



Report completed by: Down Syndrome Cheshire

Down Syndrome Act Guidance 2022
Call for Evidence

November 2022

Endorsed by:



Parent Carer Forum, Cheshire West



Parent Carer Forum, Cheshire East

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1.0 Purpose

The purpose of this report is to outline the views and lived experience of people in Cheshire who support loved ones with Down Syndrome, professionals who have worked with people with Down Syndrome and most importantly the views of people with Down Syndrome to input into the Government's "call for evidence" to support the Down Syndrome Act.

The report will outline the process of consultation and the number of participants. It will offer common themes, under specific topic areas and go on to offer recommendations on key observations. It will also outline the discussion on whether the Down Syndrome Act should cover other genetic conditions.

What is Down Syndrome

Down Syndrome is the most common genetic condition. A person with Down Syndrome has an extra copy of Chromosome 21. It occurs in approximately 1:750 live births. People with Down Syndrome have a unique and well [researched](#) learning profile. Understanding this unique [learning profile](#) for support workers, family members, health professionals and teachers is essential to ensure that people with Down Syndrome achieve their best possible outcomes.

2.0 Background to Cheshire

Cheshire is a rural county based in the Northwest of England. The population of the county is just over 1 million with approximately 750 people living with Down Syndrome in Cheshire. 97.3% of the population is white, 1.7% Asian and 0.4% black. Approximately 20,000 families received free school meals, although this figure changes

3.0 Down Syndrome Cheshire (DSC)

Down Syndrome Cheshire (DSC) is a charity that supports people with Down Syndrome (DS), their parents, carers, schools, health services and employers in the county. The charity works in over 100 schools across the borough offering specialist Down Syndrome training and advice. It employs 4 Education Advocates and a specialist Speech and Language Therapist to support parents/carers and schools in understanding the unique profile of people with Down Syndrome and how to ensure that people with DS reach their full potential.

DSC has 322 registered members with Down Syndrome who access their services regularly and support over 3,500 service users (professionals/employers/parents) across the borough. DSC are the experts of Down Syndrome in Cheshire. To find out more about the services delivered by the charity, please look at the website.

www.dscheshire.org.uk

Age breakdown of DSC's membership

Age	No. Members	% Members
0 to 5	71	22%
6 to 11	117	36%
12 to 17	57	18%
18 to 24	45	14%
25+	32	10%
TOTAL	322	100%



4.0 Consultation Process

During the Government's 16-week consultation process DSC have conducted several consultations reaching all corners of Cheshire (see area breakdown in appendix 1).

**In total, 14 separate consultations took place:
12 in person and 2 online.**

A total of 202 people took part.

**Of those 202 participants 89% were female
and 11% male.**

Ages ranged from 72 to 21 years old.

98% white 2% black.

During the consultation process DSC spoke to parents/carers, adults with Down Syndrome, SENCos, Speech and Language therapists, Social Workers, Senior Managers in Cheshire West Council, day service staff as well as their own staff team.

The consultation process focused on Education, Health, Social Care, Employment and Housing.

During each session participants were asked 3 questions:

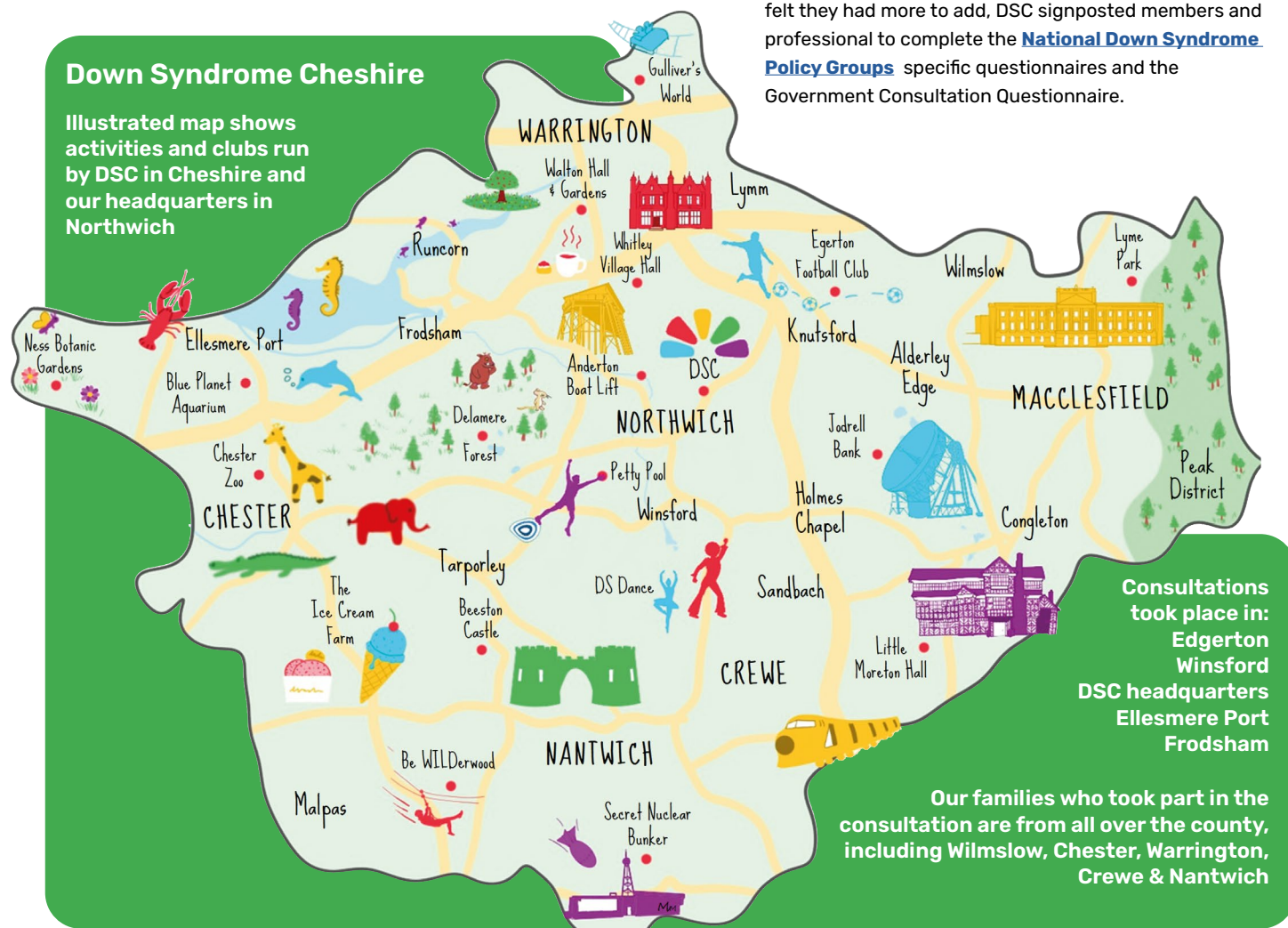
- What has worked well?
- What hasn't worked well?
- Even better if?

These sessions were all facilitated by a member of the DSC team and all participants were asked to work in groups to capture their views which were recorded in a consultation booklet. (see Appendix 2).

4.1 Additional Supporting Evidence

In addition to the consultation findings, this report will also include:

1. Input for specialist Speech and Language Therapists (Appendix 3).
2. Relevant findings from DSC's annual membership survey
3. Feedback from 144 teachers and TAs who attended specialist Down Syndrome Learning Profile Training in the last 12-month period
4. Impact reports and case studies of the benefits of employing specialist Education Advocates. (See Appendix 4)
5. For those who couldn't attend the consultations or who felt they had more to add, DSC signposted members and professional to complete the [National Down Syndrome Policy Groups](#) specific questionnaires and the Government Consultation Questionnaire.





5.0 Report Summary and Findings

There are some clear themes that run through all the evidence collected. These are:

5.1 Mandatory Learning Profile Training

A recognition that Down Syndrome has a unique learning profile that should be part of mandatory training for every professional involved in their journey from Midwives to Dementia specialists. Understanding the profile is the secret to unlocking potential of people with Down Syndrome. The training should cover not only the profile but the appropriate language to use when talking to a person with Down Syndrome and their family.

5.2 Education Health and Care Plan (EHCP)

Recommendations about automatic eligibility for an EHCP on diagnosis was mentioned in every single consultation.

5.3 DS Champion Roles

Experts trained in the learning profile of people with Down Syndrome placed in Education, Health and Social Care who understand the systems and can help guide professionals and parent carers on their journey.

5.4 Data

The need for better Data about the condition, where people with Down Syndrome are educated and are living. The introduction of a school census that allows Local Authorities know where children with Down Syndrome are. Shared data across authorities.

5.5 Automatic Allocation of services on Diagnosis

These findings range for automatic allocation of Disability Living Allowance (DLA) through to access to Speech and Language Therapy (SALT). Both professionals and carers alike recognise the fight that is involved for parents to access services. Automatic allocation of specific services that we know are intrinsically needed and linked to the condition would reduce unnecessary bureaucracy and reduce the burden on parents in their caring role.

5.6 Employment

There was consistency amongst the participants that employment should be high on the agenda for outcomes. Schools felt that it should be more integrated into the college/high school process. Social care talked about the benefits of those in their care who were working. Parents and carers talked eloquently about their children's desires to work in a career that was important to them. Most importantly, those adults who were working had a sense of purpose and focus. For those who were currently in employment, it was their main aspiration for the future. Working with businesses to enable them and achieve this going forward plays an essential role in reducing costs on the adult social care budgets as well as an opportunity to fill key vacancies in the workforce.

5.7 Support

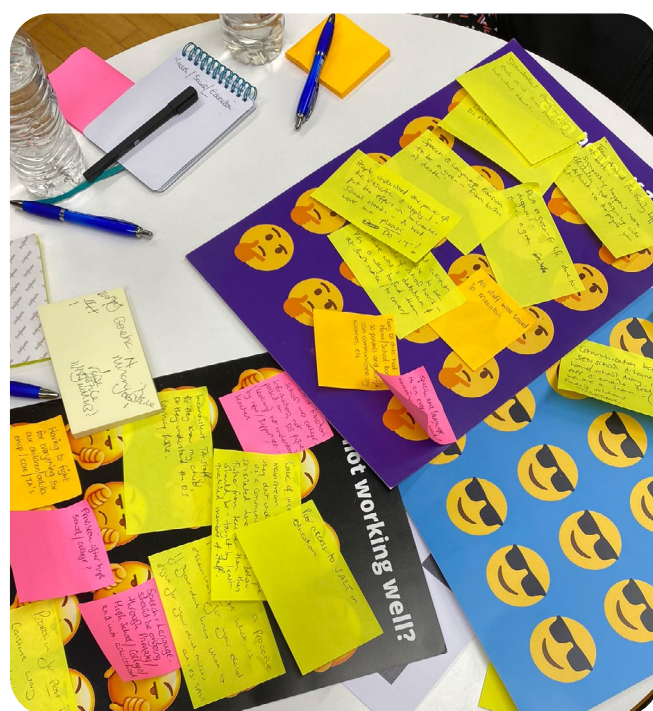
Cheshire is fortunate to have a strong pro-active Down Syndrome Charity operating in the County. The support that is offered to parent carers, schools, health professionals and employers has significantly bettered the outcomes for not only the person with DS but their families and the Local Authorities. The work that they offer around Education Advocacy has reduced school breakdowns and empowered the teachers and TAs to differentiate the curriculum to make it accessible for the children they support.

5.8 Down Syndrome Specific Act

During the consultation process the discussion around extending the Act to other genetic conditions was discussed at length. Many felt that they weren't equipped to contribute to the debate, they didn't know enough about Down Syndrome or other genetic conditions. Others who have supported people with Down Syndrome felt strongly that the Act should remain DS specific. There was an acknowledgement of two things:

1. Down Syndrome had a specific learning profile that was unique to the condition
2. Other genetic conditions should not be forced down the same profile path as people with Down Syndrome. They felt that this would be disrespectful to their own unique profile.

There was agreement that the Down Syndrome Act should be used to "lift up" or "pave the way" for other genetic conditions and where recommendation would be useful to other conditions this should be stated.





6.0 Education Summary

It is clear from the consultation that took place with both professionals and parents that there are key themes that run through the Education topic.

They are:

- The need for specialist training for SENCOs, teachers TAs and parents
- A lack of understanding of the profile leads poor inclusion and school breakdowns
- Automatic eligibility for an EHCP with diagnosis
- The school and the parents working in partnership leads to positive outcomes
- A designated Down Syndrome Champion in the LA who teachers and parents can go to for advice, this role is currently being filled by DS Cheshire
- Employment should be expected outcome for most people with DS

Professionals' views

Consultation feedback

No. of participants 101

DSC consulted with 90 SENCOs who attended 2 SENCO cluster meeting in Frodsham, rural Cheshire, Ellesmere Port (one of the county's poorer conurbations). The attendees had a range of experience of teaching, from Newly Qualified Teachers (NQT) to experienced teachers with over 30 years of experience. In total, the teaching experience of the SENCOs consulted was in excess of 1,000 years, with them having supported over 50 children with Down Syndrome.

In addition, the DSC Education Advocates and staff team were also consulted. They support over 300 people in Cheshire with Down Syndrome and have over 100-years teaching experience between them.

What worked well...



From the SENCOs and professionals we consulted it was clear that the Special Schools in Cheshire are working well to support children with Down Syndrome. For those in Mainstream settings the specialist training they had received from DSC in the use of packages such as Down Syndrome Education's See and Learn programme, Numicon and Makaton training has been invaluable.

Schools reported that the ability to be able to contact Education Advocates via DSC to get advice was invaluable to ensuring they were supporting the child with DS appropriately and have the skills and knowledge to be able to differentiate the curriculum accordingly. One school wrote *"The Maths for Life programme is a tailored approach to teach maths skills in a way that support maths for life skills"*.



SENCOs also reported that it was imperative to have strong relationships with the parents and to understand what important factors were taking place in the children's life outside of the school setting. This was often supported by Apps such as Special Words.

Having a charity providing a service to fill the gap in training and education in the borough has helped meet the needs of the professionals' educating children with Down Syndrome and in turn upskilling the child with DS to improve education outcomes.



What hasn't worked well...

There were clear messages on what didn't work well.

These can be grouped into categories:

- EHCP Process – The process to access the EHCP is long winded and complicated. Three rounds of Plan Do Review are time consuming and can have a negative impact on the children being supported.
- Lack of specialist training – The SENCOs who are supporting children with DS felt that the training that they received about the condition was inadequate. It was only after they had received specialist training that they felt able to fully support the child with DS and ensure that they reached their full potential. Although the training is free, staff have not been allowed time off to attend necessary training.
- Funding – For relevant equipment/Apps and training is often not covered in the EHCP and additional funding must be found from the school budgets. Often the funding in the EHCP does not cover the 1:1 hours required.
- National Curriculum needs to be differentiated for people with DS to be able to access it e.g. phonics reading books do not work for people with DS. Cursive writing is not accessible for our DS learners.
- Inclusion in mainstream can be difficult as there is not enough training and support for the child to be fully integrated into the school day.
- Multi-Agency Support – The SENCOs reported that there was a lack of support in school for specialist therapies such as SALT, Education Psychologists, OT and incontinence training.
- Lack of willingness from Mainstream High Schools to take children with DS even if they have had a successful primary mainstream placement.



Even better if...

Clear messages came out of the SENCos about how the current system can be improved and streamlined. They are as follows:

- The SENCos were polled on the idea of a school census to identify and track where children with Down Syndrome are educated. Over 95% of those polled thought this was an excellent idea.
- Automatic eligibility to an EHCP on diagnosis. Schools reported that it was far harder to meet need without an EHCP. It was recognised that all children with DS will have a learning disability and health need so automatic access to a EHCP would help streamline the process.
- Specialised training for Teachers, TAs and SENCos in the learning profile of a child with Down Syndrome. It was suggested that this should be incorporated into the teacher training. Those teachers who had received the specialist training felt more supported and better equipped to teach the child with DS.
- DS Cluster Groups – To set up networks that can share best practice across the borough and nationally.
- Designated DS specialist (champion) in the LA in Down Syndrome, similar to the Autism team

Professional Reports

Learning Profile Training

There is evidence in Cheshire that some of the recommendations made are working in practice at some schools across the borough.

DSC delivers a learning profile course that explains all aspects of Down Syndrome. It breaks down the hearing, visual and speech difficulties that are faced by people with DS and how a school setting can overcome these challenges. It also details how people with Down Syndrome are visual learners and suggests strategies in Numeracy and Literacy to help children who have DS to access the curriculum more effectively.

During the last 12-months Down Syndrome Cheshire has trained 144 teachers/TAs and SENCos in the specific learning profile of people with Down Syndrome.

Feedback from this training and subsequent follow up underpins the need for specialist training for Down Syndrome to help support our schools to ensure better outcomes for children with DS.

One school reported:

“As a 1:1 it helps me to understand the child I support and how I can support her better, with tools and by being more informed.”

Another said:

“Understanding the profile of a child with Down Syndrome is really helpful. I now feel prepared to work with the girl who has DS in my class next year.”

One teacher talked about understanding behaviour:

“It has provided me with knowledge and strategies to improve my behaviour management in a way that recognises the individual needs of the child I work with.”

This snapshot of feedback from schools in Cheshire demonstrates there is gap in the teacher training around the learning profile of people with Down Syndrome and that specialist training is required to help increase positive outcomes.

Education – Parent and Carers Views

No of participants 22 over 2 consultations:

7 online 15 in person,

Age range of people with DS being supported from age 9 to 36 years



What worked well...

The consistent message that came across from parents and carers was that a placement in either a special or mainstream school was successful if the staff were well trained in the learning profile of DS and when the school's culture is about inclusion.

A parent wrote *“School are inclusive and are actively looking for way for A to have a role where she can help out.”*

Another wrote *“My school have accessed all the training that DSC have to offer including Makaton, Numicon and Learning Profile. It has made a huge difference to ensuring that J is understood and that he can feel that he is achieving in the same way his classmates do.”*

Positive communication with school staff has also been reported to have worked well.

“Communication between school and home via the home school diary, class Dojo, apps and emails make me feel like we are a team finding solutions together.”



What hasn't worked well...



Consistent messages came from all those consulted about what didn't work well. They can be grouped into categories:

- The EHCP process – One parent describes it as “walking through the jungle that was so dark, there was no help until I found the DS Cheshire team”. Others wrote “I have had to fight for everything” “EHCP process was chaotic”
- Resources – Many families reported that the 1:1 who was allocated to their child was being shared with the whole class. High turnover and poorly trained TA staff led to school breakdowns.
- Access to therapies in school – Little or no access to Speech and Language, OT, sensory OT, Physio or Educational Psychology input.
- Lack of inclusion in mainstream settings due to poor understanding of the condition. Many behaviours are a form of communication, however many reported that their child was removed from the class to be taught in a corridor. This isn't inclusion.
- Lack of relevant training led to a lack of understanding about the condition.
- Lack of accessible before and after school clubs and no holiday provision for children with DS.
- Low expectations set from early years to college leavers. Many parents reported that they felt some settings were “babysitting rather than educating” their children. That the school/college staff didn't understand the condition and they “wrote their child off”
- Poor post college opportunities were also reported by several families. Many talked about the child's career aspirations that were never discussed and the college course choices were limited and unappealing to many. Not all people with Down Syndrome wanted a career in catering, horticulture, or animal care.

Even better if...



The parent carers had several suggestions about how the system and process could be improved for future generations, many of which were consistent with the professionals' suggestions such as:

- Diagnosis leads to automatic EHCP
- All SENCos training in the specific learning profile of DS and Makaton
- Designated key worker in LA who is a specialist in DS
- They suggested the idea of a school census so that the LA could track those people who have left education and who are NEET.

Employment

The parent carers made further recommendations around the link between education and employability. Many felt that their young people needed to stay in a structured education environment to help them build the necessary skills to be ready for work. Although an EHCP can be used until a young person is 25, in Cheshire it rarely is. This time could be spent working with employers on classroom-based skills that would be useful to both the young person with DS and future employees. A wider range of college courses should be available to those who want to access them – everything from sport to photography should be accessible to people with DS. This currently isn't the case.

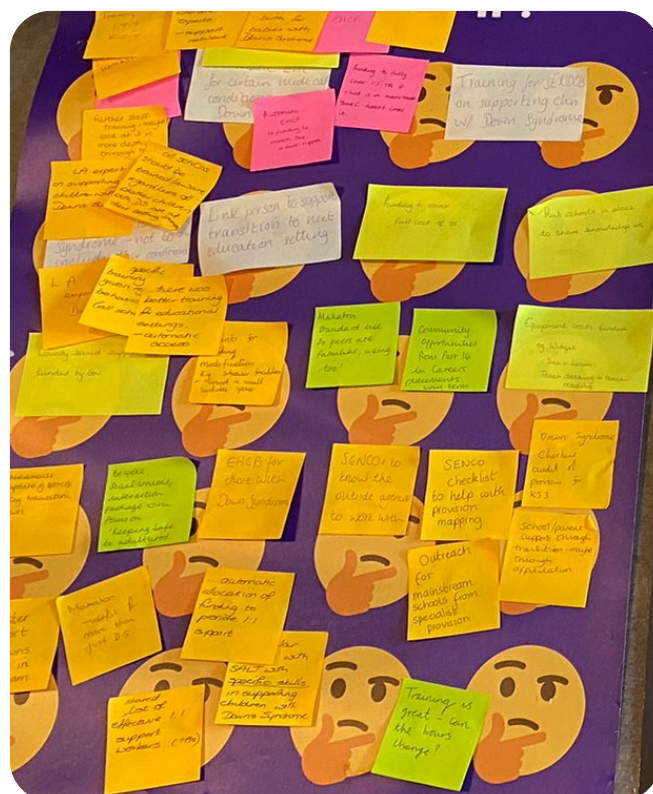
It was also suggested that the Local Authorities should work with the Local Enterprise Partnerships to identify skills gaps and roles that people with Down Syndrome would be able to fill.

Training

A clear message was that specific training is required for all those involved with children with DS. From the evidence it was clear those schools who had accessed training and those who hadn't.

Therapies

It was suggested that all SALTs are trained in Makaton sign language. All children with DS have access to a SALT from birth. There is clear evidence that early speech and language intervention is beneficial to people with Down Syndrome.





7.0 Health Summary

It is clear from the consultation that took place with both professionals and parents that there are key themes that run through Health. They are:

- The use of appropriate positive language when delivering the news that a baby has Down Syndrome
- Specific Down Syndrome Training for all health professionals to STOP diagnostic overshadowing and increase Speech and Language outcomes
- Support and signposting when done well, offers incredible benefits to the mental health of a family
- The need for sporting activities to help underpin good health outcomes
- DS Champion who is an expert in the condition and can help navigate families.

Health – Professionals

Consultation feedback No. of participants 13 including 2 Specialist Speech and Language Therapists (see Appendix 3 for report)

What worked well...



On average 10-15 new babies are born in Cheshire hospitals each year of which 10-12 are signposted to DS Cheshire. This is because of the work that has been done with the Cheshire hospitals on raising the profile of the group and the production of the Maternity Booklet that is handed out to new parents.

Maternity

Where DS Cheshire had been able to present to health professionals at local hospitals, the use of appropriate positive language was starting to be used. Health Professionals are handing out the **DSC Maternity Booklet** to parents and signposting people to DS Cheshire so support is on the increase.

Parental Support

New parents have access to a Family Support worker funded by DS Cheshire. The family support worker supports parents from pre-natal diagnosis right through to adulthood. The support offered to families has significantly improved parent's mental health.

Hopes and Fear Survey 2022 parents' comments:

"Scary at first with the unknown and lack of support but now feeling able to cope."

"Great advice, another voice that supports our understanding of our child's needs. A source of recommendation for other approaches and a sanity check."

Physical Activity



People with Down Syndrome are prone to be overweight and inactive due to problems with their Thyroids. To combat this, the charity runs weekly sporting opportunities to help keep them healthy and active. They provide weekly and bi-weekly football, dance, rugby and tennis sessions. This has had a positive impact for many in the community, has helped to develop self-confidence and friendships as well as providing the community with a healthy life choice.

What hasn't worked well...



Lack of Knowledge

This is a common theme that runs through the consultation. Again, there is evidence of gaps in knowledge and appropriate use of language with the clinicians. There is a definite need for training with midwives, health visitors and doctors about accurate up-to-date information about living with Down Syndrome in 2022.

Speech and language Therapists

The lack of the knowledge of the learning profile of people with Down Syndrome and their limited access to Speech and Language has a detrimental impact on their long term life outcome. NHS SALTs are not trained in the specific profile of a child with Down Syndrome. This is leading to them misdiagnose their needs and provide inadequate care plans to support their development. **SYMBOLUK** (specialist Speech and Language specialists in Down Syndrome) talk about a syndrome specific profile unique to people with Down Syndrome.

Termination

There is still evidence in Cheshire that the pre-natal diagnosis of Down Syndrome and the offering of a termination is delivered as part of the same conversation. This has a tremendously negative impact on the parent's mental health and their ability to come to terms with the diagnosis.

Communication

Communication within the Health Service is poor, parents are having to tell their story on numerous occasions. Links with Local Authorities are also poor, resulting in delays in accessing provision.

Access to services

Access to SALT, OT, Physio, Dental and Sensory OT is difficult. There is a lack of consistency across the county with some families receiving more services than others based on their location. Some families are having to rely on private SALT services to help resolve swallowing and feeding issues.



Even better if...



The professionals working with families with DS came up with a number of suggestions. They are as follows:

- Designated DS Key worker at NHS trust or nominated person responsible supporting families
- Automatic EHCP on diagnosis
- Training of DS incorporated into Midwife and Doctor training
- Makaton Training for all NHS Staff
- Signposting to local charity
- Automatic referral to SALT, Physio and OT
- Reintroduction of Portage services

Professionals report

Please see Appendix 3 for Down Syndrome Cheshire's SALT report

Health - Parent Carers Consultation

No. of participants 26, 3 in person consultations

Age range of people with DS being supported from age 0 to 36 years

What worked well...



The families that took part in the consultation generally had admiration for the care and support they had received from their NHS providers. Praise was given to Alder Hey's Children's hospital in Liverpool.

Collaborative work

When NHS services and private services work together this benefits the families and the children.

Support

From local charities where shared learning and peer support was available has helped to reduce isolation and increased parents' mental health and wellbeing.

Annual Health Checks

Are generally working well for Adults with DS.

Key People

Well trained informed members of the NHS workforce.

What hasn't worked well...



Language

Too many families reported that negative language was used when delivering the news that their baby had Down Syndrome. Some told harrowing stories of health professionals telling them to leave their child at the hospital and that nobody would judge them.

"At birth I was asked if I knew I didn't haven't to take him home if I didn't want to ... I really wanted him and I didn't want him taken away from me."

Lack of Services

All therapies were discussed but a particular problem with getting access to Speech and Language provision was highlighted.

Parents wrote: *"I have struggled to get SALT services and now they want to discharge my son despite the fact that poor speech is his main concern."*

Diagnosis Overshadowing

A disappointing number of examples have been given where a person with DS has been mis diagnosed as the symptoms were put down to the "Down Syndrome"

"Misdiagnosis through assumption e.g. treated hearing loss instead of communication issues."

"I am fed up with medical issues always being put down to "Down Syndrome" when clearly there are other things at play"

Respect

There was a general lack of respect shown for the individual with Down Syndrome. This was reported by several parents saying that their child wasn't spoken to directly by a clinician or there was a general low level of expectation of attainment from their child.

"Respect the individual during a consultation, talk to them not over them."

Even better if...



Training

A programme of better training about the use of appropriate terminology when delivering the news that a baby has DS. Training on the learning profile of a person with Down Syndrome that is compulsory for all health care professionals.

All paediatric hospital staff trained in Makaton.

Children's DS Co-ordinator who helps navigate a family through the NHS process

Adulthood - Continued access to services/therapies into adulthood, this should include Speech therapy

Quality Standard given to health authorities for inclusion, language, and access to services



8.0 Social Care Summary

It is clear from the consultation that took place with both professionals and parents that there are key themes that run through Social Care. They are:

- The need for specialist training for Social and care workers
- Automatic eligibility for DLA lower level
- Successful employment opportunities are crucial for people with DS to better their outcomes and should be an expected outcome
- DS Champion in Social Care who is a specialist in the condition and can help both professionals and parents navigate the benefits and social system
- Specialist Dementia Care homes for adults with DS
- Employability officer to help adults with DS into work

Social Care – Professionals

No of participants 23, including Social Workers in Adult Social Care and Day Services

DSC consulted with 12 social workers and day care assistance. Between them they had 60 years' experience of supporting several adults with Down Syndrome ranging from 18 years to 70 years.

What worked well...



Employment

Those adults who have jobs are flourishing. One of the social workers reported that one of her service users works 2-3 days a week and *"it works really well, it gives him a sense of purpose"*.

For those who are capable to access employment this should be encouraged.

Structure

Having a routine and structure for many ageing people with DS is very important. It helps give them a sense of calm. Day services help provide this for many.

Social Opportunities

Providing opportunities for adults with DS to meet up regularly teaching them work skills, life skills and even dating skills!

What doesn't worked well...



Dementia Care

This is becoming an increasing problem, those who are accessing supported living and have developed signs of dementia are not having access to the best care. Generic dementia care homes are not equipped to deal with adults with learning disabilities and the supported living carers are not adequately trained in dementia to be able to support the person with DS adequately.



Employment

Although many described their service users as capable of being able to work, the employment process was lengthy, and the candidate lost interest. The person with DS would then access day services as an alternative and they would then regress in their skills and find it difficult to break out of the routine of day services.

Lack of Training

There is a lack of training about the learning profile of DS with specific focus on dementia.

Access to Services

Access to social workers and personal assistance is difficult.

Benefits Process

The benefits process is complicated and difficult to navigate with many families unaware of the benefits they are entitled to claim.

Capacity and Sexual Relation and Education

Continuous education around consent and capacity is needed. It has been assumed that many people with DS don't have capacity to enter a relationship. The person with DS will need to have this topic taught to them frequently for them to revisit and understand what boundaries and safe relationships look like. Social workers described people with DS having opportunities for relationships being "written off".



Even better if...

- Automatic allocation of lower rate DLA apply for middle/higher by exception
- Better funded system for Personal Assistance and care workers with a fully mapped out career path
- Specialist Dementia Care
- Employment Support Officer dedicated to working with local business to find work opportunities
- Specific Down Syndrome training for social workers and care workers
- Employers incentivised to employ people with DS
- Down syndrome incorporated into dementia friends training
- Social groups for adults with DS to meet friends and potential partners



8.1 Social Care Parents and Carers

12 parent carers took part in an in person Focus group.

What worked well...



Social Workers

For those who had access to a social worker their journey into adulthood was far easier. They were signposted to services and supported in the transition to adulthood process with anything from college choices to application of PIPs.

What hasn't worked well...



Benefits process

Access to benefits is difficult to navigate, there is little understanding of the changes in benefits when their child turns 18 and is entitled to Employment Support Allowance. Parents describe they must "jump through hoops" to get the services they need. They are unclear about what they are entitled to and are "exhausted" by the process. Many describe having to be at crisis point before they got any support.

One parent describes her situation,

"Having to be an employer for a personal assistant adds pressure to me as a parent when I am already in a caring role."

Feedback from DS Cheshire Hopes and Fears Survey:

"Knowing what we can spend Direct payments on. Little support to employ a PA. Very little support to write JD, sort insurance etc.- the HR and recruitment side of things was left entirely to us with almost no help."

"No one to go to for advice on employing PAs any more e.g. I had to find a contract online. I'm never sure I'm meeting my legal obligations as there is no support with audits. Don't know where to go if I need to ask for budget changes, haven't been reviewed since well before lockdown."

"Assessments incredibly stressful and hard to work 'managed account'."

Social Workers

Patchy and inconsistent access to social workers even for those who have adult children.

Even better if...



Employment

This was the aim for most of the families who took part in the consultation. They felt their adult child would benefit from accessing employment if it didn't have a negative impact on their benefits.

Employability Officer

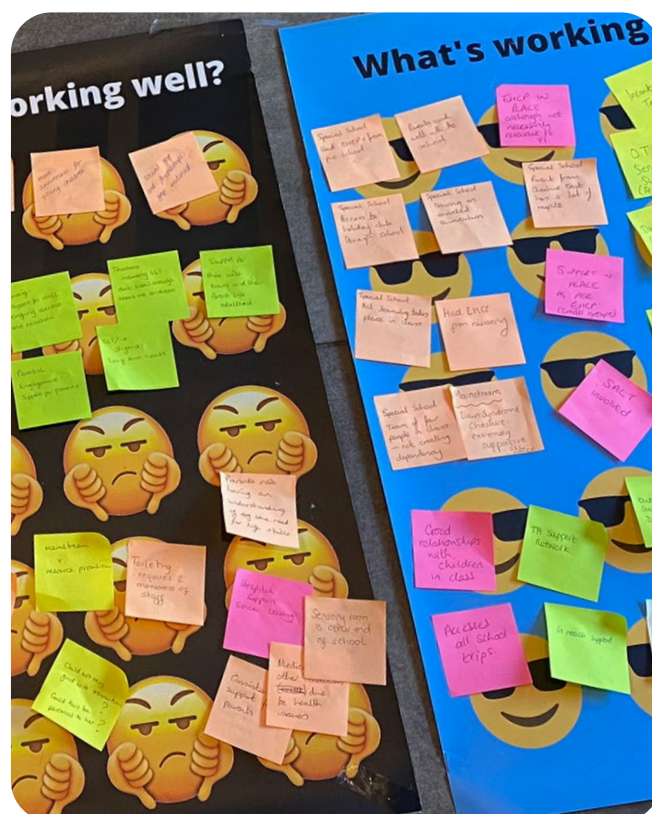
For an employability officer to work with people with DS from an early age (suggested 14 onwards). Their role would be to help build the skills of the young person with DS to ensure they were work ready when they left education. There is a gap in this offering now and adults with DS get lost in the adult social care system.

DS Champions

Have designated key workers in Social Care who are experts in DS and who will help navigate the families through the bureaucratic process of benefits.

DLA

Automatic eligibility for DLA until the child reaches 16 when they will apply for PIP. Down Syndrome is not a condition that can be grown out of.





9.0 Housing and Employment

These consultations were carried out with adults with Down Syndrome supported by scribes. We had 5 adults who contributed, 2 who lived in supported living and 3 in their parental home. The participants ranged from 21 to 53 years old.

Housing Aspirations

All participants wanted to live in a good standard of accommodation. Their aspiration was to have a large house with swimming pool, pool table, Karaoke room and a private chef. They wanted their home to be equipped with all the mod cons including washing machines, dish washers and dryers.

On further discussion with the participants, they described that they wanted to have access to social activities in the evening and would be happy for this not to be in their home.

Fears

There was genuine concern about funding and paying for their bills. They also had concerns about staff who would be needed to support them. Those in supported living are now experiencing a high turn over of staff that is making them feel anxious.

Personal Aspirations

All of those who participated wanted to have a choice of who they lived with whether this be friends or future partners. They wanted to be given independence and not "babied". They wanted to be responsible for the chores in the house, but supported in those that they felt uncomfortable doing e.g. bills.

One participant described a recent situation in her current home where she was told what time to go to bed and when she could have a cigarette. She was quite rightly put out by this and felt she should be allowed to make her own choices.

Employment Aspirations

2 of the participants had jobs - one paid, one volunteering. The remaining 3 all accessed services that Down Syndrome Cheshire offered and were receiving direct payments and other benefits.

One of the participants has a keen desire to work with wood and is a skilled crafts person. His aspiration to work in this industry is being supported by Down Syndrome Cheshire employability programme. They are hoping to set up a social enterprise business selling the crafts he makes.

All of the participants had a strong desire to work and those who weren't in employment felt a sense of loss. They had recently left full time education and they wanted to be able to earn their own money.

Limited Opportunities

There are limited opportunities for paid employment for people with Down Syndrome in Cheshire. Employers are not incentivised to employ people with DS. If done correctly with training and job carving people with DS would be an asset to any workplace.

10.0 Conclusion

Down Syndrome Cheshire have conducted a comprehensive consultation for inclusion in the Guidance to support the Down Syndrome Act. There are many commonalities between the professionals who work with people with Down Syndrome and their parent carers all of which is captured in the opening summary.

The Cheshire community believe that the Act should remain Down Syndrome specific with the caveat that all good practice should be shared with the wider SEND community.

Down Syndrome Act Call for Evidence



14 consultations
took place:
12 in person & 2 online

202 people took part

aged from
72-21
years old

89% female
11% male

Down Syndrome Act Guidance 2022

Call for Evidence

November 2022

APPENDIX 1 - 4

Appendix 1

Map of Cheshire

People have contributed to the consultation from the following locations:

Winsford
Hartford
Northwich
Malpas
Chester
Knutsford
Wilmslow
Frodsham
Congleton
Nantwich
Warrington
Appleton Thorn
Tarporley
Weaverham
Macclesfield
Shrewsbury
Crewe
Ellesmere Port



 shows locations of contributors to the consultation

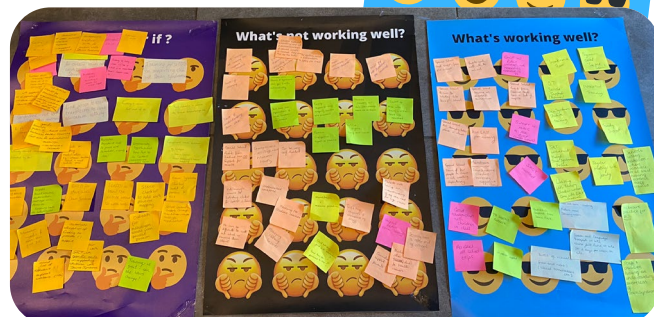
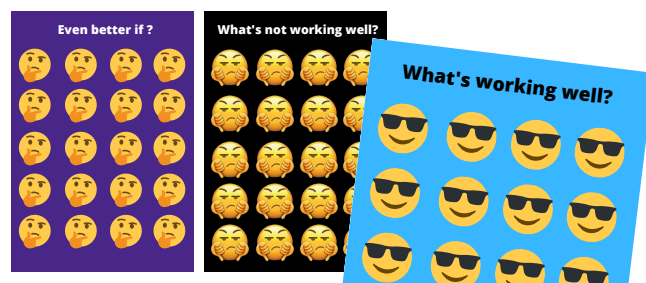
Appendix 2

Evidence of Consultation & Booklet

In-person and online consultations



Posters used for data collection



Down Syndrome Act DS Cheshire Community Consultation

4th October - Winsford Library 5.30-6.30pm (DS Dance)
6th October - Denton Drive 6.15 -7pm (DS Yoga)
17th October - 6.30pm Online via Zoom
21st October - Denton Drive 10-2pm 18+
23rd October - Egerton Football Club 10-11am (DS Footy)



Down Syndrome Cheshire

Call for Evidence Down Syndrome Act

Education

October 2022






What is the Down Syndrome Act?

The Down Syndrome Act was brought about by the National Down Syndrome Policy Group working with Dr Liam Fox MP. All MPs have an opportunity to enter the Private Members' Ballot. Dr Liam Fox MP's name was selected at random and after he was lobbied by thousands of groups and individuals, he elected to sponsor a Down Syndrome Bill. No other MP has previously chosen to do this

On 28 April 2022, the Down Syndrome Bill was signed by the Queen, making it the Down Syndrome Act 2022. It was presented to Parliament by Dr Liam Fox MP, who said, 'I hope that three things will flow from this. The first is to help to destigmatise Down syndrome. The second is to ensure current provision of services is improved. The third is long-term care, in an era where many of those with Down syndrome will outlive their parents.'

What do we need from you?

We are hosting a series of consultations throughout October to gather your views. We would like as many people to attend as possible. At those consultations we will be asking you 3 questions in 3 categories which are Education, Health, and Social Care. The 3 questions we will be asking you are:

-  What's working well?
-  What's not working well?
-  Even better if?

What will you do with this information?

All the information that we gather from these consultations will be collated and put into a report that we will be sending through to the government for inclusion in the Guidance in the document that will be sent to Local Authorities and Health Services. We are hoping that it will influence policy and make positive changes on how people with Down Syndrome so they can access Health Care that they need, are included in education settings where teachers understand the unique learning profile of a person with Down Syndrome. We also want to influence outcomes enabling and empower people with Down Syndrome to choose the life they want to live, albeit in Adult Social Care or Employment. It is our opportunity to affect positive change for our families and those children who will follow in our footsteps.

Education – What has worked well? 😊

Please think about a time that things have worked well in an education setting this could include, Nurseries, Primary/Secondary School/Colleges

Did you find it easy to get the support you needed?

Were the people supporting your child knowledgeable about Down Syndrome?

How do you feel your child's needs were being met?

Education – What hasn't worked well? 😞

Please think about a time that things haven't worked well in an education setting this could include, Nurseries, Primary/Secondary School/Colleges

Has there been a time that you feel the educator doesn't understand a child with Down Syndrome?

Has your child been excluded?

Has the system been difficult to navigate?

Education – Even better if 😊

Blue sky thinking What would you have liked to have seen and would recommend for future parents?

Diagnosis = immediate EHCP?

Nominated professional in LA who was a specialist in Down Syndrome?

Do you think that all genetic conditions should be included in the Down Syndrome Act?

Appendix 3

Speech and Language Specialist report

Amanda Holland – Specialist Speech and Language therapist

Amanda is a qualified Speech and Language therapist and works alongside SYMBOL UK to develop the service that DS Cheshire offer to their membership.



SYMBOL UK are Speech and Language Specialists for children with Down Syndrome. Amanda and the team at DS Cheshire promote the work of SYMBOL UK and follow the specific research that they, as specialists, have identified are key to people with DS. To find out more about SYMBOL UK's specific research on Down Syndrome please click [here](#)

The work of the DS Cheshire Speech and Language therapist is to enhance the offering of the NHS SALT services. The charity found that many members do not get access to SALT services and, for those that do get access, the frequency is insufficient for the needs of their child and often comes too late. There has been a lot of research that early speech and language intervention for people with DS is imperative to achieve better outcomes.

Down Syndrome Specific Speech Profile

Symbol UK identified problems with using traditional methods of assessment for people with DS.

To realise potential, learning opportunities for people with Down syndrome must be tailored to the syndrome-specific strengths and weaknesses in communication skills, and the syndrome-specific learning style (Rondal, 2007). This means moving away from some widely used practices and teaching schemes that may not be effective when used with people who have Down syndrome, which can in turn result in these learners disengaging or making little progress. In the past this has been unhelpfully understood as lack of potential for progress, rather than recognising that teaching strategies have failed because they that are not tailored to the syndrome specific profile.

The syndrome-specific profile describes differences in how people with Down syndrome develop communication skills. There are differences in how people with Down syndrome process information and learn. Child development sets out how skills develop in different areas at different ages, but for people with Down syndrome, development does not follow the same predictable pattern, even with the best support and intervention. Skills in one area do not predict achievements in other areas (Miller et al, 1999). This is true for communication skills in relation to other skill areas, as well as between different aspects of communication skills. This 'spikey profile' combined with a 'syndrome-specific learning style' means that we cannot successfully employ the same approaches and interventions that are used routinely.

What hasn't worked well for Amanda?

During Amanda's time at university where she studied Speech and Language Therapy there was little training specifically on the Down Syndrome Learning Profile. Students were taught about hypotonia and lots of medical issues that the children with Down Syndrome have however, they were not taught about how to effectively assess children with DS, as the traditional assessment tools were developed for typical developing children who have a different learning profile.

Assessments like the Derbyshire Language Scheme are good as a guide if you are struggling about where to begin assessing a child but not ideal. Blanks levels give you an idea of what level a child is working at but again not a tool that can be effectively used to levels of a child with DS.

There are never enough resources - no matter where you are!! Most of the resources used by Amanda don't need to be specialised they just need to be accessible which means that she may use resources designed for younger children with older ones as that is where they are and what they can access. To have more funds to buy the resources would help!

What's worked well for Amanda?

Since leaving university and working with the DS community Amanda has been trained in the specific learning profile of a child with Down Syndrome. She has worked alongside SYMBOL UK and has found resources that better support the DS Community such as the massage/desensitisation technique, which sitting posture is best and chewy tubes, She has then been able to deliver this to the 1:1's and to the parents in the group session.

Training in Makaton has been essential in her role in order for her to be able to communicate with babies and early years children with DS, this was a gap in her degree that could easily have been filled.

Amanda's comments:

"Being able to support the TAs is a big part of what I do, offering advice, suggestions on how to move an activity on, how to break down targets into smaller steps. In nurseries and class, talking about the use of visuals and routine boards and timetables that are personalised to the child. One big take away is giving the child time to respond and when I tell TAs to wait about 10 seconds and then see the child respond - this really makes a big difference. It's also about offering support to the TAs and parents when they need it."

"What's working really well at the moment for the charity is the after-school session on a Thursday. Those who have regularly attended have reported back that speech has improved and this has been noticed by family members."

"Running the SALT Cheeky Monkeys pre-school group has helped new parents. There is a chance for them to learn about Speech and language regarding their own child, ask questions about things they are concerned about and form friendships and support each other."

"It would be even better if at the charity we could have either another qualified SALT or assistant so that more children could be seen. Additionally, if we had a multi-disciplinary team with OTs and physios we could give a wholistic approach to therapy with sessions at the charity for parents to bring their child to."

"It will be even better when more links are made with the NHS SALTs so that we can work collaboratively with them. As a new 'thing' within the charity I realise this will take time."

Appendix 4

**Impact Report
from Employing Education Advocates**



Project: Education Advocacy

This report will detail the importance and impact of Specialist Down Syndrome Education Advocates. The impact on the parents/schools and children they support.

The story of our education advocacy project so far

2021/ 2022 saw our education advocates able to visit more schools to deliver face-to-face sessions with children following the lifting of pandemic restrictions. The project focus has been on supporting children back into their pre-schools, schools, and colleges and on building upon previous relations with settings to give tailored advice that benefits the children and their specific needs. The education advocates have been visiting settings more regularly with many children now having been supported by the project for four years. In addition, we are discovering new children and families who need support all the time. This can be a challenge as the caseload has grown considerably which has meant that the education advocates don't always get to revisit settings as often as they would like. We have recorded lower attendance figures for our Cheeky Monkey pre-school sessions post pandemic; however, we are looking at ways to build this back up once parents and carers become more confident about attending group sessions with their babies once more. Our in-house training for parents/ carers and education professionals who support children with Down's syndrome has continued with typically 2 courses per term, held over various times to cater to availability. All training is bespoke and has been rewritten to incorporate up to date research and any new resources as EA's have been able to attend CPD themselves. This year has been the first that we have employed a Family Support Worker and Speech and Language therapist, and they have been able to support the education advocacy project with their expertise. The team has been working together to create wraparound support for children with Downs syndrome and their families.

The differences we are making

Engagement figures

Activity	Total
Visits (virtually and in person)	247
Schools visited	82
Contacts to individuals (phone and email)	797
Contacts to groups (email)	90 to 2200 people

Training	38 sessions to 550 people
Cheeky Monkey's peer support	13 sessions to 62 people

Comments from parents

'Thank you so much for your support with our Education Health Care Plan. Your guidance and advice was invaluable. We could never have got the positive result that we achieved without your input. Thank you so much for your help and for caring.'

Dawn, mum to a child moving from primary to secondary school.

'I have found the training extremely useful. With the extra support I am providing for my son with numeracy and literacy/reading at home, his progress has developed fast, and this has helped his school put him into higher attaining groups. I have learnt lots of new ideas in how to do that from the courses I have attended with Down Syndrome Cheshire. My confidence has grown massively in how to support my son academically'.

Sarah, mum

Comments from schools

'The strategies suggested will be implemented by the staff working with the child. The staff will have the confidence to use the strategies and know what to do in situations where they were uncertain before the training.'

Feedback from Special Educational Needs Co-ordinator following positive behaviour training.

'I found the training most useful and I'm sure it will help me a lot in the early stages of getting to know the child I'm going to be supporting and then moving forward, it's nice to know that if I have any questions or problems, I can contact the education advocates and they will help me. It's very reassuring.'

Training delivered to a new 1-1 support on the learning profile of a child with Down's syndrome prior to the child starting at school.

Case study 1

3-year-old Joe is a twin, he also has an older sister. Joe has various medical needs, is preverbal and is peg fed. His feeding process takes a long time as he gags and has reflux issues. There isn't much time in-between feeds. Joe has started nursery and attends mornings. The education advocates got to know his family through our online Cheeky Monkey events and then met face to face at a social event. This meant that by the time Joe started nursery we had a good knowledge of his needs and were able to contribute at the CCPM (Child centred planning meetings) with the setting and local authority members such as the health visitor, NHS SALT, Physio etc, to ensure his needs were being met.

Joe is preverbal and communicates with Makaton. Staff at his nursery have received a taster session from the education advocate team so all are aware of the importance of communicating in sign. Joe's keyworker has attended Makaton training and various other training sessions such as numeracy for children with Down's syndrome. Her feedback was: *'Thank you that was so useful. The child I support is preverbal and I was worried he wouldn't be able to access numeracy, but you have given lots of ideas of how he can show his learning without speech.'*

During the education advocate's visits to the setting, it has been evident that staff are implementing elements of the training and support they have received.

Joe's Grandma supports the family with the children, and she has attended level 1 Makaton training from the group. Mum was unable to access training herself due to time limits between feeds. When it became apparent that mum couldn't communicate effectively with the Joe, Makaton training was provided in 2-hour slots when he was at nursery. Benefits for the child and parents are huge as they now have an alternative way to communicate and help support Joe's understanding and development. Joe is still preverbal but is beginning to sign key words however he understands far more than he can communicate himself.

Joe's mum says: *'When I'm with the group I just feel like I'm home, I feel so included and safe. You are like my comfort blanket. Always offering suggestions that are helpful as you know what will work for my child. Thank you so much it makes a world of difference.'*

Case study 2

Ronnie, aged 10, has been supported by the education advocacy project for four years and will be starting at secondary school in September. Ronnie has been visited regularly by his advocate at his school setting and supported remotely during the pandemic. He has also been seen by our Speech and Language therapist and a specialist from the Down Syndrome Association.

Ronnie's parents and school support staff have received training from the education advocates in literacy, numeracy, and behaviour. His advocate has attended school annual review meetings, conducted a whole school awareness assembly and whole staff Makaton training. A staff member at Ronnie's school comments: *"The support we have been given has given us an increased understanding of how to support a child with Down's Syndrome in school and helped with Ronnie's progression through school. We have benefitted from meeting with other teachers and TAs from other schools to share ideas. The feedback from Ronnie's education advocate after visits has been invaluable. We have only one child with Down's syndrome in school and therefore restricted knowledge and expertise on how to support our pupil as he moves through the school. If the service were taken away, we would no longer be able to draw on expert advice from the support group."*

Ronnie's parents have extended their thanks for the project and said: *"Our child is thought of as a full member of our school community by both staff and families. He has shown progress in all areas of the curriculum. We feel confident to try out and implement*

suggestions from the support group – especially those concerning behaviour. The support group is always very positive and encouraging.”

What we have learned

- Staff supporting children with Down’s syndrome find the training invaluable and this is evident when we visit settings and see our strategies and advice implemented.
‘My 1-1 benefited straight away from the knowledge I gained.’
‘The training will help me know(understand) the stages and approach to reading so that I can anticipate and plan for the child I teach. It’s helped me secure my knowledge and know that I’m doing the right thing.’
- When everyone works together, we see more engagement from our young people. Working with our Speech and Language therapist and Family Support worker means we can target the correct support to the right person. We liaise together and share our knowledge so everyone is given consistent advice.

How we are involving our community

- This year we have been able to engage with all our families and schools face to face and interact with the children and see them in situ. We have built up a rapport with children and parents who often email the charity for advice.
- Parents are given feedback and advice on what to do next and we signpost them to our family events which are now in person too.
- At social events we chat informally and find out what issues families are facing which informs our training events.
- During our visits to school, we see trends appearing such as children not engaged in reading which prompts us to deliver training on interventions available to support reading.

How we’re changing what we do

- We are now regularly invited to early years meetings and annual review of Education Health Care Plans (EHCP). Our reports are used as evidence and our recommendations are implemented into targets for the child. The training we have received on EHCPs and legal matters has been invaluable in supporting these meetings to make sure the final plan actually meets the needs of the child.
- Online training sessions are still popular. We have introduced more training during the evenings as this does suit parents and early years staff. Due to the pandemic staffing has been an issue and releasing staff during the day has been difficult. Evening training has been well attended.
- With the new hub we are planning to offer sessions during the day in person and evening sessions online.

- Working in partnership with other members of the charity (Speech and Language therapist and family support means we can signpost families/schools in need. We take a holistic approach and families feel well supported.
- We plan to employ an Employability Support Worker to support children as they enter 16+ with skills training and work experience opportunities. They will work with the education advocates to identify members who are leaving school and will benefit from this service

Appendix 5

**A parent's journey from Early Years to College
Ben's Story**

Our Journey from Early Year to College

Ben was born in 2005 and has DS. He had attended a mainstream private nursery from the age of 1 and had thrived as the setting was very positive and happy to engage with us on how best to meet his needs. In practise this meant additional support for part of the time he was there & adopting things like Makaton across the setting.

Primary Years

We visited several schools before deciding on a primary school. We chose the school having met with the Head who had personal experience of children with additional needs and we felt she was very onboard with how we could work together to fully include Ben. The school was also local so we could walk to school along with his peers and start the day very much part of the community. Just prior to school closing for the summer the Head called to say her circumstances had changed & was leaving the post. Obviously, we were disappointed but still felt this would work. Ben was assigned TA who was to work with him through the day. It quickly became obvious she had no knowledge of the how a child with DS learns & had also been asked to work alongside another child (without an Statement as it was at the time) who was subsequently diagnosed with Autism. Ben's behaviour soon deteriorated & I was asked to attend school for a meeting. We had several meetings across the year & our frustration grew with the setting as they refused to see that using strategies for a child with Autism was not appropriate for someone with DS. To us it was clear Ben was copying the other child's behaviour and this was not being addressed. Ben was finding it hard to form friendships something that had never been an issue previously. The final straw for me was watching the year 1 nativity where my son was sat in the corner of the hall with his TA trying to give him a Chewy tube which he kept handing back as he wanted to be part of the performance. The lack of inclusion and willingness to adapt was heart breaking, so we decided to look at other settings.

We found another school who appeared to be very willing to accept Ben, so in Spring term we moved Ben. Here Ben never looked back! He was part of the class from day 1 & given responsibilities like all the other children. His TA's were constantly asking for advice or if there was any training available for them to attend. DSC had organised meetings for Teachers & TA to share experiences and these were always attended by the school. The school adopted Makaton as a setting & all performances included signing. Having attended a behaviour course hosted by the charity the staff all commented on how it had helped with many of their pupils not just my son. In one parent's evening I was told Ben had made the Teacher rethink his usual routine which he felt had improved his teaching across the group. Any issue that arose was usually analysed & a solution sort without instant sanctions. The school understood that behaviour was Ben's main form of communication in difficult situations.

On reflection the big difference we experienced between the schools was the approach to educating Ben. One school believed inclusion was being present in the setting but never sat back and acknowledge the fact they didn't know how best the teach him and treated him as if he has global learning delay and general behaviour problems. This meant no adjustments were made to enable Ben to thrive. The second school were open to ideas & reflected on what they could do to ensure he was making solid progress. They attended all available training and spent time collectively to understand how best to include him. The feedback I got from the school was he had enhanced there setting not just by making people aware of ability rather than disability but in being more flexible in their approach to learning.

High School

As we faced high school it was clear to us Ben should attend a mainstream setting and so again we set about finding the right school. This was done through years 5 & 6 as we knew it was a big step. We chose a school having had some really positive meetings with the Head and SENCO and felt quite positive despite having had no support from the LA (they didn't even send a representative for his Year 6 review). Unfortunately, at the end of term we received a call from the SENCO to say she was leaving but a new person would be in position early the following term. Ben has been 'paired' with another pupil with DS who was in Year 11 – they believed this was a great idea (the implication was they were obviously going to be the same as they both had DS). From early in the academic year, we started to get calls from school about behaviour issues. His home school diary was full of problems, and we received very little positive feedback. The school did not understand how Ben's verbal communication was not sophisticated enough to express difficulties he was facing and so it would be his behaviour that communicated his stress. Even what I would consider minor things were reported and punished without being unpicked to understand the underlying issue. I tried to offer training to the school, but they were very reluctant to take this up. The school believed they were right in how they included Ben and refused to assess what could be modified to help him. Again, we reached a point where, having been told he would have to take RE as an option & that he could always colour in the back of the class, we decided to move schools. We chose another school after fruitful meetings with the SENCO & Head. Within the first couple of weeks we saw a real change in Ben at home. He was more confident & happier to chat about his day. A few incidents did arise & I was called to ask what I thought could be the issue – not that he was in another detention! School took up the opportunities of training and once more having attended a couple of training sessions the SENCO delivered a staff training session as he believed that the theories learnt would help many students. The report I received from school was lovely, I heard about what he did achieve rather than what he didn't. Ben's final 2 years at school were interrupted by COVID but school still maintained the positive relationship with us & encouraged him to aim 'big' in his tests!

On reflection this time the difference in schools was how one appeared to see Ben's potential & worked towards achieving this through looking at his strengths. The other setting wanted him to change to their setting, something which just wasn't possible. The understanding of how the child learns and how the barriers to accessing the curriculum can be overcome was embraced by one school but not the other.

College

The next step was college and again with no help from the LA we were left to look at possible courses for Ben. We chose a college with a Personal and Social Development course to ease the transition to college and to allow Ben to try a few different pathways to see which area he was most interested in as this was what the college could offer. I had been told there was a college bus which I was happy for Ben to use, however as we got close to the end of the summer term it became clear that there was no bus he could get unless he travelled on another public service to a pickup point for the college transport. Something so fundamental which I had raised on many occasions was completely ignored & in the end I had to threaten legal action in mid-August just to get transport! Not the best start to say the least and I have to admit to being very angry that we had been let down again by people in the system understanding my child's needs.

Once Ben started the course it became clear they saw his future was in Catering & I had to fight to allow him to try other carer options. The college underestimated him & when I asked if they could push him more out of his comfort zone, I got told it wasn't possible as they were concerned it could affect his mental health. As his Mum I felt I understood him very well & would never put him in a situation that would cause such issues. I also know he was quite capable of using avoidance, which is a well-documented strategy of people with DS, to fade into the background. I tried to explain this to college and offered to put in writing that this was a request from me but to no avail. I really feel he went backwards during this year, both academically and personally. When we started looking at other options for Ben it was clear there was no careers advice or guidance for him & the assumption that he would work in a café was obvious. I can assure you he does not see his future in this area.

Ben is now attending a different college doing a Level 2 course in Sport. He goes on the college bus & has a very good relationship with his course manager. I do feel they haven't yet worked out how to differentiate some of the assessments they are setting but appear willing to demonstrate some flexibility around this. We will see what happens as the year goes on but so far it has been a great experience and we can see this in Ben's attitude at home.

The key points from my experience are that schools and colleges have very little support for including pupils with DS. As a parent you are left to find out information and without understanding how the 'system' works you are left completely bewildered. I have experienced some very dated opinions of DS which are frankly insulting. Yes, Ben has additional needs but once these are understood and embraced, they are far from insurmountable & often benefit many other pupils in those settings. No, Ben doesn't want to work in a café, he would like to choose a career path & may change his mind in the future, just as many of us do. Yes, Ben can and will contribute to the work force, but he needs to be given the opportunity to do so which starts with our education settings have higher expectations of our children and continues through to workplaces being encouraged to look at opportunities and training for our adults.

Personally, I am very tired, and yet I know my battles will continue well into the future. What would have been so helpful was someone taking me through the EHCP system, offering schools & colleges help, helping with the transition points in Ben's education with information of what options are available & indeed someone now who can help me understand what options are available for next year & the year after that and the year after that one! I know there are websites with various bits of information on them but as a Parent I needed someone who understood this as a whole to explain to me what we could access. When you bear in mind this is just the education side of things, we as Parents have the same obstacles with health and as I am now discovering with social care it becomes exhausting and without support very isolating. I feel I have had to develop a very thick skin and be prepared to argue for some basic rights for my child.

I have 2 children and I would like them both to be able to make choices about how they live their lives & what jobs they do. Both will need training & help to do this. For my daughter this is available, and she is encouraged to look at different avenues but for my son his opportunities appear so limited, and I feel his future has been pre-determined by people who don't know him. Surely, we can do better than this?