SCOPE = Equality for disabled people

AN EQUAL FUTURE

Our strategy from 2023 to 2033

Our vision

We won’t stop until we achieve a society where all disabled people enjoy equality and fairness.

Our mission

We are Scope.
We are determined to change the future.
Together, as a collective movement of disabled people, campaigners, donors, volunteers, communities, and businesses. We work every day to challenge attitudes and end disability inequality.

Setting out our vision for the future

Our goals

We were founded over 70 years ago to change society for disabled people and people with Cerebral Palsy. Despite progress in this time to legislation and rights, to inclusion and to expectations, millions of disabled people continue to experience inequality, negative attitudes, and prejudice every single day.

Scope exists to change this. We are a social change organisation focused on ending inequality. Now and in the future.

We've worked with over 450 disabled people, colleagues, volunteers, and our trustees, to create our vision of An Equal Future.

We know that equality is a right that cannot be taken for granted. We are relentless and impatient for this right to be afforded to every disabled person.

Too many disabled people are denied work opportunities, millions of disabled people experience a financial penalty simply because of who they are, and many of us have experienced negative attitudes because of our disability.

The recent impact of a global pandemic and cost of living crisis has only made these things worse, impacting disabled households far more than others.

Our strategy sets out the 3 areas we will focus our resource and make the biggest difference. We will be flexible on how we get there but we will be unwavering in achieving our vision.

A movement of change

Our strategy also describes how we will build and be part of a movement of:

- people
- volunteers
- campaigners
- partners
- funders
- civil society
- communities around the country

to achieve our vision of an equal future.

We aim in our first 3 years of this strategy to have over 300,000 campaigners and supporters join us.
We will work with:

- disabled people
- politicians
- businesses
- funders
- charities
- the public

to make our vision a reality and achieve transformational impact.

In communities across the country, our shops and services will be places for all those who want to work with us to create An Equal Future.

We will be making greater use of digital tools and technology to enable this vision. By doing so, we aim to provide advice and support to at least 3.5 million disabled people every year.

Equality, diversity and inclusion

Scope is an open place for every disabled person. For anyone who wants to change society. In the first 3 years we will do far more to reflect the diversity of our society, to listen to those experiencing discrimination on multiple fronts and build partnerships to amplify and end this discrimination. For too long disabled people have been ignored and overlooked. Scope exists to change this. To create An Equal Future.

Being disabled in the UK

16 million people in the UK are disabled. That’s 1 in 4 people or 24% of population.

Attitudes

- Our attitudes towards disabled people research[1] has found 3 out of 4 disabled people (72 percent) experienced negative attitudes or behaviour in the last 5 years.
- 9 out of 10 disabled people (87%) who experienced negative attitudes said it had a negative effect on their daily lives.

The Disability Employment Gap

- We estimate there are a million disabled people out of work who want to work.
- The employment rate of disabled people is 54 percent. Compared to 83 percent of non-disabled people.
- The disability employment gap is 29 percent.

The Disability Price Tag

- On average, disabled households (with at least one disabled adult or child) need an additional £975 a month to have the same standard of living as non-disabled households.

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[1] Scope Attitudes research (2022)

Our strategy at a glance

We have ambitious plans for the next decade to achieve An Equal Future for all disabled people in the UK.

Our goals

Transform Attitudes

By 2026

- A significant change in media representation.
- An attitude change programme running in schools.
- A shift in attitudes in the workplace.

By 2033

- Disabled people no longer experience negative attitudes and discrimination.

End the disability price tag

By 2026

- A social energy tariff is in place for disabled households.
- A fairer, more dignified and supportive disability benefits system.
- Businesses are making goods and services more affordable.

By 2033

- Disability is no longer linked with poverty.

Close the Disability Employment Gap

By 2026

- A political commitment to close the employment gap.
- Continue to support disabled jobseekers into work.
- An Aspiring Leaders programme established.

By 2033

- All disabled people, who want to work move into, stay in, and progress in work.

What we do

1. We influence society

We are part of a movement to end disability inequality nationally and in communities. We will unleash the power of our campaigners, donors, volunteers, shops and services to achieve change. We will amplify disabled voices to end inequality.

2. We partner with others

By collaborating with Disabled People's Organisations (DPOs), governments, employers and individuals we can work together to achieve An Equal Future.

3. We provide support, information and advice

We empower disabled people and their families to have control over their own lives.

4. We are led by insight and evidence

We will use this evidence to focus on what's important to disabled people, improve our services and demonstrate what works to influence others.

Our strategic goals

Goal 1: Transforming attitudes

At Scope we have a proud history of challenging negative and outdated attitudes towards disabled people.

Our attitudes towards disabled people research[2] has found that there consistently remains a stubborn lack of understanding of disability, and negative attitudes towards disabled people are still far too common. From outright discrimination to more nuanced and subtle exclusion, disabled people and families experience negative attitudes in many parts of their lives.

From the judgement of others about what disabled people are capable of, the constant questioning and having to justify yourself, to confrontation, discrimination and physical abuse. Disabled people still face huge barriers to full inclusion and equality in society.

For disabled women these experiences are more frequent. And for younger disabled people, these experiences are more common too. For disabled people who are black, or who identify as LGBT+, experiences of negative attitudes and behaviours are rooted in racism, homophobia and transphobia.

> "When I went to the pub people looked at me. And started taking the mickey out of me, making me feel worthless and alone. I didn't socialise for a while because of how it made me feel."
>
> - Scope research participant

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[2] Scope Attitudes research 2022

These attitudes and reinforcing of stereotypes can come from lots of places and people. In our workplaces, on our streets, across social media and in the stories we consume through TV, film and other media. The impact of these negative attitudes and behaviour can be huge. For some, the experience of negative attitudes has led to leaving work, to stopping socialising and avoiding things they once liked to do. An Equal Future is possible.

> “Once you say you're disabled, they think you must be a certain way, or you must look a certain way, speak a certain way, be able to do this and not be able to do that.
> I think in the media sector, there needs to be a lot more recognition of disability, because we're actually 24 percent of the population. With discrimination, we're the highest but it's not really talked about, it's like people are too scared. Especially with hidden disabilities, because you wouldn't think straight away that I’m disabled.”
>
> - Bryony Moss

By 2033 we want to see transformational improvements in attitudes towards disabled people and disability.

At Scope we will shine a light on all those working towards an Equal Future at our Disability Equality Awards. Showcasing best practice and champions who are tackling outdated attitudes.

By 2033 we want to see transformational improvements in attitudes towards disabled people and disability.
We believe society is stronger when everyone feels included, free from discrimination, negative attitudes, and behaviours of others. And where disabled people can enjoy equality and fairness. Achieving this requires institutions, individuals and disability organisations to think differently. Government, employers, the media, our benefits system and the general public all need to play a role.

Over the next 3 years we will:

Create a movement of media companies, production houses, creative agencies, media platforms, journalists and advertisers to shift the dial on disability.
We know the media industry has a huge role to play in shifting attitudes. From the stories told on screen and reported on. To the representation of disabled people in front of and behind the camera. We will work with companies, journalists and broadcasters to tell the disabled stories that matter and transform their approach to reporting and storytelling.

Launch a new programme to address attitudes early in schools. We know proximity and storytelling are integral to shifting attitudes.
We will work with schools across the country to create a generational shift in attitudes. And aim to reach 10,000 young people within our first 3 years.

Launch and run a campaign to shift attitudes in the workplace.
Our research has shown attitudes in the workplace are a priority for change amongst disabled people. We will work with employers to begin to shift attitudes in the workplace.

Shining a light on equality champions

We will shine a spotlight on all those working towards an Equal Future at our Disability Equality Awards. Showcasing best practice and champions who are tackling outdated attitudes.

How we will track our progress

We will track external progress on this goal by rerunning our research into attitudes. In 2022, 3 in 4 disabled people said they had experienced negative attitudes or behaviours in the past 5 years. By the end of this strategy, we aim to have significantly reduced this.

> “Being a role model and raising awareness is important because it will allow the next generation to know it’s okay. Don’t be ashamed. You’re still a real-life superhero. You still can achieve.”
>
> - Jorden ‘Akes’ James

Goal 2: Ending the Disability Price Tag

Being disabled in this country comes with a price tag.

The high cost of specialist products, the extra money disabled households need to spend on essential services to keep themselves warm and charge equipment, and the penalties associated with purchasing everyday goods like insurance or using transport. These all add up.

Our groundbreaking Disability Price Tag research[3] identifies that disabled households need on average, an additional £975 per month just to have an equal standard of living.

On top of these extra costs, many disabled people are failed by our inadequate welfare system. Millions of disabled households are now living in poverty.

> "The way that fuel bills have gone up and so many disabled people are stuck indoors, meaning that bills will obviously cost more for us. It's hard, but we don't have a choice. People don't see this side of being disabled. We didn't ask to be disabled, and disability doesn't care how rich or poor or young or old you are."
>
> - Susan Donnelly

The pressure on disabled households to meet the extra cost of disability makes it harder to have a decent standard of living. It makes it harder to plan for the future, harder to participate in society and reinforces inequality. An Equal Future is possible.

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[3] Scope Disability Price Tag research (2023)

> “People don't see that disabled people pay more than anyone because they're providing double costs for their disability. As a disabled person, I feel like we don't matter. I just think everyone's walking around with their eyes shut. My spinal injury has brought about more costs. It’s more isolating because you’re worried about spending a pound over. And if you spend that pound over, you’re going to go without something else, whether it’s less on the electric, or some medical item that you need. You have to go without to buy that item, and it does mean getting into debt. It has to happen.”
>
> - Samantha Foster

By 2033 we want disabled people, households and families to have an equal standard of living and to have ended the financial inequality associated with disability.

We can end the Disability Price Tag by working together with

- disabled people
- businesses
- Governments
- politicians
- market regulators

We can create an equal society, where everyone can participate and where disability is no longer synonymous with poverty.

Through our information, support and advice we will make sure disabled households are equipped to navigate the welfare system and reduce extra costs.

Over the next 3 years we will:

Campaign to secure the introduction of a social energy tariff.

To make sure disabled people are not unfairly penalised by the energy market. We intend to achieve this by 2025.

Work with disabled people to propose a fairer, more dignified and supportive approach to disability benefits.

Making sure the welfare system provides an adequate level of benefit. We intend to achieve this by 2026.

Work with businesses to better understand their disabled customers.

Making sure that specialist goods and services are accessible and affordable.

How we will track our progress

We will track external progress on this goal by regularly publishing the Disability Price Tag figure. In 2023, the Price Tag was £975 per month. By the end of this strategy we aim to have ended the unfair Disability Price Tag.

Goal 3: Closing the Disability Employment Gap

A fulfilling and satisfying career, for those who want it and are able, can be hugely rewarding.

The Disability Employment Gap is the difference in the rates of employment between disabled and non-disabled people. And it has barely changed in the last decade.

Too many disabled people are written off from entering the workplace at a young age, experience discrimination from managers and employers, and have low expectations placed on them simply because they are disabled.

Being talked over, being turned down for a promotion, being spoken about but never to and being told to “get on with it” are just some of the common things disabled people still experience in the workplace.

Adjustments, flexibility, support and understanding are often missing.

> “I've had responses along the lines of, 'Please give us a lot of detail about your disability and then we can figure out something that means it's fair for everyone.' Which gave me the impression that they thought I was asking for special treatment rather than just asking for support in making things less of an absolute struggle”
>
> - Sarah Ollier

It is no surprise disabled people are twice as likely to leave their jobs as non-disabled people.

A huge amount of disabled talent is going to waste. An equal future is possible.

> “I've had responses along the lines of, 'Please give us a lot of detail about your disability and then we can figure out something that means it's fair for everyone.' Which gave me the impression that they thought I was asking for special treatment rather than just asking for support in making things less of an absolute struggle.”
>
> - Sarah Ollier

By 2033 we want to see every disabled person who wants a job to have got one and the employment gap to have closed.

Closing the Disability Employment Gap requires action from employers, from Government, from charities and from employment support providers so that disabled people can not only find work but stay there and reach their full potential. And this thinking is critical as ways of working, the types of work and the role of technology and automation can bring huge benefits as well as potential challenges.

Closing the Disability Employment Gap will bring huge benefits not just to individuals but to companies and society.

Halving the disability employment gap would bring huge returns to this country. If we were to do so, we would experience a £17 billion increase to the economy each year.

Increasing the numbers of disabled people in employment also benefits business by enabling them to expand markets, grow customers bases and increase profits.

Over the next 3 years we will:

Secure political commitments to close the Disability Employment Gap.
Closing the Gap requires Government leadership and action we will campaign to build political consensus on the action required of Government. We intend to do this by 2025.

Directly support disabled job seekers into work through our voluntary and tailored employment support
Our best-in-class services and colleagues have supported thousands of disabled people. We intend to continue this and use the evidence from our interventions to demonstrate there is a better, personalised and wholly voluntary way to support moving disabled people closer to work.

Work with aspiring disabled leaders through a new co-produced leadership programme.
To address the lack of senior disabled leaders and role models we will build a community of disabled leaders committed to creating An Equal Future.

We will work with employers at every stage of their journey, partnering with those who want to make UK workplaces better.

How we will track our progress

We will track external progress on this goal by measuring the Disability Employment Gap. In 2023, this gap was at 30 percentage points. By the end of this strategy, we hope to have closed it.

An equal future for all disabled people

Putting equality, diversity and inclusion at the heart of everything we do.

At Scope, we want a society where all disabled people enjoy equality and fairness. This means absolutely everyone.

To achieve this, we are transforming the way we work so that equality, diversity and inclusion are at the heart of everything we do.

We have a long and proud history of championing disability equality. But we want a more inclusive future. From our helpline to our high street stores, our boardroom to our online community we will make everyone feel included.

As part of An Equal Future we will:

- Increase understanding of our customers and supporters so we can better meet their needs.
- Partner with grassroots and other organisations to address the multiple marginalisation many disabled people experience.
- Commission large-scale research exploring intersectionality within the disabled community so that we can challenge power imbalances and push for change for our whole community.

> “I feel like being a black man with a disability, sometimes you feel like you haven't got a voice. Life's already hard being black, growing up trying to make something of yourself. It's always harder. Then bolting a condition on to it, which affects you mentally, physically, emotionally - you're having to work double-time so people look past the condition.”
>
> - Jorden ‘Akes’ James

A future that leaves no one behind

No organisation or strategy can predict with any certainty what will happen in the future across the world. Yet there are some things that are happening now that cannot be ignored.

Automation and artificial intelligence

The use Automation and Artificial Intelligence has grown exponentially in the past few years and will continue to do so over the next decade.

We will work with disabled people to understand the future of work, the role of AI in the workplace and the opportunities and challenges AI could present to disability inclusion.

Climate emergency

No one can ignore the emergency our planet faces now and in the future due to climate change. We will not ignore our role as an employer and as a campaigning organisation in responding to this emergency.

Disabled people all across the world are disproportionately impacted by both the impact of climate change and the policy response to dealing with it.

As an employer we will continue to minimise the environmental impact we have on the world. We will continue to tackle our own direct and indirect emissions.

As a campaigning organisation we will make sure disabled peoples' voices are heard on climate change and responses are inclusive and accessible.

A future that is accessible

Inside and out we aim to be accessible. Over the next decade we will continue to promote the benefits of accessibility to everyone.

As part of An Equal Future we will:

- Hold ourselves to the highest accessibility standards so that our documents, our ways of working, our advice and our communication is accessible.
- Lead the way on accessibility as default, and influence others to do the same.
- Push the boundaries in the creative and customer industries on accessible and inclusive design to demonstrate what is possible.

A movement of change

At our heart we are a social change organisation. We are impatient for progress. And impatient for action.

We campaign on the issues that matter most to disabled people and disabled families.

We want to provide a platform to disabled people and amplify their voices, as well as mobilise wider society in support of justice and equality.

We know we cannot achieve our vision and goals alone. We are part of a larger, more diverse movement that is seeking to end injustice for the 16 million disabled people in the UK.

We will add value to this movement and help achieve An Equal Future by making sure everyone has a role, and by focussing on changing the hearts and minds of those who need convincing.

Ending inequality for disabled people requires thousands of people, volunteers, businesses and communities to come together and campaign for change.

Over the next 3 years we will grow our community and movement of supporters to over 300,000 to make this happen.

Through our shops, our community hubs, our networks and relationships we will build a powerhouse of activism where disabled and non-disabled people will come together to end disability inequality.

We will seek to work far more closely with Disabled People's Organisations, in our communities to push for change locally and nationally.

We will grow our membership to 15,000 by 2033 and will make sure our members reflect the diversity of the disability community.

We will make sure that every person or organisation who interacts with us, whether donating to our shop, volunteering with us or using support services plays a vital part in our vision for a fair society.

We know we can only end disability inequality by working together. So, we'll seek to develop partnerships and relationships that can achieve transformational and sustainable change.

> "When charities, DPOs, companies, and campaigners team up, it packs a punch. They make a bigger impact, bring diverse expertise, boost awareness, and have more say in policies. Companies also add innovation, and together, they attract more funds and resources. This approach ensures that disabled voices are heard and keeps everyone accountable for pushing equality forward."
>
> - Dr Shani Dhanda

Supporting more disabled people and their families

Our services are there for any disabled person, family or household that needs us.

During our last strategy, our services reached 3.5 million people annually.

Almost 7 million people accessed our online information and advice and 8.7 million have accessed our online community. **Yet our helpline is only able to answer 2 in 3 calls.**

Over the course of this strategy, we will seek to increase the amount of people and families we can support. So that anyone who needs our advice can access it. We will use the insight we get from our services to influence others.

We will increasingly look to increase our online and digital support offer, so that people can access information in a way and at a time that suits them. And we'll be looking to make more of our shops as places for disabled communities to come together.

Through our employment services we will continue to demonstrate that a voluntary and tailored support offer is what this country needs to tackle the employment gap.

We will strengthen our commitment to coproduction. Putting disabled people and their families at the heart of our work.

> "Since talking to Scope, I've been saying, 'It's not okay.' And I've never done that before. I think it's because Scope's told me that if I'm not happy with something, I should say something, not just accept it."
>
> - Samantha Foster

Supporting those living with cerebral palsy

We are proud to support those living with cerebral palsy. It is clear this is best achieved through the 3 goals we have set out in this strategy.

We will continue to work with the cerebral palsy community, particularly where needs are not currently being met. We will seek opportunities to do this through co-production and partnerships.

Working in partnership

We are immensely grateful to every funder, trust, donor and company who works with us to end disability inequality.

We know we can only achieve An Equal Future by working with others.

With businesses who want to work alongside us in tackling the disability employment gap.

With companies who recognise their role and influence in changing attitudes.

With organisations who understand the value of accessibility and opportunity of supporting us to the end the extra costs disabled people face.

And with funders, trusts and donors who can support us to deliver interventions that get us closer to ending disability inequality.

Creating an impact

Everything we do is underpinned by robust evidence and insight with a sole focus on ending disability inequality.

Every interaction we have with anyone will be to create an equal future for disabled people.

We want our impact to be transformational not transactional. And to be sustainable, not in the moment.

We will publish our progress towards An Equal Future annually.

As part of our strategy, we will:

Be Open

By tracking and publishing our progress annually through our impact reports.

Be Connected

By building our evidence base of what life is like for disabled people through research and analysis and sharing our work with anyone who wants to use it.

Be Pioneering

By growing the size and influence of our unique research panel, working with partners who want to understand disabled people.

Be Courageous

By publishing evaluations of our services and our interventions, sharing where our interventions haven't worked so others can learn.

Be Fair

By co-producing our work with disabled people and putting our commitments to equality, diversity and inclusion at the centre of our programmes of work.

How we developed this strategy

This strategy has been created with the following people and activities:

- A Strategy Steering Group made up of disabled customers, volunteers and colleagues.
- Engagement with over 450 disabled people, colleagues and volunteers.
- Reviewing 30 pieces of existing Scope research.
- Surveys of colleagues and disabled people to understand priorities for change.
- Analysis of external datasets.

> “When I think of ‘An Equal Future’ I imagine a society where every person, regardless of their background, identity, or abilities, enjoys equal opportunities, rights, and access to resources. I envision disabled individuals living without fear of being subjected to inhumane and derogatory treatment by the media.
>
> In 10 years, I hope the UK will be a place where the principles of independent living are achievable for all, with a special focus on ensuring that disabled people can fully embrace them.”
>
> - Dr Shani Dhanda

Join us in creating An Equal Future

Our purpose is to end disability inequality. We cannot end it alone. An Equal Future will only be achieved if all of us join together.

Become a member
Donate to Scope
Volunteer
Find a fundraising event
Do your own fundraising
Campaign with us

Neurodiversity and Co-occurring difficulties

Neurodiversity is a relatively new term. It helps to promote the view that neurological differences are to be recognised and respected as any other human variation. It is used to counter negative social connotations that currently exist and to make it easier for people of all neurotypes to contribute to the world as they are, rather than attempting to think or appear more 'typically'.

Neurodiversity encompasses all specific learning difficulties (SpLD), many of which co-occur or overlap. We have explored in more detail the SpLD that most often co-occur with dyslexia.

Anxiety and mental health

Although anxiety is not a specific learning difficulty (SpLD), it is included here as studies have found that young people with learning difficulties are more likely to experience feelings of anxiety, depression and low self esteem.

It's important to remember that feelings of anxiety are normal and your child may just need support to develop tools to deal with these feelings. All young people go through stages of feeling anxious or angry and generally grow out of worrying behaviour with time and family support.

Emotional difficulties may be seen in a number of ways, such as disruptive behaviour, inattention, throwing tantrums or in physical symptoms such as stomach aches or palpitations, and refusing to engage in school/college.

If you feel your child is struggling to cope there are steps you can take to help them, and organisations that can offer you support.

How you can help

- Talk openly with your child, and let them know that they can talk to you when they're ready
- Try to encourage your child to have extra-curricular interests. If they're finding school or college difficult then helping them find an interest that they enjoy can really help to improve their self esteem
- Encourage your child to stay active. As well as the physical and mental benefits to being active, involvement in a club or team sports can help your child to feel included and boost self esteem
- Encourage your child to eat well
- Talk to the school/college teacher or counsellor. It is likely that the school will have experience of helping pupils and their families. The school should be able to provide a named member of staff who your child can go to if they’re struggling

during the day such as a counsellor, a mentor or a nurse. Your child is at school for a large part of the day so having staff aware of the concerns and keeping an eye on them during this time can be reassuring

- Talk to your GP. They may be able to offer counselling or, if appropriate, arrange a referral to the Child and Adolescent Mental Health Service (CAMHS)
- Contact a support service. We have listed some organisations below that offer support and information for young people and their parents

Attention Deficit Hyperactivity Disorder (ADHD)

ADHD is a neurodevelopmental disorder which has features relating to both specific learning difficulties and mental health. There are three main presentations of ADHD: predominantly inattentive, predominantly hyperactive and impulsive or combined presentation which includes symptoms of both. These symptoms are present in multiple settings, such as at school, at home or at work, and affect or reduce the quality of social, academic or occupational functioning.

Common ADHD symptoms include:

- Inattention
- lack of focus
- Poor time management
- Weak impulse control
- Emotional dysregulation
- Hyperfocus
- Hyperactivity
- Executive dysfunction
- Poor working memory

Similarly to dyslexia, individuals with ADHD can show considerable strengths alongside their weaknesses and difficulties. These strengths may be associated with characteristics of ADHD such as the ability to hyperfocus, as well as increased creativity, imagination and problem solving. When supporting people with ADHD it's important to understand and build upon their individual strengths, as well as support them in managing difficulties that stem from inattention, hyperactivity or impulsive behaviour. It's also important to recognise the mental health impacts of ADHD when creating a system of support, as ADHD is known to co-occur with mental health conditions such as anxiety and depression.

Autism Spectrum Disorder (ASD)

Autism is a lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them. (National Autistic Society)

ASD refers to a broad range of conditions characterised by differences in social skills, repetitive behaviours, speech and nonverbal communication. People with ASD may communicate, interact, behave, and learn in ways that are different from most other people. ASD is a spectrum disorder, which means that some people with ASD need a lot of support in their daily lives, whereas others need less.

People with ASD often have difficulties with social, emotional, and communication skills. They may repeat certain behaviours and dislike changes in their daily activities, they may experience sensory differences and a differences in social situations. Many people with ASD also have different ways of learning, paying attention, or reacting to things. Signs of ASD usually begin during childhood and typically last throughout a person's life.

Developmental Language Disorder (DLD)

Developmental Language Disorder (DLD) was previously known as Specific Language Impairment (SLI) it is a type of speech, language and communication need (SLCN).

Children with DLD are usually as able and healthy as other children in all ways, with one exception; they have enormous difficulty talking and understanding language.

There is no obvious reason for these difficulties and they are not associated with other conditions, such as cerebral palsy, hearing impairment or autistic spectrum disorders. Children with DLD are often as clever as any other child of their age but they still have difficulties with speech and language.

A child can be diagnosed with DLD if their language difficulties:

- are likely to carry on into adulthood
- have a significant impact on progress at school, or on everyday life
- are unlikely to catch up without help

Children are not usually diagnosed until after the age of 5 and until some therapy has been carried out to see if the difficulties resolve.

Dyspraxia (DCD)

Developmental Coordination Disorder (DCD), also known as dyspraxia, is a common disorder affecting fine and/or gross motor coordination in children and adults. This condition is formally recognised by international organisations including the World Health Organisation.

DCD is distinct from other motor disorders such as cerebral palsy and stroke. The range of intellectual ability is in line with the general population. Individuals may vary in how their difficulties present; these may change over time depending on environmental demands and life experience, and will persist into adulthood.

An individual's coordination difficulties may affect participation and functioning of everyday life skills in education, work and employment. Children may present with difficulties with self-care, writing, typing, riding a bike, play as well as other educational and recreational activities. In adulthood many of these difficulties will continue, as well as learning new skills at home, in education and work, such as driving a car and DIY.

Visual difficulties

Some people experience visual discomfort or disturbance when they read. Common symptoms that may significantly impair reading ability, or make reading very tiring, include:

- headaches and eyestrain associated with reading and/or other near work
- text appearing blurred or going in and out of focus
- text appearing double or alternating between single and double
- difficulty keeping place in text
- difficulty tracking across lines of text
- discomfort with brightness of the page or contrast between text and background
- text that appears to shimmer or flicker

Symptoms such as these have a variety of different causes, some of which may be due to disease or abnormality, so they must be investigated by a professional who is qualified to diagnose them correctly and give appropriate treatment. Anyone who experiences such difficulties associated with reading should consult a registered optometrist for a full assessment of eye health and visual function.

While adults may recognise symptoms, children may not be aware of them, as this is how they always experience reading. For this reason, any child who is a struggling reader should be assessed by an optometrist to either rule out or treat visual difficulties. This assessment and treatment is to check the health of the eyes and to enable clear and comfortable vision; treatment of visual difficulties is **not** treatment of dyslexia.

All children under the age of 16, and young adults under the age of 19 who are in full-time education, are entitled to a free NHS sight test with an optometrist, and to an optical voucher to help with the cost of glasses or contact lenses. The NHS sight test is sufficiently comprehensive to enable the optometrist to assess eye health and identify the likely causes of visual problems that affect reading and other near work. This should include an assessment of the ability of the eyes to focus and work together correctly (binocular accommodation and convergence).

In many cases the NHS sight test is all that is required to enable an optometrist to identify a problem and provide appropriate treatment with prescription glasses or contact lenses. Sometimes, however, the optometrist will consider that further assessment and/or other forms of treatment are necessary. The most likely of these will involve full assessment of binocular vision which may need treatment with eye muscle exercises (known as orthoptics or vision therapy) and/or pattern-related visual stress which may sometimes be alleviated using precision-coloured overlays or lenses. Such assessments and treatments are outside the scope of the NHS sight test, so the optometrist will either offer these privately for a fee or refer to another practitioner, such as an optometrist working in a specialist university clinic, or an orthoptist working in NHS secondary care (hospital). All NHS hospital orthoptics departments and university specialist optometry clinics will undertake assessment and treatment of binocular vision anomalies, but not all will offer assessment and treatment of visual stress.

The vision screening that most children undergo at school entry (age 4 to 5) is only a test of whether a child can see clearly in the distance. It is not a comprehensive assessment of eyes or vision and does not test any of the functions required for clear and comfortable vision when reading. For this reason, every child should have a full sight test when they start school, and as frequently as recommended by their optometrist after that.

Some websites and providers of education resources offer coloured overlays, tinted reading rulers, and other devices that may make reading easier and more comfortable for some children. These aids may be helpful, but it is very important that these aids should not replace or discourage full professional assessment. In particular, coloured overlays and similar aids must not be promoted as the first strategy to help children with reading difficulties. If children have visual difficulties, then it is essential that these are diagnosed and managed correctly by qualified, registered professionals.

British Dyslexia Association

Dyslexia Style guide

This Style Guide provides principles that can help ensure that written material considers the difficulties experienced by some dyslexic people and allows for the use of text to speech to facilitate ease of reading. Adopting these principles for dyslexic readers has the advantage of making all written communication easier on the eye for everyone.

When making changes consider all the ways that you use written communications, such as emails, presentations, web pages and printed materials. Consider these principles in combination with other accessibility guidance such as the Web Accessibility Content Guidelines (WCAG).

Readable Fonts

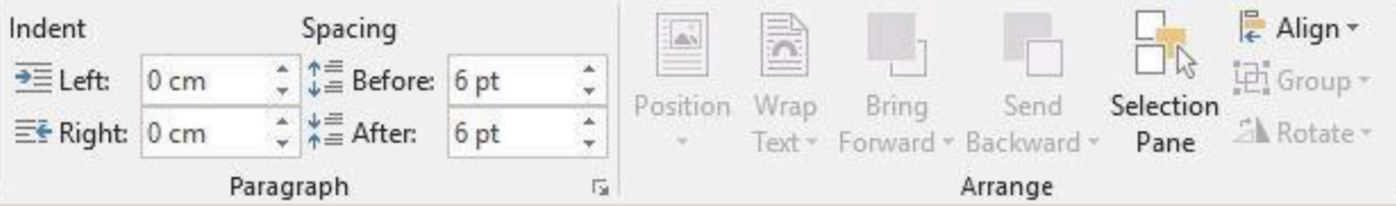
- Use sans serif fonts, such as Arial and Comic Sans, as letters can appear less crowded. Alternatives include Verdana, Tahoma, Century Gothic, Trebuchet, Calibri, Open Sans.
- Font size should be 12-14 point or equivalent (e.g. 1-1.2em / 16-19 px). Some dyslexic readers may request a larger font.
- Larger inter-letter / character spacing (sometimes called tracking) improves readability, ideally around 35% of the average letter width. If letter spacing is excessive it can reduce readability.
- Inter-word spacing should be at least 3.5 times the inter-letter spacing.
- Some dyslexic people find that larger line spacing improves readability. It should be proportional to inter-word spacing; 1.5 / 150% is preferable.
- Avoid Underlining and italics as this can make the text appear to run together and cause crowding. Use bold for emphasis.
- Avoid using capital letter and uppercase letters for continuous text. Lower case letters are easier to read.

Headings and Structure

Use headings and styles to create consistent structure to help people navigate through your content.
In Word, you'll find these tools in the 'Home' tab:

- For headings, use a font size that is at least 20% larger than the normal text. If further emphasis is required, then use bold.
- Use formatting tools for text alignment, justification, indents, lists, line and paragraph spacing to support assistive technology users.

In Word, you'll find these tools in the 'Layout' tab:



Left: 0 cm
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Before: 6 pt
After: 6 pt

- Add extra space around headings and between paragraphs.
- Ensure hyperlinks look different from headings and normal text.

Colour

- Use single colour backgrounds. Avoid background patterns or pictures and distracting surrounds.
- Use sufficient contrast levels between background and text.
- Use dark coloured text on a light (not white) background.
- Avoid green and red/pink, as these colours are difficult for those who have colour vision deficiencies (colour blindness).
- Consider alternatives to white backgrounds for paper, computer and visual aids such as whiteboards. White can appear too dazzling. Use cream or a soft pastel colour. Some dyslexic people will have their own colour preference.
- When printing, use matt paper rather than gloss. Paper should be thick enough to prevent the other side showing through.

Layout

- Left align text, without justification. This makes it easier to find the start and finish of each line and ensures even spacing between words.
- Avoid multiple columns (as used in newspapers).
- Write short simple sentences: 60 to 70 characters is optimal.
- Use white space to remove clutter near text and group related content.
- Break up the text with regular section headings in long documents and include a table of contents.

Writing Style

- Use active rather than passive voice.
- Be concise; avoid using long, dense paragraphs.
- Write in simple clear language using every day words.
- Use images to support text. Flow charts are ideal for explaining procedures. Pictograms and graphics can help to locate and support information in the text.
- Consider using bullet points and numbering rather than continuous prose.
- Give instructions clearly.
- Avoid double negatives.
- Avoid jargon and abbreviations where possible; always provide the expanded form when first used. Provide a glossary of jargon

Dyslexia In the Classroom

What Every Teacher Needs to Know

International
DYSLEXIA
Association

TABLE OF CONTENTS

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INTRODUCTION

The degree of difficulty a child with dyslexia has with reading, spelling, and/or speaking varies from person to person due to inherited differences in brain development, as well as the type of teaching the person receives. The brain is normal, often very "intelligent," but with strengths in areas other than the language area.

This "difference" goes undetected until the person finds difficulty when learning to read and write. Each individual with dyslexia is unique, but the multisensory approach is flexible enough to serve a wide range of ages and learning differences. A multisensory approach can be valuable to many; to the dyslexic child it is essential. The expertise of the teacher is the key.

The intent of this toolkit is to provide classroom teachers with basic information about dyslexia, dispel some of the myths and misconception surrounding it and be a resource that will increase their capacity to ensure the success of the diverse group of learners in their classrooms.

ABOUT IDA

The International Dyslexia Association (IDA) was founded in 1949 as The Orton Society to honor and further the work and passion of Dr. Samuel Torrey Orton. IDA serves individuals with dyslexia, their families, and professionals in the field. We have more than 9,000 members, 42 branches throughout the United States and Canada and have 27 global partners in 23 countries. Together we are working to help those with and affected by dyslexia.

We believe that all individuals have the right to achieve their potential, that individual learning abilities can be strengthened, and that social, educational and barriers to language acquisition and use must be removed.

IDA actively promotes effective teaching approaches and related clinical educational intervention strategies for individuals with dyslexia. We support and encourage interdisciplinary research. We facilitate the exploration of the causes and early identification of dyslexia and are committed to the responsible and wide dissemination of research and evidence based knowledge.

The purpose of IDA is to pursue and provide the most comprehensive range of information and services that address the full scope of dyslexia and related difficulties in learning to read and write...in a way that creates hope, possibility, and partnership, so that every individual has the opportunity to lead a productive and fulfilling life, and society benefits from the resource that is liberated.

WHAT IS DYSLEXIA?

The formal definition of dyslexia is:

> *Dyslexia is a specific learning disability that is neurological in origin. It is characterized by difficulties with accurate and/or fluent word recognition and by poor spelling and decoding abilities. These difficulties typically result from a deficit in the phonological component of language that is often unexpected in relation to other cognitive abilities and the provision of effective classroom instruction. Secondary consequences may include problems in reading comprehension and reduced reading experience that can impede the growth of vocabulary and background knowledge.*

But what does that mean exactly?

Dyslexia is a language-based learning disability. Dyslexia refers to a cluster of symptoms, which result in people having difficulties with specific language skills, particularly reading. Students with dyslexia usually experience difficulties with other language skills, such as spelling, writing, and pronouncing words. Dyslexia affects individuals throughout their lives; however, its impact can change at different stages in a person's life. It is referred to as a learning disability because dyslexia can make it very difficult for a student to succeed academically in the typical instructional environment, and in its more severe forms, will qualify a student for special education, special accommodations, and/or extra support services.

What causes dyslexia?

The exact causes of dyslexia are still not completely clear, but anatomical and brain imagery studies show differences in the way the brain of a person with dyslexia develops and functions. Moreover, most people with dyslexia have been found to have problems with identifying the separate speech sounds within a word and/or learning how letters represent those sounds, a key factor in their reading difficulties. Dyslexia is not due to either lack of intelligence or desire to learn; with appropriate teaching methods, students with dyslexia can learn successfully.

Dyslexia occurs in people of all backgrounds and intellectual levels. People with dyslexia can be very bright. They are often capable or even gifted in areas such as art, computer science, design, drama, electronics, math, mechanics, music, physics, sales, and sports. In addition, dyslexia runs in families; having a parent or sibling with dyslexia increases the probability that you will also have dyslexia. For some people, their dyslexia is identified early in their lives, but for others, their dyslexia goes unidentified until they get older.

What are the effects of dyslexia?

The impact that dyslexia has is different for each person and depends on the severity of the condition and the timeliness and effectiveness of instruction or remediation. The core difficulty involves word recognition and reading fluency, spelling, and writing. Some individuals with dyslexia manage to learn early reading and spelling tasks, especially with excellent instruction, but later experience their most debilitating problems when more complex language skills are required, such as grammar, understanding textbook material, and writing essays.

People with dyslexia can also have problems with spoken language, even after they have been exposed to excellent language models in their homes and high quality language instruction in school. They may find it difficult to express themselves clearly, or to fully comprehend what others mean when they speak. Such language problems are often difficult to recognize, but they can lead to major problems in school, in the workplace, and in relating to other people. The effects of dyslexia reach well beyond the classroom.

What misconceptions exist regarding dyslexia?

It is equally important to understand what dyslexia isn't. There are great misconceptions and myths about dyslexia which make it that much more difficult for someone with dyslexia to receive help and generally be understood.

It is a myth that individuals with dyslexia "read backwards." Their spelling can look quite jumbled at times not because they read or see words backwards, but because students have trouble remembering letter symbols for sounds and letter patterns in words.

Dyslexia is not a disease and, therefore, there is no cure. With proper diagnosis, appropriate and timely instruction, hard work, and support from family, teachers, friends, and others, individuals who have dyslexia can succeed in school and later as adults.

Individuals with dyslexia do not have a lower level of intelligence. In fact, more often than not, the complete opposite is true.

SIGNS AND SYMPTOMS OF DYSLEXIA

It is crucial to be able to recognize the signs of symptoms of dyslexia. The earlier a child is evaluated, the sooner he or she can obtain the appropriate instruction and accommodations he or she needs to succeed in school.

General problems experienced by people with dyslexia include the following:

- Learning to speak
- Learning letters and their sounds
- Organizing written and spoken language
- Memorizing number facts
- Reading quickly enough to comprehend
- Keeping up with and comprehending longer reading assignments
- Spelling
- Learning a foreign language
- Correctly doing math operations

Some specific signs for elementary aged children may include:

- Difficulty with remembering simple sequences such as counting to 20, naming the days of the week, or reciting the alphabet
- Difficulty understanding the rhyming of words, such as knowing that *fat* rhymes with *cat*
- Trouble recognizing words that begin with the same sound (for example, that *b*ird, *b*aby", and *b*ig all start with *b*)
- Pronunciation difficulties

- Trouble easily clapping hands to the rhythm of a song
- Difficulty with word retrieval (frequently uses words like “stuff” and “that thing” rather than specific words to name objects)
- Trouble remembering names of places and people
- Difficulty remembering spoken directions

It is important to note that not all students who have difficulties with these skills have dyslexia. Formal testing of reading, language, and writing skills is the only way to confirm a diagnosis of suspected dyslexia.

An individual can have more than one learning or behavioral disability. For example, in various studies as many as 30% of those diagnosed with a learning or reading difference have also been diagnosed with ADHD. Although disabilities may co-occur, one is not the cause of the other.

SOCIAL AND EMOTIONAL CONNECTION

Samuel T. Orton, M.D., was one of the first researchers to describe the emotional aspects of dyslexia. According to his research, the majority of preschoolers who were later diagnosed as having dyslexia are happy and well adjusted. Their emotional problems begin to develop when early reading instruction does not match their learning needs. Over the years, the frustration mounts as classmates surpass the student with dyslexia in reading skills.

Stress and Anxiety

Jerome J. Schultz’s informative IDA fact sheet “The Dyslexia-Stress-Anxiety Connection” is a must read for those wanting guidance on understanding the relationship between dyslexia and emotional and social difficulties, as well as the implications for academic performance and social interactions. Dr. Schultz explains his DE-STRESS model in a step-by-step guide for addressing stress, anxiety, and dyslexia.

> Stress and anxiety increase when we’re in situations over which we have little or no control (e.g., a car going off the road, tripping on the stairs, reading in public). All people, young and old, can experience overwhelming stress and exhibit signs of anxiety, but children, adolescents, and adults with dyslexia are particularly vulnerable. That’s because many individuals do not fully understand the nature of their learning disability, and as a result, tend to blame themselves for their own difficulties. Years of self-doubt and self-recrimination may erode a person’s self-esteem, making them less able to tolerate the challenges of school, work, or social interactions and more stressed and anxious.
>
> Many individuals with dyslexia have experienced years of frustration and limited success, despite countless hours spent in special programs or working with specialists. Their progress may have been agonizingly slow and frustrating, rendering them emotionally fragile and vulnerable. Some have been subjected to excessive pressure to succeed (or excel) without the proper support or training. Others have been continuously compared to siblings, classmates, or co-workers, making them embarrassed, cautious, and defensive.
>
> Individuals with dyslexia may have learned that being in the company of others places them at risk for making public mistakes and the inevitable negative reactions that may ensue. It makes sense, then, that many people

> with dyslexia have become withdrawn, sought the company of younger people, or become social isolates. (Schultz, 2013, p. 2)

This fact sheet can be found on the IDA website, www.DyslexiaIDA.org.

Self-Image

Dyslexia can also affect a person's self-image. Students with dyslexia often end up feeling "dumb" and less capable than they actually are. After experiencing a great deal of stress due to academic problems, a student may become discouraged about continuing in school.

If children succeed in school, they will develop positive feelings about themselves and believe that they can succeed in life. If children meet failure and frustration, they learn that they are inferior to others, and that their effort makes very little difference. Instead of feeling powerful and productive, they learn that their environment controls them. They feel powerless and incompetent.

Researchers have learned that when typical learners succeed, they credit their own efforts for their success. When they fail, they tell themselves to try harder. However, when learners with dyslexia succeed, they are likely to attribute their success to luck. When they fail, they simply see themselves as stupid.

Research also suggests that these feelings of inferiority develop by the age of 10. After this age, it becomes extremely difficult to help the child develop a positive self-image. This is a powerful argument for early intervention.

Depression

Depression is also a frequent complication in dyslexia. Depressed children and adolescents often have different symptoms than do depressed adults. The depressed child is unlikely to be lethargic or to talk about feeling sad. Instead he or she may become more active or misbehave to cover up the painful feelings. In the case of masked depression, the child may not seem obviously unhappy. However, both children and adults who are depressed tend to have three similar characteristics:

- They tend to have negative thoughts about themselves, that is, a negative self- image.
- They tend to view the world negatively. They are less likely to enjoy the positive experiences in life. This makes it difficult for them to have fun.
- Most depressed youngsters have great trouble imagining anything positive about the future. The depressed child with dyslexia not only experiences great pain in his present experiences, but also foresees a life of continuing failure.

So how can you help?

Children are more successful when early in their lives someone has been extremely supportive and encouraging, and when they have found an area in which they can succeed. Teachers can create an incredible support system by:

- Listening to children's feelings. Anxiety, anger and depression can be daily companions for children with dyslexia. However, their language problems often make it difficult for them to express their feelings. Therefore, adults must help them learn to talk about their feelings.
- Rewarding effort, not just "the product." For students with dyslexia, grades should be less important than progress.

- When confronting unacceptable behavior, do not inadvertently discourage the child with dyslexia. Words such as “lazy” or “incorrigible” can seriously damage the child’s self-image.
- Helping students set realistic goals for themselves. Many students with dyslexia set perfectionistic and unattainable goals. By helping the child set an attainable goal, teachers can change the cycle of failure.

Above all, it is critical that school personnel, parents, and outside professionals working with the child with dyslexia communicate on an on-going basis to provide the support needed, so he or she can become a happy and successful student, and eventually, a happy and successful adult.

CLASSROOM STRATEGIES, TIPS AND TOOLS

Schools can implement academic accommodations and modifications to help students with dyslexia succeed. For example, a student with dyslexia can be given extra time to complete tasks, help with taking notes, and work assignments that are modified appropriately. Teachers can give taped tests or allow students with dyslexia to use alternative means of assessment. Students can benefit from listening to books on tape and using text reading and word processing computer programs.

Teaching students with dyslexia across settings is challenging. Both general education and special education teachers seek accommodations that foster the learning and management of a class of heterogeneous learners. It is important to identify accommodations that are reasonable to ask of teachers in all classroom settings. The following accommodations provide a framework for helping students with learning problems achieve in general education and special education classrooms. They are organized according to accommodations involving materials, interactive instruction, and student performance.

Accommodations Involving Materials

Students spend a large portion of the school day interacting with materials. Most instructional materials give teachers few activities or directions for teaching a large class of students who learn at different rates and in various ways. This section provides material accommodations that enhance the learning of diverse students. Frequently, paraprofessionals, volunteers, and students can help develop and implement various accommodations. Material accommodations include the following:

- **Clarify or simplify written directions**. Some directions are written in paragraph form and contain many units of information. These can be overwhelming to some students. The teacher can help by underlining or highlighting the significant parts of the directions. Rewriting the directions is often helpful.
- **Present a small amount of work**. The teacher can tear pages from workbooks and materials to present small assignments to students who are anxious about the amount of work to be done. This technique prevents students from examining an entire workbook, text, or material and becoming discouraged by the amount of work.

- **Block out extraneous stimuli**. If a student is easily distracted by visual stimuli on a full worksheet or page, a blank sheet of paper can be used to cover sections of the page not being worked on at the time. Also, line markers can be used to aid reading, and windows can be used to display individual math problems. Additionally, using larger font sizes and increasing spacing can help separate sections.
- **Highlight essential information**. If an adolescent can read a regular textbook but has difficulty finding the essential information, the teacher can mark this information with a highlight pen.
- **Use a placeholder in consumable material**. In consumable materials in which students progress sequentially (such as workbooks), the student can make a diagonal cut across the lower right-hand corner of the pages as they are completed. With all the completed pages cut, the student and teacher can readily locate the next page that needs to be corrected or completed.
- **Provide additional practice activities**. Some materials do not provide enough practice activities for students with learning problems to acquire mastery on selected skills. Teachers then must supplement the material with practice activities. Recommended practice exercises include instructional games, peer teaching activities, self-correcting materials, computer software programs, and additional worksheets.
- **Provide a glossary in content areas**. Students often benefit from a glossary of content-related terms.
- **Develop reading guides**. A reading guide helps the reader understand the main ideas and sort out the numerous details related to the main ideas. A reading guide can be developed paragraph-by-paragraph, page-by-page, or section-by-section.
- **Use an audio recording device**. Directions, stories, and specific lessons can be recorded. The student can replay the tape to clarify understanding of directions or concepts. Also, to improve reading skills, the student can read the printed words silently as they are presented on tape.
- **Use of assistive technology**. Assistive technology products such as tablets, electronic readers/dictionaries/spellers, text to speech programs, audio books, and more can be very useful tools.

Accommodations Involving Interactive Instruction

The task of gaining students' attention and engaging them for a period of time requires many teaching and managing skills. Teaching and interactions should provide successful learning experiences for each student. Some accommodations to enhance successful interactive instructional activities are:

- **Use explicit teaching procedures**. Many commercial materials do not cue teachers to use explicit teaching procedures; thus, the teacher often must adapt a material to include these procedures. Teachers can include explicit teaching steps within their lessons (i.e., present an advanced organizer, demonstrate the skill, provide guided practice, offer corrective feedback, set up independent practice, monitor practice, and review).
- **Repeat directions**. Students who have difficulty following directions are often helped by asking them to repeat the directions in their own words. The student can repeat the directions to a peer when the teacher is unavailable. If directions contain several steps, break down the directions into subsets. Simplify directions by presenting only one portion at a time and by writing each portion on the chalkboard as well

as stating it orally. When using written directions, be sure that students are able to read and understand the words as well as comprehend the meaning of sentences.

- **Maintain daily routines**. Many students with learning problems need the structure of daily routines to know and do what is expected.
- **Provide a copy of lesson notes**. The teacher can give a copy of lesson notes to students who have difficulty taking notes during presentations.
- **Provide students with a graphic organizer**. An outline, chart, or blank web can be given to students to fill in during presentations. This helps students listen for key information and see the relationships among concepts and related information.
- **Use step-by-step instruction**. New or difficult information can be presented in small sequential steps. This helps learners with limited prior knowledge who need explicit or part-to-whole instruction.
- **Simultaneously combine verbal and visual information**. Verbal information can be provided with visual displays (e.g., on an overhead or handout).
- **Write key points or words on the chalkboard/whiteboard**. Prior to a presentation, the teacher can write new vocabulary words and key points on the chalkboard/whiteboard.
- **Use balanced presentations and activities**. An effort should be made to balance oral presentations with visual information and participatory activities. Also, there should be a balance between large group, small group, and individual activities.
- **Use mnemonic instruction**. Mnemonic devices can be used to help students remember key information or steps in a learning strategy.
- **Emphasize daily review**. Daily review of previous learning or lessons can help students connect new information with prior knowledge.

Accommodations Involving Student Performance

Students vary significantly in their ability to respond in different modes. For example, students vary in their ability to give oral presentations; participate in discussions; write letters and numbers; write paragraphs; draw objects; spell; work in noisy or cluttered settings; and read, write, or speak at a fast pace. Moreover, students vary in their ability to process information presented in visual or auditory formats. The following accommodation involving mode of reception and expression can be used to enhance students' performance:

- **Change response mode.** For students who have difficulty with fine motor responses (such as handwriting), the response mode can be changed to underlining, selecting from multiple choices, sorting, or marking. Students with fine motor problems can be given extra space for writing answers on worksheets or can be allowed to respond on individual chalkboards/whiteboards.
- **Provide an outline of the lesson**. An outline enables some students to follow the lesson successfully and make appropriate notes. Moreover, an outline helps students to see the organization of the material and ask timely questions.

- **Encourage use of graphic organizers**. A graphic organizer involves organizing material into a visual format. To develop a graphic organizer, the student can list the topic on the first line, collect and divide information into major headings, list all information relating to major headings on index cards, organize information into major areas, place information under appropriate subheadings, and place information into the organizer format.
- **Place students close to the teacher**. Students with attention problems can be seated close to the teacher, chalkboard/whiteboard, or work area and away from distracting sounds, materials, or objects.
- **Encourage use of assignment books or calendars**. Students can use calendars to record assignment due dates, list school related activities, record test dates, and schedule timelines for schoolwork. Students should set aside a special section in an assignment book or calendar for recording homework assignments.
- **Have students turn lined paper vertically for math**. Lined paper can be turned vertically to help students keep numbers in appropriate columns while computing math problems.
- **Use cues to denote important items**. Asterisks or bullets can denote questions or activities that count heavily in evaluation. This helps students spend time appropriately during tests or assignments.
- **Design hierarchical worksheets.** The teacher can design worksheets with problems arranged from easiest to hardest. Early success helps students begin to work.
- **Allow use of instructional aids.** Students can be provided with letter and number strips to help them write correctly. Number lines, counters, calculators, and other assistive technology can help students compute once they understand the mathematical operations.
- **Display work samples**. Samples of completed assignments can be displayed to help students realize expectations and plan accordingly.
- **Use peer-mediated learning**. The teacher can pair peers of different ability levels to review their notes, study for a test, read aloud to each other, write stories, or conduct laboratory experiments. Also, a partner can read math problems for students with reading problems to solve.
- **Use flexible work times**. Students who work slowly can be given additional time to complete written assignments.
- **Provide additional practice**. Students require different amounts of practice to master skills or content. Many students with learning problems need additional practice to learn at a fluency level.
- **Use assignment substitutions or adjustments**. Students can be allowed to complete projects instead of oral reports or vice versa. Also, tests can be given in oral or written format.

EFFECTIVE READING INSTRUCTION

Early identification and treatment is the key to helping individuals with dyslexia achieve in school and in life. Most people with dyslexia need help from a teacher, tutor, or therapist specially trained in a structured literacy approach. Many individuals with dyslexia need one-on-one help so that they can move forward at their own pace. In addition, students with dyslexia often need a great deal of structured practice and immediate, corrective feedback to develop automatic word recognition skills. For students with dyslexia, it is helpful if their outside academic therapists work closely with classroom teachers.

What is a Structured Literacy approach?

Structured Literacy instruction is marked by several elements:

Phonology. Phonology is the study of sound structure of spoken words and is a critical element of *Structured Language* instruction. Phonological awareness includes rhyming, counting words in spoken sentence, and clapping syllables in spoken words. An important aspect of phonological awareness is phonemic awareness or the ability to segment words into their component sounds, which are called phonemes. A phoneme is the smallest unit of sound in a given language that can be recognized as being distinct from other sounds in the language. For example, the word *cap* has three phonemes (/k/, /ă/, /p/), and the word *clasp* has five phonemes (/k/, /l/, /ă/, /s/, /p/).

Sound-Symbol Association. Once students have developed the awareness of phonemes of spoken language, they must learn how to map the phonemes to symbols or printed letters. Sound-symbol association must be taught and mastered in two directions: visual to auditory (reading) and auditory to visual (spelling). Additionally, students must master the blending of sounds and letters into words as well as the segmenting of whole words into the individual sounds. The instruction of sound-symbol associations is often referred to as phonics. Although phonics is a component of *Structured Literacy*, it is embedded within a rich and deep language context.

Syllable Instruction. A syllable is a unit of oral or written language with one vowel sound. Instruction includes teaching of the six basic syllable types in the English language: closed, vowel-consonant-*e*, open, consonant-*le*, *r*-controlled, and vowel pair. Knowledge of syllable types is an important organizing idea. By knowing the syllable type, the reader can better determine the sound of the vowel in the syllable. Syllable division rules heighten the reader's awareness of where a long, unfamiliar word may be divided for great accuracy in reading the word.

Morphology. A morpheme is the smallest unit of meaning in the language. The Structured Literacy curriculum includes the study of base words, roots, prefixes, and suffixes. The word instructor, for example, is contains the root *struct*, which means *to build*, the prefix *in*, which means *in* or *into*, and the suffix *or*, which means *one who*. An instructor is one who builds knowledge in his or her students.

Syntax. Syntax is the set of principles that dictate the sequence and function of words in a sentence in order to convey meaning. This includes grammar, sentence variation, and the mechanics of language.

Semantics. Semantics is that aspect of language concerned with meaning. The curriculum (from the beginning) must include instruction in the comprehension of written language.

Structured Literacy is distinctive in the principles that guide how critical elements are taught:

Systematic and Cumulative. *Structured Literacy* instruction is systematic and cumulative. Systematic means that the organization of material follows the logical order of the language. The sequence must begin with the easiest and most basic concepts and elements and progress methodically to more difficult concepts and elements. Cumulative means each step must be based on concepts previously learned.

Explicit Instruction. *Structured Literacy* instruction requires the deliberate teaching of all concepts with continuous student-teacher interaction. It is not assumed that students will naturally deduce these concepts on their own.

Diagnostic Teaching. The teacher must be adept at individualized instruction. That is instruction that meets a student's needs. The instruction is based on careful and continuous assessment, both informally (for example, observation) and formally (for example, with standardized measures. The content presented must be mastered to the degree of automaticity. Automaticity is critical to freeing all the student's attention and cognitive resources for comprehension and expression.

SCREENING, EVALUATION, AND DIAGNOSIS

Early identification and intervention with students who show the warning signs of dyslexia are critically important for better outcomes later on. Researchers have identified the specific skill weaknesses that predict later reading difficulties, making early testing, identification, and remediation possible. For most children, problems can be remediated with programs at the kindergarten and first-grade levels that take about 30-45 minutes per day.

Before second grade, it is more important to focus an evaluation on the precursors of reading development. Measures of language skills, phonological awareness, memory, and rapid naming are more suggestive of being at-risk for dyslexia among young children than are measures of word reading, decoding, and spelling. Therefore, measures of phonological awareness, memory, and rapid naming are typically included in Kindergarten and beginning first grade screening tests that can identify children who need targeted intervention to improve these critical skills so these children can meet grade- level benchmarks.

How is dyslexia diagnosed?

A comprehensive evaluation typically includes intellectual and academic achievement testing, as well as an assessment of the critical underlying language skills that are closely linked to dyslexia. These include receptive (listening) and expressive language skills, phonological skills including phonemic awareness, and also a student's ability to rapidly name letters and names. A student's ability to read lists of words in isolation, as well as words in context, should also be assessed. If a profile emerges that is characteristic of readers with dyslexia, an individualized intervention plan should be developed, which should include appropriate accommodations, such as extended time. The testing can be conducted by trained school or outside specialists.

Why is evaluation important?

An evaluation is the process of gathering information to identify the factors contributing to a student's difficulty with learning to read and spell. First, information is gathered from parents and teachers to understand development and the educational opportunities that have been provided. Then, tests are given to identify strengths and weaknesses that lead to a diagnosis and a tentative road map for intervention. Conclusions and recommendations are developed and reported.

When should a child be evaluated?

It is possible to identify potential reading problems in young children even before the problems turn into reading failure. Screenings should be used with all children in a school, beginning in kindergarten, to locate those students who are "at risk" for reading difficulty. Preventive intervention should begin immediately, even if dyslexia is suspected. How the child responds to supplementary instruction will help determine if special education services are justified and necessary.

There are numerous types of screeners; one simple one we recommend is the Colorado Learning Disabilities Questionnaire – Reading Subscale (CLDQ-R) School Age Screener. If the risk factors are present, teachers should follow the protocols set-up within their school's policies to meet with parents regarding further evaluation.

The Colorado Learning Disabilities Questionnaire – Reading Subscale (CLDQ-R) is a screening tool designed to measure risk of reading disability (i.e. dyslexia) in school-age children (Willcutt et al., 2011). Normative scores for this questionnaire were developed based on parent-reports of their 6-to-18- year- old children, as well as actual reading testing of these children. Willcutt, et al. (2011) found that the CLDQ-R is reliable and valid. It is important to note that the CLDQ-R is only a screener and does not constitute a formal evaluation or diagnosis.

School Age Dyslexia Screener – CLDQ-R

Please read each statement and decide how well it describes the child. Mark your answer by circling the appropriate number. Please do not leave any statement unmarked.

		Never/ not at all	Rarely/ a little	Sometimes	Frequently/ quite a bit	Always/ a great deal
1.	Has difficulty with spelling	1	2	3	4	5
2.	Has/had difficulty learning letter names	1	2	3	4	5
3.	Has/had difficulty learning phonics (sounding out words)	1	2	3	4	5
4.	Reads slowly	1	2	3	4	5
5.	Reads below grade level	1	2	3	4	5
6.	Requires extra help in school because of problems in reading and spelling	1	2	3	4	5

Scoring Instructions:

Add up the circled numbers and record that as the Total Score ________________

The following cutoffs apply:

- Total Score <16 = Minimal Risk
- Total Score 16-21 = Moderate Risk
- Total Score >21 = Significant Risk

See below for details for each Risk Group.

Minimal Risk: The score indicates that there is little in the child's developmental history to indicate that he/she is at risk for a reading disability (dyslexia). However, if there are concerns about the child's reading progress, an evaluation with the school or a licensed child psychologist is recommended to examine the nature of these difficulties.

Moderate Risk: The score indicates that there are features of the child's developmental history (e.g. difficulty learning letters, required extra reading help) that may be consistent with a reading disability (dyslexia). Reading disability constitutes a very common learning disability, affecting approximately 5% of the United States population. Reading disability is characterized by slow or effortful reading, difficulty sounding out new words, and problems with spelling. If there are concerns about the child's reading progress, an evaluation with the school or a licensed child psychologist is recommended to examine the nature of these difficulties.

Significant Risk: The score indicates that there are several features of your child's developmental history (e.g. difficulty learning letters, required extra reading help) that are consistent with a reading disability (dyslexia). Reading disability constitutes a very common learning disability, affecting approximately 5-10% of the United States population. Reading disability is characterized by slow or effortful reading, difficulty sounding out new words, and problems with spelling. The results of this questionnaire indicate that your child may be experiencing some or all of those symptoms. A formal evaluation with the school or a licensed child psychologist is strongly recommended, so that your child can get the reading support he/she needs, if appropriate.

ADDITIONAL RESOURCES AND FURTHER INFORMATION

There are a great many resources available for a deeper understanding of dyslexia, co-morbidities, treatments as well as specific topics including neuroscience, comprehension, fluency, other learning disabilities, response to intervention and much more.

We encourage you to go to our website, www.DyslexiaIDA.org and explore a variety of information including:

- IDA Fact Sheets
- FAQs
- IDA Provider Directory
- IDA Knowledge and Practice Standards for Teachers of Reading

There are numerous publications and books available, including those listed in the Recommended Reading for Professionals Fact Sheet, but here are some useful resources to get you started:

Moats, L., & Dakin, K. (2008). *Basic facts about dyslexia and other reading problems*. Baltimore, MD: International Dyslexia Association.

Moats, L., Dakin, K., & Joshi. R. M. (2012). *Expert perspectives on interventions for reading. A collection of best-practice articles from the International Dyslexia Association*. Baltimore, MD: International Dyslexia Association.

Tridas, E. (2007). *From ABC to ADHD: what parents should know about dyslexia and attention problems.* Baltimore, MD: International Dyslexia Association.

Further, there are extraordinary workshops, conferences, and trainings available all over the United States and Canada hosted by IDA branches; conferences all over the world hosted by our Global Partners; and the Annual IDA Conference hosted by IDA Headquarters. Please go to www.DyslexiaIDA.org to find the next event near you!

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What is demand avoidance?

Everyone experiences ‘demand avoidance’ (resistance to doing something that is requested or expected of you) sometimes. However, here we use demand avoidance to mean the characteristic of a persistent and marked resistance to 'the demands of everyday life’, which may include essential demands such as eating and sleeping as well as expected demands such as going to school or work.

Although demand avoidance is widely acknowledged as a characteristic experienced by and observed in some autistic people (and potentially other neurodivergent, but not autistic, people), there is very little research into it and the research that does exist is generally of a low quality.

Because of this, many aspects of demand avoidance – including how it is best defined and identified; how common it is; why it happens; and support strategies for someone experiencing it – are under-researched and often contested. On this page we aim to present a range of views and the best available information gathered from lived experience, research and professional practice (you can read more about how these pages are developed on our Advice and guidance content process page).

Types of demand

Below are some examples of the ‘demands of everyday life’ that a person experiencing demand avoidance may resist (note that the demand does not need to be something unpleasant to trigger distress):

- a direct demand (an instruction, such as ‘brush your teeth’, ‘put your coat on’ or ‘complete your tax return’)
- an internal demand (for example willing yourself to do something, or bodily needs such as hunger or needing the toilet)
- an indirect or implied demand (including any expectation, such as a question that requires an answer, food in front of you that you are expected to eat, or a bill arriving that needs to be paid).

Forms of resistance

Noted forms of resistance include:

- giving excuses (which may be fanciful – for example, 'I can't because I am a tractor and tractors don't have hands' or 'I can't because my legs are broken' (though they aren't))
- distraction or diversion (such as giving affection or compliments; changing the subject; making noise that makes further discussion difficult; or creating a

situation that needs more immediate attention, for example, by knocking something over)

- point blank refusal (saying "No" and not entering into negotiation; physically resisting)
- passivity/withdrawal (becoming floppy; curling up into a ball; not responding; walking/running away; withdrawing into fantasy)
- aggression (usually as a last resort, when other forms of resistance have failed. For example, pushing someone or throwing something away; hitting or kicking; biting. Aggression may be a form of resistance, but it may also be a panic response to overwhelming anxiety.)

The overwhelming anxiety of realising that a demand cannot be avoided, or that these forms of resistance have been exhausted, may result in meltdown or panic, potentially including aggression. These states are usually out of the person's control.

Examples of demand avoidance from lived experience

Because everyone experiences demand avoidance sometimes, it can be difficult to understand what is meant by a marked and persistent resistance to demands. The following real-life examples are from people’s lived experience and give a good illustration of the meaning and impact this characteristic can have.

Please note that many of the quoted people identify with the proposed condition Pathological Demand Avoidance (PDA), of which demand avoidance is the central characteristic. This is discussed in more detail further down the page.

“With my PDA kids, they will avoid things they want to do, if I put their favourite food in front of them they’ll have a meltdown because it ‘wasn’t what they asked for’ or they ‘can’t eat it right now’ or I ‘used the wrong colour bowl’. They want to eat it, they just can’t because it’s a demand. … Many PDAers will come out with reasons for why they cannot do something, often fantasy reasons such as saying they cannot get dressed because they are a dog and dogs don’t wear clothes, or they can’t get dressed because their legs are on fire.”

– Riko Ryuki, Autistic demand avoidance – an example

“Demands, particularly external ones, cause me great distress, even if I want to participate or do the action, every suggestion always has a knee-jerk ‘NO!’ response.”

– Kyra Chambers, For the love of roleplay

"Examples could include things like: there was something I was going to do, I planned to do, but before I could actually do it, before I had a chance to do it, someone intervened and asked me to do it – and now, I can't do it. ... When I say unable, I do not mean 'don't feel like it', ... it's an inability."

– Orion Kelly, Understanding demand avoidance in autism

“The single most important thing to a PDA individual is their autonomy; to decide things for themselves and be in complete control of what they do and where they are going. We need equality and fairness; it doesn’t make sense in our brains why everyone isn’t on the same level and to be treated and respected equally. This is often a cause of why we buck against authority figures so much, aside from rejecting anyone who tries to tell us what to do!”

– Jo Richardson, Different not deficient

“PDAers are masters of demand avoidance in that they are skilled at making excuses or using distraction techniques to avoid any demands put on them. These techniques can include; procrastination, manipulation, negotiation, hurting themselves so they are unable to complete the request, withdrawing into a fantasy world or physically attacking the person making the request or demand. The violence is often used when their anxiety levels are high and they don’t think that any other form of avoidance will work or that their emotions and anxiety peak and they have an explosive meltdown.”

– Jo Richardson, Different not deficient

“PDAers' demand avoidance can apply to every single instance where they perceive a demand; this could be getting up in the morning, eating, drinking, going to see a movie that they have been really looking forward to going to, playing with a new toy etc. It is uncontrollable and all encompassing.”

– Jo Richardson, Different not deficient

"If I put something in my diary, as soon as it's in black and white and it's a demand, I feel anxiety. I feel anxiety as I put it in my diary; I feel anxiety in the lead up; I feel anxiety on the morning when I wake up and that thing is in my diary. It makes me experience demand avoidance, even if it's something I wanted to do. Ditto putting a task on my 'To do' list – as soon as the demand is on my 'To do' list, it's a demand and it causes anxiety."

– Purple Ella, Demand avoidance

“Typical or traditional parenting strategies involve showing the child that the parent is in control. With PDA, the child needs to feel like they are the ones in control – which involves some pretty exhausting forward planning and sometimes quick thinking. The truth is that the more you try and make a PDA child fit into the system, by following typical parenting or education strategies, the more likely they are to feel forced into behaviour which challenges.”

– Steph Curtis, Challenging behaviour and PDA

“PDAers will sometimes go to extreme lengths to avoid everyday demands. They may be unable to agree to go and do their favourite activity even if they would actually really enjoy it, if a multitude of other demands have been placed on them that day and they no longer feel in control.”

– Steph Curtis, What is PDA?

Relationship to autism and other neurodivergences

Demand avoidance is most often conceived as a characteristic experienced by and/or observed in autistic people. It has been characterised as the key characteristic of a proposed condition or profile of autism called Pathological Demand Avoidance (PDA), although this is a controversial label that is not recognised clinically (meaning it is not included in medical manuals) and is contested within the autism community.

Although advocates of PDA most often think of it as a potential profile of autism, some have suggested PDA may be a distinct neurotype or neurological difference, not connected to autism or the conditions listed below.

Besides autism, it has been suggested that the presentation of a persistent and marked resistance to demands may be connected with other conditions, including:

- complex post-traumatic stress disorder (cPTSD)
- attention-deficit/hyperactivity disorder (ADHD)
- oppositional defiant disorder (ODD).

Context about demand avoidance and our understanding of autism

It is important to note that when demand avoidance was first described, some of the behaviours observed were considered uncommon in autistic people. However, as our understanding of autism as a spectrum condition has developed, a number of these behaviours are now understood to be more common.

For example, when demand avoidance was first described, it was thought that autistic people were largely not capable of employing some of the creative and socially sophisticated strategies listed above as ‘Forms of resistance’. Our current understanding of the autism spectrum acknowledges that many autistic people are indeed capable of these things.

This context is important when trying to understand the history of and debate around the label Pathological Demand Avoidance (PDA), which was proposed as a way to describe people experiencing demand avoidance alongside a group of behaviours that were then thought to be uncommon in autistic people (and therefore necessitated a new label, it was argued).

Because almost all research about demand avoidance has been carried out as part of attempts to validate PDA as a distinct profile or condition, it is difficult to separate what we know about the characteristic of demand avoidance from the proposed group of traits known as PDA. This is explored in more detail in the following section.

The history of and debate about the PDA label

The history of PDA

Pathological Demand Avoidance (PDA) is a term originally developed by the British psychologist Elisabeth Newson in the 1980s and first used in a published research paper by Newson in 2003. It was used to describe a group of children who did not fit into the stereotypical presentation of autism recognised at that time but who shared certain characteristics with each other, the key one being a persistent and marked resistance to demands.

Newson believed this presentation justified a distinct identification (rather than being described generically as ‘Atypical autism’ or ‘Pervasive Developmental Disorder – Not Otherwise Specified’ (PDD-NOS), which were diagnostic labels used at that time) and a list of key features for PDA was created. Some variations of this list have been suggested by researchers and practitioners, though the descriptions have remained broadly the same.

Please note that the following proposed characteristics have historically been described using language associated with the deficit model (of autism), which many people consider inaccurate and offensive; the language below represents a sanitised version, but this should not be considered an endorsement.

The proposed core characteristics most commonly cited are:

- resisting and avoiding the ‘ordinary demands of life’
- using social strategies as forms of resistance – for example, distraction, giving excuses

Other proposed characteristics cited include:

- appearing sociable, but experiencing differences in social understanding (such as recognising hierarchies)
- experiencing intense mood swings and impulsivity
- appearing comfortable in role play and pretence
- displaying dedicated and focused interests, often focused on other people.

Although demand avoidance, including the use of social strategies to avoid demands, is widely acknowledged as a characteristic reported by and observed in some people, no research has found strong evidence for the group of traits proposed for PDA or tested the validity or usefulness of Newson's theory in clinical practice (the work of healthcare professionals).

PDA is not clinically recognised (it does not appear in the international medical manual, the ICD, nor in the American medical manual, the DSM), which means you cannot receive a standalone diagnosis of PDA. There is debate around how the characteristic of a persistent and marked resistance to demands relates to autism (and other conditions) and whether its grouping with other traits as 'PDA' is helpful. For more information about this, see the following subsection 'Debate about PDA'.

Although it is not possible to receive a diagnosis of PDA, some people have a diagnosis of autism with a 'demand avoidant profile' or a 'PDA profile' noted, and others self-identify with the PDA label. 'PDAer' is how many of these people prefer to be referred to. Some object to the use of the word 'pathological' in the term 'Pathological Demand Avoidance' and have suggested 'Persistent Drive for Autonomy' as an alternative. Others think the use of the word 'pathological' is appropriate because they find these characteristics 'all-consuming'.

Debate about PDA

There are stark disagreements within the autism community (which includes autistic people, their families and allies, autism researchers, health care professionals, education professionals and more) about the validity and usefulness of the concept of PDA. One point on which there is broad agreement is that more and better research is required.

Criticism

Some critics note that there is not enough research evidence to confirm PDA as a separate condition to autism and argue that:

- the complex characteristics can instead be understood by considering the individual’s social, sensory and cognitive sensitivities, any co-occurring conditions and whether their environment is suited to their needs
- the label is unhelpful as it implies the issues are within the person and not created by the above factors, which can be addressed.

It has also been argued that the PDA label represents an unnecessary pathologising of differences in autistic people when:

- they act outside of social norms in attempt to gain autonomy (control over their lives)
- they adopt coping mechanisms or attempt to reduce anxiety associated with social norms or assert self-agency (their desire to make their own decisions.)

It has further been argued that PDA-related products, such as training and conferences, have been promoted to parents and that this creates a looping effect where parents or individuals unintentionally consider behaviour selectively to conform to the proposed traits, re-enforcing their belief in the proposed condition.

Counter-criticism

Some of the criticisms listed above have been counter-criticised by people who identify with PDA. They argue that the critics do not have lived experience of these issues and that the views of people with lived experience are being invalidated, or that they are being othered and/or patronised, by these arguments.

National Autistic Society involvement

The National Autistic Society has historically engaged with the concept of PDA through website content, training, conference events and other activities. This has created a belief that the National Autistic Society accepts the concept of PDA, and its relationship to autism, to an extent that goes beyond the evidence, which has been referenced in the debate about PDA. We have reviewed our content and approach to be in line with the evidence.

Identification and assessment of demand avoidance

It is best practice for an autism assessment to identify and record a person’s unique strengths and challenges and so demand-avoidant characteristics or a strong need for personal autonomy must be recorded, with or without the use of any particular terminology such as PDA.

A thorough autism assessment should cover a person's full neurodevelopmental profile, including:

- gathering information about all characteristics, including demand avoidance
- observation of environmental influence on a person’s characteristics.

To support all autistic (or neurodivergent) people, whatever their strengths and challenges may be, there must be:

- good understanding/recognition of neurodivergence (including of complex needs) by health care professionals
- a comprehensive assessment (including external/environmental factors)
- support personalised to align with the person’s strengths and needs.

Although the concept of PDA is not clinically recognised and so it is not possible to receive a standalone diagnosis of PDA, some people are diagnosed as autistic with a ‘PDA profile’ (or similar). However, the usage of this language in an autism diagnosis is not standardised; there is no standard assessment for PDA and usage of this terminology depends on whether the clinicians, practitioners or commissioners in your local area accept it.

Note that many autistic people use social strategies and can have dedicated and intense interests that may be focused on people (these traits may be more common in autistic women and girls, for example), so the presence of these traits is not a reason to discount an autism diagnosis.

How common is demand avoidance?

We don’t know. Because demand avoidance is currently understood as one characteristic in a person’s neurodevelopmental profile and is neither a diagnosable standalone condition nor is there a standardised assessment for the characteristic, there are no data to reliably indicate how common it may be. It is hard to draw conclusions from the limited and often low-quality research that exists.

Why does demand avoidance happen?

Evidence suggests that persistent and marked demand avoidance demonstrates an intense need for control. However, this is not well understood and more research is needed.

Some (low quality) research highlights a relationship between this characteristic and the presence of both:

- anxiety, and

- intolerance of uncertainty (needing to know what is going to happen in order to feel calm).

Demand avoidance may be driven by these factors, both of which are common in autistic people. Alternatively, some people with lived experience of demand avoidance have suggested anxiety may be the effect (not cause) of perceived threats (demands) to autonomy and control.

Impact

Evidence suggests that demand avoidance can impact those experiencing it in a variety of ways, including:

- difficulty getting to sleep, staying asleep and getting up
- short and long-term effects from anxiety and associated symptoms
- difficulty with self-care tasks such as personal hygiene, eating and household chores
- experiencing panic attacks, intense emotional distress and/or difficulty regulating emotion
- difficulties in friendships or other social relationships
- inability to attend education or employment due to distress and/or burnout, which may result in exclusion or termination.

Impact on parents and carers

The parents/carers of people experiencing demand avoidance may experience impacts including:

- distress from witnessing their child / the person they are caring for in extreme distress
- challenges and exhaustion from trying to find effective ways to reduce, disguise or remove demands and support the person
- stress and frustration from trying to access or implement appropriate support in areas such as diagnosis, education, mental health and social care.

Support strategies

It is important that people experiencing persistent and marked demand avoidance are recognised and supported using strategies and approaches personalised to their specific strengths and needs.

Research suggests that the understanding and acceptance of demand avoidant behaviour is fundamental to accessing the right support.

There is limited research on support strategies; however, general advice from personal accounts and professional resources includes:

- reducing and/or removing demands, where at all possible
- a collaborative approach that flattens hierarchies (for example, between parent and child or manager and employee) to work with them rather than ordering them around
- indirect communication styles (not making demands directly)
- avoid potential stressors such as eye contact, touch and confrontational postures/physical stances
- remove any spectators to a distressing situation (by asking people to give the distressed person space or by moving the person to a quiet space if possible)
- a coordinated approach to support, with the person, family and professionals (i.e., from education, social care, healthcare, etc) involved.

Sources suggests people experiencing demand avoidance may benefit from:

- identifying and understanding their demand avoidance (and its triggers)
- managing, reducing and disguising demands
- sensory regulation and creating a sensory environment that works for them
- therapy, counselling, mindfulness and meditation.

National Autistic Society letter to schools and local authorities

We have prepared a letter for parents and carers of children and young people who experience demand avoidance to send to schools and local authorities in situations where support may be being denied or withdrawn with reference to this characteristic. The letter explains our position on best practice in autism assessments, which must record all of a person's characteristics, including demand avoidance, and details the school and local authority's legal duties in providing support that is tailored to an individual's unique profile and needs.

Read our statement and download the letter.

Insight from lived experience

"I've found that by giving myself an 'out' then it is much easier to meet demands, because I know I can change my mind whenever I want. I'll tell myself, 'You don't have to if you don't want to', this works quite well."

– Riko Ryuki, Adult coping strategies

"Have all your bills on Direct Debit payment to avoid the demands of having to pay bills when they arrive. Try and schedule them to come out around the times when you have the most money in your account, such as right after paydays or benefits deposit."

– Jo Richardson, 15 Life Hacks for PDA

"Being actively given freedom and autonomy, through choices, self-direction, autonomous motivation, and respect of competence and consent, can empty the 'demand cup' bit by bit, and keep it emptier. Further to this, allowing plenty of demand free time and rest allows the demand cup to naturally empty."

– Tomlin Wilding, The Demand Cup

"If your child can only go to school today by being a dinosaur, hey, that is okay. If you can only go to the hospital because you are exploring a newly discovered medical facility in space, then brilliant! You have found your way through, in a way that works for you."

– Kyra Chambers, For the love of roleplay

"When others react badly to the PDAers panic or defence reaction that often they have no control over, this can cause damage to their self-esteem, mental health, and emotional wellbeing, as they are being punished for something they had no control over – punished for trying to protect themselves from a perceived threat."

– Jo Richardson, Different not deficient

Insight from parents

"Direct demands should be removed from language wherever possible; it is vital to reconsider the words we use to communicate. So no 'need, must, have to' and instead much more of 'may, could, would you like, how about' etc. More of 'I wonder if we might be able to..' or 'I'm not sure how to do this, could you show me?"

– Steph Curtis, Strategies for PDA

"As we shift our perspective to that of compassion and empathy and away from our own parental control, enforcement of rules and discipline something amazing will begin to happen. Your relationship will begin to change. Your child will start to trust you as an emotionally safe space. They will begin to see, feel and accept that you are on their side."

“Lowering daily demands will help to reduce anxiety. When you lower the demands you have placed on your child you are actually offering them autonomy. They need to feel as if they have control over their life and the environment they live in.”

– Kerissa Lyman, Supporting PDA