MIDDLESBROUGH COUNCIL

HEALTH SCRUTINY PANEL

17 DECEMBER 2012

CHILDREN WITH COMPLEX NEEDS

PURPOSE OF THE REPORT

 To provide Health Scrutiny Panel with information relating to the services for children with complex needs provided by the Safeguarding and Specialist Service within Wellbeing Care and Learning.

RECOMMENDATIONS

2. That Health Scrutiny Panel note the contents of this report.

Consideration

How does the Council define "Children with Complex Needs" in the context of Children's Social Care?

- 3. Definitions of disability vary, but these are children who need significantly more support than other children to do the things that children of their age would be able to do. The term "children with disabilities" covers a very diverse group, ranging from children who have autism or learning disability but who can undertake most tasks and activities with support, to children who have severe learning disabilities or severe physical disabilities and need all their care needs to be met by others. Some children are technology-dependent. Some have such extreme behaviour as a result of their disability that they are a risk to themselves or others if not provided with significant levels of care.
- 4. The Children Act 1989 defines a category of 'children in need' for whom children's services should provide services; the Children Act defines a disability as:
 - "A child is disabled if he is blind, deaf or dumb, or suffers from mental disorder of any kind, or is substantially and permanently handicapped by illness, injury or congenital disformity or such other disability as may be prescribed."

On the basis of that definition, how many are you aware of in Middlesbrough?

- 5. Health, Education and Social Care services define children's needs in different ways, but there is an agreement that there is a significant rise in the number of children and young people in the region with a disability.
- 6. This is particularly so in Middlesbrough, where there is an increase in the number of children diagnosed with severe visual and hearing impairments; motor disorders, including cerebral palsy; severe intellectual disability; complex language disorders; complex mental health disorders; and severe emotional and behavioural disorders.
- 7. Middlesbrough also has higher than national average incidences of children with autistic spectrum disorders, which again is causing assessment and school placement pressures. The NICE guidelines, "Autism Recognition, referral and diagnosis of children and young people on the autism spectrum" (September 2011) recognise that ASD is no longer considered an uncommon disorder, but is prevalent and often associated with co-existing conditions and learning disabilities.
- 8. Guidance issued as part of the Aim High for Disabled Children programme suggests a figure of 1.2% of the child population as a proxy measure for the number of severely disabled children in a local area. Based on ONS population estimates for mid 2009, this suggests a cohort of 376 young people aged 0-17 in Middlesbrough. The Children with Disabilities Service in Middlesbrough currently provides support to 274 children and young people.

How would the Authority normally become aware of children with complex needs?

9. Children's Services may not be immediately aware of a child being born with complex needs or a child moving into the town with complex needs. A family may make a referral themselves or there may be a referral from health staff; however, a referral can only be made with the consent of the family, unless there are safeguarding issues.

Is there any intelligence to indicate that there are children with complex needs that are not engaging with services?

10. The service does not have any information relating to children and families who are not engaging with services. Some families may take time to accept a diagnosis and may not be ready to seek support at an early stage; some families manage within their own resources.

The Panel has previously heard that appropriate care placements for children with complex needs are often out of area and very expensive. Why are they so expensive?

- 11. Following a recent review of residential commissioning, the evidence states that there are low numbers of children/young people in independent residential placements. The Children with Disabilities Team has developed some excellent services that allow children/young people to remain at home. At present there are seven young people with complex needs in residential placements and only two are significantly further than 20 miles away from Middlesbrough; they are placed in Ripon in residential educational placements. Four young people are accommodated with a provider in Middlesbrough and the most expensive placements have been with a provider in Stockton.
- 12. The outcome of the children's residential homes review has highlighted a need to develop more local capacity and it is anticipated that by the end of November 2012, NHS Tees will agree to release some capital that has been held by Middlesbrough for some time and will be used to allow Gleneagles to deliver short break services for young people with complex health needs, and the remainder of the capital will be released to Middlesbrough Council to develop or commission a small home for young people with complex needs in Middlesbrough. This will mean that many out of area expensive placements are likely to be avoided in the future.

Connected to the question above – what evidence do you have that repatriating children in out of area placements into more local ones would save money? Wouldn't staff costs be fairly fixed wherever a facility was located?

- 13. The short break resource within Middlesbrough is fairly priced and when the potential costs of an in-house facility are analysed, it is fairly matched. However, there is a resource the Council has no alternative to use in Stockton, which is very expensive and the service has struggled to get the provider to justify their cost structure as they have so far failed to engage. At present, if local capacity could be increased and use of this resource avoided, there would be a saving of £120,000 per year, per placement.
- 14. There are also significant other costs that would need to be considered when looking at the benefits of children being placed close to home. For example, when children are a long way from home there is significant expenditure on social work visits and supporting contact with families.

To what extent is there a market of possible local providers now?

15. The residential market is not fully developed in the North East for every category of need and commissioners are continually trying to work with providers in order to evidence the need and potential for developing the market. The local provider in Middlesbrough has a good working relationship with the Council and the young people in placement are doing very well. The provider has discussed the potential to expand the service, but to date no further work has been undertaken. In releasing the capital that is available to the Council, there could be the potential to offer the provider the opportunity to develop the service in partnership with the Council; however, this would be completed in line with formal procurement guidance.

If necessary, how would the local authority go about stimulating the market to encourage possible providers to establish themselves?

16. There are a number of avenues open to the local authority and given our size, we would always look to consult with the other Tees Valley/North East Authorities in order to identify any opportunities for joint commissioning, which would potentially be more appealing to the market and provide confidence that there was a definite need to be met.

What progress has been made in identifying or stimulating providers of care for children with complex needs?

17. Significant work has already taken place to encourage more providers of support services – the services used for short breaks or domiciliary care that prevent family breakdown and the need for costly placements. We now have a good range of providers, but this has taken a number of years to achieve.

What framework does Children's Social Care have in place to establish the quality of outcomes for people using the service?

18. The service relies on statutory Looked After Reviews and Ofsted Inspection Reports to monitor progress and outcomes. The Commissioning Team also monitor quality through feedback on placements.

How does the Department ensure that the views of families and the children involved influence services?

19. The service works very closely with the parents' forum, Parents4Change. They are consulted about everything the service does and are involved in the recruitment and training of staff, the giving of grants to providers and in the selection of providers. There are several mechanisms in place for seeking the views of children and families, including information/consultation days and user feedback

questionnaires. The Parents Forum is also represented on the Short Break Planning Group.

The Panel has heard previously that the Department has encountered difficulty in securing CHC funding from NHS sources to support clients? Could you provide a couple of anonymised case studies to highlight some of the issues faced?

- 20. There are, unfortunately, distinct differences between the Children's Continuing Health Care Guidance and the Adult Continuing Health Care Guidance, which has meant that very few young people have met the criteria for funding, or where they have, the NHS already has commissioned services in place, e.g. CAMHS, and therefore funding has not been provided.
- 21. Working in collaboration with Adult Services colleagues has been very positive in terms of understanding the way the service interacts with children's providers; services have adopted similar tactics when negotiating with providers; however, in the future, the service will still need to engage with Clinical Commission Groups in order to ensure that children/young people remain a priority. There is also a need to consider requesting assessments for children/young people where the Council are providing in-house services, as there may be missed opportunities to secure funding.

What intelligence does the Department have about how future demand looks for services aimed at Children with Complex Needs from population data?

- 22. As discussed earlier within paragraph 8, the Safeguarding and Specialist Service may not be immediately aware that a child has complex needs. Whilst some are identified at birth, a number of children are diagnosed at a later stage. There are many factors which contribute to rising numbers, including low birth weight, increased numbers surviving trauma and growing numbers from ethnic groups.
- 23. The number of children born with low birth weight is above average for Middlesbrough. The national average is 8%, with the South Tees Area having 10% and areas such as Park End having nearly 20%. Middlesbrough has the highest rate of pre-term deliveries in South Tees.
- 24. Environmental factors that impact on this include foetal alcohol syndrome, drug abuse and smoking during pregnancy, along with poor diet and nutrition. An increasing number of older mothers and mothers who have received infertility treatment have led to an increase in some congenital conditions and multiple births, which also increase the risk of early birth/low birth weight.

- 25. Low birth weight increases the chance of childhood illness, cognitive disorder and respiratory illness. It is likely to have serious consequences for health in later life.
- 26. Middlesbrough also has the lowest percentage in the North East of children immunised for Diphtheria, Tetanus, Polio and Pertussis before their first birthday. This results in an increased risk of adverse health conditions.
- 27. James Cook University Hospital is located in Middlesbrough and has a highly successful neonatal early births survival rate. Children survive accident and illness more frequently and live longer. Those born with severe health needs or disability survive where they would previously have died. Some are supported by new technology and remain technology-dependent.
- 28. Some children, for example those with tracheotomies, would previously have remained in hospital, but are now supported at home and in schools.
- 29. Middlesbrough has a growing number of children from BME groups. There is a higher incidence of children and young people with complex learning disabilities and genetic disorders within minority ethnic communities.
- 30. There are also increasing numbers of migrants from Eastern Europe, which include a significant number of children and young people with high or complex needs.

BACKGROUND PAPERS

- Social Work Support for Children and Young People with Disabilities Report.
- Children Act 1989, Volume 6, Guidance and Regulations, Children with a Disability.

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