



Meeting t[m40 /P zQ06103 720 540 ref0

Until everyone understands



# What we will cover



- Making sure doctors and nurses understand autism
- Getting an autism diagnosis
- Getting to see CAMHS
- What impact is the Children and Families Act having?

Until everyone understands

# Understanding autism



- Autism Act: all health and care professionals to have appropriate training. (This is only for adults, but many professionals will work with both adults and children.)
- Autistic children tell us it's the most important thing for them.
- It's not just professionals but the public too – *Too Much Information*

## What's the impact of poor understanding?

- 87% of families say people stare at their autistic child's behaviour
- 28% of autistic people have been asked to leave a public space
- 79% of autistic people and 70% families feel isolated.

[www.autism.org.uk/tmi](http://www.autism.org.uk/tmi)

Until everyone understands

# Can *you* make it to the end?



Until everyone understands

# Hot off the press! – GP records

- GPs and nurses are the frontline of healthcare.
- Autistic people face an unacceptable health inequality. There is some evidence (from Sweden) of premature mortality.
- Accessing primary care is vital to helping tackle this.
- NICE recommended a GP register:
  - Reasonable adjustments
  - National data to build an anonymous picture of autistic people's health needs.
- 



Until everyone understands

# *Autism diagnosis crisis*



**Children in the UK wait on average 3.6 years after seeking help to getting an autism diagnosis.  
(Goldsmith's University)**

- Each area arranges its diagnosis services differently, but issues revolve around:
  - **Capacity.** Having the staff.
  - **Resources.** Having the money.
- We have seen examples of diagnosis pathways being restricted (LD or MH only).



Until everyone understands

# *Autism diagnosis crisis (cont.)*



## **The impact**

- Diagnosis is a crucial milestone. It helps unlock vital support.
- Without that support, children struggle to get the help they need to reach their potential.
- This can impact the whole family.

## **What can be done?**

- Measure diagnosis waiting times across England.
- Include in NHS assurance frameworks.
- 

Until everyone understands

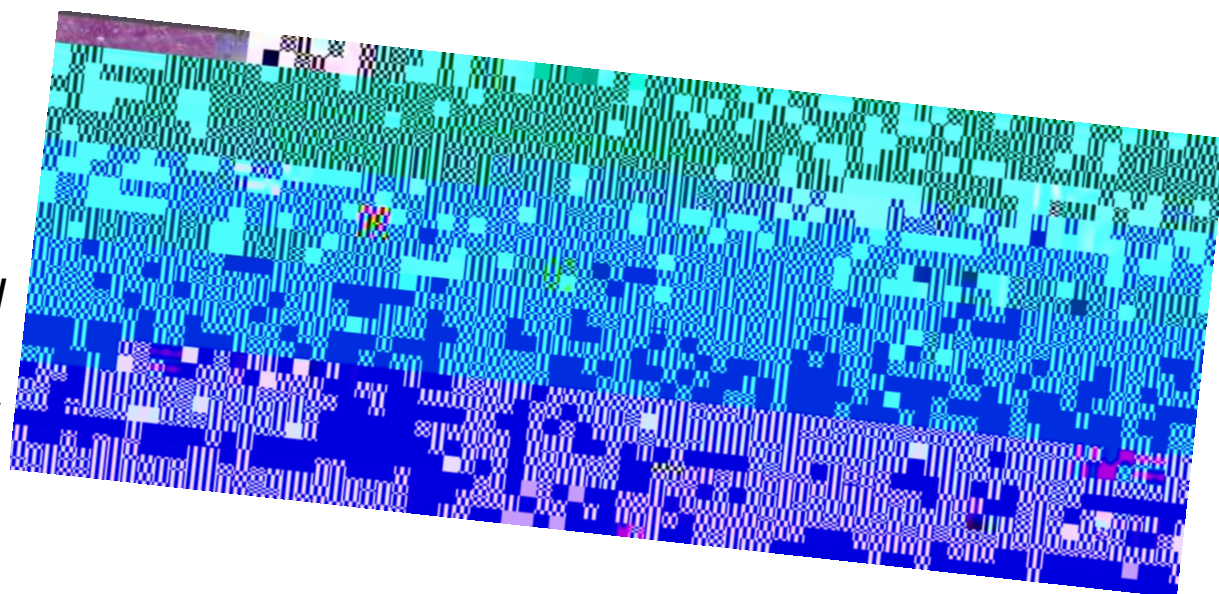
# Mental health – *You need to know*



**Autism isn't a mental health condition, but...**

**71% of autistic children develop mental health problems during their childhood. One in 10 children in CAMHS is on the autism spectrum. (Siminoff)**

- NICE Guidelines
- *You need to know* charter
- CQC CAMHS Review
- *The Five Year Forward View on Mental Health* and its autism pathway (2018 and beyond)



Until everyone understands









# Parents perceive their experience as a battle



Parents reported that:

- They are still waiting too long and fighting too hard to get the help their child needs
- They are unable to access the range of non-educational support their child needs to help them achieve their potential
- The right 'mix' of support isn't available locally
- Education staff need more understanding of autism to better support their child in the classroom

Until everyone understands



# Accessing the right support at the right time



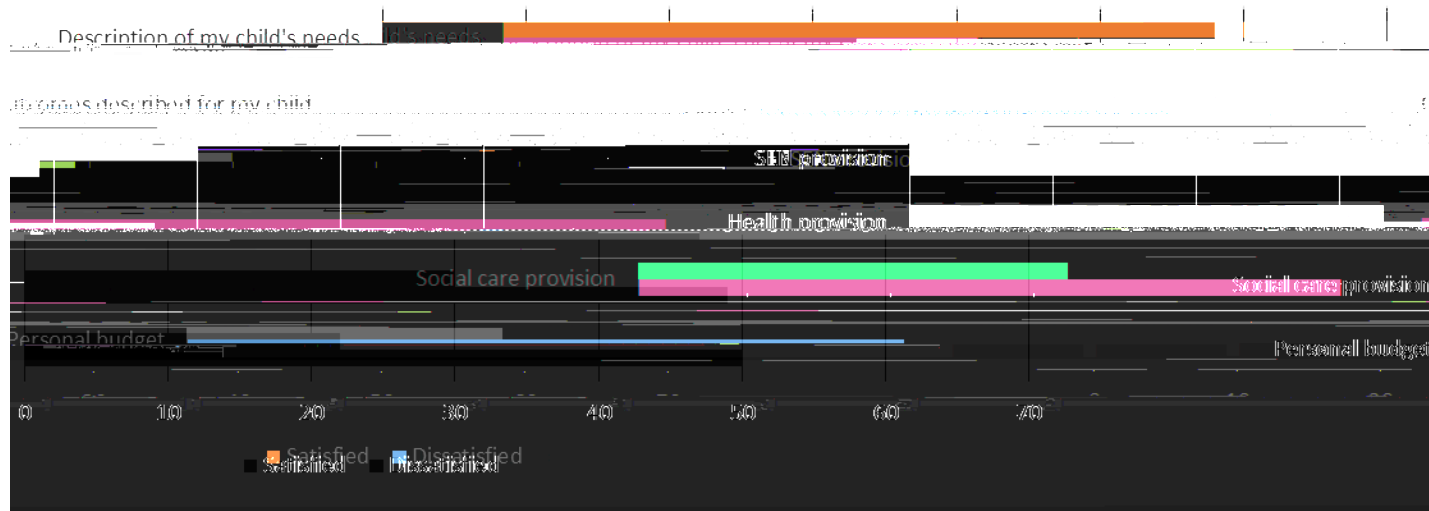
- 74% of parents say it has not been easy to get the educational support their child needs
- The time taken between parents raising concerns and their child receiving support varies greatly – 69% of parents say they waited more than a year, and 15% report waiting more than three years
- 39% of children are not in their parents' preferred type of school
  - Of these, 42% would prefer their child to attend an autism-specific special school
  - 24% would prefer their child to be educated in an autism-specific unit attached to a mainstream
- Parents who are dissatisfied with their child's current school place express a wish for their child to be educated in a place where autism is a specialism and is well understood

Until everyone understands

# Satisfaction with Education, Health & Care (EHC) plans



Many parents report that after having to fight for an EHC plan, they are relatively satisfied with the final plan. But there are significant challenges with getting the right help outside education.



Until everyone understands

# Comments from parents

On waiting:

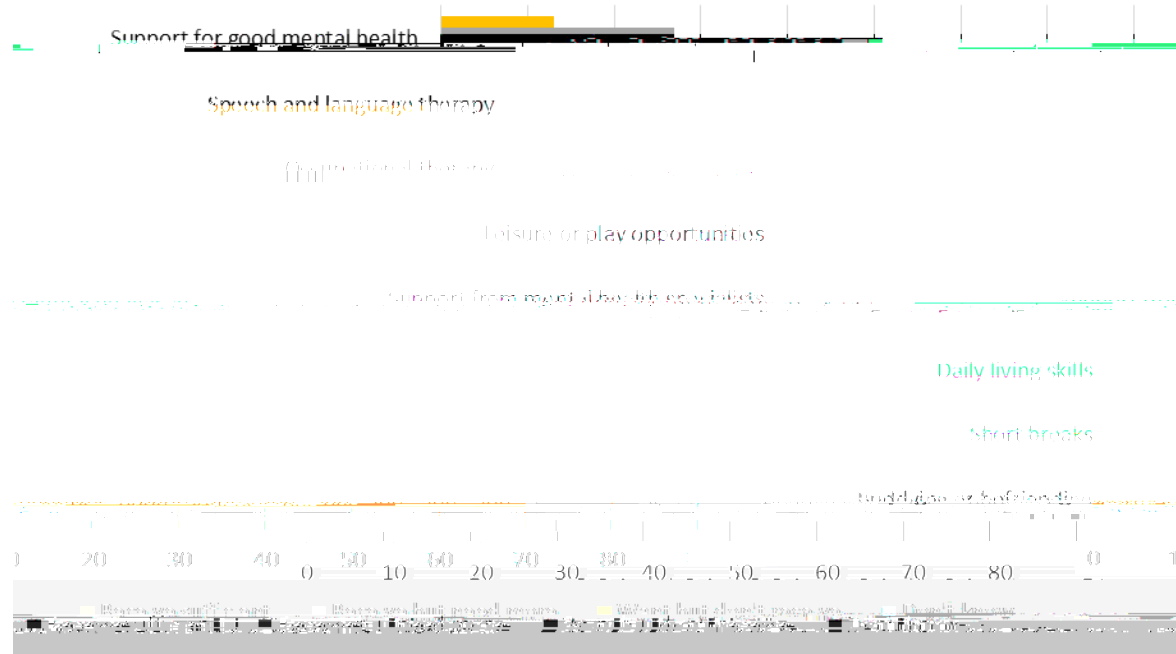


Until everyone understands



# Types of support children need

The range of support children on the autism spectrum need is often not purely educational. The need for support services far outstrips current provision.



Until everyone understands



# The Local Offer

**Parent:** *just a list of random things that may or may not actually be happening*

- SEND Code of Practice is clear that the Local Offer has two purposes:
  - Provide clear, comprehensive, up-to-date information for parents
  - Make local service provision more responsive to local needs and aspirations – and identify where the gaps are
- 52% of parents had looked at the Local Offer in their area, 42% had not
- 44% of parents who had looked at the Local Offer said it was ‘quite’ or ‘very’ easy to find information about services for autistic children, 55% said it was ‘quite’ or ‘very’ difficult
- 28% of parents who had looked at the Local Offer said they had been able to access services for their child as a result, 72% had not



Until everyone understands

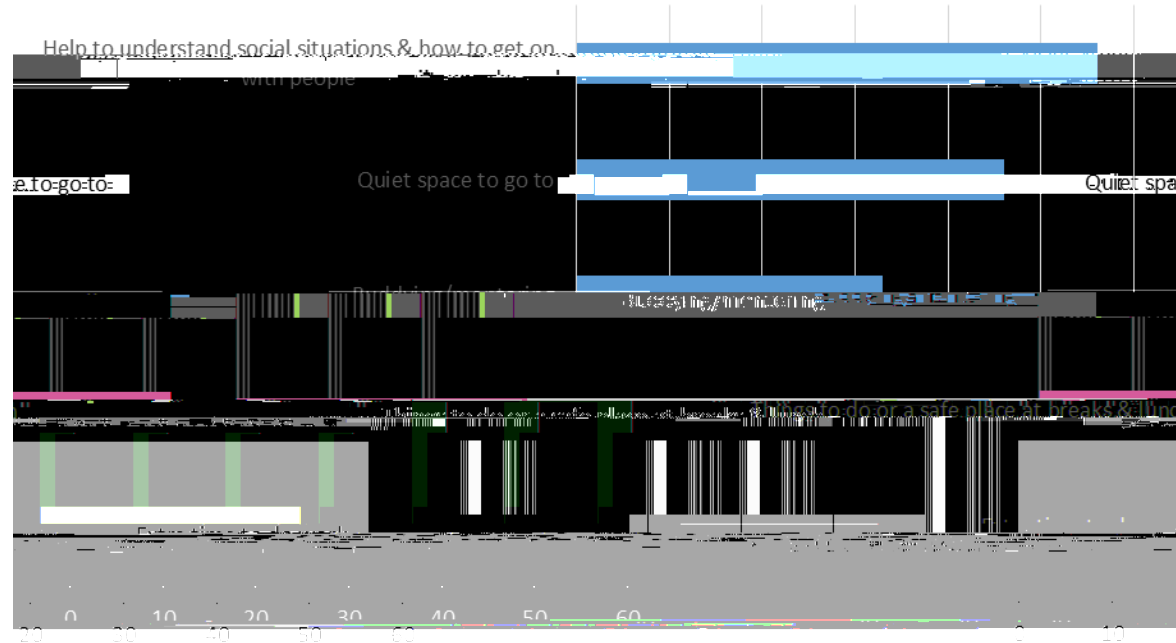




# What help children and young people would like that they do not get



Schools and colleges are required by the Equality Act 2010 to make reasonable adjustments for individual disabled children. But the picture is variable.



Until everyone understands





Until everyone understands



# Sign up to MyWorld!



<http://www.autism.org.uk/professionals/teachers/myworldhub>

Until everyone understands



# Any questions?

[tim.nicholls@nas.org.uk](mailto:tim.nicholls@nas.org.uk)



Until everyone understands

