



Listening Event for Families whose children and young people who have Down Syndrome and SEN

Hosted with Candles Down Syndrome Support Group

Parent Engagement Sessions
2023

Report by
Essex Family Forum

How the sessions were held

In July, Essex Family Forum and Candles Down Syndrome Support Group held a Listening Event with Suffolk and North East Essex integrated Care board (SNEE ICB). We were pleased to be joined by Lisa Nobes, the Executive Chief Nurse for Lisa Nobes for SNEE ICB and colleagues across the ICB who all hold responsibilities for the commissioning and delivery of maternity and children's services in North East Essex.

We also welcomed professionals from Colchester Hospital (North East Essex NHS Foundation Trust (ESNFT)), who are commissioned by SNEE ICB to deliver maternity care and children's services.

An Educational Psychologist and Engagement Facilitator from Essex County Council also attended, allowing families not only to discuss their experiences and ask questions regarding health services, but also education.

About the families that attended

The event was open to parents and carers of children and young people 0-25 whom have Down Syndrome and live in Colchester or Tendring, the Essex footprint of SNEE ICB.

It was an opportunity for parents and carers to talk to Health and professionals about their experiences of services including antenatal/maternity care and subsequent health care, including that of community paediatrics.

The event was well attended, and drew families outside of our published area, showing the want and need for parents and carers to share their experiences and feel heard. We are pleased that this event influenced a further event hosted by Upwards with Downs a Harlow based charity supporting Adults and Children with Down Syndrome in Essex and Hertfordshire, which we had the privilege to attend and will report on separately.

Aim of the event and next steps.

The aim of the event was to better understand the lived experiences of parents and carers both through their antenatal care, birth and subsequent health care provision for their Child and Young Person. Lived experience offers person-centred knowledge, insight and expertise about the services that they used and its understanding can not only support development and improvement to those services but can also support service design and delivery for the future.

We shall now share this report with the professionals who attended on the day, alongside key workstreams across North East Essex, alongside the Feedback Coordination and Oversight Group (COG), which oversees feedback from parents and carers across Essex. You can read more about this process on our website [here](#).

We also acknowledge the overwhelming feedback regarding therapy provision and as such, this report will be shared the with Therapy Project Leads for Essex who also cover Southend and Thurrock.

We are acutely aware that the experiences that families shared with us are not unique to North East Essex, so we hope that by sharing the report widely, we can start conversations and influence change across Essex.

Parent/Carer Feedback on experiences of services and provision:



The session provided a wealth of feedback, the key themes of which are:

Inequality in access

Parents and carers reported differences in their ability to access the support and health care provision that was needed to support both them and their child or young person.

"I have been really lucky (so far) in how easy it has been to access services. But again, I know others haven't been so lucky. As an example, one parent who had their child in the same hospital as me, at around the same time, has not had access to SALT, physio or OT, despite the same level of need. Access MUST be the same for all"

Parent-led support groups

Parents and carers shared the importance of being able to access peer to peer support at the right time.

"Parent Led support groups, like PADs and Candles, have been the most important support I've had. Every parent should know about these groups, from the point of diagnosis".

"When parents left the hospital, they did not have any information about groups/support etc"

Importance of Co-production and Participation

Families shared how important it is to be involved in conversations and working groups that develop service and provisions to support and develop the services and provision that they use.

"Today was great. I often find families are asked what they need but are not involved in thinking through solutions. Can we have an active working session together, to think about solutions to the issues raised today?"

Therapy provision

Parents reported difficulties in access, speech and language, Occupational Therapy (OT), Orthotics, Physiotherapy (PT) and concerns regarding discharge.

"Everything is a fight to get things going."

"Children and Young People (CYP) have to wait until 3 years old for input whereas with CYP with Down Syndrome (DS), it is widely acknowledged that there will be a speech delay, so the ask is start early to avoid delays". (Referencing Speech and Language Therapy (SALT).)

"OT, physio, speech, orthotics, etc. should not be discharged as soon as our kids are walking and start talking a bit. Due to muscle tone it's not as simple as they are ok now, lots of problems came from walking badly due to muscle tone etc. so need to be checked. Not up to parent to figure it out."

Health

Parents and carers reported varying levels of support within maternity care, during scan appointments and at birth when the baby is identified at a higher risk of, or having down syndrome. Many families reported that conversations focusing on the viability of the pregnancy, options pre and post birth and negative aspects of the diagnosis rather than provide a more balanced approach. Parents felt their pregnancy and baby was not celebrated in the same way, should their baby not have had down syndrome by some professionals.

"sadly prenatal diagnosis in particular seems to include fear-mongering , emphasising potential health difficulties, as opposed to being honest about the degree of difficulties being unknown. Access to positive, but honest, messages at diagnosis are really important."

“There needs to be a key in the system that flags when a child with down syndrome is born, not just for general learning disabilities as this is different! and have a set of checks to go through and tick off when test is done/issue resolved and ongoing treatment. (Aspiration test a must, audiology, eye sight, heart, physio, Occupational Therapy (OT), etc. all at the youngest age possible to ensure no one is missed off) and should have more help with Disability Living Allowance (DLA) and Education Health Care Plan (EHCP) and paedcs must do a section 23 form for nursery as they need them and a lot of us had to ask again and again for them etc.)”

Professionals feedback following the session.

The professionals who attended the session all expressed gratitude to those who attended and shared their experiences and valued the conversations that the session enabled them to have directly with the families who use their services.

What the professionals reported they heard was:

- That there is lack of therapy support within education settings, specifically speech and language.
- The importance of access to therapies early on in a child’s development which impacts on a child’s milestone development for example having quality physiotherapy support, will support with a child’s mobility.
- That the language used by professionals with parents is not always positive and that the potential of the child is not always recognised.
- To make sure that appropriate literature to sign post families is available within antenatal areas.
- Support screening midwives with additional training on down syndrome so they can provide the right support to families at the right time.
- Services are not always coordinated. For example, if a child or young person is having a health assessment, treatment or procedure could other checks occur at the same time where appropriate to ensure their other health needs are met, acknowledging that this reduces the stress and anxiety levels for the child or young person who otherwise may need repeated visits and/or procedures.
- Access additional training for our screening midwives
- Reach out to include families who have children with Down’s syndrome to ensure they form part of our service user feedback routes so that we can continue to improve the services we offer to families
- Having the right educational provision and assessment of needs is important.
- That communication with SEND Ops at times is not meeting the needs of the families.
- That some families from both mainstream and special schools are unaware of the support that is available to them and the school including:
 - SEND Inclusions Partner and Engagement Facilitator roles.
 - What support is out there from other agencies professionals?
 - Where to find the information such as the Essex Local Offer.
 - The Essex Local Offer SEND Roadshows