

## Questions from the Short Breaks parent/carer meeting – 10<sup>th</sup> June 2024

### Response from Brighton & Hove City Council

#### Drove Road and Tudor House Offer

- As it stands families accessing over nights will not be prioritised for summer short breaks at TH/DR. This does not seem very ‘fair.’
- They are saying that children who already receive support will not be prioritised. I am very worried about what, anything will be available to my son.
- But what do those parents do (CYP receiving respite they cannot access daytime offer). Their CYP have already been identified as having complex needs.
- So, my son is going to be penalised for having DR (Drove Road).
- Can I clarify – the CYP already receiving respite – they cannot access the daytime offer?
- Will my child be included as they have overnight provision, and they have lost my son who is already there and has lost all their summer provision at ET.
- So, children who have DR respite, what is on offer for them since they’re not being prioritised? These children cannot access mainstream clubs – they cannot access so-called inclusive clubs.
- There is no choice. Child is ineligible for DR/TH because he attends. What is left? Amaze? That is our only option.  
[Children and young people already accessing overnight short breaks at Tudor House and Drove Road will not be offered summer daycare provision at Tudor House or Drive Road. Those on the waiting list for Drove Road and Tudor House will be prioritised for summer daycare.](#)  
[Children who access DR /TH respite can also access all of the Short Break offers. Where additional support is required, we will support as appropriate. If you would like to discuss specific requirements for your child, please do let us know.](#)
- I am still not clear what the offer is at DR & TH. Would they be staying on site for the session? Going out to do something? Also – it was referred to as ‘childcare’. I do not think this is what it is. It should be for enrichment and it is for YP as well as younger ones. ‘Childcare’ is not aspirational or appropriate within Short Breaks terminology, certainly not for my nearly 16-year-old.  
[Apologies if the phrase childcare was used, this is not the intention. DR/TH will be offering a range of activities on and off-site to ensure that the children and young people will have an enriched session full of fun activities. DR / TH will contact parents and talk them through what activities are on offer and discuss your child’s likes and dislikes.](#)
- It’s hard to sign up without knowing what is being offered. For eg if it was a morning out on the bus, from going DR going up to the Downs or to a lovely park for a picnic, then great. If it is being in the garden at DR with 4 other YP who also have volatile behaviour than this really would not work.  
[The sessions at DR/TH have been carefully planned to ensure that children will be matched together so that they have the best time.](#)
- I hope Tudor can have some stand-alone events...The benefits are that the children know each other!  
[That is a good idea and we will continue to explore options.](#)

## Allocation of places for children with complex needs

- How will places at TH/DR, DSDT and Amaze be allocated fairly? Process needs to be sorted for this.
- More clarity on TH and DR about their offer and the process (which families were approached? What about families who do not use TH and DR? what is the time scale?) Need for the information to be spread around.
- Is the waiting list already done? How will other children fit in?
- Question re Amaze offer: when will we confirm if needs can be met and if not, can BHCC/agency PA be provided and who will pay for this?
- Is it first come first served?
- Can you recap – so the offer is ONE day per week of 4 hours for each child. For how many weeks?

All families will now have received an email advising them of their allocated places across Amaze and DSDT Link-up offer. This is based on those families who expressed an interest in these sessions through Eequ. As agreed at the meeting BHCC reviewed all of the requested places for both these providers, as well as referring to the Tudor House and Drove Road waiting list together with information from social workers and special schools. We can confirm that there is an equal allocation of places for those families.

Tudor House and Drove Road will be notifying parents by July 5<sup>th</sup> 2024 of their allocated places.

There are also sessions with the other providers which can be booked in addition. If 1:1 support is required we will support either via additional payment for the family's own PA, Happiest at Home or Bleep 360 provided the Direct Payment account is not in surplus.

- It's a bit chicken and egg as I don't think the community is clear on what profile fits the offer.

We have been working hard with providers and Eequ to make the offer for each session more self-explanatory. We have taken on-board previous feedback to enable parents to identify easier if their child can access that session.

- Being with your friends is so important.

Definitely. Where families have asked for support for their child to access mainstream holiday sessions, we have enabled this through 1:1 support and liaising with providers to ensure that children can be with their friends.

- It's tricky when there are groups with specific need. What does real inclusivity and compatible look like? SWANS Syndromes without a name?

We will support a family on an individual basis to ensure that their child is supported.

- Am I right in thinking that the window for booking for the Amaze club (14+) is only open for this week? But we will not see that the DSDT offer is until next week?

No. All offers have been available simultaneously to families.

- On the TA bank – what if your child is not eligible for DR? We should not be penalised for accessing short break provision because a known 1:1 resource is not made available to them because they have exclusively been earmarked for Drove Road.

We have seen a really good response from Teaching Assistants and Personal Vehicle Assistants to the expression of interest. We have balanced the need for supporting Drove Road and Tudor House against the specific needs of young people within the wider short break provision and been able to allocate the additional resource to support both.

### **Direct payments**

- Clarity needed re paying by DP for summer – mechanics of how?
- If I'm booking on EEQu how can I pay using my child's DP if they have a Supported Bank Account?

Amaze and DSDT will be accepting Direct Payments. For the other provisions parents will need to pay upfront and claim this back from their direct payments. If you have a Payment Card for the Direct Payments you can use this to directly pay for the provision.

- Are they planning to "claw back" DP surpluses? I am fearful of requesting the use of my surpluses for fear it will be taken away.

Please discuss with your social worker but the principle is that surplus doesn't exceed 8-13 weeks. However, if you are saving your DPs to pay for holiday support then please let them know. BHCC can't legally take money from DP bank accounts without parent's consent.

### **Down's Syndrome Trust Link-up offer**

- DSDT – Link Up. Open to everyone; staff will be provided with some training if needed

Absolutely. DSDT have a really robust training programme and experienced staff to support the young people.

- DSDT – can parents use Direct Payment to take children outside the offer?  
The DSDT offer is only available for children with Down's Syndrome. DSDT Link-Up is available for children without Down's Syndrome. Direct payments can be used for both.

- Question re DSDT offer: DS only sessions aren't long sessions like the Link Up sessions.

We can explore with DSDT if this could be possible.

- Are their camps open to children without DS but have complex needs?  
Yes. DSDT Link-Up has been commissioned specifically to address the gap that parents have highlighted for complex needs.
- Will DSDT staff be able to offer personal care at their sessions for incontinent young people?

DSDT are happy to support all young people's personal care.

- What is the age range for the new specialist support offer?  
All details are on Eequ for the Link-up offer but typically between 8 – 18 years old. However, DSDT are happy to speak to families if they would like their young person to attend.

- Did they say HP will not be used for summer holiday club site?

DSDT Link-up sessions will be hosted at HillPark school.

- I'm concerned that the DS only sessions won't be long enough sessions like the Link Up Sessions. The current DSDT offer are short sessions or a SUP session, but they

aren't 4 hours. My son would potentially be better matched with other SEN (nonverbal, ASC, SLD etc) than only being with other YP who have DS. So, I am concerned that he is being pigeonholed to just one provider.

All children and young people can access all of the Short Break offers. It is not restricted based on their diagnosis or presentation.

### Amaze

- Does Amaze offer post 16?  
Yes, the offer is for young people aged from 14-25.
- Will Amaze be offering full day provision & in the east of the city at all?  
The Amaze offer is 10.00 am – 2pm, 3 days a week for 4 weeks in Portslade Village Centre, for this year.

### Ongoing development

- There should be provision of respite for the parents too; that even more important for single parents  
Please could you explain further? Each case is considered on the individual family's needs. For overnight short breaks at Drove Road and Tudor House, managers meet monthly to discuss the cyp who access the provisions to ensure this meets need and to look at priority of the children and young people on the waiting list.
- No provision for younger children/under 5 years old
- Under 8'!! There is no specialist cover this group.  
Where parents have expressed a need for their children who are under 5 we have been working with them on an individual basis to meet need. However, we will be pursuing this as we develop the offer. Lorraine Hughes is meeting with the Head of Service for the Family Hubs to look at what offer is already provided to pre-school children with SEND and to look at expanding the offer.
- There is a massive cliff edge post 16.
- There is a lack of awareness of the post 16 group.
- What is the offer for post 19?
- Needs are so diverse here, developmentally the same but there's really no post 16 voice
- And what about the lack of planning around those transition to adulthood.  
We are developing how we better support young people transitioning into adulthood as part of the SEND Strategy and in response to the OFSTED SEND inspection. We have the 14 – 24 transitions team within SCDS, we currently have a Transitions Tracking meeting to discuss each child aged 14 - 17 regularly to improve transitions to adult services. This meeting is attended by a range of multi-agency professionals. We are encouraging social workers to speak to parents and carers and the young person from the age of 14 to discuss their needs when their child reaches 18.
- Sleep is an issue and overnight respite is a recurring theme in terms of long-term strategic needs planning.  
This will be part of our on-going development and will be included in the wider short break strategy.
- Inequality also an issue in housing. Great that Knowle House is available but what about new housing for people with LD in B&H – all people with LD.

- There are parents who are happy to work with the authority to help create housing options. Please use us.
- Good models all around the country on small and larger scales eg Bristol CC working with parents, Surrey CC with Linden Farm parents etc
- Is there a working group for housing? It would be useful and a range of parents who can contribute on that group.

We are looking into the wider housing issues and potentials for young people within Brighton & Hove. Conversations have taken place with Linden Farm as well as other providers.

If you would like to be involved in developing this offer please contact Jacqui Parfitt ([Jacqui.parfitt@brighton-hove.gov.uk](mailto:Jacqui.parfitt@brighton-hove.gov.uk))

### Feedback:

- Parent carers feedback their family's needs do not feel like a "priority".  
We are sorry that parents feel that way. We are prioritising all families but would be very happy to discuss specifics.
- The pressure to cope with the summer holidays is very anxiety provoking, families feel that BHCC have had since Oct 24 to prepare for the summer holidays.  
The revised Short Break offer which provided sessions for children with a range of needs, including provision for children with complex needs, was introduced at Easter 2024. We have responded to feedback from families and mobilised additional sessions to meet complex needs.
- This is a blunt assessment tool around what the needs led assessment is.  
Currently each child / young person open to Specialist Community Disability team has a needs assessment and this is how we consider eligibility for support. Head of Service for SCDS is working on a more succinct eligibility criteria for SCDS.
- There isn't fair access to the pool of PAs being developed, or those available now through 2 agencies, for those not eligible for TH/DR  
Some of the TAs who have come forward to support during the summer holidays will be working specifically with individual children to support alternative sessions. All families have access to Happiest at Home and Bleep 360 if their child requires 1:1 support to access short break provision.
- YP might be better matched with other SEN (non verbal, ASC, SLD etc) than only being with other YP who have DS. Concern that YP isn't pigeonholed to just one provider.  
Any young person with SEND can access all short breaks. Children with Down's Syndrome can access all sessions.
- Why is this being offered to mainstream kids. They've got enough stuff to access.  
The short break sessions are for children with SEND. We will support them to access holiday clubs at mainstream schools, the short break sessions are not available for non-SEND children.
- Please ask them why this is so last minute, when they had a year on from dissolving Extratime to prepare.  
We acknowledge the additional stress that parents and carers have faced since the loss of Extratime. We have taken on board all of the feedback we have had and are

working on the short breaks offer to meet the needs of as many children and young people in the city as possible.

- Those same children have also lost Extratime.  
We have more sessions available for the summer than was previously offered through Extratime. We acknowledge that it takes time to build trust but we hope that the children will enjoy the sessions as much as they did Extratime.
- Can PaCC have a chat with the developer of the booking system please?  
PaCC has attended the Provider Forums and has worked with Eequ to share family feedback and develop solutions, some of which have been implemented.