



Disability Matters launch report

Changing the landscape of disability

www.disabilitymatters.org.uk

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

George Bernard Shaw
Nobel prize-winning playwright



Introduction

Three years ago, television journalists exposed the horrific abuse of people with learning disabilities and autism at a care home in southern England.

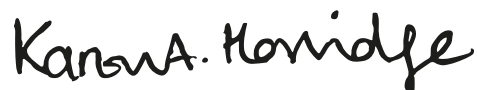
Last year, a UK confidential inquiry revealed ongoing inequalities in access to healthcare and worse outcomes for people with learning disabilities.

This year, light is on the horizon. The Department of Health (England) funded Disability Matters to challenge and positively change attitudes in our society towards disabled children and young people.

Disability Matters is freely available on the internet and is made up of 57 sessions of e-Learning and support packages for face-to-face group learning, co-produced by disabled children, young people, parent carers and other experts across statutory and voluntary sectors. It is full of real stories of lived experiences and top tips from disabled children, young people and their families for all who work or volunteer with them.

Disability Matters informs and inspires us all to be better able to include, value and warmly welcome disabled children and young people, empowering them to achieve the outcomes that matter to them, as equals in our society.

Positive, 'can do' attitudes cost nothing but can make the world of difference. Are you up to the challenge?



Dr Karen Horridge, Paediatrician (Disability) Sunderland
Chair, British Academy of Childhood Disability
Clinical lead, Disability Matters

Key statements

The Busk Family

A Family Perspective



Despite all we hear about equality, we know that there is still much to do to make disability equality a reality. It's not just about lack of physical access. Our disabled son, unlike other disabled people, cannot understand when people are not kind or refuse him things simply because he is disabled. We often feel we live in a parallel world from non-disabled people. We see the apathy, negative attitudes and fear. We feel the hurt for him.

We have to challenge the negative things we see and ensure he gets the right help and support. At the same time we are not able to challenge and fight for it all – some things we have to let go.

There can be no excuses for such experiences for disabled children and young people like our son to continue – and the launch of Disability Matters is a significant step to driving change. Disability Matters is a free and accessible training and learning programme that is aimed at reducing fear and increasing understanding. It gives practical tools and knowledge. It has been developed with parents and young people. There is much in common across different disabilities and Disability Matters captures that – so you can learn a lot from a few sessions.

Disability Matters needs to be mainstreamed so that health, education, care and other professionals and employers understand disability better and children and young people like our son can at last enjoy the same rights as their non disabled peers. Families and wider communities need to become more inclusive too. The needs of a disabled child or young person as a whole person should be at the centre of understanding: as human beings deserving of the best society has to offer.

We have had good experiences too. Those that are good tend to come from people who have direct experience of disability through their own family or friends. We want anyone who comes into contact with disabled children or young people to positively challenge and change their fears, attitudes and beliefs to give reality, at last, to real disability equality in its broadest sense. Disability Matters makes it everyone's responsibility not just families like ours.

Daniel Poulter MP

Parliamentary Under Secretary of State
at the Department of Health



I am delighted to welcome the launch of Disability Matters, which is backed by £1 million from the Department of Health. A huge effort from a wide range of organisations has got us to this point and I am grateful to everyone involved.

A single portal where all professionals and staff who work with disabled people can sign up for e-learning sessions will be utterly invaluable. It will have a significant impact on their knowledge, awareness and effectiveness and on the lives of those they care for.

The dreadful events at Winterbourne View are a sharp reminder that disabled people have not always been well served by public services, including the NHS. But we are putting things right.

Ensuring that things change – for the better – is a moral imperative for us all. Disability Matters can and will play a leading role.

“A single portal where all professionals and staff who work with disabled people can sign up for e-learning sessions.”

What does the workforce say?

The majority of workers surveyed from a wide range of workforce settings feel they need to know more about disability.¹

"It's a bit hit and miss..."

'It's a bit hit and miss, we learn from other people and how they deal with things but who's to say they're doing it right or not.'

Police, Female. 40-45

70% of workers feel they need to know more about disability for their work.

Yes
70%

Do you feel you need to know about disability more for your work?

No
20%

Not sure
10%

¹Triangle carried out a consultation with a wide sample of workers, professionals, disabled children and young people, and their parents and carers about their understanding and experiences of disability on behalf of the Disability Matters Consortium. This was administered via 1,252 online surveys, eight focus groups (with a total of 35 participants) and 71 individual, semi-structured interviews. Triangle compiled the findings of this consultation in the report: Views on the Royal College of Paediatrics and Child Health, Disability e-Learning Portal consultation findings.

Workers want more knowledge, support and information on:

- Working with disabled children and young people in their service/sector
- Communicating with disabled children and young people
- Good practice with disabled children and young people in their work setting
- How to get children and young people's needs recognised and met in relation to different services and current legislation and policy



“I have lots of experience but because there are so many different disabilities I cannot learn all the ins and outs of them all and I am not sure I need to but I do need to know how to care for the young people and communicate respectfully with them. That’s what everyone needs to know.”

Social care worker, Male. 26-39

Key Barriers

When questioned about the types of things that either stopped disabled children and young people participating in activities or getting the help and support they need, the most commonly-cited barriers across all workforce sectors related to services and resources.

“They don’t have the time to really listen...”

“I have encountered support workers, social workers, teachers and medical professionals etc. who have been impatient and patronising to the people under their care. They have not taken the time (or in many cases do not actually have the time) to really listen to and see the individual for who they are”

Art Therapist, Female. 26-39



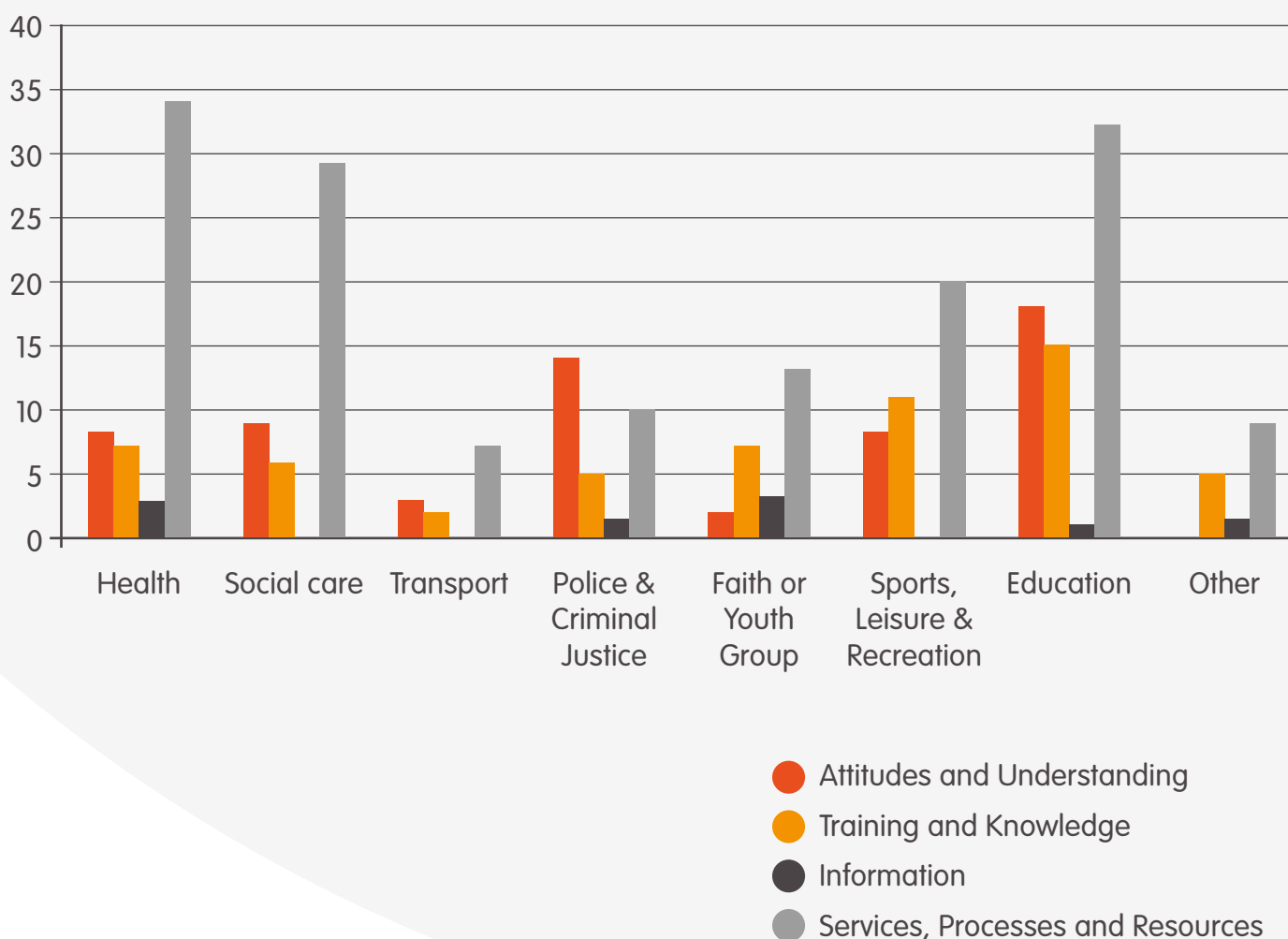
Negative attitudes and a lack of disability awareness more generally in society and in the workplace were the second most commonly-cited barriers to supporting disabled children and young people according to our research. These types of obstacles were even more apparent in the police and criminal justice sector where barriers related to attitudes and understanding were more commonly-cited than those related to a lack of services and resources.

“People don’t think how to adapt activities to make them accessible, for example at messy church it’s really noisy, so for some of the children with a hearing aid the sound is amplified”



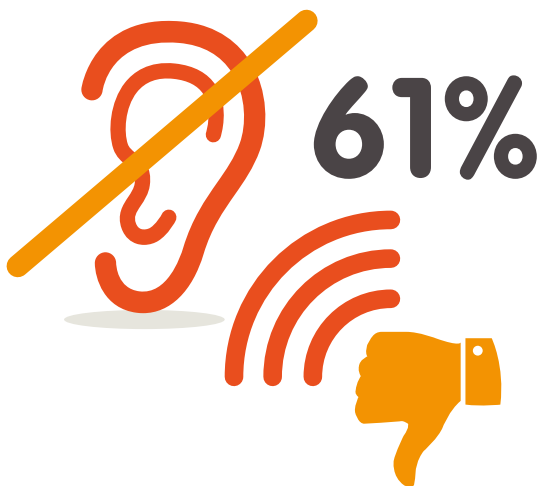
Faith Group Worker, Female. 40-46

What are the key barriers for the different groups?*



*Taken from Views on the Royal College of Paediatrics and Child Health, Disability e-Learning Portal consultation findings.

The public perception of disability



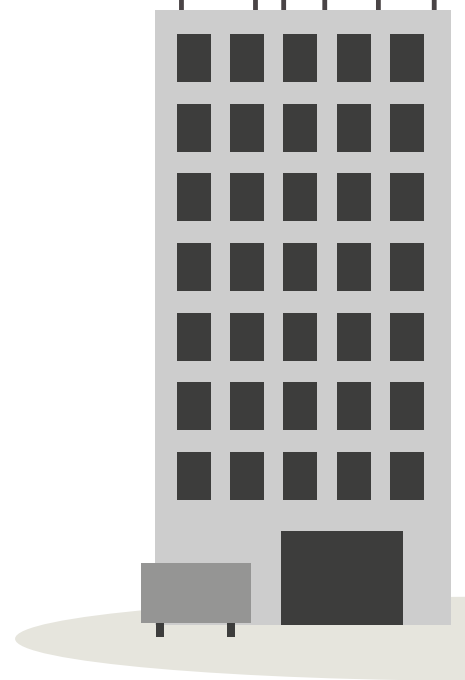
Over **60%** of Britons say they are not confident communicating with a child who is deaf

Only **5%**

... of Britons chose '**Confidence**' as one of the top three terms that describes how they feel when they meet a disabled person



8 in 10



More than **six in ten** British adults say that the figures of **180 disability hate crimes** being committed every day in the UK...

ComRes interviewed 2,064 British adults online between 7th and 8th January 2015. Data were weighted to be representative of all GB adults aged 18+. Full data tables are available at www.comres.co.uk. ComRes is a member of the British Polling Council and abides by its rules.

8 in 10 Britons agree that business and organisations **should provide more training** to ensure their staff feel confident about working with disabled people



A **quarter** of Britons **do not** feel confident communicating with a disabled child



1 in 5 do not feel confident communicating with the parents of a child who they think might be disabled



...and the fact there are **11.6 million disabled people** in Great Britain are higher than they expected



86%

...of Britons say if they had a disabled child, they would **worry** their child would **find it harder** to get a job

Disability Matters topics



Understanding Disability

What is Disability?
Reflection Matters
Hidden Disabilities Matter
Disabilities, Cultures
and Languages

Deaf Communication Matters
Learning Disability Matters
Autism Spectrum Matters
Complex Conditions Matter

Person to person (Working with me)

Feelings Matter
See the person, celebrate
achievements
Confidence Matters
Building Relationships Matters
Communication Basics
Understanding Matters for
effective Communication

Three-way Communication Matters
Communication Support Tools
Communication Matters in Health
Communication Matters in
Learning
Communication Matters in
the Legal System
Personal Care Matters
How Information is Shared Matters

Family and Society (The world around me)

Rights Matter
Meaningful Inclusion Matters
Inclusion Matters for
Organisations and Services
Working Together Matters
Safeguarding Matters
Bullying Matters

Environmental Challenges Matter
Transport Matters
Activities Matter
Family Matters
Caring for Parent Carers Matters
Finance Matters
Work Experience and
Employment Matters



Decision-making and Growing Up

Choices and Decision-making Matters for Everyone

Mental Capacity Act Matters

Best Interests Decision Making Matters for Clinicians

Advance Care Planning Matters

Deprivation of Liberty Safeguards Matter

Advocacy Matters

Supporting Independence Matters

Growing Up Matters

Transition Matters

Health and Wellbeing

Diagnosis Matters

Health needs Matter in all settings

Equal Access to the Best Outcomes Matters

Participation Matters

Continence Matters

Vision and Hearing Matters

Pain Matters



Behaviours and Emotions

The Different Meanings of Behaviours

Stress and Anxiety Matter

When Behaviours are Seen by others as Challenging

Sexually concerning Behaviours Matter

Self-Injury Matters

Current understanding

Disabled children's, young people's and parent carer's understanding of disability.

What they said:*

"I don't think of N*** as Disabled. I think of her as Enabled. I don't make allowances for her, just like my other daughter. She IS able. She just has to do things at her own pace. No-one will understand the child as much as a parent. Officially I suppose she is disabled but I don't see her as disabled."


Parent of 13 year old daughter with Down's Syndrome

"If everyone was the same in this world life would be a torment. We need people that are different. Dick and Dom (children's television presenters) they had dyslexia they said never underestimate themselves. (Interviewer: what made a difference for them?) They had help."

Male, age 14, Autism

"It can be out of your control. It's depending on the day. Sometimes, you can feel not disabled and just get on with it and other days if you're feeling a bit down and depressed you feel more disabled."

Female, age 26-39



"Officially I suppose she is disabled, but I don't see her as disabled..."

"I don't like the word disabled I think it is a negative word and really is just a word to describe difference from the norm but that is most people isn't it?"

Parent of 19 year old daughter with Autistic Spectrum Condition

"When asked about what being disabled means to her, she said its normal, and went on to talk about her identity in terms of what she can do, she said I can play ball, I can swim, its normal. When I asked her how the word disabled makes her feel, she told me OK."

Female, age 14

*Taken from Views on the Royal College of Paediatrics and Child Health, Disability e-Learning Portal consultation findings.



What disabled children and young people think

What disabled children and young people think adults should learn more about:*

- Communication with disabled children and young people
- Independence and decision-making
- Meaningful inclusion
- Advice for workers and volunteers about helping disabled children and young people who use a different language, 'cultural differences'
- Growing up, employment, coping with stress and relationships with others

"I don't like people telling me 'I should do that', 'I shouldn't do that'"



What they said:

"One of the things I'd change about the way people treat me is that when they go to talk to me, they don't do that 'bendy down thing' that they do with young children, because they mean well but it comes over as really patronising"

Female, age 25

"They think they know best. Some people have completely ignored my opinion. Because of me being different they think like "oh I'm better than you". Why think like that?"

Female, age 19

"Just how to act around people, not being really, really sympathetic but being treated like a normal child."

Female, age 11-14

"I don't like people telling me 'I should do that', 'I shouldn't do that' or 'I can't do that.'"

Male, age 20

*Taken from Views on the Royal College of Paediatrics and Child Health, Disability e-Learning Portal consultation findings.



What people need to know about to help their understanding of disability?

53.6%*

Children's feelings



39.2%*

Communicating



28%*

Children's rights



*Respondents were asked to tick all the topics that apply

What parent carers think

What parent carers of disabled children and young people think adults should learn more about:

- Communicating with disabled children and young people
- How to get children and young people's needs recognised and met in relation to different services
- The health and emotional wellbeing of disabled children and young people
- The way different agencies and workers work together
- Personal understanding by people of their own attitudes and emotional responses to disability

"They don't treat him like a normal human being"



"If you go to a local hospital where they just deal with lots of disabilities and illnesses they just treat him like a twit really. They don't treat him like he's a normal human being...it's a lack of understanding around his condition and how it affects people really."

Parent of 20 year old son who has a genetic debilitating disease, brittle bones

“The school admitted they didn’t know what to do with him. We didn’t care if they had expertise we didn’t need experts we needed someone with a non-judgmental attitude.”

Parent of 24 year old son with Autism and Social Learning Difficulties

Topics considered important for people to know about by Parents and Carers:*

- Inter-agency, multidisciplinary team working
- Communication and interaction
- Social, mental and emotional health
- The different stages or transitions in the life-course from birth through to adolescence
- Issues relating to future employment

*Taken from Views on the Royal College of Paediatrics and Child Health, Disability e-Learning Portal consultation findings.

Disability Matters and your organisation

Disability Matters is committed to supporting organisations, their workers and volunteers to develop the communications, 'can do' attitudes and problem-solving skills required to engage confidently with and empower disabled children and young people.

The programme provides employers and staff with free access to a suite of high quality online and group learning resources covering over 50 topics related to disability.

Disabled children, young people and their families challenge learners to reflect on their own attitudes and beliefs about disability, and explore the practical things they could do that could make a real and positive difference to the experience of disabled children, young people and their parent carers as they go about their daily lives and access services.

Organisations can use Disability Matters to:

- Foster an environment of inclusiveness and respect for disabled children, young people and their families
- Make appropriate decisions based on best practice
- Feel confident in their ability to engage with disabled children and young people
- Build a common language using simplified terminology and a unified approach



Developing a learning package:

RCPCH can work with you to develop tailored online learning packages that meet the needs of your workforce. We recommend that each learning package comprises no more than six e-learning topics, in order to keep the programme manageable for staff. On completion of all the e-learning topics in the learning package, participants will receive a certificate of achievement.

If you are interested in discussing a learning package for your workforce please contact disability-learning@rcpch.ac.uk



Disability Matters and Achievement for All

Achievement for All works with schools, Early Years settings, further education colleges and local authorities to ensure that the 20% of children and young people vulnerable to under-achievement thrive emotionally and socially, and succeed academically. The charity works in partnership with regional, national and international partners and governments to extend our reach and has a significant impact on improving progress in reading, writing, maths, behaviour, and attendance for children and young people from birth to 25 years of age.

Sharing similar mission and values, Achievement for All is delighted to be working in partnership with Royal College of Paediatrics and Child Health (RCPCH) to support the Disability Matters Programme through the development of an online partner module. This partner module will provide an introduction to the Disability Matters Programme for Achievement for All schools and will sit on the Bubble, Achievement for All's new online portal.

The scale and reach of Achievement for All, coupled with our coaching model, means that we are uniquely placed in supporting educational settings to engage with the Disability Matters partner module which will then provide a pathway of opportunity to the excellent online resources available in the Disability Matters Programme.

Achievement for All works in partnership with highly effective specialist Special Educational Needs and Disability (SEND) organisations like the RCPCH, drawing on their expertise to develop online partner modules that provide an introduction to their specialist SEND resources and expertise. By using Achievement for All programmes and networks to make these connections we will increase the reach of specialist SEND organisations enhancing their ability to transform the lives of children who are vulnerable to underachievement and improve the quality of commissioning and value for money for the system as a whole.

Disability Matter Consortium Members

The Disability Matters programme is led by the Royal College of Paediatrics and Child Health on behalf of a consortium of disability charities and medical bodies.

Consortium Members:

British Association for Community Child Health
British Academy of Childhood Disability
British Paediatric Neurology Association
British Psychological Society
Chartered Society of Physiotherapy
Contact a Family
Council for Disabled Children
National Network of Parent Carer Forums
Royal College of General Practitioners
Royal College of Nursing
Royal College of Paediatrics and Child Health
Royal College of Physicians
Royal College of Psychiatrists, Faculty of Child Psychiatrists and Intellectual Disability
Royal College of Speech and Language Therapists

Thanks also to:

The commitment, hard work and dedication of the disabled young people from Triangle and the RCPCH Youth Advisory Panel and the parent carers of disabled young people. Thank you for so generously sharing your skills, insight and experience.

Health Education England and E-Learning for Health
City Hospitals Sunderland
College of Occupational Therapists

Sections of this document has been adapted from the Views on the Royal College of Paediatrics and Child Health, Disability e-Learning Portal consultation findings, Dr. Lucy Hadfield, Sophie-Ella Nicholls, Michelle Mattison, Triangle, April 2014.



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