile at him, include his twin sister. Have a knowledge of SEN... it's easy to include everyone. Treat all with respect, encourage, motivate, understand, listen, get to know people, know their triggers to behaviour."

"For us, inclusion means having the maximum opportunity to live a fulfilling life in a community which respects differences and supports individuality thus enabling meaningful work, good health and, most importantly, valuable social interaction. Genuine support for inclusion can only happen when providers understand what is required to facilitate inclusion in each different circumstance: that requires training/ experience, flexibility creativity and motivation."



### Learning Zone

For further information on how to make small changes that really welcome disabled children, young people and their families, you can try the following free e-learning sessions:

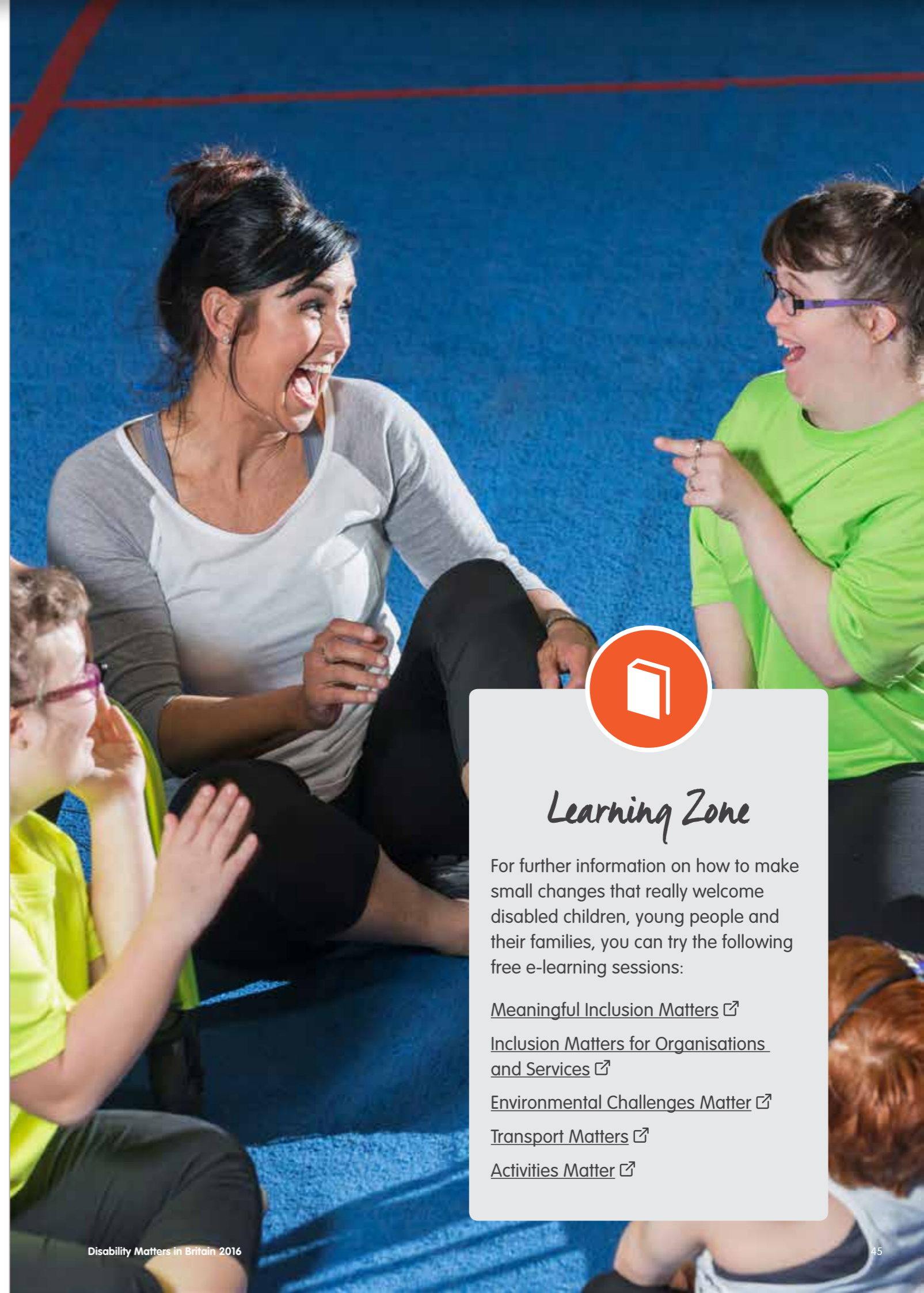
[Meaningful Inclusion Matters](#) ↗

[Inclusion Matters for Organisations and Services](#) ↗

[Environmental Challenges Matter](#) ↗

[Transport Matters](#) ↗

[Activities Matter](#) ↗





# 3. Teenage Years



## Growing Up

**“Treat me like a normal person – I don’t like being singled out as different, I want to be treated the same as everyone else.”**

### 17-year-old young man

The teenage years can be a difficult period for any young person, and disabled young people can find them particularly challenging.

Alongside the physiological changes taking place in their body, there may be worries about moving from child to adult services, and a desire for new experiences or relationships away from their family. Parents have reported feeling concerned and anxious about the gradual reduction in their parental responsibility (at least in legal terms) and tensions can arise if they feel they are being shut out of important decisions about their child’s health and future opportunities.

It is vitally important that professionals working with disabled teenagers remain sensitive to these nuances, and ensure that their actions support both the young person’s move into greater independence and the desire of their parent or carer to protect and nurture their child.

When responding to our Call for Evidence, parent carers of disabled teens raised a number of concerns relating to:

- Limited opportunities for their teenagers to socialise and safely develop their independence
- Transition between child and adult services
- Funding cuts
- Difficulties in finding and accessing information
- Understanding the rights of teenagers and their parents, often in regards to education

Parent carers of disabled teens universally hit out at the lack of opportunities for their young people to socialise with others in a safe and supported environment. Reductions in funding and people’s unwillingness to meet the needs of their young people, or adapt their service offer to provide additional support, were the primary barriers. A lack of knowledge and understanding around key conditions such as ADHD and autism, along with unhelpful or uncaring attitudes, was also mentioned.

Many parent carers expressed their belief that with better training and awareness, greater flexibility and the development of more inclusive attitudes, the providers in their local areas could adapt their services to include their young people.

As part of our Call for Evidence, we asked parent carers to highlight services they had found easy to access. We also invited professionals and volunteers to tell us about the service or activities they offer to teenagers, and to explain what they do to make these inclusive.

In the following pages, we will explore the different areas concerning young people and parent carers and some positive examples of inclusive practice that were shared by a number of individuals and organisations:

- Socialising and friendship
- Multimedia advocacy
- Teen health and wellbeing
- Vital role of school nursing



“My son does not find it easy to access any services. We no longer try to take my son to things such as Scouts and Boys’ Brigade, as the volunteers there just do not have the skills to deal with him. He is discriminated against at school too, as his hidden disabilities make the teachers treat him differently.”

**Parent of 12-year-old boy with ADHD**

## Socialising and Friendship

### Friendships are vital to everyone's health and wellbeing, regardless of age or life stage.

While we all face challenges in forming and sustaining healthy relationships, disabled teens face additional barriers, particularly in relation to difficulties in accessing and participating in leisure opportunities.

Many of the activities taken for granted by non-disabled young people, such as after school clubs, cinema and shopping trips, sports, drama or music clubs, were reported as being made only partially accessible, and were often placed entirely out of reach.

The testimony submitted to our Call for Evidence makes it clear that many teens and young people continue to face the following challenges:

- Environmental barriers (e.g. transport)
- Difficulties accessing leisure spaces
- Fewer opportunities for social activities away from the company of their primary carers
- Unhelpful and/or hurtful attitudes from others, who are unwilling to make adjustments to meet their additional needs

In the face of environmental, attitudinal and communication barriers, it is not uncommon for fear of rejection, and feelings of isolation, loneliness and vulnerability to combine to make it emotionally as well as logistically difficult for disabled teens to develop and benefit from friendships with others their own age.

"At college the lift broke and took months to repair – I was unable to access the same areas as my friends, which made me feel isolated as I had to go to the library. Potholes are another hazard and are difficult to see when it has been raining. Once my wheelchair got stuck in a pothole which was hidden by what appeared to be a shallow puddle – I was very frightened as my wheelchair lost power and I was on my own."

17-year-old young person

"I find it difficult to access mainstream services like youth clubs. They think you are thick... they speak to me like I'm three."

24-year-old man

"Difficulties with transport and accessible shops/entertainment venues remain. Going to gigs with my friends often means I have to book separately and then have to sit in a different part of the arena."

17-year-old young person

"My daughter is almost 15 and still totally dependent. Socially, her attendance at activities has been extremely important but this has become a problem in school because of the transport. She can no longer attend activities as her taxi leaves at 3.15 and won't come back to collect her at a later time. This means trying to collect her myself which is not easy, as I already have to balance work, hospital appointments and the needs of my other children."

Mother of a 14-year-old girl



Sometimes it is not the obvious things that are actually the barriers. It's important to talk with the person and make sure that everyone knows their needs and how to deal with the issues they raise.

**Organisations or services that actively provided and supported opportunities to develop friendship were highly prized by the parents and young people who responded to our survey.**

## Active Impact

Gloucestershire



Active Impact [↗](#) coordinate the 'Of Course We Can' programme in conjunction with eight partner organisations. They offer a range of residential and non-residential activities for small groups of disabled young people alongside non-disabled peers. Activities include professional cooking lessons, wild camping, 'Make a Musical in a Week', events with animals, dragon boating and a carnival.

"The providers are hardworking, kind and intelligent people. They provide the much needed hope that life can be enjoyed, that there are good people out there that will help, that they are worth supporting. When councils look at budgets, do they see that the providers are not just educating, and supporting, but making life worth living? Showing a future that can be bright with possibilities?"

**Parent of 'Of Course We Can' programme participant**

**"It's about working together and having a positive attitude that makes things happen."**

## Action for Children

National



Action for Children [↗](#) is a national provider working across the UK to offer over 90 short break services for disabled children and young people. An overarching goal is to provide breaks that enable children to enjoy universal sport, leisure, play and cultural activities. Some services aim to develop the child and family's confidence to participate without support in the longer term, and an element of their work includes building confidence and knowledge of the activity provider through general and specific awareness raising, information and guidance.

"Children and young people tell us they want to do the same thing as their non-disabled peers and be involved in their communities. Through participating in sport or activities like drama or dance, children achieve person-centred goals, which might include: meeting or making friends; learning to swim; developing confidence through drama; keeping active and healthy through sport or dance, etc."

## Blue Wave Hydrotherapy Pool

Margate



The Blue Wave Hydrotherapy Pool & Gym Complex [↗](#) has been built to support students' and young people's rehabilitation and recreational activities at the Royal School for Deaf Children Margate, Westgate College and within the Community Living Services for adults. Since 2014, the facility has been open to members of the public and offers exercise and swimming facilities that are accessible to all. The facility includes fully accessible changing areas, with an overhead hoist that makes it possible to access the hydrotherapy pool from any of the changing rooms and a poolside hoist. It has lift access to the gym on the first floor, which boasts fully accessible exercise equipment as well as an overhead hoist.

"Our inclusive approach has really helped young people be able to access an environment where they are catered for with a team of staff who have an understanding of many different disabilities. The young people and families who access our pool enjoy being able to come to somewhere accessible no matter what their ability. This approach also transfers over to our gym area for individuals who are 16+ and the progress made for many has been nothing but incredible – for many, their mobility, stamina and strength have improved tenfold."

## Solihull Life Opportunities

Birmingham



Solihull Life Opportunities (SoLO) [↗](#) is a charity that enables children, young people and adults with learning disabilities to enjoy social and leisure activities that they may not otherwise have access to. SoLO does this by providing a number of meaningful activities that are specially designed to add value to the lives of individuals with learning disabilities in a meaningful way. There are a wide variety of groups and activities to suit individual interests, such as Teen Open Door, Musical Youth, Totally Arts and Adventure Playground.

The Plan4U team has been established within SoLO for over eight years, and supports people to plan for their future, covering Support Planning, Housing Support, Essential Life Style Planning and Transition Support. Plan4U works with young people from ages 14–25, and provides invaluable support to help young people achieve the independence and autonomy they desire. Many disabled young people would like to attend mainstream social and leisure activities alongside their peers; however, this is not always possible due to organisations lacking the staff, skills and confidence needed to make reasonable adjustments and provide the necessary support for a young person with additional needs.

When asked what inclusion meant to them, SoLO said: “Parents feeling that they have enough confidence to approach a mainstream group, that their child will be included, and that they won’t be told to go away”.

Plan4U works to ensure that disabled young people can attend a mainstream leisure group by providing a member of their staff to accompany the young person to the group, to provide any extra support or help the young person may need.

“Children with disabilities all have something to contribute, and really enjoy being part of groups in the community.”

Many of the young people involved go on to attend these activities unaccompanied, which would not have been possible without Plan4U.

## About with Friends

Cromer

## About with Friends

About with Friends [↗](#) run a number of programmes, including a Youth Booster programme for 13–18 year olds that offers a wide choice of activities at varying times (one night a week, three weekends and school holidays). Once they have joined (referral through children’s services), teen members can access any social event they wish to attend. The charity has also opened a Community Cafe, which the members can learn and work in, and looks for opportunities for young people to go on holiday in this country and abroad. The Youth Booster programme offers:

- Cinemas, theatre, live music, dance, drama and discos
- Games, circus skills, bowling
- Theme parks and zoos, fun fairs, festivals and day trips
- Crafty sessions, e.g. art, pottery, paper craft, painting
- General ‘chill out’ sessions with Wii games and music

“The activities, skills development and work we offer is available to everyone, regardless of disability. We have members with physical disabilities, autism as well as learning disabilities. Our young people have the opportunity to live their lives like other young people, accessing work, skills and a social life with friends.”

# Multimedia Advocacy



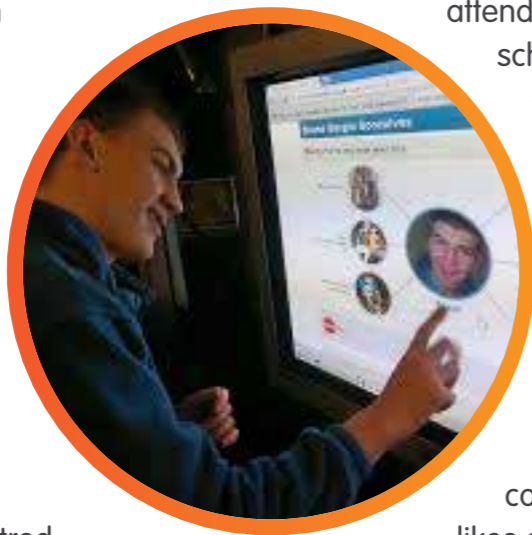
## Rix Media Wikis

[www.rixresearchandmedia.org](http://www.rixresearchandmedia.org)

**RIX Research & Media is the company behind the development of the Wikis – a multimedia tool that can be used to support people with learning disabilities and a range of communication needs.**

They have recently launched a free open course in collaboration with the Open University: it is available to anyone who is keen to develop an understanding of the application of new media for the education, health and social care of people with learning disabilities. It presents the theory behind multimedia advocacy, drawing from principles of inclusive and reflective learning, communication, advocacy and person-centred approaches to care and support. If you are interested, you can register online at [www.rixresearchandmedia.org](http://www.rixresearchandmedia.org)

We received a number of submissions from professionals using Wikis to improve the care and services they offer (see right). However,



it was this submission, from the mother of a 17-year-old non-verbal boy, that really explained the positive benefits of multimedia advocacy, and the difference it had made to her son's life:

### Using a Wiki made a huge impact for this young man

"Our son is non-verbal but uses a number of idiosyncratic signs. It is vital that they are both understood and acted on. Having a RIX Wiki with videos of all my son's signs ensures that he will be understood. In April 2015 our son started a Saturday club. This is the first club outside school our son has ever attended. Working closely with his school, sharing information and having access to the RIX Wiki made this happen. We met with the organisers and shared information via our son's RIX Wiki, which gave the organisation essential information about my son with regards to his communication, care, and likes and dislikes. This information was used to identify the best person to support my son. It was also used to determine appropriate days out. Our son loves going on days out with the Saturday club and spending time with his peers. It also means we can now spend quality time with

his brother. There is other vital information on the Wiki, e.g. explaining where our son needs the most help and, more importantly for us, where he doesn't. Sometimes people assume that he cannot do certain things for himself, and having videos on his RIX Media Wiki, which we can share with everyone working with our son, ensures he is encouraged to be as independent as possible, as well as receive support where needed.

"The best experience he had was at a local animal sanctuary where he got to improve his tolerance of animals in general. It was wonderful to receive photos of the days out and see and celebrate our son's progress. We were then able to make a lovely video to music about his experiences for his RIX Wiki to share with his school friends. It's great to have technology to help my son share his experiences with others via video, as unlike his mainstream peers he cannot just go to school and talk about what he has been doing."

### Strathmore School, Richmond, Greater London

"We have built and opened a new secondary school building that is co-located with a comprehensive school. We have written a new post-16 curriculum based on preparing for adulthood, which aims to be relevant and purposeful. We have begun using Wiki websites, including for Section A of the Education, Health and Care (EHC) plan.

The Wiki websites have been an opportunity for pupils to share information from the different areas of their lives and be the centre of their whole context."

### Croydon Council

"We have begun to develop Wikis in order to challenge the barriers faced by children/young people with SEND. The Wikis are in their early stages but will enable services to communicate better with each other and also understand the child or young person's needs more effectively."

### Cambridgeshire Community Services NHS Trust

"Over the past five years, there has been an attitude change within the service that has seen a shift from a medical-style respite service where the focus was the parents having a break from a child/young person to an approach that focuses on the aspirations and goals of the child, e.g. their ability to access their own community, go to school. We have invested in joint working with local authority and Clinical Commissioning Group commissioning to look at ways of improving information gathering and sharing, e.g. through Wikis. The focus is always 'can do' and 'how to' rather than 'no way, too difficult'. This attitude is catching!"

## Teen Health and Wellbeing

**We received a mixed response from health professionals and parent carers of disabled teens regarding the provision of healthcare.**

**40%** of 96 respondents in the health sector felt their organisation was average or below average at communicating with disabled children and young people

**1 in 3** believed their organisation's approach to identifying barriers to inclusion was average or below

These figures were underlined by the parental evidence, which located the barriers in the attitudes of professionals, inefficient communication, lack of staff understanding and an inflexible approach:

"Access seems difficult for various reasons. My child has Asperger's... I am given varying advice from one source that will then conflict with advice from another. I cannot get my son to actually ATTEND a GP appointment due to his severe anxiety, therefore this in itself is an enormous barrier. GPs do not fully understand autism spectrum disorder (ASD)."

**Parent of a 12-year-old boy**

"The so called 'specialist' dental service is very difficult to access. They simply don't understand the needs of severely disabled children. CAMHS has been difficult to access – literally, no disabled parking..."

**Parent of a 17-year-old young man**

Some parents had had a more positive experience:

"Stafford's children's hospital unit and CAMHS Stafford have been excellent in their accessibility and care."

**Mother of a 16-year-old young woman**

"Paediatrics were excellent with appointments and relatively easy to access."

**Parent of a 16-year-old young man**

We received submissions from a number of health and social care professionals who have made small adjustments with lasting impacts. These case studies show the value of cultural and behavioural change, and prove that, with some creative thinking and a willing attitude, positive patient experiences can be achieved at minimal cost:

**Continuing care nurse coordinator**  
Rotherham, Doncaster and South Humber NHS Trust

"My role is specific to continuing care needs and over the last year I have developed a more robust, structured approach to assessments, which has been of benefit to a range of target groups (including teenagers). My appointment has helped in the coordination of continuing care packages and their subsequent effectiveness, particularly transition plans and communication with social care. As a result of my appointment, staff have become more skilled in completing assessments, and this has resulted in a more efficient and effective service for disabled young people."

**Paediatric occupational therapist**  
Kent

"We have worked hard on our referral criteria to allow best practice to be carried out for all children with special needs and provide an equitable service across Kent. If a piece of equipment is not available on the

NHS, we coordinate with charities to try to provide what is required. The translation/ interpretation service has been improved to allow families who have no or little English to access our service more easily."

**Paediatric consultant surgeon**  
Location unspecified

"We are a large teaching hospital and do everything we can to help all children and young people. I personally bend over backwards to accommodate requests regarding clinical assessments and listing patients for theatre. Disabled children can have a difficult cluster of problems and even getting to clinic with me for a 15-minute appointment can be a momentous task, let alone surgery. They will probably never know the lengths I or my colleagues go to, but hopefully our actions make their lives a bit easier and better."



### **NHS doctor**

Location unspecified

"I try to see a patient with autism who hates noise and unfamiliar environments as soon as I can within the emergency department. In addition, I try to obtain a separate side room and to do as much examination as necessary for the clinical scenario without overly distressing the child."

### **Community nurse**

Abertawe Bro Morgannwg UHB

"Some areas have established appropriate changing areas for children with disabilities in acute settings such as hospitals – as the real need for this has long been overlooked. These much-needed facilities mean that patients/clients can now use the bathroom as required, and not be forced to wait until they have finished at the hospital!"

### **Consultant community paediatrician**

Oxford

"I look after a large number of children with a variety of disabilities, many of whom have multiple complex medical problems. Over the last year, I have worked closely with colleagues in different medical specialties to try to establish joint clinics. By seeing children in joint clinics, families have fewer appointments in the hospital, saving them and their families time, meaning the children miss less school and the parents

miss less work, and hopefully ensuring more of their issues are dealt with at each appointment – I hope this leads to reduced suffering and improved health."

### **4Children youth worker**

National

"Last year, I delivered disability awareness and reasonable adjustment training to a sexual health clinic; they have now made some small but really important changes. The receptionist now asks people if they have a disability and need any adjustments and the clinic is buying some more forms of accessible information."



## Vital Role of School Nursing

**School nursing is an arm of health services that is constantly under threat from cutbacks and funding restrictions.**

However, as these case studies show, the diverse range of services provided by school nurses plays a vital part in ensuring disabled children and young people have equal access to healthcare and the chance to build a relationship with someone they can trust. School nurses are also ideally placed to act as conduits between children, young people, families and schools, and can provide much-needed advocacy on behalf of the child or young person.

We urge commissioners and health trusts to safeguard school nursing services and ensure that the health and wellbeing needs of disabled students continue to be met in safe and accessible environments.



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School nurses are also ideally placed to act as conduits between children, young people, families and schools.

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### Sexual health clinic

Bromley, London

“As a school nurse, I am passionate about supporting our more vulnerable young people and providing them with services. I would love to continue this vital work. However the Bromley school nurse team is an area which Bromley Council has suggested cuts may be made in 2017.”

“I am based at a special school and provide a number of services, including:

#### Health promotion

“The focus is on healthy living, puberty, safety work around private parts (what is private and what is public, what is good touch and bad touch), small group work around sexual exploitation and relationships, and sexual health.”

#### Drop-in service

“I am available one day a week for the students to come and discuss any health concerns they have, which ensures that disabled students have a professional that they know and trust, and can ask questions of a private nature in a confidential setting. I also work very closely with the school counsellor to ensure the students’ physical and emotional health needs are met.”

#### Sexual health

“I provide a C-card sign-up service and condom provision, with the aim of preventing unplanned pregnancy. An education programme runs alongside this to provide students with the support to understand their right to say no and enable a better understanding of themselves and others.”

#### Information provision

“I regularly liaise with parents/carers and use a school nurse app that provides families with easy access to the whole school nurse team and general health information.”





## County council school nursing service

Location unspecified

“Over the last 12 months, we have reviewed our school nurse service, and as a result we have:

- Delivered new sessions on accessing healthcare to enable students in Years 10 and 11 to learn about how to access their GP and what will happen at appointments (this is part of activities around transitioning between services in school)
- Established drop-in access for students to see a school nurse
- Introduced new workshops for parents/carers on key issues of concern
- Reviewed documentation to make it easier for those with learning disabilities to understand

We have had some great results, including a reduction in our teenage students’ anxiety about accessing health appointments and an increase in students contacting the school nurse to talk about things they are concerned about.”

## Professional lead for school nursing

Southern Health NHS Foundation Trust

“As a service, we wanted to make sure that the introduction of the childhood flu immunisation to school age children in Years 1 and 2 was inclusive for children with learning or communication difficulties.”

“One of our special school nurses developed a simple information booklet that she could use with children and parents to explain the nasal flu immunisation procedure. This could also be reinforced by school staff and by parents prior to the immunisation session taking place.”

“As a result, we found that children with learning and communication difficulties were included in the consent and decision-making process. They knew what to expect prior to the session taking place and were better prepared. As immunisations are not normally given intra-nasally, it also helped the children to understand the situation.”


## Senior School

**Many families find navigating school life during the junior years difficult and tiring: for many, these challenges continue as their son or daughter matures into their teenage years.**

Where their child’s disability was diagnosed later than early childhood, parents have reported real concerns about teacher’ attitudes and willingness to understand late onset and more complex conditions.

For many parent carers, efforts at inclusion felt tokenistic and were not designed to truly include their son or daughter within the classroom or extracurricular activities.

 **65%** of respondents from the education sector felt their organisation did an outstanding job at identifying barriers to inclusion

 However, **20%** of respondents felt their place of work was only average at working with individuals or families to overcome them



## Supporting choice

Class trips and subject selection were highlighted as problem areas:

"My son has never been on a school trip and was blocked from attending sports day last year despite me being willing to take responsibility for him."

**Parent of a 14-year-old**

"My son is in Year 9 and the school haven't made it possible for him to go on any residential trip as yet – without requesting that a parent go to monitor blood glucose levels overnight."

**Parent of a 13-year-old boy**

"My son was not offered the full GCSE option choices as he was classed as a 'less able' child. I have since argued with the school about this and he has been given the same choices."

**Mother of a 13-year-old boy**

Despite some pockets of good practice, parental evidence suggests that schools must remain vigilant with regards to establishing and maintaining positive practices, reviewing their policies around inclusion and ensuring they continue to adopt a person-centred approach throughout a child's school journey.

## Education, Health and Care plans

As with younger children, parents of disabled teens in England have struggled to navigate the introduction of EHC plans and access assessments for their child. One parent reported that she had:

"...had real problems with Education, Health and Care plans. Information from providers is confusing and hard to understand. There is a real attitude of 'well, at the end of the day, if they are too ill to go to school they can just claim ESA'. This is not the answer and is no way to treat a child with a long-term condition."

**Mother of 15-year-old young person**

### Another parent explains:

"Despite our family's positive outcome, I find the whole process disjointed. One service may be good while another very poor and communication lacking. We were put off getting an EHC plan but now have been told that we must start – it often feels as if the local education authorities or County Council's do not want to give them out; however, a child's support now and beyond school relies on it. These plans are an integral part of getting a young person support for the transition from adolescence into adulthood and I do not know why the process is made so hard. Having a complex and debilitating condition is hard enough on the child and family. More should be done to recognise this and make what is essentially a passport to support easier to obtain."

**Mother of 16-year-old young person**



# Case study 1

## Sarah's 15-year-old daughter Abi has experienced both the best and the worst types of special educational needs (SEN) provision for children at mainstream school.

Abi was diagnosed with a brain tumour in Year 2, and in the summer before starting Year 5 had a stroke that led to her experiencing difficulties with language. Her experiences of inclusion in primary school were poor, as her mother describes:

- Abi was miserable and didn't feel welcomed, feeling like a "thorn in their side"
- A lack of inclusive attitudes meant staff weren't willing to make the extra effort it takes to support a child with additional needs
- Her additional needs weren't catered for – she was made an example of when she took longer than the rest of the class to get ready for games, and the whole class was made to wait while she finished changing
- She often went whole days at school without once being spoken to by other pupils
- With the help of an educational psychologist, the school created a 'circle of friends', which involved playing in a quieter space than the playground during break and lunch – however, this was removed after six months, which was worse than it never being put in place, as Abi felt rejected
- She went back to being very isolated at school
- For a six-month period she refused to go to school and her parents had to force her

After finishing primary school, Abi started Wilncote High School, which her family chose based on the performance of its SEN department. There were initial issues with the provision of transport, which were resolved after they took the local authority to a tribunal and Abi now loves attending school. "She's valued, welcome and succeeding."



### Her mum told us:

- Abi felt immediately welcomed by all staff including the head teacher, who said how pleased they were she had chosen Wilncote High School. This welcoming attitude has continued and she feels completely appreciated and included
- Abi has been entered into GCSE Art and History – something that her parents never expected she would be able to do
- The school are helping with her educational transition post-secondary – the SEN department have made her aware of what her options are after school, and have experience with what has and hasn't been successful with previous SEN students. On the advice of the school, she plans to enrol in agricultural college after finishing her GCSEs, since she has a particular interest in animal care
- The school support and engage in communication with home, including a home diary and parental support meetings

### Sarah's key message to schools is:

**"Celebrate the fact that someone has trusted you to look after their child."**

Sarah praised [Independent Parental Special Education Advice<sup>8</sup> \(IPSEA\)](#) for the invaluable advice and support they provided when writing Abi's (EHC) plan, and mentioned the [Tribunal Helpline](#) as being particularly valuable when going through a daunting and confusing tribunal process. She also praised [Special Needs Jungle](#) for the parent-led information and resources they provide for parents and carers of disabled children and young people.

# Case study 2

**“My son (C) is now 15, and his schooling is currently provided through the local authority by a company called First Class Tailored Solutions.”**

“This is an off-site education package, and is structured around his complex and fluctuating health needs. The teachers are fantastic and flexible, and have built a great relationship with C in the three years they have been teaching him.”

### Importance of diagnosis

“It has not been an easy ride as my son’s illness is complex and was not easy to diagnose. After he received his diagnosis it was easier, and the teachers made a real effort to gain more understanding and insight; the school have been absolutely fantastic and I know they have a great relationship with the SEN team. His provision is regularly reviewed to see what needs to be added.”

### Mental health and wellbeing

“My son’s personal tutor has been a mentor to C, restoring a lot of his emotional wellbeing. C is now learning to trust authority figures again through this person, so class time has been about a lot more than just learning lessons. Overall his teachers are fantastic and we have a great relationship. I really could not ask for more.”

### Signposting and information

“It would have helped to know exactly what my child was entitled to legally... there should be a document for parents that tells them what the options are, how much education your child is entitled to if they’re unwell, and what kind of services you can try to get... it would have helped if that was there from the start because I think my child could have been in education at least two years before he actually was with the package he’s got.



“The facilities and the services to help disabled children do exist and they are there... I just think it needs to be made easier for parents to be able to get, because I think they are going through enough already... and if there was a way of saying this child needs some support in education, this is what is available, this is what we can do...”

**“His teachers are fantastic and we have a great relationship.”**



## Learning Zone

For further information, please visit:

[Transition Matters](#)

[Worry and Anxiety Matter](#)

[Activities Matter](#)

[Three-way Communication Matters](#)

[Working Together Matters](#)

[Feelings Matter](#)

[How Information is Shared Matters](#)

[Diagnosis Matters](#)

[Complex Conditions Matter](#)

[Communication Matters in Learning](#)

[Advocacy Matters](#)

[Meaningful Inclusion Matters](#)

# Signposting and Information

**Improvement required across all sectors!**

We asked professionals and volunteers to score out of 10 how well they thought their organisations provided information in a range of accessible formats, e.g. large print, easy read, etc.

**By sector:**

Education.....	7.3
Social Care .....	6.9
Travel, Leisure, Other.....	6.8
Community.....	6.6
Health.....	6.0
<b>Average score.....</b>	<b>6.7</b>

1 = very poor 10 = outstanding

*More needs to be done to signpost families to sources of information and advice, work with them to overcome barriers and make services more accessible*

## Taking Part

Shropshire

**“The amount of change, information and services that families have to navigate is overwhelming for many...”**

[Taking Part](#) supports projects in Shropshire by helping children with healthcare and social needs to access mainstream services, e.g. Sports Village in Shrewsbury. They provide children and young people with formal and informal advocacy and have supported families to gain an understanding of their rights under the Care Act and to have a better understanding of personal budgets, EHC plans and the local offer.

“We offer social projects for those going through the transition into young adulthood at the Hive and Buttermarket venues, plus creative sessions through Artstart. We want teenagers to feel confident about accessing mainstream services. Our aim is to help mainstream services gain a better understanding of the real needs of disabled people – to appreciate that they are individuals and are the same as the rest community, just needing reasonable adjustments to access their services... and that’s not just a ramp!”

## Continuing healthcare nurse coordinator

Rotherham, Doncaster and South Humber NHS Trust

“Over the last 12 months, my team has worked hard to engage with other services and we now have stronger links both with partner agencies that provide social activities for young people with additional needs and with social care in regard to short break provision. This improved communication means staff have more awareness of these services and can support and signpost families to providers more effectively.”



## Learning Zone

For further information, please visit:

- [Rights Matter](#)
- [Caring for Parent Carers Matters](#)
- [Family Matters](#)
- [Finance Matters](#)
- [Advocacy Matters](#)



# 4. Young Adulthood

## Transition from Child to Adult Services

### The transition period between the teenage years and adulthood is often a very difficult time for disabled young people.

This time of uncertainty was described by many as the result of a combination of overnight becoming ineligible for a range of support services and leisure activities, the sudden lack of structure and certainty of school, and uncertainty and difficulties when finding employment. These commonly resulted in feelings of purposelessness, isolation and hopelessness, and for some a deterioration in their mental health.

### Parent carers and young people cited some of the main difficulties as:

- Losing access to services and support overnight
- Difficulties accessing adult mental health services
- Finding it much harder to access adult services than children's services
- A lack of support and information on what a young person can do post school or college
- Difficulty in accessing disability services or support and reasonable adjustments while at university
- A lack of flexibility of educational institutes regarding attendance at courses, e.g. full attendance not always possible, but no other options available
- Difficulties with transport and accessibility of shops and venues hindering independence and social outings
- Difficulties finding employment and work experience
- Experiencing low expectations of what they can achieve, and how independent they can be
- Turning 18 and being unable to attend the sport and leisure activities they had accessed previously

"The transition from children's to adult services has been a nightmare. Overnight you lose access to so many things. Rules change. Criteria change. We have struggled to find activities now that she officially is an adult!"

**Parent of a 20-year-old woman**

"I have found it difficult to access mental health treatment. I was on a waiting list for months for CBT (cognitive behavioural therapy) through IAPT (Improving Access to Psychological Therapies) that was completely inappropriate for my condition. In the end I had to use my benefits to pay for therapy privately."

**18-year-old woman**

"Difficulties with transport and accessible shops/entertainment venues remain. Going to gigs with my friends – I have to book separately and then have to sit in a different part of the arena."

**17-year-old man**

### One mother told us about her 22-year-old son's experience of entering adulthood:

"It shouldn't be such a struggle to enable our son to make life choices and access opportunities, but it is... his expectations are very modest; he wants the life that he sees as a normal family life: work, own front door and freedom to come and go as he chooses as far as possible. For all of that he needs support. There is an assumption that he should settle for less, but to do so would be emotionally devastating."

**Another parent of a 25-year-old explained** how a lack of information and support for her son about what he could do after finishing college led to him feeling abandoned, and consequently developing mental health problems:

"The lack of information, even when searching online for support for young adults with autism, has meant my son has become more and more isolated and led to him developing mental health issues. There was no guidance on where to go for further support after leaving college as a student with special needs and it left my son feeling very abandoned."

### Physiotherapy department – Northumberland Tyne and Wear Foundation NHS Trust

"Our staff working in the special schools have improved the way they engage with and involve parents/carers and school staff in training to help a young person maintain/improve their ability to learn and participate in school activities. We have also developed a new, clearer transition protocol to ensure that young people continue to get the support and treatment they need as they move into adult services."



## Learning Zone

For further information, please visit:

[Transition Matters](#) ↗

[Supporting Independence Matters](#) ↗

[Inclusion Matters for Organisations and Services](#) ↗

[Transport Matters](#) ↗

[Environmental Challenges Matter](#) ↗

[Choices and Decision-making Matters](#) ↗

[Mental Capacity Act](#) ↗

[Best Interests Decision-making Matters for Clinicians](#) ↗

## Further Education

### Access is improving, but more can be done.

When a disabled young person wants to pursue their studies at a further education college or university, they may need additional support to enable them do this. Parents and young people told us about their experiences of further education, and what they thought could be done to improve access and inclusion within these settings.

"I have recently started university and they have been very helpful in finding me suitable housing as well as ensuring that my lectures are mostly in accessible buildings and rooms. Their disability services team are also easy to get in contact with if I ever have a problem."

**19-year-old woman**

"The provision of student support at university has been invaluable – it works best when tailored, but even the generic services currently available allow him to become familiar with new places (a note taker and campus guide were provided for the first few days) and learning experiences. (His Asperger's mentor in particular has a more tailored approach and identified his main areas of difficulty (forward planning and assignment organisation), helping him draw up a timetable for completion."

**Parent of a 24-year-old man**

### Respondents mentioned the following challenges:

- Physical accessibility
- Being unable to access the same activities or spaces as their friends
- A lack of understanding of disability

"I don't believe that some of the top universities understand how it can be harder to achieve top grades due to unforeseen medical circumstances."

**19-year-old man**

Proactive identification of individual needs and putting the right adjustments in place can make inclusion meaningful.

"He had a note taker at university, but the standard varied. He could not always read the notes and the note taker did not appreciate that he could not hear anything of the lectures."

**Parent of a 21-year-old man**

"I go to college and crossing the road is difficult in places and sometimes I can't cross the road in a straight line and have to travel some distance up the busy road to find a drop kerb on the opposite side of the road... the lift broke and took months to repair – I was unable to access the same areas as my friends, which made feel a bit isolated as I had to go to the library."

**17-year-old man**

"During her education she has received additional support, been allocated a scribe during exams, and been provided with a laptop and other equipment. It was not easy to get this set up initially as we had to arrange and pay for a physiological report before she went to uni; this cost around £225 and was not refunded."

**Parent of a 21-year-old woman**





## Employment

**Finding fulfilling and meaningful employment is something that many disabled young people aspire to; however, disabled young people face additional barriers when finding it, and are often poorly supported to deal with this period of change.**



Some common challenges and concerns that parents mentioned regarding their young people's opportunities for employment were:

- Employers not willing to provide work experience because they feel they cannot meet the needs of the young person
- Employers using the young person for work experience but never hiring them
- A lack of guidance and support on what a young person's options are after college or school

**One parent told us about her 26-year-old son's experience of finding employment:**

"Finding employment is impossible. Employers do not want to know and use my son for work experience and have no intention of offering him employment. So I do not believe that my son has the same access to activities and services and he is discriminated against."

We received evidence from some providers who are working to support young people in this area – they highlight what can be achieved when people have a can-do attitude and are willing to be flexible in their approach. We have showcased the work of Changing Our Lives, who are based in the West Midlands, and London Youth.

## Changing Our Lives

Hagley, West Midlands

[Changing Our Lives \(COL\)](#) is a rights-based organisation that works in coordination with disabled people of all ages to help them lead 'ordinary lives'. Their work is rooted in the belief that no one is too disabled to lead an ordinary and independent life, and disabled people should have equal access to the same opportunities as their non-disabled peers. Changing Young Lives (CYL) works with young disabled people to speak up for their rights and be recognised as young people first, whatever their disability, and is committed to tackling the challenges that disabled young people face when seeking meaningful employment.

"We all know that the best way someone can improve their living standards, whether they have a disability or not, is through steady, well-paid employment. It improves health outcomes, mental health and wellbeing and for disabled people it is a powerful message that you are an equal to a person without a disability, and breaks down the prejudice in the workplace and society."

CYL worked with the Wolverhampton Clinical Commissioning Group (WCCG) to launch the exciting pilot project 'Sky's the Limit', which worked with four young people going through transition, who all had complex health and social needs. This involved

working closely with the young people to identify their hopes, dreams and aspirations, and any additional support they may need to achieve them. These aspirations included finding a job, moving into their own home, and being connected with people in the community. The CYL young leaders then hosted an event that challenged community, public and private sector providers to make the young people an offer to support them to help them achieve their goals.

"You have young people who had never been asked these questions before, which seems ridiculous but true, and then you have families... who had very low expectations for their sons or daughters or the people that they were caring for. Because from day one they hadn't been told that they might be able to live in their own home, have a job and do the very normal things that we all have out of life."

Sky's the Limit not only aimed to help four young people achieve their hopes and dreams, but also aimed to tackle the misconceptions and prejudices that employers often have about employing disabled people, and raise awareness that disabled people have talents, passions and strengths that can be hugely beneficial to employers.

“The biggest barrier of all is that they have no experience of employing disabled people, certainly not people on the autistic spectrum, or people with a learning disability... I think there’s a fear of the unknown, I think that people don’t really understand what that will mean, that the employer will be under the impression that they will have to support somebody, they would have to do all that work.”

“Employing disabled people is no different than employing somebody without a disability, it’s just understanding that there may be a little bit of support and there may be some reasonable adjustments that are needed.”

“In relation to what you get out of somebody, versus what you have to put in early on, it is paid back tenfold... it’s not about employing somebody because they’re disabled, it’s about getting the best out of somebody and making sure they can add something to your business.”

The results of Sky’s the Limit will not only help four young people get a step closer to achieving their hopes and dreams, but will additionally help shape the future working practices within WCCG and Wolverhampton City Council, and their partners, to ensure that young people going through transition are directing their own support so that it is driven by their needs, desires and aspirations for a brighter future.

Sky’s the Limit is just one of the initiatives COL and CYL have used to ensure that disabled young people have access to the same opportunities as their non-disabled peers. COL also held ‘Keep Up’ practice development sessions in Wolverhampton, where professionals from education, health and social care were challenged around the terminology they use, and how they support disabled people to aim high and achieve their aspirations. ‘Keep Up Revisited’ was hosted a year later, and celebrated the pledges that the professionals have achieved; the participants which included Interim Children’s Commissioner of WCCG and the Commissioning Officer of Wolverhampton City Council. These are just a few examples of the fantastic work that COY and CYL have done to improve employment outcomes for disabled young people going through transition; they are continually striving to ensure disabled people are valued as equal and contributing members of their local communities.

**Image gallery** (Click on numbers to view)

## London Youth

London

[London Youth](#) is a network of 400 community youth organisations supporting and challenging young people to become the best they can be.

“Our organisational strategy compels us to work with all young people, but we place a particular emphasis on those who wouldn’t otherwise have access to the kind of opportunities we offer. In 2013, our senior team and board made a commitment to prioritise a focus on inclusion to enable young people with disabilities to achieve the same outcomes as their peers when participating in opportunities with London Youth. To kick-start and facilitate this work, we wrote an operational plan for inclusion for the first time and also recruited a team of ‘Inclusion Champions’ to spearhead the improvements.”

London Youth has developed a specific Inclusion Operational Plan, holds quarterly Inclusion Champions meetings throughout the year and since September 2016 has embedded inclusion principles throughout all team plans. These steps have made it possible for London Youth to improve its offer for disabled young people at Hindleap Warren, an outdoor education and personal development centre, in the following ways:

- Introducing continuity of delivery staff for all disabled groups

- Visiting specialist schools and residential centres to learn more about best practice
- Purchasing specialist equipment, including a profile bed and pressure-relieving mattress, pro-move slings, buggy and self-propelling commode and shower chair
- Installing pictorial eye-level signage

Part of London Youth’s vision is that all young Londoners will be able to navigate a fulfilling career. London Youth supports young people to develop the confidence, resilience and relationship skills they need to do this through its network of community youth organisations and their two residential centres.

London Youth works very closely with [Talent Match London](#), which is a partnership of organisations testing innovative youth-led solutions to unemployment. It provides one-to-one support to young people, which provides the skills, confidence, resilience and networks that young people need to navigate future career pathways.

London Youth also releases a weekly e-bulletin, which features opportunities for exploring different careers, including job vacancies and training opportunities.



## London Youth’s top tips for...

### developing an inclusive offer for disabled children and young people

- Go to where the disabled children spend their time and talk to them about inclusion
- Talk to professionals and parents of disabled children so that you have a better understanding of how their child communicates/prefers to engage
- Understand and respect that every child or young person is an individual, and disabled people do not all react in the same way
- Accept that everyone has different social skills or abilities – if a child responds differently to others, don’t automatically assume they do not want to engage with you
- It is vital to engage with disabled children and young people on their terms – this means being understanding and not collectively thinking that all children with SEND are the same



## Learning Zone

For further information, please visit:

[Transition Matters](#)

[Growing Up Matters](#)

[Rights Matter](#)

[Environmental Challenges Matter](#)

[Supporting Independence Matters](#)

[Inclusion Matters for Organisations and Services](#)

[Work Experience and Employment Matters](#)

[Choices and Decision-making Matters](#)



# 5. Summary

## What You Can Do

- Take **responsibility**. Be part of the solution to enable better and more meaningful inclusion for everyone
- **Reflect** on your own attitudes and beliefs about disability and towards disabled people
- Using Disability Matters resources, improve your **communication** and **problem-solving** skills, **knowledge** of disability **rights** and the issues that disabled children, young people and their families face, in order to better support and more meaningfully include them
- **Commit** to working through at least one Disability Matters session (takes about 20 minutes). Even better, commit to working through at least one Disability Matters session every month for a year
- **Share** this report with everyone in your organisations and networks. Encourage others to take up the Disability Matters challenge
- **Tell us** about what a positive difference using Disability Matters makes for you and in your organisations and communities. We want to share feedback on the Disability Matters website to encourage others to take up the challenge. Contact us at: [disabilitymatters@rcpch.ac.uk](mailto:disabilitymatters@rcpch.ac.uk)
- **Collect** and record **robust data** in your locality about the multifaceted needs of disabled people, so that these needs can be **visible** to those who commission, govern and provide services. Make sure that the needs of disabled people, including all infants, children and young people, are on everyone's agenda
- Involve disabled people in the **review and design** of local services, to make sure they are achieving the outcomes that matter most for them



## Acknowledgements

The 250 participants who completed our survey – and the young people, parent carers, professionals and volunteers who shared their stories and agreed to be quoted in this report.

### Our organisational case studies:

[Active Impact](#)

[Blackmarston School](#)

[Brownies/Girlguiding UK](#)

[Challengers](#)

[Changing Our Lives](#)

Continuing Care Team, Rotherham, Doncaster and South Humber NHS Trust

[East Stour Primary School – Ashford, Kent](#)

[London Youth](#)

[RIX Wiki](#)

[Rushcroft Primary School – Oldham](#)

Salford Royal Foundation Trust – Speech and Language Therapist

School Nurse (Sexual Health Clinic), Bromley Healthcare

[Solihull Life Opportunities](#)

[Strathmore School – Richmond, Surrey](#)

[Taking Part](#)

Tesco

Thrive

[Young Healthwatch – Northamptonshire](#)

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## Useful Links

[About with Friends, Cromer](#)

[Achievement for All](#)

[Action for Children](#)

[Active Impact, Gloucestershire](#)

[Anti-Bullying Alliance](#)

[Barnardo's](#)

[Blackmarston School, Hereford](#)

[Blue Wave Hydrotherapy Pool, Margate](#)

[Brownies/Girlguiding](#)

[Buckinghamshire Learning Trust](#)

[Challengers](#)

[Changing Our Lives, Hagley](#)

[Civil Aviation Authority](#)

[Contact A Family: Professionals and parents in partnership](#)

[East Stour Primary School](#)

[Fairplay, Chesterfield](#)

[First Class Tailored Solutions](#)

[General Medical Council guidelines on discrimination](#)

[IPSEA](#)

[Joseph Rowntree Report on 'Disabled teenagers' experiences of access to inclusive leisure'](#)

[KIDS](#)

[London Youth](#)

[Mencap](#)

[Rushcroft Primary School](#)

[Solihull Life Opportunities, Birmingham](#)

[Special Needs Jungle](#)

[Strathmore School, Richmond](#)

[Taking Part, Shropshire](#)

[Talent Match London](#)

[The Percy Hedley Foundation](#)

[Thrive](#)

[Yorkshire Wildlife Park](#)

[Young Healthwatch Northamptonshire](#)

## References/Notes

<sup>1</sup> Main page of: <http://www.un.org/en/events/disabilitiesday/>

<sup>2</sup> 261 detailed qualitative responses were submitted during the six weeks that our Call for Evidence was open. Responses were received from 128 professionals and volunteers working with disabled children and young people, 123 parent carers of young disabled children, and 10 disabled young people.

<sup>3</sup> <http://www.gmc-uk.org/learningdisabilities/200.aspx>

<sup>4</sup> Good Medical Practice, paragraph 59.

<sup>5</sup> Arch Dis Child 2005;90:1053–1057, Community child health, public health and epidemiology “Contact A Family”: professionals and parents in partnership.

<sup>6</sup> Extract from the Challenging Behaviour Foundation’s Fact Sheet: Challenging behaviour: a guide for family carers on getting the right support for children: <http://www.challengingbehaviour.org.uk/learning-disability-files/SCIE-Guide-for-children.pdf>

<sup>7</sup> MacMillan, M., Tarrant, M., Abraham, C. and Morris, C. (2013). The association between children’s contact with people with disabilities and their attitudes towards disability: a systematic review. *Dev Med Child Neurol*, 56(6), pp.529–546.

<sup>8</sup> IPSEA is a registered charity that provides parents of children with SEND with free, legally-based advice. They offer an information service and advice line, which provides advice on: problems with schools, statutory assessment requests, statements and EHC plans, annual reviews, disability discrimination and exclusion. Additionally, they offer a tribunal helpline, which offers advice on SEN and disability discrimination appeals, and tribunal support for families appealing to the Special Educational Needs and Disability Tribunal.

<sup>9</sup> First Class Tailored Solutions Limited is a one of a kind service that provides good-quality and personally tailored education to suit each pupil’s individual needs and circumstances. They offer a varied service, which includes the provision of teaching, mentoring and support for young people mainly in Nottinghamshire and the surrounding areas.





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