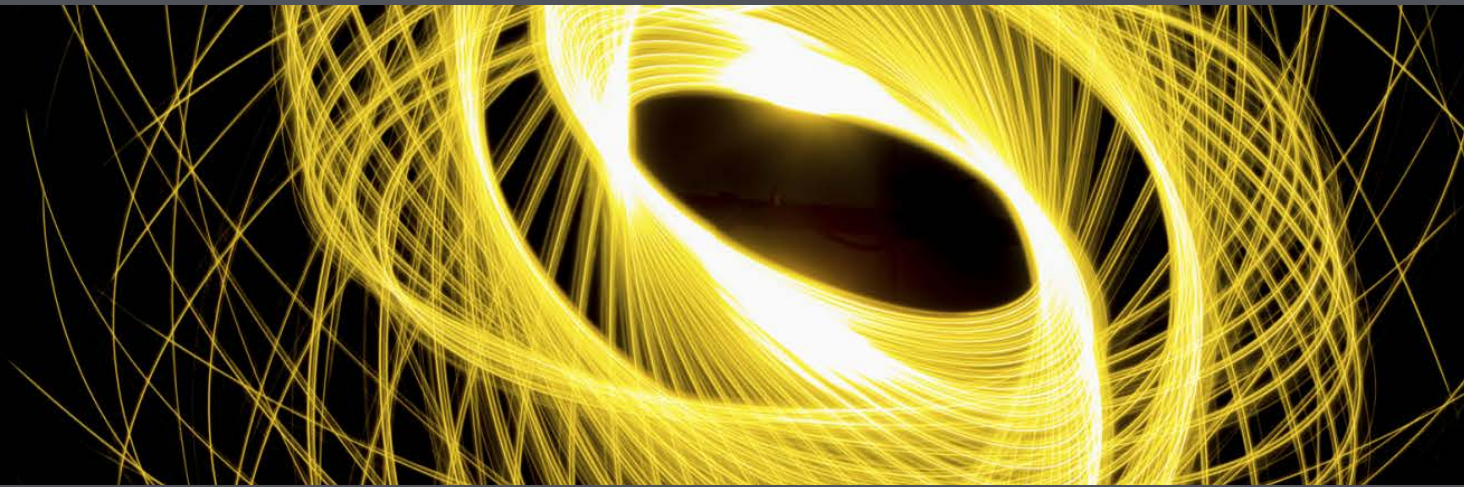


# BARRIERS & FACILITATORS TO INCLUSION: THE MAINSTREAM SCHOOL EXPERIENCES OF AUTISTIC CHILDREN AND THEIR FAMILIES



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# INTRODUCTION



OXFORD  
BROOKES  
UNIVERSITY



# TODAY'S TALK

- **Context**

- Autism-focused but generalisable to other 'hidden' conditions
- Emphasis on the challenges
- Emphasis on the parent experience

- **Content**

- What we currently know about the education of autistic children
- The parent experience
- Discussion – how can we make a difference?

# AUTISM & EDUCATION: THE STATS

- Autistic children account for 1.3% of the English state-funded school population – 108,403 children in all
- Of these, over 72% are educated in mainstream schools
- Around 25% of autistic children in mainstream schools have a Statement of SEN or an Education Health and Care Plan

# AUTISM & EDUCATION: THE STATS

- We know that autistic children can struggle at school
- We know autistic children and young people are more likely than their typical peers to:
  - Be excluded
  - Experience bullying
  - Have mental health difficulties
  - Have lower GCSE attainment
  - Experience difficulties accessing work/post-16 education opportunities

# AUTISM & EDUCATION: EXCLUSIONS (SEN)

- Pupils with SEN accounted for almost half of all exclusions in 2015/16
- Pupils with SEN were almost 7 times more likely to be permanently excluded than pupils with no SEN
- Pupils with a Statement of SEN or an EHCP had the highest fixed term exclusion rate

# AUTISM & EDUCATION: EXCLUSIONS (ASC)

- The rate of exclusions of autistic children has been steadily rising over recent years:

	2013/14	2015/16	% increase
Fixed Period	6150	9040	68
Permanent	90	150	60

# AUTISM & EDUCATION: UNOFFICIAL EXCLUSIONS

- Charities such as the National Autistic Society and Ambitious About Autism are also worried about the rise of ‘unofficial’ exclusions i.e. those that do not feature in official statistics because they go unrecorded e.g:
  - Being sent home to ‘cool off’
  - Internal exclusions
  - Part time timetables
  - Exclusion from after school clubs and school trips
  - Parents being asked to keep their child at home during an Ofsted inspection
  - Encouraging a family to move their child to another school

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<http://www.autism.org.uk/about/in-education/exclusion/grey-areas-england.aspx>

<https://www.ambitiousaboutautism.org.uk/understanding-autism/education/exclusions>



# AUTISM & EDUCATION: UNOFFICIAL EXCLUSIONS

- The Children's Commissioner 2017 report refers to the current situation with exclusions in our schools as 'a scandal':

"In 2009-10, if you were a Black African-Caribbean boy with special needs and eligible for free school meals you were

**168 times**

**more likely to be permanently excluded from a state-funded school**

**than a White girl without special needs from a middle class family."**

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<https://www.childrenscommissioner.gov.uk/wp-content/uploads/2017/07/They-never-give-up-on-you-final-report.pdf>

# AUTISM & EDUCATION: UNOFFICIAL EXCLUSIONS

- The Children's Commissioner 2017 report goes on to say:
  - Parents do not complain about this treatment.
  - They are unaware of their rights, and those of their children.
  - They trust the school to act in good faith.
  - They do not realise schools are not legally permitted to act in this way
  - They feel complaining would be futile, that they would not be listened to, or their child would suffer the consequences if they did.
- **“There is no point sending your child to a school that doesn't want him”.**

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<https://www.childrenscommissioner.gov.uk/wp-content/uploads/2017/07/They-never-give-up-on-you-final-report.pdf>

# AUTISM & EDUCATION: BULLYING

- Those on the autism spectrum are considerably more likely to be bullied than those with other or no SEND
- Prevalence estimates vary, but they are always worryingly high, with the highest rate reported as 94%.
- Those most at risk of bullying include:
  - Those with AS and/or with milder deficits in social understanding
  - Early adolescents
  - Those attending mainstream school
  - Those with concurrent behavioural difficulties

# AUTISM & EDUCATION: MENTAL HEALTH

- Mental health difficulties are very common among autistic children
- Studies have found:
  - 70% of autistic CYP (10-14 yr-olds) have one co-occurring condition
  - 41% have two or more
  - Most common co-occurring conditions are:
    - Phobias
    - OCD
    - Social anxiety disorder
    - ADHD
    - ODD

# AUTISM & EDUCATION: GCSE ATTAINMENT

- GSCE results 2015-2016
  - General school population 5 GCSEs A\*-C: 63%
  - Autistic school population: 30.6%

# AUTISM & EDUCATION: POST-16 OUTCOMES

- Recent studies show that around 25% of autistic adults are in sustained 'competitive' employment
- The National Autistic Society (2016) reports lower figures:



# THE EXPERIENCE OF PARENTS

- Perhaps unsurprisingly, many parents describe the experience of raising an autistic child as a 'fight':

"'I'm a bit of a mini Hitler really'  
(Sheila, teacher, daughter aged 23)

"'You use every weapon in your arsenal'  
(Sonia, full-time carer, son aged 6)

'I will fight his corner for him'.  
(Louise, dinner lady, son aged 7)

'I have no problem with the fight I know I am going to have for him'.  
(Chris, part-time administrator, son aged 8)"

# THE 'FIGHT': DIAGNOSIS

- 84% of parents notice something different about their child before the age of 5 years
- They tend to wait around a year before making first contact with a healthcare professional
- They typically encounter a delay of between 3 - 4 years from first contacting a healthcare professional and receiving a formal diagnosis of ASD for their child
- Delays tend to be longest for those with Asperger Syndrome



# THE 'FIGHT': DIAGNOSIS

- Post-diagnostic support tends to take the form of written reports & signposting
- 35% of the sample received no offers of help or support at all.
- 56% of the sample found the diagnostic process 'very stressful'

*“After the very considerate diagnostic process and level of care, we were left in the dark. We were given no information ... a few leaflets”*

# THE 'FIGHT': SCHOOL SUPPORT



<http://www.autism.org.uk/get-involved/campaign/appga/highlights.aspx>

# THE 'FIGHT': SCHOOL SUPPORT

**Fewer than half**



of children and young people on the autism spectrum say they **are happy at school**

Seven in ten say that their peers do not understand them and five in ten say that their teachers do not know how to support them

**70%**

**of parents** say that

**support was not put in place quickly enough for their child**

Nearly 70% waited more than six months for support and 50% waited more than a year



**Fewer than 5 in 10** teachers

say that they are **confident about supporting a child on the autism spectrum**

**6 in 10**  
**young people**

and seven in ten of their parents say that **the main thing that would make school better for them is having a teacher who understands autism**



# THE 'FIGHT': SCHOOL SUPPORT

**42%**  
of parents



say their child **was refused an assessment of their special educational needs the first time it was requested**



Only **1 in 10** parents

say they are **very satisfied with the process of agreeing an education, health and care (EHC) plan for their child**

# THE 'FIGHT': BROADER SOCIETY



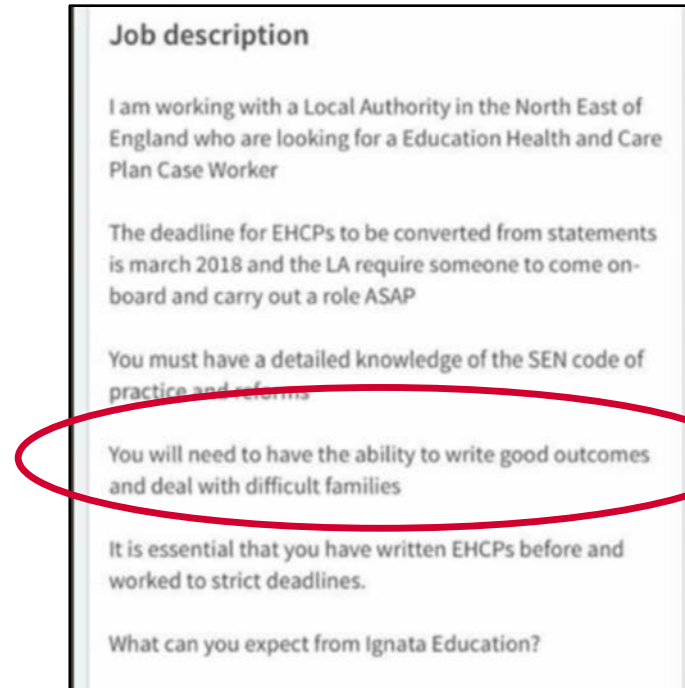
<https://www.thetimes.co.uk/article/autism-is-vastly-overdiagnosed-its-the-parentswayout-xzwlg2wsx>

# THE 'FIGHT': BROADER SOCIETY



<http://www.bbc.co.uk/news/uk-wales-40717652>

# THE 'FIGHT': BROADER SOCIETY



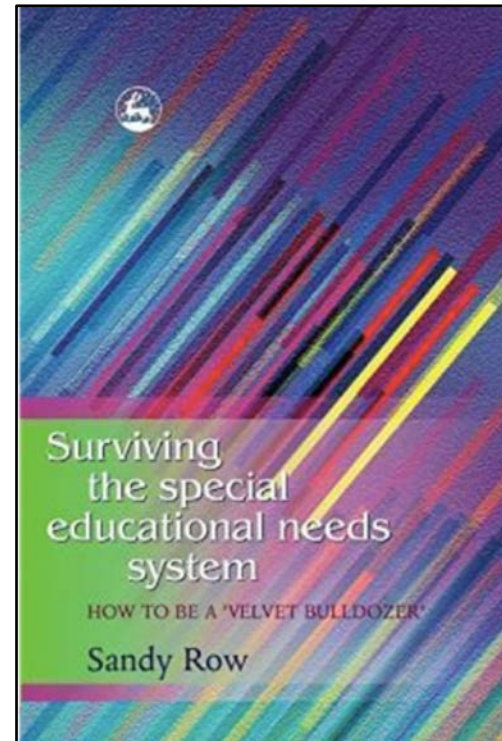
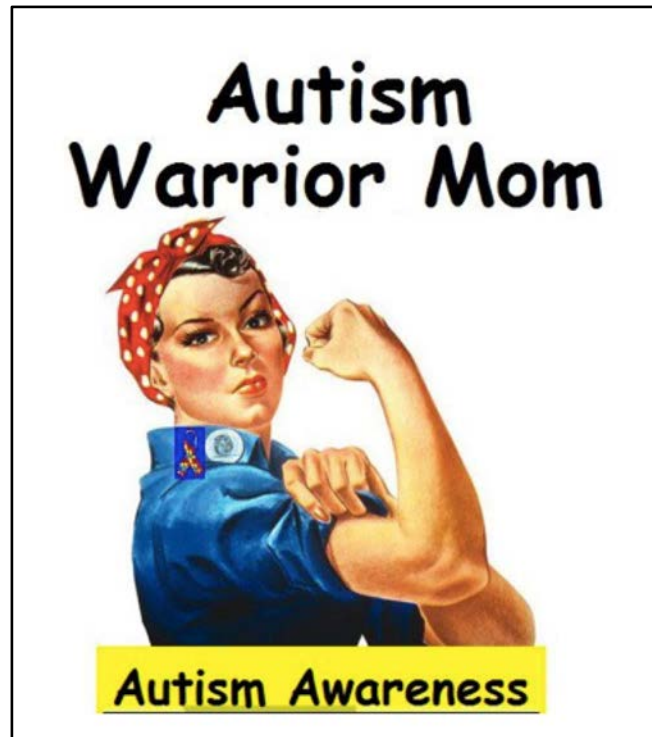


# THE 'FIGHT': PERSONAL IDENTITY





# THE 'FIGHT': PERSONAL IDENTITY



# GOVERNMENT & POLICY

Prior to the 2014 SEN reforms:

“Hundreds of thousands of families have a disabled child or a child with SEN, and **parents say that the system is bureaucratic, bewildering and adversarial** and that it does not sufficiently reflect the needs of their child and their family life.”

# GOVERNMENT & POLICY

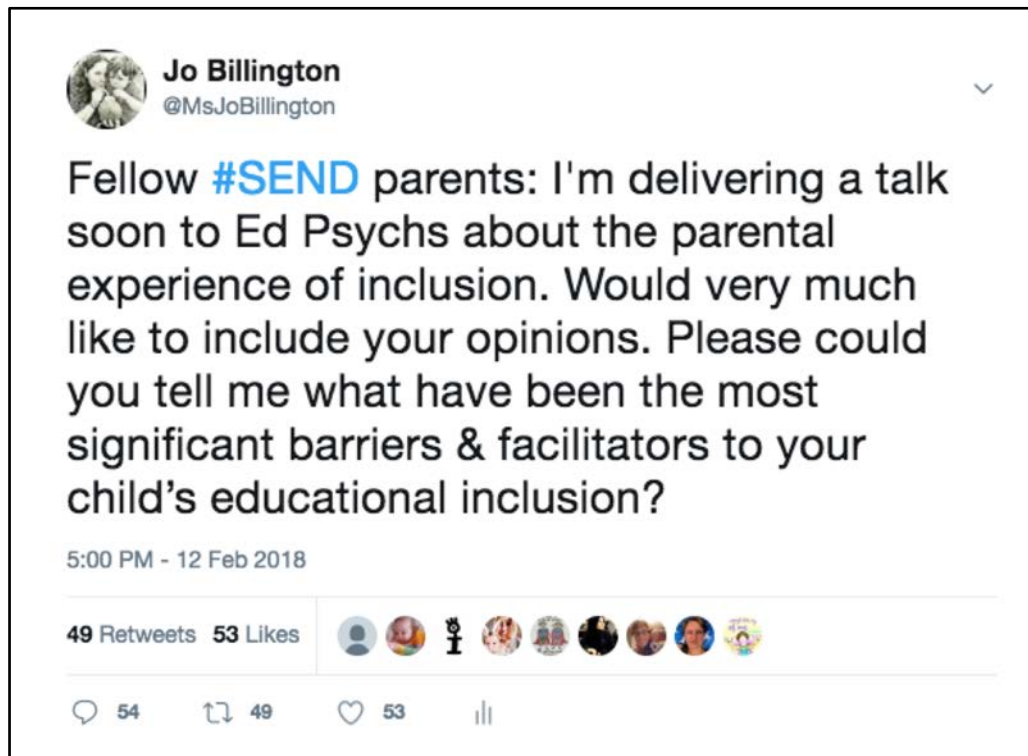
“The system to support children and young people who are disabled or who have SEN often works **against the wishes of families**.

Children’s support **needs can be identified late**; families are made to put up with a **culture of low expectations** about what their child can achieve at school.

**Parents don’t have good information** about what they can expect and have **limited choices** about the best schools and care for their child

**Families are forced to negotiate** each bit of their support separately.”

# THE PARENT VOICE: TWITTER



# PARENT VOICE: BARRIERS

- **Lack of specific SEN expertise/training/understanding/awareness**
  - Limited understanding of legal responsibilities and duties
  - Assuming that integration = inclusion
  - Reluctance to see beyond behaviour to understand the underlying need
  - Lack of whole-school approach but specific issues with senior leadership

# PARENT VOICE: BARRIERS

- **Communication difficulties**
  - Between school and home
  - Between school and other professionals, specifically CAMHS and Eps
- **Feeling excluded/judged/not listened to or valued**
  - By professionals, school staff, the wider school community

# PARENT VOICE: FACILITATORS

- **The opposite of the barriers!**
    - Feeling listened to and valued as an expert
    - Being included in their child's education and updated on a regular basis
  - **A flexible and adaptive approach**
    - Focused on solutions rather than problems
  - **Having the right mindset**
    - Welcoming and acting on the advice of professionals
    - Recognizing the individual child rather than the 'label'
-

# THANK YOU FOR LISTENING

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# REFERENCES

Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the united kingdom. *Autism*, 20(2), 153-162.

Department for Education, (2011). Support and aspiration: A new approach to special educational needs and disability, a consultation (available at: <https://www.gov.uk/government/publications/support-and-aspiration-a-new-approach-to-special-educational-needs-and-disability-consultation>)

Department for Education, (2016). SEN absences and exclusions: additional analysis (available at: <https://www.gov.uk/government/publications/sen-absences-and-exclusions-additional-analysis>)

Department for Education, (2017a). Special educational needs in England: January 2017 (available at: <https://www.gov.uk/government/statistics/special-educational-needs-in-england-january-2017>)

Department for Education, (2017b). Revised GCSE and equivalent results in England: 2015 to 2016 (available at: <https://www.gov.uk/government/statistics/revised-gcse-and-equivalent-results-in-england-2015-to-2016>)

Department for Education, (2017c) Permanent and fixed-period exclusions in England: 2015 to 2016 (available at: <https://www.gov.uk/government/statistics/permanent-and-fixed-period-exclusions-in-england-2015-to-2016>)

# REFERENCES

- Howlin, P., Moss, P., Savage, S., & Rutter, M. (2013). Social outcomes in mid- to later adulthood among individuals diagnosed with autism and average nonverbal iq as children. *Journal of the American Academy of Child & Adolescent Psychiatry*, 52(6), 572-581.e571.
- Humphrey, N., & Hebron, J. (2015). Bullying of children and adolescents with autism spectrum conditions: A 'state of the field' review. *International Journal of Inclusive Education*, 19(8), 845-862.
- Leyfer, O. T., Folstein, S. E., Bacalman, S., Davis, N. O., Dinh, E., Morgan, J., . . . Lainhart, J. E. (2006). Comorbid psychiatric disorders in children with autism: Interview development and rates of disorders. *Journal of autism and developmental disorders*, 36(7), 849-861.
- Ryan, S., & Cole, K. R. (2009). From advocate to activist? Mapping the experiences of mothers of children on the autism spectrum. *Journal of Applied Research in Intellectual Disabilities*, 22(1), 43-53.
- Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child & Adolescent Psychiatry*, 47(8), 921-929.
- Taylor, J. L., Henninger, N. A., & Mailick, M. R. (2015). Longitudinal patterns of employment and postsecondary education for adults with autism and average-range iq. *Autism*, 19(7), 785-793.