



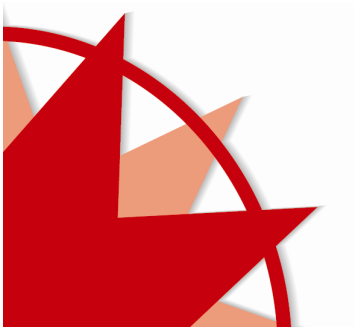
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Children with Disabilities Review

Gateshead Children and Young People's Partnership

Report by SOLACE Enterprises
January 2009



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1. Introduction

This report contains the main conclusions and recommendations of the Children with Disabilities Review. The review was commissioned by the Gateshead Children and Young People's Partnership. The Review brief is attached at Appendix A for reference.

The summary of the Review recommendations is set out in Section 2 below.

1.1 Review Methodology

The scope of the review was designed to focus primarily on services for children with more complex disabilities. The review has gone beyond this scope when it has been necessary to include the role of universal services in responding to children with complex needs.

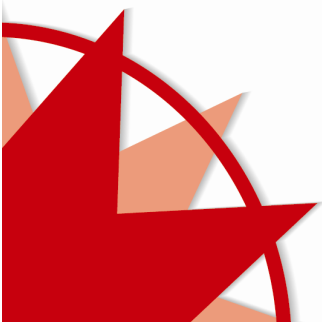
The methodology underpinning the review involved:

- Desk top research of information provided by Gateshead CST, national policy, national and regional research incorporating some models of good practice;
- Questionnaires sent to all providers of services for disabled children with complex needs;
- 26 Semi-structured interviews with key stakeholders and managers across core services provided by health, education, social care, and the voluntary sector;
- Workshop attended by managers from health, education, social care, and Gateshead Barnardos Resource Centre;
- Meeting with the Children with Disabilities Managers' Group.

To further support the evaluation of services, originally it was planned to look at some case studies as this facilitates an insight into the translation of policy and standards into practice and outcomes. However, within the elapsed time of the project the CST concluded that this would not be feasible.

The decision was made by CST that all financial data was not to be included in the review in view of the time scale and difficulties in obtaining the information. This resulted in the systematic breakdown of funding streams not being available. Performance data is only related to referrals, waiting lists, and caseloads. The review has therefore not sought to assess the cost effectiveness of the different services or to evaluate specific outcomes.

Feedback from children and parents has been obtained through a number of sources including the Short Break Report produced by Barnardos, the Review of Provision for Young People with Autistic Spectrum Disorder and the SEN review consultation.



2. Schedule of Recommendations

We set out below a schedule of the recommendations contained in Section 7 of the report.

2.1 Strategic Direction

- The Partnership now needs to take ownership of the inclusion and transformational agenda for all disabled children, (including SEN and children with life limiting conditions) through the development of its overarching strategy, priorities and spend capacity.
- It is essential that an integrated management structure is developed. This should include a nominated champion to take the overall lead for services for all disabled children (SEN, disabled children and children with life limiting conditions) and have accountability for reporting to the Partnership on Gateshead's total capacity to achieve its vision and priorities, its overall performance and how this is improving outcomes for disabled children.
- A commissioning strategy for Children with disabilities needs to be informed by this strategic direction and resource allocation, underpinned by this needs analysis, resource analysis and stakeholder consultation, of which this review is a part.

2.2 Inclusion Agenda

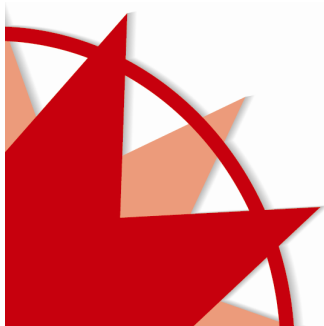
- It is recommended that the inclusion model for the provision of services is based on Model A.
- To develop self-directed care as appropriate according to the specific needs of the disabled child.

2.2.1 Workforce development

- Review how specialist staff may support staff in mainstream settings to gain the skills required to improve access for children with disability to mainstream services
- Conduct an audit of all staff that have received specialist training in communication skills to assess the frequency and effectiveness in the utilisation of their skills.

2.2.2 Financial Considerations

- It is recommended that further work is undertaken to estimate the financial implications for the model of inclusion to be translated into operational reality. The option of developing an integrated shared budget approach should be considered with funds being assigned from individual partners into a single budget.



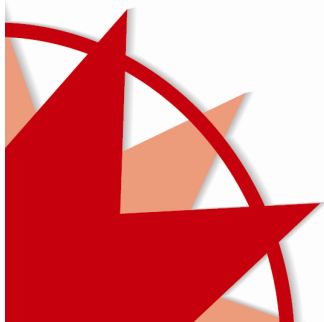
2.3 Integration across the Children and Young People's Partnership

It is recommended that

- Gateshead Children and Young People's Partnership to develop a new management structure that is more closely aligned to enabling and supporting integrated multi-disciplinary working and increasing the capacity to streamline resources and utilise them as flexibly as possible to achieve the best outcomes for children and their families. Examples of models are contained within the main body of the report.
- The Children and Young People's Partnership should consider developing an integrated team joining the SEN support staff, the Disabled Children's social work service and the educational psychology services together under one senior manager.
- The PCT should ensure that comprehensive service specifications are in place for all commissioned services. These specifications should include clear and robust outcome and performance measures in line with national policy and guidance. The annual child health mapping should be used to identify the total resource allocation for PCT commissioned services.
- The PCT should utilise World Class Commissioning competencies as a key driver in delivering locally driven services with a focus on improving quality, effectiveness and efficiency of care. By utilising these competencies and the strengthening of joint commissioning through local Children's Trust arrangements services will be more closely matched to local need, resulting in better quality of care, improved health and well being and a reduction in health inequalities across the local community.
- Consideration to be given to how various teams work together to provide integrated assessment, diagnosis, and seamless services to disabled children and their families
- A Mapping exercise is undertaken by managers:
 - Mapping the number, purpose and outcomes of meetings with a view to streamlining them as far as possible; (There is a considerable investment of staff time in meetings – management should determine how this can be streamlined and reduced)
 - Mapping the actual range of resources, including staff who have been specifically trained to support community nursing, speech and language etc.
 - Mapping the effectiveness of the resources to improve outcomes for disabled children
 - Mapping disabled children so that the population of children for whom Gateshead Children and Young People's Partnership is providing services is better understood.

2.4 Integrated Service Offer

It is recommended that consideration is given to an integrated service offer which reflects the core offer from Aiming High for disabled Children and takes account of the following:



- An overview of all disabled children with severe and complex disabilities is maintained, including the further development of the statutory register for disabled children.
- Developing joined up assessments and co-ordinated packages of care and support
- Through effective tracking of disabled children ensure that at key transition or developmental stages there is appropriate planning and preparation in place for all children with complex disabilities, including children with life limiting conditions;
- Ensure transparency and access to information for disabled children and their families
- Using additional short breaks funding to develop personalised models of short break support
- Provide emotional and practical support to families immediately following diagnosis

Gateshead Children and Young People's Partnership should also consider bringing together the Disabled Children's Team with SEN support staff, and the educational psychology service.

2.5 Joint Commissioning and Planning

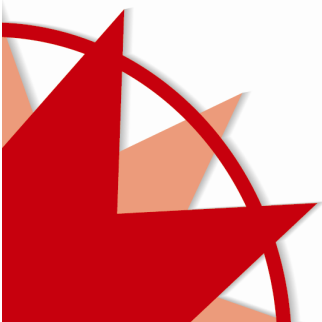
- Continue to review data collection systems to improve the provision of a properly analysed assessment of need, gap analysis and costed services to support commissioning processes.
- It is essential that the collection of data is improved to ensure that there is a common set of information at both individual case level and in collecting statistics to assist management planning and assessing the effectiveness of the services provided and the outcomes for disabled children.
- As part of the commissioning strategy to identify a range of providers that can offer support and services to children with disabilities.

2.6 Promoting the Children with Disabilities Register

- It is essential the resources are identified to proactively manage the statutory register
- It is important to discuss and agree with families the value of the register and the incentives that are most likely to encourage families to register their disabled child

2.7 Information and Communication

- Developing a communication strategy to ensure parents are informed about the range of services available.
- Need to progress a Gateshead Charter for Disabled Children and their Families to improve transparency and equity in line with the core offer in Aiming High for Disabled Children.
- Need to develop the core pathway so that the pathway is streamlined, and understandable to both professionals and families.



2.8 Early Support Services

- Develop a coherent strategy for the provision of childcare and nursery placements for children with SEN, disabled children and children with life limiting conditions.
- Undertake a review of the community nursing service with a view to developing a 24/7 service model.
- Review the future role of the Barnardos Gateshead Family Resource centre.

2.9 Short Breaks

- It is recommended that the short breaks pathfinder be incorporated into the overall strategic direction in order to achieve transformational change for disabled children.
- Using additional funding from the short break pathfinder to develop personalised packages of support to disabled children and their families

2.10 Transition

- It is recommended that a review of transition arrangements be undertaken including consideration of where teams are sited.

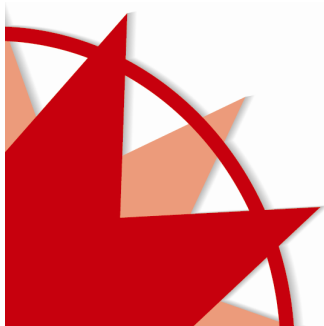
2.11 Expanding the hours of service delivery

- It is recommended that access and availability of services is reviewed to ensure that services meet the needs of families.

2.12 Children with ASD

That Gateshead Children and Young People's Partnership should:

- Continue to re-model the care pathway to ensure timely interventions.
- Develop services to enable autistic children with higher functioning intellect levels gain improved access to specialist services and mainstream services



3. National Context

3.1 Government Agenda

The government is strongly committed to making a difference in the lives of the 770,000 disabled children and young people and their families living in England. Currently, increasing numbers of premature babies are surviving birth and early childhood and moving into school with, in some cases, high levels of multiple disabilities. This presents a real challenge to central and local government, specialist resources in education health and social care as well as families and communities. The government's agenda for change, new initiatives and re-organisation which have characterised the last five years, show little sign of abating with the programme of work underpinning Aiming High for Disabled Children Agenda, the establishment of the Lamb Inquiry, the new 14-25 Learners with Learning Difficulties and Disabilities (LDD) agenda, the Bercow Report – A Review of services for Children and Young People (0 – 19) with Speech and Communication Needs, and the current consultation around the proposals for continuing care for children and child health strategy.

3.2 Aiming High for Disabled Children

Aiming High for Disabled Children is an important Government driver for transformational change to improve outcomes for disabled children. Three key priority areas are:

Access and Empowerment

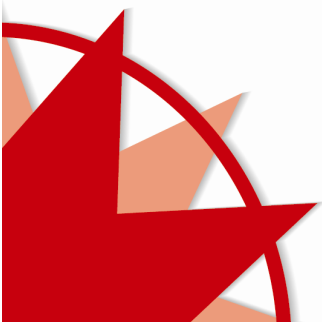
- Improved provision of information and greater transparency in decision making;
- Putting families in control of the design and delivery of their care package;
- Supporting disabled children and young people and their parents to shape services.

Responsive services and timely support

- How to develop a better understanding of the disabled children population to help with more efficient planning, commissioning and provision of services;
- The role of the new performance management framework;
- Incentives to provide support and interventions early in a child's life or at key transition stages, including better evidence on which early interventions are most effective;
- Joined up assessments and co-ordinated packages of care, with planning around the child and family;
- Support to ensure a smooth transition to adulthood.

Improving Service quality and capacity

- Short breaks to support disabled children and families;



- Child care provision to facilitate parental employment, reduce family stress and increase a child's social, emotional, and educational development;
- Provision of appropriate equipment and wheelchairs to maximise mobility or communication;
- Specialists to respond proactively to the diverse and differentiated needs of the disabled child to enable them to maximise their opportunities and abilities;
- Training of staff in universal services to improve their knowledge and understanding to help make universal services more accessible for disabled children and their families.

3.3 Childhood Disability is changing

There is now very clear evidence of the changing nature of childhood disability. This creates a major challenge for local authorities, services and schools. The report of the Prime Minister's Strategy Unit ('Improving the life chances of disabled people, 2005') noted that disabled children form the fastest growing group of disabled people (a 62% increase from 1975). The number of children with complex health conditions has similarly increased, largely due to improvements in health care and, in particular, neo natal care. There is a similar increase in the complexity of need of many children with sensory impairment. Philippa Russell, Disability Rights Commissioner wrote in an SEN Policy Options Paper (January 2006) 'that in effect there are not only more children with very complex needs within the 'system', there are also clear messages about the importance of:

- Better identification and early identification;
- Access to appropriate specialist advice and support across all children's services;
- Recognition that the number of children with low incidence disability or SEN is increasing with corresponding pressure on expensive out of area services unless mainstream and local capacity is enhanced.'

3.4 Audit Commission

The Audit Commission's report on "Out of Authority Placements for Special Educational Needs (2007)" strongly recommends that councils and their partners, including Health Trusts should:

- Review the way they manage delivery of services to children with complex needs, to integrate strategic planning, budget planning, commissioning and the management and monitoring of services better;
- Take a more strategic approach to the joint commissioning of support for pupils with complex needs to take account of the current short comings in respite care, therapies and mental health support identified in this study and others.

3.5 National Service Standards 6 and 8

The National Service Standards 6 and 8 also underpin the transformational agenda to improve outcomes for disabled children and young people and those who are ill and

have complex health needs. They set out the standards to be achieved by Children Trusts.

Standard 6: Children and Young People who are ill

All children and young people who are ill, or thought to be ill or injured will have timely access to appropriate advice and to effective services which address their health, social, educational and emotional needs throughout the period of their illness.

Standard 8: Disabled Children and Young People and Those with Complex Health Needs

Children and young people who are disabled or who have complex health needs receive co-ordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion, and where possible enable them and their families to live ordinary lives.



4. Local Context

Gateshead Children and Young People's Partnership has already made significant progress towards this transformational change. This review is designed to assist the Children and Young People's Partnership decide on its key actions to further its capacity to improve outcomes for disabled children. Gateshead is also a pathfinder authority for short-breaks, which has brought additional resources to support its programme of transformational change through the provision of innovative packages of support designed around the needs of the child and their family.

The disabilities review has taken place within the context of significant change throughout the Children and Young People's Partnership. This includes

- the restructuring of the PCT;
- the restructuring of social work services and area based teams as part of the Change for Children programme;
- the SEN review;
- the implementation of Aiming High for Disabled Children Short Break Pathfinder which has brought significant resources to the borough to develop short break services for disabled children and their families;
- linking with the implementation of the recommendations from the family support review which aimed to develop a clearer whole system approach to family support.

In Gateshead, as with many other parts of the country, as consideration is given to how services can be remodelled to increase flexibility for families, there is a need to stimulate new markets and to deal effectively with the many challenges this poses.

Within Gateshead it is perceived that there are five driving priorities to achieve the overall strategic vision for children with disabilities:

- Inclusion for all SEN and disabled children, including children with life limiting conditions;
- Integration and CAF processes including the Team Around the Family;
- Flexible and timely services responsive to the needs of the child and the family;
- Commissioning needs led quality services;
- Empowerment and Personalisation.

Gateshead Children and Young People's Partnership has an established reputation for being at the forefront of practice and for delivering quality services in response to the needs of children and their families. This is demonstrated by its selection for pathfinder status.

In line with Government policy to promote the equality of young people (as identified in Aiming High and Better Care: Better Lives and the wishes of young people and their parent(s)/carer(s) articulated through local consultation, such as the SEN Consultation), the partnership has embarked on an Inclusion Strategy so that disabled children and young people have access to mainstream services. These are additionally resourced by specialist and targeted services as and when required to meet the needs

of SEN and disabled children with severe and complex disabilities, including life limiting conditions.

The Partnership is committed to supporting integrated working and early interventions with care and specialist support packages designed around the needs of the child in consultation with the child and their family. Front line services demonstrate a real commitment to integrated working. This is demonstrated through the increased use of the CAF and the Team around the Child/Family approach. Inclusion is a significant element within this work in line with government thinking.



5. Local Needs Analysis

5.1 Children with Disabilities Data Sources: The National Picture

In 2008 the Thomas Coram Research Unit reported after a national survey that:

'Due to the varying sources of data available to local authorities, the lack of a consistent definition of disability, and the different categorisations and interpretation of service provision, it is not possible at the current time to assess accurately the level of health and social care services provided for disabled children and their families, nor the variation in services between local authorities'.

The Thomas Coram Report made use of local information on Special Educational Need statement (SEN) numbers and the numbers of Disability Living Allowance (DLA) claims for children as proxy but accurate data on local prevalence were not made explicit.

5.2 Children with Disabilities Data Sources: The Local Picture

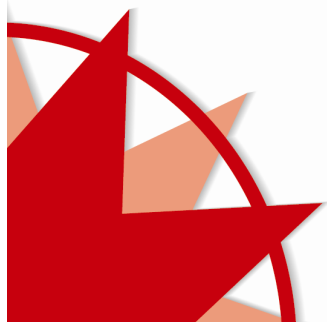
Supporting information from the Family Support Services Review found that in Gateshead, more than half of Gateshead's population of children and young people live in areas generally marked by economic deprivation. These areas contain wards with twice the borough's average rates of alcohol and drug misuse, domestic violence, and crime and disorder. Education and skill levels are low; depression, poor health and teenage pregnancy rates are high.

These areas do not necessarily have a monopoly on the problems and deprivations described here. There are other small, more geographically dispersed areas, with the same levels in some cases, and other areas that are not far behind the most noticeable concentrations.

In addition, general public consultations have consistently shown that public transport facilities are a problem in the West, for example, and that this may affect the ability to use the informal services that may be available. This is particularly pertinent for disabled children and their families who may experience significant difficulties in accessing public transport, which can increase their isolation. This has implications for the location and planning of services and building support packages around the needs of the child, including taking resources into the family home.

Overall the importance of this for Disability Services is that if more than half of Gateshead children live in deprived areas then it is likely that most children with disabilities will too. This is not a cause and effect relationship but a function of the concentration of numbers. The SEN review concluded this is particularly the case for children with high incident disabilities, such as dyslexia for example, but less so for children with more severe and complex disabilities.

It is difficult to be certain of the exact number of disabled children aged 0 – 19 within Gateshead, since it varies depending on the source of data.



- The Children's Disability Register, which is voluntary, indicates 759 (updated at 9th January 2009, after the detailed analysis presented in Fig. 2 was obtained).
- The Disability Living Allowance Claimants register numbers 2370.
- The 2008 school census shows a total of 5410 if all the children with School Action, School Action Plus and a Statement of SEN are totaled. When taking School Action Plus and Statement of SEN this suggests 1830 children with more severe and complex difficulties.

This range is not untypical nationally. Indeed, within the review, the picture in Gateshead mirrored the national difficulties evidenced in that there are no clearly defined and agreed definitions of disability. Consequently it does not provide sufficiently consistent and robust figures to enable a clear understanding of the number of disabled children being reached through the mainstream or specialist services. Notwithstanding this the review endeavours to provide a local picture based on the best sources of locally available information.

The report "Improving the Life Chances of Disabled People" noted that:

- *'1 in 20 of children aged under 16 have a disability'*. The Gateshead equivalent would be around 2,000 children aged 0-17. The DLA data shows 2,210 claimants in this band.
- *'29% of people with a disabled child in the house live in poverty'*. This seems to be borne out by the numbers in postcodes found in Gateshead deprived wards.

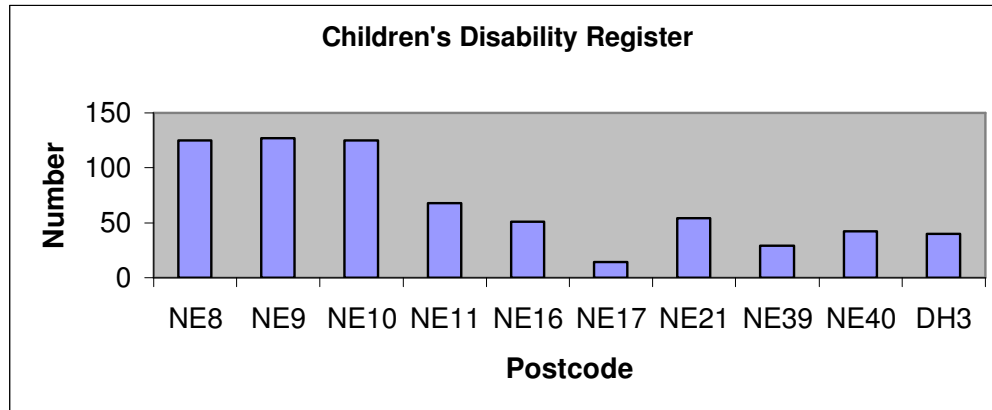
For the purposes of this review the local data sources accessed were the Gateshead Network of Children with disabilities database, the DASLne database, Special Educational Need data and DLA claimant figures.

The council's statutory register of disabled children, the 'Network of Children with Disabilities database', provides a snapshot of the needs and prevalence of families with disabled children. There are currently 759 children and young people aged 0-19 on the register (updated at 9th January 2009 after Fig. 2 below was produced). The regional database of children with Autistic Spectrum Disorder, DASLne, held by Newcastle University and registration is also voluntary. Based on a 53% response rate, this suggests there are about 144 high dependency children in the Borough. This is very different to the picture presented through SEN figures.

5.3 Gateshead Network of Children with Disabilities Register Database

The Children Act 1989 requires a local authority to maintain a Children's Disability register that records the number of children categorised as living with a disability in their area. It is a voluntary register that is completed by parents or carers and as such relies heavily upon the detail supplied by them and may lead to over representation of particular diagnosis depending on how proactive services are in referring families into the network (e.g. a large number of referrals are received from the ADHD clinic at the Child and Family unit). However, the data is still of value and the latest available statistics have been used.

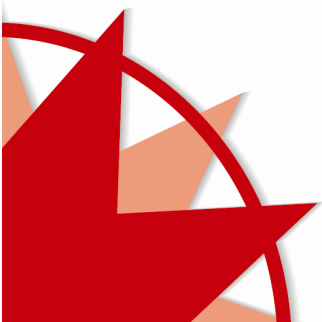
Fig 1.



The data from the register has been broken down further in the next 2 tables to identify the age range of each child within each Neighbourhood area.

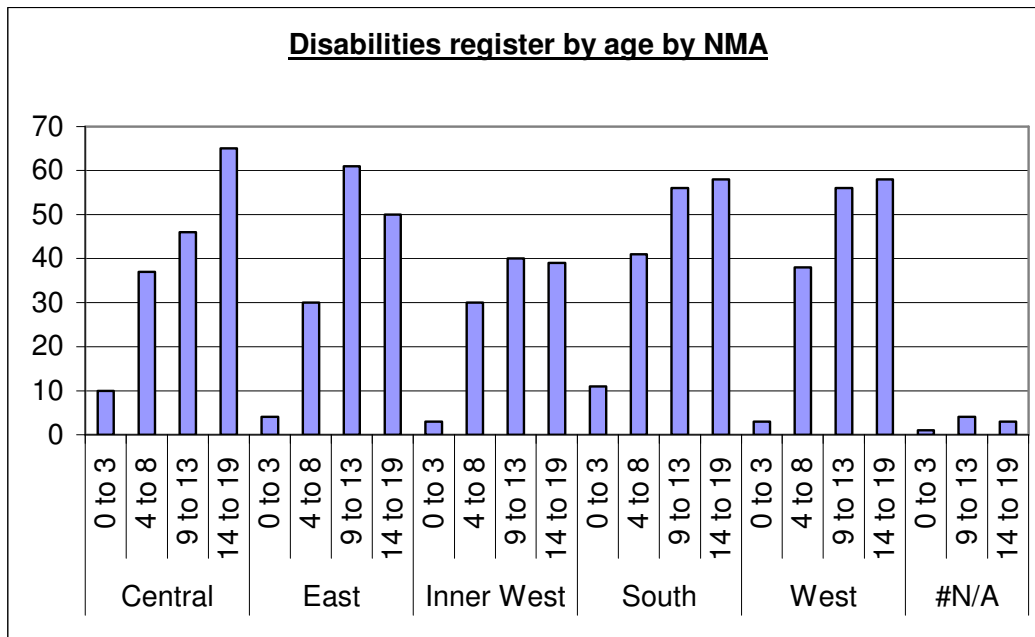
Fig 2.

NMA	Age Range	Total
Central	0 - 3	10
	4 - 8	37
	9 - 13	46
	14 - 19	65
Central total		158
East	0 - 3	4
	4 - 8	30
	9 - 13	61
	14 - 19	50
East total		145
Inner west	0 - 3	3
	4 - 8	30
	9 - 13	40
	14 - 19	39
Inner west total		112
South	0 - 3	11
	4 - 8	41
	9 - 13	56
	14 - 19	58
South Total		166
West	0 - 3	3
	4 - 8	38
	9 - 13	56
	14 - 19	58
West total		155
N/A	0 - 3	1



	9 - 13	4
	14 - 19	3
N/A Total		8
Grand total		744

Fig 3.



It is noticeable that, once the age groups are balanced for the two oldest groups to reflect the different number of years in each of the two groups (5 years in 9-13 and 6 years in 14-19), Central area is the only one of the five where the average number of registered disabled children of each age increases in the 14 - 19 age group (10.8) compared with the 9 - 13 group (9.2). This is at variance with decreasing numbers in the other areas. East shows a fall of 12.2 to 8.3 registered disabled children of each age, Inner West 8 to 6.5, South 11.2 to 9.7, and West 11.2 to 9.7. Without further investigation, it is unclear whether this indicates a different approach in Central or whether it is a statistical anomaly.

There are clearly some anomalies in the Disability register and as a voluntary database this is inevitable. The register as it stands provides a useful mechanism for families with disabled children to network and to access a leisure pass allowing free entrance to a number of leisure facilities. However in light of the low numbers registering in comparison to those numbers registering for DLA, Gateshead may wish to review how the register is used and promoted.

With the recent reorganisation of services to children and young people into area structures and increased co-terminosity with groups of schools, a greater understanding of neighbourhood profiles, including the characteristics of SEN and disabled children should be facilitated.

The data below has been broken down by diagnosis group, the largest of which by a wide margin is cognitive function - communication and behaviour, which includes children with a diagnosis of ASD or ADHD.

Fig 4.

Count of POSTCODE	
DIAGNOSIS GROUP NO	Total
1. Chromosomal abnormalities, syndromes etc	70
2. Cancers, tumours etc	5
3. Cognitive function, communication, behaviour (inc. ASD and ADHD)	395
4. Neurological (inc. cerebral palsy, muscular dystrophy, spina bifida, hydrocephalus etc)	109
5. Sensory (inc. visual and hearing impairments)	69
6. Gastrointestinal (inc. bowel abnormalities, faecal incontinence etc)	12
7. Renal tract (inc. urinary incontinence, neuropathic bladder etc)	4
8. Respiratory (inc. cystic fibrosis, chronic asthma etc)	22
9. Endocrine/Metabolic (inc. diabetes, thyroid disease etc)	14
10. Cardiovascular (inc. Congenital heart condition, acquired heart disease etc)	9
11. Muscular skeletal (inc. limb abnormalities, scoliosis etc)	32
12. No diagnosis	55
13. Other	2
Grand Total	798
NB Children may have more than one diagnosis	

5.4 Autistic Spectrum Disorder (ASD)

Nationally the number of children with Autistic Spectrum Disorders is increasing, and we see the same picture in Gateshead. In view of this, the review in section 7.12 has focused on drawing together some of the key implications for Gateshead. Some of the issues addressed in this analysis equally apply to other groups of disabled children, but the same level of depth of analysis is not feasible to report in the context of the scale of this review. The data from the register has been broken down further in the next table to identify the age range of each child with Autism within each Neighbourhood area.

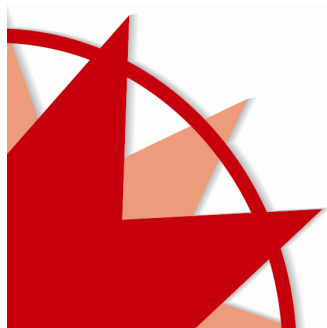
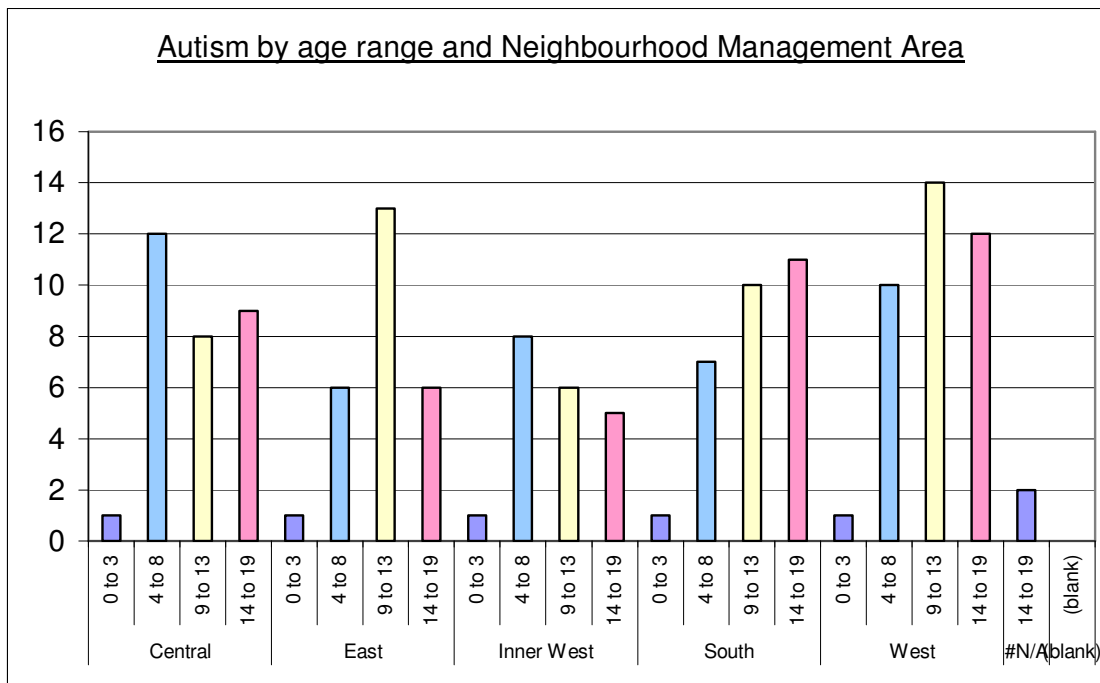


Fig 5.



5.5 DASL North East Regional ASD Register

DASLne is a regional database managed by Newcastle University. In an initial survey phase it has concentrated on contacting families of children aged up to 13 years (born after 31 Dec 1992), to maximise the consistency of identification of children with an Autistic Spectrum Disorder diagnosis. It is voluntary and so far in the region an average of 55% of families of children potentially identified have responded, so the data is currently incomplete. However, they are able to give an indication of minimum numbers of high-dependency children in each authority. The provisional lists are compiled by local coordinating groups from separate caseloads within health, education and social services, and continually updated with newly diagnosed children.

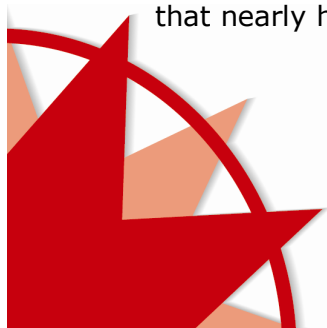
Fig 6.

DASLne as at 17th March 2008

Gateshead	Provisional List	Consents	Refusals	Percentage Response
	154	77	5	53%

5.6 Gateshead Disability Living Allowance Claimants

DLA is paid to claimants over 3 years and less than 65 years at several different levels according to the extent of need for help with personal care and/or mobility. As with most specialist benefits there is a suspected level of under claiming, and it is known that nearly half of the claims are disallowed, at least initially.



Nevertheless, given the financial incentive to claim the numbers doing so are likely to be a more accurate record of need than those on a voluntary database where little incentive to take part is offered. The Gateshead position on DLA claims is shown below.

Fig 7.

Gateshead Disability Living Allowance Claimants – May 2008

Condition	Under 5 yrs	5 – 10 yrs	11 – 15 yrs	16 – 17 yrs	18 – 24 yrs
Any disabling condition	130	380	430	160	420
Muscle/joint/bone disease	10	30	20	10	30
Blindness		10			10
Learning difficulty	50	110	110	40	140
Other mental health causes		60	110	40	90
Epilepsy		10	20	10	10
Deafness		10	10	10	20
Malignant disease		10		10	10
Chest disease	10	10			
Heart disease	10				
Diabetes mellitus		20	50	20	10
Skin disease		30	10		
Other disabling condition	30	90	80	20	70
Actual Totals	260	770	850	330	840

Notes – these are:

- 1) DLA categories: only the conditions for which there are Gateshead claimants have been included in this chart.
- 2) These are the main conditions where more than one is present.
- 3) Figures are rounded to the nearest 10, figures under 5 excluded from the chart but added to each total; therefore actual totals exceed the numbers given.

Source: ONS Labour Market Statistics (NOMIS)

The best estimate is that there are 2370 0-19 yr olds, using DLA claimants' data, which amounts to 5% of the 46,456 population of children and young people aged 0 -19 living in the borough. This equates to approximately 1:20 which is the same rate of prevalence as the national picture.

A detailed breakdown also shows that for the three age groups covering 5 to 17 year olds, the number of male claimants is just over double the number of females. For 18 – 24 year olds, there are just over 1½ times as many males, but for under 5s there are less than a third more males than females. It is impossible at this time to know whether this is a changing trend or a random variance.

When the numbers of claimants in each super-output area are mapped according to Council neighbourhood areas, most of the 16-24 years age band are living in areas noted for multiple socio-economic deprivation. For children under 16 years age this is less noticeable, but there is an obvious 'cluster' in the Chopwell and Rowlands Gill areas, where there is deprivation and also public transport problems.

5.7 Gateshead School Census Data

The autumn 2008 School Census in Gateshead showed 3,580 children with School Action, 1,079 with School Action Plus and 751 with a Statement of Special Educational Need. The total of 5,410 here amounts to 11.5% of the 46,456 population aged 0 to 19 years. Some will presumably also be DLA claimants.

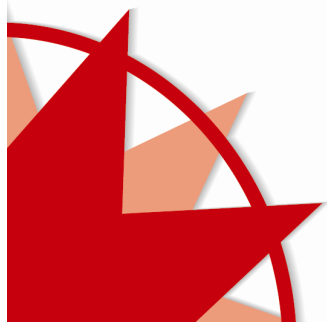
Postcode mapping these children indicates they are seen to be broadly but not exclusively concentrated in areas of deprivation.

The table below breaks down the Statements of Educational Need in Gateshead as at October 2008, by cause.

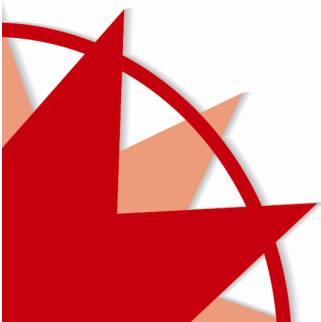
N.B. the total here is larger than that quoted in the autumn census above because this one includes out-of-borough placements. The largest single category is moderate learning difficulty at 26% of the total. Other large single categories are behavioural difficulties and speech and language difficulties, both at 13%. 380 Statements, 47% of this total, have some category of learning difficulty as the cause.

Fig 8.

SEN Database Category	No. - Oct 08	%	Ofsted Categories
Medical condition (other than physical difficulties)	3	0.4	
Attention control difficulties	16	2.0	Behaviour Emotional & Social Difficulty
Behavioural Difficulties	109	13.4	
Emotional Difficulties	0	0	
Severe Autism	64	7.9	Autistic Spectrum Disorder
Other Autistic Spectrum Disorder	51	6.3	
Selective mutism	0	0.0	
Speech & language difficulties	106	13.1	Speech, Language & Communication Needs
Moderate learning difficulty	212	26.1	Moderate Learning Difficulty
Profound & multiple learning difficulties	20	2.5	Profound & Multiple Learning Difficulty
Severe learning difficulties	67	8.3	Severe Learning Difficulty



Specific learning difficulties - dyspraxia	8	1.0	Specific Learning Difficulty
Specific learning difficulties -dyslexia	81	10.0	
Hearing impairment - Moderate	5	0.6	Hearing Impairment
Hearing impairment - Profound	13	1.6	
Hearing impairment - Severe	7	0.9	
Multi Sensory Impairment	0	0	Multi Sensory Impairment
Physical difficulties ambulant	16	2.0	Physical Disability
Physical difficulties wheelchair / ambulant	9	11	
Physical difficulties wheelchair / non ambulant	11	1.4	
Visual impairment	14	1.7	Visual Impairment
Total	812	100	

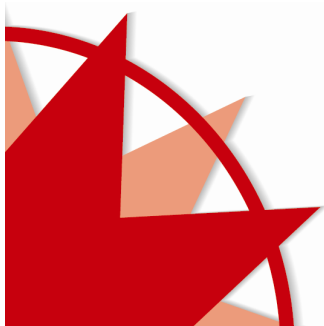


6. Local Analysis of the provision of Targeted and Specialist Services

As part of this review, information was required regarding prevalence of local need in order to plan services to more appropriately meet those needs. A questionnaire was distributed to targeted and specialist support services that work with children with disabilities and their families, to gather further information. Partial information was provided within a number of the questionnaires.

This exercise has not however provided a detailed comprehensive picture as had been hoped. The questionnaire, in line with the national picture, was unable to provide consistent robust information due in part to the varying definitions of disability that are prevalent within the various services. The review has therefore been unable to establish a clear and complete picture of targeted and specialist need.

However, the information gleaned through the questionnaire exercise has been supplemented through the schedule of interviews with managers and key stakeholders, together with the workshop event. Participants at this event included a number of key managers and professionals whose services fall within the remit of the review. This qualitative analysis, alongside information from the SEN review and information drawn from children's centres, has enabled some conclusions and recommendations to be identified and drawn together in this report.



7. Evaluation and Recommendations

7.1 Strategic Direction

Aiming High for Disabled Children sets out the Government's overall vision and strategic ambitions to support and guide local authorities achieve transformational change, which will improve outcomes for all disabled children.

The Children and Young People's Partnership has previously approved the strategic direction for SEN, which translates into operational reality the Partnership's commitment to the inclusion of disabled children into mainstream provision. This is only one aspect of improving the life chances of disabled children. Improving their educational, social and emotional development, together with their opportunities for employment, independent living, choice and control are all part of this.

Recommendations

- The Partnership now needs to take ownership of the inclusion and transformational agenda for all disabled children (including SEN and children with life limiting conditions) through the development of its overarching strategy, priorities and spend capacity.
- It is essential that an integrated management structure is developed. This should include a nominated champion to take the overall lead for services for all disabled children (SEN, disabled children and children with life limiting conditions) and have accountability for reporting to the Partnership on Gateshead's total capacity to achieve its vision and priorities, its overall performance and how this is improving outcomes for disabled children.
- A commissioning strategy for Children with Disabilities needs to be informed by this strategic direction and resource allocation, underpinned by this needs analysis, resource analysis and stakeholder consultation, of which this review is a part.

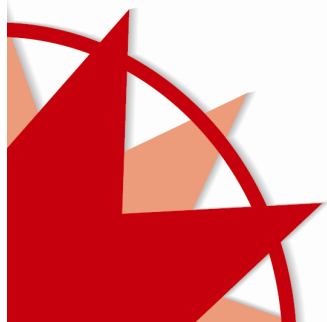
7.2 The Inclusion Agenda

The SEN review clearly articulates the vision and approach of the Children and Young People's Partnership to the inclusion of disabled children into mainstream school and early years provision. This envisages that children with severe and complex needs arising from their disability or life limiting conditions will be accommodated in additionally resourced schools or, in exceptional circumstances, in special schools.

In relation to other provision, such as children centres, play and youth services, a comparable model should also be applied.

In support of Gateshead's approach to inclusion, the review team suggests there are two possible models. These are presented below:

Model A. All the mainstream provision is enabled to respond effectively to children other than those with the most severe disabilities. This means the design of services must meet the following criteria:



- Accessible to disabled children as required under the Disability Discrimination Act.
- All staff have basic training in working with disabled children and in the safeguarding of disabled children.
- All providers working with disabled children have to be fully aware of the increased needs relating to safeguarding and child protection

A disabled child with more severe and complex disabilities and life limiting conditions can be equipped with an additional resource package according to their differentiated and individual needs. This may also need to be designed to improve the capacity of the providers to meet the child's needs through specific input from different specialist providers.

This model already seems to be having very positive outcomes in play services. The review team were provided with excellent evidence of children and young people with severe and complex disabilities accessing and benefiting from mainstream play services supported by individually designed support packages.

Some specialist services will be offered specifically for disabled children such as short break provision, health assessments, health support etc.

The short break pathfinder is looking to promote self directed care/personalised packages which can be utilised by families to access mainstream services as well as provide additional supports to the child and their family.

Model B. This involves the development of a centre-based facility designed to provide a 'team around the child' specifically for disabled children including children's centre services, health services, short break, play, youth etc.

Lakeside children's centre is such a resource and has been written up as part of the National Strategies programme (The National Strategies SEN/LDD Inclusion Network Meeting – Mainstreaming in a children's centre).

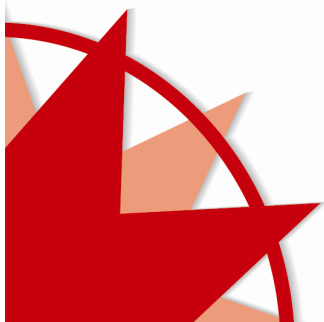
However this model has less fit with the development of provision in Gateshead and given the Inclusion policy being furthered by the SEN review, it is suggested this would not be the most appropriate model to pursue.

Recommendation

- It is recommended that the inclusion model for the provision of services is based on Model A.
- To develop self-directed care as appropriate according to the specific needs of the disabled child

7.2.1 Workforce Development

In order to provide an inclusive service, Gateshead Children and Young People's Partnership needs to develop the workforce to ensure they have the appropriate skills to support children with disabilities in mainstream settings.



Recommendation

- Review how specialist staff may support staff in mainstream settings to gain the skills required to improve access to mainstream services for children with disability.
- Conduct an audit of all staff that have received specialist training in communication skills to assess the frequency and effectiveness in the utilisation of their skills.

7.2.2 Financial Considerations

It is evident that the inclusion agenda will cost money.

- It has workforce implications relating to training and additional support services;
- It has implications for demand on specialist health services such as community nursing, physiotherapy, and occupational therapy as the services will be working in an increased number of locations and training up an increased number of staff;
- It will pose additional demands on the aids and equipment budget. For example special chairs may be too heavy to transport with the child and therefore may have to be provided in the different resources accessed by the child.

Currently there are a number of staff across education, youth, play and short breaks with designated roles involving the inclusion of disabled children. It is an imperative that where there is duplication or overlapping of roles these are streamlined in order to save money to support reinvestment elsewhere.

Recommendation

It is recommended that further work is undertaken to estimate the financial implications for the model of inclusion to be translated into operational reality. The option of developing an integrated shared budget approach should be considered with funds being assigned from individual partners into a single budget.

7.3 Integration across the Children and Young People's Partnership

Gateshead Children and Young People's Partnership has been committed to joined up working and the move to more personalised services for children and families for some time. This has been supported by a number of successful bids to be national Pathfinders. These not only bring in extra funding but also support the translation of innovative and leading edge practice into operational reality. In 2006 Gateshead was one of six authorities involved in research conducted by the Thomas Coram Research Unit looking at models of good practice in joined-up assessment: working for children with 'significant and complex needs'. The Early Support Programme was the focus for joined up assessment bringing together a collaborative assessment involving professionals from social services, education, and health. The research identified the need for an agreed infrastructure to support joined up working.

The Partnership continuously strives to achieve joined up assessments. Throughout the front line services there is clear evidence of workers' commitment to joined up working and an overall commitment to making a difference for disabled children. There is also a strong commitment to any assessment being needs led, within the concept of services that 'wrap around the child'.

Key professionals are currently working together defining the core care pathway and the core offer to parents together with the standards to be met at each stage of the process. The amount of change generated within the Partnership is considerable and generates an enormous workload. Currently a number of managers and stakeholders are involved in different reviews and work streams to define and implement change.

Joined up working on the front-line is far from easy and there is no simple recipe for success. Joined up working is about a journey, continually reviewing and building on the lessons learned, continually supporting the capacity to make a real positive difference to disabled children and their families.

To support effective joined up working, there is a need for a jointly agreed infrastructure. Factors which support joined up working are agreed priorities, agreed criteria, shared definitions and understandings, shared data, systems for sharing information, combined with a capacity to be solution focused and able to make a difference. Currently there is evidence that different priorities and changes in one service have had negative consequences for other services and led to delays.

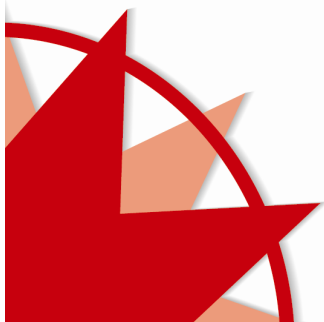
There is also evidence that differentiated performance targets in health can slant the timescales for responding to different professionals. For example the national requirement for a Foundation Trust to respond to a GP referral within 5 weeks means priority will be given to the GP's referral over other referrals.

7.3.1 Health

Health is particularly complex in the light of restructuring of the PCT, and the changing agenda for commissioning is changing the roles and relationships of commissioner and provider.

Currently there are a number of different health providers delivering universal and specialist services to disabled children and those with life limiting conditions. By its very nature, the different providers are governed by different priorities, performance data, and criteria. Some of these may also be driven by different government performance indicators and priorities. Disabled children and children with life limiting illnesses are only a small fraction of the budgets of the PCT or trusts. All these factors militate against maintaining agreed priorities and agreed resources for disabled children.

For instance, when looking at the specialist health teams working with children with profound learning disability the specialists, although working in the same building, are employed by different Health organisations. They are working to different criteria and priorities. This limits the flexible use of resources and leaves gaps in service provision that are not addressed. Staff are also working to different priorities which can



suddenly change the level of resources available and have a negative impact on the ability of another service to deliver a quality service.

Within the governance of the Gateshead Children and Young People's Partnership there does not appear to be an agreement on how the pluralist nature of the health provision can be co-ordinated to achieve dedicated resources and agreed priorities for disabled children and children with life limiting conditions. It may not be appropriate to pursue the pooling of budgets as NHS commissioning may offer a way to reconfigure services in a more integrated way reporting to a single lead agency.

7.3.2 Current Structures

The structure around disabled children is still locked into the traditional structures of health, social services, and education. This generates a tendency to look at how the resources are used within each line management structure rather than to address the needs of disabled children as a whole. For instance the SEN review may have a consequential impact on the capacity of other services to respond effectively to disabled children. But this holistic analysis is not built into the review to help guide negotiations in relation to the different professional services, specifically those provided by health.

Also as a consequence of the SEN review there are plans to disaggregate central resources such as SENSS and SENCO into the additional resourced schools and special schools. But this may have consequences.

- The Ofsted Report 'Inclusion: The Impact of LEA support and outreach services (July 2005)' cautions against this approach as it diminished the capacity of many LAs to monitor the progress of pupils with SEN.
- In the light of very scarce resources it is suggested that there may be a need for a more holistic and innovatory approach to how the SENSS and SENCO resources are utilised in helping the Children and Young People's Partnership achieve the broader transformational agenda for disabled children.

For instance when working with ASD children, it is recognised that communication and behavioural techniques need to be consistently applied across school, the family and with other services and providers. This requires significant integration across education, social care and health and such resources as SENSS and SENCO to work seamlessly to improve the response to the disabled child and their family.

Integrated working practices generate a more complex organisation than a straightforward vertical hierarchy. When integrated working is primarily built around virtual teams, which is the case in Gateshead, this can be even more complex without a clearly defined infrastructure and capacity to make decisions on the balance of resources and agreed priorities. It also puts additional strains on communication and information sharing. This may go some way to explaining the number of different meetings that many managers and practitioners attend. The purpose and frequency of meetings needs to be reviewed with a view to streamlining the process.

Within Gateshead Children and Young People's Partnership there are three hierarchical structures, education, health, and social care. In such an environment it is potentially more difficult to make critical decisions about how to respond to changing needs or resource gaps, delays in services because of under resourcing, picking up consequential changes in one service and the impact on another, and how services can become more flexible.

The review team also felt there were some conflicts and unnecessary hoops built into the system. For instance it appeared to the review team that:

- a virtual team comes together with the disabled child and family to conduct a joint assessment of need and engage the child and family in how their assessed needs can be met;
- Based on this needs assessment a proposed intervention plan is agreed;
- The primary objective is then to get the resources to the child and family;
- However as part of the gate keeping of resources, the intervention plan appears to require approval through a resource panel;
- However the resource panel may involve the same people as the assessment team. This seems to be a duplication of effort and may delay the provision of the package.

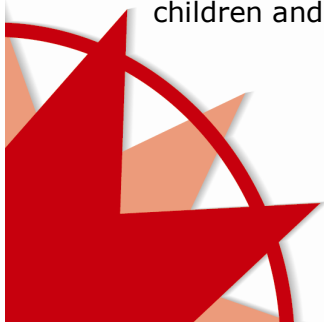
It is suggested this process could be streamlined by delegating responsibility to the virtual team for integrated budgets, costed around sample care packages.

Within Gateshead there is a highly committed, enthusiastic workforce who, through joined up working in relation to disabled children, are striving to achieve better outcomes for those children. They also have a clear idea of the barriers and gaps in service provision, but have not been able to action the necessary changes. The Children and Young People's Partnership needs to consider how they can free up and empower the front line staff to make a real difference by finding and implementing solutions which also recognise and address the consequential impact on others.

7.3.3 Integrated working

There are examples of authorities that have been more successful in moving forward towards transforming virtual integrated teams into actual integrated teams. One example is Sheffield, where local health staff have been seconded into the local authority to join locality based teams for all children, and the city wide CWD services have been brought together under the management of the local authority. This has joined together health services, CWD social workers, education SEN case officers and education psychologists under one overall manager. This model has increased knowledge about the needs of disabled children, actual available resources, and the outcomes. It has meant gaps are more quickly recognised and resources can be used more flexibly.

The London Borough of Croydon currently have an integrated Children with Disabilities and SEN service within the local authority, with a joint occupational therapy service line managed by the local authority with professional support provided by the health authority. The aim of the service is to provide a joined up approach to disabled children and their families. This also facilitates a more co-ordinated approach to



understanding the needs of the disabled child population and to a more flexible utilisation of resources.

It is clear that all Children's Trusts are now working towards integrated services in line with government expectations, but no-one is claiming to have all the answers. Much depends on the current level of the journey and whether more formally integrated models are now the next stage of the journey for Gateshead.

7.3.4 Resources

Currently resources are locked into different agency, departmental and divisional budgets and services. There is some alignment of budgets but the majority of resources are still very much locked into traditional funding streams. Where there is a degree of budget alignment, it is not to the extent of having pooled budgets with agreed objectives and outcomes.

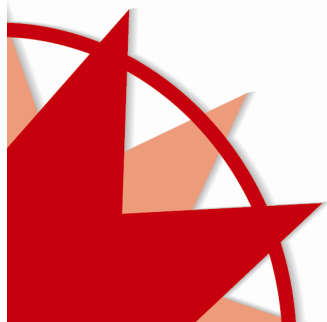
There are different budgets such as the personalisation budget, the continuing care budget, and money that can be made available through the short breaks. However these all have different criteria, are based on different priorities, and have different gatekeeping processes before they can be released.

It is recognised that both the local authority and the PCT are under significant budgetary pressure and that there is no room for growth. But there are also some shortfalls in meeting the needs of disabled children. For instance

- Some services have built in delays because of resource shortfalls;
- Services have restrictive criteria – for instance the Children with Learning Disability Nursing service only responds to children over 5;
- There are gaps in provision for children with ASD;
- The disability managers group have identified that higher functioning children with autism do not receive a service;
- The services need to be more flexible in operating times to better respond to the needs of families;
- As part of the inclusion agenda, some staff have been trained up to support speech and language. But it is open to question whether these staff are now being fully engaged to provide those skills in day to day practice with disabled children.

All these have resource implications, which may be better addressed with a more coherent integrated management structure and leadership. This would increase the capacity to recognise gaps and make changes and remove the duplication of resources. Currently there are two potential duplications which may benefit from closer analysis.

- Both the local authority and the PCT provide the occupational therapy service. Although ostensibly different roles, families may not understand this and it can lead to confusion for them. Merging these two should be considered, which is also likely to improve their overall effectiveness.



- The role of the School nurse should be considered to determine whether it could be adjusted so that they complement the role of the Community nursing service.

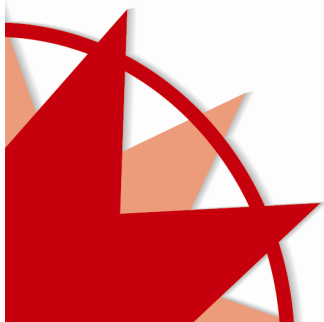
7.3.5 Child Development Team

Currently the child development team primarily involves health professionals in the assessment of disabled children. This is now perceived as a traditional model and Gateshead Children and Young People's Partnership may wish to consider a more integrated child assessment approach, in which social workers work alongside health professionals in the assessment. In this way the team seeks to improve the quality of life of the whole family, addressing the needs of the disabled child, their family, and siblings. Two examples identified by SCIE (Social Care Institute for Excellence) in their knowledge reviews are The Lighthouse Child Development Centre in Southend and the Ryegate Children's Centre in Sheffield.

7.3.6 Recommendations for 7.3

It is recommended that

- Gateshead Children and Young People's Partnership consider developing a new management structure that is more closely aligned, enabling and supporting integrated multi-disciplinary working and increasing the capacity to streamline resources and utilise them as flexibly as possible to achieve the best outcomes for children and their families. Examples of models are contained within the main body of the report.
- The Children and Young People's Partnership should consider developing an integrated team joining the SEN support staff, the Disabled Children's social work service and the educational psychology services together under one senior manager.
- The PCT should ensure that comprehensive service specifications are in place for all commissioned services. These specifications should include clear and robust outcome and performance measures in line with national policy and guidance. The annual child health mapping should be used to identify the total resource allocation for PCT commissioned services.
- The PCT should utilise World Class Commissioning competencies as a key driver in delivering locally driven services with a focus on improving quality, effectiveness and efficiency of care. By utilising these competencies, and the strengthening of joint commissioning through local Children's Trust arrangements, services will be more closely matched to local need, resulting in better quality of care, improved health and well being and a reduction in health inequalities across the local community.
- Consideration is given to how various teams work together to provide integrated assessment, diagnosis, and seamless services to disabled children and their families
- A Mapping exercise is undertaken by managers:
 - Mapping the number, purpose and outcomes of meetings with a view to streamlining them as far as possible; (There is a considerable



- investment of staff time in meetings – management should determine how this can be streamlined and reduced)
- Mapping the actual range of resources, including staff who have been specifically trained to support community nursing, speech and language etc.
 - Mapping the effectiveness of the resources to improve outcomes for disabled children
 - Mapping disabled children so that the population of children for whom Gateshead Children and Young People’s Partnership is providing services is better understood.

7.4 Integrated Service Offer

The Disabled Children’s team provides a valuable service with a specific focus on the needs of disabled children with complex and severe disabilities. The team holds considerable knowledge about and skills in working with the disabled child and their family. They are valued by other professionals although this is offset by some frustrations with the somewhat restrictive criteria which the team has to apply because of their limited resources.

Recommendations

It is recommended that consideration is given to an integrated service offer which reflects the core offer from Aiming High for Disabled Children and takes account of the following:

- An overview of all disabled children with severe and complex disabilities is maintained, including the further development of the statutory register for disabled children.
- Developing joined up assessments and co-ordinated packages of care and support
- Through effective tracking of disabled children ensure that at key transition or developmental stages there is appropriate planning and preparation in place for all children with complex disabilities, including children with life limiting conditions;
- Ensure transparency and access to information for disabled children and their families
- Using additional short breaks funding to develop personalised models of short break support
- Provide emotional and practical support to families immediately following diagnosis

Gateshead Children and Young People’s Partnership should also consider bringing together the Disabled Children’s Team with SEN support staff, and the educational psychology service.

7.5 Joint Commissioning and Planning

Commissioning can provide opportunities to achieve change. This depends on the overall vision and direction of the Children and Young People’s Partnership and how



much they perceive the need to incorporate joined up thinking into their overall strategic plan for disabled children, SEN, and children with life limiting conditions.

7.5.1 Developing a Better Understanding of the Disabled Children Population

Developing a Commissioning Strategy relies on having good quality management information. Nationally and locally there is recognition that there needs to be “better local level data on disabled children and regular monitoring of the progress made on improving outcomes for disabled children, with much greater use of comparisons across the country to judge how different local areas are performing”.

Two expert groups have been set up by the NHS Child and Maternal Health observatory (CHIMAT) to support local authorities and PCTs to obtain this information. These are the Improving Data Group and the Disability Definition Group.

The government have also introduced a PSA measure by which to manage the performance in this area *Reference: Better Care / Better Lives NHS*. Local Children’s Trusts will need to develop comprehensive data sets and analysis of need in order to meet these new expectations. The local data set will include:

- SEN data
- Children in Need Census data
- Child Health data
- CWD register data
- Specific conditions data
- DLA claims

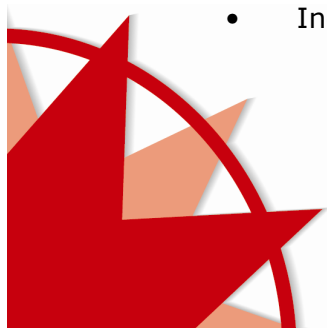
To further refine the analysis of need Gateshead Children and Young People’s Partnership could consider breaking this information down into its 5 local areas combined with gathering local data sources.

Currently Gateshead Children and Young People’s Partnership does not appear to gather the data relating to individual disabled children in a co-ordinated way across the agencies. This results in there being no clear understanding of the actual number of disabled children who are accessing services. One child may be separately reported in the statistics of a number of different agencies all working with the same child and their family. Nor is there readily available analytical information regarding the levels of each type of intervention or the most frequent combinations of interventions for individual children, together with outcomes.

Although the review team has not seen customer satisfaction levels, all the returned survey questionnaires indicate this was collected for each case. Whilst it is recognised that different types of service might need variations, there should be some common approaches to assessing satisfaction for comparatives and to identify performance trends. Such information should also be readily accessible and reported regularly.

The following is a possible model for systematically collecting data, which builds into a performance management system:

- Individual stories



- Integrated audits
- User satisfaction surveys
- Specific user forums
- Analysis of interventions and outcomes
- Actual number of children with whom the services is working
- Actual level of needs and continuum of care packages.

It would also be useful to utilise the tracking systems to facilitate a proactive approach to ensuring appropriate planning and support at key transition points in a child's life.

7.5.2 Market Development

Short Break Providers

There is a short fall in the availability of short break support for children and their families. Currently the Aiming High Disabled Children Pathfinder Steering Group is addressing some of this shortfall by procurement routes to stimulate the market but, with the tensions that the traditional routes of grant funding are experiencing, this may only be an option if the provider is prepared to provide services on a very flexible basis.

Community Nursing

To achieve the flexibility required to meet the needs of individual disabled children and their families, there is a need to recruit locum nurses. However, currently there is a shortfall in agencies providing nurses with the capacity to work with disabled children.

7.5.3 Recommendations for 7.5

- Continue to review data collection systems to improve the provision of a properly analysed assessment of need, gap analysis and costed services to support commissioning processes.
- It is essential that the collection of data is improved to ensure that there is a common set of information at both individual case level and in collecting statistics to assist management planning and assessing the effectiveness of the services provided and the outcomes for disabled children.
- As part of the commissioning strategy to identify a range of providers that can offer support and services to children with disabilities.

7.6 Promoting the Children with Disabilities Register

A much better understanding of the actual numbers of disabled children and children with life limiting conditions residing within the area of Gateshead is required. The statutory register, although voluntary, can provide basic information in relation to disabled children; it can also be designed to help collect the range of data required. However it has to be proactively managed and families need to be encouraged to put the name of their child on the register. Families can be supported in doing this by

improving their understanding of the benefits, including information relating to core standards and core packages of support.

Nationally some Children Trusts have used incentives to encourage families to register. As part of increasing transparency and proactive communication and information with families and disabled children it is worth exploring what incentives are most likely to encourage families to register their child. Promotion of the benefits of registration should also take place with GPs and health visitors to ensure they are actively encouraging families to register their child on the database. This could be supported by information in GP's surgeries.

In the London Borough of Croydon, these latter two activities have achieved some success with an increased number of families registering their child.

Recommendation

- It is essential the resources are identified to proactively manage the statutory register
- It is important to discuss and agree with families the value of the register and the incentives that are most likely to encourage families to register their disabled child

7.7 Information and Communication

Increased transparency about individual entitlements and increased availability of information at a local level should contribute to greater equity in access to resources between families within the same area.

On behalf of the Gateshead Children and Young People's Partnership, Barnardos produced a series of documents which explained how families could access key people and resources. These provided an excellent guide for families, explaining the roles of the different professionals with whom they may come into contact. However these did not particularly focus on enabling people to understand the criteria for accessing services.

As part of the Children and Young People's Partnership's overall commitment to empowerment and transparency a charter is being developed and a core pathway being defined. Both of these will provide disabled children and their families with increased transparency so that they know what they are entitled to, the eligibility criteria, what standards they can expect and how to access services. This will also facilitate putting families in control of the design and delivery of their care package and services, which is a priority for the Children and Young People's Partnership.

Universal services and other professionals also need to understand the range of specialist services and how they can be accessed, together with how flexible packages of support can be built around the needs of the disabled child and their family.

All professionals need constant updating as to the changing nature of the work of the Children and Young People's Partnership and how it is improving the outcomes for disabled children. This is particularly relevant in view of the fast pace of change to



ensure all people are kept up-to-date and can continually contribute to the development of the Partnership.

Recommendation

- Developing a communication strategy to ensure parents are informed about the range of services available.
- Need to progress a Gateshead Charter for Disabled Children and their Families to improve transparency and equity in line with the core offer in Aiming High for Disabled Children.
- Need to develop the core pathway so that the pathway is streamlined, and understandable to both professionals and families.

7.8 Early Support Services

There are considerable resources located within early years. The review being undertaken by the Co-ordination group should identify ways in which the streamlining of services can release resources for alternative developments, including the further resourcing of children's centres.

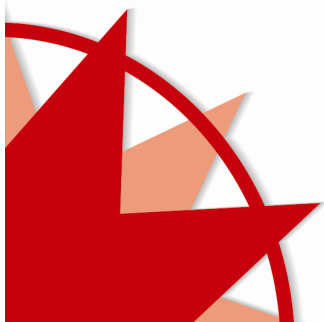
With the development of the children's centres, the role of Barnardos Gateshead Family Resource Centre should be reviewed. It is recognised that the Centre delivers according to different contracts with the Children and Young People's Partnership. However, whether they are providing the most relevant services in the light of the changes within provisions by the Partnership should be assessed. The service could expand its role in relation to short breaks or expand the service it provides for children with autism and their families.

Currently the Gateshead Child Care Sufficiency Plan evidences a low take up of childcare by disabled children and SEN despite 98% of providers of childcare stating they can meet their needs. The lack of take up may suggest that parents lack confidence that their child's needs are fully understood or catered for by the setting. Such findings should be taken into consideration with regard to inclusion in universal settings.

In addition, particularly relating to Community Nursing, there is an increasing need for the service to be available on a 24/7 basis. This is not continuously but on a needs led basis. This needs to be resourced from suitably trained, qualified and experienced nursing staff. This poses a particular challenge for the workforce. Alternative options may be collaborative contracting arrangements with other PCTs.

Recommendation

- Develop a coherent strategy for the provision of childcare and nursery placements for children with SEN, disabled children, and children with life limiting conditions.
- Undertake a review of the community nursing service with a view to developing a 24/7 service model.
- Review the future role of the Gateshead Barnardos Family Resource centre.



7.9 Short Breaks

Being a short break pathfinder facilitates more innovative and creative responses to meet the needs of the disabled child, their parent(s) and siblings. This has a significant capacity to reduce stress on the family. However short breaks need to be on going, so that the disabled child and their family can rely on support that is responsive to their needs. The criteria for change should be according to the changing needs of the family not according to rigid criteria relating to time scales.

Across the review we have been aware of how short breaks can be used to enable disabled children and young people to access leisure, play, youth, to take up new hobbies such as music, or to enable young people to build their confidence through overnight stays or week-ends away from the family as part of their growing independence and life improving experiences. They can also be used to build the capacity of parents to maintain their care of the siblings as well as the disabled child.

It has been recommended within the report that the disabled children's team should be provided with a pool of money so that they increase their capacity to organise bespoke support with the disabled child and family. Individually tailored support is currently being developed through personalisation. However what needs to be planned during the period of the Pathfinder is where the money will come from out of mainstream resources at the end of the project. How to achieve this flexibility out of mainstream provision will be a significant challenge, particularly in the light of the inclusion agenda.

Recommendation

- It is recommended that the short breaks pathfinder is incorporated into the overall strategic direction in order to achieve transformational change for disabled children.
- Using additional funding from the short break pathfinder to develop personalised packages of support to disabled children and their families.

7.10 Transition

The Education Act 1996, SEN regulations and the SEN code of practice set out a statutory transition planning process for young people with SEN statements from Year 9 onwards.

Youth Matters: Next Steps has set out plans for comprehensive information, advice and guidance for all young people with targeted support for those with complex needs. It also sets out how Children's Trusts will work holistically to achieve more personalised, integrated and efficient support services for disabled children. There is also a core standard within the National Service Framework for Children, Young People and Maternity Services on 'Growing Up into Adulthood'.

Parents of children with complex and enduring disabilities and health needs want to know what the future holds for their children and how they can support their child on the journey to adulthood. Gateshead Children and Young People's Partnership have put in place a review system at age 14 to start the planning for the young person's

future with the active participation of the young person and their family. This brings together key professionals, including the school, Connexions, key worker from the Children with Disabilities Team and a key worker from the Transitions Team, which is positive practice.

Through the dialogue with the Transitions Team, the Review team felt they brought an enthusiastic and refreshing approach, giving excellent examples of enabling the young person to purchase a range of support services from different sources through the direct payments scheme and the short breaks money. There was evidence of services being built around the needs of the child. This includes direct carer support to enable the young person to take up universal services such as youth, leisure etc. They are also working with young people to prepare them for independent living, including accessing accommodation. The biggest shortfall is access to work based learning, which is being addressed through the Connexions service.

Generally the Disabled Children's Team and the Transitions Team co-ordinate planning until the young person is transferred to the Transitions Team, which is located in Adult Services, at the age 16. This means that thereafter the legislative framework within which the team has to operate is within the Governance of the Children and Young People's Partnership, but the subsequent service is located outside the remit of the Partnership. It is within the areas of care, care support and independent living when conflicts may be experienced between an adult approach and young person approach because of the different legislation, safeguarding, and care standards.

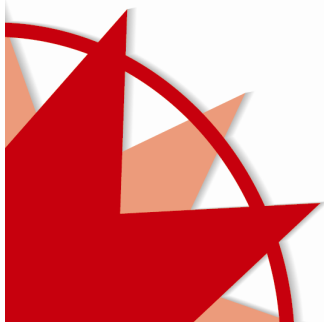
The legislative framework of school and social care underpinning the child's emotional, social and educational development including welfare, safeguarding and care all suggest the Transition Team should be sited within the framework of the Children and Young People's Partnership. This is particularly the case if the Children and Young People's Partnership is developing an integrated coherent strategy, particularly in the light of the functions of the Learning Skills Council, including those for young adults, being transferred into the LAs.

Although the policy standards address transition to support young people moving from adolescence to adulthood, effective transition planning is also critical at all key development stages in a child's life. This is demonstrated through such research as that conducted within the North East with children with autism.

This identified that children with autism are more able to cope with transition when there is careful preparation both of the service and the child/young person. It is crucial that effective planning is in place at all key development and change stages in the life cycle of the disabled child to adulthood. This also cross references with recommendations within 7.4 relating to support post diagnosis.

Recommendation

- It is recommended that a review of transition arrangements be undertaken including consideration of where teams are sited.



7.11 Expanding the Hours of Service Delivery

Throughout the review it became evident that the majority of mainstream services are operating 9 – 5. But repeatedly we hear from families they need support outside these hours. This was also captured in the review of family support services. The community nursing service is currently piloting flexible services providing support to families throughout the night. It is important to consider which services need to be available during the evenings, during the night, and during weekends so that parents can receive appropriate support.

While most services are available on a largely 9-5 basis there are some out of hours services operating throughout the borough, for example through crossroads, short break services and residential short breaks.

Recommendation

- It is recommended that access and availability of services is reviewed to ensure that services meet the needs of families.

7.12 Children with ASD

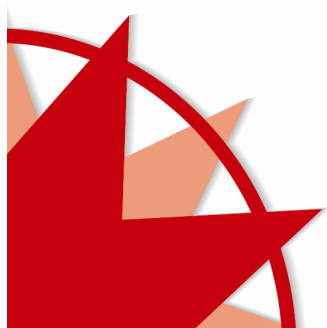
Nationally the number of children with Autism and Autistic Spectrum Disorders is increasing and we see the same picture in Gateshead. Children with ASD whose needs cannot be met within the Children and Young People's Partnership place very heavy demands on the resources. Additionally it removes children from their natural environment and pursuits in their local communities.

Currently there is limited practice research on which to base assumptions that improved early interventions will directly reduce the demand for out of authority specialist placements. However there is evidence from practice which contributes to our understanding that improved interventions designed around the need of the child can improve the life opportunities of young people with autism and ASD and can increase the capacity of families to maintain their care of their child and siblings.

An autistic spectrum disorder is a complex developmental disability that affects social and communication skills. Autism is diagnosed by identifying behaviours that reflect the underlying triad of difficulties which occur in the areas of:

- Social interaction
- Social communication
- Imagination

Unlike some developmental disorders, autistic spectrum disorders are difficult to diagnose at birth since the behaviours necessary for assessment and diagnosis do not become evident in the developing child until 18 months. The health visitor and GP are crucial people in recognising that children may be displaying autistic behaviours and referring the child and family to a specialist team for assessment, diagnosis and early intervention.



ASD is closely associated with learning disability. Some children also have severe learning disability. Increasingly it is also recognised that some children with ASD have a higher level of intellectual functioning but still have requirements relating to communication and behaviour and autistic aware environments.

Within Gateshead Children and Young People's Partnership, the Child and Family Unit provides the diagnostic service for children with Autism with post diagnostic support being provided by for example CFU, Barnardos Resource Centre or Early Support Services. To access any services provided through the National Autistic Society and to meet their national standards requires a child to be diagnosed with autism.

Recently changing priorities in different providers have meant increasing delays in the diagnostic process. This has also limited families' access to support and some interventions. These are particularly those associated with the National Autistic Society. GPs however are able to access the diagnostic services more quickly than other professionals, because of standards required of Health Trusts to respond to a referral from a GP within 5 weeks. Routes to the Child and Family Unit are also more protracted when the referral is being made either by a health visitor or other professional, being required to first go through the Child Development Team.

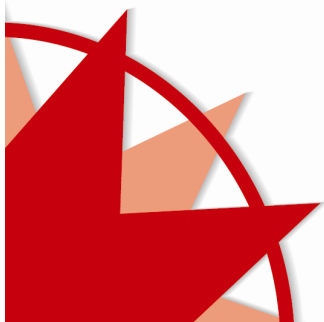
Different intervention services such as early years, family centres, Barnardos, schools, play, youth, and the children with disabilities team all demonstrate an awareness of the needs of children with ASD. Training is commissioned from such organisations as the North East Autistic Society to provide greater insight for workers to support their generation of autistic aware environments and practice.

Short breaks money is being used with autistic children and their families to generate innovative support packages to relieve pressure on the families but also to provide children with access to different pursuits and interests contributing to building their life experiences.

The growing number of children with autism will put increased pressure on communication and behaviour services. It is crucial that effective techniques used in schools are equally taught to parents and other universal and specialist providers to generate consistency in approach. Speech and language therapists are frequently involved in training staff to meet the communication needs of children with autism. It is important that such staff are consistently engaged in such work to maximise the benefit for the children and justify the time expended by the Speech and Language Therapists.

The Bercow report has raised awareness of the range of communication needs, which poses challenges for Children Trusts to decide how to respond.

In the North East research into the needs of autistic children, families identified how helpful they found knowing how to access provision, who to contact, and the nature of support services available. It is also recognised how children with autism benefit from effective planning at key points of transition throughout their developmental life cycle.



Currently it is generally reported to the review team that autistic children with higher functioning intellect levels are less likely to meet the criteria for input from specialist services.

Recommendation

That Gateshead Children and Young People's Partnership should:

- Continue to re-model the care pathway to ensure timely interventions.
- Develop services to enable autistic children with higher functioning intellect levels gain improved access to specialist services and mainstream services



Remit and Methodology

This review is commissioned by the Improve Wellbeing Board. The scope of the Consultants role will cover but not be limited to the following:

- Co-ordinate the assessment of needs in order to inform the wider Children with Disabilities (CWD) Commissioning agenda;
- Report in person to the Commissioning Support Team once monthly;
- Submit a report by 20 December 2008 to the Children with Disabilities Strategic Group (sub-group of the Improve Well Being Board);
- Ensure report recommendations that are developed are evidence based.

The review should take into account the context of significant change in Gateshead and specifically:

- The SEN review and its proposed new model for the delivery of school based special educational needs support.
- The restructure and culture change amongst many services including social work services and area based teams as part of the Change for Children programme (Information available at www.gatesheadcyptrust.co.uk).
- Implementation and delivery of the Aiming High for Disabled Children Short Break Pathfinder which has brought significant resources to the borough to develop short break services for disabled children and their families.
- Implementation of the recommendations from the family support review which aimed to develop a clearer whole system approach to family support.

The review is to be conducted as outlined below and set out in two parts as follows:

Part A

A full needs assessment utilising various data sources including a full evaluation of existing services using the methodology framework below. Please note it is not our intention that the consultant spends significant time on Part A, as there is data available which has already been collected in Gateshead by the CST. In addition there will be no need to carry out consultations with parents/carers/service users and children & young people, as we will use quantitative data we have from previous consultations and from national sources. We are aware of the limitations with using disability data in developing service provision and our experience reflects the findings of a recent national report which the successful consultant will find very helpful. It was carried out by the Thomas Coram Research Unit in 2008 and is entitled 'Disabled Children: Numbers, Characteristics and Local Service Provision' it can be found at www.dcsf.gov.uk/research.

Part B

The consultant is expected to focus more on Part B which is an evaluation of services and recommendations that incorporate the views of stakeholders and national indicators/outcomes. The evaluation of unmet needs, gaps in services, duplication,

wastage in processes and recommendations based on Part A should inform a future commissioning strategy, covering

- How resources could be better used to meet needs;
- How services could be remodelled in the future;
- How services should relate to and work with universal services such as children's centres.

It is anticipated that the review will deliver the first three steps of the joint commissioning cycle for children's services as follows:

Look at the outcomes for children and young people – a focus on improving outcomes will lead to a change in the way in which we think and work. As we see a shift in emphasis to integrated service delivery and a focus on outcomes the significance of a scheduled programme of service reviews has become evident.

Look at particular groups of children and young people – the information gathered in the above step should be analysed and mapped with a view to identifying local priorities. To make services more accessible there needs to be understanding of where children are located and a comparison made with the location of existing services.

Develop integrated needs assessment with user and staff views – professionals involved in the planning or commissioning of services will need to analyse both qualitative and quantitative data in a way that will allow them to understand 'trends and causal relationships' and 'improve the quality of data'. In order to develop a locally owned needs assessment, there has to be effective consultation with key stakeholders, the community and users.

Should issues be identified around groups of children and young people not covered by the scope of the review, these issues should be highlighted throughout the review process and in the final report.

The review should evaluate and make recommendations in relation to the following core services for children with disabilities which are provided or commissioned (in full, or in part) by Gateshead Council or Gateshead Primary Care Trust:

- Children with disabilities service (Children and Families, Gateshead Council)
- Children's Community Nursing Service (Gateshead Primary Care Trust)
- Community Learning Disabilities Service (Gateshead Primary Care Trust)
- Physiotherapy (Gateshead Health NHS Foundation Trust)
- Speech and Language Therapy (Gateshead Primary Care Trust)
- Occupational Therapy (Gateshead Primary Care Trust)
- Occupational Therapy (Gateshead Council)
- Family Support (Children and Families, Gateshead Council)
- Barnardos Family Resource Centre
- Special Educational Needs Support Service (Gateshead Council, refer to the SEN review)
- Educational Psychology (Gateshead Council, refer to the SEN review)
- Area SENCOs

- Early Years Inclusion Team (Gateshead Council)
- Integrated Community Equipment Service (managed by Gateshead Primary Care Trust)

The review should also make recommendations in relation to universal settings such as schools, play services, children's centres and universal health provision in relation to inclusion, communication, working together and standards of service delivery.

Disability Categories

For the purposes of this review categories for children with disabilities are as follows:

1. i) *Communication and Interaction (DCSF SEN)*

1. ii) *Autism Spectrum Disorder/Complex Social Communication Disorder (medical)*

Developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before the age of 3, that adversely affects educational performance. Characteristics often associated with autism are engaging in repetitive activities and stereotyped movements, resistance to changes in daily routines or the environment, and unusual responses to sensory experiences. Including children diagnosed with Complex Social Communication Disorder.

1. iii) *Speech or Language Impairment (medical)*

Communication disorder such as stuttering, impaired articulation, a language impairment, or a voice impairment that adversely affects a child's educational performance.

2. i) *Cognition and learning categories (DCSF SEN)*

- Specific Learning difficulty
- Moderate Learning difficulty
- Severe Learning difficulty
- Profound and Multiple difficulties

2. ii) *Learning Disabilities including developmental delay (medical)*

Below average general intellectual functioning, existing concurrently with deficits in adaptive behaviours and manifested during the developmental period.

Likely to include:

- Down's syndrome
- Other named syndromes
- Chromosomal abnormalities
- Developmental delay
- Cognitive function disorders
- Severe Dispraxia and Dyslexia

2. iii) *Profound and multiple disabilities (medical)*

Complex physical and learning disabilities.

Concomitant impairments, the combination of which causes severe additional needs.

3. i) *Sensory, Physical and/or medical (DCSF SEN)*

3. ii) *Deafness/Hearing Impairment (medical)*

3. iii) *Blindness/Visual Impairment (medical)*

3. iv) *Physical disabilities without other significant impairment (medical)*

Not including those with other significant impairments in terms of learning disability.

Likely to include:

- Muscular Dystrophy
- Spinal Muscular Atrophy
- Cerebral Palsy
- Spina Bifida
- Scoliosis
- Congenital dislocation of the hip
- Cranio facial abnormality
- Congenital limb abnormality
- Acquired limb abnormality
- Arthritis
- Other muscular skeletal
- Achondroplasia

4.) *Behavioural Emotional Social Difficulties (DCSF SEN)*

These relate to difficulties which involve behaviour that directly interferes with the pupil's own educational progress or the progress of other pupils in the same school and class. The behaviour often has its roots in social factors and disrupted family histories but, in some cases, may be the result of medical or physiological factors.

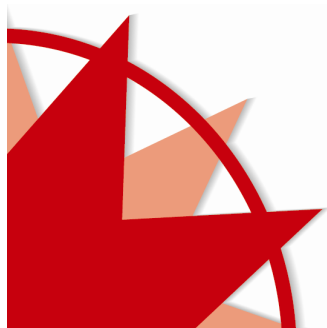
5.) *Complex/Chronic Health Need of Illness (medical)*

Chronic or acute health problems requiring ongoing and regular specialist medical intervention.

Specifically including children requiring the assistance of technology, including children with a tracheotomy, gastrostomy, oxygen dependency or requiring ventilation.

Likely to include:

- Leukaemia
- Other tumours



- (Epilepsy)
- Hydrocephalus
- (Tuberose sclerosis)
- (Neurofibromatosis)
- Degenerative central nervous system disorder
- Congenital bowel abnormality
- Faecal incontinence
- Chronic constipation
- Other gastrointestinal
- Urinary incontinence
- Intermittent catheterisation
- Chronic renal failure
- Cystic fibrosis
- Diabetes
- Thyroid disease
- Phenylketonuria
- Congenital heart condition
- Acquired heart disease
- Liver disease
- Myalgic Encephalomyelitis
- Epidermolysis Bullosa
- Pityriasis Rubra Pilaris
- Tracheostomy

6.) *Acquired Brain Injury (medical)*

Acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both.

Likely to include:

- Brain tumour
- Head injury
- Other acquired brain injury

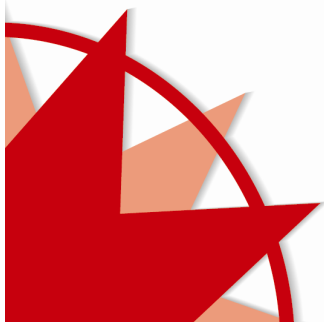
7.) *Life Limiting Conditions*

Conditions where a child or young person is unlikely to reach maturity. There is likely to be a need for specialist palliative care services within the community and / or in a hospice setting.

Please note disability categories are based on medical categories and DCSF Special Educational Needs categories.

SEN School Action and School Action Plus categories of need are required to be included in data collection.

Data will need to be collected under different headings as agencies collect and report in specific ways.



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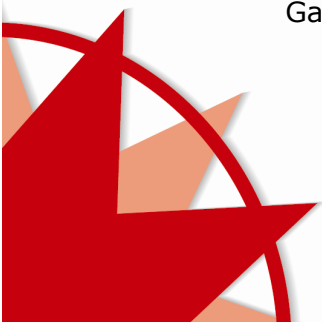
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