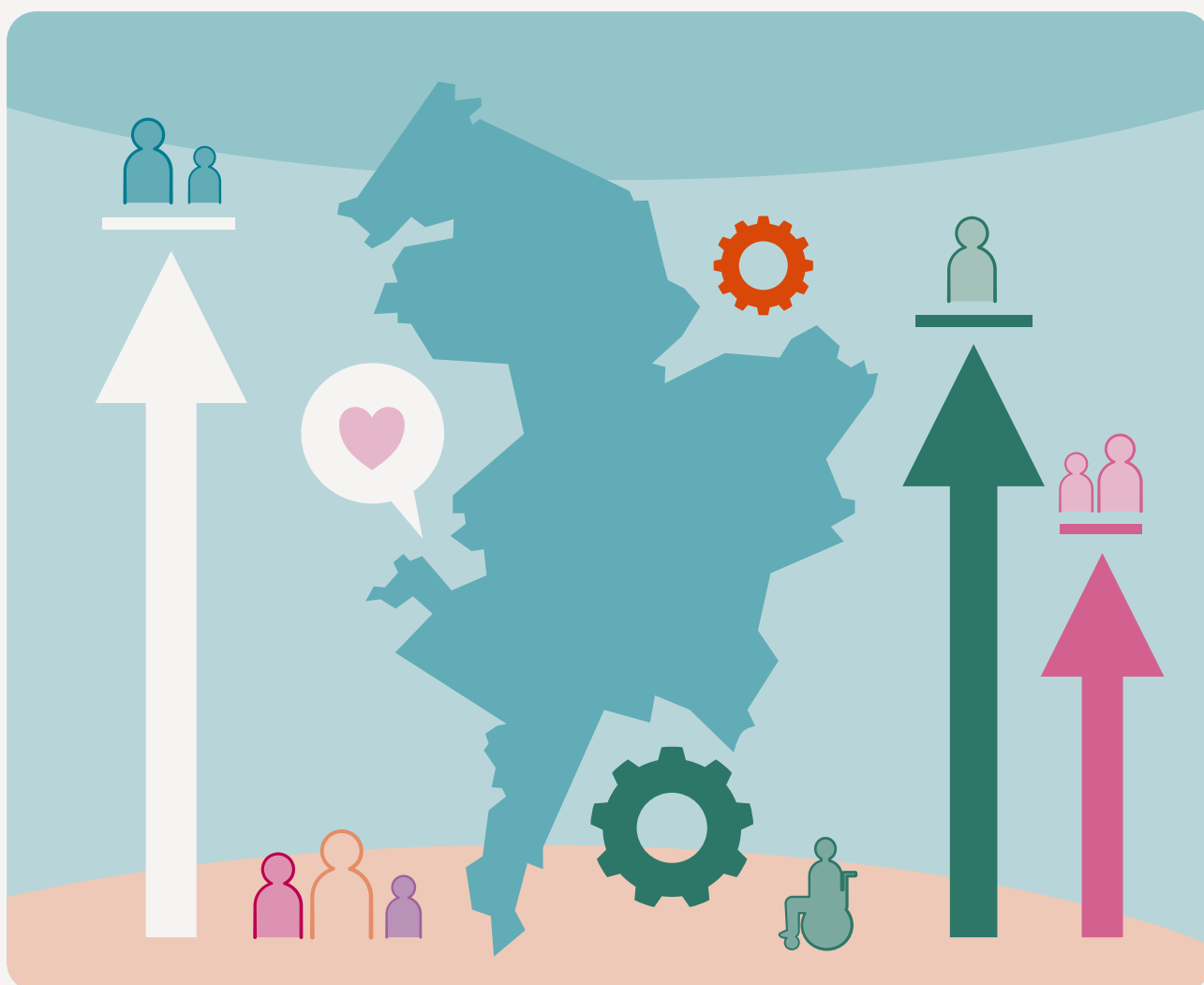


Out of school Additional Support Needs (ASN) services in East Ayrshire:

families' experiences and recommendations for improved access and support



November 2022

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Executive Summary, key findings, and recommendations

This report outlines the findings from a research project commissioned by East Ayrshire Council to understand families' experiences of accessing out of school (or recreational) additional support needs (ASN) services in the local area. Council representatives contacted the Health and Social Care Alliance Scotland (the ALLIANCE) to carry out this work after families engaged with East Ayrshire Council over the summer of 2022 to voice their concerns that ASN holiday provision, particularly for those with high levels of need, did not meet the requirements of children, young people, and their parents and/or carers.

Through engagement with parents, carers, and ASN support staff, the research aims were:

- To gather evidence of disabled children's, young people's, and their families' lived experience in terms of accessing out of school ASN services, over the summer holidays as well as during term time.
- To identify what children and young people with high levels of need, and their families, would like to see change about the out of school support they can access.
- To inform East Ayrshire Council's services commissioning plan to support children and young people with high levels of need, and their families.
- For East Ayrshire Council to work in partnership with children, young people, and families/carers in deciding what are the priorities to improve out of school ASN service provision.

Data collection through one-to-one interviews (telephone or Zoom, depending on participants' preferences) and focused group discussions (both online and in-person) took place from September to October 2022. The following key findings emerged:

- Access to information and support: participants said that it is difficult to find information about available out of school ASN support and other entitlements.
- Suitability of activities: families said that they have often been reluctant to take their children to available activities (including those described as open to children and young people with ASN) as they feel these do not meet their needs. Insufficient amount of staff, large groups of participants, very broad age-ranges, and sensory overload were often quoted as factors that stop families from accessing services.





- Familiarity of location and staff: all participants (both parents/carers and ASN staff) considered familiarity of location and staff to be two of the most important factors to ensure that ASN activities would meet the needs of their children.
- Need for one-to-one support: some families said that their children require one-to-one support to be able to attend activities, whether to provide them personal care, administer medication, or for safeguarding reasons.
- Time of activities: several participants mentioned that a lot of the activities on offer are held at times that are not suitable for parents in full-time employment to take their children, (e.g. mid-mornings on weekdays), or at times that are unsuitable for the children (e.g. film nights during evening hours).
- Understanding of individual circumstances: there was a sense from participants that there was a lack of understanding for each family's individual set of circumstances and needs. Many expressed feeling like the Summer Scheme promoted a general, or 'one size fits all', vision of ASN.
- Holistic family support: participants felt that understanding their children's individual needs would also promote a more holistic approach to providing services, with consideration for the whole family unit's needs.
- Different views on inclusion: a point of contention among participants was on the approach to inclusion that the Summer Scheme promoted. To several families, a vision of inclusion which seeks to bring children with ASN into mainstream settings is inadequate. Others, however, were more in favour of an approach to inclusion which sought to make mainstream activities and settings accessible to all children and young people, including those with ASN.
- Out of school ASN provision is not just about respite or childcare provision: several participants highlighted that out of school ASN provision should not just be viewed as a form of respite for families or a childcare service; rather, they emphasised that it is about children and young people having meaningful experiences, just like children attending mainstream settings.
- Need for continuity of services across the lifespan and improved transitions: most participants said that access to out of school ASN provision is 'not just a summer holiday problem'. Consideration should be given to the fact that ASN services and supports need to be made available to children and young people throughout term time and other holidays, as well as across their lifespan.

Based on participants' accounts and own suggestions for change, the following recommendations are put forward:

- Establish a clear communication channel with parents (e.g. through Parent Councils) with clear expectations about feedback loops between decision-makers and families.
- Increase the offering of ASN out of school provision, with higher staff to children ratio, in familiar places and with familiar staff. It should be clear in service descriptions what kind of provision will be made available to users (e.g. personal care, one-to-one support, etc.). The groups should be age appropriate.
 - Provision should be available during term time and other school holidays like Easter, not just the summer.
- Understand children and young people's individual needs from the outset (e.g. through a questionnaire), so that staff running activities will know their triggers, medical requirements, etc.
- Make it easier for families to hire personal assistants, whether through social work Offer activities at times that are convenient for working parents to take their children (or make more personal assistants available to take children to activities).
- Provide training on inclusion and ASN to Local Council representatives, professionals, and other decision-makers involved in shaping ASN out of school provision.
- Create opportunities for parents who wish to be part of peer support groups to get together.
- Centralise information about available ASN out of school provision, making it available in accessible formats, and keeping it up to date.
- Allocate a budget for a designated disability / ASN services hub, with a key point of contact within the Council.
- Invest in building respite care infrastructure.
- Invest in building changing facilities in community settings.
- Provide ASN staff training and invest in staff recruitment.
- Continue investing in creating fully accessible recreational areas and community spaces.





- Engage with disabled children and young people, not just parents/carers, to understand their needs and what they would like to see change in the services they access.
- Develop a stronger transitions to adult services plan in the local area.
- Adopt the **Scottish Approach to Service Design** in delivering services (both for children and young people with ASN and those who access mainstream services).

The rest of this report will provide a more detailed background to the project, and the national and local context within which this research was carried out. An explanation of the research design, methodology, and guiding principles is also included, before presenting the key findings in further detail, using participants' own accounts.



Introduction and background

This report outlines the findings from a research project commissioned by East Ayrshire Council to understand families' experiences of accessing out of school (or recreational) additional support needs (ASN) services in the local area. Council representatives contacted the ALLIANCE to carry out this work after families engaged with East Ayrshire Council over the summer of 2022 to voice their concerns that ASN holiday provision, particularly for those with high levels of need, did not meet the requirements of children, young people, and their parents and/or carers. Families also expressed that service provision during the school term and other holidays is often not sufficient for them.

Through engagement with parents, carers, and ASN support staff, the research aims were:

- To gather evidence of disabled children's, young people's, and their families' lived experience in terms of accessing out of school ASN services, over the summer holidays as well as during term time.
- To identify what children and young people with high levels of need, and their families, would like to see change about the out of school support they can access.
- To inform East Ayrshire Council's services commissioning plan to support children and young people with high levels of need, and their families.
- For East Ayrshire Council to work in partnership with children, young people, and families in deciding what are the priorities to improve out of school ASN service provision.

It is important to highlight that this research was carried out while Scotland (and the rest of the world) is still amid the ongoing COVID-19 crisis. Whilst participants were engaged with at a time during which there were no longer any restrictions put in place by the Scottish Government to mitigate the consequences of the pandemic, the impact of school closures, lockdowns, and other restrictions were still discussed by families as having significant and lasting impact on their lives, even in the present context. As other third sector organisations and academics have voiced, "children have suffered considerably as a result of school closures, with the burden falling disproportionately on those with ASN, especially those experiencing additional social disadvantages."¹ In addition to social isolation, impact on physical and mental wellbeing, and widening gaps in educational attainment caused by restrictions, professionals in educational settings have also raised that they have seen an increase in the number of children with ASN starting or re-entering education since the start of the

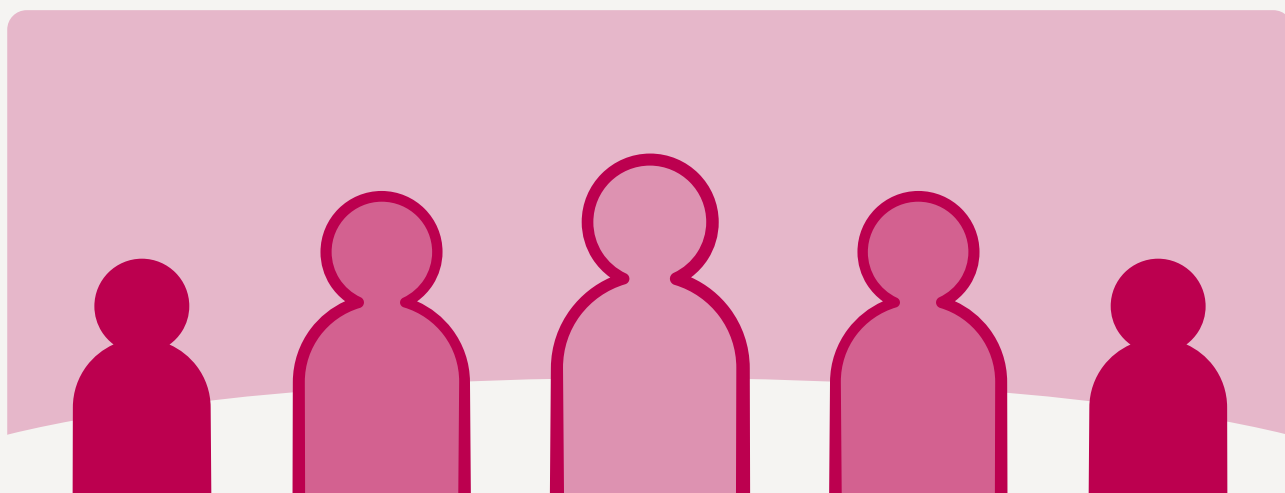
¹ Couper-Kenney, Fiona & Sheila Ridell. 2021. 'The impact of COVID-19 on children with additional support needs and disabilities in Scotland,' in *European Journal of Special Needs Education*, 36:1, 20-34, pgs.32-33. Available from: <https://www.tandfonline.com/doi/pdf/10.1080/08856257.2021.1872844?needAccess=true>

pandemic,² in line with patterns also happening in the rest of the U.K.³ These general trends were reflected in the conversations carried out with participants in this research project, and have also been voiced by key stakeholders in the children's policy arena in Scotland due to the implications that the pandemic has had for children's rights. As the Children and Young People's Commissioner in Scotland has pointed out:



A rights-based approach helps recognise that particular groups of children and young people risk being disadvantaged by COVID-19 and its consequences [...] Children and young people who were already at risk of rights violations, due to such reasons as poverty, being care experienced and/or in contact with the law, from a migrant background and having disabilities or additional support needs. These risks are likely to be amplified.⁴

As will become evident in the 'Findings' section of this report, the research carried out in East Ayrshire shows that guaranteeing that adequate ASN support is provided to those who need it is also about ensuring that children's right to childhood is recognised and upheld.



2 The Times Educational Supplement. 2020. 'Call for more ASN resources as pupil numbers rise again.' Available from: <https://www.tes.com/magazine/archived/call-more-asn-resources-pupil-numbers-rise-again>

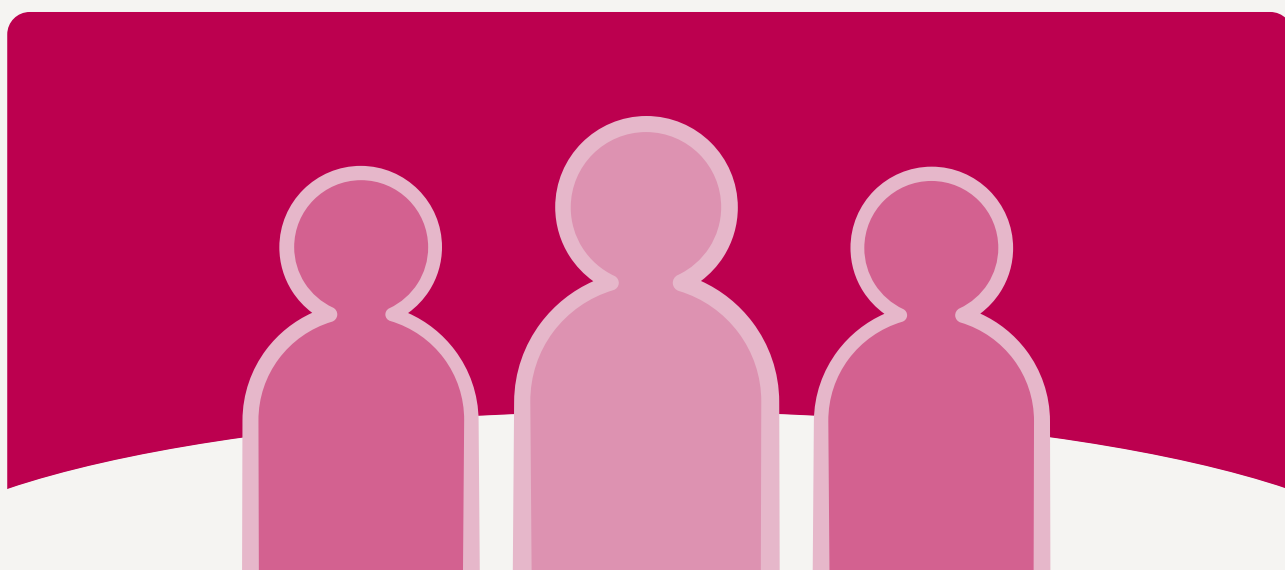
3 BBC News. 2022. 'Child speech delays increase following lockdowns.' Available from: <https://www.bbc.com/news/education-63373804>

4 Observatory of Children's Rights in Scotland & Children & Young People's Commissioner Scotland. 2020. 'Independent Children's Rights Impact Assessment on the Response to Covid-19 in Scotland,' pg.48. Available from: <https://www.ed.ac.uk/sites/default/files/atoms/files/mh-cria-2020.pdf>

Children and young people with ASN in Scotland

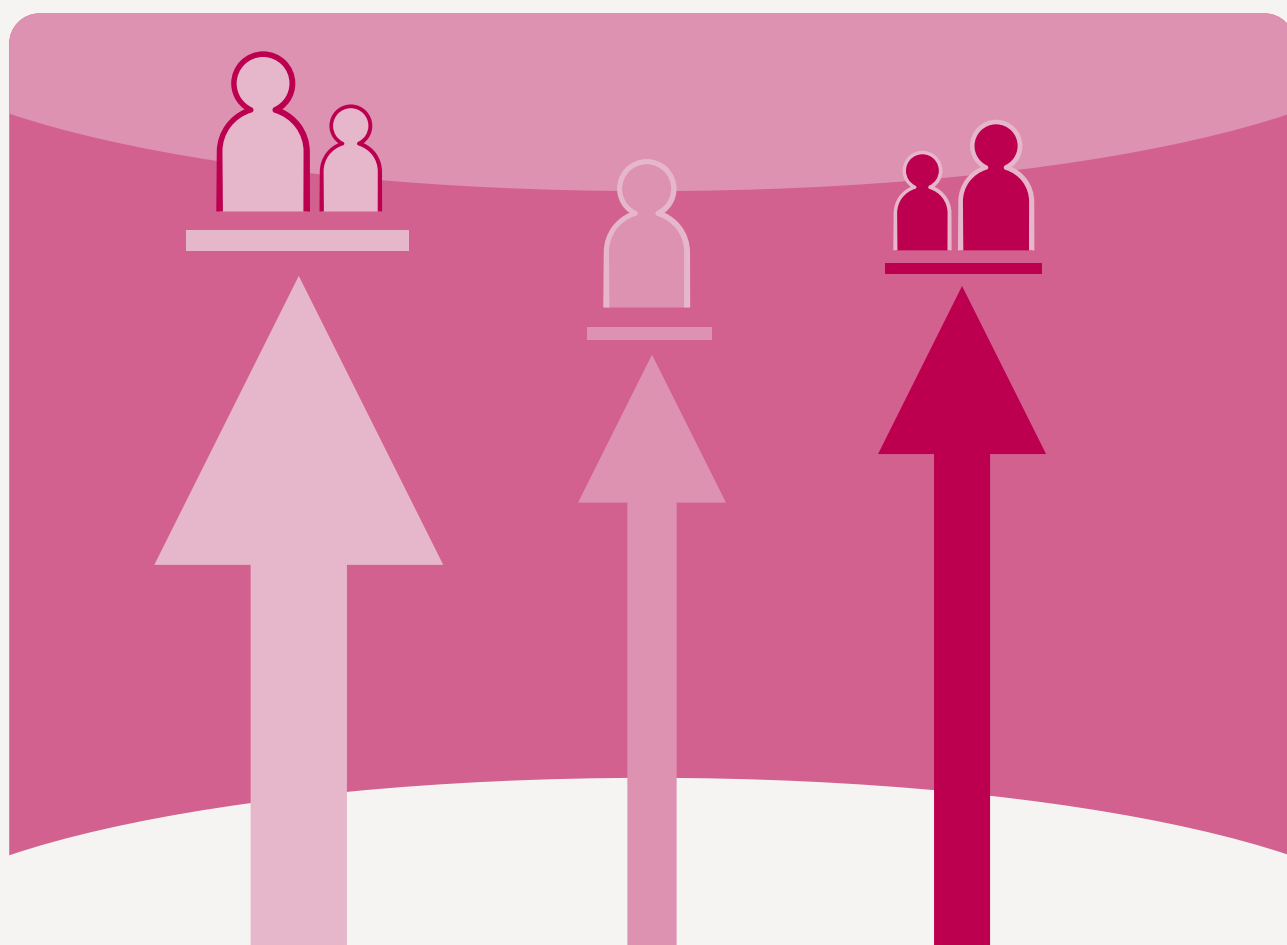
The latest statistics for Scotland show that there were 232,753 children and young people with ASN recorded in 2021 (33.0% of all pupils),⁵ and 14,210 children with ASN registered to Early Learning and Childhood Centres.⁶ In East Ayrshire, there are currently 4,910 children and young people recorded as having ASN; this includes children registered to Early Learning and Childhood Centres that have access to the local authority's education management recording system (private providers do not currently have access to this system).

Within an educational context, the definition of 'additional support needs' follows the term introduced into law by the Education (Additional Support for Learning) Act 2004.⁷ Within this definition, there are four areas that are identified as requirements for additional support to be provided to a child or young person: the learning environment, family circumstances, disability or health needs, and social or emotional factors.⁸



- 5 Scottish Government. 2021. 'Summary statistics for schools in Scotland: 14 December 2021,' pg.19. Available from: <https://www.gov.scot/binaries/content/documents/govscot/publications/statistics/2021/12/summary-statistics-schools-scotland/documents/summary-statistics-schools-scotland/summary-statistics-schools-scotland/govscot%3Adocument/summary-statistics-schools-scotland.pdf>
- 6 Scottish Government. 2021. 'Additional early learning and childcare tables 2021.' Available from: <https://www.gov.scot/publications/summary-statistics-schools-scotland/documents/>
- 7 Education Scotland. 2021. 'Education (Additional Support for Learning) (Scotland) Act (2004).' Available from: <https://education.gov.scot/improvement/research/education-additional-support-for-learning-scotland-act-2004/>
- 8 Scottish Government. 2019. 'Additional Support for Learning: Research on the experience of children and young people and those that support them,' pg.2. Available from: <https://www.gov.scot/binaries/content/documents/govscot/publications/research-and-analysis/2019/03/additional-support-learning-research-experience-children-young-people-those-support/documents/additional-support-learning-research-experience-children-young-people-those-support/govscot%3Adocument/additional-support-learning-research-experience-children-young-people-those-support.pdf>

This report specifically looks at the experiences of children and young people who have ASN because they live with a disability or a long term condition. This group includes a broad range of individuals who will all have different, varying, and unique degrees of support needs, including those with profound and multiple learning disabilities (PMLD).⁹ Approximately 0.05 per 1,000 people in Scotland live with a PMLD (about or 2,600 to 3000 people),¹⁰ and will require a high level of support and care throughout their lives. Due to medical advances and improvements in available support and care, people with PMLD are now living longer lives; as such, systems and structures to provide medical and other support to this group need to be made available throughout the life course. It is important to explore the lived experiences of all people with ASN to ensure that they can be supported to reach their full potential, both in childhood and in their adult years.



⁹ “Children and adults with profound and multiple learning disabilities have more than one disability, the most significant of which is a profound learning disability. All people who have profound and multiple learning disabilities will have great difficulty communicating. Many people will have additional sensory or physical disabilities, complex health needs or mental health difficulties. The combination of these needs and/or the lack of the right support may also affect behaviour. Some other people, such as those with autism and Down’s syndrome may also have profound and multiple learning disabilities. All children and adults with profound and multiple learning disabilities will need high levels of support with most aspects of daily life.” Mencap. 2016, pg. 3. Available from: <https://www.mencap.org.uk/sites/default/files/2016-11/PMLD%20factsheet%20about%20profound%20and%20multiple%20learning%20disabilities.pdf>

¹⁰ Brown, Michael, et al. 2021. ‘Transition from child to adult health services for people with complex learning disabilities,’ pg.3. Available from: <https://pamis.org.uk/site/uploads/health-transitions-brief-report-2021.pdf>

Research design, methodology, and participant recruitment

The project was carried out between September and November 2022 by Dr Francesca Vaghi, Senior Development Officer at the ALLIANCE (henceforth 'the researcher') and was designed following a qualitative research approach. The project was developed in accordance with the ethical guidelines of Scotland's Third Sector Research Forum.¹¹ An internal peer review process was in place throughout the duration of the project to ensure that the research was carried out in a robust and ethical way from beginning to end.

A literature review was conducted both before and after data collection, first to understand the general context on ASN provision across Scotland and to inform the design of the research questions, and second to validate the findings gathered by the researcher (e.g. by evidencing that the themes which emerged from the research reflect, and are in line with, broader patterns happening in Scotland, as well as the rest of the U.K.).

The data collection methods were one-to-one semi-structured interviews (carried out over the telephone or on Zoom, depending on participants' preferences), and focused group discussions (carried out on Zoom and in-person). Developing a flexible approach to data gathering was considered important by the researcher; given the various circumstances of participants, particularly those of parents and carers, the intention was to provide enough options and opportunities to allow for everyone who wished to participate to do so.

Recruitment was carried out with the support of a key point of contact within East Ayrshire Council, who circulated the ALLIANCE's call for participants in late August 2022 via networks in the local Education and Social Work Departments. People who were interested in participating contacted the researcher directly by e-mail expressing their interest to take part. Project information and consent forms were emailed to participants ahead of one-to-one interviews and focused group discussions. Some participants returned a signed consent form to the researcher ahead of being interviewed or taking part in the group discussions; in cases where it was not possible for participants to return a completed and signed consent form, verbal consent was sought from participants before engaging. To ensure the anonymity of all who took part, each participant has been given a pseudonym in this report, and any easily identifiable information has been removed. All personal data and information has been stored and handled in accordance with GDPR.



¹¹ Scotland's Third Sector Research Forum. 2020. 'TSRF guide to applying ethical research principles.' Available from: <https://evaluationsupportscotland.org.uk/wp-content/uploads/2021/02/DRAFTTSRF-guide-to-applying-ethical-research-principles-for-conference-pack.pdf>

One-to-one interviews lasted between thirty minutes to one hour and were carried out exclusively by the researcher with parents or carers of children and young people with ASN. These were audio recorded and transcribed by the researcher. Focused group discussions, both online and in person, lasted between one hour and one hour and a half, and were facilitated by the researcher. What people shared during focused group discussions was captured through note-taking, with the support of two ALLIANCE colleagues who took notes during the sessions (both by hand and typed). All data gathering took place between mid-September to the end of October 2022.

Limitations of the study

It is important to note that whilst it is hoped that the call for participants reached as many families and ASN staff members as possible, it is inevitable that some voices will not be represented when carrying out a qualitative research project within a tight time scale. The research findings are considered representative enough of most of the families in East Ayrshire with disabled children and young people, however, it is also recognised that there will be other experiences that may not be accounted for in this report. Additional and periodic engagement with families accessing ASN provision should be carried out to ensure that as many viewpoints are captured and included. Furthermore, engagement should also be carried out directly with children and young people accessing services.



Lived experience, models of disability, and human rights based approaches

In line with the ALLIANCE's vision to put the voice of people with lived experience at the centre, this report's key findings and recommendations are based on what participants shared with us; their accounts are taken at face value, as we consider them to be experts about their own lives and, as such, to be best placed to inform what their needs and requirements are, in collaboration with decision-makers and other professionals.

The ALLIANCE also advocates for the social model of disability; whilst "the medical model holds that disability is a personal problem, situated within an individual and to be overcome by that individual, the social model posits that disability is instead the result of a failure of society to be inclusive or accessible."¹²

In this project, the researcher has chosen to take this concept further and follow the *social relational model of disability*, because it emerged both through literature review and in conversation with families that focusing only on environmental or material changes is not enough to make society fully inclusive. This is particularly true for people with learning disabilities:



the social model overestimates what can be accomplished by environmental changes, for instance for people with severe cognitive disabilities. In disability rights terms, the social model also appears to be better suited for accessibility and anti-discrimination legislation, than types of legislation where [more complex] eligibility criteria will have to play a role.¹³

¹² Disability 101. 'Models of disability'. Available from: <https://disstudies101.com/perceptions/models-of-disability/>

¹³ Tøssebro, Jan, 2004. 'Introduction to the special issue: Understanding disability,' in Scandinavian Journal of Disability Research, 6(1), pg.5. Available from: <https://www.sjdr.se/articles/10.1080/15017410409512635/>

Rather than looking at solutions that are based simply on making changes to infrastructure to address accessibility and inclusion, the social relational model of disability also looks at how relationships between people (not just environmental or material factors) create barriers to access and participation for disabled people and those living with long term conditions. The social relational model:



understands disability to be those restrictions of activity that result from the exercise of the power to exclude: disability only comes into being when restrictions of activity are socially imposed [...] It can then be accepted as self-evident that other restrictions of activity in the lives of people with impairment do arise directly from their impairments.¹⁴

Indeed, this was the understanding of disability that was communicated by research participants in this project. For instance, many believed that a view of inclusion that promotes bringing disabled children and young people into mainstream settings would not meet their requirements, especially for those with high levels of need. As explained in the quote above, this comes as a result of relationships between people rather than material circumstances. For example, many children and young people with ASN will face discrimination and bullying within mainstream environments, or staff members in this kind of setting might not have an adequate enough understanding of all the conditions that disabled children and young people are living with. The social relational model of disability thus tries to take a more holistic approach in narrowing the gap between a person's capabilities and the demands created by their social and physical environments,¹⁵ recognising that "disability is a complex phenomenon, requiring different levels of analysis and intervention, ranging from the medical to the socio-political" and that "disability is not a minority issue affecting only those people defined as disabled people."¹⁶

¹⁴ Thomas, Carol, 2004. 'Rescuing a social relational understanding of disability,' in Scandinavian Journal of Disability Research, 6(1), pg.29. Available from: <https://www.sjdr.se/articles/10.1080/15017410409512637/>

¹⁵ Universell (National Coordinator of Accessibility of Higher Education in Norway). 2018. 'Disability Country Report – Norway,' pg.1. Available from: <https://www.universell.no/fileshare/fileupload/2352/Country%20report%20Norway%202018.docx>

¹⁶ Shakespeare, Tom. 2006. 'The social model of disability,' in Lennard, J. Davis (ed.) The disability studies reader, pg.202. New York: Routledge. Available from: http://thedigitalcommons.org/docs/shakespeare_social-model-of-disability.pdf

Finally, the ALLIANCE follows and promotes a human rights based approach to health and social care, advocating for greater involvement of people with lived experience in shaping the policies that affect their lives (e.g. through co-production).¹⁷

The participants

Eight parents and one kinship carer took part in one-to-one telephone or Zoom interviews. All participants were female. Some participants had more than one child with ASN.

Six parents (one of whom also took part in a one-to-one interview) participated in an in-person focused group discussion held in a community space in Kilmarnock, East Ayrshire. Some participants had more than one child with ASN.

Four ASN staff members took part in an online focused group discussion via Zoom. All participants were female; all worked as classroom assistants and two also worked as personal assistants to children with ASN outwith school hours. All worked with disabled children that had high levels of need.

Families and ASN staff who took part in one-to-one interviews and focused group discussions are based across East Ayrshire, including larger towns like Kilmarnock and Cumnock, as well as more rural areas such as Kilmaurs.

Participants' children were of a variety of ages, some as young as four years old, up to 16 years old. They lived with a range of diagnoses and long term conditions, including autism, cerebral palsy, Foetal Alcohol Spectrum Disorders (FASD), epilepsy, hearing loss, and Downs Syndrome. One of the children was also a wheelchair user. Most of the children and young people attended the local specialised schools, although some attended mainstream settings.

To protect people's anonymity, all participants have been given pseudonyms in this report. No further details about children's profiles have been given, also for anonymity purposes.

Analysis

Following data collection, all interview transcripts and notes from focused group discussions were coded using a thematic analysis approach.¹⁸ This involves searching for and finding patterns in the narratives of participants, which can then be grouped as overarching themes and topics. The themes that emerged from the analysis were then summarised as findings, which are expanded on in the section below.

¹⁷ The Health and Social Care Alliance Scotland (the ALLIANCE). 2017. 'Being Human: a human rights based approach to health and social care in Scotland.' Available from: <https://www.alliance-scotland.org.uk/policy-into-practice/wp-content/uploads/2017/11/ALLIANCE-Being-Human-publication-2017-1.pdf>

¹⁸ For more on thematic analysis: <https://www.thematicanalysis.net/understanding-ta/>

Findings

Access to information and support

Several families expressed that it is **difficult to find information about available out of school ASN support and other entitlements** due to the large number of services offering recreational activities (Council-led, charitable, and private). Participants explained that the information they access they find out mostly through word of mouth or through their own research, the latter which is often time and energy consuming:



[...] you find out about things in dribs and drabs and only if you ask the right people what's going on. I think it would be really useful if there were a central directory of services, or even a 'central disability hub', you know, where people could come and find out what's going on. Because I don't know... you have to go and ask each individual place what it is that they offer, and sometimes that's more energy than I have. And then of course, you have to try and liaise that with the support staff that may be able to take him [...] East Ayrshire is a huge area and there's probably a lot going on, it's just that people need to know how to access it.

- Moira (kinship carer)



There should be more access to recreational activities outside of school for kids with ASN [...] I am trying to [get my child] involved in swimming lessons, and it's through my own research that I found out that there's a club in South Ayrshire that provide ASN swimming lessons, but I feel like it's not publicised an awful lot. And even with things like [the sports club we attended] we don't really have anything that's suited to kids who are on the spectrum.

- Linda (mother)

Families also spoke about sometimes (or often) being faced with **long waiting times to access support from social work**, and having to do **a lot of paperwork to access entitlements**:



Speaking to other parents, I know that they already have a social worker assigned to them, and that's not something that ever happened for [my son], I don't know if that's something I should have handled personally...no one gives you a handbook unfortunately when something like this happens, when your child has a diagnosis. No one tells you what to do, where to go...no one ever said to me, if you have a social worker they will help you get more support, so for us... I'm not where everyone else is because we don't have that yet. I don't even know how I would go about it yet, if it's something I would get through the school or...just contacting them myself.

- Jen (mother)



Lack of support from social work is a major issue within the Council structures [...] social services don't attend meetings with parents and there is a lack of joined up support and communication.

- June (mother)

The difficulty of finding and navigating information about support and entitlements was similarly echoed by participants in a recent project also published by the ALLIANCE, on disabled children and young people's access to health and social care support during the pandemic:



Finding out about the state benefits and supports their children were entitled to was perceived by parents as a process mainly led by them, with some support from social workers. When asked how they find out about the benefits and support they could apply for, the majority of participants mentioned friends, school teachers, and through doing their own research. Parents and children entered the social security system mostly by chance. Many applied for benefits and grants suggested to them by friends, school teachers or neighbours, with only some being contacted or advised by healthcare and social workers in the first place.¹⁹

19 Arias-Urueña, Liliana and the ALLIANCE. 2022. 'Disabled children's, young people's, and carers' experiences of accessing healthcare services and supports during the pandemic: a qualitative research report,' pg.34. Available from: https://www.alliance-scotland.org.uk/wp-content/uploads/2022/08/The-ALLIANCE_DCYP-access-to-support-during-Covid_report.pdf

Suitability of activities

Families said that they have often been reluctant to take their children to available activities (including those described as open to children and young people with ASN) as they feel these do not meet their needs. **Insufficient amount of staff, large groups of participants, very broad age-ranges, and sensory overload** were often quoted as factors that stop families from accessing recreational activities:



[...] the age range is too wide, it's five to fifteen, which is a massive age range, so if you have a child who's in his teens it's not appropriate for them to be in an environment with five-year-olds [...] There isn't always enough staff, and also the staff don't always seem to have awareness of the conditions of the people that they are supporting.

- Shona (mother)



[My child's] attention span isn't there for that long [...] so the couple of times that we did take him [to the sports club] he was left to do his own thing [...] there was only one staff member leading the class so he couldn't spend time with [my child], there were about 15 kids there [...] we felt [our child] was not really getting anything from it [the activity].

- Linda (mother)



[It's important] to have activities in a place that [my son] is used to, like the school, or even in a place where there's no other crowds...the swimming that we took him to, the whole place was shut apart from us in the pool, so it was just four kids and us [parents/carers], and the helpers around the pool, and that was great because I could take him to the changing room and there wouldn't be...my son is terrified of hand dryers, so if we were in a packed place, with stuff like that going on, and people wouldn't understand...people who don't have kids like mine just go to the hand dryer and use it, or talk really loudly, so having somewhere that's quiet is essential I would say.

- Stephanie (mother)



There is a lack of awareness about what the issues are. With a visible disability, like being in a wheelchair, you know what the issues are, like if there are steps instead of a ramp to a building. A disability that is not so obvious is much harder. You want him [my son] to fit in without having to give him a back story. With a hidden disability it's a lot harder, and you don't want him to have a stigma.

- Frances (mother)

Familiarity of location and staff

Participants were disappointed that many of the activities provided as part of the Summer Scheme were in locations unfamiliar to their children, and with staff that were not known or trusted by them. **All participants** (both parents/carers and ASN staff) **considered familiarity of location and staff to be two of the most important factors to ensure that ASN activities would meet the needs of their children:**



[My son] has a hard time being around people he doesn't know, he takes some time to learn new things, and there didn't seem to be that consistent support available to him to allow him to engage in a meaningful way, he didn't get anything from being there, and when we asked him if he wanted to go back it was a very firm 'no'.

- Shona (mother)



[...] the consistency of having something, some sort of summer school, it needs to be run by people who understand my son, like the classroom assistants, that can deal with his behaviour, and that I will be comfortable leaving him there. And they would do days out as well, like take them to the park, take him swimming...all these sorts of things, even just to get food at McDonald's. And it's a really good way for him to see his peers and learn to be with other kids, he's not used to other children...

- Stephanie (mother)



The school staff are invaluable, they are the people who know your child best [...] staff need to be paid well and take holidays when suitable to them [...] Trust needs to be built up with practitioners over several years; off the cuff activities cause anxiety for parents because you don't know who you're handing your child over to. Parents need reassurance before they can pass care on to someone else.

- Suse (mother)



In line with the importance of familiarity of location and staff, families mentioned that **the Summer Scheme in the years before the COVID-19 pandemic had met their children's needs**, and some said they would be happy for this provision model to be reinstated:



Looking at the Summer Scheme time table from four years ago, having four weeks where they could go in to school and do activities that they're used to doing throughout the year is a big thing...we need to keep consistency, because [this year] we basically had eight weeks where my son was locked in the house, I can't take him out because he gets distressed, and I was covered in bruises because his meltdowns were more frequent [...] so if there is one thing that I would like for the Council to hear is that the way they had it [the Summer Scheme] before was great, and if they could put the funding towards paying the classroom assistants...they are the ones that know our children almost as well as us, so that's where the money should be going, it should be going towards helping them, to make us feel more comfortable...putting on events for all types of kids.

- Stephanie (mother)



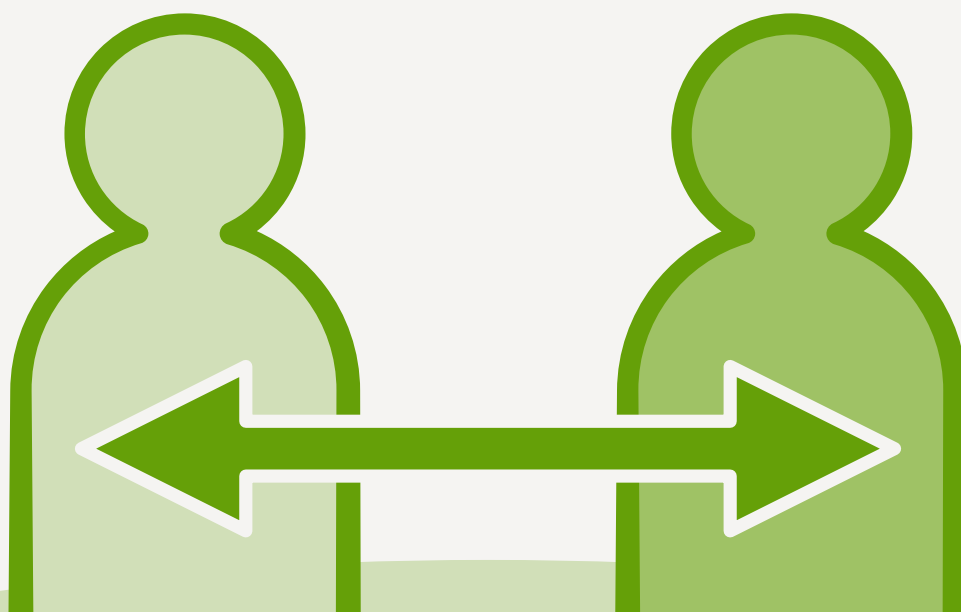


[My son] used to love going to the Summer Scheme before COVID, because it was a familiar place to him and the staff are familiar to him, even if they were going out and about for a day he would happily go because he was comfortable with the staff, particularly. I was happy with him going there, because I knew the staff, and knew he was safe, and that they were properly trained and experienced. So pre-COVID it was a very positive experience.

- Grace (mother)

Need for one-to-one support

Some families said that their children require **one-to-one support** to be able to attend activities, **whether to provide them personal care, administer medication, or for safeguarding reasons**. As explained in the section above around the importance of being in a familiar location and with trusted staff members, many families feel like their children cannot be left alone. This currently means that parents and carers have to be present during the activities their children access (providing no respite to families). Some families said an alternative would be to have a personal assistant accompany and take part in the activities with their children, however many participants said that personal assistants have become increasingly difficult to procure:





If my son is home while I am working...he needs support for everything, he needs support for his hygiene and personal care, he needs to be told when to eat, he needs to be told when to drink. So I am up and down the stairs making sure he's got his drink, and he'll just be sitting on his iPad all day, that's what he'll do unless he has someone to interact with him [...] and sometimes I have to rely on my younger son for support, and then I feel awful for that, and he feels a duty to stay at home to help me rather than to go out and be with his friends. That's not fair for him either.

- Shona (mother)



I cannot give him that one to one care the whole time [...] when the school is open, all the infrastructure and facilities are there, it has everything that these children need, and their friends, that's crucial. They need to see each other.

- Rachel (mother)



I was told about an organisation called Peace. I don't know if it's a Council run thing...but one of [my son's] friends goes and she quite likes it. I don't know an awful lot about it, I joined their Facebook page and had a look through it, some of the things they've done I think [my son] would love, and apparently this group provide one-to-one support to ASN kids. So I emailed them and asked for availability, was told there wasn't any, that there was no one-to-one support available, so again, there's only a certain amount of children that will be able to access that.

- Jen (mother)



[...] the PA thing definitely [would help], because they [the Council] can say, 'We will put this thing on for your kids,' but we need to be there with our kids, all the time. There is no way I can leave my kid unattended.

- Stephanie (mother)

Time of activities

Several participants mentioned that **a lot of the activities on offer are held at times that are not suitable for parents in full-time employment to take their children**, (e.g. mid-mornings on weekdays), **or at times that are unsuitable for the children** (e.g. film nights during evening hours):



The Summer Scheme, that's where the Sofa Champs and Champs Club were organised...and those were in the evening, 6.30 and 7.30pm in the evening. So you've got the children sitting at home all day...one of them was at 8 or 9 o'clock at night, and I was thinking, what kind of support is that for the summer holidays, you've got parents who are home with their children all day and then in the evening, when it's time to wind down, you're expected to take them somewhere that wouldn't meet their needs.

- Shona (mother)



A lot of the activities fall within times during which I might be at work [...] a lot of these things are expensive as well, they're not part of the Council or the School, they are private companies that have dance classes available, for example, but there is a cost with that.

- Jill (mother)



I struggle to access things because I work full time, and a lot of parent meetings, like the National Autistic Society set up a lot of parent meetings where it's maybe for the older autistic kids or maybe for the parents, they do them during the week at 10am in the morning, and I can't access that, and I don't get any help, I don't get to speak to people who are going through the same thing that I am. I know there's lots of people in my situation, where we're working full time, we're locked in the house at the weekend, there's nowhere safe where we can go, where we can be understood...

- Stephanie (mother)

Understanding individual circumstances

Overall, there was a sense from participants that there was **a lack of understanding for each family's individual set of circumstances and needs**. Many felt that the Summer Scheme promoted a general, or 'one size fits all', vision of ASN:



[The Council needs to] specifically understand the needs of our children...individually understanding the needs of our children. Not collectively assuming that all our children will do the same thing in the same way, just because they all have ASN, I mean, how wrong can that be?

- Shona (mother)



[...] one cap doesn't fit all with our children. You're not going to get an activity staffed by people they don't know that will work for them [our children].

- Jill (mother)



[It's important to] tailor activities to kids and asking them what their needs are. You can tell by their expression or behaviour, what upsets a child. Familiar staff will know this, and they're great with the kids.

- Beth (mother)



For learning disabilities, or disabilities which aren't obvious, it is a lot harder to receive support. You don't want to feel like children need to disclose their disabilities, but if you don't, children will get labelled as 'bad' or 'naughty'.

- Frances (mother)

In addition to ensuring that sessions can be organised in familiar places with trusted staff, **giving enough time** for children and young people to settle into activities and to take part was highlighted by some participants as very important:



There needs to be additional time for activities for children with ASN, to talk through activities, this is a main barrier to accessing mainstream activities. Explaining activities, preparing, going to and from services, that all takes longer for children with ASN.

- Frances (mother)



My daughter enjoys horse riding, and we had to pay for an extra hour to allow her to feel safe and in control during the session [...] So we paid for two hours but she only had thirty minutes on the horse.

- Suse (mother)





Moira:

He goes out with Rainbow Services support staff twice a week. But all he actually does is he goes for a little walk and get some fish and chips, which is a bit of a waste of time we think...



Researcher:

Is that because he doesn't enjoy that?



Moira:

No, just because they only have a two-and-a-half-hour slot by the time they have travelled here [to pick him up], and to just stick to the routine of other children it doesn't end up being that much time in the end. It is quite difficult...it is nice for him to go out, but it's not what I would call productive...it's the sort of thing that we would do with him anyway [...] it would be nice if he did something more active.

- Moira (kinship carer)

To make it easier for individual circumstances to be understood, **families consistently suggested that communication between families and the Council needs to improve.** Several participants mentioned that the Parent Councils already established in different schools would be a good starting point to formalise that communication channel, with others also mentioning that social media is a common means through which they find out information and would find out about opportunities to engage with their local representatives. One participant also suggested the idea of a 'local disability hub', as a place to access information and communicate with the Council, but also to find peer support:



I think it would be really useful if there were a central directory of services, or even a central disability hub, you know, where people could come and find out what's going on [...] If families knew who to contact [within the Council] with suggestions that would be useful. Because we're new to it [caring for a disabled child], it's not something we've chosen. It's something that's come our way. And there are people out there who are three steps further along the way, who have tried things out and who might have suggestions, and can point you in the right direction, so it's very much about peer support as well.

- Moira (kinship carer)

Holistic family support

Participants felt that **understanding their children's individual needs would also promote a more holistic approach to providing services, with consideration for the whole family unit's needs.** Participants spoke of the impact that being able to access out of school ASN support has on other family members, for example, on siblings with whom parents also need to spend time with, or have to take to their own recreational activities. In some cases, lack of access to ASN out of school provision also evidenced how much families rely on their own networks to provide support and care to their children; when circumstances change (for example, when grandparents become too elderly to help with childcare) and there is no alternative available to compensate for the support that has been lost, this had significant consequences on the whole family. As participants explained:



Summer provision was the only provision that [my daughter] had. I'm over-protective and when it comes to those times in the year, we are normally OK, but my support systems have fallen apart. It affects so many people to have some type of service [...] Parents need that, my other children need that. I want the time I spend with my child to be good, and I need a break [...] You need time to rest and recuperate [...] I have received no successful support for out of school services. I relied heavily on my fantastic support network around me, but after my dad got dementia and my brother moved away, I now recognise the difficulties other parents and carers have in supporting their children with ASN. Having no out of school support really affects families.

- Suse (mother)



Circumstances change, my mother used to be able to care for my son but now she has high levels of care needs herself, so she can't help me anymore, and East Ayrshire need to take that into consideration, that families' circumstances change.

- Rachel (mother)



Obviously we're all feeling the pinch money wise just now, and I need to be thinking how I can support my family...and the only way I can do that is to work more hours, but I have no childcare outwith [my son's] school time.

- Jen (mother)



There is a service in Bristol called 'Gympanzees' - it was so inclusive, the brothers and sisters without ASN could also access it, and there was a café for parents and carers to relax in.

- Moira (kinship carer)

Different views on inclusion

A point of contention among participants was on the approach to inclusion that the Summer Scheme promoted. **To several families, a vision of inclusion which seeks to bring children with ASN into mainstream settings is inadequate**, and said that they feel like, with this approach, inclusion is thought of more as 'an add-on' rather than being adequately factored in from the outset. As Shona, one of the parents, said:



There didn't seem to be any real emphasis on positive inclusion...that was my experience anyway. [My son] has a hard time being around people he doesn't know, he takes some time to learn new things, and there didn't seem to be that consistent support available to him to allow him to engage in a meaningful way.

This view was shared by some participants during the in-person focused group discussion which took place in Kilmarnock, particularly for those who had children with high levels of need:



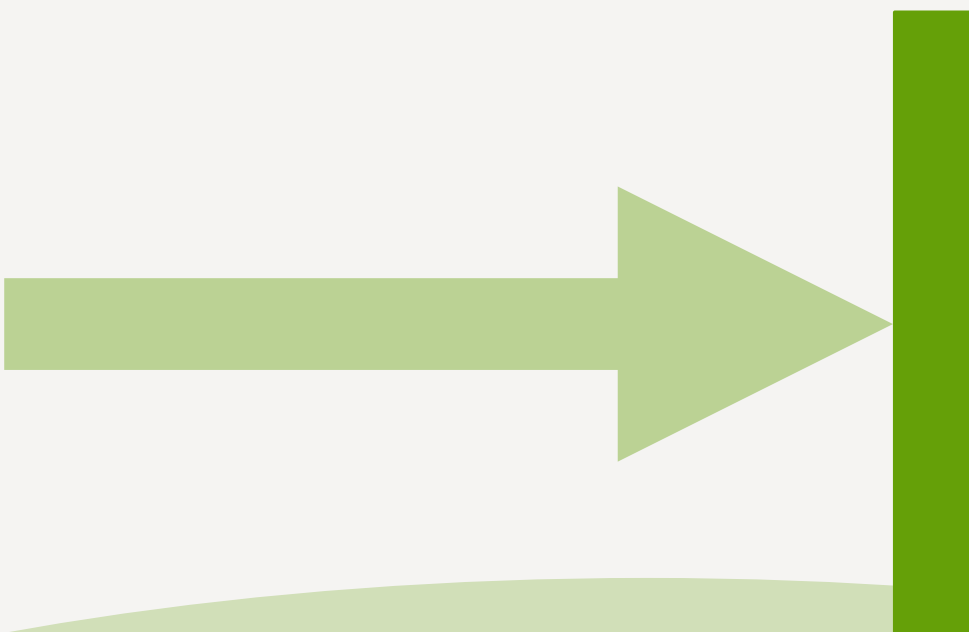
It is about making sure children with ASN are getting similar opportunities as other children, with the support and resource available, not trying to fit them into 'super schools' with other children who cannot or do not understand their additional needs.

- Beth (mother)



For children with moderate ASN, inclusion isn't too difficult when accessing mainstream activities - there are levels of disability mainstream children will accept and nurture, but others will experience bullying and discrimination.

- Suse (mother)



Others, however, were more in favour of an approach to inclusion which sought to make mainstream activities and settings accessible to all children and young people, including those with ASN. Whilst it was recognised that there is still a long road ahead before activities and services can be considered fully inclusive, to some participants this is the goal that society should ultimately aspire to, and said that this can only be achieved in well thought-through stages. As one parent put it:



The reason inclusion doesn't work at the minute is because we are not prepared for it: we are trying to go from exclusive to inclusive straight away without the middle ground. Everyone needs support, the question is, how much?

- Frances (mother)

These two approaches to inclusion have long been a cause for debate, and also relate to the difference between equality and equity:



Equality means each individual or group of people is given the same resources or opportunities. Equity recognizes that each person has different circumstances and allocates the exact resources and opportunities needed to reach an equal outcome [...] Understanding the difference between health equality and health equity is important to public health to ensure that resources are directed appropriately.²⁰

²⁰ Milken Institute of Public Health, George Washington University. 2020. 'Equity vs. Equality: What's the difference?' Available from: <https://onlinepublichealth.gwu.edu/resources/equity-vs-equality/>

Regardless of the approach to inclusion that is adopted, an important point to take into consideration is that when it comes to inclusion, participation “is not about activity type but the manner in which all activity is undertaken,” as Jonathan Rix and colleagues argue in a paper on carrying out participatory research with disabled people.²¹ This means, as many participants in this research shared, that meaningful inclusion “involved [carrying out activities] in places people enjoyed, formal and informal spaces that were familiar and accessible. Access was more than a physical issue; it was an ongoing process that requires flexibility and listening.”²² This is also in line with what the social relational model of disability advocates, as explained in an earlier section of this report.

Given the variety of viewpoints, needs, and experiences of children and young people with ASN, and their families, **many participants voiced that there needs to be better awareness and education about inclusion and ASN within East Ayrshire Council and among other decision-makers:**



Authorities need to also educate themselves, be a bit more considerate about the terminologies that they're using. Look into how different all these children are. There are some ASN kids who can attend mainstream schools, who are verbal, or can get by...but you get kids who are on the opposite end of the scale, who are non-verbal, who have severe disabilities, need a wheelchair, things like that. So educating themselves a wee bit...one cap doesn't fit all with our children.

- Jill (mother)

²¹ Rix, Jonathan; Garcia Carrizosa, Helena; Seale, Jane; Sheehy, Kieron and Hayhoe, Simon 2020. 'The while of participation: A systematic review of participatory research involving people with sensory impairments and/or intellectual impairments,' in Disability and Society, Vol: 35(7), pg.19. Available from: <http://oro.open.ac.uk/67187/2/The%20while%20of%20participation%20-%20Rix%20et%20al%202019.pdf>

²² *ibid*, pg.15.



I just think there's a lack of recognition for the different needs of the kids [...] I think the people in the Education Department should be a lot more cognisant because they're all very well educated people [...] for some of them it suits to just go down the route of inclusion without actually looking at equity, so it's easy to just say, "Oh, everyone can come" but you have to bring them, you have to stay with them, it's only for an hour and a half...it just didn't work from that point of view. I find across the piece there's just a lack of training.

- Samantha (mother)



More training is needed on different aspects of disability, children's needs, potential issues that could arise...this could help us move towards a more inclusive society.

- Frances (mother)





There should be inclusive communication training across all local authority areas and organisations, including Makaton²³ training.

- Suse (mother)

Out of school ASN services are not just about respite or childcare provision

Several participants highlighted that out of school ASN provision should not just be viewed as a form of respite for families or a childcare service – although it was also recognised by participants that if this is a need that families had it should also be met. Rather, they emphasised that **it is about children and young people having meaningful experiences**, just like children attending mainstream settings. Parents mentioned this as a matter of **equal opportunities** for their children compared to their peers without additional support needs:



The Summer Scheme is not just about the respite... it is about the respite, but it is also about the children, and what they need during the summer...they need that time, and we need it as well...

- Rachel (mother)

²³ "Makaton is a unique language programme that uses symbols, signs and speech to enable people to communicate [...] With Makaton, signs are used, with speech, in spoken word order. This helps provide extra clues about what someone is saying. Using signs can help people who have no speech or whose speech is unclear. Using symbols can help people who have limited speech and those who cannot, or prefer not to sign." Makaton. 2022. Available from: https://makaton.org/TMC/About_Makaton/What_is_Makaton.aspx



The whole point of the summer holidays is to get your child to go and have some experiences of their own, not for us to be with them the entire time, that doesn't give us the chance for respite either, and he doesn't get any purposeful experiences [...] I am not looking for childcare, I am looking for meaningful experiences for my son...I pay to have childcare, the Summer Scheme is not about childcare it's about meaningful experiences for my son.

- Shona (mother)



For me...respite was never part of it, it was for my 11-year-old son to get the same opportunity as any other 11-year-old child, to enjoy their time over the summer [...] I watched my son over the summer sitting by the window watching the other kids playing outside. And he's non-verbal, I don't know what he's thinking, but to me, I think he's wondering, "Why am I not outside playing?" And it's just an opportunity to get him to see his school buddies for a few days a week...it would have made a huge difference for him, because that period of time outside of school does affect his mental health, it made his meltdowns more frequent [...] And even if it is about respite for some people, you know, there isn't anything wrong with that [...] if some parents are in that situation it's entirely within their rights to have that, they're not any less deserving of that, because there's nothing else available.

- Jill (mother)

As mentioned in the Introduction, this point in particular is evidence not of only the positive impact on wellbeing that providing ASN out of school services has on children and young people, but also the important role this plays in ensuring that their right to childhood is met and fulfilled. As participants said:



My 11-year-old has no friends, he has missed so much already, and he knows he is different...he needs opportunities to be a child.

- June (mother)



My son is going to need support all the rest of his life. Make their childhood as happy as can be.

- Lillian (mother)



It is also important to highlight, however, that whilst families emphasised that out of school ASN provision should add value to their children's lives by providing meaningful experiences, many families also mentioned that having access to reliable and adequate respite care should be seen as a priority by the Council:



The respite system is insufficient. You have to use your [SDS] budget...to either hire a PA or a care provider, both of which are unreliable [...] and you're desperate, because I also work full time, and [my son] needs 24 hour care...it's just constant [...] it's physically and mentally exhausting [...] I just wish there was somewhere my son could go overnight where he would receive a good level of care and I could get some respite. [What is available in East Ayrshire] is not up to my standards, and I see other local authorities and I see better services in place, which should be replicated here.

- Rachel (mother)



[My son] has a social worker which he only gets for six hours a week, and we had to fight to get that, it used to be four hours every second weekend, and then we fought again and got four hours every weekend, and now six hours every weekend. And the respite...we get 13 nights a year, which means...say my husband and I would want to go on holiday for a week, say by the time we drop [my son] off and pick him up etcetera, that would use up our entire quota.

- Grace (mother)



Respite services are lacking in the area...he has access to [a local respite centre] for six nights a year, so basically that's there in case of emergency...but they have now got two permanent residents so its capacity is basically full, so it's very hard to access. It took us a long time...we asked in January if he could access it, and he was able to access it in June.

- Moira (kinship carer)

Need for continuity of services across the lifespan and improved transitions

Most participants said that access to out of school ASN provision is 'not just a summer holiday problem'. Consideration should be given to the fact that **ASN services and supports need to be made available to children and young people throughout term time and other holidays, as well as across their lifespan**. Indeed, some families also expressed concern over what would happen to their children once they turned 18 and would transition to adult services:



It's not just a Summer Scheme problem, it's a whole year problem [...] The older my son gets...you know, I can't keep taking him to soft play, he's 10 years old. Things get tougher the older and bigger they get.

- Jen (mother)



We talk about all children having a positive destination and path after school, going to college, a job, an apprenticeship, but where is my son's positive destination? Nobody can tell me what's out there for my son. Social work don't know...they tell me, don't worry, we'll see then [when he turns 18]...but I do worry, I want to know what will be in place for him, he's getting older.

- Rachel (mother)

This is a common concern for families of disabled children and young people, as well as disabled children and young people themselves. The recently published report by Arias-Urueña and the ALLIANCE mentioned earlier, on disabled children and young people's access to support during COVID-19, also explores this theme from both the point of view of children and young people as well as parents.²⁴ Organisations such as PAMIS and ARC Scotland have for years been campaigning to improve the transition from children to adult services, and a 2017 report by the ALLIANCE also looked into people's experiences of transitions to adult services, from which came a list of recommendations.²⁵ The ALLIANCE has also responded to the Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill,²⁶ again with recommendations for improved transitions. Similarly, The Promise Scotland is working to improve transitions to adult services for care experienced children and young people, among other areas.²⁷ All these considerations are particularly pressing, given the ongoing discussions on the establishment of the National Care Service (NCS) in Scotland, and potential inclusion of children's services within this.^{28,29}

²⁴ Arias-Urueña, Liliana and the ALLIANCE. 2022. 'Disabled children's, young people's, and carers' experiences of accessing healthcare services and supports during the pandemic: a qualitative research report,' pgs.11, 41, 46. Available from: https://www.alliance-scotland.org.uk/wp-content/uploads/2022/08/The-ALLIANCE_DCYP-access-to-support-during-Covid_report.pdf

²⁵ The ALLIANCE. 2017. 'Experiences of Transitions to Adult Years and Adult Services.' Available from: <https://www.alliance-scotland.org.uk/wp-content/uploads/2017/11/ALLIANCE-GIRFEC-Experiences-of-Transitions-to-Adult-Years-and-Adult-Services-2017-1.pdf>

²⁶ The ALLIANCE. 2022. 'ALLIANCE response to the Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill.' Available from: <https://www.alliance-scotland.org.uk/blog/news/alliance-response-to-the-disabled-children-and-young-people-transitions-to-adulthood-scotland-bill/>

²⁷ The Promise Scotland. 2021. 'Plan 21-24,' pg.24. Available from: <https://thepromise.scot/resources/2021/plan-21-24.pdf>

²⁸ The ALLIANCE. 2022. 'Children and young people and the National Care Service.' Available from: <https://www.alliance-scotland.org.uk/blog/news/recording-available-children-and-young-people-and-the-national-care-service/>

²⁹ The Promise Scotland. 2022. 'National Care Service Consultation Analysis.' Available from: <https://thepromise.scot/news/national-care-service-consultation-analysis>

ASN staff perspectives

The views shared by the ASN staff members we spoke to were very much in line with those of the families that took part in this research, especially the importance of ensuring that services and activities are provided in familiar locations and with trusted staff. This was particularly evident when we asked practitioners, 'What do you think is the most important part of your role?':



The importance of continuity and having the same people seeing them [the children] every day, if they are non-verbal then their needs are met as well. They need consistent people that they are familiar with.

- Eilidh (classroom assistant and personal assistant)



For me it's about understanding the child, that they can communicate with you. They need you to be their voice.

- Natalie (classroom assistant)



Knowing them [the children] for a long time, you are with them for years [...] You are familiar to them. You build up some sort of relationship and understand the background around them.

- Charlene (classroom assistant and personal assistant)



That children are properly looked after, their welfare is the number one priority.

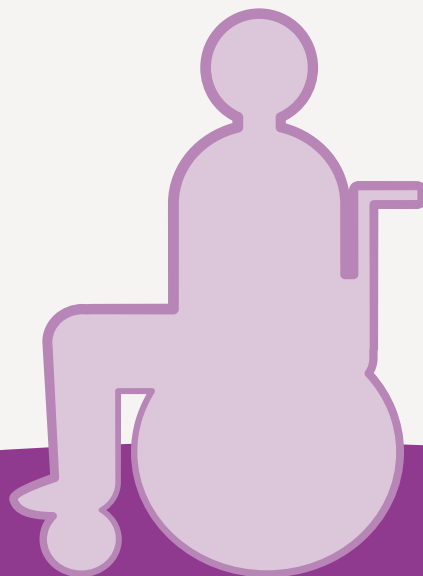
- Anne (classroom assistant)

ASN staff also spoke about some of the challenges that they face in their roles, again showing the importance of ensuring that the services that children and young people with ASN access are staffed by people who know them and their needs:



The class I am in is very medical, all of the children are in wheelchairs. You could have your whole day mapped out, but it can take one small thing to mess things up. You need to have a good team around you to know who can take on what [...] The training we get is crucial: moving and handling, personal care, and medical requirements. Not everyone appreciates that these things have to happen.

- Charlene



When it came to accessing out of school ASN services, staff mentioned that activities advertised as being open to children and young people with ASN are not always suitable and, similarly to parents, that a lack of trained staff and/or adequate facilities can often be a barrier to accessing services:



I am a support worker for a child out of school, and there is not much out there for them in the evenings and weekends [...] or by the time they were coming in and accessing the activities it was time for them to go home [...] I have seen programmes for mainstream children that are run for children with ASN, and the sessions that they have added in as ASN, 'autistic badminton' or football, a few sessions would be suitable [...] but it's in a different building, with staff that are not trained and with staff that don't know them. It's still not what they need.

- Charlene



The room that was used for the group [I took the child I support] was in a room upstairs, and if the only lift that's there doesn't work then we can't go [because she's in a wheelchair]. There are no strategies in place to deal with situations like that. There seems to be a lack of training and thought.

- Eilidh

We also asked staff what could support them to carry out their roles. Training was identified as a need, however it was recognised that time constraints rarely allow them to access opportunities for professional development:



It's a time element with training, we are all busy in class. The training is difficult to deliver because we are all needed in class, and cost wise, there isn't a bank of staff to cover us. I think it is difficult for us, and management too.

- Natalie

In addition to this, peer support was also mentioned as an important factor that can help staff fulfil their role, as well as the opportunity to engage with other professionals involved in supporting children and young people with ASN:



The tips that I have picked up from Natalie are great and have helped me an awful lot in my role. It has been a massive help as she has been [working] there longer and is able to help me.

- Anne



Using everyone's strengths is important, people cope with things differently. You have to tell colleagues not to be anxious because it will be fine. Sometimes you need a colleague to calm a situation down and you take a step back.

- Natalie



Physiotherapists come to the school quite a lot, and we have got to know them quite well, they gave me some pointers on hydrotherapy.

- Anne

Finally, when asked what they thought is needed to ensure that children and young people with ASN have a good experience when accessing out of school provision, participants said:



It would need to be within their own environment, in a building they know [...] with staff who know how to use their equipment. And for children with wheelchairs, you need a tracking system and hoists, including personal care, not all children can be changed in a disabled toilet [...] and parents need to know their child is going to be safe and looked after by people that know them [...] I think as well that it's important to remember that if provision does go ahead that it is done with plenty of notice for the parents.

- Charlene



The child's own dignity is very important. If they are not being offered personal care in the right place, respect and dignity can be forgotten.

- Natalie



Being a personal assistant with a child from school means working with a familiar face, and can help build a friendship. It is a really positive thing that we can get offered the role first.

- Eilidh



Meeting the needs of siblings within the family and being able to enjoy activities with their mums and dads. Not just respite and support for children. The whole family unit deserves to have a service that suits them all.

- Natalie

For a smooth running of future Summer Schemes (or other term-time or holiday schemes), staff also said it would be important to involve them in planning discussions and allow them plenty of time to share ideas and suggestions to run the activities.

Recommendations

Based on participants' accounts and own suggestions for change, the following recommendations are put forward:

- Establish clear communication channel with parents (e.g. through Parent Councils) with expectations about feedback loops between decision-makers and families.
- Increase the offering of ASN out of school provision, with higher staff to children ratio, in familiar places and with familiar staff. It should be outlined in service descriptions what kind of provision will be made available to users (e.g. personal care, one-to-one support, etc.). The groups should be age appropriate.

■ Provision should be available during term time and other school holidays like Easter, not just the summer.

- Understand children and young people's individual needs from the outset (e.g. through a questionnaire), so that staff running activities will know their triggers, medical requirements, etc.

■ Parents shared a good practice example of questionnaires being used by **Centre Stage** when registering children for ASN sessions.

- Make it easier for families to hire personal assistants, whether through social work or third-party agencies.
- Offer activities at times that are convenient for working parents to take their children (or make more personal assistants available to take children to activities).
- Provide training on inclusion and ASN to Local Council representatives, professionals, and other decision-makers involved in shaping ASN out of school provision.
- Create opportunities for parents who wish to be part of peer support groups to get together.
- Centralise information about available ASN out of school provision, making it available in accessible formats, and keeping it up to date.
- Allocate a budget for a designated disability / ASN services hub, with a key point of contact within the Council.

■ A good practice example can be drawn from Children in Scotland's CHANGE Hub Project in the East End of Glasgow: <https://childreninscotland.org.uk/change/>

- Invest in building respite care infrastructure.
- Invest in building changing facilities in community settings.
- Provide ASN staff training and invest in staff recruitment.
- Continue investing in creating fully accessible recreational areas and community spaces.

Work has been ongoing and more funding agreed to invest in accessible play park infrastructure across East Ayrshire: <https://docs.east-ayrshire.gov.uk/r/?f=https://docs.east-ayrshire.gov.uk/CRPADMMIN/2012%20AGENDAS/CABINET/19%20January%202022/Play%20Park%20Investment%20Plan%202021-22.pdf>

- Engage with disabled children and young people, not just parents, to understand their needs and what they would like to see change in the services they access.

The project carried out on behalf of the ALLIANCE by Dr Liliana Arias-Urueña, mentioned at different points of this report, outlines a clear approach to engage with disabled children and young people, including those with high levels of need: https://www.alliance-scotland.org.uk/wp-content/uploads/2022/08/The-ALLIANCE_DCYP-access-to-support-during-Covid_report.pdf

- Develop a stronger transitions to adult services plan in the local area.

ARC Scotland's Principles Into Practice Framework is already being successfully piloted in different parts of the country: <https://scottishtransitions.org.uk/principles-into-practice-draft-framework/>

Consider the potential of PAMIS' 'digital passports' for improved transitions, but also better communication between services during childhood: <https://pamis.org.uk/services/digital-passports/>

- Adopt the Scottish Approach to Service Design in delivering services (both for children and young people with ASN and those who access mainstream services).

Available services in other areas of Scotland and the U.K.

Participants were asked to share any good practice examples of out of school ASN provision in other parts of Scotland and the U.K. known to them, so that East Ayrshire Council could consider procuring similar services. The following list is a compilation of examples of services that families have accessed outwith the local area:

One-to-one interviews lasted between thirty minutes to one hour and were carried out exclusively by the researcher with parents or carers of children and young people with ASN. These were audio recorded and transcribed by the researcher. Focused group discussions, both online and in person, lasted between one hour and one hour and a half, and were facilitated by the researcher. What people shared during focused group discussions was captured through note-taking, with the support of two ALLIANCE colleagues who took notes during the sessions (both by hand and typed). All data gathering took place between mid-September to the end of October 2022.

- Several participants mentioned South Ayrshire Council had a good variety and availability of ASN sessions, like swimming and horse riding, which participants said met their children's needs.
- The Glasgow DASH (Disability After School Holiday) Club: <http://dashclubglasgow.org.uk/>
- Blue Sky Autism: <https://www.blueskyautism.com/>
- Indepen-dance: <https://www.indepen-dance.org.uk/>
- Gympanzees: <https://www.gympanzees.org/> (England-based)
- Touch Trust: <https://www.touchtrust.co.uk/> (Wales-based)

The ALLIANCE has also collected the following good practice examples from member organisations:

- PAMIS, multisensory story-telling: <https://pamis.org.uk/site/uploads/pamis-resources-multisensory-storytelling.pdf>
- Guide Dogs Scotland, sensory story-telling and habilitation: <https://www.guidedogs.org.uk/getting-support/information-and-advice/learning-through-play/>
- Contact, 'Better Together' events (for families of children and young people with ASN): <https://contact.org.uk/help-for-families/workshops-and-events/better-together-events/>

Conclusion

One of the guiding research questions in this project was, 'What would families in East Ayrshire like to see change in terms of out of school ASN provision?' The findings of this report, informed by the voice of lived experience, provide a comprehensive answer to this question, and point not only to the changes that are needed but also service gaps that have existed for years, not just in East Ayrshire, but all over Scotland and the rest of the U.K.

However, participants' accounts also express trust in decision-makers' commitment to improve disabled children and young people's circumstances. In the words of one of the parents we spoke to, when asked what they would like for East Ayrshire Council to take away from this project:



Take this opportunity to make East Ayrshire an example that can be held up to the rest of the country. And what does this mean? Better overnight respite, better support and respite in the house, better use of the specialised schools, better use of facilities that are already there, like Centre Stage.

- Rachel (mother)

It is hoped that this report will provide a useful starting point for positive change to take place in East Ayrshire, and indeed for it to cascade to other parts of Scotland, as the participant above so eloquently suggested.

Further reading and other sources

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About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of over 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces, Libraries and Access Panels are also members.

The ALLIANCE is a strategic partner of the Scottish Government and has close working relationships, several of which are underpinned by Memorandum of Understanding, with many national NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims. We seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.



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people at the centre

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