

HEALTH SCRUTINY PANEL

A meeting of the Health Scrutiny Panel was held on 15 January 2013.

PRESENT: Councillors Dryden (Chair).

ALSO IN ATTENDANCE: J Adams, Regional Manager, Contact a Family
S Lewis, Regional Information Officer, Contact a Family

K Blenkinsop, Acting Strategic Lead Children's Therapies, South Tees Hospitals NHS Foundation Trust
Representatives of Parents 4 Change.

OFFICERS: J Bennington, J Catron, J Dalby, H Douglas, E Kunonga and J Ord.

APOLOGIES FOR ABSENCE were submitted on behalf of Councillors Biswas, Cole, Harvey, Junier, Mawston, Mrs H Pearson and P Purvis. .

DECLARATIONS OF INTERESTS

There were no declarations of interest made at this point of the meeting.

12/30 INQUORATE MEETING

In the absence of a quorum and in view of the number of external witnesses in attendance at the meeting it was agreed by all present to continue on an informal basis to receive information from representatives of Contact a Family and Parents 4 Change on their experiences of having a child with complex needs and the services available to assist.

NOTED**12/31 MINUTES - HEALTH SCRUTINY PANEL 17 DECEMBER 2012**

The minutes of the meeting of the Health Scrutiny Panel held on 17 December 2012 had been circulated.

AGREED that consideration of the minutes of the meeting of the Health Scrutiny Panel held on 17 December 2012 be deferred to the next meeting of the Panel.

12/32 CHILDREN WITH COMPLEX NEEDS- EVIDENCE FROM CONTACT A FAMILY AND PARENTS 4 CHANGE

The Scrutiny Support Officer submitted a report the purpose of which was to introduce representatives from Contact a Family and Parents 4 Change who addressed the Panel on their experience of having a child with complex needs and the services available to assist. The Chair welcomed all in attendance at the meeting. In order to assist deliberations a series of questions had been provided to the organisations prior to the meeting.

As part of the background information and in the report submitted and PowerPoint presentation an overview was given of the national organisation of Contact a Family the key objectives of which were to assist families with disabled children to know how to get the right support; be more confident to deal with challenges they face; ensure that the families were understood, valued and included as equals in their communities and society as a whole; and reduce the financial disadvantage that such families faced.

Contact a Family was the only national charity that existed providing advice, information and support to families whatever their condition or disability from 0 to 25 years. It was pointed out that 320,000 families had been supported in the UK last year. In the North East, last year the organisation had received 1,149 enquiries over half (51%) of which were directly from parents/carers. Quarterly newsletters had a circulation of over 4,000 with 2,972 going directly

to parents/carers in the North East. It was acknowledged that with so many large scale changes to services the demand for Contact a Family's support and advice was greater than ever.

In response to a survey of families about the top three issues they were most concerned about now and over the next three to five years it was confirmed that education matters was the top issue closely followed by concerns about access to specialist services for their children. Stress had ranked the third most important concern. In terms of the specialist services it was noted that whilst some related to standard services different areas operated different criteria to access such services and that in some cases for very complex cases there may be only one centre in the UK which could cater for certain rare disabilities. The organisation could assist in signposting families to such specialist centres and also assist in putting families in similar circumstances in touch with each other.

Other concerns of parents identified from the survey included benefits and financial support following Welfare Reforms.

In 2011 parents had been surveyed about GP's which showed that 76% of families did not visit their GP about their child's disability or condition. Other issues identified included a lack of access to therapy services and child development teams; delays in getting diagnosis and not getting support in school until there was a diagnosis; issues gaining access to CAMHS; issues with continence service; support for child's health needs in school; and issues getting support to manage their child's sleep or behaviour.

Discussion took place around the reasons why such a high percentage of families didn't visit their GPs. It was noted that in the first place many families sought advice from specialist services. In terms of future planning of services It was acknowledged that given major health reforms there was a need to continue to develop relationships with the Clinical Commissioning Groups. The representatives of Parents 4 Change indicated that there was a concern at the level of understanding and lack of specialist knowledge of GPs hence many families accessed professional services for their child's condition and needs. It was pointed out that certain conditions during a child's development took longer to be diagnosed. The Chair was keen to ascertain how GPs were kept informed and made aware of developments. Reference was made to a new booklet with guidance for GPs as part of a detailed pack of information. The representatives indicated that whilst it should be the consultant (s) to keep a GP informed it was often the parent. From experience it was noted that often potential difficulties were not noticed until a child attended school and that in majority of cases the parents asked for an assessment rarely through a GP. Specific reference was made to a particular case which had taken seven years to get a diagnosis during which time the family felt they had been passed from one service to another adding to the stress of the family. It was considered that given the complexities of many conditions GPs had shown some reluctance in giving an indication of diagnosis wanting to err on the side of caution.

Reference was made to good parenting courses but from experience many families had shown reluctance to seek more support as they were insecure and in some way felt they were likely to be judged by others to be blamed for a child's disability. One of the aims of Parents 4 Change, a Middlesbrough based group was ensuring that professionals and parents made contact and shared their knowledge and expertise and to discuss challenges facing similar families to inform and influence change to children's disability services in Middlesbrough. Such a group enabled families in similar circumstances to gain confidence and assist each other.

As part of the remit of Contact a Family it was considered important to give families with disabled children the skills and confidence by providing good quality advice and information on any aspect of caring for a disabled child such as national Helpline, online or in person. Other measures included putting families in contact with each other through a network of parent support groups and online communities. In the North East they had an office based in Newcastle and provided a quarterly newsletter, weekly e-bulletins, workshops for families and worked in partnership with other organisations.

In discussing what improvements could be made the representatives indicated that there

should be improved communication channels and raised awareness through GPs. Although there was joint working across service areas it was considered that this should be further developed. Health was just one entity amongst other important aspects and one of the challenges as previously indicated was linked to the Clinical Commissioning Groups and areas of specialism and availability of funding to cope with greater needs and complexities.

Although in terms of advocacy services Contact a Family were not in a position to provide a one to one service they worked with parent support groups and helped signpost families to known local support groups.

From a parent's perspective the key areas for development were seen as having the opportunity to have representation on appropriate bodies around planning for future services; networking with other professionals; raising awareness to available support; opportunity for families to get together and share information and concerns; have a central point of initial contact and further guidance provided to GPs. Although it was felt that there were noticeable changes especially with regard to social care and service provider panels the main focus of communication with parents was in relation to actual changes in service provision rather than having a constructive say and influencing how such services should be provided.

From the perspective of the STHFT an indication was given of current engagement with families and the intention for future development to ensure a more meaningful pathway which was the most appropriate to a child's needs.

Contact a Family considered that one of the main issues facing services for children with complex needs was the Welfare Reform Act which would impact on families unable to work due to their caring responsibilities and that services would be challenged to continue to meet the needs of families with a limited and decreasing budget. They also indicated that proposals set out in Support and Aspiration would not be deliverable unless the structures set up by the Health and Social Care Act in England provided clarity for child health. It was indicated that the lack of statutory duties on health services was a significant weakness to providing joined up services for families and would result in confusion amongst services and families as to responsibilities and duties. It was also stated that the Health and Social Care Act did not provide a platform for education providers to take part in local decision making at Health and Wellbeing Board level which would make integrated commissioning more difficult.

The information provided by Contact a Family referred to the impact of public sector recession on services for children with complex needs. Evidence suggested that local authority budget cuts were reducing impacting on a range of services for disabled children including short breaks and vital specialist services such as speech and language therapy. It was considered that unless disabled children were a priority for local authorities and there was strategic planning to assess need and ensure adequate provision more families were likely to hit crisis point and ultimately result in higher costs for a local authority in the long term. It was considered vital that services continued to have an open dialogue with parents to ensure they remained an integral part of the decision making process.

AGREED as follows:-

1. That the representatives be thanked for the information provided which would be incorporated into the overall review.
2. That it be recommended that a representative of Parent 4 Change be co-opted onto the Panel for the duration of the current scrutiny investigation in respect of Children with Complex Needs.

12/33

CHILDREN WITH COMPLEX NEEDS - EVIDENCE FROM PUBLIC HEALTH RELATING TO CHILDHOOD IMMUNISATION

An introductory report of the Scrutiny Support Officer and detailed report of the Speciality Registrar Public Health relating to Childhood Immunisation in Middlesbrough had been circulated.

AGREED that consideration of the matter be deferred to a future meeting of the Health Scrutiny Panel.

12/34

CHILDREN WITH COMPLEX NEEDS - EVIDENCE FROM DEPARTMENT OF WELLBEING, CARE AND LEARNING

An introductory report of the Scrutiny Support Officer and report of the Director of Wellbeing, Care and Learning in relation to the educational needs and existing educational provision for Children with Complex Needs had been circulated.

AGREED that consideration of the matter be deferred to a future meeting of the Health Scrutiny Panel.

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12/35

DEPARTMENT OF HEALTH - LOCAL AUTHORITY HEALTH SCRUTINY CONSULTATION RESPONSE AND NEXT STEPS

A report of the Scrutiny Support Officer in relation to the recent Department of Health publication regarding Health Scrutiny had been circulated.

AGREED that consideration of the matter be deferred to a future meeting of the Health Scrutiny Panel.