

**Making the difference for  
autism inclusion , challenges  
and opportunities**

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# Today's presentation

- Autism and neuro diversity issues have an increasing public profile. This presentation looks at the issues and challenges for different groups of young people across the continuum , where we are now and what the opportunities are for a truly inclusive society.

# The challenges

- Issues of diagnosis
- Understanding girls
- The “othering” of people with complex needs

# Challenges at diagnosis

- Latest NHS statistics show that over 140,000 people are currently waiting for an Autism assessment
- In some areas children can wait over 3 years
- Is the diagnosis itself an issue or the fact it is needed to unlock support ??

# Expanding the Diagnosis: Needs Led Diagnosis

*“There is a need for Keyworkers for all complex children”*

## Response:

Diagnosis was a key factor across the board where it was felt:

- there was a major delay in a formal diagnosis *“quite a lot of young girls generally who are not yet diagnosed...in a significant element of crisis”*
- there needs to be a shift from a diagnosis lead to a complete needs lead system.

There is a strong sense of a diagnosis being *“just a bit of paper”* that *“means nothing”*

# Issue for girls and women

- Emerging evidence of masking and poor recognition
- Evidence of girls who are cognitively able falling out of the mainstream school system
- Changing nature of the Transforming Care Programme and patterns of in patient care

# National Safeguarding Review into children with disabilities and complex health needs.

- **Purpose and focus of National Review** This review will examine the experiences of children placed in Fullerton House, Wilsic Hall and Wheatley House, and how agencies acted to ensure the rights, voices, and needs of children placed there were respected and addressed.
- The key lines of inquiry below have developed from initial evidence; they will be further developed with the appointed reviewer(s) and as the review begins to consider cases involving individual children.
- **Key Lines of Inquiry**
- How were children placed at Fullerton House, Wilsic Hall and Wheatley House, and what procedures and practices were in place to ensure that they were safe and well?
- How was the quality of care for each child kept under review?
- How did concerns arise and what was the quality of the response?
- Is what happened to these children reflective of practice more generally and how could the safeguarding system be improved?

# Key conclusions in Phase 1

- Children were placed significant distance from home and in settings that did not meet their needs.
- There was practice, regulatory and quality assurance failure at all levels and this allowed abuse to flourish.
- The workforce at the settings was not managed, supported and trained in a manner that enabled children to thrive.
- Concerns were raised, but these did not give rise to thorough investigations that might have prevented further abuse.



# Areas for recommendation

- For children to have advocacy and children and families to have information and support
- Much stronger links to DSR processes
- A challenge to make these children a shared multi agency responsibility with guidance that underpins this

# Areas for Recommendations 2

Key recognition of workforce challenges both for community services and within residential settings

Over half of these children should and could have stayed at home with better multi agency community support so clear need to understand that development

We do not have effective commissioning strategies for these children , locally, regionally and nationally

Clearly QA is not working effectively , so need to look again

# How about opportunities !

- Across the country, young disabled people are leading the way in their chosen field of expertise. We know that they are ambitious and work immensely hard to achieve their goals, as well as having a positive impact on their community. We don't hear about their successes often enough. Their achievements should be celebrated and their skills acknowledged. Having spent most of my own working life focused on improving outcomes for disabled children and young people, I am consistently inspired by young people's determination to create change, often in the face of great adversity

- Their stories will inspire the professionals working in our schools, colleges, and care settings, but should also show how important employers can be in all of our lives. We should have the highest aspirations for our young people. Dan Watkins, one of the young people featured , says, “everyone should feel wanted, valued and part of something special. There’s a place for everyone in the community.” We still have a long way to go in creating a world that is accessible and inclusive for young disabled people, and we will maintain our commitment to that objective.

# Tomorrow's Leaders

<https://councilfordisabledchildren.org.uk/help-resources/resources/tomorrows-leaders-world-beyond-disability>



**TOMORROW'S LEADERS  
A WORLD BEYOND DISABILITY**

The Education and Training Foundation (ETF) and Council for Disabled Children have published: Tomorrow's Leaders – A World Beyond Disability.

This exciting new publication profiles the achievements of over 30 inspirational disabled young people who are leading in their communities, with ambition, hard work and dedication to improving society.

# ANDREW SMITH

- Andy is an Inclusion Ambassador/SEND Advocate for Bury Council.
- His passion for ensuring that young people's voices and views are heard has led to him creating the world's biggest consultation of autistic children with over 2,900 responses and this being shared as a manifesto of top 10 priorities for autistic children. In addition he then made a rap video of the responses to the survey which has had over 150,000 views.
- Andy's experiences at school and later at university made him realise that he'd been trying to fit in and be like everyone else rather than accepting and valuing his differences. The real turning point was when he shared how he was feeling on Twitter resulting in responses from dozens of autistic people. His perspective changed from 'I need to be like everyone else', to 'I have to live a different life to everyone else, but that doesn't mean it has to be an unhappy one'. I
- have one goal in life that is more important than anything else: making sure as many SEND young people avoid the challenges mine and previous generations of disabled people have faced

# Andrew Smith

- Since then Andy's life has transformed, now in his spare time he:
  - Co-chairs the North West SEND Young People's Coproduction Steering Group
  - Created and chairs the Greater Manchester Selective Mutism Network
  - Participates in The Autistic Cooperative, a network of over 600 autistic advocates
  - Is a neurodiversity ambassador at the ADHD Foundation
  - Helps to run, set up and support SEND young people to attend inclusive local social groups.

# AARON EVANS

- Aaron is a Young Consultor for the self-advocacy group, Our Way.. He is often asked by schools for his advice to help improve their ways of working and create changes that promote inclusion. He is a fantastic public speaker and has been delivering assemblies on disability awareness and anti-bullying to hundreds of students in local schools.
- As a young person delivering assemblies, speaking confidently and sharing their own experiences, Aaron has had a huge impact, inspiring the young people who hear him. Aaron attended Kidderminster Academy where teachers recognised his strengths and worked with him to achieve his aspirations. The young people in the assembly really pay attention and listen to a young person. They admire the guts it takes to stand up on a stage and speak out loud My life goal is to help kids and adults with Autism and Learning Disabilities to have a better life and not have to go through the same struggles as I did



## Some more quotes from the Tomorrow's Leaders...

Everyone should feel wanted, valued and part of something special. There's a place for everyone in the community



Never be ashamed of being different: it is this difference that makes you extraordinary and unique



I'd like to pass on to younger people, the empowering possibilities of working in disability whilst disabled and owning your identity to empower you to succeed. We offer a unique perspective on inclusion and our voices are needed to shape the future of education and care

I want to encourage young disabled people to aspire to become elite athletes, by not placing limits on themselves, and by feeling confident to ask teachers and coaches to have high expectations of them and to create opportunities for them to compete



## Learning for Further Education providers from the Tomorrow's Leaders project...

Out of the **39** young people featured in Tomorrow's Leaders - A world beyond disability only **56%** mentioned their FE provider as playing a part in their journey to success.

Of those, **68%** were positive about their experiences while the remaining **32%** highlighted some of the things they wished had been done differently.



“ This is something that I was always told would not be possible ... so it is amazing to prove them wrong!

Young person, reflecting on studying at University



Words used by young people to describe the way FE staff supported them well

“ I had a really great experience in high school because the school, my mum and me worked together and they understood how to help me be the best I could be.

“ I would have had disabled role models and examples of disabled people living, working and in relationships or with children perhaps, to show me that I could lead a typical life if I wanted to.

“ I face and observe others facing, professionals undermining their ability: too willing to disregard opportunities rather than making them accessible.

**100%** of those young people who had a positive experience in FE described the tailored, individual, person-centred support they received as contributing to their achievements

### What did they like:

- ★ Schools, FE providers, parents and young people all working together to understand what support they need
- ★ Appropriate reasonable adjustments including:
  - ◇ the correct tools (hardware and software)
  - ◇ learning support
  - ◇ personalised academic and career guidance
- ★ Promoting independence including:
  - ◇ Job coaches
  - ◇ Travel training
  - ◇ High aspirations
  - ◇ Being treated with respect and understanding
- ★ Dedicated support and consistent relationships

### What could be better:

Remember, what works well for one young person may not work for another...

# Examples from the workplace

- **Working with NIB**
- **Aviva**
- **Deloittes**
- **From Classroom to Boardroom !!**
- **Developing practice at NCB**

# Background to the 'ND At Work' Study

- NiB partnered with Birkbeck, University of London (Centre for Neurodiversity at Work) on an academic study led by Professor Almuth McDowall and Dr Nancy Doyle. This research initiative was the first of its kind to contrast supply and demand to provide meaningful insights into:
  - Challenges for corporations and businesses when integrating neurodiversity into their diversity, equity, inclusion and accessibility strategy as well as examples of good practice
  - Challenges for neurodivergent people at work and examples of effective support
- The results will support ND individuals to better understand how corporates are implementing neuroinclusive support strategies and areas for improvement in their workplaces. The data will help organisations to understand the challenges of implementing inclusive practices to support their ND employees to strengthen:
  - Effective neuroinclusive support strategies and data on current sector practice, including challenges to implementation
  - Development of resources and guidance on neuroinclusion best practice
  - Future research priorities

# Developing resources



# Examples from the workplace

- **Working with NIB**
- **Aviva**
- **Deloittes**
- **From Classroom to Boardroom !!**
- **Developing practice at NCB**



*"The greatest danger is not that our aim is too high and we miss it, but that our aim is too low and we hit it"*

Michelangelo

