SHARED CARE SCOTLAND
East Lothian Health & Social Care Partnership
East Lothian Council

Holidays or isolation?
A local perspective

Contents

Introduction

In April 2020 Shared Care Scotland published a piece of research called “Holidays or Isolation”[1] which highlighted the experiences and challenges faced by disabled children, young people and their families over the holiday periods. In East Lothian we aimed to build on this and understand what would make a difference in accessing holiday activities locally.

Parents and carers of children with additional support needs have caring responsibilities which are often over and above parents of other children and while parents can generally find it difficult to find suitable childcare or things to do, especially during the long summer break, those with children with additional support needs are further disadvantaged by significant lack of activities and spaces they can access. Instead of looking forward to holidays this can be a very stressful and potentially lonely time with some parents describing how they feel stuck in their homes.

This discussion comes at the time of significant promise to carers with the legal right to a break having been given royal assent and implementation set to take place over the course of the next parliamentary term.

To deliver this fundamental right for carers of young people with additional support needs will need significant investment. But firstly, we need to hear from people with experience to understand what will make a difference.

We thank all those that contributed to the surveys, sessions and discussions, especially the young people, parents and carers but also those from local organisations who expressed such genuine desire to make things better for people locally.

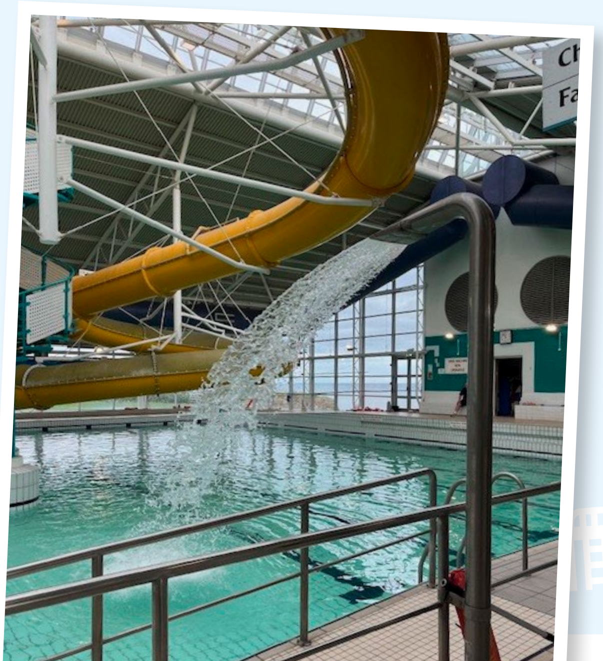
This was very much a joint piece of work between East Lothian Health and Social Care Partnership and Shared Care Scotland. Together we were able to engage young people, carers and providers to think about the design of local spaces and activities and come up with solutions to improve people’s experiences.

Local context

Feedback from local carers and organisations supporting carers has been telling us that families are finding it difficult to do the things others might take for granted like going to the park, having a day out together at a local attraction. Finding childcare/activities that are suitable for young people with additional support needs during the holidays is also particularly challenging.

Data from the 2024 pupil census shows that 2,749 or 32.81% of children in East Lothian’s primary schools have additional support needs rising to 2,961 or 44% in secondary schools. These figures reflect a wide range of additional support needs but show how many families this affects and highlight how big an issue this is.

This work aimed to explore that with young people, carers and providers of activities and then think about what could be done to improve these families’ experiences.



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[1] **https://www.sharedcarescotland.org.uk/media/wpkkeefw/holiday-activity-provision-research-report-2020.pdf**

Methodology

The Health and Social Care Partnership (HSCP) strategic planning and commissioning officer was keen to explore carers experiences around holiday activities after informal feedback highlighted this as a significant area of stress for parent carers, the potential project was raised with children's services to discuss engagement with this group. Carer support is delegated to East Lothian Integrated Joint Board (IJB) and therefore delivered by the HSCP, whereas support for children and young people is not delegated and is managed by East Lothian Council (ELC).

It is very clear therefore that carer support cannot be improved without improving availability and access to supports for the cared for person so we were keen to work together from the start. Children's services suggested involving Families Together, an ELC team who provide tailored support to help deal with some of the challenges that come with family life. It was noted that 53% of the families they work with state neurodiversity as the main reason for needing support and many more report other additional support needs. East Lothian HSCP approached Shared Care Scotland as Scotland's leading organisation supporting breaks from caring with the initial project plan and they have been a key partner, offering invaluable ongoing support in both planning and delivery of this project.

Project team members: Kate Hogarth and Christopher Hooper, Shared Care Scotland Chief Executive and Head of Operations; Maria Burton, ELHSCP strategic planning and commissioning officer; Jillian Peart, ELC Children's services Service and practice development officer; and Zoe Thomson, Participation officer, ELC Families Together.

The initial plan was to hold a series of four sessions; one for young people, one for carers, a provider session and a final provider and carer session designed to come together to share experiences and look together at potential solutions.

One of the most important discussions was how we would engage with people that had a wide range of experiences. We knew from providers that young people and in particular carers were keen to share their experiences but we were very conscious that we wanted everyone taking part to be able to share their experiences openly and without concern about impact on a specific service or support they access.

We chose not to approach young people and carers through providers they were already linked up with for this reason, but also because we wanted to hear from those who might not yet have experience of or had experienced barriers in accessing support. Young people and carers were approached more broadly and providers were offered the opportunity to get involved through our local Children and Young People's Network which is facilitated by our third sector interface.

The whole programme of engagement was intended to take place after the summer holiday period so that people's experiences were fresh in their minds and they would have the chance to reflect on what could have made this a better time for them.

Young people's session

The Tartan Class base is a specialist education provision based at Tranent's Ross High. We approached this group as they have a range of different support needs, experiences and children attending from across East Lothian. We were able to go to the young people in their own environment where they already felt comfortable and designed an activity to support the discussion around what they did during the summer holidays and what else they might have liked to do. Zoe and Jillian facilitated this session, hearing from 10 young people of early secondary age. The young people designed posters for their perfect holiday club while staff supported 1:1 discussions.

Zoe and Jillian met with teaching staff prior to the session to make sure this activity was pitched at the right level for the young people taking part and to discuss any communication needs. The class teacher was also part of the session and supported pupils to participate too.

Carers session

We were very aware of consultation fatigue among carers and aimed to make the session accessible for carers, initially scheduling this to follow school drop off at the school many of the children attended. Carers were invited, both the parents of the young people that had participated and other families known to the Families Together team. Invites were accepted from eight parents and carers but a number dropped out in the lead up and on the day before as a sickness bug effected the children at the base so parents were required to support them at home. This reinforced what we know about pressure on carers of young people with additional support needs with many already juggling work and caring responsibilities and led us to re-evaluate our approach.

Zoe offered carers the chance to have a 1:1 or small group discussion as an alternative and through this heard three carers in depth experiences.

Carers also confirmed that while they would like to hear from and meet with providers they were not going to be able to attend a follow up session so this approach was also revisited.

Maria and Zoe approached the local carers organisation and other local organisations supporting families of children with additional support needs with the aim of offering more 1:1 or small group discussions through their existing groups. The carers centre parent carer group no longer have a regular meeting and other local organisations did not choose to spend their limited sessions on engagement.

The carers centre shared their experience that although response to surveys can be low, they had previously had good response to surveys from the parent carer group and had feedback that this was an easy way for working carers to share their experiences so we did a short survey through the carers centre and other local organisations offering support to families with additional needs and neurodivergence leading to 34 responses.

Provider session

Providers were initially invited to two sessions with the intention of the second session coming together with carers, sharing experiences and finding a shared understanding under which to come up with potential solutions. With the carers availability the providers session was reworked to include thinking about solutions and a discussion about how information from each group could be shared. As many local organisations have developed and are led by parents who have recognised gaps and developed services or activities in response to this many also had personal experience as carers of children with additional needs.

Five organisations were represented by eight participants. Feedback was very positive with one participant sharing *"it was so uplifting to be in a room full of likeminded people. The desire and passion to see change happen was really motivating and feels like the start of something exciting"*.

What we heard

Young people's experiences – the Tartan Class

This was a short one-off engagement session with students with additional support needs to understand what they would want from holiday provision.

The class members were asked to make a poster for their perfect holiday club, whilst they were chatted to individually about their experiences.

Most of the young people talked about activities and things they like to do rather than naming specific places or providers.

Places young people mentioned were added to our map of spaces and activities in East Lothian **(purple for younger people)**.

We know there are differences between young children and children of secondary school age as parents take less of a lead in organising and supporting activities and get togethers between friends, but for this group of young people who may be less able to organise things independently it can be difficult just to get together with friends outside of school and they are less able to go along to a youth club, to go to the forest or to arrange to meet somewhere.

What came out very clearly was that these young people didn't want anything their peers don't have: they wanted to be able to spend time with their friends doing fun things. Although they talked about a mix of activities and some were exciting and adventurous, a lot of the time they just wanted space and time to hang out together and chill. Young people mentioned specific activities such as learning to play an instrument or how to perform circus skills, but they also spoke of being in the woods in a hammock or sitting around on bean bags.

From what the young people told us they often didn't know what was out there for them or what they might be allowed to do or go to which suggests there could be improvements in information sharing about local resources, especially information that is accessible to these young people and their families.

We asked – What would a good holiday club look like?

Young people said:

- Lots of different activities
- Mixture of exciting and adventurous activities with more chill ones
- Focus on snacks and food (hotdogs)
- Not sure about duration

We asked – what places or summer clubs you did go to?

- Young Base camp
- Bank foot
- Venturing out
- It could be a dancing club
- Wave project

We asked – What would have made the holidays better?

Young people said:

- Crafts and other activities
- Tables of food
- Sunny at the beach (nice weather)
- Having options (quiet space and free time)
- Hanging out with friends

We asked – What got in the way of doing the things you wanted to?

- Didn't know the activities existed
- It doesn't exist unless it's mainstream
- It doesn't exist
- I don't know what I am allowed to do

Other things young people said

- I want to sit on a bean bag and hang out
- I want to read my book in a forest

Carers experiences

The overall feeling from carers was of a very difficult time with limited choices of places to go and things to do that suited them and their children with additional needs.

Carers described feeling restrained, restricted and stuck with many feeling universal activities were not possible for them but that there was a lack of more specialist supports and competition for places in what specialist provision is available.

> “There was nothing for him to go to and it was pure hell.”

> “Even when we are off there is no where to go to with H to meet similar people and join in activities. It is very isolating and depressing.”

> “I have a 14 year old son who is autistic, as well as three much younger neurotypical children aged 7,6 and 4. Summer is very challenging. The playparks are excellent but my autistic son finds them overwhelming, I’m constantly balancing his needs against those of my other children.”

Carers described their arrangements to allow them to continue working during this long holiday period.

Where there were two parents in the household, they often split their annual leave in order to provide care, meaning there was nothing left for time together as a family. Others talked about having to take children to work with them or to get extra help from other family members, however there was a feeling that other people couldn’t cope with children’s needs and this often didn’t work for families.

> “A low point for me was the worry I felt on the lead up to the holidays and making sure all the childcare was covered. And as my children are getting older this is becoming harder.”

Where parents and carers were on their own or families felt children’s needs could not be met by any supports the strain was obvious and sometimes meant that families didn’t go out much at all, really impacting on the mental health of both the young people and their carers.

> “We spent most of the summer trying to juggle work and childcare. We can’t take the whole summer holidays off work so it’s really difficult to fit in time for any fun activities. Have to take my autistic child to work some days.”

> “Summer was very challenging for us. As a single parent of 8 year old autistic twins and a 5 year old, I had no extra support and had to manage everything on my own. Most days were spent at home because going out with three young children, two with additional support needs, is very difficult.

> I don’t know if my kids are aware of the struggles I face as I want them to be as carefree as possible. I try and have dedicated time for each of them, but I worry my lack of time will affect them in the future.”

Lots of families did share their experiences of spaces that work well for them. Places carers mentioned were added to our map of spaces and activities in yellow.

What came across was that sometimes simple accessibility features can be the difference between a family being able to enjoy some time together or not. Many families mentioned places that were too busy for their children to cope with or spaces that didn’t allow them to relax, for example because they didn’t have the right changing facilities, or were not secure. Some families shared that their young person was ‘a runner’, and that brought particular danger/vigilance, They shared examples of places where these kind of needs were supported and the difference that made.

> “Ormiston park is great as it has the safety harness in a safe locked box and with the radar key you can unlock the box and get the harness so our child can safely use the swings.”

> “High point was going to yellow craigs beach. We had a BBQ and watched the sunset. Everyone was happy and all their needs could be cared for. There is a path to push the wheelchair up and a table we can all sit at. There are also toilets for everyone to use.”

Although we heard about lots of places and spaces that work well for families and young people with additional needs there were also lots of other families who stated that there was nothing suitable for them. Often they didn’t have the information about places and activities that might work for them or they didn’t think their young person could access what was on offer. Additionally they reported feeling that there was so much competition that they would never get a space in more specialist activities or provision.

A lot of feedback told us that families are looking for places and spaces that will provide additional support need (ASN) specific or quiet sessions. More venues are offering these as local people want them and many find going to somewhere like the swimming pool or softplay too busy and overwhelming at times they are open to all.

Parks and outdoor spaces are generally really well used but some small changes could make this so much less stressful for families, for example having a play park that is fully fenced or a swing that is truly wheelchair accessible. People described playparks that were accessible in themselves, but couldn’t be reached by wheelchair because of unsuitable surfaces in the wider area.

But families also want to go the places everyone else can safely and without constant worry, especially where they are balancing the needs of different children.

Families really felt the inequality of caring for a child with additional needs compared to a child without additional needs. They told us how other families can drop their children off places while they have to stay because the staff may not be able to support their young person’s needs. They told us how holiday clubs and childcare settings can not meet their child’s needs and therefore they can’t use them to get a break or to work at this time.

Families also described the impact of getting the right support and how this can transform the experience of this time for the whole family.

> “Summer was so nice for our family this year. We had our children in Can Do for the first time and so (even though we both work) we were able to have a breather and feel like we were on top of everything. Like on a Friday, I don’t work, but the girls were still being cared for so I was able to tidy the house and cook some meals ready for the following week. I was also able to go to the gym. This meant that when my wife was off on the weekend, she could spend more time with the kids and also have some of her own time as there weren’t so many chores to do. The first summer in a while I have felt a bit sad for schools to come back.”

> “Pennypit centre in Prestonpans ran loads of activities that were affordable and inclusive, Pennypit sports club – absolute lifesaver for burning off my child’s energy and giving him the opportunity to spend time with peers.”

Spaces and activities map

The spaces and activities map was created over the three sessions with young people adding their activities in purple, carers highlighting things they knew of in yellow, and providers adding theirs in pink.

It shows the cluster of activities around the main towns, and the different levels of awareness of services and activities.

Providers experiences

It was very clear that organisations work really hard to offer a very wide range of options for young people and families. Between them they offer individualised support within a range of services, creating spaces for play, supporting social interaction and family bonding, providing more specialist support and signposting to other sources of support where required.

Providers show a very genuine will and energy to make things better for families in East Lothian and it was obvious that their desire to improve people’s experiences is central to informing and directing everything they do.

However, organisations recognised many challenges in delivering support to young people and families who need it and many gaps that exist.

From what we heard challenges for organisations are along two themes. The first around the high levels of need they know exist within East Lothians communities and the huge variety of needs between young people, with the recognition that one size doesn’t fit all. They are very aware that what is inclusive for one is not inclusive for all, that every young person they support is different and while some for example can be easily over stimulated and need quiet spaces others enjoy noise and lots of stimulation.

Organisations found it challenging to manage the balance between bookable and open access, knowing that families need flexibility to attend and that for these young people and families there are often days that don't go to plan. But on the other hand organisations need to have the right number of staff to support those who do attend and especially where needs are higher the young person and family need consistency and to build trusted relationships with those delivering support. Many offer a number of secured places while trying to maintain a degree of flexibility.

The second was more about the many challenges they face as organisations that make it difficult to deliver more for families and young people locally.

Organisations experience a number of challenges around attracting and retaining staff, from what we know is a small pool of suitably qualified individuals, and in finding volunteers to support their core teams or as board members or directors. A number noted that individual young people and families can become very reliant on one person providing support who may offer support at school or in another setting and then also support out with this, as a personal assistant for example. Staffing challenges include appropriate time for supervision and training and are amplified by funding arrangements meaning staff have insecure roles and may receive late notice of whether projects will be able to continue or not.

Funding arrangements and organisations experiences of the cycle of applying for funding are a key challenge to all third sector organisations and are inequitable with statutory provision. Having to manage short term funding cycles which require a huge amount of resource to make applications and fulfil reporting requirements mean organisations spend huge amounts of time in management of these tasks where with more certainty and longer term funding they could use this resource to more effectively plan and deliver services.

While some organisations had specific guidance around who they were able to support others tried to be open to all. This means between them they are reaching a range of people but they also recognised different groups they felt unable to reach.

Can Do specifically noted that although they are there to support children from age 8 they recognise that due to long waiting lists they are typically only supporting children of secondary school age, meaning there is a gap for younger children with complex additional needs.

> Families moving to East Lothian may have 'aged out' of our pathways and referrals, waiting lists

Similar to feedback from families, providers noted a number of difficulties in accessing local places for activities with play park being a focus for many people. Can Do take groups to Fife to be able to go to a play park that will have something for everyone and although many people have really good things to say about the play parks in East Lothian a lot of the feedback was also around why parks didn't meet the needs of young people and families. We know that there is Scottish Government funding which is being targeted at regenerating outdoor spaces. However, feedback tells us that this is not adequately informed by the experience of those who use these spaces and understand what works.

> "There is not one disabled access swing in East Lothian."

Everyone who attended recognised that those families most in need may not have the energy or capacity to navigate the complex systems and access support, this may be a particular challenge where children aren't attending school and are not well known with opportunities for outreach provision very limited and resource intensive.

They thought families should have access to the same kind of training that they do as a work force, when schools or services cannot meet the young persons' needs or the young person has a 'bad day' parents are often asked to step in but they are not offered the same opportunities for training in understanding the young person's condition and strategies to manage behaviours that are really challenging.

Providers also talked about what organisations see as opportunities for them, what support might be needed for them to flourish and what the partnerships prioirities should be around supporting providers like them.

People felt that one of the biggest opportunities was to ensure that future improvement work actually met the needs of those it was intended for, members of the group were very keen that upgrades and changes to spaces, including access and sensory elements actually meet the needs of families and that they use their voices to ensure this happens.

> "If we could make one space in East Lothian that was an example of true accessibility and inclusion it could be held up as an example others could follow."

What we have learned

Although we already know that holidays are a difficult time for families of children with additional support needs, what really came across was just how hard it is and how this impacts on the whole family.

The lack of access to places and activities means many families of children with additional needs have to ensure they can be around for their children for the whole holiday. This has a huge impact on carers ability to work and on families spending any time together.

Lots of families shared their experiences of spaces that work well for them and how staff at different places can make a huge difference. Sometimes simple accessibility features can be the difference between a family being able to enjoy some time together or not. Both carers and providers told us about the problems of a lack of secure spaces in East Lothian and the difference an accessible swing would make or a fenced park.

Where families told us there was nothing available to them or that they didn't know where to start some of this could be addressed through better information sharing.

In summary, families need us to do more to make the places and activities we all go to more accessible and welcoming for children with additional needs but also to increase ASN specific sessions and specialist provision to meet the needs of those with more complex disabilities.

What happens when it works

One of the most striking points was hearing from families who described the impact of getting the right support and how this can transform the experience of this time for the whole family. The comments below highlight how being able to access the right support changes everything for the young person, parents and carers and other family members.

> "This year we smiled our way through the holidays. Our daughter was an entirely different person compared to how she's been in previous years. She was happy, stimulated, slept quite well, enjoyed being in the company of other young people. She thrived on the routine which she desperately needs every day, her confidence grew in a way we didn't expect to see, and she had very few meltdowns. My husband, who works from home, was able to focus on his job without the distractions of her meltdowns or upset and didn't have to take time out of his demanding schedule to help support me. I didn't feel as if I was going to break mentally or physically and for the first year didn't get so burnt out that I fell ill. My son didn't have to watch his parents fall apart, or feel helpless watching his sister become so dysregulated that she was self harming.

> It made a huge difference.

> In complete contrast, every year prior to this year has been absolute hell. My daughter cannot cope when the routine of school and all that it brings is suddenly taken away from her. Despite my best attempts to give her what she gets from a school environment (structure, routine, interaction with other young people or adults), every single year I've failed. She has become angry, upset, self harms, doesn't sleep and generally an extremely unhappy girl.

> This year has highlighted the huge difference having holiday support in place can gave for a child like my daughter. It is bittersweet because after years of battling against the system and fighting for more support as we go through trauma after trauma during the holidays, we were finally given a taster of how it could have been. I truly believe that if she'd had that support from a much earlier age, she would be better equipped to deal with social situations and environments. My daughter (and my family) have been failed year after year by the system who absolutely did not get it right for her."

The challenge to services is how do we deliver this kind of experience for more families and reduce the numbers feeling alone, isolated and overwhelmed.

Next steps and what we will do locally

Our aim is to ensure more young people and carers are having these positive experiences, that getting the right support allows them to have a little space, to do things they enjoy as individuals and as a family and to find joy in spending time together.

Experiences gathered through this work have already been used as part of the children's disability service review. The review now *"has a delivery plan with actions on how to expand flexible support and choice for families, explore holiday provision, expand voice in our service planning and delivery and intelligent use of data. Our actions are focussed around best use and value of the resources we currently have, working in partnership and developing choice in supports for children and young people affected by disability in East Lothian."*

In line with the feedback around access to specialist play schemes *"East Lothian Council's children's disability service are exploring options to provide more options for children with complex needs over holiday periods."*

We have made the first steps in creating a playpark advisory group, bringing together a group of providers and carers with the aim of ensuring local improvements meet the needs of different families.

We will share the information gathered here by young people, carers and providers with our third sector interface who have committed to a new locator app and promote this so that families know where to find out about what's on in their area for everyone and for families supporting someone with additional needs.

Everything we have learned will inform East Lothian's local carers strategy, published in June 2026 and the actions that will be published.

Breaks from caring is already a priority outcome in East Lothians current carers strategy but what we have heard through this series of conversations tells us that carers of children with additional support needs have to be a focus of this work and that we need to work with our partners in to increase access, specifically during holiday periods but also across the year, so families don't face this inequality and dread but can plan for and enjoy these times together.

As implementation of the carers right to a break progresses under the Care Reform Act we will push for sustainable funding to allow third sector organisations to focus on delivering support and meeting the needs of the individuals they have come together to support.

APPENDIX 1:
Young peoples session

Holiday Provision Engagement Session Plan

Who: Tartan Class (Ross High)

Where: Ross High

When: After summer break (TBC)

What: A short one-off engagement session with students with additional support needs to understand what they would want from holiday provision.

The class can make a poster for their perfect holiday club, whilst they are individually asked questions.

Questions:

- What do you in the school holidays?
- Or out of school, what fun things do you like to do?
- What’s fun?
- Spend your free time?
- What did you do during the summer?
- Could some pre prep be done?
- What did you do with specific services/ summer clubs? Be lead by earlier conversation.
- What would a good summer holiday club look like to you? How would you get there? What would you do? Who would be there? Where would it be?
- Even better if... Ensure expectations are set.
- Is there anything you would have liked to have done that you couldn’t do?
- Any barriers?

APPENDIX 2:
Carers discussion prompts

Holiday activities for children with additional support needs

Carer conversations

Why we're asking you?

We want to understand what opportunities are available in East Lothian for young people and their carers to access over holiday periods and think about what we can do to make activities and spaces more accessible. We are talking to young people, carers and providers of activities to try and build a picture of what we have and how we can make things better.

This information will be used to inform the updated carers strategy due in 2026 and as part of childrens services review of provision for children with additional needs.

Remind carers all responses will be anonymous.

Questions

SECTION 1, what was your experience?

- What was summer like for you?
- What did you do in your holidays? (prompt to think about what enabled carers to do things, informal networks, good places to go, playparks etc) Who was involved? What else are you aware of? Anything you wanted to do you couldn't, why?
- If conversation lulls, what was highlight and low point?
- What benefit/ impact did that have on you/your child, wider family, siblings etc

SECTION 2, what could make it better?

- What would even better look like?
- Managing expectations, what else would you like to see?
- What could make things easier to take part in?
- As a closer, What single change would make the biggest difference

APPENDIX 3:
Carers survey questions and responses (raw data)

1. Please tell us what summer was like for you. What did you and your child do during the holiday period? – Summer activities
2. In addition to the above, are there any other places / activities that you would recommend to families with children with additional support needs? – Your recommendations
3. Were there other things you wanted to do that you couldn't?
4. How did the holiday period and access to different places and activities impact you?
5. What could make the summer holidays better for you and your child?

APPENDIX 4: Carer information sheets

Holiday activities for carers of children with Additional Support Needs

Carer Information sheet

You have been invited to take part in a series of sessions where we are aiming to hear from young people, carers and providers about their experiences of the holiday period to share your experiences of the holiday period.

- **What** – Carer session
- **When** – 2nd September, after drop off, 8.30/9-11am
- **Where** – Families Together East Lothian Base, Ross High, Tranent

Please have a think about how the holidays were for you, what you and your child did or wanted to do, what made these things possible or more difficult and anything you couldn't do you or your child would have liked to.

We will work in small groups to hear your thoughts. Everything you share will be anonymised in note taking and there will be an opportunity for you to write down anything you don't want to share with the group.

After this session we will invite you to a second session with providers of activities, we will share your experiences of the holidays and theirs of providing activities and we will try and develop a shared understanding of what works and think about what could make things better for young people and families/carers.

- **What** – Bringing together carers and providers
- **When** – 23rd September, 10am-1pm
- **Where** – Fraser Centre, Tranent, to be confirmed

We are not expecting you to have all the answers but would like to hear your thoughts and for you to share what you think our priorities for improving holidays for people with additional support needs and you as their families/carers.

Tea and coffee will be provided and carers will be given a small voucher as a thank you for your time and for sharing your experience.

We are speaking to different groups to hear from young people, carers and providers about their experiences of the holiday period and the different activities people were able to take part in.

This will inform the Health and Social Care Partnerships updated carers strategy and most importantly the actions we take with the aim of improving carer support at a local level.

If you would be interested in sharing your views we would be happy to come along to an existing group/meeting to have this conversation or to set up a session you could attend.

In advance we would ask you to please have a think about how the holidays were for you, what you and your child did or wanted to do, what made these things possible or more difficult and anything you couldn't do you or your child would have liked to.

Everything you share will be anonymised in note taking and there will be an opportunity for you to write down anything you don't want to share with the group.

We are not expecting you to have all the answers but would like to hear your thoughts and for you to share what you think our priorities for improving holidays for people with additional support needs and you as their families/carers.

We will arrange for refreshments to be provided and carers will be given a small voucher as a thank you for your time and for sharing your experience.

Appendix 5:
Providers session outline

Welcome and introductions

- Purpose of session to gather their views
- Feedback will be anonymised
- Not looking for them to ‘fill gaps’ in provision or put them on the spot
- Honest conversations to help inform East Lothian thinking but also influence RTAB and policy influencing

What would you do with an hour? An afternoon? A week?

- How hard was it to think of something?
- Did they feel pressure to make the most of their time?
- Did they feel like they could be honest?

Encourage reflections on how this exercise would have differed for those with caring responsibilities. Would their responses have been the same?

Introduce your organisation, and put it on the map.

- Building a picture of what provision already exists and what’s available within East Lothian

Breakout discussion 1:

What do you do really well as an organisation? What are the challenges you face?

Who are your main service users? How do you involve them in shaping your service?

Who are you not able to reach? Are there people you have to turn away?
Can you see gaps in provision?

Breakout discussion 2:

What do you see as the opportunities for your organisation?

What support do you need to flourish? From orgs like Shared Care Scotland?

What should the health and social care partnerships priorities be around supporting groups?

Information sharing

Providers were all keen to be kept up to date and will receive a copy of this report. Relationships have been made and organisations are already working more closely together on local actions.