Intensive Support Teams and Alternative Accommodation

This is a write-up of discussions held during the Challenging Behaviour – National Strategy Group national meeting on May 1st. These discussions were facilitated by Wendy Ewins, a commissioner within Black Country Healthcare NHS Foundation Trust (which has implemented an effective intensive support team and crisis accommodation offer) and Polly Somervell, a family carer who is currently a project worker in the Black Country for the CBF's Forward Together project.

Participants in these discussions included family carers, support providers, housing providers, commissioners, learning disability nurses, psychologists, psychiatrists, legal professionals, researchers, VCSE representatives, and representatives from both adults and children's learning disability and autism services from local government/ICBs. Many attendees had direct experience of either working within or being involved in establishing/running an intensive support team/alternative accommodation setting, or of their relative using these services. Others shared experiences where the lack of these services led to negative outcomes for their relatives or for people that they have been involved in supporting.

Key Findings

- Intensive support teams and alternative accommodation can provide effective support to children, young people and adults with learning disabilities and/or who are autistic in the community, helping to prevent them from being admitted to hospital
- Intensive support teams and alternative accommodation are viewed as 'safety nets' by social care providers and families and increase their confidence in their ability to support the individual/their relative (which in turn has contributed to the individual being able to remain supported in the community) – this confidence is enhanced by measures such as 24/7 commissioning
- There is tension between pressures to ensure maximum efficiency and avoid voids/times where services are running 'under-capacity' (which are seen as not cost-effective), and the need for alternative/crisis accommodation to be available to the individual at the point of need (which necessitates being empty when not in use)
- Intensive support teams and alternative accommodation need to be viewed as parts of a wider system, rather than as panaceas in themselves – in particular, they should sit within a wider community offer that includes a skilled, resourced community learning disability team

Key strengths of intensive support teams and alternative accommodation

Safety nets/reducing perceptions of risk

Intensive support teams and alternative accommodation offers are seen as 'safety nets' by providers and families, which increases their confidence in supporting the individual/their relative.[1] Providers and families feel that they are not alone and that they are not wholly responsible for risks, as there is something to fall back on should things go wrong, which in turn means that they feel confident to continue supporting someone with a learning disability/who is autistic when without this safety net they might feel that they could no longer offer this support. Attendees highlighted examples from their own experiences where the presence of these safety nets have prevented individuals from being admitted to hospital.

Conversely, providers that attendees had spoken to had stated that they would not be willing to work in areas where there are not these 'safety nets'/where the provider feels that they would be solely responsible for holding risks. This suggests that creating an environment where a provider feels confident that they will receive support from e.g., commissioners if it is needed is a key factor in ensuring that there is sufficient community support within an area.

> *"If they feel that it isn't going to be a collaborative, supportive situation to work in, I've heard people say we would never accept business from that local authority or that team, because we know that as soon as there's difficulty, they'll just wipe their hands and say 'it's your fault'."* - Social care professional

Enablers – what makes intensive support teams and alternative accommodation work

24/7 commissioning

Commissioners in the Black Country are on-call 24/7, meaning that they can be contacted e.g., during the night or at weekends. Alongside enabling support to be provided in times of crisis, for example if an individual needs to use a crash pad (alternative/crisis accommodation service) at short notice in the middle of the night, the response from

[1] This aligns with feedback on intensive support teams provided to Skills for Care as part of their DHSC-commissioned research to find out what social care providers, commissioners, user-led and Deaf and disabled people-led organisations know about the Bill and how ready they feel for the changes it will make

providers and families in the Black Country indicates that this has improved their confidence in providing support to individuals as it has reduced the amount of risk that they need to hold.

Attendees highlighted that in other areas, a barrier to intensive support teams operating at full effectiveness is that they do not operate out of core hours, which means that they are not able to react if there is a problem at e.g., 5pm on a Friday. Crises can happen at any time and if an individual needs additional support (e.g., a safe place to stay outside of their home) outside of core hours, if commissioners cannot be contacted, they are likely to be admitted to hospital. The presence of 24/7 commissioning as is in place in the Black Country overcomes this issue.

Feedback shows that knowing that they would be able to contact someone should something go wrong 'out of hours' has enabled providers/families to continue providing support over weekends when previously they might have felt that they were unable to do this with confidence as if something went wrong they would not be able to seek additional support. This links with the finding that having a 'safety net' and a collaborative/supportive culture within an area is a key factor in ensuring that there is the right support, and suggests that the presence of 24/7 commissioning can contribute to developing such an environment.

Integration with community learning disability teams

Attendees were clear that intensive support teams and alternative accommodation need to be considered as parts of a wider system of support, rather than as a solution in and of themselves. Some attendees also highlighted that in places where there is a highly-skilled, well-resourced Community Learning Disability Team (CLDT) with sufficient local infrastructure, it is not always necessary for there to be a separate IST as the CLDT is able to provide the needed support – they emphasised that developing ISTs should not come at the cost of resourcing CLDTs. While highlighting the ways in which ISTs can be beneficial, attendees made clear that they should be embedded in wider community services like the CLDT, with senior leadership working across both the CLDT and IST – this provides continuity of services and leadership, ensuring both that staff and services are working jointly rather than separately and that individuals and their families are able to build relationships with professionals.

Monitoring outcomes

Drawing on work that has been done around outcomes monitoring in the Black Country, it was suggested that it would be beneficial to capture outcomes for people on dynamic support registers that relate to housing and use of alternative accommodation. Attendees

highlighted that it is not enough to monitor whether or not an area has an alternative accommodation offer, it is also important to be monitoring the experiences of individuals within the area – for example, have they needed to use alternative accommodation, and if so was this because their housing situation broke down in a potentially preventable way?

Barriers – what factors prevent intensive support teams/alternative accommodation working effectively

System pressure to avoid voids

Commissioners/ICB and local authority representatives stated that they face pressure to avoid voids (times where accommodation is empty) due to its perceived cost-ineffectiveness. However, for alternative accommodation to be effective in preventing an individual being admitted to hospital, this accommodation needs to be available at the point that the individual needs it, which attendees highlighted can be at very short notice e.g., in the middle of the night.[2] Attendees stated that, in order to be effective, alternative accommodation needs to be empty when it is not in use by an individual, so that it is available at this short notice. Examples were also shared where systems which use forms of alternative accommodation that are not kept empty in case they are needed, for example by using pre-existing respite and short breaks options, have been unable to access these at times when they are needed due to them already being in use by others, reducing their effectiveness at preventing admission.

Relatedly, attendees highlighted that providers also face pressure to avoid voids, raising the point that while the best way to provide support to an individual with a learning disability and/or who is autistic is small and personal, this also amplifies risks for providers. For example, if someone being supported in their own home by a small provider goes into hospital (even if this is for e.g., a physical health condition rather than a mental health hospital), any lack of payment during this time could badly impact the provider.

[2] Attendees highlighted that this is particularly the case for autistic people without a learning disability as the system may be less prepared for these individuals to reach crisis due to e.g., masking, whereas there can be (although are not always) earlier indications that someone with a learning disability might require these services in future e.g., the development of behaviours that challenge which indicate that they are not receiving the right support currently

Distribution/accessibility of funding

Attendees working within intensive support/community teams shared that in their experience, a barrier to being able to work successfully is that funding to do this work is split into different pots with different eligibility criteria. In particular, section 117 funding was raised – this funding can be used to provide support for an individual but it is only available once they have been into hospital.[3] For intensive support teams, this means that funding might be available to help prevent readmission, but not the initial admission.

Lack of awareness of intensive support teams/alternative accommodation

Family carers stated that information about intensive support teams and alternative accommodation is not accessible to them.

> *"It's often something you only find out about once you get into crisis… we don't really know what's out there until it's kind of too late."* - Family Carer

There needs to be further consideration of how information about these services can be better communicated to family carers of people with learning disabilities and autistic people.

'Hands-off' approaches

Attendees raised that teams that they had worked in/with were constrained by 9-5 working, as this does not reflect the need for intervention at any time. Attendees highlighted the need for teams to be on-call outside of 9-5 and at weekends in order to meet needs. Some attendees who had experience of working in/with these teams over a period of many years reflected that teams that they had worked with had previously been more flexible/more responsive outside of core hours and had also been more hands-on rather than behind the scenes, but in recent years this had changed and that this did not reflect what services/the workforce and individuals/families wanted from an IST.

Insufficient input from social care

Attendees stated that intensive support teams would benefit from working more closely with social care providers and skilled support workers. It was highlighted that ISTs do not always

[3] Section 117 funding will not be available to people with a learning disability and autistic people who do not have a mental health condition following the reforms to the Mental Health Act as this is not available to people who have been detained under section 2. Work is ongoing to

have significant social care input, which is a barrier to them working as effectively as possible.

One attendee currently working within an intensive/community support team highlighted that issues with accessing funding prior to an individual's initial admission into hospital is one of the barriers to working more closely with social care, as the funding to involve them is not available. A different attendee stated that skilled support workers within ISTs can play a key role as a team leader and a model of good practice for the individual's support team if needed.

Other related factors/points raised by attendees

During these discussions, attendees raised related points regarding:

- Transition to adulthood
- Separation of housing and support
- Home ownership to support quicker discharge
- House design
- Role of keyworkers
- Disjointed systems
- System values

<u>Transition to adulthood</u>

Family carers highlighted that respite services and short breaks are extremely valuable forms of alternative accommodation, enabling them to better support their relatives, but highlighted that children and young people often have greater entitlement to these services before losing eligibility as they transition from children's to adult services. This in turn increases the risk of crisis and the potential of an individual being admitted to hospital.

This links with other work that has shown that transition from children's to adult services is a danger point due to the 'cliff edge' faced by young people in terms of not being able to access services with continuity/the same levels of services.

<u>Separation of housing and support</u>

Attendees highlighted that one of the factors that increases the need for alternative accommodation is that in many cases (including residential care) both housing and support are provided by the same organisation. This means that, should there be an issue with the

support, e.g., the individual wishes to change support provider or the support provider is no longer able to meet the individual's needs, the individual will lose access to their home as well.[4] Attendees highlighted that ensuring that housing and support are provided separately can prevent a breakdown in support leading to the person losing their home, thereby reducing the need for alternative accommodation and/or admission to hospital.

Home ownership to support quicker discharge

Attendees highlighted that having the security of owning your own home, e.g., through the HOLD scheme, supports people to be discharged from hospital more quickly as there is a place for them to be discharged to (rather than needing to identify a place for them to live, potentially purchase it, make any adaptations). The most recent published data shows that a lack of suitable housing was a factor in 56% of delayed discharges.[5]

Attendees who had been involved in supporting discharge from hospital also shared experiences of people being discharged with a tenancy (e.g., into rented supported living/residential care) and then, if there were any issues during the settling-in period e.g., behaviours that challenge, they would be given 28-days' notice by the provider and end up back in hospital, whereas moving into an owned property reduced the likelihood of this occurring.

House design

A family carer described how their relative was being supported in a bespoke house, which incorporates a bungalow-style annex. This annex has been designed so that it can be used in a similar manner to a crash pad should it be needed, so that their relative can be supported in a familiar but separate space should this be needed. Their relative has previously been in hospital and this housing was designed as a measure to reduce the likelihood of future readmissions. Other attendees felt that this was an example of person-centred support and that lessons could be learned from how the teams and people involved

[4] This is exacerbated by the issue of 28-day eviction notices – for people with severe learning disabilities whose behaviour challenges, 28 days is not enough time to identify an alternative placement and ensure a smooth transition where the individual and the staff who will be supporting them can get to know each other. The importance of a smooth transition in these circumstances

[5] NHS Digital Assuring Transformation Dataset, March 2024, sheet 3.3; the questions relating to delayed discharge factors changed in the version of the Assuring Transformation questions used from April 2024 onwards, and the publication format has not been updated since there. Data is still being collected (Q48a-48c) and it would be useful to access/publish this to reflect on current factors that contribute to delayed discharge.

in this individual's care, including their family, had worked together to design housing that meets needs and reduces the likelihood of admission.

Role of keyworkers

Related to ISTs, attendees discussed the value of the keyworker role.

> *"I think they are an invaluable tool for families, who often are navigating a system, and are completely overwhelmed by everything that's going on. I was trying to spin a lot of plates at the same time, burnt out and worn-down by the system, and where the keyworker can add some real value is they're able to be that voice for the family where maybe they are not in a position to speak up for themselves."* - Family Carer

The interaction between the keyworker programme and intensive support teams was discussed, with support for ISTs and keyworkers working alongside each other. Attendees also suggested that a national job specification/revised policy for keyworkers would be beneficial – currently, the keyworker role can vary depending on where in the country they are operating and there is not sufficient clarity around their role and responsibilities. A professional working in a local authority stated that within their area, the recommendations and guidance from keyworkers do not seem to carry sufficient weight within the system, and stated that a clearer specification/policy would result in keyworkers having more 'clout'.

Disjointed systems

Related to the issue of lack of information, family carers stated that the siloing of different parts of the system is a barrier to their relative accessing the right support. This also relates to the points made by other professionals that there should be integration between ISTs and CLDTs, and that there should be greater input from social care professionals within ISTs.

Attendees highlighted that either they or families that they worked with had experienced systemic barriers when seeking support for their relatives. They drew attention to the issue of parental blame as highlighted by West Midlands ADASS's report on Autism and Parental Blame. Other useful resources on parental blame and the trauma caused by navigating the system, which also provide details of what a pathway should look like and how such a pathway could be implemented, include:

- Broken (Challenging Behaviour Foundation, 2020)
- A survey of complex trauma in families who have children and adults who have a learning disability and/or autism (Baker et al., 2021)

- Institutionalising Parent Carer Blame (Clements and Aiello, 2021)
- Family Trauma: A Broken Care System (KMTV et al., 2023)
- Support Not Suspicion: Social Care, Ethnicity, Disabled Children and Their Families (Disabled Children's Partnership, 2024)

System values

Related to the example of 24/7 commissioning, attendees highlighted how the values of a system are important both in terms of increasing – or reducing – confidence of system partners such as providers, and also in how they incentivise or deincentivise particular ways of thinking.

Attendees highlighted that thinking of social care 'packages' or 'contracts' and housing 'placements' makes it harder to view these as key parts of a person's life – for example, their home – and that when areas and people working within the system are better able to focus on the individual, it results in better outcomes for both the person and the system.