

Future of Social Care Commission - West Cheshire Autism Hub

West Cheshire Autism Hub opened its doors in May 2021 (mid-covid). It currently has three dedicated staff, and a handful of volunteers. Between May and December 212 autistic adults engaged with the Hub, some briefly and some at length, but with some notable common themes for the Social Care Commission.

The NHS Transforming Care programme in 2015 recognised that autistic people made up a disproportionate number of the places in mental health hospitals, at significant cost. In particular this was the case for those **without** an accompanying learning disability (previously labelled 'high-functioning'), and since the programme these numbers have continued to increase (Assuring Transformation NHS Digital Data December 2021).

The Autism Hub was set up in recognition of this: with the aim to support those who fail to meet thresholds for care. This often starts in school when academic intelligence prevents them from securing support, and then progresses into adult life where they struggle to maintain friendships, relationships, tenancies, paid work and as a result their mental health declines. They are extremely vulnerable to exploitation.

Of the 212 individuals who have contacted the Hub most have difficulties managing day to day living, with 23% having significant difficulties. These manifest in consistent ways:

Poor mental health
Poor self-care (including poor nutrition)
Unemployment
Debt
Threatened tenancies and/or homelessness
Exploitation

Staff and volunteers at the Hub are clear that these are people who have always needed a level of care and support. Without this care their lives quickly spiral into significant difficulties and often full crisis, resulting in referrals to high cost services. A low level of care and support earlier would prevent this crisis.

The key issue here is that these people present as superficially independent. Often articulate and highly intelligent, their care needs go unnoticed by those who 'gate keep' services and support. There is a clear need for care and social work professionals to be trained to identify those who are vulnerable in this way. It is apparent that the care system and services consistently fall short, in terms of meeting the needs of this cohort.

Some examples that we have come across:

A is in his 30s and has a first class honours degree in mathematics and physics. He presents as extremely articulate and friendly. He has however failed to maintain friendships and also to access paid work, although he continues to try. He is heavily dependent on his Mum, who lives some distance away for day to day advice. He struggles with his mental health. He admits to regularly not eating and rarely sleeps well. He accesses voluntary sector mental health services in the community, but continues to struggle. He has 'masked' all of his life, so his needs are now underestimated by his continued 'masking'.

B also in his 30s, is also highly intelligent. He is articulate, but when stressed his speech becomes unintelligible. When he is overwhelmed he paces and talks to himself. This has resulted in a number of cautions and arrests for being apparently under the influence of drugs or alcohol - he wasn't. He spent most of his life in care

after childhood abuse. B has been exploited financially in the past and presented to us at the point of eviction. Over time it became apparent that he was being exploited by his landlord, and the Hub have been supporting him to move somewhere more suitable. Only by the Hub advocating strongly for him, was it recognised that he needed a low level care setting - finding somewhere however, is proving difficult. On entering his current home, support staff found he had little furniture or possessions, few clothes and no food. He is unable to plan, shop and cook without support.

C is a qualified electrician, who used to be the 'star' employee on the building site, as he could wire and certify houses quicker than anyone they'd ever come across. When he was employed C had his own rented home, set up the way he liked it. He has high sensory issues and OCD around cleanliness. Through unemployment, anxiety and deteriorating mental health, he ended up homeless. C has since lived in three homeless hostels which is exacerbating his mental health issues. C likes to live healthily, he doesn't drink, smoke or take drugs, but he is surrounded by people who do. He was removed from one hostel due to stuffing a towel under his door, and therefore being accused of smoking in his room - he was in fact trying to block out the smell of cannabis from outside his room. He likes to cook, but is unable to use the unsanitary shared kitchen due to his sensory and OCD issues. When he tried to use cooking equipment in his own room, the equipment was removed. When he left cooking equipment in shared areas it was stolen. Some days he presents well, on other days he doesn't. He will only access the shared bathrooms if they've been recently cleaned. C states 'if I am in control of my environment, I can move mountains. In the hell hole I live in now, I just can't function, I don't eat for days'.

There are many more of these cases. Often apparently capable individuals, can't plan ahead, can't manage money and can't cook. There is a distinct difference between expressive and receptive communication ability, which is frequently not appreciated. For example, an autistic individual may be able to express themselves at times verbally, but this can hide a need for extra processing time and difficulty remembering information. Their level of disability is in effect masked by their verbal ability. Even those individuals who are independent, can quickly deteriorate to the point of complete dysfunction if they become overwhelmed. It is well documented that autistic people's functioning level drops as stress increases. Autistic burnout is a

frequently experienced phenomenon which can lead to a loss of skills. Many autistic individuals report at least one period of autistic burnout in their life experience. It is characterised by:

“complete exhaustion, a loss of executive functioning and a reduction in personal care, plus their ability to cope with sensory stimuli and social interaction”. (Boren, 2018 cited in McGuinness, 2021, p. 60).

In C’s case above, he went from complete independence to being unable to wash and eat.

There appears to be a need for greater understanding of the needs of autistic adults in the care system. The effect of masking, anxiety and sensory issues are underestimated. Training for social workers and care staff is desperately needed. Looking through the autistic lens often generates strategies and avenues of support. Furthermore,

“The greatest test of empathy is to: to understand the world of someone unlike you.”
(Lipsky, Richards, 2009, p. 64)

Many of these adults need a low level supported care environment. They need small touches of practical support, protection from exploitation, and their own front door. However these settings aren’t out there. These adults are considered too able for supported living, so often end up in social housing in challenging areas, where they become exceptionally vulnerable to exploitation. County lines gangs are known to target such vulnerable young people and adults, and cuckooing is common (whether blatant or veiled as a relationship).

In the experience of the Autism Hub staff, these adults are seen as capable and left without support. The truth is that they’re not, and without support they end up in crisis, at significant cost to themselves, the purse and society.

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