

## **Service user views and experiences**

### **Overview and context**

To support the effective development of the All Age Disability Strategy for Staffordshire County, it was considered essential to understand the views and experiences of service users. To enable this, a survey was conducted with parents and carers of children aged from birth to twenty-five who have Special Educational Needs (SEN) and/or other additional needs or disabilities.

The analysis here considers service user experiences and views with regards to services from birth to school, and transition into adulthood. Views have been gathered from a sub-set of open-ended questions within the survey, which respondents were free to answer with as much or little detail as they liked. Analysis is based upon the responses of a total of 136 parents and carers from across all districts and boroughs within the county.

### **Emerging themes**

#### **Access to support**

The ability to access appropriate support is the most prevalent theme amongst the survey responses, and is something that parents and carers clearly feel strongly about.

A number of parents and carers feel that early years universal services, namely Children's Centres, do not offer support that is appropriate to their child's needs – however, there are also parents who comment that they have benefited greatly from accessing high quality Children's Centre support.

It is possible that there is a need to understand whether there is consistency in the services for children with additional needs delivered across Staffordshire's Children's Centres. There may be opportunities for centres to share their experiences and best practice with one another, so that more parents with young children with special needs are able to access services. It may also be possible that parents and carers are not always aware of Children's Centre services and support.

Overall, access to support appears to be raised as a theme more often by those who have found this to be an area of challenge than those who have had no difficulties; a number comment that they have had to "fight" on their child's behalf to ensure that they receive adequate support. This is especially acute amongst those whose children attend mainstream schools.

Exploring these comments in more depth, it is clear that a number of parents and carers feel that support is not available unless their child has received a formal diagnosis or statement of additional needs. For these parents and carers in particular, there are some issues around communication and engagement with professionals – with some feeling that they and the professionals are on opposing sides.

While diagnosis of additional needs at the earliest possible opportunity can be preferable, it is not always possible. This is particularly the case when identifying if an individual has autistic spectrum needs. It appears from this survey, that parents and carers of children with autism feel as though it is a challenge for their children to access support. There is perhaps an emerging need to better manage parents' expectations in terms of the support that might be available to their child, but also to ensure that schools are fully aware of and are delivering children's needs-based entitlements.

The need for an understanding of entitlements, available services, and how to access them is something that parents and carers considered to be very important for both themselves and their children - particularly as their children approach 18 years of age, and prepare to leave statutory education and become more independent.

## **Emerging themes**

### **Level and quality of support**

Parents and carers who have accessed support for their children report mainly positive experiences. Many have received support from an early stage which has been very effective in meeting their child's needs. A number share comments about instances where practitioners have gone to what the parents consider to be great lengths, in order to support their child, or secure or co-ordinate additional support from other agencies.

There are some particular examples of good practice which could be replicated across the county, for instance; practitioners caring for young children accessing training with regards to nasogastric tubes, excellent liaison between teachers and parents to ensure consistency in strategies used at home and in school, and examples of a single practitioner co-ordinating multiple agencies involved in a child's care.

Considering the support their children will need when they approach 18 years of age, there was a broad consensus that there needs to be a focus on developing general life-skills and independence – but that this should be an ongoing theme throughout their time in school. In general it was felt that support and care plans should be more long-sighted, and focussed on achieving long-term positive outcomes, not just short-term academic milestones.

### **Awareness and understanding of special/additional needs**

The awareness and understanding of additional needs, and how they can present, is something which parents and carers also felt strongly about. There are strong links between this theme and comments regarding access to support.

A number of parents and carers held the view that many professionals with mainstream school settings had a very limited understanding and awareness; particularly relating to autism and needs on the autistic spectrum, but also to dyslexia/dyspraxia. For some, it was felt that this perceived lack in awareness and understanding had meant that their children were not provided with appropriate support, or did not have their needs taken into account.

In a small number of extreme examples, it was commented that this had resulted in children refusing to attend school, and in a small number of cases resulted in parents/carers paying for private tuition to enable children to achieve as well as their peers.

There is possibly an emerging need to consider how existing training opportunities support those who teach in mainstream schools to identify potential autistic spectrum needs, potentially through the sharing of best practice between mainstream and special schools.

### **Summary of emerging themes**

The feedback provided in comments, the prevalent themes that emerge, and the context that they are provided in, seem to suggest that parents and carers of children with high levels of need – and who access specialist services – have an overall positive experience. The responses suggest that it is those whose children require some support, but within mainstream universal services, who sometimes have more challenging experiences.

Those who have had more challenging experiences refer to difficulties in accessing support – sometimes because their child has not received a formal diagnosis or statement of educational needs, sometimes because they feel that practitioners do not have a good enough understanding or awareness of their child's needs, and sometimes because they feel it takes too long to achieve the support that they want for their children.

The variation in opinions and experiences between some parents and carers, may be an indication that there is not an equal awareness of available support services and referral pathways amongst parents and carers, and also that there is variation in the levels of parental expectation in terms of the support that their children can expect to receive.

## **Survey Sections**

### **1. Post-natal Support**

#### ***"What post-natal support was your child offered? What was your view of this support?"***

Forty-three parents and carers responded to this question; twelve of those who responded did not access any post-natal support for their child. Those who did access support at this time were mainly supported by statutory post-natal services, in particular, health visiting – with a few accessing multi-agency support including services from Speech and Language Therapy. The majority of feedback back related to the services accessed, with a limited number sharing their views of the support itself.

Of the forty-three who responded to this question, there were six who stated that their experience of post-natal services was quite negative – primarily because they had found it challenging to gain access to services, or hadn't been offered support.

*"None. [we were] just left"*

*"None. We had to fight for everything"*

Four responded more positively, with one giving a particularly good example of multi-agency co-ordination, where they were allocated a personal key worker who managed access to all involved services.

#### ***"What post-natal support were you or your family offered? What was your view of this support?"***

Forty parents/carers gave feedback on their experiences of post-natal support that they accessed themselves, although many (fourteen) stated that they did not access any. Many accessed statutory support from health visiting, with a small number accessing follow-up support for post-natal depression. The majority did not share their views about the support that they had accessed.

As with post-natal services for children, a recurring theme amongst those who shared views was that parents and carers felt that the support they had been offered was minimal, and appeared difficult to access.

*"Initially very little support [...]"*

*"[...] bare essentials"*

*"Not much support"*

*"Minimal"*

Equally, there were examples of positive experiences, with one stating that ongoing support from a local psychology service had been vital, and another stating that access to support groups with other parents of children with additional needs had been valuable.

## **2. Early years, Children's Centres and Childminders**

**"What was most important to you when your child was in their early years?"**

The dominating theme for parents and carers with regards to their child's early years was around being able to access to support. The majority of views were neutral – with access overall being the most important factor.

However, it was highlighted that some had experienced delays in accessing support or had not been offered services, and that this had a negative impact.

*"Getting early intervention, but it was dismissed until it was too late  
and far too many years had been lost"*

*"Everything was missing. We received nothing other than a diagnosis"*

*"[...] Support and understanding was important to me but not available"*

Some respondents raised that at this early stage, it would have been beneficial to have been given more information about their child's disability. Beyond information, it was expressed that it would be beneficial for parents and carers to be provided with effective training so that they could better meet their child's needs at home.

*"For me to understand autism and how it affects my child [...] so that I can put strategies in place to help him at home"*

Within this, there was a desire amongst some for more long-sighted planning at this early stage, with a view to building towards long-term independence.

**"How did your local Children's Centre or childcare provider help support you with your child?"**

The level and quality of support experienced by those who accessed these services was seen to be generally positive – with some examples of excellent support, including a childminder accessing training to be able to support with a child's nasogastric tube.

*"[the nursery] organised private speech therapy for my girl, they went out [their] way to support me and my daughter so they could try and help her develop"*

There were, however, mixed experiences when it came to practitioner awareness and understanding of how additional needs can present in children, and in particular those relating to Autistic Spectrum Disorders.

Experiences of parents ranged from practitioners being able to very quickly identify needs at an early age and sharing their concerns with other agencies, to parents feeling that practitioners just "didn't understand at all".

Some felt that the Children's Centres just didn't offer activities that were appropriate for their children's individual needs. One in particular felt that the centre did the best that they could, but were overwhelmed by their child's needs.

### **3. Experience of schooling**

***"Did you feel the school was effective in assisting your child to achieve their full potential?"***

There were mixed feelings amongst parents and carers about whether their child's school had been effective or not; 45% felt that the school was effective, and 55% felt that it was not.

Some had mixed experiences overall, where they their child had initially accessed mainstream schooling, but ultimately moved into special school to better meet their needs. There was a recognition that sometimes even though there was a personal preference for their child to be educated in a mainstream setting, this wasn't always appropriate and in order to meet their potential they required a specialist setting.

*"Once we moved our [child] to the special school we noticed a huge difference in his behaviour and symptoms, school really helped him they looked at his individual needs and also would help with any problems /issues we had at home to ensure continuity."*

Receiving an appropriate level and quality of support was integral to parents and carers positive attitude towards the effectiveness of the school their child accessed. Generally, those whose children were in specialist settings had a more positive outlook on the effectiveness of their child's schooling.

*"[...] highly trained staff have enabled my child to develop confidence to access the curriculum. The curriculum is very personalised and my child feels included, has friends and loves school."*

Experiences of those within mainstream schools was more mixed. Similarly to experiences of early years services, many felt that in mainstream settings, there was a lack of awareness and understanding of how needs may present – again mainly relating to those with Autistic Spectrum needs.

The majority of those who shared their experiences and views regarding the awareness and understanding of additional needs in schools, did so in a negative context, with a number in particular saying that the school their child was in had no awareness or understanding of autism at all.

*"[...] for my child to make reasonable and appropriate progress [the school] needed to have an appropriate understanding of Autism and acknowledge how Autism affects my child"*

Access to support overall appears to be a concern for some; an underlying theme which sits within this relates to the ability to obtain an accurate formal diagnosis. There is a clear view that without a formal diagnosis of additional needs it is not possible to access the support that is perceived to be appropriate.

*"Until I got a piece of paper with a diagnosis on school were not interested"*

This theme also appears amongst questions about early support, but is most prevalent when parents and carers discuss schooling.

#### **4. Support into adult life**

***"What help would make the most difference as children approach 18, when they might get less support?"***

Parents and carers felt that there is a need to ensure that those with additional needs are able to develop key life-skills (such as self-care, cookery, managing money etc.) in order to secure their independence.

There is a feeling that some of this should be built into the support that those with additional needs receive throughout their time in education, and that the support they receive overall should be more long-sighted than it is at present.

*"My son has the ability to go to university, but I am concerned that he may not be able to deal with personal care [and] the usual daily living tasks"*

An issue that sits within this, is that several feel that the transitions between different tiers of education and services are not adequate. There are some suggestions from parents and carers that having a dedicated transitions worker would be beneficial so that there is continuity in support. However, there was discussion of the value of mentoring and peer support at the right time to help young people who are approaching the end of statutory education.

Falling within the wider area of transitions in support, equipping young people approaching the age of eighteen to understand their entitlements, available support services, and how to access them was considered to be important. It was felt that schools or colleges should adopt the role of supporting young people with this.

## Appendix

### A1 – Responses to selected questions

Question	Responded	Did not answer
<b>Q6</b> Tell us what post-natal support you were offered - what was your view of any support offered to your child?	33	59
<b>Q6</b> Tell us what post-natal support you were offered - what was your view of any support offered to yourself/family?	31	61
<b>Q7</b> What was most important to you when your child was in their early years?	66	26
<b>Q8</b> How did your local Children's Centre or childcare provider help support you with your child?	62	30
<b>Q12</b> Did you feel the school was effective in assisting your child to achieve their full potential?	84	8
<b>Q13</b> Please explain the reason for your answer above [Q12].	82	10
<b>Q14</b> What help would make the most difference as children approach the age of 18 when they might get less support?	78	14

### A2. Broad theme within comments and views provided in responses

Theme raised	Overall context in which the theme was raised					
	None	Negative	Neutral	Positive	Mixed	Total
Access to support	16	39	57	3	5	120
Level / quality of support		11	9	27	9	56
Awareness / understanding		20	6	7	5	38
Overall well-being / health / development			16	1		17
Developing life skills / independence		1	14	2		17
Diagnosis / care plan		6	6	1	2	15
Communication / engagement		4	4	4	1	13
Long-sighted planning / support		4	8	1		13
Consistent / on-going support		3	8			11
Support with transitions		1	9			10
Mentoring / peer support			9	1		10
Understanding / accessing entitlements		1	8			9
Multi-agency working		1	2	6		9
Inclusive treatment / support with non-additional needs peers		1	3	1		5
Parental respite			1			1