

# Observations for Learning Disability/Autism Social Care

## Social Care Commission 2022

In addition to my role as the parent of a 24 year old with LD and Autism, my 'day job' for the last 20 years has been working in disability services in CWAC and Cheshire East, both with children and adults. I have led support groups, been on the steering group for the Parent Carer Forum, and was one of the first volunteers to be trained for the now Information Advice and Support Service. I was on the interview panel for the Project Lead of Aiming High for Disabled Children, and have managed short breaks services for over 10 years. In these roles I have supported many young people and their families through their transition to adulthood, and have witnessed the resulting outcomes.

My observations and thoughts on adult social care for this group are:

- Parents now increasingly have an expectation that their disabled young adults will live independently and work. This is a change from the days when parents looked after their 'children' for as long as they could and then handed over to siblings or institutionalized care.
- Schools (particularly special schools) focus heavily on life and work skills as their students approach adulthood. Outcomes and targets set for preparation for adulthood are rightly increasingly aspirational.
- SEN students are therefore also increasingly aspirational, with most students expecting to leave home and work in the same way as their siblings do.
- Many of these young adults are expressing a wish to have their own front door - moving away from the more established model of shared houses. However we currently have very few supported living arrangements of this kind.

- Choice of location is very limited, often meaning young people start their independent lives away from familiar communities and family.
- Current supported living arrangements and social housing (with domiciliary care) are often in challenging areas. Whilst this means the property is economical to buy/rent or build, it leads to inevitable issues around vulnerability and abuse, and the crisis costs associated with it.
- In my opinion social care focuses too strongly on elderly and multiple/complex needs support, to the neglect of those with less obvious but nevertheless significant needs. See below.....
- In my role as a volunteer at the West Cheshire Autism Hub, we see on a daily basis the difficulties faced by those who present as 'independent', but who absolutely aren't. Threatened tenancies, homelessness, debt, cuckooing, theft, abuse and spiralling mental health issues have all been seen in just a few months. These adults can present as very competent, but with just a few questions it is easy to establish their inability to cook properly, keep a property clean, deal with often unprofessional landlords, plan and budget financially, keep themselves safe, and their extreme vulnerability is all too obvious.
- Those with autism, Down Syndrome and other genetic syndromes, learning disability, ADHD and more can present as not needing high levels of care. With good preparation from parents and schools many can and should be taught life skills which point to independent living - this does NOT mean they don't need care and protection. Why are they an afterthought?
- My own experience over many years of watching young people transition to adulthood, is that those with multiple and complex needs have not been the ones who have had poor outcomes or ended up in crisis. It is those who are assumed to need little or no care, who have often ended up with particularly poor outcomes. Within my son's very limited friendship group from school, two are currently in prison, one has just transitioned out of a long spell in a secure mental health unit, and another has finally settled into a community home

after years in ATUs hundreds of miles from home. All of these boys presented as 'capable' and I believe their outcomes were as a direct result of their needs being underestimated. How much have their deplorable outcomes cost?

- The care industry is currently too provider led. Social Workers are often swayed by the views of care providers, who are judged on their delivery of progression, and who profit from higher level care packages. No wonder then that adults are moved out of supported accommodation into social housing, with limited support, at every opportunity saying their needs aren't high enough - it's in the provider's interests to do so. Often parents, carers and others who know these people well are not listened to. If the provider says they are independent, that is taken as read, but is often not the case. Care should be assessed and led by social workers and those who know the adults well - not care providers.
- Sometimes what appears to be independence, is not as it appears. A common issue with autism is the adult who can handle cash (but can't calculate change), or who can use a bank card but has no idea what their income and/or budget is, or the person who can shop for food in a supermarket, but buys all premium products because that's what they recognise, and buy far more than they need as they don't understand relative size and value. That quickly causes serious financial difficulties.
- There is a need for care settings for disabled adults who have lower day to day care needs, but who need access to care as and when they need it on an 'on-call' basis, as well as protection and welfare checks due to their vulnerability. Often these adults are able to manage 'the basics', but will struggle if something changes or is a little more out of the ordinary. Examples would include: needing to change the heating timers in summer/winter, an electricity cut, setting up utilities, being ill, a hospital appointment, buying presents for family, correspondence etc.....and these will not be solved by a telephone helpline!

- We can and do deliver the model above in elderly care settings in retirement villages - people who may only need touches of support, and some who need a little more, some who only need support to go out into the community, or when something goes wrong - we know this works, so why can't we do it for this group?
- Mental capacity remains a troubling issue. Whilst care providers and social workers must respect the capacity of adults to choose their own pathway, aspirations and wishes, they also need an eye for those who are not self-aware enough to understand their own limitations and difficulties. This is particularly true of the younger people coming up through the system, whose aspirations are higher. It's a balancing act.
- With increasing numbers of people in social housing with domiciliary care, we do need to address poor training and often unreliable providers. Carers simply not turning up is just far too common.
- We need to not just look at care delivery in this commission, but also look at where else funding ends up being used. How often are we having to defend legal challenges which should never have happened? How many people are in receipt of high level care that they may no longer need? How much are we spending on crisis management and why? Where potentially could we reduce costs, by getting it right or preventing crisis?

[name and address supplied]