

October 2017

Karen Hall, Family Voice
Worker (SEND)

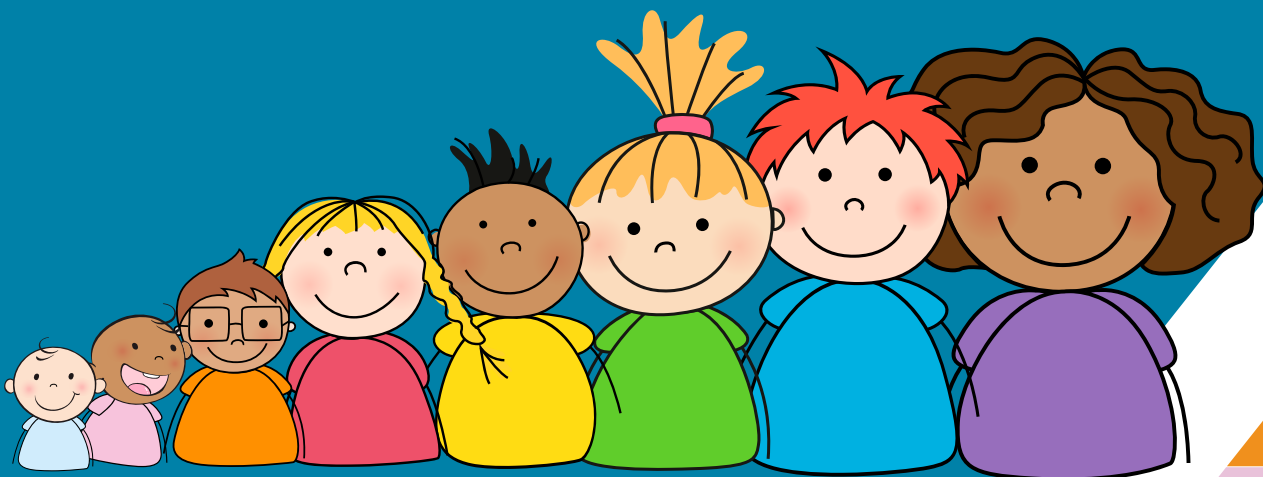


Leicestershire
County Council

Voice Work Report



Voices of Children and Young People
with Special Education Needs and
Disabilities and their Parent Carers



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Section 1

What we did and why?

Purpose

Leicestershire County Council's SEND (Special Educational Needs and Disabilities) department requested a period of Voice Work to be completed throughout May-September 2017. The purpose was to gather feedback from Children and Young People with SEND and their parent and carers in relation to how they felt about services and support in Leicestershire under the Local Offer.

What we did

Over 100 children and young people and 100 parent carers were met over the 5 month period in a variety of settings. These included youth clubs, maintained special and independent schools, summer activities, forum settings, support groups and a film project. Informal interviewing techniques were used and the questions asked were based on the signs of safety approach and focussed on:

- What's working well?
- What's not working well?
- What do they think needs to change?

Children and Young people were asked these questions using a variety of methods which included post its notes, emojis, miniature white boards, one to one and group discussions. Some discussions were facilitated by key workers using Makaton to enhance further communication.

Parents were able to contribute via informal discussion focussing on their own areas of priority which fed into those 3 questions.

This created a wealth of varied data, however, after analysis we were able to see themes emerge from their responses which are explained in more detail in the next sections. Views gathered from a joint event with Leicestershire Parent Carer Forum have also been included in the report.

Section 2

Services and support

What is working well and why? – a parent's view

The parent carers who were part of the research were able to share some common themes in relation to the areas of support which they felt were working well, these will be explored in more depth in this section. Although people often have differing opinions with regards to specific services or individuals within those services, the key points described below are as a result of those common reoccurring themes shared by the parents.

Key workers

When families have a key worker involved – their experience of the diagnosis process and support is more effective and very positive. Parents mention having support from “amazing” and “fantastic” practitioners such as Speech and Language therapists, Family Support Workers, Family Outreach Workers and Health Visitors. The practitioners were able to signpost the parents to the appropriate services that parents felt, would have otherwise been unaware of and also offer practical support. These workers were often the catalyst for beginning the diagnosis process. One parent, when speaking about her Family Outreach Worker and said:

“She was amazing and made a real difference, it wasn't until she became involved that things happened and got co-ordinated.”

Parents also spoke highly of the portage service and felt the team are a very good source of support.

Special schools & nurseries

Their experiences with special schools and nurseries are very positive; they talk about being treated as the experts in their children's lives and the individual needs of their children being met. These provisions also appear to offer the family a network of support. Several parents refer to one area special school as being “absolutely brilliant”. The difference between main stream and special school is also mentioned throughout feedback gathered.

Interestingly, one parent talks about the benefit of her child attending a mainstream school until he was 9 years of age, he was able to learn social skills and model behaviours that she felt would not have been able to learn in a special setting and would welcome more access to dual placements or an increase in mainstream schools having units.

Speech and Language Therapy (SALT)

Although there were a couple of negative experiences in relation to SALT, which appear to be primarily down to lack of staffing, the definite overall consensus was that those who have experience of SALT found it a positive experience. The service has helped support with eating issues in school, carry out visits in nursery/schools and have begun the process for diagnosis.

Group support

Parents value group support, both parent support groups and also online social media groups. Parents feel that this is their main source of information and gain practical advice and information about other groups, provision and entitlements. During the sessions which were focussed for children with special education needs, parents felt that the other parents “understand what it’s like” and wouldn’t feel like they were being judged if their child had a “meltdown” Many parents had been referred to the groups via their support worker, which also concurs with points raised in the key worker section. However, this poses the worry about those parents who are not known to services and who have a lack of knowledge around what is available to them. This will be discussed in the next section of the report.

What isn’t working well and why? – a parent’s view

Local offer of services

The most prominent point raised by parents was the confusion around what services were available to them. They felt that there was a lack of signposting by other agencies and parents had great difficulty in finding out about provision. Parents felt that a lot of their access to support relied on the word of mouth of other parents which felt inconsistent. They also explained the need to carry out their own research into what was available to them.

Along with parents being unsure what services are available to them, all parents of children who have PMLD expressed that there is a lack of suitable provision or services that meet their children’s needs. This includes services not being wheelchair friendly and also not offering an appropriate level of stimulation and interaction which their children would benefit from.

Parents being at crisis point

Parents were frustrated with not being able to access support unless they were at risk of family breakdown. Parents felt it was inappropriate to be asked if their family was at risk of breakdown when they contacted First Response to seek support. Families spoke about being at “crisis point” before services listened and gave them the help they needed. They felt that asking for support should be enough and that they shouldn’t have to pretend their situation is worse than it is or be at crisis point before they were offered help.

“The amount of mums that say “tell them your depressed etc” I shouldn’t need to tell them that or to pretend to cry or my marriage is breaking. The fact is, I’m here and I’m asking because obviously I need some help and that should be enough”

Mainstream Schools and SENCo’s

Often when there is a diagnosis of ASD or ADHD, parents felt there was a lack of understanding of their child’s needs or their disability by teachers within mainstream schools. Parents also express the difficulty in accessing their SENCo’s due to the increase in their teaching commitments. Parents have also been advised by certain mainstream schools that they are “unable to meet their child’s needs”.

Paying for private services

Many parents spoke about paying privately for services. This included Occupational Therapists, Physio and diagnoses. The reason for this included health services being unable to provide the amount of session they felt their child needed, for example in relation to Physiotherapy. Some parents also spoke about using charities and fundraising to be able to purchase the relevant equipment that their child needed as this also wasn’t available through the NHS. Private reports however, are not then used in the EHCP process which parents also raised as an issue.

Transport

Some families feel anxious in relation to possible changes to school transport, there is currently a period of change and consultation. Feedback from the Parent Carer Forum highlights a worry from parents around communication issues with the SEN transport department. The Forum are keen to explore this in further depth

Transition

Many parents spoke about the metaphorical “cliff edge” that their children fall off when they turn 18. “It’s not as big as it once was but it’s still there” Parents feel that the choice of further education is being taken away from their children and believe there is a lack of joined up working across education, health and social care.

School/College

“School is working really well. School feels really safe because of teachers and friends. I have a one to one worker now who knows my signs which gets me in less trouble.”

Most young people feel that their school or college is working well for them. They talk about their relationship with teachers playing an important role in their overall experience at school and the extra-curricular opportunities on offer.

Transport

Although for some young people they felt their transport was an issue, (duration, escorts & lateness) interestingly, the same amount of young people felt that their transport was working well; they enjoyed the journey to school and felt the time in the bus was just right. One young person shared that “the long journey to school helps me focus and think”. It is unclear at this stage if there is a correlation between those young people who travel by taxi or bus and their views around their journey to school.

Preparing for adulthood

Young people spoke about their impending transition on to college; they see work experience in school/college as a positive and spoke often about the vocational aspects of their curriculum being things they enjoy. Some young people have part time jobs which they also felt were areas that were working well for them. Independent living skills such as travel and shopping also featured heavily in the young people’s responses, many young people enjoyed shopping with their parents at the weekend.

Section 4

Services and Support – professionals’ views

Several practitioners took part in an information sharing session to gather their views in relation to services and support in Leicestershire. The overall views appear that services like ADHD Solutions, Autism Outreach and Supporting Leicestershire Families Youth Clubs are good and offer useful support and information for both service users and professionals. However, similarly to the views of parent carers, there was a distinct view that there is a lack of services to support children and young people with SEND, particularly the younger children (under 11) and young adults (over 18). Professionals also echoed the views of parents in that they felt other services were not well equipped to meet the needs of children with SEND, interestingly, this included specialist teams such as CSE and the Police as well as schools.

Section 5

Children, Young People and Parent’s recommendations for commissioners

Better understanding for all

Parents, young people and professionals felt that teachers and professionals should have a better understanding of SEND and more training should be delivered around ASD/ ADHD. They also felt that there should be consistency in the offer of support schools provide, especially to children with SEN. Many parents still receive inappropriate comments from professionals with regards to their children, specifically health professionals and parents would like to see more awareness raised around what is acceptable language to use in relation to disabilities.

Improve our Local Offer of services

“Having the information of all different services and having them coordinated in one place that everyone knows about.”

Several suggestions were made in relation to having a centralised system where services and departments were joined up better. Also flow charts, eligibility criteria, “what to expect leaflets” and “one number for all” were all suggestions which families felt would make the support offered to them and their journey better.

Some parents and professionals would like more local provision, for example, certain services only run in the centre of Leicester which parents don't feel able to access, especially with regards to provision for children with PMLD. Professionals also felt there is a lack of services to be able to signpost children and families to and that there is a need for more provision to be offered in the voluntary sector.

Earlier Intervention – Help us when we ask for help

Families felt that an earlier response to their requests for help and support would have made the biggest difference to their journey. When asked what would they have changed, many parents responded with comments such as “If someone had listened and believed me earlier” Similarly, although parents were understanding of procedures, many felt if their diagnosis could have been quicker, this would also improve things as without a diagnosis, many parents stated that they were unable to access further services or support.

Families also felt that earlier signposting to services and information would be beneficial especially when children are born with disabilities, the parents we spoke to suggested the following:

“Information when you've given birth – like a pack. They knew really early on that xx will have developmental difficulties, more could have been done”

Section 6

Key themes and areas for further development

Theme	Areas for further development
Transport	Suitability of buses versus taxis Acceptable travel times
School	Provision of specialist units within mainstream school Training for school staff in understanding ADHD/Autism
Family Support	Key working model Right support at the right time

Section 7

Recommendations

1. This report is shared widely with parents; commissioners; SEND Board and other key stake holders
2. Use the key messages in this report to help inform the delivery and implementation of the SEND Strategy
3. Provide ongoing opportunities for children, young people and their families to be able to partake in voice activities
4. Provide opportunities for co-production with children, young people and their families to enable them to be involved in the designing and commissioning of services

Diagram of groups visited

