

HD 16

Rôl awdurdodau lleol o ran cefnogi'r broses o ryddhau cleifion o'r Ysbyty

The role of local authorities in supporting hospital discharges

Ymateb gan: Cymdeithas Genedlaethol Awtistiaeth

Response from: National Autistic Society

About autism: Autism is a lifelong disability which affects how people communicate and interact with the world. There are over 700,000 autistic adults and children in the UK. Without the right support or understanding, autistic people can miss out on an education, struggle to find work and become extremely isolated.

About us: The National Autistic Society is here to transform lives, change attitudes and create a society that works for autistic people. We transform lives by providing support, information and practical advice for the 700,000 autistic adults and children in the UK, as well as three million family members and carers. Since 1962, autistic people have turned to us at key moments or challenging times in their lives, be it getting a diagnosis, going to school or finding work. We change attitudes by improving public understanding of autism and the difficulties many autistic people face. We also work closely with businesses, local authorities and government to help them provide more autism-friendly spaces, deliver better services and improve laws. We have come a long way but it is not good enough www.autism.org.uk

The National Autistic Society welcomes the opportunity to respond to the Local Government and Housing Committee's inquiry into the role of local authorities in supporting hospital discharge. Our focus in this response concerns the specific group of autistic people who are detained in Mental Health Units, often for years at a time. We are supportive of the aims and objectives of the 'stolen lives' campaign, and are also involved in the Welsh Government's Task and Finish Group that aims to provide recommendations to resolve this issue.

However, despite our focus being on this issue, we should note that autistic people can also face the same delays in being discharged from hospital that other groups face. Autistic people can also find these delays even more damaging, as often hospitals are not the most suitable environment for autistic people – they can be noisy, have excessive lighting, can be over-crowded, staff are not always trained to understand autistic people, and they are unfamiliar places. If it is not medically necessary for an autistic person to be in hospital, then the health service and local authorities should be prioritising ensuring suitable care and support in their community is available.

The issue of autistic people being detained in Mental Health Units is a human rights issue. The recent cross-party debate in the Senedd¹ highlighted the strength of feeling amongst all political parties that this issue must be seen as such an issue. The debate heard many stories from the families of autistic people and/or people with a learning disability about the experiences of their loved ones, with many people spending years of their lives detained in Mental Health Units and environments that are not suitable for autistic people. The experiences of those families highlighted that there are many barriers that must be addressed if we are to ensure that detention in mental health

¹ See <https://record.assembly.wales/Plenary/14208#A92593>

units is only used when necessary, offers high quality adapted support from staff who have been trained in autism, is as brief as possible, and prevented from happening again by ensuring the community support services are in place.

Local Authorities can play a key role in helping to realise that aspiration. They have responsibility for social care and putting in place care packages that can enable speedier discharges from mental health units and help to prevent those people from needing to return. They also play a key role in housing policy, and arranging suitable accommodation can often be the key factor in supporting a person.

But there are many barriers that prevent Local Authorities from being able to fulfil their responsibilities and ensure the smooth running of the overall system. These are as follows:

1. Lack of data

One of the asks the Stolen Lives campaign made was for better data. As a result of this, the Welsh Government announced in the debate that in October 2024 there were 140 people with a learning disability receiving care in an inpatient setting (22 in England). However, this data is not published regularly and does not include autistic people who don't have a co-occurring diagnosis of learning disability. Furthermore, the existing data on 'pathway of care delays' that is published only covers the overall picture – it is not possible to use that data to specifically measure within mental health services performance over a period of time, the reasons for the delay, and whether geographical variations exist (which you can do for the overall hospital system).

The lack of ability to scrutinise progress on this issue, and to pinpoint where specific problems may exist, is a barrier to resolving the issue. The National Autistic Society therefore recommends that better data is collected and regularly published on this issue down to local authority level. Such data needs to include: autistic people, autistic people with a learning disability, breakdowns by gender, age and ethnicity, the length of time they have spent waiting to be discharged, the legal power under which they are detained, the reasons for the delayed discharges, and where they live and are currently treated.

2. Financial (actual and mental models)

The main barrier that is regularly highlighted as a factor in delayed discharges from mental health units is the lack of appropriate community support. Understandably many clinicians do not want a person being discharged into an unsafe situation. It is well-documented that local authorities have faced considerable financial challenges over the past 15 years, and may continue to do so. This evidently has an effect on the number of people who can be supported and the quality of that care, with eligibility criteria being pushed up in some areas². Unfortunately, this means that people who have not yet reached crisis often do not get their needs met. Therefore, their health

² See <https://www.gov.wales/sites/default/files/statistics-and-research/2019-07/160218-evaluation-autistic-spectrum-disorder-strategic-action-plan-en.pdf>

may deteriorate to the stage where admission to an inpatient mental health unit is necessary. The financial pressures also mean that local authorities can struggle to ensure care packages are available when a person is ready to leave a mental health unit and be supported in the community. This can mean a person stays in such a unit for longer than necessary, risking their health deteriorating further from being in the unit and away from their family.

But perhaps more significantly than this is the silo thinking and short termism within the system. Those with expertise in the system implicitly understand that the overall cost to the system of having autistic people spending years in inpatient units is considerably greater than had those people been properly supported in the community. This is both in terms of the direct cost of providing services, and the indirect costs of the lost economic contribution that autistic people could have made with proper support. However, far too often individual commissioners and finance departments are too often focused on short term financial considerations to their own budgets, rarely making decisions with the overall financial health of the system in mind. Even merely focusing on local authority budgets, it is often the case that one department making a saving by reducing care merely leads to other departments facing the bill. As one participant told the recent Cross Party Autism Group, there is no resource for keeping things right but resources are always having to be found for when things go wrong.

These issues are by no means confined to this specific policy issue, and tackling the overall problem of short termism and silo thinking may be beyond the scope of this inquiry, but it does need to be noted. The National Autistic Society recommends the Committee examines this issue and gets a proper look at the costs to the whole system of delayed transfers compared to the cost of funding community care services that both prevent the need for inpatient treatment and can enable faster discharge of people from those settings.

3. Lack of suitable housing

The social housing shortages in Wales have been well-documented and are known. More specifically in relation to this issue, the lack of suitable accommodation is a known issue. Autistic people may require adaptations to their homes and supported living arrangements may be required for some (especially those with other conditions). The lack of such accommodation is often a significant barrier, with autistic people facing long waits for suitable accommodation to be found. In the meantime, the person will remain in the inpatient setting.

The National Autistic Society recommends that as part of its wider plan for increasing social housing, the Welsh Government ensures that the need for adaptable homes and supported independent living/supported accommodation forms part of that plan. We recommend that local authorities, local health boards, and the Welsh Government share data to robustly map housing needs for autistic people now and in the future, including provision for those currently in mental health units. The Welsh Government should ensure funding is in place to meet this need.

In addition to these significant barriers at local authority level, we should also know that tackling the problem of delayed discharges must also involve

communication between public services, better availability of independent advocacy, and a society that works better for autistic people.

We also think the Committee should examine the proposed changes to mental health legislation that the current Mental Health Bill in the UK Parliament would introduce. Our recent Cross Party Autism Group meeting heard many concerns that the Welsh Government and Local Authorities are not prepared for these changes, and new duties that may result from it. Without better preparation and investment in community-based care services, autistic people may continue to have their lives stolen and the aspirations of this legislation may not be met.

We are happy to discuss any of these issues further.

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