

PARENTS' VOICES

EXPERIENCES AND IDEAS OF ENGAGEMENT AND CONSULTATION



contact

For families with disabled children



This report was commissioned by the Scottish Government.

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Executive Summary

INTRODUCTION

In March 2023, parents came together with Contact to share their experiences and have their voices heard.

Below are the discussion questions used in the three engagement sessions, the key findings from those discussions, and recommendations based on the key findings.

In each of the engagement sessions parents' discussions and views were facilitated and captured using the following questions.

- What is your experience of planning and support as a parent and what should effective planning and support look like?
- What are your experiences of consultation and engagement and how could engagement and consultation be improved for families?
- What are your views on the proposed national policies of the National Care Service and the National Transitions to Adulthood Strategy?

KEY FINDINGS

A summary of these is set out below.

1. Planning and Support for Families

- Worryingly, parents described a lack of planning and support for families with disabled children.
- The lack of planning and support is leading to 'crisis' situations for children and young people and their families.
- Families do not feel listened to by schools and CAMHS.
- Parents want early intervention and support at diagnosis stage and to be supported when they identify their child or young person needs assessment for additional support.
- Families need information and ongoing support at diagnosis on all key areas especially financial.

2. Consultation and Engagement

- Consultation may take place however one of three things happens: no one follows up; nothing changes; parents are not being listened to, with services doing what they wanted and not what parents said in the consultation.
- Often parents find in a consultation there are only one or two parents in a room of professionals.
- Parents are concerned that meeting with a few parents is described by authorities as consultation and representing all families. They sense it is a 'tick box exercise'.

- Consultation and engagement should have no set agenda, include open questions, and be in-person and online to meet the needs of parents - and take on board what they have said.

3. National Policy

- Most parents were not aware of the National Care Service (NCS) or the National Transitions to Adulthood Strategy.
- Parents are concerned about the disjointed nature of the health service and hopes are that a NCS will improve this.
- Parents experience negative attitudes and some parents expressed that there are still suspicious feelings towards social services and hope this will change.
- Parents want to be reassured that a Transition Strategy will improve the experiences of their young people and the current confusing system of support.

“Until it is crisis point or flagged up as something serious there isn’t any planning, let alone effective planning.”

Parent carer

“Before coming here I googled the NCS and it says it will have equality, dignity and human rights at its heart I hope this is the case because we are sitting here and things are not working right now for our children.”

Parent carer

RECOMMENDATIONS

- Parents voices are listened to and heard by services, including education and CAMHs, and families need to know their views are being considered.
- A review of Disabled Children’s Services in the light of these findings, in conjunction with families.
- Take on board the areas that would improve engagement and consultation with families.
- Ensure there are small and accessible engagement events for families on NCS and Transition Strategy.

Introduction

BACKGROUND TO THE PROJECT

In December 2021, partners Down's Syndrome Scotland, Family Fund, Promoting a More Inclusive Society (PAMIS) and Contact created a sub-group of the Disabled Children and Young People Advisory Group (DCYPAG). Partners wanted to consider how disabled children and young people with complex support needs and alternative communication and their families could be involved in meaningful ways to influence Scottish Government policy and services.

The sub-group was granted funding for six months, from November 2022 – March 2023. Each partner engaged with the families they worked with and created their own small engagement activities with children, young people, or parents.

"I thought college would work for him,' one parent said, 'but when young person doesn't like it, what do we do after that? The theory is great, but practical aspect is much more challenging."

Parent carer

AIMS OF THE PROJECT

The two main aims of the project were to:

- **Identify and develop tools and methodologies to support meaningful engagement and participation of disabled children and young people whose needs are complex** - and whose voices are rarely heard - and their families, and importantly share learning on these approaches.
- **Capture what matters to this cohort of disabled children and young people and their families** within the context of effective planning and effective support, and to contribute to the design and development of the National Care Service and the National Transitions to Adulthood Strategy for disabled young people.

HOW WE ENGAGED FAMILIES

Contact engaged families they support and worked with parents and group leaders from BANG Scottish Borders, SHIP Perth & Kinross and Differabled Greater Glasgow to plan and register interest among parents.

We ran three events:

- One in-person, two and a half hour session in Glasgow, which provided parents with a relaxed and comfortable setting late morning/lunchtime.
- Two online, two-hour sessions, one in the morning and the other in the evening.

Parents were invited to attend one of these engagement sessions in mid-March.

WHO WAS INVOLVED

Eighteen parents registered and were sent the questions and topic discussions prior to the session. Fifteen parents attended, with an average of four to five parents at each session.

Contact's Scotland Manager facilitated the discussions.

HOW WE CAPTURED FEEDBACK

Feedback and comments were scribed at the facilitated session. Recordings of the online sessions were made, with permission, to ensure that parents' voices were fully captured.

Parents were also given the opportunity to send further comments and ideas by email after the engagement sessions.

Incentives to taking part

Parents were offered shopping vouchers to acknowledge and respect their valuable time to attend the sessions outwith their caring responsibilities.

WHO WERE THE PARENTS

Some parents self-identified as single parents, from BAME communities and as disabled themselves.

WHO WERE THE CHILDREN?

Children's conditions included neurodiverse, sensory, learning disabilities and difficulties and rare conditions. Children were of school age and going through transition into adult services.

Contact's findings have been brought together in this executive summary and main report.



Planning and support for families

WHAT ARE PARENTS' EXPERIENCES OF PLANNING AND SUPPORT?

Parents don't feel there is planning and support for their families. Families described finding support as "*stumbling across*" it or they are driven to "*crisis situation*" before support is available.

Parents sense that services are overwhelmed, with pandemic practice still impacting services.

Some parents experienced long waiting lists from CAHMS services. They are concerned that the service is focused with "*parenting*" rather than supporting their child or young person with the skills to take control of their condition. Parents also described a "*postcode lottery*" of support, that is affected by cuts to budgets and question why budgets for disabled children are not ringfenced.

DIAGNOSIS AND ASSESSMENT

Having a diagnosis and assessment for a family is like having a "*golden ticket*" and without it there is limited or no support. Parents said they and their child/young person were "*not being listened to*" by schools. Parents used terms like "*fight*" to get assessments and are pushed to obtain a private assessment to get support for their child.

AT SCHOOL

Some parents feel their child's additional learning support needs are viewed as a "*behavioural problem*", yet the child is in the learning support system. Their experience of teaching staff is that there is a lack of understanding about their child's condition. They also feel schools are not willing to look at options and choices that parents suggest when parents know their young person is struggling with the traditional mainstream system.

Not being listened to

Parents described their child's experiences and how they as a parent can be "*shot down*" when they explain that their child will not cope in mainstream. They feel they are not listened to when their child needs learning support in mainstream settings. They described a school system where there is nothing inbetween a young person who does not identify as needing learning support or full mainstream. The system doesn't get it right for the child.

Lack of understanding and choice

Other parents described how professionals misunderstanding is evident in their questioning of their young person, who answers out of respect to authority and not what their actual needs or feelings are because of their learning disability. Parents are frustrated with limited subject choice for young people at school in Year 5 and national level qualifications. Parents feel their young person is being "*pushed through the traditional school system*" with limited subject choice to meet their needs.

A box-ticking exercise

Parents defined GIRFEC, SHANARRI and Curriculum for Excellence as “*lovely buzz*” words. In their experience they are about ticking boxes with little meaning for children with additional support for learning.

SUPPORT FROM OTHER PARENTS

The best support parents receive is from other parents. Parents often know through their own experiences which local, national charities and services will offer good support. Some parents found that peer to peer support at a crucial time when they felt “*absolutely helpless*” as their child grew older and young person was experiencing changes that affected their behaviour. Parents asked why early intervention in a young person’s life to help them deal with their condition isn’t there for children. Some parents said they discovered the card a child or young person can carry explaining their condition to professionals like police and teachers (which prevents misunderstandings) late in their child’s development.

KEY MESSAGES

- Diagnosis and assessments are important for children to get the right support and planning.
- Reducing waiting times for CAMHS is imperative for children and young people’s mental health.
- Training and development for professionals with parents would be a game changer.

“You spend weeks dealing with the crisis. You must keep chasing and then there is no plan or there is no funding for the plan. Feel you are totally wasting your time which you should be using to spend with your kids and that is what gets to you. The time I should be spending with my kids I spend chasing things for them.”

Parent carer

“It felt like banging my head against a brick wall because ‘professionals know better’. You can see change in your child.”

Parent carer

“It feels like a complete free fall of chaos that is family life all the time.”

Parent carer

What would effective planning and support look like for families?

A KEY WORKER

Parents feel that at diagnosis stage they should be offered a key worker. This early intervention would assist families to steer their way through knowing who they should contact at the right time and what is available to them.

Parents felt *“left out in the cold”* at this stage and having to find out things out by themselves.

INFORMATION

Parents described needing the right information at this key time and that:

- having an information pack at diagnosis would assist families by helping to signpost families to the key services of support.
- financial information is imperative because caring responsibilities mean that parents must often give up their job or go part time.

They felt that all services should promote and inform families about their financial entitlements and which organisations can support families. Parents describe how they *“must seek out the information, support, and services to meet their child’s needs, you must have the drive to do this”*.

MENTAL HEALTH AND EMOTIONAL SUPPORT

Parents want more mental health and emotional support for children, young people, and parents, particularly at diagnosis stage and at periods of change in a child or young person’s life.

Parents who have gone through an assessment or diagnosis for themselves when they are an adult, have then been able to access Self-directed Support. This has allowed them to discover therapies and emotional support that has been beneficial to them as a person and a parent. However, parents felt that all parents with a disabled child should be offered therapies and support that would benefit them.

FUNDING

Parents are concerned that parent-led groups and charities who support families are not funded appropriately and have to spend so much of their time trying to secure funding. It is reassuring for families to know this support is always going to be there for them, they worry when support like this disappears when funding run outs or cuts are made.

OUT OF HOURS SUPPORT

Families describe support at weekends and holidays as non-existent. One parent heartbreakingly said *"I dread Saturdays"*. They expressed how important it was to be able to speak to someone outwith 9 to 5 support and that services should meet families in person.

Support in an emergency

Families need emergency 24-hour CAMHS services like the Samaritans to help them keep their young person safe, so they are not forced to call the Police. This is where parents described the invaluable support from other parents and how they have helped them individually and to become part of a group and charity that supports parents. Parents and in particular a single parent said, *"it all falls down to me to do everything"*.

SUPPORT FOR MULTIPLE NEEDS

Parents of children with a rare condition explain that their child could also have multiple conditions. Families need support and access to a range of services to support their child with each condition they experience, and for them not just to be viewed through the lens of the rare condition.

AT SCHOOL

Parents need schools to listen to them and their child, young person when assessments are requested.

They want to see more help and understanding for young people who do not fit the traditional mould of learning support unit or mainstream.

A constant battle

Parents described how hard they work to ensure good relationships with teaching staff and have been doing it from nursery through primary into secondary school.

Parents feel that information and advertising is needed for the public to understand disability. Families want people to understand what their child can do and that having a disability should not be negative and stigmatising.

KEY MESSAGES

- Early intervention and support for families at diagnosis and assessment would prevent longer term issues and challenges later.
- Information and support on financial entitlements for children and families at diagnosis stage would prevent families struggling.
- Emotional and therapeutic support for children, young people and parents would prevent challenges escalating later in life.

"That's the thing, it is always on the parent carer to chase up things. It's not like things are identified and then go in place, instead you must stamp your feet, and shout a bit louder, it is exhausting."

Parent carer

Consultation and engagement

WHAT WERE PARENTS' EXPERIENCES OF CONSULTATION AND ENGAGEMENT

Some parents have been involved in consultation exercises at local level. Parents described their experiences where three things tend to happen:

- no one follows up
- nothing changes, and
- they are not listened to. For most families the most frustrating was the feeling of not being listened to.

In this situation parents described how the services went ahead with what they wanted to do, not what parents said in the consultation.

Too few parents involved

Some parents find there are only one or two parents at the consultation and the expectation is that they will represent other parents. Parents felt this pressure to be representative challenging because they can only bring their own experience.

Parents were also concerned that at some consultations they were the only parent carer or disabled person, and the other attendees representing parents are professionals. They felt that although professionals may try to share parents' concerns, the viewpoints will be different.

Parents are also concerned that meeting with a few parents is described by authorities as consultation and representing all families. They described this as a "tick box exercise" by local authorities.

No seat at the table

Parents feel that the list of Stakeholders in the National Care Service consultations does not include unpaid carers like them. They feel it refers only to private providers, councils, unions, and professionals. One parent involved in a charity-organised consultation on National Care Service was frustrated with the process and described it as "*all stakeholder utilitarianism*". Although the intention was a "*bottom up*" process they were suspicious of institutions who are not happy to give up their perceived power.

Barriers to participation

Parents want to be involved in consultation to create change, but there are many barriers, including how precious their time is away from parenting and caring responsibilities and the energy needed to attend.

"They ask the question, and they are told don't do that, and yet the council go ahead and do it. When asked why they did that, the council response is - well we consulted with disabled people. But they don't say - yes but those disabled people said NO to that in the consultation."

Parent carer

KEY MESSAGES

- Consultation and engagement do happen, but changes are not being experienced by families.
- Engagement and consultation must meet the needs of parents, children, and young people, to be effective and their voices are endorsed in the changes.
- There is a perceived power imbalance that must be understood and addressed.

WHAT ARE BETTER WAYS TO ENGAGE?

Parents felt the most important aspect of consultation and engagement is the follow up with parents. This helps them know what has been considered, that their voices have been heard, and experience change and improvements.

Offering different ways to participate

Families with disabled children have differing needs, and parents would like to see consultation taking place in different ways for parents who are time-pressured, for example:

- in-person
- online, and
- hybrid events.

They would also like to be offered:

- daytime
- evening, or
- weekend consultations.

Parents stressed the importance of being given advance notice of consultations, so they have time to prepare and make arrangements to ensure their children are supported so they can attend.

Training for parents

Some parents are at a stage in their life where they feel able to give back or can find the time to share their knowledge and experience to represent other families. But parents feel their circumstances must be taken into account so they can attend consultations. They need good practice tools training to ensure they are able to represent other families.

Parents believe that co-design and co-production with services and authorities around training, information and resources would make a difference to disabled children's services and improve the support needed for families.

Consultation with schools

Consultation or engagements with schools at an individual parent meeting or as a group were not positive experiences.

Parents would like to see co-designed training for teaching staff to build teachers' confidence and improve their knowledge of children's conditions.

Schools tend to consult with Parent Councils, and not all parents, because of poor response rates. However parents feel that children with additional support needs are too often missed out or overlooked in these consultations. They suggested that there should be dedicated ASL Parent Councils or that charities could link and work with Parent Councils to inform, train and develop their roles with learning support and mainstream schools.

The role of charities

Parents believed that charities have a key role to play in supporting parents to be involved in consultations. Regular small group discussions and sharing parents' views at strategic groups are vital when some parents are so time-bound with fulltime caring responsibilities. Parent would like meetings organised with local authorities, MSPs and MPs.

EXAMPLE OF A GOOD WAY TO ENGAGE

Some parents were involved in Expert Panels when Social Security Scotland was in its inception, and they gave this as a good example of engagement and consultation. Parents felt the engagement and consultation made a difference to the delivery of this service and the people delivering the service are friendly and interested in helping families. Some parents who attended these focus groups have seen changes in their forms and audio resources. This is a real positive for families.

Other parents felt further consultation with this service would help improve aspects of the service that families have experienced, like long waiting times to get through and using the chat function on the website.

KEY MESSAGES

- Parents want to engage and be part of the solution, they see co-production and co-design being a major part of that.
- Parents do understand that it is difficult to change services and change does take time but they must be included in the planning and solutions.
- There are good examples of engagement and consultation in new services.

"The pressure is immense. We have a child who will always be our responsibility. Twenty years of worrying every day - that is so different to other parents. Which others don't appreciate until you are in that situation, because we won't have a young person going off to university and will be able to fend for themselves."

Parent carer



National policy

CURRENT SERVICES

Parents said that within current health and social care services their young person's condition is considered "*not bad enough*" or does not meet the criteria for mental health support. Parents also experienced being told their child was "*not disabled enough*" for support services.

NATIONAL CARE SERVICE

Most parents at the sessions were not aware of the National Care Service (NCS) or the National Transitions to Adulthood Strategy. Some parents had heard about the Transition bill.

When asked what their thoughts were on the NCS, parents were concerned about the lack of joined up health services. Their expectations were for a NCS that would change this.

Parents also hope that a NCS will mean attitudes around their children being "*not disabled enough*" for services would change.

Parents have high hopes for a NCS that will alleviate the fears parents have in accessing services and the stigma that still resonates around social work services and the problems with self-directed support.

TRANSITION TO ADULTHOOD

Some parents described the problems families face when their young person turns 18. The young person's condition doesn't change, but there is a real difference in support from paediatrics to adult services, often to the detriment of the young person.

Parents described finding their role being dismissed or removed and yet they know what support their young person still needs.

Different experiences of transition were shared from each area, describing support that is hidden, or services refusing to discuss contingency planning if what is in the young person's Care and Support Plan doesn't work.

PARENTS' CONCERNS AROUND TRANSITION

Some parents said they were "*dreading when we get to that stage*". Other parents described having to search for options and opportunities themselves, but being disheartened and worried that if an option doesn't work out what else can they do.

Many parents' apprehensions focus on their young person not being able to live independently and never having a job, things others take for granted. One parent said, "*The pressure is immense because we will always be responsible for our child, and you have years of worrying every day*". Parents feel they must address these concerns by putting in place Trust Funds for their children's future.

Parents described other situations that drive their anxiety for their child with a learning disability, from the simplest everyday things of going to a shop, to having to worry about being followed by security guards because they are a male and the colour of their skin: "*We have to think about these things every day and the worries never leave us.*"

NATIONAL TRANSITIONS TO ADULTHOOD STRATEGY

Parents with school-age children have high hopes that a National Transitions to Adulthood strategy will change support and services by the time their young person goes through transition at 16. Parents welcome the strategy and want to be reassured that this will improve support and services for their young people.

Parents hope that a strategy will address the confusion of services recognising adulthood at different ages: some at 16, others at 18 and 19.

Some parents questioned if the transition strategy will include those young people who have missed out on school or have been home schooled or leave without qualifications and address university processes around qualifications. Currently parents described supporting their young person to gain a place at college or university as *“fighting the system”*.

Language used

Other concerns around these major policy agendas centred on the policy language and jargon that creates barriers to being engaged. Parents expressed a need for information that is:

- Easy Read
- in different languages
- written in friendly, readable plain English.

Length of documents

Time and energy are always against parents when for example they are sent a 50-page report in response to their question or complaint about a service. Parents also felt that consultation documents are too long and too many questions. They recommended no more than 10 or less questions in a survey or consultation.

ONLINE OR IN-PERSON CONSULTATIONS

Some parents fear that in-person events are increasing again, and online events will reduce. For a lot of families being part of online events made a difference to feeling less isolated and more connected. However, parents were also aware of families who do not use the internet nor have access to it and can't afford it. Parents emphasised the role that charities play to support consultation and engagement, by helping families get online, providing equipment, and striving for accessibility in communities.

KEY MESSAGES

- Small engagement events supported by the charity sector are needed to ensure families are aware and involved in policy consultations.
- There are high expectations of The National Care Service improving support for all families with disabled children, realised through co-design.
- The Transition Strategy into Adulthood needs to be inclusive of disabled children who are in different school settings, have missed out on school life and those children who are home schooled, and opportunities and expectations are improved.

Recommendations

1 REVIEW DISABLED CHILDREN'S SERVICES CONSIDERING THESE FINDINGS, AND WORK WITH FAMILIES

Parents talked about the lack of planning and support they have experienced as a parent and a carer for their child. Hearing about 'crisis' situations building up for their child and family waiting on support from services is not what GIRFEC and Scottish Government policies want for children and young people. Parents want early intervention and ongoing support at diagnosis and assessment. Parents expressed the importance of families and services working together, and they and their young person knowing they are being listened to.

2 TAKE ON BOARD SUGGESTIONS THAT WOULD IMPROVE ENGAGEMENT AND CONSULTATION WITH FAMILIES

Parents want to be involved and have good experiences of engagement and consultation. They would like more families to be involved, who do not have the experiences of consultation and having their voices heard and see the changes. Parents would like opportunities that will fit with their child's and family's needs to be able to engage, offering different times, modes of engagement and support to engage and involve more families.

3 ENSURE THERE ARE SMALL AND ACCESSIBLE ENGAGEMENT EVENTS FOR FAMILIES ON THE NCS AND TRANSITION STRATEGY

Parents were not aware of policy areas relevant to them, and feel there needs to be ways to ensure parents and carers voices are heard. These are major policies that will affect the lives of children, young people and their parents and carers. They must feel that they are a stakeholder.





We are Contact,
the charity for
families with
disabled children.

We support
families, bring
families together
and help families
take action
for others.




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