

Involving people.  
Transforming services.



# Short break services Project report

South Tyneside and Sunderland NHS Foundation Trust

March 2025



## Contents

<b>1. Executive summary .....</b>	<b>3</b>
<b>1 Introduction .....</b>	<b>9</b>
<b>2 Involvement methodology .....</b>	<b>12</b>
<b>3 Situation review.....</b>	<b>13</b>
<b>4 Individual conversations .....</b>	<b>15</b>
<b>5 Survey and analysis.....</b>	<b>17</b>
<b>6 Field trips.....</b>	<b>25</b>
<b>7 Research into other accessible short break services.....</b>	<b>38</b>
<b>8 Feedback session 9 December 2024 .....</b>	<b>39</b>
<b>9 Co-design session 13 December 2024 .....</b>	<b>43</b>
<b>10 Appendices.....</b>	<b>48</b>

# 1. Executive summary

This project focused on co-designing a new model for short breaks services in South Tyneside, building on involvement activities that took place in 2022.

The North East and North Cumbria Integrated Care Board (ICB), working with Sunderland and South Tyneside NHS Foundation Trust, have involved people with learning disabilities, their families and carers in-line with NHS England's Involving People and Communities guidance which states "*people with lived experience are often best placed to advise on what support and services will make a positive difference to their lives*" (NHS England).

In March 2020, at the start of the COVID-19 pandemic, all those people with learning disabilities and their parents and carers were contacted about the temporary closure of Elmville due to safety reasons. They were further contacted in November 2022 with an update about the temporary closure.

The Elmville Unit is part of a range of services which also includes day services and other community provision that supports people with learning disabilities. These help people to participate in activities, explore interests, make friends, develop relationships, gain new skills, and make a positive contribution to the community.

With the Elmville Unit having been closed for some time, there are some complex regulatory and staffing issues to address. This was a difficult decision and it's understandable that families are anxious to know about the future.

Sunderland and South Tyneside NHS Foundation Trust and the North East and North Cumbria Integrated Care Board engaged people with learning disabilities, their families, and carers in South Tyneside to understand their needs and experiences with short break services, including those at the Elmville Unit.

Feedback from family members and carers following the previous engagement suggested there was a clear and unmet need for the service, prompting the ICB to agree on progressing towards the co-design of a new service.

Building on this, a further involvement continuation programme was launched to shape the future short breaks model.

This phase took place July - December 2024 and involved:

- Reviewing national and local policies regarding the provision of short break services.
- Re-engaging previous participants and reaching new families who would use short break services in South Tyneside.
- Facilitating family visits to out-of-area short break services and gathering feedback.
- Co-designing service suggestions with families.

Managed by Stand and Twisting Ducks, in partnership with Sunderland and South Tyneside NHS Foundation Trust and The North East and North Cumbria Integrated Care Board, the programme followed best practice for public involvement and aligned with NHS statutory duties to involve, the Public Sector Equality Duty and NHS England's people and

communities involvement guidance. In-depth qualitative research is preferred when exploring lived experiences, especially for people with learning disabilities, as it captures nuanced insights, personal contexts, and the complexities of individual perspectives.

Families were invited to try out some short break services free of charge and share their feedback during co-design sessions. Of those contacted, nine expressed interest, with three families participating in the trips.

The insights from this phase built upon what was learned during earlier involvement and will guide the development of an inclusive short breaks service model tailored to the needs of South Tyneside residents.

## Summary of findings

### Field trips

Three families participated in overnight stays at two different short break services:

- Calvert Kielder: Families reported overwhelmingly positive experiences. The venue provided safe, comfortable accommodation with specialist equipment, attentive staff, and inclusive activities like archery and a king swing. Families emphasised trust in the staff, the joy of seeing their family member with learning disabilities participate and expressed a desire for similar services in South Tyneside.
- Cresswell Towers, Northumberland: Feedback was mixed. While the venue felt safe, accessibility concerns (e.g. cramped spaces, lack of hoists) and limited activities due to weather and time constraints hindered the experience. The family recommended accommodation be adapted for diverse disabilities.

Families highlighted the need for local, accessible services with familiar well-trained staff, appropriate equipment, and engaging activities. They valued short breaks for their ability to recharge but travel distance and awareness of services remain barriers.

### Survey

Three families who completed the survey have used services recently, with positive feedback on quality and safety. Those who haven't, stated this was owing to a lack of suitable or available services since Elmville's closure. Families seek breaks for rest and opportunities for the person with disabilities to enjoy tailored activities such as swimming, cinema, and sensory rooms.

Safety, care quality, staff experience with complex needs, and activity suitability are the biggest concerns, whilst safety measures, personalised care, consistent staff, quiet environments, and clear communication are their top priorities. Barriers to using short break services are limited awareness of funding and lack of service availability.

Most families would use services monthly if suitable, and prefer in-person, email, and phone communication regarding opportunities for short breaks, over online or social media.

## Feedback and co-design sessions

The feedback session provided families and individuals an opportunity to hear insights gathered from the survey, field trips, and examples of different short break service models. Families who participated in the trips shared first-hand accounts of their experiences, fostering discussion and mutual understanding at their tables.

During this session, families collaboratively identified ***eleven principles/ways of working*** and ***twelve key elements*** they wished to see in a short break service.

### Principles/ways of working

- People-centred care
- Professional excellence of staff
- Safety and security
- Accessibility
- Communication and trust
- Fun
- Family support
- Continuity of care
- Inclusivity
- Flexibility
- Professional standard

### Key elements

- Physical facilities
- Medical support
- Personal care facilities
- Activities and equipment
- Trained staff
- Security features
- Communication systems
- Accommodation
- Dining facilities
- Transport
- Technology

This foundational work informed the subsequent co-design session, where the eleven principles were refined and distilled into *five core principles* deemed most important.

### 1. Communication and trust with staff

Families expect staff to be well-trained in accessibility needs and medication administration. Transparency is key; they want clear information on how policies and procedures are adapted to individual needs, with thorough documentation shared transparently before respite care begins. Continuity of care is crucial - staff should know the individual well, including their preferences, and any changes in staff should involve a detailed handover to maintain consistency.

### 2. Person-centred care

Families want advance information about available equipment and facilities, ensuring these are tailored to the individual's preferences, needs, and interests. This customisation should be based on prior conversations between families and staff.

### 3. Safety and security

Families prioritise reassurance that care aligns with individual needs, supported by well-equipped facilities and trained staff. This includes the security of the buildings and boundaries. Proximity to local medical facilities for emergencies was considered important, and having medical staff available on-site in a non-hospital setting is considered ideal.

### 4. Flexibility

Families value the ability to adjust dates for important events like weddings and access emergency support for carers and families during unforeseen situations, such as medical emergencies.

### 5. Service integration

Short break services should be designed to complement social care, specifically targeting individuals with complex needs that exceed standard social care criteria, such as those eligible for Continuing Healthcare (CHC). These services should also provide opportunities for additional community-based activities.

The twelve key elements were further prioritised into *high*, *medium*, and *low* categories, table with families defining what "good" should look like for each. Families did not categorise any elements as a low priority.

High priority	What good looks like
<b>Clinical support</b>	Appropriately qualified and properly trained staff to do the role and ensure they can deliver on a bespoke care plan.
<b>Personal care facilities</b>	Clean, spacious areas with good wheelchair access, transfer facilities with flexibility of equipment that as much as possible mirrors the range that they have at home.
<b>Security</b>	Secure boundaries and appropriate CCTV for the protection of individuals and staff when used in the right way.

<b>Accommodation</b>	Profiling beds, ceiling hoists and accessible bathing facilities. Emergency call and locking system on doors to prevent unsecured access.
<b>Trained staff</b>	Needs to feel safe and secure with staff. Ensure they are qualified and trained to make the right decisions and they have an understanding of the individual's needs and routine. Values of the staff member are as important as skills/qualifications, making sure that they 'feel right'.
<b>Communication systems</b>	Good communication between staff, carers and families is essential. Ensure that there is a clear and understood process for handover between staff, such as clearly displaying previous and following days activities.

<b>Medium-High priority</b>	<b>What good looks like</b>
<b>Physical facilities (sensory rooms)</b>	Places to relax and the opportunity to listen to music that is accessible to everyone.
<b>Family support</b>	A good long term, pre-plan and book-in system for both planned and short notice provision.
<b>Specialised activity zones</b>	Having appropriate staffing to support a range of enjoyable activities.
<b>Activities and equipment</b>	Provide the opportunity and ability to go out and about and they are accessible including soft flooring and trackways

<b>Medium priority</b>	<b>What good looks like</b>
<b>Transport</b>	Need availability for families who do not have transport and the provider needs to have accessible vehicles.
<b>Dining facilities</b>	This is very personal and depends on the individual. Therefore it needs to be a nice place to eat with the right equipment and choice of food depending on individual preferences.
<b>Additional support services</b>	Opportunity for additional support depending on the needs and choice of individual and carer, such as offering massage therapy.
<b>Community access</b>	A variety of community spaces on offer such as parks and water as well as shopping centres and places to go.
<b>Technology</b>	Technology such as WiFi and entertainment systems in individual rooms can meet the communication needs and are available and accessible to all.

## Conclusion

Families who participated in the co-design session provided invaluable insights into the essential components of effective short break services. They emphasised principles such as safety, quality care, and clear communication, alongside practical features tailored to meet diverse needs.

Incorporating these priorities into the design and delivery of short break services will not only meet families' expectations but also build trust and long-term satisfaction. By placing families' voices in this process, the resulting model can better respond to their needs and aspirations.

This report will be shared with South Tyneside and Sunderland NHS Foundation Trust and the North East and North Cumbria Integrated Care Board to consider the feedback.

Easy read and accessible English versions of the report will be produced, and all reports will be shared with the families who took part in the project.

We are grateful for the engagement and contributions of all the families involved, as their insights and experiences are crucial to shaping inclusive and effective short breaks services.

# 1 Introduction

## 1.1 Context and background

Respite care and short break services are hugely important for people with learning disabilities and their families. All families or carers who provide care to someone with a learning disability and require respite, should be able to access these services.

Short breaks and respite play a vital role in helping families and carers cope with the ongoing demands of their role, as well as helping individuals to access specialist support, have new experiences, and develop new skills.

One of the local services for short breaks in South Tyneside, the Elmville Unit, was temporarily closed for safety reasons due to the pandemic. Elmville provided short break healthcare provision for adults with learning disabilities who also have associated health needs.

In November 2022, 18 people with learning disabilities and their parents and carers were contacted about the temporary closure of Elmville due to safety reasons.

This was a difficult decision and it's understandable that families are anxious to know about the future. The feedback from family members and carers of individuals who were accessing this service prior to its closure were keen to understand what will happen in the future.

The Elmville Unit is part of a range of services which also includes day services and other community provision that supports people with learning disabilities. These help people to participate in activities, explore interests, make friends, develop relationships, gain new skills, and make a positive contribution to the community.

In 2022, North East and North Cumbria ICB undertook a programme of involvement with people with learning disabilities, their families and carers in South Tyneside who had previously been users of learning disability respite services provided at the Elmville Unit at Monkton Hall. A report of the exercise told commissioners about the needs of the people with learning disabilities and their families and carers, what is important to them, and their thoughts on Elmville and other short break services.

Local service leaders considered the report from the initial phase of involvement in 2022-23 and agreed that the involvement programme needed to continue to inform and shape the South Tyneside approach to providing short break services.

With the Elmville Unit having been closed for some time, there are some complex regulatory and staffing issues to address.

The objectives for involvement were to:

- Undertake an updated policy review to inform issues and questions for the involvement activities.

- Build on the insights gained from previous work with people with learning disabilities 2022-23
- Re-engage people and their families and carers who were involved in the previous work and engage potential adults living with learning disabilities in South Tyneside, and their families and carers.
- Arrange and report on family visits to current short break services outside the South Tyneside area.
- Use the feedback from these activities to co-design suggestions for future short breaks service provision in South Tyneside.
- Report the outputs in January 2025.

## 1.2 Why we need to involve

NHS bodies in England such as Integrated Care Boards (ICBs) have a statutory duty to involve patients / service users (including their carers and representatives) and the public (“by means of providing information, consultation, or in other ways”) in:

1. Planning commissioning arrangements
2. In the development and consideration of proposals for changes services; and
3. Decisions they make

NHS England’s document Working in Partnership with People and Communities: statutory guidance, published in July 2022 states that key requirements of ICBs and trusts include that they:

- Assess the need for public involvement and plan and carry out involvement activity
- Clearly document at all stages how involvement activity has informed decision-making and the rationale for decisions
- Have systems to assure themselves that they are meeting their legal duty to involve and report on how they meet it in their annual reports.

This report is evidence of planning and operational activity to discharge these national duties, which in turn is aligned to the ICB’s own involvement strategy.

## 1.3 Project management and involvement

This phase of involvement activity was delivered by [Stand](#), an independent stakeholder, patient and public involvement organisation. Stand’s team also delivered the initial involvement activity in 2022-23. Stand were commissioned by South Tyneside and Sunderland NHS Foundation Trust. The project was managed at place level in South Tyneside.

The project was managed using a best practice approach, aligned to the North East and North Cumbria Integrated Care Board’s Patient and Public Involvement Strategy, which

ensures compliance with legal and regulatory requirements to involve people in service developments and the Public Sector Equality Duty.

Stand worked with and sub-contracted Newcastle-based learning disability charity [Twisting Ducks](#), specialists in using creative approaches to support people with learning disabilities and autism to have a voice about issues that are important to them.

People and their families who participated in the initial phase of involvement were directly invited to give their views via a survey, participate in a short break field trip free of charge and to feed back their experiences of different types of short break services. In addition, people and families who could be potential users of short break services in South Tyneside were identified and written to by the Continuing Healthcare (CHC) team from South Tyneside Borough Council and invited to take part.

All families were invited to attend two in-person sessions – the first to share the feedback from the survey and the field trips, and the second to a co-design session aimed to gather thoughts and ideas on what the new short break service model should look like in South Tyneside.

#### **1.4 Learning from short break service users in the initial involvement**

The views of the people with learning disabilities and their families that were gathered during the initial involvement phase in 2022-23 were used to develop the next involvement activities.

The most important elements for people were the ability to take part in activities they enjoyed and to feel part of their local community.

They said they enjoyed a range of activities including listening to music, watching television, going to the disco, swimming, using sensory rooms, and going for walks and drives out to different places. They wanted activities that were tailored to their interests and to be able to attend services with people with similar interests.

Being part of the community of South Tyneside was seen as important and to be able to do the things they enjoyed within the borough.

## 2 Involvement methodology

The key activities for involvement were:

- A situation review which considered the earlier involvement findings and updated review policy
- Individual conversations with the families and carers
- A survey for families and carers
- Short break field trips with people with learning disabilities and their families
- Research into other types of accessible short break services
- One two hour feedback session to share what was learnt from the survey, conversations and field trips with other families and stakeholders which took place on 9 December 2024.
- One two-hour co-design session was held on 13 December 2024 to discuss and refine ideas previously shared by families, their carers, and other partner organisations, providers and commissioners about what is important to them in short break services. The session aimed to develop guiding principles, with participation from partner organisations, providers, and commissioners.

The following sections describe the involvement methodology and a summary of what was learned from each involvement activity.

A project working group played a central role in guiding and overseeing the involvement activity development. They provided feedback on the creation of questions, selected suitable venues for engagement, and contributed to the development of family information packs, offering valuable guidance on language and accessibility. The group benefited from the expertise of a Commissioning Officer with lived experience, ensuring the process was inclusive and relevant. Regular project updates were shared with the group, and monthly meetings were held to monitor progress and ensure key project milestones were achieved.

## 3 Situation review

The situation review assessed national and local policies, service availability, and the challenges faced by individuals and carers, with a particular focus on short break services for adults with learning disabilities in South Tyneside. It built upon insights gained from earlier phase in 2022-23, including feedback from people with learning disabilities, their families, and carers. This information informed the development of survey questions and discussion guides for co-design sessions.

The review also identified innovative models, such as the Shared Lives scheme, while highlighting gaps, such as service closures. It drew on research and lived experiences to provide a good understanding of the current short break landscape.

The full situation review is available in Appendix 1, which includes details on national policy, the cost of respite, findings from research papers on short break services, and local policies, strategies, and short break service providers in South Tyneside.

### 3.1 Key findings

National policies play a crucial role in shaping the provision of short break and respite care services for adults with learning disabilities. The Care Act 2014 established foundational rights for carers, mandating local authorities to support carers, including offering respite care. The 'Building the Right Support' initiative from 2015 further emphasised the transformation of care, shifting from inpatient settings to community-based services, enhancing the quality of life for individuals with learning disabilities. As part of this NHS England committed to closing inappropriate and outmoded inpatient facilities with a view to establish stronger support in the community.

The Health and Care Act 2022, while broad in its scope, does not specifically address respite care for adults with learning disabilities. However, the NHS Long Term Plan (2019) outlines commitments to increase the availability of short break services, aiming to provide carers with necessary rest and support.

The 'People at the Heart of Care' white paper (2021) sets out a ten-year vision for adult social care, recognising the importance of respite care and proposing additional funding to enhance these services. The Labour Government has expressed intentions to review and potentially revise this white paper, indicating a commitment to improving social care funding and integration.

Local policies in South Tyneside align with national directives, providing tailored respite services through initiatives such as the Shared Lives scheme. These services support individuals with learning disabilities by offering community-based, person-centred care, reflecting the principles of national policies. There are a multitude of residential providers offering respite for adults with learning disability, but without the support of adult social care professionals the system can be difficult to navigate.

As part of developing a case for change for short break and respite care services In South Tyneside, the South Tyneside Partnership (STP) are developing a new service offer as part of their post COVID-19 recovery. The *Building the Right Support* guidance issued by NHS England in 2015 has a series of principles around which services for individuals with learning disabilities should be commissioned and provided. The fourth principle identifies “My family and paid support and care staff get the help they need to support me to live in the community” which means that, in practice:

- All families or carers who are providing care and support and who require respite, should be able to access this support
- Respite must meet the needs of both the person and their family/carer
- Short breaks should be personalised, creative and flexible in their approach
- Commissioners should work to understand what both individuals and families/carers want from a short break service
- Individuals should not be expected to slot into a model of a short break that will not meet their needs

Short break services in South Tyneside were last reviewed in 2012, and any new services should be developed in line with the transformation of the learning disabilities agenda and South Tyneside Council’s health and wellbeing strategy. This takes into account that there are often many queries between health and social care teams to find suitable respite options for the person. It’s clear that the current respite bed-based offer needs to be enhanced to suit a variety of needs within South Tyneside and that respite support should be centred around the outcomes and goals of the person and their family.

## 4 Individual conversations

Families and carers who agreed to be involved were contacted by telephone to discuss the involvement project.

- Nine expressed interest in joining the short break trips and co-production sessions.
- Five could not attend the trips or sessions but wanted to stay informed.
- Two declined to participate.
- One could not be contacted despite follow-ups.

Once consent was gained, families were contacted to introduce members of the Stand team and explain the project. Families were offered support to complete a survey and were asked if they wanted to participate in short break trips and/or the feedback and co-design sessions.

The conversation covered:

- Re/introducing Stand and Twisting Ducks, whom people remembered from the earlier work
- Background to the involvement including the outputs of the initial phase of involvement in 2022-23.
- The plan for the next phase of involvement
- Providing dates and information about the short break field trips to establish whether they wished to and were available to take part
- To ask what support they needed to be able to take part in one of the short break field trips.
- Promoting the survey and confirming the dates for the feedback and co-design sessions.

For those interested in the trips, a follow-up telephone call was arranged with Twisting Ducks to understand the specific needs of the individual. This step ensured suitable matches for the selected short break locations at Calvert Kielder and Cresswell Holiday Caravan Park.

### 4.1 Those who decided not to take part

Of the nine families who expressed an interest in taking part in the field trips, two felt that the venues would be too far for the person they care for to manage and decided not to take part any further.

One family mentioned a particular issues around the fear of a caravan and seagulls, so did not want to take part in the trip to Cresswell.

One of the families had concerns that the security of the doors wouldn't be suitable as their person liked to try to go out at night and didn't want to take the risk due to safety.

Two families said that their person wasn't well currently enough to take part or would be away during the times identified for the trip.

## 4.2 Those who were able to take part

The two families who agreed to visit Calvert Kielder had their needs assessed in advance. With their permission, this information was shared with the short break provider to ensure appropriate arrangements. This included provisions such as suitable meals, a profiling bed, a hoist, and a bed rail. Activities were based upon individuals preferences and abilities.

Of the remaining two families staying at Cresswell Towers Holiday Park, one was unable to participate at the last minute. For the final family, discussions were held to ensure their stay would be as comfortable as possible. Arrangements were made for a welcome pack, which included essentials like bread, tea, and coffee-making facilities, to be provided at the caravan.



## 5 Survey and analysis

Families were invited to complete a survey in October 2024 which was designed to find out the needs and experiences of people with learning disabilities, and their families and carers specifically regarding short break services.

All families were provided with the survey and a dedicated support telephone number for assistance with completion and two families took up the offer of support. Eight families responded in total.

The survey explored:

- Past use of short break services: Families were asked about the services they had accessed in the past two years and their experiences using these services.
- Barriers to using short break services: Families who hadn't used any short break services during this period were asked the reasons why.
- Current needs and preferences: Families shared what they need from short break services, why these needs are important, and their preferred frequency of service.
- Funding arrangements: Families were asked how their current short breaks are funded.

A full list of the survey questions is available in Appendix 2.

### 5.1 Summary of survey findings

#### **Q. Have you used a short break service in the past two years, or are you currently using one?**

Three families currently use or have used short break services in the past two years. This includes Real Life Options, Bisley Drive and Gosforth Respite service. Their experiences were overall very positive, with respondents rating the quality of service and activities provided very highly and commenting how happy and safe the person with learning disabilities felt during their stay.

All were satisfied with the information they received before and during their stay, with comments being made about the ability for them to familiarise themselves with the service before the stay. The only negative aspect identified was in relation to Gosforth Respite service which is only able to provide support for those who are able-bodied and not using wheelchair.

Five families said they have not used short break services in the past two years, the reasons provided were:

- There hasn't been a service available.
- There are none available or not offered since Elmville closed.

- A family and the person they care for reported having no respite care since before the COVID-19 pandemic began. (Their daughter used to attend Elmville)
- A family and the person they care for reported not offered any respite / short break service for the past four and a half years.
- There are no suitable services currently available.

**Q. What would be your main reasons for using short break services?**

The families and carers would most commonly use short break services to give themselves and other family members a break and time to rest as well as give the person they care for a chance to participate in enjoyable activities.

To make the short break experience more enjoyable, respondents talked about two key elements:

- Having plenty of fun activities and outings
- Having access to safe locations that meet the individual's specific needs.

Suggestions of activities which individuals don't currently have access to include swimming, fishing, cinema, sensory rooms/areas and regular social activities.

The most important factors for the families and carers when using short break services are:

- Personalised care plans tailored to individual needs.
- A break that also gives carers a chance to rest and relax.
- Quiet and sensory-friendly environments.
- Reliable and consistent care from familiar staff to build trust.
- Trained staff experienced in managing complex behaviours.

**Q. Do you have any worries about using short break services?**

The key concerns about using short break services relate to the safety of the person and the quality of care.

Of slightly lesser concern is uncertainty about the staff's experience with complex needs, how the person will adjust to the new environment, and the suitability of the activities offered.

**Q. What are the most important factors in your decision to use or not use short break services?**

When deciding whether to use short break services or not, a number of factors were considered equally most important:

- Positive experiences, reviews or recommendations
- Safety and security measures in place

- Personalised care that meets specific needs
- Good communication with staff before and during the stay

Of slightly lesser importance were proximity to home or ease of transportation, quality and variety of activities offered and flexibility in planning and availability.

**Q. Are you aware of how to access funding to pay for short breaks?**

Three family members or carers are aware of how to access funding to pay for short breaks, whilst four were not. Just one of the three individuals who were aware currently use or have used short break services in the past two years.

**Q. How frequently would you consider using short break services if you find them suitable?**

If short break services were found to be suitable, one family would consider using these weekly whilst five would consider using these on a monthly basis. The remaining respondent would consider using these services on an emergency or as needed basis.

**Q. What format would you like to get information about short break services?**

The preferred methods for receiving information about short break services are in-person meetings or information sessions, emails and phone calls. Preference was lower for information being shared online and via social media.

## 5.2 Respondent profile

The following provides a summary of the equality data monitoring information completed by seven of the eight respondents.

It was unclear whether respondents provided equality monitoring information for themselves or the person with learning disabilities.

- Two were aged 25-34 years, one 45-54 years, two 55-64 years, one 65-74 years and one 75+ years.
- Three were female and four male; all said their gender identity matched that at birth.
- Four had a disability or long-term condition / illness; this included a long-standing illness / health condition (3 respondents), a physical difficulty or mobility issue (2 respondents), being blind or partially sighted (2 respondents), a social or communication difficulty (1 respondent) and being deaf or partially deaf (1 respondent).
- None were currently pregnant or had given birth in the last year, nor had any children at home.
- Six said they were heterosexual / straight, whilst one chose not to respond.
- Five indicated that they were Christian, whilst two chose not to answer.

- Four resided within Jarrow (NE32) and three within South Shields (NE34).
- Seven filled the survey in themselves, whilst one had assistance.

### 5.3 Recent experiences of short break services

Three families or carers have used a short break service for their person in the past two years or are currently using one.

Two currently use or have used **Real Life Options, Bisley Drive** for planned care. Both rated the quality of service and different activities provided as very good and said that the activities and services provided met the person with learning disabilities' needs.

*“Excellent and meet son's needs, let son stay and clean as this is what he likes to do and also helps the handy man.”*

*“Great staff, enjoy every activity. They did their best to accommodate what [family member] wanted to do.”*

Both said their person felt very happy during their stay and that they were made to feel very safe. Both rated the information they received before and during the stay as excellent with one noting how they were “*shown around before the visit*” and the other that they were “*always kept informed*”. Neither identified a negative with the service.

The other response indicated that they use or have used the respite service at **Ashleigh College, Gosforth** on multiple occasions for both planned and emergency care. Again, the service was rated very highly as were the different activities provided. The response described how the person with learning disabilities particularly enjoys going to the pub with a member of staff.

*“[Family member] is very happy attending, they take him out on trips, he goes out for a pint with a member of staff.”*

The service was felt to meet the needs of the person with learning disabilities who is reported to feel very happy and safe during their stay. The staff were likened to those who worked at the Elmville Unit.

*“Very happy about going, he waves dad off when he gets there.”*

The family rated the information they received before and during their stay as excellent. They described how they were shown around the building and the bedroom where the person with learning disabilities would be sleeping.

It was noted that the Gosforth Respite service is only available to able-bodied individuals, which was felt to be the only negative.

The remaining four responses indicated that they have not used short break services either because there are no suitable ones available, or they have not been offered any. Two specifically mentioned that they used the Elmville Unit in the past.

*“My daughter has not been offered any form of respite/short break service for the past 4 and a half years.”*

*“[Family member] and myself have had no respite care since before the covid pandemic began. [Family member] used to attend Elmville but they never reopened after pandemic.”*

## 5.4 Preferences for short break services

### Q. What would be your main reasons for using short break services?

Family members would most commonly use short break services to:

- Give themselves and other family members a break and time to rest (4 rating this as very important).
- Give the person with learning disabilities a chance to participate in enjoyable activities (3 rating as very important).

Notably, two respondents did not respond to the question and instead indicated that all reasons were equally important.

One respondent highlighted the importance of continuity of care and ensuring that the staff know and are able to care for her family member:

*“I would like to think that if, as a sole carer, I became ill my daughter would be going somewhere where the staff already knew her and how to care for her which in return would give me peace of mind that she is being well cared for”*

*Note: The remaining questions within the survey were completed by seven out of the eight respondents.*

### Q What could be done to make your, or your family member with learning disabilities holiday experience more enjoyable?

To make the short break experience more enjoyable, families and carers talked about two key elements:

- Having plenty of fun activities and outings.
- Having access to safe locations that meet the individual’s specific needs (for example a hoist profiling bed and adequate space for an electric wheelchair).

*“The more attention the better. She thrives on attention. Music of any kind. Going out for walks.”*

### Q. Do you have any ideas for additional activities you don’t currently have access to?

Some suggestions were made of activities that individuals don’t currently have access to:

- Swimming

- Cinema
- Sensory rooms (with lights and music)
- Regular social activities
- Fishing

*“She doesn’t have access to any activities at present so anything is a bonus.”*

**Q. What specific needs or preferences do you and your family member or person you care for have for short break services?**

Six out of seven rated a break that also gives carers a chance to rest and relax, personalised care plans, quiet and sensory-friendly environments, reliable and consistent care from familiar staff and trained staff experienced in managing complex behaviours as most important.

Additional comments related to all factors being important and how trained staff are needed to administer specialist medications and assist with peg feeding.

Response	Number rating as very important
A break that also gives their carers a chance to rest and relax	6
Personalised care plans tailored to individual needs	6
Quiet and sensory-friendly environments	6
Reliable and consistent care from familiar staff to build trust	6
Trained staff experienced in managing complex behaviours	6
A safe and comfortable place where they feel secure and well-cared for	5
Accessible facilities for physical disabilities	5
Proximity to home or easy transportation options	5
Regular communication and updates during the stay	5
Flexibility in booking to fit our family’s routine	4
Special dietary accommodations	4
Opportunities for social interaction with peers	3
A variety of activities that match my family member’s interests	2
Opportunities to socialise and make friends with others	2
Fun activities that match people’s interests and needs	1

*Table 1 What specific needs or preferences do you and your family member with learning disabilities / person you care for have for short break services? (N=7)*

**Q. Do you have any worries about using short break services?**

The key concerns that families and carers have about using short break services relate to the safety of the person with learning disabilities and the quality of care (7 and 6 respondents selecting this as a concern, respectively).

Of slightly lesser concern is uncertainty about the staff's experience with complex needs, how their family member will adjust to the new environment and the suitability of the activities offered (4, 4 & 3 respondents selecting this as a concern, respectively).

Other concerns / comments made by respondents stressed the importance of quality of care with comparison being made to the Elmville Unit, as well as continuity of care and low staff turnover.

*“That staff are properly CRB [DBS] checked, caring and will look after clients properly.”*

*“Would like somewhere that does not have a high turnover of staff.”*

Response	Number who have a concern
Worries about my family member's safety	7
Concerns about the quality of care	6
Uncertainty about the staff's experience with complex needs	4
Worries about how my family member will adjust to the new environment	4
Uncertainty about the suitability of activities offered	3
Concerns about my family member feeling lonely or isolated	2
Concerns about communication with staff during the stay	2
Concerns about the cleanliness and condition of the facilities	0

Table 2 Do you have any worries about using short break services? (N=7)

### Q. What are the most important factors in your decision to use or not use short break services?

When deciding whether to use short break services or not, families and carers considered the following factors as equally most important:

- Positive experiences, reviews or recommendations
- Safety and security measures in place
- Personalised care that meets specific needs
- Good communication with staff before and during the stay.

Of slightly lesser importance were proximity to home or ease of transportation, quality and variety of activities offered and flexibility in planning and availability. Cleanliness and comfort of the facilities was not considered important.

Response	Number selecting as important
Positive experiences, reviews or recommendations from others	5
Safety and security measures in place	5
Personalised care that meets specific needs	5

Good communication with staff before and during the stay	5
Proximity to home or ease of transportation	4
Quality and variety of activities offered	3
Flexibility in planning and availability	1
Cleanliness and comfort of the facilities	0

*Table 3 What are the most important factors in your decision to use or not use short break services? (N=7)*

**Q. What format would you like to get information about short break services?**

The preferred methods for receiving information about short break services are in-person meetings or information sessions (6 respondents), emails (4 respondents) and phone calls (3 respondents).

Respondents showed least preference for information to be shared online (via a website / online portal, videos / webinars) and via social media.

## 6 Field trips

This section presents feedback and analysis of the experiences of three families who participated in an overnight stay at two different short break services: Calvert Kielder and Cresswell Towers Holiday Park, both located in Northumberland.

Initially thirteen families expressed an interest to take part in field trips to explore other types of short break services, which were arranged at no cost to them. The goal of these field trips was to gather valuable feedback on their experiences and assess each service, with the insights contributing to the co-design session for a new model of short break services in South Tyneside.

The working group played a key role by providing information about short break services they were familiar with. This helped identify 28 potential venues for review, enabling the group to make well-informed decisions on which services to approach for the field trips.

The venues that were considered were:

Short break service name	Location
Alan Shearer Centre	Newcastle upon Tyne
Barndale House School	Alnwick
My Life	Leigh, Lancashire
Paercy Hedley	Wansbeck House
ESPA - Education Services for People with Autism	Gosforth, Newcastle
Renal Health Ltd	Newcastle upon Tyne
Salutem Care	Hebburn
Potens	Darlington
Potens	South Hetton, Co Durham
Potens	Stanley, Co. Durham
Potens	Langley Moor, Co. Durham
Potens	Saltburn by the Sea, Cleveland
Roseberry Care, South Quays Blyth	Blyth, Northumberland
Melrose House Cullercoates Ltd	Cullercoates
Picktree Court Care Home	Chester-le-street
Flexible Support Options Ltd	North Shields
North East Disabilities Resource Centre	Sunderland
Jane Percy House	Cramlington
Abbeymoor Neurodisability Centre	Gateshead
Beachcomber Care Home	Seaham
Care and Support Pathways - Stanley	Stanley, County Durham

Hawthorn House	Durham
Beddell House	Durham
Lambton House Care Home	Fencehouses, County Durham
Lindisfarne Care Home - Seaham	Seaham
Dairy Lane Care Centre	Houghton-le-Spring
Northumberland Cottage	Northumberland
Adapted canal boats	Various

Venues were contacted regarding their suitability and availability and two services were selected:

- Calvert Kielder Respite Care, Kielder Water, Northumberland
- Parkdean Resorts, Cresswell Towers Holiday Park, Northumberland

For planning purposes, there was capacity for nine families to take part in the field trips.

From the initial 13 families that expressed an interest, several families decided they were unable to take part owing to constraints. This included not being available on the dates proposed, venues not being able to accommodate the needs of the person, changes to the person's health and the travel distance.

A detailed briefing pack which included easy read version was prepared and shared with participating families and carers in advance. It provided detailed information about the field trip including:

- Overview of each service and location
- Visit dates, timings, and whether the visit was a day trip or overnight stay
- Expense payment information
- Pre-visit information including location, activities and venue details
- Consent for participation and use of their images and interviews for the feedback report and session
- Transport details
- Risk assessment
- Guidelines for providing feedback

The packs and the questions asked during the field trips were co-designed with the commissioning officer with lived experience.

### **Visit 1: Calvert Kielder Respite Care, Kielder Water, Hexham**

Calvert Kielder provides fun, supported breaks for adults with disabilities, offering adapted activities in a safe and inclusive environment.

**Date:** 13 to 15 November 2024

**Travel:** Families were offered transport or reimbursement for fuel. One family opted to travel independently, while another used transport provided by Twisting Ducks.

**Activities:** Buggy rides through the forest, archery, the King Swing, and climbing - all adapted to ensure inclusivity. Meals and accommodation were included.

**Participation:** Two families attended.

### **Visit 2: Parkdean Resorts, Cresswell Towers Holiday Park, Northumberland**

This visit allowed the family to experience caravan accommodation at Parkdean Resorts. The family supported their individual with learning disabilities, so no additional care was provided during the stay.

**Date:** 19 November - 20 November 2024

**Travel:** The family used the transport provided

**Participation:** One family attended (change of circumstances prevented another from participating). Activities included dining at a local restaurant. The scheduled visit to Northumberland Zoo the following day could not take place owing to a change in circumstances of the family.

Families were accompanied by members of the Stand and Twisting Ducks teams. Feedback was gathered through notes, audio, and video recordings during the visits. Microphones were used for audio recordings, and these outputs were shared during the feedback session on 9 December 2024. Families were also encouraged to document their experiences through notes or videos.

Taking part in the field trips and experiencing a respite short break firsthand allows participants to provide more considered and in-depth feedback, as they can reflect on their immediate experiences and offer insights grounded in real-time interactions and personal relevance.

## **6.1 Key findings from the field trips**

The experiences of the families who attended Calvert Kielder were overall very positive. The families felt safe and secure during their stay and that the needs of their person were catered for with all specialist equipment they required being available and friendly, attentive staff. With support from staff, the people were able to participate in a range of activities, the king swing being a particular favourite. One family were initially uncertain if their person would be able to take part in the activities and was surprised that they were able to do everything. They were delighted to see the joy on the face of their family member whilst participating in these activities and were thankful that they got to experience these opportunities.

Both families were unable to identify anything that would have enhanced their experience and desired to have a service like this in the South Tyneside area.

Of the two families identified for the caravan trip to Cresswell, one family dropped out the day before the trip due to a change in circumstances.

The experience of the family who stayed at Cresswell Towers Holiday Park was somewhat different with snowy weather and time constraints limiting their ability to explore the facilities on site and participate in any activities. Despite the accommodation being perceived as safe and secure, the family member had significant concerns about its accessibility for wheelchair users. Specifically, the lack of space in the bedroom and bathroom made manoeuvring the person with learning disabilities difficult and the absence of a hoist in the bathroom made bathing impossible. For this reason, the family would be apprehensive of using this short break service in the future for anything more than a one-night stay.

In terms of the accommodation, it was felt that more adjustments are needed to cater for individuals with differing disabilities, such as the provision of specialised equipment.

Short break services have in the past allowed family members to relax and “*recharge their batteries*”, something that they are unable to do when the cared for individual is at home. They have also given family members a chance to have time to themselves as well as to get jobs done around the house.

The families voiced their frustration about the lack of respite opportunities that have been available to them.

One family member who didn't use short break services until their person was 21 years of age described how hard it is as a parent to hand responsibility for their loved one over to someone else. They explained it takes time to build relationships and trust with staff, which gradually helps them to feel more relaxed when using these services. The family member further added how important communication is between services and families, particularly as their cared for individual is unable to communicate. Receiving feedback from the service in terms of what time they slept, what they ate, what they did – is therefore very useful as changes to any of this can be a way of indicating whether they have enjoyed the short break experience, or not.

The distance required to travel to these short break services was an issue for two of the families, who felt this would be a barrier to using these services. For one family, future use would depend on whether transport was available. There was a lack of awareness of the cost implications.

During the visits, the families talked about what they want from short break services:

- Somewhere that is local and easy to get to (otherwise transport would need to be provided).
- A place where the person with learning disabilities is comfortable and is able to participate in the activities they enjoy.
- A place where families have trust that their family member with learning disabilities will be looked after properly so they have confidence to have a proper break. As part of this the families talked about:

- Good quality, well-trained and familiar staff who are attentive, engaging and have good understanding of the person's needs.
- Appropriate support ratios.
- Access to specialist equipment.

## 6.2 Venue 1: Calvert Kielder

The following provides an overview of the experiences of two families, who attended the venue from 13 to 14 November 2024.



### 6.2.1 General experience

**Feedback was very positive from both families; comments were made about their experience being “out of this world” and how they “couldn’t have asked for anything better”.** The families considered the whole experience a fabulous opportunity for their family members and were unable to identify any improvements that would have enhanced their stay.

*“It’s been out of this world – fabulous, we have really enjoyed it, everything was spot on.”*

*“Totally blown away by the place, it has been amazing watching the other family’s daughter and the way the staff looked after her.”*

### 6.2.2 Services and environment

Both families felt safe and secure during their stay. One family discussed how they were initially apprehensive about the stay, particularly how their daughter would react, but were pleased that she stayed calm throughout.

The accommodation was felt to have “*comfy beds*”, with one family likening the facilities to a hotel room:

*“I liked being in a room with [individual]. You had a kettle in the room as well which is just like being in a normal hotel room. I wouldn’t change anything.”*

One family commented upon how the equipment that her daughter needed i.e. a hoist and a profiling bed, was provided on arrival. Positive comments were also made about the food.

A slight negative was identified by one family who encountered difficulties with the shower in their room and the TV which had “*no signal*”.

### **6.2.3 Activities and support**

Both families participated in the buggy ride, archery, king swing, indoor climbing, and the sensory room. The swing was the favoured activity for both families.

*“My son loved it all, the climbing wall, the swing, archery, the food has been fantastic and the staff have been brilliant.”*

One family was surprised at how many activities their family member was able to participate in and were thrilled to see the joy on her face. They put this down to the staff and how they made her feel calm and comfortable.

*“I couldn’t believe the smile on her face and loved that she could also come along on the buggy ride. I was sceptical that she would be able to do the activities – especially the climbing wall. They were so good with her, they stayed calm and relaxed therefore she was comfortable. I want to look into doing more of this kind of stuff with her in the future. She loved every minute and the staff were amazing with her.”*



The families did not bring their swim wear and were therefore unable to use the facilities. This is something that one of the people with learning disabilities would have loved.

*“My daughter loves the pool and would stay in it all day long.”*



#### **6.2.4 Staff quality and care**

The families could not rate the staff at Calvert Kielder more highly. They noted how the staff recognised the needs of the cared for individuals straight away and how they interacted with them and took the time to get to know them and their quirks.

*“The staff I've met are fantastic. I was watching them interact with the others that were there for respite and they knew all about each person and what they liked doing. The thing I really liked is that they knew XX's name straight off and made him feel welcome like they'd met him before.”*

*“Caring staff is so important they treated XX with respect within minutes they understood his little quirks like when he says 'bye' to everyone.”*

#### **6.2.5 Making things easy for everyone**

The distance to travel to the service was identified as a barrier for one family who noted that it would be too far for them to use the service each month. However, for the other family travel was not an issue.

*“There was no bother for us on the travel we just got in the car.”*

The families did not identify any other barriers to using the service, although one family commented that they never knew it existed, which may have prevented them from exploring this service before.

*“I never knew this place existed; I can't believe how good it is.”*

One of the families expressed an interest in bringing the whole family, including the dog, to stay in one of the pet-friendly lodges.

*“My other children would love to experience this; we would like to come as a family. I'm looking for a price list for a lodge, and I am pleased some lodges accommodate dogs.”*

### **6.2.6 Family impact**

In the past, short break services have given the families a chance to relax and rest, something they are unable to do when the person with learning disabilities is at home. They have also enabled families to take some time for themselves i.e. to do odd jobs around the house, go for a pint, have a lie in and take a holiday / break.

*“When XX goes to respite I get to rest when XX is at home I can't really rest. If she's not having a good day, I can't do what I need to as she won't want to be in her wheelchair.”*

*“XX enjoys being away from me he goes to college during the week which is good, when he was in Elmville I could go out and have a pint, lie in late but now you are on your guard all the time.”*

### **6.2.7 The future**

The families talked about what they would want from short break services:

- A supportive home-from-home environment where families have trust that their family member will be looked after properly so they have the confidence to have a proper break.
- Where the person with learning disabilities feels comfortable.
- Good quality staff (similar to those at Elmville).
- Appropriate support ratios.

The families desired to have a service similar to Calvert Kielder in South Tyneside, acknowledging that for disabled people living in the area, there is no “sense of adventure”.

*“It would be good to have something like this in South Tyneside, we would come every month, but I don't think it will happen.”*

*“I'd like you just to pick this up and move it. This place is built for exactly what we need in Tyneside, Newcastle Gateshead area.”*

The families expressed their frustration about the lack of support. Although one-to-one support was perceived to be ‘good’, it was considered no match to Elmville.

One person described how they have had to ‘fight for support’ since their family member left school, and how this is becoming harder as they get older. They noted how they are entitled to 52 nights a year.<sup>1</sup>

*“Struggling to find something for my daughter with such complex needs. I have had to fight for everything for my daughter, she is not getting any easier and I am not getting any younger. I don’t want her to go into full-time residential. I want her to be at home with me.”*

### 6.3 Venue 2: Cresswell Towers Holiday Park

The following provides an overview of the experiences of one family, who attended the venue from 19 to 20 November 2024.



#### 6.3.1 General experience

The person experienced some issues with the accommodation which impacted on her experience. Additionally, the family did not get the chance to explore the site or participate in any activities, as by the time they had looked around the caravan the afternoon had become dark, and it had been snowing. They acknowledged that if it had been summer, their experience would have been different.

*“Would have been nicer in the summer, everything is nice in the summer.”*

---

<sup>1</sup> The number of nights a person is eligible for is determined by the Community Care Act Assessment.

### 6.3.2 Services and environment

The family felt safe and secure in their accommodation; however, they had some concerns about its appropriateness for wheelchair users with the bedroom and bathroom felt to be small and cramped.

They described how their family member slept in a single, profiling bed, which is different to the double bed she is used to at home. Although the bed could be lowered, they were not happy with the height, and would have preferred something to have been put on the floor in case she was to fall out.

Additionally, the bed was positioned next to a radiator, which meant that the radiator could not be on as it would have been unsafe. It was not possible for the bed to have been moved to a different position.

The family explained how at home they use a monitor when the person with learning disabilities is put to bed. They did not take this with them on the stay, and struggled to check on them during the night as the room was too dark.

The family questioned how it would work if the person with learning disabilities was on a short break alone, and how the carers would check on her.

*“If a carer was looking after her, I would assume that... Well, I don’t know whether they sleep at night or not. I don’t know how they work. When she used to go to the other respite, I was told that they were checked on every hour during the night, so the staff shouldn’t have been asleep.”*

In terms of the bathroom, the family member noted how there was not enough room to be able to hoist the person with learning disabilities from her wheelchair to a shower chair. For this reason, they did not attempt a shower and stated they would be reluctant to use this short break service for any longer than one night.

*“The caravan would be suitable for a very short overnight stay, because the bathing facilities aren’t suitable it couldn’t be any longer. It just wouldn’t work for people who are wheelchair dependent.”*

Adjustments were felt to be needed to make the accommodation more accessible for wheelchair users, i.e. larger bedrooms and bathroom, and provision of specialist equipment such as a hoist to help manoeuvre individuals more easily.

*“Well, for other people, I think it was fine. It’s just certain adjustments for different individuals.”*



### 6.3.3 Activities and support

The family did not get to experience any activities due to the limited amount of time they were there, nor were they aware of what was available.

The family explained how the person with learning disabilities is limited in the activities that she can participate in and does not need anything specific.

*“XX likes to go out for walks, a ride in the car. She doesn’t need anything specific. She likes to be out in the open air.”*

On discussion of some of the activities that are available, the family thought the person with learning disabilities would have enjoyed swimming and watching live entertainment; activities that the family faces considerable barriers to doing by themselves.

*“There are hydro pools around here but you can’t get access to them. Filled all the forms in for the Alan Shearer Centre but never heard anything.”*

### 6.3.4 Staff quality and care

The family didn’t see any staff during their stay nor were they offered any support.

They discussed how they would want to see staff / carers who do their best, who get to know the person with learning disabilities and their ways, and know how to look after them properly.

### 6.3.5 Making things easy for everyone

The distance to travel to the service was a problem for the family as they hate driving and lack confidence going too far away from home. Future use of the service would therefore depend on whether transport was available.

With the person with learning disabilities being unable to communicate, the family explained how in the past it has been very hard to assess whether they have enjoyed their short break experience or not. Receiving feedback from the service in terms of what time they slept, what they ate and what they did, would be very useful as changes to any of this can be a way of indicating whether they have enjoyed the experience.

*“XX loves eating, that makes her happy, when she went somewhere in the past she didn’t eat, to me that was her saying she wasn’t comfortable.”*

### 6.3.6 Family impact

The family explained how they didn’t use short break services until their family member was 21 years of age. They described how hard it is as a parent to hand responsibility over to someone else.

Over time, the family was able to build relationships with staff which started to make them feel more at ease in leaving their loved one. They explained that they got to the point where they felt confident enough to go away for a couple of nights;

*“Gradually, because the staff were consistent, I got to know them. I started to relax and got more relaxed about her going. I could relax to the point that I could go somewhere for a couple of nights – to London to see my son.”*

Short break services have in the past provided the family member with a chance to ‘recharge their batteries’ and allowed them to do things that they couldn’t do when the person with learning disabilities was around, such as getting work done on the house.

*“You are on the go constantly, day in day out, without a break. I’ve not had respite for 5 years.”*



### 6.3.7 The future

The family has not had any short break services for the last five years, they indicated that any provision would be nice.

They were unable to recall any ideas or services that they had seen elsewhere, perceiving that more seems to be available for children and young people as opposed to adults. However, it was felt that their family member would love some of the activities that are available for this younger cohort.

*“Although XX is an adult, she is very childlike. She would love some of those activities – like sitting in a ball pool / sensory rooms / music.”*

In terms of an ideal short break service, the family discussed:

- Somewhere that is local and easy to get to (otherwise transport would need to be provided).
- A place where the person with learning disabilities is comfortable and is able to do the things that make her happy, such as listening to music, going for walks and being well fed.
- A place where everyone knows her (familiarity of staff).
- Staff who are attentive, engaging and patient.
- Appropriate support ratios (they require 24/7 2:1 care, and being supported with all aspects – feeding, bathing, moving and handling).

## 7 Research into other accessible short break services

To gather a wider range of views and feedback, Twisting Ducks engaged their group members and their families who have experience of using short break services and asked them to identify other services and the questions they wanted to ask about them.

They contacted a range of other short break providers and arranged question and answer sessions with the aim of gathering information to help families explore different services and support options, particularly for individuals attending without family assistance.

An accessible film which contained the information gathered was produced and shown at the family feedback session on 9 December.

An overview of these services can be found in Appendix 3.

## 8 Feedback session 9 December 2024

The purpose of the feedback session was for families and people to hear feedback from the survey, residential trip and different models of short break services.

People who attended the session included:

- Three families who attended the field trips and four families who had not attended the field trips
- Representatives from North East and North Cumbria Integrated Care Board (NENC ICB)
- Representatives from South Tyneside and Sunderland NHS Foundation Trust (STSFT)
- Team members from Twisting Ducks
- Stakeholders from:
  - Your Voice Counts a charity that supports people with learning disabilities, autistic people and people who are at risk of exclusion due to disability, illness or other challenges.
  - Equal People - an Involvement Group based in South Tyneside made up of people with a learning disability, who get involved to improve services for all people with learning disabilities. To do this, they gather the views of people with learning disabilities and make sure these views are listened to by decision makers

Attendees were split into three tables with a mix of families (those who attended and didn't attend the trip), project team members, and stakeholders to ensure a range of perspectives and insights.

A film documenting the respite field trips was shown during the session and families who participated in the trips shared firsthand accounts, detailing what worked well and areas for improvement. This encouraged open dialogue, allowing others at the table to ask questions and contribute ideas. Table facilitators kept discussions focused and ensured all voices were heard. This film can be viewed at: <https://www.youtube.com/watch?v=1sbn2ADDCW0>

Recording feedback instead of relying on written suggestions improved the flow of conversations and captured nuanced insights.

A second short video showcased various types of short breaks available across the country, highlighting the additional benefits they offer to families considering a short break. Showcasing alternative provisions encouraged families to think creatively about service possibilities.

This provided a basis to start thinking about principles and elements of a new model. The tables discussions were centred around:

- Identify key principles to be taken into consideration when designing the new short break services model, and;
- Key elements considered important to be included in the new model.

The session fostered collaboration among families, stakeholders and facilitators ensuring diverse perspectives informed the development of some key principles to be used in the co-design session on 13 December.

## 8.1 Key themes of feedback

After viewing the videos and hearing the feedback, discussions took place to consider what was important to people and their families when using short breaks.

Several themes emerged:

**Staffing and support:** The importance of consistent, well-trained staff was a recurring theme. Families emphasised the need for staff who deeply understand complex needs and behaviours, with medical professionals available to provide specialised care. Good staffing ratios, such as 2:1 support when necessary, were identified as critical to ensuring individual needs are met effectively.

**Activities and programming:** Families highlighted the value of a balanced approach to programming, combining indoor and outdoor activities with flexible scheduling. Activities should cater to both active and calm preferences, including sensory experiences, swimming, arts, and crafts. Providing options for both group interactions and individual activities, along with attention to night-time routines, was considered essential.

**Personal care and medical support:** The capability to manage complex medications and handle medical emergencies is non-negotiable for families. Appropriate personal care equipment and an understanding of individual routines were equally vital. Proximity to local hospitals for emergencies was also stressed as important.

**Communication and trust:** Regular and transparent communication between providers and families is crucial. Families suggested using communication diaries and providing updates on activities and incidents. Pre-visit meetings, detailed care plans, and clear documentation were identified as essential practices to build trust.

**Impact on families:** The lack of adequate short break services is taking a toll on families. Many reported increased stress, health issues, and financial difficulties due to the current service gap. Families expressed the need for respite opportunities to manage daily life and attend important events.

**Service flexibility:** Flexibility emerged as a key requirement, with families seeking services that can accommodate varying stay lengths, emergency respite needs, and advance bookings. Compatibility among user groups and the ability to adapt to individual routines were also seen as critical.

**Funding and access:** Families highlighted the need for clearer and more accessible information about funding and services. Simplified application processes and consistent support from social workers were frequently mentioned as areas for improvement.

**Historical concerns:** The closure of the Elmville facility without an adequate replacement deeply affected families. This experience has left many concerned about transparency in service changes and the future provision of short breaks.

**Future requirements:** Looking ahead, families envision local, purpose-built facilities staffed by professionals who prioritize safeguarding and individualized care. They emphasized the need for programming that balances activity and rest, tailored to the unique needs of each individual.

The consistent message was the need for local, well-staffed, properly equipped respite services that can meet complex needs while providing reliable support for carers.

We began by analysing the initial insights and recordings, which led to the development of a comprehensive list of principles and key elements. In this context, the **principles** represent the 'what' — the core values and goals we aim to achieve. The **elements** are the 'how' — the specific actions, methods, or steps that will help us implement those principles effectively.

## 8.2 Key principles

All the feedback gained so far in the process had been distilled down into eleven **principles/ways of working** that provided the basis for further discussion. There were:

- Person-centred care
- Professional excellence of staff
- Safety and security
- Accessibility
- Communication and trust
- Fun
- Family support
- Continuity of care
- Inclusivity
- Flexibility
- Professional standard

### 8.3 Key elements

These insights were put into a list of twelve **key elements that they wanted to see** in a short break service which provided the basis for further discussion for the co-design session to be held later that week.

- Physical facilities
- Medical support
- Personal care facilities
- Activities and equipment
- Trained staff
- Security features
- Communication systems
- Accommodation
- Dining facilities
- Transport
- Technology
- Community access

## 9 Co-design session 13 December 2024

This session focused on building on learning from the earlier session and working together to co-design principles and a model for future short break services.

Following good co-design practice, attendees were organised into three groups which allowed smaller discussions and reported back into the wider group.

Each group discussion facilitated by Stand and included at least one family who attended the residential trip.

As well as the families and the people with learning disabilities, stakeholders and partners were invited to attend including:

- Working group members including a commissioning officer with lived experience.
- Stakeholders from Cumbria, Northumberland, Tyne and Wear (CNTW) Trust
- Representatives from North East and North Cumbria Integrated Care Board (NENC ICB)
- STAC Stakeholders from South Tyneside Council
- Representatives from South Tyneside and Sunderland NHS Foundation Trust (STSFT)
- Team members from Twisting Ducks

Tables featured an even mix of families, project team members, and stakeholders, who guided families by listening and asking thoughtful questions.



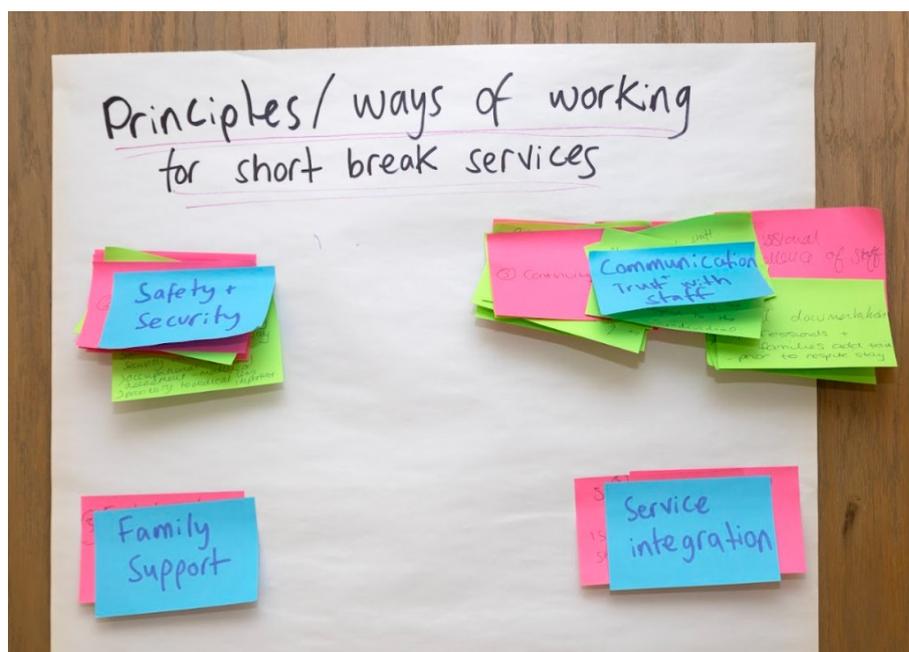
The first activity involved reviewing the list of eleven principles which were developed in the feedback session held earlier in the week and families were asked to debate and discuss which were the five most important to them.

The second activity focused working through the list of twelve key elements which families considered to be important in a new model, prioritising them as high, medium or low priority and for each element defining 'what good looks like' for it. Families did not categorise any elements as a low priority.

The project team provided an overview of next steps and answered any remaining questions.

## 9.1 Principles/ways of working for short break services

From the list of the principles/ways of working from the feedback session the families determined five principles most important to them.



### Communication and trust with staff

This brought together the principles of communication and trust, professional excellence of staff and continuity of care. This was put forward by every table.

- There is a minimum expectation that staff are well trained to fulfil accessibility needs and provide medication.
- They want transparency on how policies and procedures work and how they are suitable/adapted to the individuals. They would want investment in understanding this pre-respite care and link this to a good documentation of these needs, which is transparent for the families.
- Continuity of care is very important, that the staff know the individual well, and their likes and dislikes. In cases where there is a change, there should be an in-depth handover.

*“She struggles with new faces and would feel safer with familiar faces.”*

## Person-centred care

This brought together the principles of person centred care, accessibility and inclusivity. This was put forward by every table.

- They want to know what equipment and set up is available beforehand and this is adapted based on a prior conversation between families and staff on what an individual likes, wants and needs.

*“She wants to be out of the wheelchair, so would need to consider something to help with comfort on the floor.”*

## Safety and security

This was put forward by all tables.

- Families need to feel reassured that individuals are looked after linked to their needs, both in the set-up of facilities and the training of staff.
- Proximity to medical facilities is less important. It would be ideal if there were medical staff on-site, in a non-hospital environment.

## Flexibility

This brought together flexibility and family support. This was put forward by two tables, but agreed to be important by the other table.

- They would like the flexibility to swap dates to attend family/friend engagements such as weddings.
- They would like an option for support for carers and family in an emergency, such as a carer suffering a medical emergency.

## Service integration

This was put forward by one table but agreed to be important by the other two tables.

- There need to be links between short break services and social care.
- There should be opportunities for additional community-based activities.

## 9.2 What should be included in the design of short break services

During session one, families developed a list of what they wanted to be included in the design of short break services. In this session, they were asked to prioritise eleven key elements into high, medium or low priority and to tell us “what good looks like” from their perspectives.



High priority	What good looks like
<b>Clinical support</b>	Appropriately qualified and properly trained staff to do the role and ensure they can deliver on a bespoke care plan.
<b>Personal care facilities</b>	Clean, spacious areas with good wheelchair access, transfer facilities with flexibility of equipment that as much as possible mirrors the range that they have at home.
<b>Security</b>	Secure boundaries and appropriate CCTV for the protection of individuals and staff when used in the right way.
<b>Accommodation</b>	Profiling beds, ceiling hoists and accessible bathing facilities. Emergency call and locking system on doors to prevent unsecured access.
<b>Trained staff</b>	Needs to feel safe and secure with staff. Ensure they are qualified and trained to make the right decisions and they have an understanding of the individual's needs and routine. Values of the staff member are as important as skills/qualifications, making sure that they 'feel right'.
<b>Communication systems</b>	Good communication between staff, carers and families is essential. Ensure that there is a clear and understood process for handover between staff, such as clearly displaying previous and following days activities.

Medium-High priority	What good looks like
<b>Physical facilities (sensory rooms)</b>	Places to relax and the opportunity to listen to music that is accessible to everyone.
<b>Family support</b>	A good long term, pre-plan and book-in system for both planned and short notice provision.
<b>Specialised activity zones</b>	Having appropriate staffing to support a range of enjoyable activities.

<b>Activities and equipment</b>	Provide the opportunity and ability to go out and about and they are accessible including soft flooring and trackways.
---------------------------------	--

<b>Medium priority</b>	<b>What good looks like</b>
<b>Transport</b>	Need for availability for families who do not have transport and the provider needs to have accessible vehicles.
<b>Dining facilities</b>	This is very personal and depends on the individual. Therefore it needs to be a nice place to eat with the right equipment and choice of food depending on individual preferences.
<b>Additional support services</b>	Opportunity for additional support depending on the needs and choice of individual and carer, such as offering massage therapy.
<b>Community access</b>	A variety of community spaces on offer such as parks and water activities as well as shopping centres and others places to go.
<b>Technology</b>	Technology such as WiFi and entertainment systems in individual rooms can meet the communication needs and are available and accessible to all.



## 10 Appendices

The appendices can be found as an accompanying document with this report.

Appendix 1 – Situation review

Appendix 2 – Survey for families – short breaks

Appendix 3 – Other accessible respite or short break options