

Being Well Informed can be Scary but it has Never Been More Important – PACC Blog

It has been a difficult few weeks for families supporting children and young people with Learning Disabilities and/or Autism. A number of pieces of information have been published that are understandably worrying for these families, but even when it is hard to hear, it is important to understand what the realities of their children's lives might be. If families understand and are aware of this, it places them in a better position to change things and to ensure that their child has the chance of having a good experience of care. It is scary to know that our children might be more vulnerable, but it also gives us a better chance to make sure they are well looked after by those we trust to care for them.

At the end of October, the Care Quality Commission published their report Out of Sight – Who Cares. You can read this national review of restraint seclusion and segregation for autistic people, people with learning disabilities and / or mental health condition [here](#).

The report shares a disturbing picture of the systems failure to deliver quality support to the autistic and learning disabled community. This failure impacts all ages and reflects a long-term lack of investment in developing quality, person centred services at a community level, resulting in individuals experiencing inappropriate long term stays in hospitals, where they are too often subject to restraint, seclusion and segregation. People get 'stuck in the system' because the right support isn't available in their community, close to family and friends.

Autistic people, people with Learning Disabilities and/or mental health conditions often have complex needs that require careful consideration and understanding of how best to support them, yet too often they find themselves in unsuitable environments, that are noisy, chaotic and overwhelming. This lack of a therapeutic approach inevitably triggers behaviour that challenges, and the report states individuals become seen "as a condition or a collection of negative behaviours".

This situation is sadly not a new one and while not enough has been done, work under the Transforming Care Programme, now called the Learning Disability and Autism Programme, has started to address some of these failings. In Shropshire, PACC has recently joined the local Learning Disability and Autism Programme board and is pushing for early intervention at a community level, so that families and young people receive the support they need before they reach crisis point. We are also working to improve transparency in the system so that families know where to go when they need help, as well as ensuring that services are responsive to them. The Shropshire Written Statement of Action identified the failings of the local Autism / ADHD diagnosis pathway and ensuring that this is addressed is a key priority in Shropshire.

One of the major issues is that too often young people fall through the gaps of a failing system and opportunities to intervene early are lost. Local areas are now required to maintain a Dynamic Support Register (DSR), which should record any young person with a Learning Disability and/or Autism who is at risk of going into crisis, which may result in a hospital admission or an out of county placement. You can [find out more about the DSR here](#).

If a young person with a learning disability and / or Autism goes into crisis then a Care Education and Treatment Review (CETR) should be considered. This is a meeting that brings all those involved in a young person's care together, with a person-centred focus on the needs of the young person and their family. Data shows that where a CETR takes place in the community, then in over 80% of cases an admission to hospital is avoided. [You can read about CETR's here](#).

In addition to the CQC review the Government has recently responded to the 'Joint Committee on Human Rights reports on the Detention of Young People with Learning Disabilities and/or Autism and Human Rights and the implications of the Government's COVID-19 response'. In this response the Government accepts numerous recommendations made in the report. [You can read the response here.](#)

More recently Adults with Down's Syndrome have been added to the Covid 19 Extremely Clinically Vulnerable list and Public Health England published a report which was a review of available data on the deaths of people identified as having learning disabilities in England during the COVID-19 pandemic. [You can read more about it here.](#)

In both cases this information was scary reading, but forewarned is forearmed. After initial confusion, families supporting young adults with Down's Syndrome were advised to seek individual medical advice and colleges started to complete individual risk assessments, ensuring that each young person could receive the support they needed.

The Public Health England report highlighted the impact of something that is already well known, autistic people and people with learning disabilities and/or mental health conditions, experience poorer health outcomes throughout their lives. It highlights that Covid 19 is happening in a wider context, as the blog from VoiceAbility stated *"This isn't because the virus targets people with learning disabilities. It is because we are failing as a society to take enough action to support the health and wellbeing of people who are at the sharp end of structural and health inequalities."* [You can read the VoiceAbility blog here.](#)

Meeting the physical and mental health needs of autistic people and people with learning disabilities and/or mental health conditions, has never been more important. Families need to be supported to do this from the earliest point and the health system need to be challenged to change. GP surgeries and hospital services should be accessible to everyone, opportunities and support to be physically active should be available for all and not just some, and nobody should feel excluded from their community and not valued for who they are and what they can achieve. Understanding and knowing that this isn't happening yet is an important step along the way.

This work will be a major area of activity for PACC over the next 12 months and we will keep you up to date on progress and any new proposals. If you would like to know more about any of the above please do get in touch. If you have experienced any of the above and are struggling to secure the right support please also contact PACC and we will do our best to help.

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