healthwatch
Cheshire West

Identifying Gaps in Service Provision for Disabled Children/Young People, their Families and Carers

June 2016

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Introduction

Over the past 18 months Healthwatch Cheshire West have been gathering and sharing views regarding services for disabled children and young people. This focus for our work was identified as a priority by members of the public and groups across Cheshire West and Chester placing services for disabled children and young people within the top five issues and concerns.

At engagement activities with groups and individuals a number of comments were made, particularly by parents and carers, telling us that they had deep concerns that traditional services that parents relied on and valued including the continence service; speech and language service; physiotherapy; the wheelchair service; the laundry service were disappearing.

These conversations took place at a time when many of these services were under review.

Some services were being delivered in a different manner but people commented that they were often unaware of changes until they looked to access a service causing problems to occur. Parents and carers told us that they had not been made aware of new or alternative arrangements until it was time to review their child's case.

In some cases comments were specific e.g. about the laundry service. Healthwatch Cheshire West understands that the laundry service had been completely remodelled – that this service is now 'bought in' by hospitals from different companies - but that the service has not been extended to home care. Parents commented that they were told that this service could be "bought in" by using their child's personal budget however accessing a similar service was proving difficult. One parent of a young adult with severe disabilities who spoke to us commented, ***"I was told to use the nearest laundrette!"***

Information and feedback on the impact of changes to services on children and their families, both on the negative impact of cuts and on positive aspects of service delivery, was shared in 'real time' with commissioners of services, and helped inform the current Cheshire West & Chester Council's Disabled Children's Review consultation.

This report summarises information we collected and shared during the past 18 months and ongoing actions.

About Healthwatch Cheshire West

As the independent consumer champion for health and social care in Cheshire West, our role is to champion the needs of everyone and make things better for the most vulnerable in our area.

There are a number of key activities that Healthwatch Cheshire West carries out:

- Provides information and advice about local health and social care services
- Gathers local people's views and experiences about services
- Helps people to get their views, experiences and concerns heard
- Reports any issues and concerns to those who plan and provide services
- Involves local people in monitoring the quality of provision and experience of local services
- Challenges those who plan and provide services and makes recommendations
- Reports findings to regulators such as Care Quality Commission.
- Shares local views and experiences with Healthwatch England.

Project overview:

To work with disabled children and young people (0-25), their families, carers and key partners to identify, understand and report on gaps in service provision which affect their ability to lead healthy and independent lives.

- Disabled children and young people are a group whose voice is seldom heard by those who plan or provide services
- Healthwatch Cheshire West has received a number of comments from parents/carers of disabled children and young people regarding gaps in service provision
- Service provision for disabled children and young people scores highly on the Healthwatch Cheshire West Priority Setting Tool
- Close working relationships have been established with key partners and stakeholders such as Cheshire West and Chester Council (CWAC), Parent Carer Forum, National Autistic Society and the Learning Disability Partnership Board
- There is an appetite for a collaborative piece of work which can feed into the Local Offer and influence the future commissioning of health and care services.

Initial feedback received from members of the public and key partners revealed particular issues around access to:

- Incontinence services
- Laundry services
- Counselling services
- Speech and Language services
- Physiotherapy services
- Children and Adolescent Mental Health Services (CAMHS).

Objectives

A key focus of the work was to bring the voice of disabled children/young people (ages 0-25) their families, carers and key partners to the fore and present findings to those who plan and provide services by:

- Collecting voice and experience regarding the different services that exist, how they were accessed and what was and wasn't working for people.
- Collecting people's views on how they felt services could be designed and delivered to better meet the needs of the people using them.
- Identifying innovative ways that services could be tweaked and changed to achieve mutual benefits in the context of budgetary pressures.
- Acting as a critical friend and providing challenge to local commissioners and providers in relation to their duty of care to disabled children and young people, and their families.

Methodology

We focused our information gathering around four key questions. We asked people - in relation to all services for disabled children and young people delivered across Cheshire West & Chester:

- What works well at present and why?
- What doesn't work well at present and why?
- Are there any gaps in provision?
- Have you got any ideas for new and improved services?

In order to ensure engagement with a wide range of people we:

- **Disseminated an online questionnaire** - *Hard copies were also taken to all engagement events throughout the year.*
- **Engaged with disabled children/young people (0-25), their families, carers and key partners** - *Healthwatch led workshops in locality areas of CWAC and attended the Parent Carer Forums to encourage parents/carers to share their views.*
- **Attended meetings, events and networks of stakeholders to consult and engage with their users** - *We held two drop-in events for parents and professionals to come along and talk to us.*
- **Arranged drop in sessions at schools and colleges** - *We attended the School Champion Group; Hebden Green Parents' Support Group; Rosebank Special School Support Group; and a Learning Disability Workshop.*
- **Liaised with multi-agency professionals** - *We attended staff meetings of the Disabled Access Resource Team; Carers' Support groups; Disabled Children's Team; Vale Royal Clinical Commissioning Group; West Cheshire Clinical Commissioning Group; National Autistic Society (NAS); Learning Disability Partnership Board; Cheshire Centre for Independent Living (CCIL) and the Learning Disability Forum. In addition, the questionnaire was sent to all special schools and Third sector organisations.*

- **Workshops -** *These were hosted by CCIL Community Engagement Team for young children and adults. A DVD was made and a piece of artwork created.* *https://youtu.be/UJK9uWseC0E*
- **Collated information and findings.**
- **Presented and discussed findings with those who plan and provide services.**

Key issues from the Questionnaire - *"A summary of some of the answers."*

(Full information in Appendix section)

Q1 - What works well at present and why?

School nursing provision - We received many comments and examples of this working well within schools. Some comments, however, indicated a worry that this service may change.

Buzz Group activities - Lots of feedback of this being an excellent service with people asking for this to be continued/extended during the school holiday period.

Short Break provision - Comments received indicated this works very well if you can get this payment. However, families told us that it appears only available on a first come first served basis and some comments stating that they wait a long while, as people don't leave. Comments suggested more provision would be useful.

Third Sector organisations – specific mention was made of the following organisations/groups providing good services that worked well for disabled children and families:

- Carers Trust
- CCIL – Buzz Group Activities – Creative Breaks
- NAS
- Making Space
- Cheshire Autism Practical Support (ChAPS).

School Paediatricians - Families reported that this service worked well within the special schools.

Multisport on a Saturday - Children really enjoyed this provision and would like more in holidays particularly.

Service provision up to 16yrs – Comments indicated services work well but also that they have to travel quite a distance to get to appropriate services.

Q2 - What doesn't work well at present and why?

Communication – Comments indicated services between agencies could be better.

Dentists – Comments suggested that positive experiences for disabled children were lacking.

Schools – Appeared not to give out information or work with social care.

GPs and Nurses – Comments suggested a need for training on how best to interact and treat disabled children and young people.

Accessing specialist services in education and social care was seen as troublesome with particular mention given to:
- Speech and Language services,
- Physiotherapy services,
- Incontinence Service.

Diagnosis of Autistic Spectrum Disorder – Comments indicated that waiting lists are too long, not enough experts to diagnose and pathways unclear.

CAMHS Service – Comments that waiting lists are long and that workers lack knowledge and understanding of dealing with children and young people with Autism.

Information – Comments told us information given to parents post diagnosis was inconsistent across Cheshire West and individuals would like to see a clear pathway (linked to the development of the Local Offer).

Transition - Many parents/carers appeared to be having issues with this including **Post 16** – relating to information and resources.

Social Worker involvement – People told us that they had no clear Social Worker to contact and return to when needed, and had the perception that each case was opened at crisis involvement and then closed again.

Hospital inpatient – Individuals commented that no quiet area was provided to sit in whilst waiting for appointments and staff had no consideration that they were interacting with a disabled child/young person. Parents said that no thought appeared to be given for teenagers entering into hospital and that they are placed on adult wards after 13yrs of age which is not always appropriate.

GP – People told us that parents/carers are not always linked to their child/young person on databases that are used and this can cause problems - making it difficult to get results, make appointments and discuss their child. Parents also said that Data Protection rules can make things difficult.

Q3 - Are there any gaps in provision?

Buzz Group – Parents valued this provision and commented that they would like to see more Buzz Group activities in the Northwich area for older young people up to 25yrs.

Dentists – Parents commented on this service indicating a possible shortfall in training for Dentists and their receptionists and nursing staff.

Transition – Comments received suggested that clear transition pathways were lacking. Healthwatch Cheshire West was aware that this was being addressed and a Transition team had been put in place within Cheshire West & Chester Council.

Holiday Cover – Parents that work full or part time and have a disabled child or young person tell us that seeking care for children during holiday periods can be very distressing and commented that there is no safe environment or care unless paid for privately. ***"If you are on a low income this is not always possible."***

Teenage Wards at the hospitals – Parents' perception appears to be that at the Countess of Chester Hospital there is no teenage provision - so after the age of 13yrs children are expected to go into an adult ward. This was felt to be inappropriate.

16 – 25yrs – People felt that there is not enough provision for things to do for disabled people in this age group and that there needs to be more club or society events with social interaction.

After care from diagnosis – People felt that Health, Education and Social Care should be working together to make this process more efficient.

CAMHS – People felt there needs to be a method of quick access for children or young people.

Autism clinic – Views were expressed asking for a properly joined up approach for children and young adults with Autism - a holistic approach with a one stop clinic for advice and support.

Q4 - Have you got any ideas for new and improved services?

Activities for young adults – People wanted to see more opportunities as there was very little provision at the time for young adults, and suggested that existing groups, such as Buzz, would be in a strong position to work with this age group.

Carers Assessments – People wanted more information, perhaps placed on the Local Offer, to allow for a better understanding of entitlements and what was on offer.

Training – A recurrent theme was of training for professionals on interacting with disabled children and young adults, and better understanding of their access needs - this included consultants, social workers, nurses, dentists receptionists etc. The training should be delivered by disabled people.

Advocates – There was an identified need for an increase in advocacy services to bring together families and professionals to better understand each other.

Social Workers – More availability of social workers or key workers to be the parent/carer’s first point of call. Parents/carers need someone they can trust to speak to who understands their case and provides both reliability and consistency.

Autism Specialist Clinic – Reference was made to a specialist team that operates in Liverpool covering all areas of Education, Health and Social Care. People commented that partnership working would allow provision for teams with specialty in Autism to work together under one roof and allow parents/carers and young people a safe place to go to get diagnosis, support, advice, follow on, counselling etc.
The suggestion is that it could be a great opportunity for both Cheshire East and Cheshire West to come together to provide a similar service.

Activities – Requests were made for improved funding for activities to include extension of existing provision to provide holiday support; increase in young adult activities; and to provide better choice.

Creative Breaks – People feel that the eligibility criteria should be opened up so that more families can access the scheme. People’s perception is that funding is lacking.

Outcomes:

People shared with us a wide range of views during the life of the project. These were fed back in real time to commissioners and providers and have helped inform the CWAC Disabled Children's Review.

Below is an update on some of the areas mentioned in the feedback from our questionnaire and engagement activities:

Buzz Group – *Parents valued this provision and commented that they would like to see more Buzz Group activities in the Northwich area for older young people up to 25yrs.*

> The Connect service, run by the Community Engagement Team at CCIL that also runs the Buzz Group, now offers Training and Support to community sports or leisure groups to ensure that there is a limited period of support to allow young people to become integrated and independent within the community.

Transition – *Comments received suggested that clear transition pathways were lacking. Healthwatch Cheshire West was aware that this was being addressed and a Transition team had been put in place within Cheshire West & Chester Council.*

> Cheshire West and Chester have now employed a Transition Team and are very focused on getting this part of a young person's life right. The service runs from 16 – 25yrs and starts working with young people from age 14 in special schools.

Holiday Cover – *Parents that work full or part time and have a disabled child or young person tell us that seeking care for children during holiday periods can be very distressing and commented that there is no safe environment or care unless paid for privately.* ***"If you are on a low income this is not always possible."***

> The Launch of the Local Offer has allowed more community groups and private clubs to promote what they can provide families and young people during the holiday periods and weekends.

Teenage Wards at the hospitals – *Parents' perception appears to be that at the Countess of Chester Hospital there is no teenage provision - so after the age of 13yrs children are expected to go into an adult ward. This was felt to be inappropriate.*

> This continues to be the case, but with consultation prior to the young person going into the Countess of Chester Hospital, the Matron can discuss your case and assist as best they can with your requests.

16 – 25yrs *– People felt that there is not enough provision for things to do for disabled people in this age group and that there needs to be more club or society events with social interaction.*

> There are a number of really good services beginning to appear on the Local Offer. CWAC Apprenticeship scheme has been very successful and is continuing to build up employers who are able to take on young people. The Bren Project has launched based at LIVE, again giving young people a chance for good quality work experience.

After care from diagnosis *– People felt that Health, Education and Social Care should be working together to make this process more efficient.*

> The CWAC Disabled Children's review has brought together all services to co-produce an outline of a new way of thinking. This project has already been fed into this review and the consultation period is now taking place.

CAMHS *– People felt there needs to be a method of quick access for children or young people.*

> The CAMHS service has undergone a review and is working to improve their overall services for young people with a Disability. They have reported at the SEND Strategy Group that they are working more with partners like the Transition Team to ensure a more joint working approach is used in reviews.

Autism clinic *– Views were expressed asking for a properly joined up approach for children and young adults with Autism - a holistic approach with a one stop clinic for advice and support.*

> This remains on the agenda of many local organisations, such as NAS, Parent Partnership and Autism Strategy Group, to be discussed and reviewed. The NAS have opened up a Library at Rosebank School in Barnton, Northwich. The times of opening are on the Local Offer.

Activities for young adults *– People wanted to see more opportunities as there was very little provision at the time for young adults, and suggested that existing groups, such as Buzz, would be in a strong position to work with this age group.*

> The Community Engagement Team at CCIL run a service called Connect alongside the Buzz group; this is run extremely well and parents are happy with this provision but would very much like this extended to include more for young adults. The Local Offer does have a list of community and voluntary groups who are providing more for this age group. New opportunities have opened up at the Bren Project and for CWAC

Apprentices. Live Youth Centre is also opening up provision during the day for adults to attend using their direct budgets.

Carers Assessments *– People wanted more information, perhaps placed on the Local Offer, to allow for a better understanding of entitlements and what was on offer.*

This is now happening and we have been informed by carers that the Local Offer is a great source of information for them.

Training *– A recurrent theme was of training for professionals on interacting with disabled children and young adults, and better understanding their access needs - this included consultants, social workers, nurses, dentists' receptionists, etc. The training should be delivered by disabled people.*

The Local Authority and CCG have given instruction for their staff to undertake some training on Autistic Spectrum Disorders (ASD). It does remain an issue and Healthwatch receives complaints from parents about the treatment of their disabled child or young person, particularly around going to the Dentist.

Some doctor's surgeries are better than others; one surgery in Winsford is now allowing parents and children to sit in their cars and wait to be called in for their appointment rather than sitting in the surgery.

The issue of training has also been raised during the Disabled Children's review around raising awareness in general.

Advocates *– There was an identified need for an increase in advocacy services to bring together families and professionals to better understand each other.*

The Advocacy service has changed and is now working through a Commissioned Service only, provided by a partnership between Age UK Cheshire and CCIL. Recipients of the service should be over 19 and need to fulfil Care Act criteria. The Local Offer has all the detail and contact information.

The People's Choice group, which acts as a link between the Learning Disability Partnership Board and the Learning Disabled Community across Cheshire West is still in operation at present and again the details are on the Local Offer.

Social Workers *– More availability of social workers or key workers to be the parent/carer's first point of call. Parents/carers need someone they can trust to speak to who understands their case and provides both reliability and consistency.*

> **Social Workers** – More social workers available to be the parent's/carer's first point of call or a key worker if no more social workers are employed. Parents/carers need someone they can trust to speak to who understands their case and provides both reliability and consistency.
>
> The Disabled Children's review consultation, which runs until 18 September, will be looking at points of contact for parents and carers. A Transition Team has now been put in post, and all social workers should have training on ASD.

Autism Specialist Clinic *– Reference was made to a specialist team that operates in Liverpool covering all areas of Education, Health and Social Care. People commented that partnership working would allow provision for teams with specialty in Autism to work together under one roof and allow parents/carers and young people a safe place to go to get diagnosis, support, advice, follow on, counselling etc.*
The suggestion is that it could be a great opportunity for both Cheshire East and Cheshire West to come together to provide a similar service.

> This is still being monitored by local third sector organisations. There is no new money available to develop this service, but the NAS have opened with the assistance of volunteers a Library at Rosebank School in Barnton Northwich.

Activities *– Requests were made for improved funding for activities to include extension of existing provision to provide holiday support; increase in young adult activities; and to provide better choice.*
and
Creative Breaks *– People feel that the eligibility criteria should be opened up so that more families can access the scheme. People's perception is that funding is lacking.*

> Both of the above were discussed at the Disabled Children's review. It is hoped that the new service with take into account the need for provision during school holidays to allow parents to continue to work. There are a number of private services available, promoted on the Local Offer, which can be paid for by direct payments or PIP. CWAC are committed to providing Creative Breaks but at present it does run on a first come first served basis.

Next steps

This report will be added to our website and sent out to all third sector agencies and to all statutory organisations, West Cheshire and Vale Royal CCGs, Social Care and Education Commissioners.

Healthwatch Cheshire West will continue to participate in forums and meetings where issues affecting disabled children and young people, and their families, are raised.

Healthwatch Cheshire West will actively promote the consultation on Cheshire West & Chester Council’s Disabled Children’s Review to ensure parents and carers views are heard and considered. We will provide a further update once the results of the consultation are known.

The Local Offer website has been launched during the life of this project. Healthwatch continues to encourage organisations to contribute to the site and to get the message across to parents/carers of the benefit of using this service.

Our thanks go to everyone who has contributed to this project including disabled children and young people, their parents and carers, the Parent Carer Forum, Buzz Group, Carers Trust and NAS.

Appendix 1

Feedback from Parent Carer forum 04/02/15 (Attended by 80 people)
ALL VIEWS for HEALTHWATCH ACTIVITY

Q1 - What works well at present and why?

Table One	Table Two
• Family Support Workers • Cygnet Course • Parent Partnership/IASS • Paediatrician – Countess of Chester • Cheshire Branch of National Autistic Society • CHAPS	• Good that you can tell GPs that you are a Carer. • ESAT Family Support Work, Notification to services re information. Acted as a key worker role. • Dental Services - that provide support for SEN. • OT Most beneficial access – signposted to relevant support. • SALT sessions currently work.
Table Three	**Table Four**
• GP recognition and subsequent involvement. • Very good support from dentist (not SEN trained but good). • Ongoing CAMHS support (after initial delay). • Reports thorough but delayed. • OT – good thorough assessment and ongoing work. • Paediatrician good - but waiting time to get there.	• Provision of Teaching Assistant support in Mainstream is vital. • Provision of incontinence pads is good. • Good teacher for Deaf and SALT • Good SENCO and very good Speech and Language Therapist despite a heavy workload. • Good after-care from Manchester cochlear implant centre. • Good support through adoption process.
Table Five	**Table Six**
• SALT in school/parents/SENCO phone call/advice. • CDC/P/SALT/OT Early Years Support for children and families. • Leaflets of SALT.	• If a letter includes a phone number, name of person who has written the letter, date, plain English (no jargon), who is copied in. • School was pro-active in referring to SALT. • Dietician service, very contactable, always helpful and approachable. • SALT - they listened to me and were very sensible (General views on the table)

Table Seven	Table Eight
• NHS Choice • Speech and Language - good support during Statement process. • Walk In centre at Countess A&E works well for children. • GPs recognising carers - as long as you register. • Dentists specialising in Autism (understanding SEN need). • CAMHS - good support in school. • Open Door (Passport Access) at Leighton and Countess for children's cancer. • Oncology Community Nurses are fantastic.	• Speech and Language assessments process. • Chester Catholic High School, Speech and Language bespoke to child. • St Werburgh's school - communication between parent/carers and school is good. Buddy Scheme in school. • Attachment Disorder UK - Forum online. • School based well being programmes. • Young Carers Service - positive response and offered training to school setting.

Q2 - What doesn't work well and why?

Table One	Table Two
• Access to OT for sensory needs/specialist equipment. • Consistent support for speech and language communication. • GP understanding of child with autism. • GP Ring back facility. • Staff in surgeries - understanding of needs and conditions • Dental appointments - Staff understanding of needs and conditions	• Risk of cutting SALT and trying to reduce sessions despite evidence of SALT ongoing and requirements of the sessions currently allocated. • Waiting lists are long. • Communication - repeating story multiple times and other groups not talking to each other. • Continence service a lot of pressure on parents re toilet training. • CAMHS - ASD- Don't do anything; long waiting lists.
Table Three	**Table Four**
• Communication between school and health professionals/school not recognising needs initially. • Pathways for diagnosis not straightforward. • Teachers need to know more about the health systems. • Waiting for referrals - to CAMHS and SALT - up to 10 months. • Think SALT should have been provided within school. • CAMHS - good but didn't communicate back to school. • Change of health commissioning has caused lack of service in new area. • OT - functional assessment not sensory. • Dentistry - referral and hospital - procedures unnecessary - very high levels of anxiety - e.g. 20 weeks with abscess. • Mental health services for YP - not adequate/autism specific. • S&L Therapy closed case - difficult to re-open despite diagnosis.	• Very rude response from Assessment and Monitoring Team. • Reduction in SALT • If no engagement from child/teenager - there should be support provided to encourage. • Lack of TA support in reception for children with SEN - should be in place from Day 1. Lack of preparation as to needs of child. • Additional funding in school not being used for TA support - lack of protocol when child is absent. • Insufficient time to complete forms and it is a very stressful process. • Professionals not listening to parents. • Lack of knowledge about hearing impairment from GP. • No cross region working together for looked after/adopted children. • Adoption support from authority where child comes from should provide more support and funding.

Table Five	Table Six
• Lack of awareness of services. • Consistency of provision. • Identification by school. • Access to CAMHS.	• Continence and CAMHS not really working together. Working in isolation. CAMHS closed case when referred to Continence and then waiting for re-referral again. Takes time to be re-referred. • Continence service said if we didn't do what she said and comply our case would be closed. Poor attitude of staff. Conflicting info in relation to un-used nappies - money wasted. • OT – unused equipment gathering dust in garage. • Person/company/charity providing equipment not interested in taking it back. • A&E “grey” area between 16-18; parent left, ignored and excluded. Concerns about child/YP not being listened to. • Physiotherapy – have said no resources/time to offer help and parent should continue to pay privately. Child is four with hypermobility won't treat. • SALT – Letters are difficult to understand - need guidance notes. Letters aren't dated and no signature.

Table Seven	Table Eight
• Health Visitors – not enough capacity to meet demand. • Co-ordinating and organising healthcare professionals to deliver training in schools (e.g. feeding). • Postcode lottery. • Limited amount of nappies. • Speech and Language – very long waiting times – parents being advised to go private. • Long waiting lists in general e.g. SALT, CAMHS and Physiotherapy. • Hard to get back into system once discharged. • Counselling services for siblings (cancer) – long wait and not easy to access. • Not enough professionals to support children with SEN.	• Access to CAMHS/advice and support difficult to obtain and time delay for appointment. • Follow up support after Speech and Language assessment. • No consistent approach in Speech and Language. Appears to be high turnover of therapists. • Commissioning bodies need to be more cohesive. • Transition points difficult to negotiate and manage. • Lack of multi-disciplinary working: parents/carers repeat information, no joined up thinking. • Database/IT which holds information for all Professionals to access. • Parents/Carers/Professionals are often unaware of events/forums like today. • Speech and Language stops at 16 years. Start all over again and physiotherapy and CAMHS

Q3 - Are there any gaps in provision?

Table One	Table Two
• Doctors’ surgeries and dentists are not responding to SEN needs. • Training in awareness for health colleagues. • Co-ordination of review meetings in Special School.	• Information about services isn't clear. • Postcode lottery - some have assessment, some don't - depends where you live. • Border issues i.e. England/Wales work differently • Different legislations and communication routes.
Table Three	**Table Four**
• GP to have lists of support services / Specific person to signpost to services. • Database of health services. • Greater links with school and health - access to more info for teachers.	• Speech and language provision for help with the understanding of language. • Training for teaching staff on attachment issues particularly for behaviour issues. • More support from Social Care in respect of 'looked after ‘children. • A club which targets children with SEN which encourages a healthy lifestyle - staffed by trained staff. • Better communication between service providers.
Table Five	**Table Six**
• GP appointments. • Dysphasia joint working in schools. • TAF approach to respond to early identification. • Incontinence services – nappies. • Social Skills and Independence skills support for adults and children with autism.	• Lack of joined up working, don't read patient's notes. • When re-referring have to start all over again. • Training for GPs on autism and surgery staff and A&E doctors. • Lack of info about sensory processing disorder. • Lack of joined up working between services.
Table Seven	**Table Eight**
• Adult physiotherapy (on a long term basis for long term conditions). • Feeding training and support. No specialised service. • Sensory issues. • Family emotional support (e.g. Cancer, Long-term conditions). • Autism and other diagnoses. • Young people with mental health problems – early intervention.	• Yes, everything from 19-25 years! • Speech and Language 16+ years. • Feel there is a gap in provision when a child falls just below the level for services.

Q4 - Have you got any ideas for new and improved services?

Table One	Table Two
• Add details of child or parent need on file/flag screen. • Ring in advance for medical appointments. • Autism Lead to share knowledge. • Text parent to pre-warn of appointments or availability of professional in clinic. • NHS: Education Parents- SALT Training – School and Home.	• Key Worker • One Stop Shop to access information and support. • Information Sharing Protocols. Re: Sharing Health Information with other Hospitals/Medical professionals. • Working together/communicating better. • Have a Parent/Carer Service.
Table Three	**Table Four**
• List of support services. • Useful network of professional teams - What do they all do? How do you know what services are out there? • Drop In "Listening Ear" service for families affected by children's cancer.	• Better training. • Less ignorance. • Move funding across the board. • Clubs/activities for disabled children staffed by trained staff. • More BSL training for all professionals.
Table Five	**Table Six**
• SALT mapping. • Promote Local Offer/IAS. • Promotion of pathway through newspapers and GPs • Visible factsheets at schools and pre-school • Play Therapists at GP/Hospitals. • Team around Family (TAF) Process for Healthcare. • Access Augmentative Alternative Technology.	• Drop-In/Queuing System at GPs rather than having to ring and wait for an appointment in a few days. • Extended hours 6-8pm or on Saturday mornings at GP. • When diagnosis given, it would be helpful to be given more information about the condition, services that can help - Local Offer should include.
Table Seven	**Table Eight**
• Clear joined up links between Health and Education and Local Offer e.g. NHS website link to Local Offer. • Outreach training team made up of different professionals depending on need. • Specialist feeding clinic to include a Dietician, SALT, sensory expert. • Training Service for families to include workshops, seminars, advertised on Local Offer. • Forum for signposting primary care centres that have expertise in SEN and disability.	• Overview on transition services between nursery and school, also over 16 years so that parents aren't telling their story over and over. (SALT, Physiotherapy etc). • Form filling - one document to be used for all details. • Pathway for social/behavioural is being piloted by Dr Isaacs - this could be extended.

Appendix 2

Healthwatch Questionnaire results
28 people responded

Q1 what works well at present and why?

Responses

1	My daughter has the services of Physiotherapy, portage and Speech therapy. She has received these services from a very early age and it works well.
2	Currently we are not accessing any help from anyone, because he was diagnosed from nursery though our own GP and then we have not been given anything. No support or advice, no information, nothing. I have been trying to research what is out there for us to access. My son will be attending Russett School in September. I am hoping I will get some support from the school. We have seen a paediatrician and the Child Development Team, but they have not given me anything other than the contact for schools.
3	Social Care works really well for me and my son who has Autism. We are really happy. He attends Greenbank School and is very happy there.
4	The school nursing provision at Hebden Green is excellent and provides a continuity of care which would otherwise make attending school difficult for her. We are confident that she is in safe, capable hands with her medical needs while at school. The Buzz youth group run by CCIL is an excellent group providing social skills and independence and which she enjoys immensely.
5	My elder daughter has a diagnosis of LD and attends Dorin Park special school in Chester. She struggles to go out without me but she does attend LIVE and is enjoying volunteering for them in the kitchen and with the younger groups. She feels more comfortable at LIVE and feels accepted.
6	9yr old daughter - diagnosed with Autism. She attends Acresfield School and is very happy there, the SENCO department are excellent with her and very encouraging. Buzz Group activities - she really benefits from these sessions and they are very reasonably priced the trips they do and the activities. Wish there was more of them especially during the school holidays. LIVE - she attends and fully participates in the activities at LIVE, she does not feel at all different from the other children and mixes well with the group.
7	At the present moment in time I do not know what works well as unfortunately I have not experienced this.
8	My 21 year old autistic daughter's support living placement at Weatherstones Court, Neston is working well. She has a core team who provide consistent, structured support for her - she has a personalised support plan. She is autistic, is registered blind and has severe learning disabilities including coeliac's disease, neutropaenia, hypotonia, and osteapaenia - so is very complex. She doesn't speak, read or write so needs full care - also is doubly incontinent.
9	My dental and GP services are good.

10	GP services work well (York Road Practice Ellesmere Port). As he needs hoisting they must make house visits. No problem in getting an appointment. Consultants at Chester (Countess of Chester) efficient and liaise well with Alder Hey (Children's Services). I am not sure how that will change when he is 18 and goes to adult services. Direct Payments system works well.
11	GP Surgery- Neston Surgery always open - doctor available in an emergency situation at late notice.
12	Only ChAPS provides any kind of service for my son with Aspergers syndrome, and I am able to access some training via the NAS, ProACT (training company). Thank God for these charity funded lifelines. I have recently become connected with the Cheshire Carers Centre who offer lots of opportunities for Carers in general. However, a lot of this is geared towards those full time carers who are really in need who perhaps have a day care respite for the person they care for and so can get out for a coffee and chat. I am in a position where I work during the school day, juggle childcare and work during school holidays and cannot put my kids in respite care for a night off as they are not severe enough. They would not qualify for a respite place and would be way too normal to settle there in any case. So how do I get a break? I have used Specialist babysitting services, like 'Time Specialist Support' but at £12.50 an hour this is really beyond budget. Special People North will actually stay overnight, but we have never used them as the cost is too high - there should be provision for this from the local authority - just as there would be if my boys were physically disabled.
13	We have recently moved from Stockport and the school my daughter now goes to here is good. She has speech therapy once a week - before it was once a term. Her speech has really improved. The carers coffee mornings and meetings are very useful. This is a great way of meeting people who are in similar situations and also finding out information.
14	My GP generally works well for my autistic son, and he is treated with respect - but sometimes common sense would be nice. Like a GP insisting on seeing my son before he issued a second sick note for ESA, in case his condition had improved his Autism? Really? Identifying gaps in service provision for disabled children/young people, their families and carers needs to be a priority.
15	Having a community school nurse and school based community paediatrician in a special school setting has worked well for me, I asked the paediatrician for an assessment for autism for my son and this diagnosis was given very swiftly. I was able to share important health information with the school nurse who ensured the information was logged and acted upon properly at school.
16	We have a dentist and a GP practice in Malpas. GP practice is easy to access and it's reasonably easy to see the same GP.
17	My son's school are very keen to listen to all my concerns and school (particularly the SENCO) is proactive in suggesting services and workshops to access. Once accessed, the services have been helpful.
18	Six sessions at CAHMS were well structured and helpful. Information given to take home seems useful. School doctor provides support to child and family and is accessible. Help and support provided through autism resource base at Chester Catholic High School - would not manage in main stream school

	without support and would not have been educated. Mountain View Lodge - reasonable priced, stress free accommodation for whole family.
19	My GP (Dr Julia Dancy at Tarporley Health Centre) is excellent and is very sympathetic to both my son's needs and my own needs. It is easy to get an appointment at the surgery and all of the surgery staff are very pleasant, sympathetic and helpful. However, I find that her hands are often tied by the existing health care contracts from Cheshire West.
20	Specialist CAMHS has been a very positive service for us. This was our second engagement and made much better because the health care professional understood the specific implications of our child's autism. We have experienced consistently high care from a very competent practitioner who has also taken into account the needs of his whole family.
21	Services up to 16 seem well coordinated. We use CCIL following a social care assessment when he was very young. He has lots of different health issues so he has many outpatient appointments and operations at both the Countess and Alder Hey. None have ever been cancelled and staff have a good understanding of his needs. I ask if there's a long wait/queue, explain my son's difficulties and go for a walk and come back.
22	The professionals who work in this area have a very broad knowledge of the needs and issues of young people and the services which can be accessed to provide assistance. The 'student house' project linked with West Cheshire College is a valuable project to assist 'older children/young adults' to develop life and independence skills for adulthood.
23	I get three hours per week of Direct Payments. This helps me (the carer) to keep on top of housework.
24	I go to a great club - Multisport on a Saturday. It gets me out, and I meet friends and we do sports so I get fit. I go to Monday Buddies too which is a youth club and it gets me out to see my friends. My doctor at Firdale is brilliant. He talks to me, not my mum like everyone else does. I do football, with a disability team on a Monday night. I love football and I want to keep playing.
25	Not sure as we are unaware of any services in Cheshire West our child can access. We know there are lots of activities and support in Cheshire East for children living with autism but that is quite far for people in our area to travel.
26	My son attends DART sessions which he really enjoys as he usually attends with a small number of children of similar age/ability.

Q2 - What doesn't work well at present and why?

Responses

1	We are happy with the services we receive.
2	As we have not been given any support from anywhere - communication obviously doesn't work well! The agencies should work better together to give families the information and support they need.
3	Nothing. Happy with the service we get.
4	There is not enough school holiday clubs/care - run at times to help working parents. Some of the activities that are run start too late in the morning for us to be able to get there because of work which means our daughter misses out on trips she would really enjoy doing.
5	Dorin Park Special School have been struggling with her diagnosis and feels she should be on the ASD not LD, I have a younger daughter with a diagnosis of Autism which I had to pay for and my older daughter is worse than she is. She will not go out of her room unless I make her and she will then only go with me, she will not always wash, or change her clothes independently. I have to tell her to do everything. She will certainly not go clothes shopping at all. I have tried to get her diagnosed but feel I am hitting a brick wall. School have set up a work placement for her in a nursery, but I am worried that she will fail and become depressed without any support for her autism. I could pay again but I am struggling financially at present so having to save up. Dentist - both daughters have had awful experience at the Dentist Surgeries, we have found one now who is more understanding but still not Autism aware.
6	Dentists - major problems when she needs to attend - the dentist has no idea of how to handle a child with Autism. We have recently changed and found a dentist who is more approachable and is working better for her. It would be better to include dentists and receptionist in any autism awareness training. Would like more social groups in the holiday times.
7	Communications between hospital and parents. If communication does happen - then keeping their promises!
8	In health - GPs and hospital seem to back off and she can't get blood tests done easily - she would fight anyone who tries! Instead of trying to find a way around it they say, "We will leave it..." Same with any tests or checkups. A GP thought she needed ear syringing but a nurse who tried didn't have a clue how to deal with her - so they just said put oil in ears! Dental - special needs Christine Arnold said her teeth can't be cleaned - would need putting out, she said no point they would only get dirty again!
9	I still have issues accessing health services in specialist education. Where a child has complex health needs it is expected the OT physiotherapy/speech and language services, incontinence services etc. should be involved and working together to support and plan strategies ‘holistically’ for that child. This is not the case. My son accesses specialist provision and has very limited SALT, OT and physiotherapy. As a parent I have to drive and push for their involvement. Reports produced annually

	by these health staff are often not followed up and outcomes are not shared. SALT has been limited 18 hours per week in the school and it is in a tiny room, which is not best suited for 1-1 Interventions (no windows in a little box room). Incontinence service has not contacted me for over a year. They only come to the school when I contact them and there is a problem getting strategies reviewed and engaging with staff at school who support the child. There is no follow up at school or support at home. The head teacher at school said she had no control over health and what they are able to deliver at school. This is not my view as a parent. I expect my son to be supported in school by all professionals - health and education - and who can work with me as part of a team in a person centred approach to discuss, plan and review outcomes on a regular basis. As a parent I need someone to take the lead as I am tired of having to constantly contact individual professionals chasing what they are doing. Communication is vital and schools need to work harder to communicate. Ideally all parents should be included in all IEPs. This in my experience has been a barrier. Teachers have been reluctant to engage with parents to gain insight of parents prior to the setting of education targets. My views as a parent may be different. I place more importance with life skills. My son's ability to take himself to the toilet is more important than science. Incontinence - My son has complex epilepsy and uses on average 6-7 nappies a day. Incontinence services have a rule that only 4 nappies are issued per day. I have argued that this is a ridiculous allowance for my sons needs and there is an exception. I need to find this shortfall myself. I find this totally unacceptable.
10	Too long to get a diagnosis. People do not listen when patients/families say what is wrong. Waiting for treatments /Appointments. Cancelling operations several times
11	Direct Payments scheme works well except for a different rate of pay for a child and an adult. Parents have to use the same agencies and the same staff so under the age discrimination laws - should it not be the same?
12	Referral system – across borough and county boundaries e.g. Wirral and Cheshire. Not clear communication. Waiting time to access services CAHMS / Consultant Paediatrician
13	I wish there were more swimming lessons available for ASD kids. Swimming is essential.
14	CAHMS have very little to offer to my Aspergers son and nothing for my ADHD boy. They only seem to help if things are at danger or crisis point and also there is too much emphasis on the parent as facilitator. Parents are already desperate. We are not experts in autism, mental health, child behavioural issues, play therapy, CBT, ODD, PDA etc. These therapies should be provided by trained professionals, by the NHS. I recently suffered tennis elbow and was provided with eight sessions of physiotherapy close to my home, until the problem improved. Neither of my sons has been offered a single therapy session for his lifelong condition, to help him socialise/learn to manage his behaviour or condition. I have also had six sessions of CBT, on the NHS - as an adult

	woman and mother having anxiety and depression. NOTHING is available it seems of this nature for my sons!!!! There are no support groups for them or me in this area. When I mentioned this to our GP she asked if I would like to set one up? With what time and energy exactly? I am already working only part time so that I can get to 2 lots of paediatric appointments, forums from parent partnership, seminars on bullying, anger management, constant meetings at school re incidents and behaviour problems. What exactly is the NHS offering us?
15	They could do with more information on signposting to services. When your child has a diagnosis you get left to it and have to find out a lot of information yourself. It can be very daunting finding out there is something wrong with your child and there should be a better after care service.
16	Hospital treatment is patchy, ranging from brilliant, to utterly dreadful. Knowledge of Autistic Spectrum Conditions is still generally poor. Doctors look at you like you're an idiot when you are cautious about pain, as people with Autism experience pain differently. This is commonly known and respected in the Autism Community but they look at you like its an old wives tales. Dentists can be a nightmare. As sensory difficulties are underestimated, many parents are travelling across the county to visit Dentists with the slightest sympathy or understanding. Social Services are patchy and respite/care/direct payments are badly underfunded. Divorce rates in families with a dependent with autism are extremely high, and I'm not at all surprised. Stress levels are incredibly high. This is mainly due to lack of services suitable to Autism for children or adults!
17	Information about services is often only given to those who ask for it. Not everyone would feel able or be knowledgeable enough to request support e.g. overnight respite. My son's case used to be open to Social Care but the case was closed. I think they should all remain open and accessible if only just with a FSW so the family can liaise with someone and ask advice at any time. Our children's disabilities are not going to disappear. I am currently undergoing a new assessment by Social Care because I am aware I needed to ask for one to access some new support because of family changes. There must be a lot of people who can't or don't know how to ask but really they shouldn't have to.
18	Dentist has steep steps up to the front door. I don't know if there is another entrance for those less able.
19	I have had an experience where GP was unaware of my son's needs and refused to refer him for a service that was required. I had to contact the surgery and a different GP referred him straight away. I think awareness is generally good but there are certain people who remain ignorant. Carers of young people may not be aware of benefits such as DLA and carers allowance. More communication would be needed.
20	From referral by school doctor to CAHMS it took about eight months to start therapy. This is unacceptably long. No follow up appointments were able to be offered from CAHMS but this would have been very beneficial to reinforce the techniques and ensure they were working longer term.
21	A postcode lottery means that I have to pay for my son's therapy with Dr

	Linda Buchan (£100 a session) - If I lived a few miles down the road in East Cheshire or Vale Royal this would be free - same therapist, same place, same everything. Despite the fact that they are further away from where she practises - in Chester. The Cheshire West Clinical Commissioning Group will only offer my son generalist therapy and offer no alternative therapy from an autism Specialist like Dr Buchan. Despite the fact that my autistic son is currently suffering from severe depression; and has indicated frequently that he would like to end his life; West Cheshire CCG seem not to regard his condition as serious enough to find funding for his treatment. His psychiatrist has said that these funding issues would not go down well in a Coroner's Court but obviously I don't want us to end up finding out if he is correct or not.
22	During the referral process into CAMHS, a disregard of X’s autism almost resulted in his refusal to engage, and it was only my persistence and ability to be his advocate that prevented this. GP doesn't take autism into account at all. I worry about post-16.
23	Once my son reached 16 last year he was discharged from Alder Hey and transferred to services at the Countess. Orthotics department were really disappointing, there was no handover, so they didn't know about his LD or Autism and questioned why I was accompanying him. Transition from CAMHS to adult services was also difficult and involved us having appointments with adult services only to be told they weren't suitable. We were then referred to 16 - 19 services to be told the same and eventually passed to the LD team who agreed to work with my son.
24	Transition services from children's to adults’ is patchy and requires improving to make it seem less.
25	Although my son is deemed to be in 'substantial need' he no longer even has a social worker. When he did have a social worker who visited him regularly, he was able to talk to him. My son doesn't leave the house, is nocturnal, has severe sensory issues and other issues with food. His BMI is low (under 18). We are totally alone with all of this. I have given up expecting help for him.
26	I understand that ‘Multisport’ might have to close because they don't get council funding anymore. They try to get other money, but they said that everyone wants the grants now so they keep getting turned down. It’s the same with Buddies, the Council have said they won't pay for it anymore. If both close, I won't see my friends and get out. I will be 18 in July and too old for football. There isn't an adult team in the evenings. They say there's one in Chester and one in Stockport but I can't get there. There is a day centre one but I have Autism and I'm not physically disabled and I'd be too fast for them. Lots of my friends are the same, we don't know what we're going to do after we leave school in the summer. I don't like going to the hospital because I am autistic. I get really stressed when we can't park. I can't have a blue badge because I can walk fine. The staff talk to my mum and talk too fast. I look normal which doesn't help.
27	My child’s school, in particular, are very poor at recognizing the support children living with ASD require and this gives off a feeling of arrogance. Headteachers in particular need to be more proactive and understanding and, although we appreciate they have a big struggle with schools

	becoming busier, their lack of knowledge is not good enough and this creates uneasy relationships throughout the child's time there. So more training needs implementing for staff and Headteachers.
28	Try to avoid sudden cancellations of/changes to sessions as this can disturb my son. Consider child's needs as not all children can cope with sudden changes in venue or date offered. Consult with parents to make sure that sessions offered are actually on days that the child can do. This is perfectly ok to do by paperwork if necessary. Would be helpful wherever possible to give advance notice of dates to be offered and to try to be consistent on days if agreed that a particular day is suitable.

Q3 Are there any gaps in provision?

Responses

1	No, we are happy with what we receive.
2	As we have not been offered any I am unable to comment on this. But we have been trying to get SALT sessions for my son. This seems to be a gap in provision.
3	Perhaps more after school provision in the area we live in.
4	There needs to be a Buzz Group for older children in Northwich.
5	Training for Dentists and receptionists. Support to get a diagnosis without going private! Better transition process within school and Job centre plus/colleges. Carers support I currently get nothing - no help at all.
6	Holiday cover for parents. Carers' breaks and support. Diagnosis - although my daughter now has a diagnosis, I did have to pay privately for her to be seen. It is a lot of money for someone on a low income but it has made all the difference.
7	Teenage wards - At present at Countess of Chester Hospital, once a young person hits 14 they are classed as an adult Therefore, being admitted to an adult ward. Does this not present Safeguarding issues? No parental supervision! This was my experience in day care unit!
8	Dental services for people with learning disabilities - hit and miss. Not great (same for dementia patients!) LD people do not really get the same health care normal people do because of reluctance of health professionals to pursue best way - may be sedating or knocking out. LD health checks are a joke! Some get them - a lot don't.
9	Support for children with complex needs to access local clubs. The need for 1-1 support is often a barrier to attending clubs. As a parent is needed to go along to support (which defeats the point of parent/carer getting respite)
10	Holistic approach not used.
11	Dentistry is not very well equipped it appears for wheelchair users who need hoisting/transferring. We go to one in Guilden Sutton which has very good facilities but does not have hoisting equipment. I believe that you must go to a hospital if you need hoisting.
12	Medical need support/advice.
13	There are no services **at all** in this area for high functioning autistic kids! These young people have so much to offer. They are so intelligent and are educated in mainstream schooling, yet they need great help to socialise with their peers. There are absolutely no courses or groups to teach social skills for these children - it is all down to the parents to teach. Not all parents have the skill/aptitude/knowledge/time to do this - where is the parent training for this in any case? The only groups I have found are run by ChAPS charity, and training for parents via ProACT, NAS etc. My Aspergers son was excluded from a holiday club recently, due to a typical

	frustration incident. What do I now do in the holidays? He is very mild in his autism, most people are not aware of it. He seems sensitive and immature, but "normal". He simply does not fit into the offering of "disabled" care/short breaks groups, but also cannot always withstand mainstream provision. How do I work during school holidays? I cannot get higher rate DLA for him. I also have a child with ADHD, yet again zero provision. No support groups, no parent training, no specialist childcare or holiday clubs, no therapy for my child who again is educated in mainstream schooling. If my children had medical conditions it would all be provided for. At present we have no provision of any kind from the health or social services -we are totally on our own. What happens when my boys become adolescents; when they have social issues and frustrations; when I hope they don't get into trouble and end up in borstal/juvenile prison etc. then the state will be paying out for them. Please provide funding now for support, so it is not needed later. We are a middle class family, with above average salary. We therefore, fall outside of the social services net, which I can understand. However, there should be services available to us at least (specialist babysitting, holiday clubs, social training courses and social clubs) which we can at least access and pay for - if necessary. I regularly drive a one hour round trip to get to a ChAPS social club for my son and this means sitting in the pub with my youngest during that time as there is nowhere else to be - hardly ideal. We have travelled to Stockport from Tarporley to attend a trampolining session at Jump Space as nothing exists of that nature in this area, Nothing! We tried a local "inclusive" gymnastics club, for the two boys but were humiliated in front of all the parents by being thrown out when the boys started fighting together and tried to kick the teacher. Naturally the other parents (of neuro-typical kids) were horrified at my "violent" kids, not knowing anything of their conditions. How then do I keep my boys active and fit, if the only specialist active/sport groups are one hour away and are charity funded? Jump Space in Stockport is truly wonderful, but is 50 minutes drive each way and about £100 per block of sessions. This should be available in Cheshire West.
14	I can't stress enough about the lack of after care for families after being diagnosed. May be some kind of hub you could be referred to where a package could be made up to help with whatever the child's needs are as not everyone requires a social worker.
15	Autism specific services.
16	Buddy support is a huge gap which isn't properly filled by the Charity sector. I asked for a buddy months ago to support my teenage son to attend a gym (paid for through Direct Payments) which is essential for his health. No one has got back to me despite several enquiries. The buddy he had previously for a short time was unreliable. Also my son was supported with CWAC to commence the 'Travel Training' programme but the person allocated was employed on a zero hours contract and when other more lucrative work was offered he continually let my son down and then gave up. A request for another worker was made in Sept 2013 - I am still waiting, This puts extra strain on families as we have to make time to support our son and can't always do this!

17	Yes. There are not many services for those with disabilities in rural areas. My son travels 1.5 hours each way to the nearest school with the provision for his needs. He stays over for two nights a week which is great, but in September because of funding this is being cut to one night a week. There is no provision for social activities i.e. youth clubs for those with special needs. Malpas has a dedicated Young Persons Centre, but I was told my son could not attend! There is no support for carers as well as those with disabilities. It is easy to feel isolated and lonely.
18	Benefits and finances are complicated and confusing especially around the age of transition. DIAL House have been very helpful but they do not have a service or worker which focuses on young people.
19	When a child says I am always anxious and feel I can't cope and I need help it is not acceptable for the help to not be available for eight months.
20	Proper joined-up care for autistic people, both at the diagnostic stage and post-diagnosis for example, an autism clinic, like there are diabetic, ophthalmology, audiology, etc clinics.
21	Quick access mental health services - the process takes far too long when a child is mentally distressed. Shouldn't need to reach crisis point.
22	Not so much gaps but difficult transitions. The last year has been spent going back to the GP to get new referrals because my son has turned 16 and needs adult services. (OT and Physio).
23	Yes transition from children's to adult's
24	There is no 'provision' for someone like my son (Asperger Syndrome)
25	My Mum told me that Northwich and Winsford have lots more young people with disabilities than other parts of Cheshire, but they get less money. Why? The council are supposed to provide short breaks, but they provide about three days a year for about eight kids!
26	Yes, my daughter aged seven would love to go to community clubs or sport events or anything which will support her to be more involved and confident in the community. It’s very hard to settle a child with Autism and have taken her to several activities but for sensory reasons she has become distressed and not been able to carry on.
27	Getting any provision at Christmas is very difficult especially considering that not all families have access to support at this difficult time of the year. Some support over the festive break would be greatly appreciated. Groups of support for more able 'disabled' children e.g. Aspergers as they have their own needs but do not readily identify themselves with the more obviously 'differently labelled' children/young people. Summer clubs for the above group would be especially useful especially those in secondary school who no longer have access to 'holiday club' provision due to their age. They do not get offered or would not attend the more traditional clubs such as 'LIVE'. They still need encouragement to participate and to socialise appropriately.

Q4 Have you got any ideas for new and improved services?

Responses

1	More groups and clubs.
2	I would like a regular speech and language therapist to visit regularly. This would assist greatly when he starts school as my son is not talking properly.
3	I would like to see more activity groups for young adults of his age and maybe after school activities run by the school or near the area in which we live - as we live in Chester and he goes to school in Hartford.
4	More holiday provision - sports - social clubs to allow parents to work.
5	Social skills groups for young adults with Autism and LD, she can attend LIVE but this is all for her age. Awareness training Carers support and information.
6	Carers assessments - more information of what is out there for children with Autism especially during the school holidays as there is no consistency during this period.
7	Communication - improve it! Look at teenage provision – Honestly! Continuity of care?
8	Health professionals need more training to deal with LD, Autism (and dementia falls into same bracket). LD Health Team at Eastway doesn't seem to work with GP Health teams - they have their own practice nurses who don't seem to be trained with LD and Autism. Countess - still hit and miss experiences there by people with LD, and autism. I think LD patients with ongoing health problems are poorly served. Continence is a major area of concern - 4 pads a day only for adults! and carers told to re-use damp pads or smeared pads. It is degrading.
9	Need to allocate families or advocate leader (to help families to access services, to bring together key professionals and support the family in getting their child's needs met). Unfortunately social workers are a rare breed now and this should be their role but in reality they don't have the time to give to families in this way. My experience of social workers is to only intervene when I am on my knees! They will then do a new assessment to go to panel to get extra funding from the panel. Unfortunately the panel do not get to see the families or meet the children, and the offer is always the minimum, which is never enough. This means families have to appeal and go back to the panel. The extra stress has a huge impact on families who can be under so much stress already and they tire of having to constantly fight for the support they need. My Social Worker told me he could not ask for all I wanted as he knew it would get knocked back. So the drip, drip approach was best. I find this disheartening. I apply for help with support because I need it. To give me half of what I ask for means I am still not getting the help I need e.g. I ask for extra night time support but get offered half of what I want. Who thinks it is fair and right for me to not sleep for half a week and still be able to function?

10	Doctors’ surgery has no hoisting facilities. Maybe it is worth considering a mobile hoist with the patient bringing in their own sling.
11	To be able to access some services without a social worker. For example, my daughter has a diagnosis of Autism but is very active, we don't need a social worker, but there are still things we could access. A hub centre (similar to like a careers advice centre), may be have a centre at hospitals or clinics where children are diagnosed and then families could go and collect all the information they need and maybe request if they need an assessment for at home as some people will struggle on at home until they reach crisis point!
12	Consistency and reliability are very important factors in our lives particularly for a young person with autism. All information relevant to them should be shared amongst all agencies. I should be offered advice without having to ask about documentation which I believe is available to give an overview of all information about my son so I can produce something to clearly give his condition/needs in new situations. Parents are left to find things out for themselves – in the past a FSW would have probably helped with this. I constantly have to duplicate information about my son.
13	A support group for those living with disability or learning difficulties. Services that occasionally come to us rather than having the expense of going to Chester to access services. For example, support group or Youth Services.
14	I think having someone that could have told me what was available after my son was diagnosed would have been really helpful. Like a central database.
15	There should be more opportunities for supported volunteering and work experience placements.
16	Transition from child to adult services needs work. Wouldn't it be possible to have a brief description of my son's difficulties on his NHS records so we don't have to explain them each time we attend an appointment?
17	Fund the good ones that exist before they close. Set up a learning difficulties adult football team in Northwich or Winsford, for people who are fit but have learning difficulties. The day service league doesn't help when you're at college during the day. Train staff in autism at hospitals, and have parking spaces that can be booked for people with learning difficulties.
18	Setting up a dedicated transition team.
19	An Autism specialist clinic. There is a lot of current research that indicates that autism is in fact not just a mind disorder but a whole body disorder. In a recent guide for healthcare professionals prepared by Treating Autism it is stated that “Autism is increasingly being recognised as a whole body disorder, with the core deficits in communication, social interaction, restrictive and stereotypic behaviours being surface manifestations of a systemic and complex disease process. Immune dysregulation appears to be a key feature.” There needs to be a service that takes this into account so that people with ASD and their carers/parents are not left traipsing around lots of different clinics and getting conflicting advice, treatment and

	information. The LSE recently calculated that autism costs the UK more than the combined cost of heart disease, stroke and cancer. Surely this fact alone should mean that Autism provision /healthcare/ treatment needs to be urgently regarded as a priority.
20	A specialist social worker trained in high functioning autism. A service of some kind which visits him at home, builds trust and a relationship. A totally integrated approach which takes his physical health difficulties seriously. A specialist therapist trained in CBT for adults with Aspergers. Personally I think this is all 'pie in the sky'. I have come to terms with the fact that there are simply no services out there that could meet his needs - especially in the current economic climate. I have had ongoing correspondence with Norman Lamb's department about the Care Bill: the idea sounds good but in reality it is unworkable for people like my son. The numerous so called 'consultations' don't seem to move anything forward or filter down to the 'clients' / 'service users'/actual living people with personalities This is the last one will be taking part in. After years of 'discussion' I am now totally cynical! (as you may have gathered)
21	Any activities which Cheshire East currently have, which could be implemented in Northwich would be brilliant.

Appendix 3

Healthwatch Activity including specific feedback on speech and language therapy (SALT).

Healthwatch are gathering evidence from parents, carers and young people about gaps in service provision for children and young people who have additional needs. They have a questionnaire which can be accessed via www.healthwatch.org.uk They attended the parent carer forum to find out the views of the group. They wanted to know what works and what isn't working. The feedback from the group is below. Also attending the group was a commissioner from Cheshire West and Chester who wanted to find out specifically about speech and language services. The first section below includes the specific information relating to speech and language but is also included in the information to be provided to Healthwatch.

Speech and Language

Q1 - What works well at present and why?

- SALT sessions currently work
- Good teacher for deaf and SALT
- Good Special Educational Needs co-ordinator (SENCo) and very good SALT despite a heavy workload
- SALT in school/parents/SENCO phone call/advice
- Child Development Service (CDS)/Physio/SALT/occupational Therapist (OT) Early Support for children and families
- Leaflets for SALT
- School proactive in referring to SALT
- SALT –they listened to me and was very sensible (general views on table)
- SALT-good support during statementing process
- SALT assessments process

Q2 - What doesn't work well and why?

- Consistent support for Speech and language communication
- Risking cutting SALT and trying to reduce sessions despite evidence of SALT ongoing and requirements of sessions currently allocated
- SALT closed case -difficult to reopen despite diagnosis
- Reduction in SALT
- SALT -letters are difficult to understand-need guidance notes. Letters aren't dated and no signature
- SALT -very long waiting times-parents advised to go private
- Long waiting lists in general e.g. SALT, CAMHS, Physiotherapy
- Hard to get back into system once diagnosed
- Follow up support after SALT assessment
- No consistent approach in SALT. Appears to be a high turnover of therapists
- SALT stops at 16. Start all over again and physiotherapy and CAMHS

Q3 - Are there any gaps in provision?

- Speech and language provision for help with understanding of language
- Speech and language 16+ years
- NHS-Education parents-SALT training-school and home
- SALT mapping
- Specialist feeding clinic to include a dietician, SALT sensory expert
- Overview on transition services between nursery and school and over 16 years so that parents aren’t telling their story over and over.

Appendix 4

Workshop - Children and Young People's Project

26th February 2015

All Saints Church Chester

26 people attended

Q1 - What works well at present and why?

- Fallen Angels: Recovery Dance Group
- CCIL: A range of services for disabled C&YP and Adults
- Buzz Group: A service for disabled young people and families
- Local children's centre supported young carer
- Team around the family (TAF). Sharing information once with all relevant parties involved.
- Community care teams work well
- Personal Health Budgets and Direct Payments
- Short Breaks
- Travelling community meeting with health and engaging with service users.
- The parent forum
- CAMHS have realistic expectations on how we manage the decisions the parents of children have to make.
- There is an openness to alternative strategies
- Buddying scheme
- Finding balance between independence and direct support

Q2 - What doesn't work well at present and why?

- Limited/lack of support for siblings
- Lack of knowledge about services available
- Lack of knowledge about services available particularly for carers
- No statutory support for people in recovery - parents/carers
- Transition / Signposting from services to services
- Cannot get support from service centres unless signed up
- Time gap between asking for support and receiving support
- Lack of contact after asking for support / service
- Follow up service is a big gap (slow response)
- Not enough training for parents, children and carers
- Lack of peer monitoring services.
- Lack of attendance at TAF meetings
- CAMHS too long to set up
- Services under pressure
- Lack of responsibility from coordinating TAF meetings
- Lack of training across the board (GP's Service User Groups)
- Poor communication with travelling community
- MDT meetings: Families find it overwhelming (transition to adulthood)
- Lack of consistency with social workers

- GPs not linking parent/carer to the child
- Support for parents and family carers
- Autism team do not follow through
- Needs more independent support
- Almost stigmatised
- Potential loss of funding (Greenbank)
- Lack of information about direct payments
- Complicated to access direct payments/personal budgets set up if alone and looking after a disable child and other children.

Q3 - Are there any gaps in provision?

- Education/ Health & Social Care plans are not joined up.
- Education/ Health & Social Care plans take too long to process
- Education/ Health & Social Care plans are up to age 25 – social services cut of at age 18.
- Support for parents regarding training
- Access for schools for educating psychologists
- Accessible transport
- Money
- Include Autism team in general assessment
- Transition gap (young person into adult services)
- Young people at the end of education drop off the radar
- Social housing gap (services stopped)
- Agencies fighting against each other
- Service user should be at the heart of the services
- Scaffolding removed (too quickly) when leaving somewhere like Greenbank
- Lack of interagency working
- Lack of intergenerational working
- Services for extended family
- Peer mentoring groups
- Transition of information
- No support for transition at all ages
- Lack of preparation for adulthood (more than in the past but still not enough)
- Money from the young to fund older people
- Independent advocacy – public awareness of services.

Q4 - Have you got any ideas for new and improved services?

- Local services to meet the needs of service user groups
- More support for charitable organisations
- Peer mentoring for families
- Educating families
- Standardise training pathways bespoke to service users
- Reduce the amount of time it takes to make decisions
- Person centred approach
- Transition service for work

- Support from multi-agencies – communication needs to work (The Manchester Model)
- Working together – joined up service
- Need for a good robust and flexible transition plan
- Training for employers of potential employers
- Skills for life training
- Link into employment (Apprenticeships / NVQs)
- Alternative provision – increase respite
- Increase training for GPs to understand parents and children
- Local offer/generational working
- One opportunity to tell your story – access
- Interlinked IT service
- Ensure current services are working and stay working well
- Flexibility - Extend C&YP to 25 to reflect new legislation
- Interagency training opportunities for professionals.

Appendix 5

The Buzz youth Activity Group was commissioned by Healthwatch Cheshire West to plan and deliver a consultation event with disabled young people aged 5-19 years. The aim of the consultation was to ensure that disabled young people are given a voice about local services they access across the Cheshire West Local Authority area.

Buzz Youth Activity Group Consultation report	
Consultation on behalf of Healthwatch	
Date	14th April 2015
Venue	St Michaels Church Hall, Devon Road, Kingsway
Objective	To consult with disabled young people to ascertain • What is working well for them • What is not working well for them.
Delivery Mode	The consultation was delivered in 2 x 2 hour activity sessions. Members aged 5-11 years participated via an art project and 1-1 discussion with the staff and volunteer team. Members aged 12-19 years participated via an art project, a film project and 1-1 discussion with the staff and volunteer team. The Buzz Youth Activity group staff and volunteer team supported each young person to participate in their chosen format and collected feedback in the following ways: • Written • Artwork • Films.
Results	The following is a summary of the comments made by the young people when taking part in the consultation. The quotes used in each category where noted by the staff team at the point of discussion and recorded to ensure accuracy for reporting. **What is working well?** Feedback from the participants was varied and was predominantly about their leisure time outside of the school environment: • **Buzz Group**: it's a fun place to be, everyone helps me we get to choose things we want to do Mum doesn't have to come with me, I meet all my friends there. • **School (Primary)** : *I have friends at school and the teachers help when I need it*

	• **Activate Arts**: *I go every week and its fun* • **Live** : *I go in school holidays and we do lots of fun activities with my friends from school* • **Swimming (Making Waves, Chester University)** : *I go every Saturday and Mum does not have to get in the water with me* • **Taekwondo** : *I go every week and its fun* • **Scouts** : *I go with my Mum and she helps me do everything* • **The Zoo** : *I have a membership and can do whenever I want and Mum doesn't have to pay* • **Going out with friends but no parents** : *I do this with a buddy and sometimes with the Buzz Group, I like going out without my mum and dad* • **Dance Club** : *its great* • **Football** : *I go to a proper group and do all the training* • **Choosing things I like** : *I like to say what I want to do and not be told what I have to do, I like to choose where I go and if I go with friends I like to choose where we are going. Most of the time I get told what I am going to do especially at school and I don't like this. I don't like going out to places I don't want to go.* • **Special Olympics :** *I go every Saturday, there are lots of different sports I can do, it's really good and I do football* **What does not work?** • **School (mainstream)** ; *I don't like it, I get into trouble and it's not my fault, I get sent home when I don't want to go, there is no one there that likes me and gets me* • **Transport to get to places** : *If Mum or Dad can't take me I can't get anywhere, I can't get the bus as it does not stop near my house and when I got the bus the driver said I couldn't go on my own, I can if I want but he said no* *I would like to go out with friends on the bus like my sister but I can't do that which is shame* • **No one to help at school**: A number of young people stated that they do not have anyone at school who they can ask for help or they don't know who to go to and ask for help. The young people attended a mix of mainstream and SEN schools. • **No one to help at group** : *I can't go as no one can help me when I need it, my Mum said that they couldn't help me with my medicine so I can't go.* A parent advised that their young person is often excluded from community groups because the staff don't understand their behaviour • **Don't know where to go :** *I don't know any other club that's like the Buzz, how do I know where they are? I asked Dad but he doesn't know.* • **Nothing after 19 No reply to letters:** Mum is waiting for a

	reply to a letter from the Council but she isn't getting one and its really bad: we don't know what to do when I am 19, it is not fair that we don't get any reply, I think it is rude. - **Being told what to do by adults:** I don't like it when people tell me what to do and what I like. Sometimes people tell me what to do and they don't even know if I like it or not, thats just not very nice, sometimes I feel like shouting but I don't. (young person said this happened in school and when they go to meetings about the future) - **Bulling at school:** I got really upset and had no friends because I was bullied, no one did anything at the school so my mum told me to go to Buzz so I went and I made new friends. I was really upset about the bullies because they did it on my phone and when I went to school, they are horrible people.
Reported completed by	Melanie Hinde, Community Engagement Team Manager, Cheshire Centre for independent living. (CCIL)
Date	20th April 2014

Glossary of Terms and Abbreviations

A&E	Accident and Emergency
ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autistic Spectrum Disorder
BSL	British Sign Language
CBT	Cognitive Behavioural Therapy
CCG	Clinical Commissioning Group
CCIL	Cheshire Centre For Independent Living
CAMHS	Children and Adults Mental Health Service
CDC	Council for Disabled Children
ChAPS	Cheshire Autism Practical Support
CQC	Care Quality Commission
DART	Disabled Access Resource Team
DLA	Disabled Living Allowance
ESA	Employment Support Allowance
ESAT	Early Support Access Team
FSW	Family Support Worker
GP	General Practitioner (Doctor)
IEP	Individual Education Plan
IAS	Information, Advice and Support
IT	Information Technology
LD	Learning Development
LIVE	New Scene Youth Club Chester
LSE	London School of Economics
MDT	Multi-Disciplinary Team
NAS	National Autistic Society
ODD	Oppositional Defiant Disorder
OT	Occupational Therapy
P	Physiotherapy
PDA	Pathological Demand Avoidance
S&L	Speech and Language
SALT	Speech and Language Therapy
SEN	Special Educational Need
SENCO	Special Educational Need(s) Co-ordinator
TA	Teaching Assistant
TAF	Team Around Family
YP	Young Person/Young People