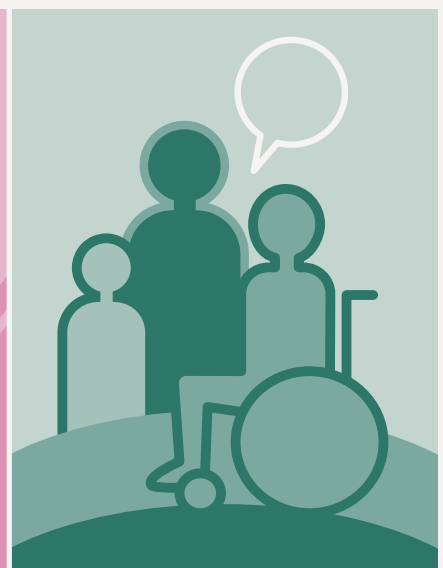


Seen

Heard

Included

Meaningful engagement with disabled children and young people with complex needs and their families



ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

Project developed by the Disabled Children and Young People Advisory Group (DCYPAG) Engagement Sub-group

Report

August 2023



Family Fund
Helping disabled children

contact For families with disabled children

pamis
promoting a more inclusive society



Down's Syndrome Scotland



Scottish Government
Riaghaltas na h-Alba

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Project background and context

Introduction

This report aims to provide a summary of what is required to carry out meaningful engagement with disabled children and young people with complex support needs and their families. The report highlights some of the key learning and is supported by additional project outputs on the Health and Social Care Alliance (the ALLIANCE) website.¹ This report is intended to support anyone looking to undertake meaningful engagement activities.

In May 2022, in partnership with the ALLIANCE, colleagues from Contact, Down's Syndrome Scotland, Family Fund and PAMIS (henceforth 'delivery partners') developed a three-year proposal to ensure voices of disabled children and young people whose needs are complex, were heard and to share learning and good practice from the approaches undertaken. A commitment to single, rather than multi-year funding was able to be made, and the sub-group was granted funding from Scottish Government for the remaining months of the 2022/23 financial year, (November 2022 – March 2023).

This project was funded by the Scottish Government to:

- identify and develop tools and methodology to support the meaningful engagement and participation of disabled children and young people whose needs are complex and whose voices are rarely heard, and their families, and share learning on these approaches; and
- capture what matters to this cohort of disabled children and young people and their families, and within this context what effective planning and effective support is required. This could contribute to the design and development of the National Care Service and the National Transitions to Adulthood Strategy.

The small-scale engagement activities with children, young people and/or families, provided important learning and recommendations which the group hopes will assist those designing and undertaking engagement with disabled young people with complex needs, and their families, in the future.

Key delivery partners

Each delivery partner was identified to carry out the engagement activity because of their expertise in engagement and the existing relationships and trust already built with their network of disabled children and young people, their families and carers. The ALLIANCE, the national third sector intermediary for health and social care in Scotland provided the administration and co-ordination element to the project.

Engagement methods and what we learned:

- Contact is a charity supporting families with disabled children, whose purpose is to provide guidance and information, bring families together to support each other. And to help families to campaign, volunteer and fundraise to improve life for themselves and others.
- Down's Syndrome Scotland is a member-led charity, established in 1982. They are the only charity in Scotland dedicated solely to supporting people with Down's syndrome and their families and carers.
- Family Fund is the UK's largest grant-making charity for families raising disabled and seriously ill children, on a low income. Providing ways for families to share their experiences, so that they can influence lasting change on issues that matter to them, is fundamental to Family Fund's mission.
- PAMIS is the only organisation in Scotland that solely supports children, young people and adults with profound learning and multiple disabilities and their families to lead healthy, valued and included lives. With 32 years' experience in family support, inclusive practice, learning and development, research and campaigning, PAMIS understand the complexity of care and support required by this group.

Methods and what we learned

Prior to carrying out any new engagement activity, delivery partners first provided relevant research and existing data as a foundation that could help inform the design and development of the National Care Service (NCS) and National Transitions to Adulthood Strategy. This included a literature review published by the ALLIANCE summarising what children and young people had already shared about their experiences of social care.² Where appropriate, delivery partners used existing data in addition to new activities designed to suit the project e.g. Family Fund utilised their existing quarterly family poll data from families in Scotland to draw out learning. The motivation for this was to ensure that information which children, young people and their families have already shared is listened to, and to avoid them having to retell their story.

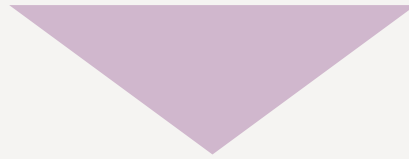
Project engagement activities were carried out between November 2022 and March 2023. Each delivery partner developed their own methodologies and tools to engage with their groups of children, young people, their families and carers.¹ The existing trusting relationships delivery partners had with these target groups was highlighted as being of particular importance throughout this project.

The visual below highlights the different methods used to engage with participants. Each delivery partner developed a flexible approach to gathering data, considering the circumstances of individual participants, particularly considering the complexity when working with families where the child or young person may have complex disabilities and alternative communication methods. It was the intention of the delivery partners to provide options and opportunities to allow everyone who wished to participate in the project to do so.

Engagement activities included:	
• Literature review of existing evidence	
• Films	
• Surveys	
• Digital Passports	
• Events (online and in-person)	
• Multi-sensory storytelling	
• Graphic recordings	
• Interviews	

Outputs are available on the ALLIANCE website,¹ where you can see in more detail the activities carried out and the learning gathered.

What we learned



Limitations

It is important to emphasise that engagement activities were carried out in a short time frame, less than six months, and while all delivery partners delivered on their planned outcomes, the project would have benefited from a longer life span. The length of time needed is hard to quantify as there are many factors to take into consideration. When engaging children, young people and families additional time must be factored in for their preparation within their existing busy lives. For children and young people attending school, additional support services even hospital appointments, and for parents at work and or having caring responsibilities they need time to plan well in advance. We must be mindful during any planned engagement activities what might affect their ability to attend or be present at a session. We must look through the lens of the young people and their families and allow flexibility and contingency planning.

Meaningful Engagement

Key learning from engagement activities highlights purposeful and meaningful activities for disabled children and young people with complex support needs, whose voices are seldom heard, need to provide purpose for participants and that these have to be shaped with the individuals in mind. It was apparent that for engagement activities to have been as successful within the time parameters, it was advantageous that delivery partners already had established trust and relationships. We need to spend time with people who know and understand the individual to ensure we provide a range of activities that are right for the person. One size does not fit all. Accessible and inclusive activities need to be planned for all, and this often takes time, but it is vitally important for meaningful engagement.

Conclusion

If we consider the needs of those with the most complex needs, we work towards getting it right for everybody. The hope is that those who wish to carry out similar engagement activities can learn from the work of the project and explore opportunities to carry out meaningful engagement that can be turned into meaningful action. Families must know they have been seen, heard and included. They must gain from the experience as well. Finally, robust support mechanisms and aftercare must be thought of to ensure the safety of those sharing their experiences.



Barriers and limitations

This report's findings and recommendations are based on what participants shared with delivery partners; their accounts are taken at face value, as we consider them to be experts about their own lives.

The following section of the report highlights some of the barriers and limitations that children, young people and their families face in relation to informing the design and development of national policy.

- **Understanding of long term conditions and complex needs**

Concerns were raised about the lack of understanding of long term conditions and disabilities. It is the hope for those who wish to carry out engagement activities, that they consider what it means for people living with a long term condition. In real terms, this can mean people are keen to engage but arising health conditions may present barriers and a range of opportunities to engage should be considered.

- **Geographic spread**

There is a need to consider the geographical spread when carrying out engagement activities to gather the views of a range of communities. For engagement to be truly meaningful, it cannot exclude anyone. Communities across Scotland have vastly different experiences of services and if we only engage in large, urban communities we risk not fully understanding the reality for those who live in remote areas.

- **Whole-family approach**

Individuals living with complex needs will need support which may be from their family in order to communicate and participate in engagement activities. Organisations need to work to ensure activities are inclusive and that families are also supported e.g. engagement out with working/school days, sometimes financial support for travel/carers etc.

- **Purposeful and meaningful activities**

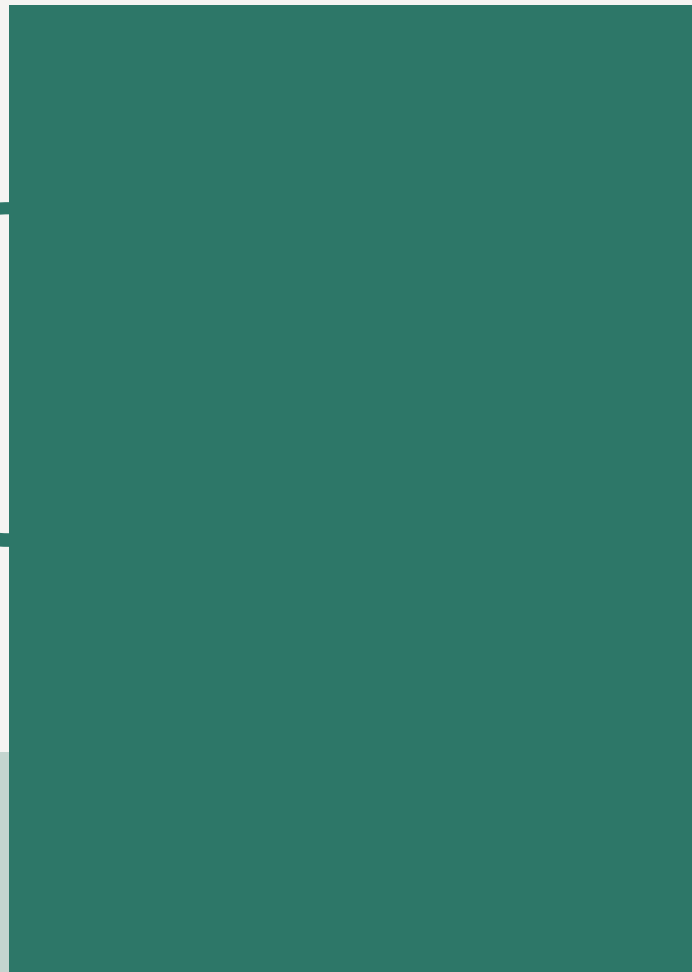
Engagement activities cannot be a tick box exercise. For families to commit their time to sharing their experiences, they must know the purpose. A robust feedback loop must be in place. Responsibility lies with those seeking engagement to feedback on how experiences shared are being used to drive forward change and longer-term, it involves communication in showcasing the change.

- **Language and communication**

The language surrounding policy and legislation can be difficult to interpret and can create a barrier to inclusion. Families sometimes feel unable to contribute to the design of new policy because they are unsure how it relates to them. Preparation is vitally important which could include time for setting context and space for questions.

- **Digital technology**

Digital solutions are not always appropriate and should not automatically be the default for carrying out engagement activities. It cannot be assumed that everyone has access to digital technology. Digital technology has a role and for some families, it has created opportunities to engagement, however, families must be supported to connect digitally if required.



Key policy areas

The project was created to contribute to the design and development of two main policy areas. These were:

- **The National Care Service (NCS)**

The Scottish Government has committed to establish a NCS by the end of this parliamentary term. The NCS aims to ensure the best possible outcomes for people accessing care and support and end the 'postcode lottery' of care. A decision has not yet been made on whether children's social care and social work services should be included in the NCS, but it is important the views and needs of children, young people, their families and carers are considered to improve outcomes for them regardless of inclusion.

- **A National Transitions to Adulthood Strategy for disabled young people**

The Strategy, a 2021 Programme for Government commitment, and more recently reaffirmed in the First Minister's Policy Prospectus - Equality, opportunity, community: New leadership - A fresh start,³ is intended to support disabled young people as they make the transition into adult life, providing joined-up guidance and support to unlock better educational and employment opportunities and health outcomes.

Feedback from the engagement activities regarding these developing policy areas highlighted that the language currently used meant that many children, young people and families were unaware of how the policies played a role in their own lives.



Our greatest ideas and lofty ambitions will remain just that in the minds of children and young people with additional support needs if our language is complex, over-structured and remote. We may have to start by de-constructing our 'grand ideas' into a plain statement of simple outcomes

Down's Syndrome Scotland

It was also felt by parents and carers that engagement activities that aim to provide opportunities to be involved in consultation at service, local and national level can be seen as a tick box exercise:



Consultation meetings happen where the decision has already been made

Contact UK



Consultation did not make a difference to delivery of service

Contact UK



Many parents don't know how to engage or are too exhausted

Contact UK

Parents and carers shared examples of what would make better engagement with families:



Charities invested in to support parents to be involved at engagement, consultation, co-production and co-design

Contact UK



Parents supported to be able to attend

Contact UK



Short surveys - no more than 10 questions

Contact UK

Families emphasised taking a child centred view:



I would say always include children in decisions no matter how big or small. Ask questions of what they need as it can be completely different from what you think they need

Family Fund



Be patient and listen to them

Family Fund



Never look at the diagnosis, look at the child as an individual with their own unique personality

Family Fund

PAMIS highlighted the benefit of utilising story and narrative as a means to engage:



Stories can support individuals to change their own narrative, they can support community in their understanding of the people living within it, and they can enable those working with people with profound and multiple learning disabilities (PMLD) and their families to better understand the aspirations and needs of the people they are supporting.

Feedback from all delivery partners highlighted that families with lived experience are keen to engage with the design of new policy and be part of the solutions however, engagement must suit the needs of families in relation to lead in times to engagement events, types of engagement activity, support provided to attend engagement events which could include hosting events at different times in the day, funding provided for carer support, in-person and online opportunities. There was a strong understanding that service redesign is a process and won't change overnight but there is a willingness to be involved.

Recommendations for those engaging with disabled children, young people and their families

1. Work using a rights-based approach, aligning particularly with Article 12 of the UNCRC, 'Respect for the views of the child'. Every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously. Also with Article 13, 'The child shall have the right to freedom of expression'. Measures should be taken to ensure engagement activities are designed to facilitate this.
2. Take a considered approach when engaging with disabled children and young people whose needs may be complex. Understand that health may fluctuate, or individuals may not have the capacity to engage if timescales are limiting. It is essential that all stakeholders should have the opportunity to engage with the design of new policy.
3. Review previous consultation and engagement data, including that which is held by third sector partners, before carrying out any new engagement activities to ensure there is no duplication for children, young people and families in sharing their experiences.
4. Employers should invest in training and awareness raising of long-term conditions and complex needs to help professionals increase understanding of what it means for individuals and their families, and how to effectively engage with these groups of young people.
5. At an early stage, consult with third sector organisations who have the expertise and relationships with disabled children whose needs may be complex to support engagement and consultation activities and consider making additional resource available to facilitate this.
6. Agree timescales based on the specific requirements of participants and methods of engagement. In order to successfully and meaningfully engage with children, young people and their families, time is needed to build relationships and trust.
7. Ensure engagement activities are accessible for all participants. Digital technology should be considered where appropriate. Event materials should be provided in suitable formats which could include easy-read and plain statements of intent.
8. Ensure there is a geographical spread for engagement on key policy areas. Consider those living in remote and rural areas and provide opportunities for those to have their voice heard.

9. Recognise the contributions of those living with lived experience and their families. All accessibility costs should be paid for or reimbursed.
10. Policy makers must ensure robust feedback mechanisms are built into initial plans to inform participants how their contributions have helped shaped policy. Recognising that all changes may not be possible but that actions have been considered.
11. Make certain there is flexibility in designing the policy to fit engagement findings. No meaningful engagement activity will be successful if there are preconceived ideas of what should happen. Any limitations should be explained clearly in advance to set expectations.

Conclusion

It cannot be underestimated the emotional impact the project had - not only the children, young people and families who selflessly gave up their time to contribute - but the impact this had on all delivery partners. The learning is insurmountable, and we just cannot stop here.

Working with the support and encouragement of partners within Scottish Government has proved we have opportunities to enable real change when it comes to future support and planning.

We plan to work further with colleagues in the Scottish Government to consider wider dissemination of the findings of this report, to shine a light on good practice and appropriate ways to engage with disabled children, young people and families in designing policy. We will act as advocates on their behalf in highlighting what works and what can be done better.



Our lives and their pathways are not fixed in stone; instead they are shaped by story. The ways in which we understand and share the stories of our lives therefore make all the difference. If we tell stories that emphasise only desolation, then we become weaker. Alternatively, we can tell our stories in ways that make us stronger, in ways that soothe the losses, in ways that ease sorrow.

-David Denborough, [The Charter of Storytelling Rights](#)

Acknowledgements

Thanks, first and foremost, go to the children, young people, families and carers who volunteered their time to take part in this project: your insights are invaluable, and it is hoped that what is captured within this report alongside additional resources does justice to your experiences.

The ALLIANCE would like to thank our key delivery partners: Contact, Down's Syndrome Scotland, Family Fund and PAMIS who carried out the engagement work for their dedication and commitment to this project.

A thank you to Scottish Government for funding the project and continued support throughout.

Endnotes

1. The Health and Social Care Alliance Scotland. Seen, Heard, Included. Available from: <https://www.alliance-scotland.org.uk/policy-and-research/policy/getting-to-know-getting-it-right-for-every-child/engagement-seen-heard-included/>
2. The Health and Social Care Alliance Scotland. 2022. Literature review: Children and young people's experiences of social care in Scotland. Available from: <https://www.alliance-scotland.org.uk/blog/news/alliance-literature-review-children-and-young-peoples-experiences-of-social-care/>
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About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for health and social care, bringing together a diverse range of people and organisations who share our vision, which is a Scotland where everyone has a strong voice and enjoys their right to live well with dignity and respect.

We are a strategic partner of the Scottish Government and have close working relationships with many NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our purpose is to improve the wellbeing of people and communities across Scotland. We bring together the expertise of people with lived experience, the third sector, and organisations across health and social care to inform policy, practice and service delivery. Together our voice is stronger and we use it to make meaningful change at the local and national level.

The ALLIANCE has a strong and diverse membership of over 3,500 organisations and individuals. Our broad range of programmes and activities deliver support, research and policy development, digital innovation and knowledge sharing. We manage funding and spotlight innovative projects; working with our members and partners to ensure lived experience and third sector expertise is listened to and acted upon by informing national policy and campaigns, and putting people at the centre of designing support and services.

We aim to:

- Ensure disabled people, people with long term conditions and unpaid carers voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change that works with individual and community assets, helping people to live 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 cross-sector understanding and partnership.



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