

SENsational Families

Paediatric Speech and Language Services
in Norfolk: an update to the HOSC

February 14th, 2019

Introduction

Over the last year the joint commissioning group, East Coast Community Healthcare (ECCH) and groups representing SEND children and their families such as ourselves, have been asked to submit evidence regarding ECCH's ability to deliver a fit for purpose speech and language therapy service to children and young people with speech, language and communication needs (SCLN) in Norfolk.

The purpose of this report is to directly reply to ECCH's claim to our organisation, that their speech and language therapy service is not obliged to provide intervention to children with as autism spectrum disorder (ASD) diagnosis, or to provide specialist long term interventions to other children with complex SCLN such as those with Down's syndrome (Appendix 1).

Additionally, we would like to once again address the findings of the Independent Review of Speech, Language and Communication Provision in Norfolk produced by Better Communications CIC in August 2018. Unfortunately, SENsational families were not made aware of any subsequent actions taken by the joint commissioning group and ECCH until this month. We welcome the opportunity to contribute to the discussion on behalf of the 1250-member families we represent across Norfolk who have been negatively affected by the issues raised.

As a result of ECCH's reply to our questions and the findings of the independent review, we have raised further questions to ECCH and the joint commissioning group regarding the future delivery of speech and language therapy in Norfolk. These can be found at the end of this report and we hope the HOSC will again forward them on our behalf.

Response to ECCH regarding non-delivery of service to children with complex SCLN

When we met with members of the HOSC in September 2018, our members identified multiple areas of concern regarding the speech and language service. One of the more egregious findings from our members (their comments can be found in Appendix 2 and 3) is that children with an Autism Spectrum Diagnosis (ASD) were being discharged by ECCH immediately after assessment with no further therapy, intervention, advice or signposting offered. This is despite the identification of complex needs and deficits as part of either ECCH or other SLT assessments.

Further, children with other complex SCLN such as those that occur as a result of Down's syndrome, were either being discharged immediately or only offered a basic six-week course of therapy. After this, regardless of progress made, children were again discharged, and families were forced to either seek re-referral and its associated waiting time or attempt to access speech and language through other means such as fighting for personal budgets through the local authority or via expensive private services. As of today, these conditions are still being experienced by our families. This is leaving the children with the most complex SCLN without any kind of speech and language therapy.

Our questions regarding these issues were put forward by HOSC to ECCH and the commissioners of the service. In response to the question **"What evidence is there that SLT is not beneficial for children with autism and Down's syndrome?"**

ECCH replied in detail regarding their approach to both conditions (Appendix 1).

*For SLT interventions for autism spectrum disorders (ASD) the response states that ECCH are not responsible for providing “direct support to schools and families” to implement social communication and therapeutic strategies they have “identified as part of a broader assessment.” In terms of ASD they are only “commissioned to contribute to the Autism Spectrum diagnostic assessment and provide intervention for a speech and language disorder **alongside** there Autism.” (Appendix 2, emphasis mine).*

Firstly, pervasive impairments of social communication and interaction are one of two core diagnostic features of ASD (APA, 2013). The universal speech, language and communication impairments of those with ASD cover a large spectrum including pragmatic language (Parsons et al., 2017), receptive and expressive language (Mody and Belliveau, 2013), figurative language (Kalandadze et al, 2016), language and auditory processing (Bavinet et al, 2014; Arnett et al, 2018) and social communication (Kasari and Patterson, 2013).

In terms of complex and pervasive language disorders such as ASD and Downs syndrome, there is evidence that individualised direct and indirect specialist intervention from a well-qualified speech and language therapist leads to improvement in the child’s speech, language and communication (Ebbels et al, 2018). The Royal College of Speech and Language Therapist’s (RCSLT, 2009) publication regarding the delivery of service to individuals with ASD, referenced to in the answer to SENSational families, directly contradicts ECCH’s position that they are not obligated to treat children with an ASD diagnosis. The RCSLT are clear there is

“evidence of the effectiveness of different targeted approaches to the treatment and management of social communication impairments and functioning of children with ASD.” (RSSLT, 2009 pp. 2).

Further, the SEND code of practice, which details the statutory obligations of the CCG’s and local authority in jointly commissioning services as part of the SEND reforms 2014, state that speech language and communication needs are a “feature” of autism spectrum disorders. Specifically, the code of practice says,

“Children and young people with ASD, including Asperger’s Syndrome and Autism, are likely to have particular difficulties with social interaction. They may also experience difficulties with language, communication and imagination, which can impact on how they relate to others.” (Department for Education and Department of Health, 2015 pp.97)

As it is well established that speech, language and communication needs are part of autism spectrum disorder, we question the basis on which ECCH claim they can discharge and refuse intervention to children with an ASD. Additionally, we feel it is important to know whether the joint commissioning group were aware that ECCH were not going to deliver interventions to children with speech, language and communication needs as a feature of their ASD diagnosis before they accepted their bid to run the service. To entirely exclude a group from receiving intervention from an SLT service, whose condition is characterised by SLCN, is discriminatory and short sighted. To leave children with an ASD diagnosis without speech and language intervention contradicts both the current literature, the SEND code of practice and the recommendations of Bercow: 10 Years On (iCAN and RCSLT, 2018).

Response to Independent review of Speech, Language and Communication provision in Norfolk (Better Communication CIC, 2018)

The independent review of speech and language produced by Better Communications CIC in August 2018 has identified many of the issues our members have personally experienced in their dealing with the paediatric SLT service delivered by ECCH. Some troubling issues were highlighted.

Children are not receiving interventions or therapy after assessment by ECCH

This is a topic raised in the report and is an ongoing area of concern for our families. The experiences of the families we represent are reflected in the findings. Combined, we have identified several failings in the delivery of the SLT service that have contributed to the lack of access to speech and language therapy.

- **ECCH's SLT service model does not follow a whole system approach**

The independent review suggested that ECCH's service model does not adhere to the one endorsed by Better Communication CIC. The Balanced system, created and offered by Better Communications, provides a 'whole system' framework in which all services that commission speech and language therapy, including education, the local authority and Norfolk CCG's, offer a fully integrated service (please see <https://www.thebalancedsystem.org/> for more information). This reflects the statutory guidance in the SEND code of practice (DofE and DofH, 2015) and the recommendations of Bercow: Ten Years On (iCAN and RCSLT, 2018).

The review concluded that ECCH's basic SLT model is a 'pick and mix approach' of different models that 'lacks clarity' (Better Communications CIC, 2018). Further, the model delivered by ECCH does not follow a 'whole system' approach as schools have not been included as joint commissioners. This has led to gaps in service especially at the targeted level, which provides interventions such as training school staff to deliver a programme of therapy where progress is regularly tracked and monitored by an experienced SLT (Gascoigne, 2013). There is also a lack of direct therapy by experienced SLT's at the specialist level. These gaps are reflected in the experiences of our members who have been left with no ongoing intervention or therapy despite obtaining assessments that clearly state their children have major deficits in their speech, language and communication skills.

We believe this piecemeal approach to delivering the service is leading to confusion for families about whether health, schools or the local authority are responsible for delivering SLT to children with special educational needs that include complex SCLN. Considering the service is supposed to be integrated and jointly commissioned, this is a major failing in the SLT delivery model.

- **Underfunding**

Better communications suggested the ECCH's current model was heavily underfunded. Further it will not meet the future predicted needs of Norfolk's population. The report could not find any way the service could be run more efficiently as it stands and requires more top-level funding from the commissioners to include schools. As the ECCH group made over

£600,000 in profit in the 2016/2017 financial year (ECCH, 2017) and runs private speech and language training (<https://www.ecch.org/our-services/services/cf-children-and-young-peoples-speech-and-language-therapy/training/>) we are interested to know what percentage of this money is reinvested back into the SLT

- **No performance tracking required for outcomes of assessment, type of intervention offered, and long-term impact of therapy on children with complex SCLN**

The report criticised the Key Performance Indicators (KPIs) as being heavily biased toward referral numbers and wait times, with no real tracking of the impact of assessment or therapy. Considering the KPI's assess whether ECCH is delivering the service it is required to, it seems absurd they do not assess the nature or success of the speech and language therapy offered. We propose the KPI's include numbers of children discharged directly after assessment, the number of children offered ongoing therapy, the nature of that therapy, and the outcome of that therapy. Given the number of children with ASD and other SCLN related disorders being discharged we would also like to know the percentage of children with these diagnoses being directly discharged after assessment versus those offered therapy.

- **One size fits all approach to therapy**

For children who are deemed to have sufficiently severe SCLN, an 'enhanced offer' of a six-session block of intervention is given followed by discharge, regardless of the complexity or long-term nature of the SCLN. If further intervention is required, families are forced to re-enter the referral system and wait for a further assessment where intervention may or may not be granted.

ECCH sought advice from Better Communication CIC in 2015 before the bid was submitted to the joint commission and were warned not to submit it as it was only funded to provide 55% of Balanced system model. They submitted anyway and won the bid.

ECCH sought advice from Better Communication CIC, the authors of the independent review about their bid for paediatric SLT in 2015 prior to submission and were told, "the modelling concluded that the tender was only funded to 55% of what would be need to fund the balanced model." (Better Communication CIC Independent Review of Speech and Language, August 2018, p.17). They state further that the authors, "counselled [ECCH] against attempting to deliver the model without a strategy for schools making specific enhanced contributions to the commission in their roles as commissioners of services for population they serve under the 2014 SEND reforms."

We find it extremely troubling that ECCH went forward with their bid, and won, despite being warned by the creators of the programme they were emulating that they could not deliver the whole system model set out in their contract bid. It is clear from the independent report and from the experiences of our members there are now massive gaps in service especially at the targeted and specialist intervention level due to this failure to deliver the whole system service that was needed to meet the SCLN of children in Norfolk.

Conclusions

- ECCH have made it clear to SENSational families that they are not obligated to deliver targeted or specialist therapy and interventions to children with complex SCLN that arise out of diagnosis such as autism spectrum disorder and Down's syndrome.
- ECCH knew their bid was only funded to 55% of the full Balanced system model. This implies they knew they could not deliver a whole system approach to SLT that included education, before they submitted their bid to the joint commissioning group in 2015.
- We agree with the findings of the Better Communication CIC independent review into SLT in Norfolk. ECCH have failed to deliver speech and language therapy to children who need targeted and specialist ongoing intervention provided either directly by an SLT or indirectly via specialist training with frequent monitoring and oversight by trained SLT's
- We find that ECCH is not delivering a fit for purpose speech and language therapy service. Children with speech, language and social communication disorders are still being discharged with no intervention in place despite assessments stating they have complex SCLN
- SENSational families will continue to fight for an easy to access, fully integrated SaLT service in Norfolk that delivers therapy to ALL children with complex SCLN, so they can progress and reach their full potential

Questions for ECCH and the joint commissioning group

1. Were the joint commissioning group aware that ECCH had sought advice regarding their SLT model prior to bidding, and were warned not to submit their bid as it could not deliver a whole system service due to be severely underfunded?
2. Considering the independent review, our reply and the continued complaints from the families we represent, are ECCH going to start delivering ongoing targeted and specialist interventions to children with ASD, Downs Syndrome and other complex speech, language and communication needs that arise out of their diagnosis? If not, who is supposed to be delivering this much needed service?
3. Will future key performance indicators for ECCH's paediatric SLT service include percentages of children immediately discharged, their diagnosis, types of therapy offered and the impact that therapy?

References

- American Psychiatric Association (2013) *Diagnostic and Statistical Manual of Mental Disorders: DSM-5*. 5th ed. Arlington, VA: APA. [Online] Available at: <https://ebookcentral.proquest.com/lib/open/reader.action?docID=1811753> (Accessed 11th February 2019)
- Arnett, A. B., Hudac, C., DesChamps, T., Cairney, B., Gerdts, J., Wallace, A., Bernier, R., Webb, S., (2018) 'Auditory perception is associated with implicit language learning and receptive language ability in autism spectrum disorder,' *Brain and Language*, Vol. 187, pp. 1-8 [Online]. Available at <http://www.sciencedirect.com/science/article/pii/S0093934X18300130> (Accessed 11th February 2019)
- Bavin, E. L., Kidd, E. , Prendergast, L. , Baker, E. , Dissanayake, C. and Prior, M. (2014), 'Severity of autism and language processing,' *Autism Research*, Vol. 7, no. 6, pp. 687-694 [Online]. Accessed at: <https://onlinelibrary-wiley-com.libezproxy.open.ac.uk/doi/full/10.1002/aur.1410> (Accessed 11th February, 2015)
- Better Communications CIC (2018). *Independent review of Speech, Language and Communication Provision in Norfolk*. [Online]. Available at <https://www.norfolk.gov.uk/-/media/norfolk/downloads/children-and-families/send/introduction-to-send/independent-review-of-speech-language-and-communication-needs-provision-in-norfolk-2018.pdf?la=en&hash=5FAC2AADDEBD07E0364C59CA152BA0E665E7241D> (Accessed 13th February 2019)
- Department for Education and Department of Health (2015) *Special educational needs and disability code of practice: 0 to 25 years*. [Online]. Available at: <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25> (Accessed 11th February 2019)
- East Coast Community Healthcare (2017). *ECCH Annual report 2016/17* [Online]. Available at <https://www.ecch.org/media/16308/ecch-annual-report-2016-17-final.pdf> (Accessed 13th February 2019).
- Ebbels, S. H., McCartney, E. , Slonims, V. , Dockrell, J. E. and Norbury, C. F. (2019), Evidence-based pathways to intervention for children with language disorders. *International Journal of Language & Communication Disorders*, Vol. 54, pp. 3-19. [Online]. Available at <https://onlinelibrary.wiley.com/action/showCitFormats?doi=10.1111%2F1460-6984.12387> (Accessed 11th February 2019)
- Gasgoigne, M., (2013) *Definitions of universal, targeted and specialist levels* [Online]. Available at <https://www.bettercommunication.org.uk/definitions%20of%20universal,%20targeted%20and%20specialist%20levels%202013.pdf> (Accessed 13th February 2019)
- iCAN and the Royal College of Speech and Language Therapists (2018). *Bercow: Ten years on* [Online]. Available at <https://www.bercow10yearson.com/wp-content/uploads/2018/03/337644-ICAN-Bercow-Report-WEB.pdf> (Accessed 13th February 2019)
- Kalandadze, T., Norbury, C., Nærland, T., & B Næss, K.-A. (2018). 'Figurative language comprehension in individuals with autism spectrum disorder: A meta-analytic review, *Autism*, vol. 22, no. 2., pp. 99–

117 [Online]. Available at <https://journals-sagepub-com.libezproxy.open.ac.uk/doi/pdf/10.1177/1362361316668652> (Accessed 11th February 2019)

Kasari, C., & Patterson, S. (2012). 'Interventions addressing social impairment in autism.' *Current psychiatry reports*, Vol. 14, no.6, pp 713-25. Available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3492515/> (Accessed 13th February 2013).

Mody, M., & Belliveau, J. W. (2013). 'Speech and Language Impairments in Autism: Insights from Behavior and Neuroimaging,' *North American journal of medicine & science*, Vol 5, no. 3, pp. 157-161. [Online] Available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3862077/> (Accessed 13th February 2019).

Parsons, L, Cordier, R, Munro, N, Joosten, A & Speyer, R. (2017). 'A systematic review of pragmatic language interventions for children with autism spectrum disorder', *PLoS ONE*, vol. 12, no. 4, pp. 1–37 [Online]. Available at: <http://libezproxy.open.ac.uk/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=122604698&site=ehost-live&scope=site> (Accessed 11th February 2019).

The Royal College of Speech and Language Therapists (2009). *Resource Manual for Commissioning and Planning Services for SLCN*. Available on request from the Royal College of Speech and Language Therapists.

Appendix 1

Responses provided by the commissioners and provider of the integrated Children's Speech & Language service, central & west Norfolk – in response to issues raised following Norfolk Health Overview and Scrutiny Committee Members' visit with SENsational Families Group on 20 September 2018

East Coast Community Healthcare provided a comprehensive response to question 1. Therefore, the text below includes extracts from Appendix one, which describes the approach for children with particular needs in more detail.

1. *What evidence is there that SLT is not beneficial for children with Autism & Downs Syndrome?*

As a profession Speech and Language Therapists are required to take an evidence based approach to their work, whatever their specialism. Evidence based practice can be defined as;

"Evidence-based medicine is the integration of best research evidence with clinical expertise and patient values." (Sackett, 2000)

Whilst all healthcare professions are required to work within an evidence based framework it is acknowledged within the profession that:

"In many instances there will be little or no evidence to support a particular approach." (Reilly, 2004)

Children's speech and language therapists typically take a developmental approach to assessment and intervention. There will be points in an individual child's development where there is greater or lesser need for "therapy" from a speech and language therapist. This will depend on the child's attention and listening skills, their cognitive development, the ability to cope with the demands of therapy, and the support available from their home, nursery or school setting.

East Coast Community Healthcare Children's Speech and Language Therapy are commissioned to contribute to the Autistic Spectrum Diagnostic Assessment and provide intervention for children who have a speech or language disorder alongside their Autism. The service will recommend social communication strategies and therapeutic approaches if identified as part of a broader assessment; however they do not then provide direct support schools/families to implement these.

There is no one size fits all approach or intervention and whatever intervention is implemented it should be based on the individual's needs (NICE, 2013).

'The number of studies that have evaluated the effectiveness of [Speech and Language Therapy] intervention in relation to Down Syndrome are few'. (Buckley S. J., 2000).

There is some evidence that proposes children with Down syndrome should be seen at least monthly in school, targets reviewed and activities set for parents, teachers and assistants to include in their daily routines (Buckley S. J., 2002). Some children with Down's syndrome of school age may benefit from weekly individual or groups sessions of speech and language therapy (Buckley S. J., 2002). At all times, intervention should be provided by, or overseen by an appropriately qualified Speech and Language Therapist (The Royal College of Speech and Language Therapists, 2010)

Sue Buckley presents evidence that addresses issues such as the benefits of naturalistic, language interaction intervention compared to direct teaching approaches, and the benefits of direct work on phonology. (Buckley S. J., 2000). As with all clients, speech and language therapists must adapt interventions to suit individual interests, learning styles and needs. Because speech and language therapy should take into account individual needs and circumstances, it's not possible to specify a format or amount of speech and language therapy that will be right for everyone who has Down's syndrome at a particular age or in a certain situation (Baksi, 2006).

2. How much is spent fighting tribunals for access to SLT and on settling appeals in parents' favour before the case goes to tribunal (for all children, not just ones with autism)?

It is not possible to easily extract the cost of tribunals in relation to Speech and Language Therapy alone. Usually, tribunals relate to concerns about a whole range of provision; and most often the placement Norfolk County Council are stating (special or mainstream). It should be noted therefore that costs for SLT will sit within the total cost envelopes detailed in table 1.

Table 1. Breakdown of costs for tribunals over last three financial years

Academic year	Cost (£)
2015-16	85,570
2016-17	106,923
2017-18	219,498

3. What is the success / failure rate of cases that go to tribunals?

Equally, it is a complex task to extract information on the outcome of cases that go to tribunals specifically relating to Speech and Language Therapy however, Table 2 shows the number in broader terms for the last 12 months:

Table 2. Breakdown of outcomes relating to tribunals

Outcome	Number
Cases heard at full hearing and resolved in NCC's favour	9

Cases heard at full hearing and resolved in parents' favour	6
Cases withdrawn / LA determined prior to full hearing	55
Cases yet to be determined/in process	30
Total number of cases since November 2017	100

Appendix one: Approaches to Speech and Language Therapy for children with particular needs

Context

As a profession Speech and Language Therapists are required to take an evidence based approach to their work, whatever their specialism. Evidence based practice can be defined as;

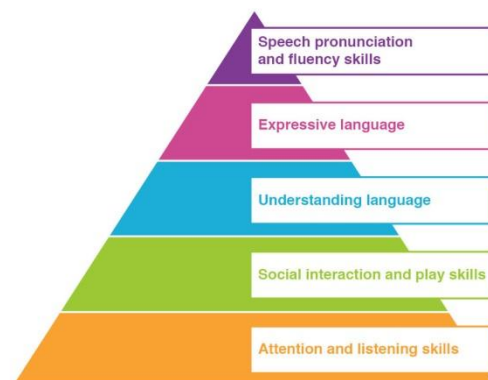
"Evidence-based medicine is the integration of best research evidence with clinical expertise and patient values."

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Whilst all healthcare professions are required to work within an evidence based framework it is acknowledged within the profession that:

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Children's speech and language therapists typically take a developmental approach to assessment and intervention. There will be points in an individual child's development where there is greater or less need for "therapy" from a speech and language therapist. This will depend on the child's attention and listening skills, their cognitive development, the ability to cope with the demands of therapy, and the support available from their home and nursery or school setting.



Speech and Language Development Pyramid.

Children develop language skills from the bottom of this pyramid upwards, so in the early days the focus will always be on developing a child's attention, listening and understanding.

What evidence is there that SLT is not beneficial for children with autism?

The Royal College of Speech and Language Therapists provide detailed guidance regarding clinical evidence base for approaches which aim to support children with Autistic Spectrum Disorder to develop their speech, language and communication skills, (The Royal College of Speech and Language Therapists, 2009)

Specialist programmes may be devised which target areas of identified need including social communication skills. Social Stories™ have for example, been shown to be an effective approach for improving social skills and understanding appropriate behaviour (Quirmbach LM, 2009), however the evidence base for this is limited and would benefit from further investigation (Francis, 2005).

A number of different Alternative and Augmentative Communication (AAC) approaches are used to support communication development and opportunities. One system with a stronger evidence base is the Picture Exchange Communication Card System® (PECS®), which has been used in facilitating communication with a specific cohort of children. Sign language, interactive communication boards, general visual support, communication cue cards, conversation books, and voice output communication aids have all been used with people with ASD.

There is some evidence to indicate that particular approaches will support skills acquisition but there is limited evidence that these skills will be maintained and/or transferred into other situations. For example, specific social skills training (SST) programmes have been shown to result in low levels skill maintenance and generalisation in part due to 'contrived, restricted and decontextualized settings' e.g. pull-out sessions and resource rooms rather than day to day settings (Gresham, 2001). There are social communication interventions which are demonstrated to have some benefit for children with ASD. The evidence from (Bellini S, 2007) suggest the best outcomes are achieved when programmes are implemented within the child's normal day to day environment and this what ECCH would advocate.

East Coast Community Healthcare Children's Speech and Language Therapy are commissioned to contribute to the Autistic Spectrum Diagnostic Assessment and provide intervention for children who have a speech or language disorder alongside their Autism. They are not commissioned to provide social communication intervention for this group of children, when no additional needs are identified. The service will recommend social communication strategies and therapeutic approaches if identified as part of a broader assessment; however they do not then support schools/families to implement these.

There is no one size fits all approach or intervention and whatever intervention is implemented it should be based on the individual's needs (NICE, 2013).

What evidence is there that SLT is not beneficial for children with Downs Syndrome?

Children with Down Syndrome have a number of features of their appearance and their skills and abilities which are similar. For example they generally have low muscle tone, leading to delays in their development of the fine tuning of their movements; there is an increased incidence of glue ear leading to impacting upon hearing as well as variability in their visual acuity, often requiring glasses. They have smaller lower jaws leading to the impression of a large tongue and all will have some degree of

learning disability which impacts on the development of all of their skills. It is important when determining the best therapeutic input to remember that children with Down Syndrome develop at different rates and ways, having individual strengths, needs, talents and interest at different points in childhood.

“The number of studies that have evaluated the effectiveness of [Speech and Language Therapy] intervention in relation to Down Syndrome are few”. (Buckley S. J., 2000).

There is some evidence that proposes children with Down Syndrome should be seen at least monthly in school, targets reviewed and activities set for parents, teachers and assistants to include in their daily routines (Buckley S. J., 2002). Some children with Down's syndrome of school age may benefit from weekly individual or groups sessions of speech and language therapy (Buckley S. J., 2002). At all times intervention should be provided by or overseen by an appropriately qualified Speech and Language Therapist (The Royal College of Speech and Language Therapists, 2010)

Sue Buckley presents evidence that addresses issues such as the benefits of naturalistic, language interaction intervention compared to direct teaching approaches, and the benefits of direct work on phonology. (Buckley S. J., 2000). As with all clients, speech and language therapists must adapt interventions to suit individual interests, learning styles and needs. Because speech and language therapy should take into account individual needs and circumstances, it's not possible to specify a format or amount of speech and language therapy that will be right for everyone who has Down's syndrome at a particular age or in a certain situation (Baksi, 2006).

There is a strong body of evidence to suggest that using signing supports the development of understanding of spoken language for young people with Down Syndrome and it will be important for parents to sign for their child. All experts identify that language is learned all day, every day, as children are involved in communication with their families and friends, therefore the focus of effective therapy must be to share skills with parents because they will be their child's best therapist. (Buckley and Provost 2002).

It will usually be the role of the speech and language therapist in the pre-school and primary years to set the goals and next steps in a child's language development journey and sometimes this will involve direct therapy sessions but more often it will involve coaching those people who work with the young person on a daily basis. These people are best placed to offer these opportunities in real life contexts to support using these skills in a meaningful way. There is little value to a child being able to use a word out of context such in a picture book and not being able to use it in real life situations.

East Coast Community Healthcare Children's Speech and Language Therapy provide support to a number of children from weekly intervention to monthly dependant on current need and circumstance. When speech and language therapists do weekly speech and language therapy sessions with children, we expect the child to master a new skill week on week. Children with Down Syndrome typically need more time to practise and consolidate new skills and therefore it would be rare for weekly therapy to be indicated on an indefinite ongoing basis. On occasions we will advise that

intervention is not advised because the individual child is not receptive to a specific approach/therapy at that point in time.

Children with Learning Disabilities

Children with a learning disability have equal access to the ECCH service. When assessing an individual child's needs it is important that the therapist considers the child's overall cognitive ability alongside their speech language and communication skills. If a child's speech language and communication skills are in line with their general development it may be considered that direct speech and language therapy may add little or no benefit to their progress. In these cases specific advice and strategies would be provided for the team around the child to implement. If a child with a learning disability has an additional identified need e.g. cleft palate or eating and drinking difficulties is for all children with this need and they will be seen by a therapist with expertise in that specific clinical area.

Works Cited

- Baksi, L. (2006). *How_much_is_enough?* Retrieved November 14, 2018, from <http://downsyndromedevelopment.org.uk:>
http://downsyndromedevelopment.org.uk/wp-content/uploads/2013/03/How_much_is_enough.pdf
- Bellini S, P. J. (2007). A meta analysis of school based social skills interventions for children with autism spectrum disorders. *Remedial and Special Education*, 153-162.
- Buckley, S. a. (2002). Speech and Language Therapy for Children with Downs Syndrome. *Down Syndrome News and Update*, 70-76.
- Buckley, S. J. (2000). Speech and Language Development for Individuals with down Syndrome - An overview. *Down Syndrome Issues and Information Service*.
- Francis, K. (2005). Autism interventions: A Critical update. *Developmental Medicine & Child Neurology*, 493-499.
- Gresham, F. M. (2001). Interpreting Outcomes of Social Skills Training for Students with High-Incidence Disabilities. *Exceptional Children*, 331-344.
- NICE. (2013). *Autism spectrum disorder in under 19s: support and management*. Retrieved November 17, 2018, from National Institute of Health and Care Excellence: <https://www.nice.org.uk/guidance/cg170>
- Quirnbach LM, L. A.-G. (2009). J Autism Dev Disord. 2009 Feb;39(2):299-321. doi: 10.1007/s10803-008-0628-9. Epub 2008 Aug 13. *Journal of Autism Developmental Disorder*. 2009, 299-321.
- Reilly, S. (2004). *Evidence Based Practice in Speech Pathology* Eds Reilly, S, Douglas, Chichester: Whurr.

Sackett, D. L. (2000). *Evidence-Based Medicine: How to Practice and Teach EBM*. London: Churchill Livingstone.

The Royal College of Speech and Language Therapists. (2009). *Resource Manual for Commissioning and Planning Services for SLCN*. Retrieved November 15, 2018, from RCSLT: https://www.rcslt.org/speech_and_language_therapy/commissioning/asd_plus_intro

The Royal College of Speech and Language Therapists. (2010). *RCSLT Policy Statement: Speech and Language Therapists' Responsibility around delegation and training the wider workforce*. Retrieved November 15 , 2018, from RCSLT: https://www.rcslt.org/members/docs/training_wider_workforce

Appendix 2

Comments given to the HOSC meeting from SENSational families regarding SLT, July 2018

We welcome the findings of the independent review as it largely reflects what families have been telling us and we have been feeding back ever since ECCH took over in 2016. That waiting times for therapy are too long and that for many children the current approach of assess, discharge and re-referral isn't working.

There are a few things we would like to highlight:

The independent review hasn't mentioned the amount of families paying for private therapy for their children. In our survey many families stated that they were funding private therapy as they felt they had no other option. The answers ranged from a couple of hundred pounds so far to one person having paid over £5500.

It's a shame that the Independent Review hasn't shared the results with families' comments from the surveys as has happened with previous surveys such as the SEND sufficiency consultation as this gives a more personal view. Had we known this was the case we would have submitted a paper with all of our data and comments from our survey.

I will share a couple of those comments now as it shows the level of feeling about this subject.

"As I understand it, there are not enough therapists to cope with the amount of children. I am also a SENCO and have stopped advising other parents to refer to ECCH due to the constraints of the service. I feel many children are being failed. This is not the fault of individual therapists. Relatives cannot believe that my son who is 5 and non verbal, does not receive regular therapy. It feels like ECCH are thinking he is beyond hope!"

"I have twins, they need to be seen and treated as individuals, not squeezed into one appointment. They are totally different. Please do not copy and paste a report and then leave the wrong name in, or get the child's details wrong, it is very upsetting. There is no hands on speech support, it's handouts and generic. When every child's needs are different and learn in a different way. The wait for some appointments is too long and then they're signed off after 9 months, regardless of the child's needs. Then another 6 months before you can refer again. It's a nightmare and disgraceful how we have been treated"

One of our questions in the survey was about ECCH having held a number of 'Community as Teachers' events around the County as this was something ECCH were asked to do at the last HOSC. Feedback we received was that most parents weren't told about them and they weren't promoted widely. We only found out because someone spotted it online and shared in our group.

Because of this, very few parents attended.

The survey wasn't promoted widely enough. We were told that there had been a similar number of responses to this survey as the SEND sufficiency one. But SALT isn't just a SEND issue. This was shared via the Local offer, Healthwatch, Family Voice and ECCH.

Initially the survey wasn't on the home page of the Local Offer, we asked for it to be moved as it was hard to access - several clicks away from the home page. Families do not browse the Local Offer, it's an information resource base and people tend to look for something specific. Healthwatch is great but again, not something families are aware of. We hadn't heard of it until Stuart Brunton-Douglas mentioned it.

ECCH did not share the survey initially on their website but did later on when the survey had been running for a while and we highlighted this with Stuart BD. And again, this is not a website people go to browse. A far more effective way of getting the survey into the public domain would have been to email families who had been referred to ECCH (almost 10000 over the 2 years according to the report). This would have meant that those families whose children didn't have SEND would have been given the opportunity also. When we raised this we didn't receive a reply for ages and then were told that due to GDPR this was not possible. So instead of 140 families who responded we could have a much more representative sample. Families shared that Speech Therapists did not mention the survey to families either when they were having their SALT sessions.

Family Voice did not share the survey initially. We had to email and ask them to share which they did on their FB page but they didn't share via email until we asked them to- even tho they had shared the dental survey. It felt as if the council didn't want to know what people had to say.

The report states that drop in centres received the most positive feedback. This has not been our experience. We wonder if it was mostly professionals who rated it positively rather than families as most kids with SEND won't access drop ins.

This is an account from a mum who was recommended to attend a drop-in clinic after concerns were raised about one of her children. She has 3 children under 4, 1 diagnosed ASD and twins one suspected ASD.

'When a drop-in was recommended I explained I would find it incredibly difficult however she then went on to say there are lots of them and hopefully we could find one that could suit as the waiting list for a home visit was extremely long and would be the 18 weeks just to get him seen to be referred. She told me a couple of drop ins in this area and even told me ones as far as Thetford however agreed that would be too much. They found a closer one at Bowthorpe sure start centre. It was at 9.30 so I had time to drop eldest child at school and get over to Bowthorpe for the drop in. I was told that as the drop in was 9.30-11.30 I was best to get there early as they see you in the order of arrivals but no mention of numbers being capped etc.

I decided I would do it.. I could go with just the two and juggle it...

I dropped eldest off as quickly as possible and drove to Bowthorpe.. by the time I got the boys out of the car into the buggy etc it was 9.15am when I arrived however was greeted by 2 ladies from ECCH and was told they already have their 6 families and wouldn't be able to see us and was turned away.

When I got slightly upset at that point as just how hard it was to get there to be turned away she then went on to tell me that it's a drop in and they have no control on how many will turn up so could never guarantee anyone to be seen it's a case of first come first served.

Also they were supposed to have a second therapist but that therapist was ill so wouldn't be seeing the 12 families they originally had planned and unfortunately I would need to try again at another drop in..

Obviously I got upset as I couldn't possibly keep chasing them at drop ins on the chance I might be seen.. I also explained how I was feeling let down, I told them I have a child that has ASD and was non verbal at 3 and didn't get speech therapy and how I had to fundraise to get the support.. and now I have another child and he needs to be seen.

I went outside and just burst into tears in frustration... a lady from the sure start centre come out after me, she tried to help get them to see me but obviously couldn't.'

Families have been told that NCC will not accept reports from private Speech therapists as they are not the commissioned service. The line that has been taken by both ECCH and some EHCP co-ordinators is that as they are private therapists, they could be overstating a child's needs in terms of therapy as they have to 'pay the bills'. This is something we have heard time and time again and not only is it an insult to the therapist, many of whom used to work for the NHS before ECCH took over, they are also governed by the same professional body and to do this would be highly unprofessional and unethical.

However, the report also hasn't highlighted that ECCH themselves have been offering private therapy to some families whilst they wait for the child to reach the top of the waiting list. Marie from Better Communication told us that this has been resolved and won't happen again but we felt it should be noted that this has happened and given what has been said about private therapists, it seems a bit rich that ECCH have been charging £50 per 30 mins for therapy when the going private rate is £30-35.

We know of several parents who have had to fight for up to 2 years and attend mediation / start tribunal proceedings before their child has received an appropriate level of SALT or a Personal Budget for private therapy. Families haven't got the time, energy and shouldn't have to go to these lengths. Those families will always ask themselves: How much more progress would my child have made and how much further could they have come, if the right provision had been in place to begin with?

The Independent Review has highlighted several areas of concern and recommendations of how to improve Speech and Language Services, however in the future we feel surveys could be shared in a more effective way as this approach felt a bit half hearted and many of the responses have come from us promoting it. To gain a truly meaningful picture every method of contact should be used. Email and text are commonly employed as ways of sharing satisfaction surveys, particularly within the NHS and we feel that this should have happened here.

It is an established fact that early intervention in children with any kind of additional need is crucial to their development and future outcomes. Denying or reducing levels of support to young children is a false economy as their problems do not simply 'go away' they actually become obstacles in accessing education and ultimately employment. These young people are likely to need further intervention later on, incurring more cost and potentially increased reliance on public services throughout their lives.

One of the 'emerging themes' from the Independent Review states:

'The service specification was ambitious in attempting to provide a whole system approach for SLT in Norfolk. Challenges in terms of service funding, resources and the allocation of resources outside of this contract have led to a series of unintended consequences.'

At the Children's Services Committee on Tuesday NCC admitted they had under estimated and therefore under resourced their EHCP department which last year resulted in only 9% of EHCP's being delivered within their target time and leaving more than 90% of children with SEND potentially unsupported in their educational setting.

As parents, we pose the question:

Is NCC's continued efforts in trying to reduce costs and make savings from all of their budgets, putting vulnerable children and young people in Norfolk with SEND at risk?

Appendix 3

Responses to the 2018 SENsational families survey regarding ECCH paediatric speech and language therapy in Norfolk

1. I am so disappointed by NCCG and NCC that I am looking into legal aid for judicial review of SALT provision and my son EHCP.
2. The current SALT provision provided by ECCH is not meeting the needs of the children it has been commissioned to help. In particular the children with complex SALT needs.
3. I haven't heard of any events.i feel very much on my own this time. We have work sheets and we are waiting for a 6 week block which I have been told will be quite a wait. The 6 weeks M has been offered apparently won't scratch the surface of his issues.
4. The waiting lists are far too long. I'm not sure if the policy has changed as we have not had a recent appointment, but the automatic discharge policy, placing the onus back on the school/parent to request a child is seen again, is disgraceful. All the individual therapists who have assessed my son have been helpful and professional, but the waits are far too long and more input is required. Scrimping on this is so short-sighted as improvements in communication and interaction will have huge benefits in terms of ability to access the curriculum and make progress in other subjects, as well as enabling the child to verbalise problems rather than having to show distress through behaviour.
5. ECCH are not providing 'actual therapy sessions' for our children. The service is not appropriate any more and is failing out children's needs. I as a parent am left with no advice, no help and hefty private SALT bills! It's totally unacceptable that such an important thing as being able to communicate.
6. As I understand it, there are not enough therapists to cope with the amount of children. I am also a SENCO and have stopped advising other parents to refer to ECCH due to the constraints of the service. I feel many children are being failed. This is not the fault of individual therapists. Relatives cannot believe that my son who is 5 and non verbal does not receive regular therapy. It feels like ECCH are thinking he is beyond hope!
7. I have twins, they need to be seen and treated as individuals, not squeezed into one appointment. They are totally different. Please do not copy and paste report and then leave the wrong name in, or get the child's details wrong, its very upsetting. There is no hands on speech support, its handouts and generic . When every child needs are different and learns in a different way. The wait for some appointments is too long and then signed off after 9 months, regardless of the child's needs. Then another 6 months before you can refer again. Its a nightmare and disgraceful how we have been treated.
8. No specific support considering my son has ASD. The last SLT came to see him without contacting me and then couldn't answer my questions about the ASD traits of his speech difficulties. He has seen an SLT twice in two years.

9. Too Long waiting between report identifying that the child needs speech therapy waiting time so far not seen is 5 months- child will start at school in July 2018.
10. Your provision is utterly disorganised and without consistency. Your staff are immature and pointless
11. Since moving to ECCH the service has gone downhill. I have a non verbal child who has progressed to phase 5 PECS using a private therapist. I am a single parent not working. In January an advanced offer was agreed to support her in school. Not heard anything since. It's disgusting and I am going to the papers about this. You shouldn't get away with leaving children like they are just another number. Should be ashamed of yourselves.
12. We were told that my son aged 3.5 who has significant SALT needs due to Down syndrome does not require SALT !!! as he is too young . This is obviously inaccurate and all evidence indicates that children with DS benefit hugely from early intervention . He has benefitted a lot since starting regular private SALT . He now understands many signs , can sign back and is making different Soeech sounds . He is also attempting done words now . Discharging a child with obvious need shows the service is not fit for purpose . A friend with a child of same age and similar communication issues has been seen regularly for one to one sessions 4-6 weekly . There is a complete inequity in service . Is it because my son has Down syndrome ?
13. Our grandson has a speech problem - he sometimes whistles as he speaks. EECH did an assessment over the telephone and stated he did not need intervention. More than words did a face to face assessment - he has a speak problem that can be corrected with therapy. How can EECH therapist correctly diagnose a child over the phone - it was not a skype call just a normal telephone call - I have serious concerns over their assessment process.
14. Our son had really been let down by ECCH, he is in clear need and has been recognised as having a need however we receive no support. Lots of nothing. When someone does come to see him to review he always has the wait and see with Home sheets and signed off. Not good enough! His progress isn't due to ECCH it's due to us having to find funds to help our son privately. Shocking service
15. Waiting lists are too long- we need more SALT's to help our children
16. When we see a therapist , she is very helpful and very professional . However the wait between the sessions are so long . When you can see how your child's life is being effected due to not being able to communicate fully , and you don't have as much support as you feel you need , it can make you feel very helpless as a mother . The difficulties in communication have effected almost every part in her life , from making friends to asking if for food. Speech and language is vital for children if it is needed. There seems to be such a demand for this service and not enough staff,
17. Some members of staff were amazing but actually getting seen was very frustrating following transfer to your service. I was constantly chasing as my daughter was rapidly heading towards school and was not being seen routinely.

18. Provision is inadequate and failing children who are most vulnerable. Communication is the key to so many other developmental aspects - failing children when they need it most and when a positive input could make such a wide reaching difference. We are setting our children up for a school career (and potentially a lifetime) of disillusionment, emotional well-being difficulties, poor social interaction, poor prospects. My child is no less deserving of the richest and broadest of opportunities just because he was born with this difficulty.
19. The service is appalling. Our children are being let down. Assessment and discharge is not good enough.
20. We do total communication as part of everyday life & at nursery. My child learns & thrives on concentrated regular 1:1 speech therapy. This doesn't exist. The East coast model is a cop out & is setting my child up to fail in mainstream.
21. I feel that intervention at an early age would help more than waiting until a child is 3, as by then they have already adjusted to life without speech and dealt with the frustrations it causes.
22. Since discharging in May/June speech is has got worse, school have now made a referral back, what a waste of a year!
23. No service other than assessment provided
24. When my son received his autism diagnosis at age 15 he was not seen by a SALT. He was diagnosed via CAMHS. No pathway for young people it appears. Ignore them and they will go away?
25. Simple question, for WHAT you are paid???? Doing nothing????!!@
26. The service offered for our son was disjointed from the outset, no clear messages about the process for us as parents. Emphasis was very much on sign and no encouragement to use speech. Once using private services our sons speech developed massively. I am worried about this service and the way it works to support children to communicate. Staff were trying hard to get things right but they talked about the system being wrong, no time to work with children and frustration about funding.
27. Service seems to be underfunded especially since being split from NHS. Our visits reduced drastically after that and we have had to chase to get these reinstated even with my child's severe and complex needs.
28. I think the money spent on SaLT at ECCH would be better spent at 'More Than Words'
29. ECCH appear to want to discharge the children ASAP ! In 2013 our daughter was having weekly sessions then cut down to 1 every few months and then bizarrely discharged to have to be referred again and be put on a waiting list ??? Seen again and discharged only to have to be referred again as we are trying to obtain a personal budget and co-ordination said we could not use a private report as we had to have confirmation that the NHS do not provide

the therapy she requires. We duly did this and now LA have changed the goal posts and said school can do this. Teachers are not qualified SALT therapists so ECCH should provide this therapy or we should be able to have a personal budget to pay privately !!!

30. Feel my son's speech and language needs are not being met and that he has been left to it because he is almost non verbal.
31. Under staffed Too many cases miss/ undiagnosed. Once diagnosed no treatment provided just a plan for schools and families to follow. Thank goodness we have used a private therapist to assist in the mean time! We would have a son with serious behaviour issues otherwise. He is damaged as a result of not getting enough support earlier. With glue ear not diagnosed despite school hearing screening and with other difficulties (possible ASD/ SPD) he will need a lot of input. More earlier on may have been more cost effective in the long run. Just need more therapists to be able to provide the sessions with child straight after assessment. Waiting times horrific still. Just not good enough. Norfolk has a huge S&L problem. It's not about to disappear. More funding, support, professionals, sessions desperately needed. Schools are at breaking point over this and other underfunding issues. Our children are losing out and putting a greater strain on resources.
32. ECH are failing most if not all the children in Norfolk, this will be detrimental to our children's future. The long term effects of this lack of service will cost Society in the future, making a very high proportion of these children unemployable, benefit claimants costing society thousands. When this next generation need not be unemployable because there SALT needs were not addressed (early intervention) but ignored and discharged.
33. The service provided by therapists is hugely variable, we are 'lucky' to now have a very knowledgeable therapist who has been really helpful. However prior to this was a different experience and meant my children did not receive an acceptable service. The delay between referrals and therapy commencing is unacceptable. The provision of private therapy by ECCH to the same children they see on the NHS is ethically questionable and needs investigating.