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Needs Assessment for Children with Diabetes, Epilepsy and Complex Health Needs

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Abbreviations & Acronyms

ADD	Attention Deficit Disorder
ASD	Autistic Spectrum Disorder
DNA	Did not attend
A&E	Accident and Emergency
BGM	Blood Glucose Monitoring
CYP	Children and Young People
DCSF	Department for Children, Schools and Families
DFES	Department for Education and Skills
DGH	District General Hospital
DH	Department of Health
DSN	Diabetes Specialist Nurse
ESDW	East Sussex Downs and Weald
ESESCCS	East Sussex Early Support and Care Coordination Scheme
ESHT	East Sussex Hospital Trust
ESN	Epilepsy Specialist Nurse
FISS	Family Intensive Support Service
GP	General Practitioner
HES	Hospital Episode Statistics
H&R PCT	Hastings and Rother PCT
JSNA	Joint Strategic Needs Assessment
LA	Local Authority
MYEs	Mid-year population estimates
NICE	National Institute for Clinical Excellence
NSE	National Society for Epilepsy
NSF	National Service Framework
NST	National Support Team
PCN	Paediatric Community Nurse
PCT	Primary Care Trust
RCN	Royal College of Nursing
SHA	Strategic Health Authority
SHNA	Sexual Health Needs Assessment
WTE	Whole time equivalent

Who are Options UK?

Options UK is the UK programme of Options Consultancy Services Ltd, a leading provider of technical assistance, consultancy and management services in health and the social sectors. Options UK was launched in early 2006 to provide technical expertise to service providers, policy makers and commissioners in the UK.

With expertise in sexual health, adolescent health, service design, needs assessments, monitoring and evaluation, policy and practice and user consultation the multidisciplinary Options UK team provide fresh, innovative and practical advice, support and solutions to providers and commissioners of adolescent and sexual health services. Options UK have recently published a How to Guide for SHNAs – commissioned by the NHS National Support Teams for Sexual Health and Teenage Pregnancy.

To learn more about Options UK and other projects visit www.options.co.uk/uk

Options UK were commissioned in January 2009 by NHS East Sussex Downs and Weald (East Sussex Downs and Weald PCT), NHS Hastings and Rother (Hastings and Rother PCT) and East Sussex County Council to undertake a needs assessment for children with chronic disease (focusing on diabetes and epilepsy) and complex health conditions. The project consisted of a focused programme of qualitative service user engagement to generate primary in-depth data about the needs and issues of children and young people, parents and carers and key practitioners affected by or working with those affected by:

- Diabetes
- Epilepsy
- Complex Needs

Although it was decided to prioritise the conditions listed above, local asthma data is presented in Appendix 6.

EXECUTIVE SUMMARY

Methods

Between 29th January 2009 and 5th May 2009 Options UK interviewed a total of 94 people for this needs assessment: 27 parents, 42 children and young people and 25 staff and practitioners.

Key Informant Interviews and Engagement:

Service providers, included paediatricians, consultants, nurses and other paediatric specialists and adult specialists involved in transition services, as well as staff and practitioners from East Sussex County Council specifically, Family Intensive Support Service and East Sussex Early Support & Care Coordination Scheme. Staff from Grove Park School and Beacon Community College were also interviewed as were representatives of the National Society for Epilepsy and local parent support groups including Eastbourne District Diabetic Youngsters group (EDDY) and Seaford Parents Support Group.

Service Users, involved focus group discussions and one-to-one interviews with parents and carers of children and young people (CYP) with complex health needs, epilepsy and diabetes and focus groups and one-to-one interviews with children of a range of ages. Discussions with children with learning disabilities in addition to complex health needs included visual picture cards (different activities, services and feelings) and school or club staff assisted with communication as needed.

Data Collection

Data was collated and analysed from a mixture of national and local sources and also sourced from a range of existing reports and surveys that the commissioning bodies forwarded to Options UK.

Findings

The engagement process enabled parents, children and the staff and practitioners who provided them with services an opportunity to raise their concerns and frustrations with using or delivering local services. People also took the engagement as a chance to praise services and, in many cases, the individuals that they were in contact with from those services.

The results found that both service providers and service users believe there are gaps in local services, there are capacity issues and in some cases services are of a poor standard.

Importantly, though there was consensus about what these were and what the priorities were for addressing them. Service users were realistic and well aware of resource constraints. The extent to which, on the whole, their aspirations matched those of service providers means there is a solid platform for future service improvement that will meet the local needs identified.

Cross-cutting Issues and Themes

Several issues emerged from the engagement that affected all the parents and carers, irrespective of the health condition of their children. Three of the main cross-cutting issues are highlighted here and others are identified throughout the condition specific sections.

Diagnosis

The importance of sensitive and timely diagnosis was raised by many parents. Many reported that the handling of the diagnosis of their children had been poor. They all acknowledged that diagnosis was a traumatic time in any case but they felt that health practitioners were in some cases unnecessarily negative, that they inundated them with technical information they were not ready to absorb, or in some cases no information at all, and left them "to get on with it". There is more discussion of this in each of the sections.

Parents, and some health practitioners, said that there needed to be a period of assimilation after diagnosis and then a prompt follow-up appointment with the paediatrician at which questions could be asked and support and further information sources signposted.

Informal Support

Being able to meet with or speak to other people in a similar position, was identified by many parents, and children themselves, as something that they valued. Some said without such support and experience they would not have known about or gained access to the services that were available. Some interviewees said that support groups and informal support helped to fill the gap that there was around psychological services and therapies, although both service users and service providers were keen to clarify that they should not be a substitute for expert psychological support. A comment that was made on numerous occasions was that knowing who to go to, or “*knowing the system*” was key to accessing services.

Transition

Transition between services, or at different ages, in both health and education were identified as particularly difficult times for families and children and young people. Health services were not in all cases meeting guidelines on transition and parents and young people from all the target groups interviewed reported feeling particularly unsupported and abandoned by services once they entered into adult services.

Diabetes

All parents and young people engaged were asked what they thought would help improve local health services for CYP with diabetes. There was universal consensus among parents and the older children that the top three priorities were:

- More and improved specialist dietician services
- More Diabetes Specialist Nurse (DSN) capacity
- Psychological/psychiatric support

Parents also prioritised:

- Improving local specialist skills and ensuring specialist staff were abreast of current diabetes care and management regimes.
- More joined-up care in terms of the role of schools with attention being on school nurses being able to inject and staff being trained in Glucagon use in emergencies.
- 24 hour access to specialist health support via phone or email especially at diagnosis.

Younger children said they wanted to see:

- Smaller and more discreet equipment, which covered blood testers and pumps
- Treatment options of their choice
- Staff that listen
- A non-hurting cure / management with tablets
- A good dietician

Staff and Practitioners

There was an acknowledgement among all the health practitioners engaged in the project that paediatric diabetic services locally were below national guideline standards specifically in terms of:

- The ratio of children to DSNs
- The provision of paediatric dietician services across both PCTs
- Lack of psychological therapies and support

It was also widely acknowledged that pump therapy could not be offered locally without increased dietician resources and structured education for children and parents.

Staff were also aware of the difference in services between the two PCT areas especially in relation to dietician services and the lack of a diabetic paediatric dietician covering Hastings.

Another mismatch in service related to transition or young people's clinics and the fact that those delivered through the Conquest were restricted at present to daytime hours. The parallel service at the District General had early evening provision. Hastings had identified this as an issue and also believed it might be contributing to a high level of did not attend (DNA) figures for these services. Health staff also felt that their service should be more flexible and that clinics for adolescents or those in transition might be better delivered in a community setting to increase accessibility.

Service Priorities

The concerns that health staff had about the services they delivered consistently matched those of the parents and carers spoken to. Capacity, in terms of DSN and dieticians, was identified as an area that needed increasing resources simply to cope effectively and fairly, in terms of the two PCT areas, with current need without a local pump therapy service. Health staff identified the following as their priorities for an improved paediatric diabetes service to meet present needs but also to enable future service improvement through the provision of a local pump therapy service:

- More DSN resource
- Increased paediatric diabetes dietetic service in both acute and community setting
- Psychological support (a restricted service is being piloted)

Epilepsy

For most of the parents of CYP with epilepsy interviewed, their concerns about local services and their needs were inextricably bound up with the complex health needs of their child rather than specifically the epileptic element of their condition. For all respondents, however, there was consensus around the long waits associated with diagnosis and particularly access to MRI scanning; although the complexity of the condition was acknowledged as a factor in the drawn out experience most had of diagnosis.

The young people and other respondents whose experience of epilepsy was less complex identified the following factors as priorities:

- Psychological or counselling support
- Increased support/access to specific support for young people with epilepsy
- Raised public awareness to decrease stigma and improve knowledge

Staff and Practitioners

Health practitioners across the two PCT areas reported increasing numbers of children and young people with epileptic disorders. This was in part due to better diagnosis and in part due to increasing numbers of complex health conditions of which epilepsy was an aspect.

There was internal consensus that local paediatric epilepsy services were not meeting national guidelines. A specific gap was the lack of paediatric specialist epilepsy nurses in the two PCT areas. This resource was needed to increase the educative and information side of the service for parents, patients and schools and to ease consultant time pressure.

Service Priorities

There was consensus among health practitioners and support groups that the priorities for the paediatric epilepsy service were:

- Two paediatric specialist epilepsy nurses (one for each PCT area)
- Increased staff hours (to include specialist nurse time) to provide triaged telephone/email support services
- Increased resources to enable quicker investigation of patients with first seizures
- Increased provision of educational material and information for young people with epilepsy through a support group

Complex Health Needs

Despite the range of complex health needs and the abilities of the children of the parents interviewed, there were key things that parents said would improve theirs and their children's lives. Not least of these was a more positive and encouraging emphasis on what their children were rather than what they were not. Other service priorities were:

- Key workers throughout childhood and into adulthood
- Joined up agency working and improved communication between agencies
- Easier access to special equipment when needed
- Coordinated and accessible therapies and early intervention
- Better access to respite care and a more flexible and responsive service
- Increased dedicated leisure activities and improved access to mainstream provision
- Non-emergency phone support

Staff and Practitioners

Clearly many dedicated, passionate and hard working people work across the county to try to meet the needs of children with complex health needs, but there was universal consensus that there were gaps in services and inequality of access to services. A lack of capacity in community paediatrics was identified by many practitioners as leading to unacceptable waiting times for families and children and difficult workloads for staff. Other practitioners said that there was a lack of clearly commissioned services, which meant working arrangements depended on goodwill and historical arrangements.

Concerns were also raised about the 'safeguarding agenda' and the need for more resources to enable appropriate and timely responses on that front. It was felt that practitioners in community posts needed to run a daytime rota for rapid response to child death and sexual abuse medicals and that this requirement needed to be built into community staff job descriptions.

Service Priorities

Staff and practitioners identified the following as priority areas for change and improvement in order to meet the needs of local children, and their families, with complex health needs.

- Increased psychological support for children and families
- Increased capacity in community paediatrics
- The development of community liaison teams to assist when children with complex needs are hospitalised and receive mainstream acute care
- Improved communication between agencies and more multi-agency working
- Clarity about who held funds for equipment and coordination between health and social services to ensure equipment needs were met

Increased key worker provision and *"key workers for life"*