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# ‘Join Us On Our Journey’: developing a new model of care for children and young people with type 1 diabetes

Final report for NHS Diabetes, March 2012

Prepared by Dr Nicky Kime & Elizabeth Carlin

“I feel ‘sorted’ and confident. Getting Sorted has given me the chance to talk with other young people about diabetes, now I know I’m not the only one.”  
(Young person from Hull)

“Everyone with diabetes needs to come on Getting Sorted because it’s great, it’s fun, it’s relaxed and not like anything I’ve done before. I’m completely sorted- my diabetes and everything is better now.”  
(Young person from Leeds)

“This session has made me think about my diabetes and how I need to look after myself. I have enjoyed having this session with someone who knows what I am feeling.”  
(Young person from Durham)



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# Executive summary

NHS Diabetes commissioned Leeds Metropolitan University to undertake a 3-year research project called 'Join Us On Our Journey'. The aims of the research were to develop a model of care that will deliver the aspirations of the policy document 'Making Every Young Person with Diabetes Matter' and improve the care provision for children and young people with type 1 diabetes in England.

Children and young people with type 1 diabetes, their families and professionals, in nine acute trusts throughout the Yorkshire and the Humber region, participated in talking group discussions and individual interviews to find out about their experiences of diabetes care provision.

Findings show that there are certain aspects of the care pathway that need to be addressed. In particular, diabetes care, resources, education, psychological support, school/college and transition were found to be the main areas of concern.

## Diabetes care

Participants who attended the paediatric diabetes service were happy with the care they received. Young adults who accessed the adult diabetes service were less positive. Staff attendance at clinic and discontinuity in care were the main concerns raised. Access to 24-hour diabetes specialist care was not always available. Allocated clinic sessions and appointments were often too short. Diabetes teams had taken steps to improve clinic, but many aspects of clinic organisation were beyond their control.

## Resources

Professionals highlighted insufficient diabetes specialist nurses and administrators, a lack of dietetic and psychological support and inadequate staff training, especially regarding ward staff and their knowledge of diabetes, as major concerns.

## Education

Structured education was regarded as important, but time and resource limitations prevented diabetes teams from delivering structured education and reinforcing key aspects of continued education. Paediatric diabetes education tended to be ongoing, tailored to the individual and delivered at the 'right' time. Dose adjustment for normal eating (DAFNE) courses were provided for young adults. Awareness of type 1 diabetes among GPs and the public needed to improve.

## Psychological support

An acute lack of psychological support was evident region-wide and few services had access to a psychologist. Many young people and parents had no one to talk to about the impact of type 1 diabetes on their lives and would talk to a psychologist if available. Professionals identified a clear need for a health psychologist as an integral member of the diabetes team to support families and professionals.

## School

Diabetes management in schools varied enormously. Greater consistency in school policies and practices was needed, as well as more diabetes specialist nurses to support children, young people and parents in schools. Increased awareness of type 1 diabetes amongst staff and pupils was highlighted as important.

## Transition

Participants did not necessarily know what transition meant and when they were in transition they were often unaware of what was happening and why. Transition was regarded as a vital time in respect of a young person's diabetes journey and had important implications for the ways in which young people continued to manage their condition. Differences in record-keeping between paediatric and adult diabetes services region-wide had important implications for continuity of care.

## Areas for improvement

Staff training; structured education; psychological support; transition; young adult diabetes care; staffing levels; clinic; annual assessment and monitoring of complications; 24-hour on-call provision; record-keeping; GP and public awareness of type 1 diabetes and care provision; and type 1 diabetes education within schools.

Recommendations have been made indicating how current practice needs to change if the care of children and young people with type 1 diabetes is to improve. It is recommended that:

- A standardised, formalised staff training programme is in place, with all staff trained in diabetes care.
- A mainstreamed, standardised structured education programme is implemented within all diabetes services.
- A standardised, formalised diabetes management protocol is introduced in primary and secondary schools.
- Every diabetes team have a designated health psychologist.
- A transition plan is introduced within all diabetes services that is centred on the young person.
- A holistic approach to diabetes care is adopted and all young people and parents need to be actively involved.
- A universal record-keeping system is introduced across all diabetes services.

# Section 1 Introduction

In 2004 funding was provided by Bradford and Airedale Teaching PCT to undertake work with children and young people with life-limiting conditions, their families and healthcare professionals. The purpose of the work was to carry out discussions with children, young people and parents to find out about their experiences of continuing health care. From these discussions an idea was developed by Liz Webster and Jan Lee (Bradford and Airedale PCT), in conjunction with children and young people, called 'Join Us On Our Journey', which referred to the collective journeys of children and young people living with a complex and life-limiting condition. The phrase 'bus stops' was created by the children and young people to describe the various points along their journey where they felt they needed to 'get off the bus' to access support for their condition from different professionals and organisations, whether that support was medical, emotional, social or educational.

The decision was made to use the original idea, 'Join Us On Our Journey' incorporating 'bus stops', as a basis for the development of a generic model of diabetes care provision for children and young people. A research project was conceived that focused on creating a template of care for children and young people with type 1 diabetes, combining the 'Join Us On Our Journey' model and the specification from the policy document, 'Making Every Young Person with Diabetes Matter' (Department of Health [DH], 2007). Subsequently, the 'Getting Sorted' programme, based at Leeds Metropolitan University, was commissioned by NHS Diabetes to undertake a 3-year research project in the Yorkshire and the Humber region called 'Join Us On Our Journey' with a funding period from April 2009 to April 2012.

## Section 2 Aims

The aims of the research project were twofold.

1. To develop a model of care that will deliver the aspirations of the policy document 'Making Every Young Person with Diabetes Matter'.
2. To improve the care provision for children and young people with type 1 diabetes in England.



# Section 3 Methodology

Process-mapping, using talking groups (a term coined by the young people to describe focus groups) and individual interviews, were the main methodological components of the research. The talking groups were used to generate discussions with groups of children, young people, parents and professionals about their perceptions, beliefs and attitudes in relation to diabetes care provision in the region. Individual interviews were employed on those occasions where people preferred not to, or were unable to, participate in a group discussion, but still wanted to contribute to the research on an individual basis. The rationale behind using the process-mapping approach was to map the type 1 diabetes journey for children and young people who have the condition, which meant establishing what works well, what works less well, where the areas of inefficiency are to be found and how a particular area needs to improve. In the case of diabetes care provision for children and young people, this approach enabled the complete process from start to finish (i.e. from diagnosis through to transition from paediatric diabetes services into adult diabetes services) to be fully realised.

## Process-mapping

A process-mapping exercise took place in nine sites across the Yorkshire and the Humber region to ascertain the baseline position for diabetes care provision. As well as finding out the current situation, this process identified where the gaps were and what needed to change by documenting the activities and different stages of diabetes care experienced by children, young people, parents and professionals. There were three broad, overarching questions:

- what is currently happening?
- what is missing?
- what needs to happen?

## 'Bus stops'

'Bus stops' were used to represent the different stages along the child's and young person's diabetes journey. These were aligned to the 'Making Every Young Person with Diabetes Matter' (DH, 2007) policy document. The 'bus stops', along with their key themes, are indicated in the table below.

<b>Bus stop 1</b> Diagnosis and initial management	<b>Bus stop 2</b> Annual assessment of the continuing care plan and monitoring for complications	<b>Bus stop 3</b> Management of complications	<b>Bus stop 4</b> Structured education	<b>Bus stop 5</b> Mental health and emotional well-being	<b>Bus stop 6</b> Support of child and family
<b>Bus stop 7</b> Early years and school setting	<b>Bus stop 8</b> Promoting good health and healthy choices	<b>Bus stop 9</b> Sexual health and pregnancy	<b>Bus stop 10</b> Transition	<b>Bus stop 11</b> Benefits	

The 'bus stops' represented the main points for discussion in the talking groups and individual interviews. All participants were asked the three key questions above in relation to each 'bus stop' theme.

## Data collection

The table below illustrates the sites involved in the research and the number of individuals who participated in the research.

Research sites	Children and young people (6–25 years of age)	Parents	Professionals	Total number of participants at each site
Airedale	5	7	2	14
Bradford	14	16	4	34
Calderdale/Huddersfield	12	17	4	33
Harrogate	14	16	2	32
Hull	11	14	2	27
Leeds	19	24	12	55
Mid Yorkshire	17	24	12	53
Northallerton	8	10	3	21
York	16	13	3	32
<b>Total</b>				301

## Ethics

Central research ethics approval was obtained from the National Research Ethics Service using the online Integrated Research Application System (IRAS) and local ethics approval was obtained from the Leeds (Central) Research Ethics Committee. Individual research governance approval for the nine sites participating in the research was obtained through each trust's research and development department.

## Data storage

Only members of the 'Join Us On Our Journey' research team were granted access to the study data. Personal data relating to the research participants were stored on university computers and all computer files were password protected. Any other research material – for example, hard copies of transcripts – were securely stored in university filing cabinets that were locked when not in use. Participant confidentiality and anonymity were strictly assured at all times throughout the research. A coding system was in operation to protect participants' personal information; this was initiated at the beginning of the recruitment process and continued through to completion of the research.

## Analysis

Data analysis was undertaken by members of the 'Join Us On Our Journey' research team. The results from the research were analysed according to thematic analysis. This process involved generating categories and coding data so that common themes and links could be identified, whilst at the same time ensuring the data remained faithful to, and accurately reflected, the participants' comments. Individuals were selected from those who participated in the research to verify the themes and thereby further establish the reliability of the research findings.

# Section 4 Findings

For the purposes of this report, the findings from the children, young people and their parents are presented separately from those of the professionals. In each case the findings clearly demonstrate that there are specific areas in a child's and a young person's care pathway that need to be addressed.

## Children, young people and parents

The interim report highlighted key areas of concern among children, young people and parents, including: treatment; communication and support; education; school/college; and transition. In the intervening period since the interim report was published, work with additional children, young people and parents has resulted in research findings that have reinforced these concerns. In addition, further evidence has emerged from the talking groups and individual interviews that endorses apparent inconsistencies within and between diabetes services across the region. Each key finding is now explained, including, where appropriate, additional material that has emerged since the interim report.

### Diabetes care

In general, all participants who accessed the paediatric diabetes service were extremely positive about their diabetes care and commented on how helpful and supportive both the consultants and diabetes specialist nurses were.

*I like it that they're (doctors and nurses) trying to make it better for me and making sure I have the best treatment I can have and I'm really thankful (young person, aged 7)*

Most participants stated that the care in clinic was good, but unfortunately their experience of time spent on the hospital wards was less positive. Participants commented on how nursing staff on the wards seemed to be unsure as to how to treat children and young people with type 1 diabetes and, in particular, had little knowledge of treatment around carbohydrate counting and insulin dosages. In addition, when children and young people were admitted to hospital in diabetic ketoacidosis (DKA), parents indicated that ward staff often sought their advice regarding the numbers of units of insulin to give their child and asked them for the amount of carbohydrates in their child's meal.

In general, participants were positive about the relationship they had with their consultants and diabetes specialist nurses, although there were aspects of their care they thought could be improved. For example, participants stated the time spent in clinic waiting to see the consultant and/or nurse was too long and then when they did eventually see their consultant the appointments were too short. Furthermore, appointments were often changed or cancelled. Young children in particular thought the waiting rooms were not child friendly and felt overwhelmed by the clinic environment. Children and young people thought the waiting rooms needed to be geared towards all age groups and not just the very young children.

*I would change the waiting rooms. Sometimes we have to wait a long, long time and there's only a few fluffy toys. They could have more to do and stuff so it's not as boring (young person, aged 8)*

In terms of a child's or a young person's continuing care, few participants were aware of a care plan or had any idea what was meant by a care plan. Very few participants had been given

information following diagnosis about what would happen next, either in the short or long term and, in addition, they had been told little about potential complications, especially long-term complications. Participants thought children and young people needed to be told about and involved in discussions relating to alternative treatments, including pumps and multiple dose injection therapy (MDI).

*Just because it's a child doesn't mean we can't learn to go with these treatments* (young person, aged 19)

Those young people who accessed the young adult diabetes clinics were not as happy with their care and made frequent comparisons between the care they had received in paediatric services and the current care they received in adult services. Staff attendance in clinic was a major issue. Many participants were unhappy with the staff available and felt there was no continuity because they always saw a different consultant whenever they attended clinic. Participants reported they found it incredibly frustrating and a waste of time seeing different consultants every time they attended clinic.

*... at the children's clinic I had thorough appointments and saw doctor, nurse and dietitian. More recently, my appointments are a complete waste of time, seeing a different doctor every time for a maximum of 5 minutes ... I can't remember the last time I saw a nurse or dietitian* (young person, aged 22)

*I have only seen my consultant once in over 4 years. I have been passed along to various other doctors during clinic appointments* (young person, aged 24)

The major drawback was that appointments were repetitive and unhelpful as most of the appointment time was taken up by participants having to give a full medical history. In addition, participants stated they had established a trusting relationship with their paediatric consultants as a result of the care and attention they had received and yet this was not the case with their adult consultants. Participants reported that the adult consultants did not really know them or understand their diabetes.

Participants commented on the annual assessment process and how this was no different from their usual clinic appointment. Participants thought that clinic appointments were far too short and, in particular, that annual review appointments should be allocated even more time and thorough checks should be carried out as part of the procedure for monitoring of complications, including the eyes and feet. Foot checks seemed to be very 'hit-and-miss'.

One issue relating to clinic appointments that young adults found inconvenient was the outsourcing of blood tests to GP surgeries. For them it meant that extra time was taken up attending two separate appointments when they would prefer to visit one clinic for all aspects of their diabetes care.

*I really view appointments as pointless. I get my HbA1c and my weight done and that is all. It really would be much easier to go to my GP's instead* (young person, aged 22)

Whilst young adults were very positive about the fact that adult diabetes specialist nurses were DAFNE trained, they thought that consultants needed to be as well. Some young adults reported no longer having access to their consultant once they had completed the DAFNE course, which they saw as a backward step.

*It's great nurses are being given more control but a regular appointment with a consultant I think is important in order to reinforce treatment adherence* (young person, aged 19)

## Communication and support

Many participants who accessed the paediatric diabetes service had a good relationship with their diabetes team; communication was generally not a problem as they could contact their diabetes specialist nurse at any time via the telephone. Many of the children and young people – in particular, those who were in their early teens and were therefore at an age where they had a fuller understanding of their diabetes – wanted to have a greater input into their care, to be involved in decision-making and to be given more responsibility. They felt their diabetes was controlled by their doctor and their parents rather than by them. Children and young people, even those of a relatively young age, stated they often felt ignored during consultations and the adults tended to talk to one another as if they were not in the room.

**I don't like it when they all talk about me at the same time ... they talk about me as if I'm not there** (young person, aged 8)

Young people stated they would open up more if they had a one-to-one consultation with their consultant; there were issues they did not feel comfortable discussing with their parent(s) present. However, some young children were reluctant to initiate a conversation with their doctor.

**I get really, really scared about asking my doctor; I feel too shy** (young person, aged 6)

A lack of support, particularly psychological support, was a major issue amongst participants. For the younger children parents were their main source of support. Adolescents and young adults stated that counselling or input from a psychologist would have helped them cope better with their diabetes as they did not feel able to talk to their consultant, especially those who saw an adult consultant. However, it was extremely important to have someone other than their parents to 'offload to'.

**Because if you keep it all in then you end up doing stupid things like not checking your blood sugars** (young person, aged 24)

**I find it hard to cope sometimes and get extremely stressed/down about things where counselling would have helped** (young person, aged 23)

Many children and young people stated they felt isolated among their peers. While they did not want necessarily to tell everybody about their diabetes, they thought they would benefit from the opportunity to talk to others of their age who also had type 1 diabetes. Those who had attended a diabetes camp or a programme such as 'Getting Sorted' commented on how helpful they had found it, simply because everyone had the same condition and therefore having diabetes was seen as 'normal'.

Parents commented on how, at diagnosis, they found the amount of information difficult to cope with. Diagnosis was often a time of crisis for the families and, therefore, parents were often incapable of taking in all the information given to them.

**The information was useful but it kept coming and coming and coming!** (parent of 16 year old)

Whilst some parents had access to a parents' support group, many parents had no support at all. They commented on how useful it would have been to have the support of a parent group, psychologist or counsellor to help them deal with the shock of diagnosis and to provide ongoing support. Some parents had paid for private psychological support as none was available through diabetes services. Parents stated they would benefit from a counsellor in attendance at clinic as there was often no one to talk to at this time and they would make use of a psychologist if available.

I couldn't have managed without the staff. If there was a psychologist available to talk to I'd be there like a shot! (parent of 9 year old)

Parents were often reluctant to talk to their diabetes specialist nurses as they were acutely aware of how overstretched the nurses were. Online forums were said to be helpful, although these were mostly American and therefore, sometimes, culturally inappropriate, plus they were more useful for specific issues relating to diabetes, such as carbohydrate counting, rather than providing parents with coping strategies. All participants stated they would appreciate having access to individual support groups aimed specifically at children, young people, parents and siblings.

## Education

A lack of awareness of type 1 diabetes amongst GPs was highlighted as a major concern. Parents stated GPs seemed to be slow to detect the symptoms of diabetes and, in general, families had to go to their GP on two to three occasions before the condition was correctly diagnosed.

I went to the doctor on three occasions and was told each time nothing was wrong. On the third occasion I was told I would be reported to social services as an over protective parent! (parent of 16 year old)

Participants thought that the ward staff needed more education on how to manage children and young people with type 1 diabetes. Their experiences illustrated that many of the staff were unaware of how to treat the condition and were too reliant on specialist diabetes nurses. As far as education relating to healthy lifestyles was concerned, little advice was given on diet, weight and exercise and the impact of this on someone with type 1, other than when a young person was already active and involved in sport. Many young people stated they had never been given any information in the form of advice or leaflets relating to sexual health or pregnancy. Many parents and recently diagnosed young adults had had to be proactive and conduct research on the internet in order to find out most of what they needed to know.

Pretty much had to teach myself (parent of a 7 year old)

Participants also believed a lot more needed to be done to raise public awareness of type 1 diabetes as most people were not aware of the difference between type 1 and type 2. In their experience, this lack of awareness led to a delay in diagnosis and created misconceptions amongst friends and teachers as to why a young person had type 1 diabetes.

There needs to be more done to increase public knowledge about diabetes. I only found out I had diabetes after having a general blood test because I had been suffering from nightly leg cramps for 4 months (young person, aged 23)

[teachers say things like] 'oh you get diabetes if you're fat' ... they don't say type 1 or type 2 (young person, aged 12)

Whilst many participants were in receipt of benefits, typically Disability Living Allowance (DLA), some families had no knowledge of their potential entitlement to benefits and had not been given any information. Regarding the ways in which information was provided, some children and young people said that information given on a one-to-one basis was adequate, whereas others would prefer to attend structured education workshops similar to the DAFNE course offered as part of adult services. The main reason given was that a group approach enabled children and young people to meet others in the same situation. Those participants who had attended a workshop commented on how helpful they found the session.

I was invited to a carb-counting class to help me understand how to read labels and be confident with carb-counting. This class was really helpful (young person, aged 17)

However, children and young people who had attended structured education sessions were in the minority. Participants said they had learnt most about their condition from others with type 1, either through a support group or a chance encounter with another person who had the condition.

## School/college

There was a clear difference in the support provided for children and young people with type 1 diabetes between primary and secondary schools. In general, children in primary schools had a more positive experience than young people in secondary schools. Regardless of the age of the child or young person, all parents met with a member or members of staff when their son or daughter was diagnosed, in order to discuss their care and day-to-day management. In general, the head teachers were said to be helpful, but the assistance they personally provided or initiated was limited. They were unfamiliar with type 1 diabetes and, therefore, had little knowledge of what a child or young person needed. This meant that monitoring and day-to-day management was usually the responsibility of a volunteer in school or the parents. Many parents and young children in particular, relied on volunteers within schools to help them, rather than the enforcement of school policies, which were often not in place. The volunteer was usually the receptionist rather than the school nurse or a teacher.

Feel really dependent on people's goodwill within school to help (parent of 9 year old)

When their son or daughter was diagnosed, many parents had to take time off work to go into school at regular intervals, typically every 2 hours for up to 2 weeks. Parents felt it would be beneficial to have a dietitian in school, certainly in the immediate post-diagnosis phase, to help with the carbohydrate counting of school meals. They commented on how much easier it was if they provided their son or daughter with a packed lunch because they could control to a greater extent what their son or daughter ate. However, some schools did not allow packed lunches, which created further difficulties in terms of diabetes management. Furthermore, parents did not want to enforce the packed lunch option and then risk their son or daughter feeling singled out as being different from their peers.

Whilst some parents felt that much of the ongoing education of school staff was left to them, the majority stated the diabetes specialist nurses attended school when their child was first diagnosed, in order to provide training for teachers and other staff. The general consensus amongst children, young people and parents was that there needed to be increased awareness amongst all school staff and pupils within the school. They wanted the diabetes specialist nurses to provide more information sessions as part of teacher training days and assemblies. Parents and young people thought it was a good idea for diabetes specialist nurses to work with families and school staff to implement a structured diabetes plan in school from the start, when children and young people were first diagnosed with the condition. In the same way that there was an allocated child protection officer in schools, some parents suggested there should be a member of staff with responsibility for 'long-term conditions', including, for example, asthma and epilepsy. When asked about school nurses, in many cases the parents and young people were unaware of a school nurse or, if there was one, they did not know who the school nurse was.

More needs to be done to help schools and educate them. I don't even know if there was a school nurse (parent of 11 year old)

When the children and young people were asked about their experiences of school, in general it seemed the children in primary school were better catered for, in respect of their diabetes care, than those in secondary school. The young people attending secondary school stated most of the school staff did not know how to deal with them because they had type 1 and they had more negative experiences than positive ones as exemplified below.

Teachers complain about me having to have snacks and have drinks and go to the toilet  
(young person, aged 15)

Test kit has been stolen out of bag on 4–5 occasions and then I get into trouble because they say I shouldn't have had it in school!  
(young person, aged 16)

It was clear that families' experiences in schools varied dramatically and the parents, in particular, believed this was partly because of the attitudes of teachers and school staff. Whilst many staff were prepared to take an active role in helping children and young people manage their diabetes in school, others were not. Children reported instances of teachers sending them on their own to the school office to fetch their kit for treating a hypo or even teachers leaving children as young as 6 years of age in a classroom on their own to check their blood glucose levels. In one extreme case, parents took their 8-year-old child out of one school and transferred him to another, in order to ensure his safety.

We've had a lot of issues with schools and [son] has actually changed schools because of his diabetes  
(parent of 9 year old)

Those young people who attended college or university reported having no problems. This was largely because they managed their diabetes independently. In most cases the young adults were not even sure whether college or university staff were aware they had type 1 diabetes. For those young people who worked, their diabetes had no impact on their performance, although in some cases they had found initial difficulties securing employment because of employers' ignorance of the condition.

## Transition

The general feeling regarding transition from paediatric to adult diabetes services was that young people and parents needed to be better informed of the process. They did not necessarily know what the transition process meant and when they were in transition they were often unaware of what was happening and why. Young people and parents stated too much was assumed by the diabetes teams, particularly the paediatric teams, regarding their knowledge of transition. They felt more communication was needed between paediatric and adult diabetes services regarding young people's individual needs, rather than assuming that all young people moving into adult services were a homogeneous group. Those young people who had been through transition thought the time spent in transition was important. Ideally, they believed a year or more was appropriate for the transition process. This enabled the young person to spend time with the paediatric and adult diabetes teams and, therefore, build up a comfortable rapport.

I was told a year before transition what it would be and how it would happen  
(young person, aged 17)

I moved sites at 16 and both sites were supportive  
(young person, aged 17)

In some instances young people and parents felt they were provided with all the necessary information on the transition process in advance of it happening. In fact, they commented on how at the time they remembered thinking it was an excellent service. However, some young people felt that, in reality, the process was not followed through. Consequently, the transition process was very



confusing, not only for the young people, but for their parents, as they were expecting a number of things to happen that did not materialise. Young people and parents commented on how the period of transition was a vital time in a young person's diabetes journey and, therefore, greater emphasis needed to be placed on ensuring young people and their families were assisted through the process.

*I was originally told that because I was 13, I would be slowly put into the adult clinic but I'd spend half of my time in paediatrics and half of my time in adults to get me used to swapping over but that never happened. I didn't know I was in a transition clinic (young person, aged, 22)*

## Inconsistencies

Inconsistencies were evident both between diabetes services and within diabetes services.

- Young people and parents received conflicting information from consultants and diabetes specialist nurses when attending clinic. This applied region-wide, whether it was young people within the one hospital seeing the same diabetes specialist, young people within the one hospital seeing different diabetes specialists or young people within different hospitals seeing different diabetes teams. In one instance a young person was given information at one appointment and then different information at another appointment with the same diabetes specialist nurse.

*I have thought about moving to another hospital or paying to get a second opinion because of conflicting advice. (Parent of a 15 year old)*

- There seemed to be huge inconsistencies across the region regarding the use of pump therapy, both between diabetes services and within diabetes services. This generated a large amount of discussion amongst children, young people and parents. One parent was told her child could not have a pump because of her daughter's poor control, i.e. her HbA<sub>1c</sub> levels were too high, whereas another parent was told her child could not have a pump because they were only available for those young people who had poor control.
- Young people and parents commented on the variable level of care and differing quality of advice amongst ward staff. They agreed that ward staff were not always knowledgeable about type 1 diabetes, but what was more confusing was that ward staff often gave advice and information conflicting that from the diabetes specialist nurse or consultant. As one young person stated:

*Refused to do what was told in hospital ... get diabetic doctor to come, because on ward staff kept giving very different directions (young person, aged 15)*

- Children, young people and parents commented on the inconsistencies in clinic. As far as monitoring of complications was concerned, different checks were conducted in clinic, both within and between the various diabetes clinics across the region. Some young people received checks in relation to their feet every year whilst others did not, despite being told they required the foot checks. The type and amount of education was different depending on the hospital that the families attended. Some families had the opportunity to attend group workshops, for example, on carbohydrate counting; others were given information on a one-to-one basis. Some families were told to access information in books or on the internet, which they did not find entirely satisfactory.

*We've moved hospitals because wasn't happy with the first one. I had to do most of the research and ask most of the questions rather than the team giving information (parent of 7 year old)*

- As previously discussed, the provision of psychological support was a major area of variability. Whilst some services had support from a psychologist for a set number of hours per week, others had no access to a psychologist.
- There appeared to be a huge difference in the diabetes care provided across the region depending on whether care was part of paediatric or adult services. Young people who had experienced the paediatric diabetes service commented on the stark difference in the approach to their care when they moved to adult diabetes services. Notable differences occurred in the length and organisation of clinic appointments, the quality of care and the relationship with the adult consultants.
- Families spoke of variable policies within and between schools, in particular between primary and secondary schools. Parents stated it needed to be made explicit what children and young people could and could not do in terms of the day-to-day management of their diabetes, especially in larger secondary schools where buildings were spread across a wide area. For example, they needed to know the procedure for eating and drinking in class, where it was appropriate to inject insulin, where it was safe to store medication, what to do if feeling ill and which member of staff to contact.

## Professionals

The particular areas of concern for professionals were focused on resources, clinic, education, psychological support, schools/college and transition. Each of these is now explained.

## Resources

Staffing levels and time were the most talked about resources in discussions with professionals. Both of these had important implications for the delivery of the individual diabetes services and the care provision available to children, young people and parents. Throughout the region staffing levels were such that diabetes teams were barely able to meet the demands of their caseloads. In most sites there were insufficient diabetes specialist nurses, part-time dietetic support only and limited, if any, psychological provision. The result was that diabetes services were operating at a sub-optimal level, with particular aspects of service provision in need of improvement, including diabetes care on the ward, staff training, psychological support and structured education. Without doubt, diabetes teams were performing as best as they could, given the limited resources available to them, but as the workload increased they felt under increasing pressure.

... it's just that it feels like an elastic band at the moment and it's fully stretched and ready to snap

In terms of care on the ward there were differences relating to standard operating procedures depending on the age of the young person and whether they were admitted to a paediatric or adult ward. As far as paediatric admissions were concerned, the different sites had a protocol in place, usually in the form of a checklist, which was referred to by the ward staff. However, a checklist was not necessarily available for young adults who were admitted with type 1 diabetes onto an adult ward. This, coupled with the lack of mandatory diabetes training for ward staff and the variable knowledge of diabetes treatments amongst ward staff, meant the level of care within a hospital and between hospitals was different. This was especially problematic for young adults with type 1 diabetes on adult wards, but the situation was prevalent on both paediatric and adult wards. Notably, there was a lack of formalised, continuous staff training in respect of the protocols and procedures that ward staff should follow when a child or young person was admitted with type 1

diabetes; the absence of this could lead to problems in terms of incorrect or inaccurate information being given to families. Most sites recognised this was an area for improvement.

Ward staff are trained and updated on any changes to diabetes care every few weeks, but this is an area where improvement is needed and it needs to be more formalised

Some paediatric wards had link nurses who were trained in diabetes care by the diabetes specialist nurses and who, therefore, provided appropriate education and advice when the diabetes specialist nurse was not available. However, problems arose when the link nurse was not on duty and a member of the diabetes team was not available, often due to staffing limitations. In some cases, especially if there was no link nurse, the diabetes specialist nurses facilitated regular teaching sessions on the wards to which all staff, including doctors, were encouraged to attend.

Most sites provided an on-call diabetes service, but this did not always include an out-of-hours service. Although the aim was for a newly diagnosed person to be seen by a diabetes specialist within 24 hours, this did not always happen, particularly if someone was admitted on a weekend. Nevertheless, the need to administer appropriate care was regarded as paramount.

Type 1 diabetes is not common so it needs to be done correctly. Over the weekend what's more important is that someone gets insulin and that somebody realises that they have type 1 diabetes, so that the actual details of it can wait

In all sites, each newly diagnosed person did not leave hospital until they had been seen by a member of the diabetes team and their condition had stabilised. Some sites reported that increasingly children and young people were remaining in hospital for longer, in order that they could receive the appropriate care and education. Following discharge from hospital, families had continued access to their diabetes specialist nurse. In all the sites, especially during the initial management phase, diabetes specialist nurses visited families at home and made regular telephone calls to monitor families and provide education. In addition, families could contact by telephone a member of the diabetes team, normally a diabetes specialist nurse but in some cases, their diabetes consultant. Parents of a child or young person with pre-existing diabetes could also contact their diabetes team by telephone and in all cases, if this was outside normal working hours, they were transferred to the ward. In all the discussions with professionals it was felt that the telephone service built a good partnership between families and the diabetes specialist nurses.

The giving of time was an important issue for professionals. All the diabetes teams stressed the importance of investing the time to build a rapport and establish a bond with the child or young person with type 1 diabetes and their parents at diagnosis. This was seen as crucial for laying the foundation for a successful working relationship in the future. This and the attitude of the diabetes team were regarded as vital prerequisites for helping a person cope with diabetes in the long term. It was important that members of the team were perceived as friendly and accessible and that the approach taken by professionals was individualised to meet each family's specific needs.

... the impact of what happens around diagnosis usually stays with someone forever so if that's handled well, that can help somebody learn to manage their diabetes probably more successfully

However, professionals spoke about their time being eroded because of increasing workloads and the number of new cases they had to take on. The issue of insufficient time was a constant theme running through all aspects of the different diabetes services, impacting on clinic, the level of support provided and the amount of education, particularly structured education, offered.

Technology was highlighted as an issue in some sites. Advancements in technology were sometimes blocked through bureaucracy within the trusts; the effect of this was that diabetes teams were prevented from providing the level of care they wanted.

Administrative support was severely lacking in many of the sites. In some cases members of the diabetes teams had to undertake their own administration, which only served to add to their workloads and create further pressures.

Administrator will be in one day ... but if the letters won't wait a week to go out then we end up typing our own letters which impacts patients' care because I'm not the quickest typer

## Clinic

Most professionals stated clinic appointments were not long enough and it was a struggle to achieve all that was necessary in such a short time. For some diabetes teams, clinic was a concern largely because caseloads were constantly increasing and yet, instead of being allocated more clinic time, they were expected to see more patients in the same or less time. This was a particular problem at annual assessment when there was more information to work through in the same amount of time. As a consequence, staff felt they were doing their families a disservice, even though in reality they tried their best to accommodate all families, which inevitably meant that clinic appointments generally ran beyond their allotted time. Advances in technology as well as more complex treatments had created further pressures. For example, the use of Diasend (a tool that allows for data upload from glucose meters, insulin pumps and CGM directly to a central website), although a useful tool, had had the effect of lengthening appointments.

New technologies add to clinic discussions but the timings have never moved forward to reflect this ... there has been no allowance for that in the length of clinic and it simply doesn't work

In situations where clinic appointments routinely took up more time, professionals commented on how difficult they found this, in particular feeling overworked and, therefore, not being able to give 100% to the young people, especially those booked in at the end of clinic. They felt they were constantly 'chasing their tail' and this had an impact on what they could achieve in the time available. For example, diabetes specialist nurses felt they did not have the time to talk to individual families at length about their concerns. At the same time, professionals were aware of the need to be encouraging and to focus more on the positives rather than dwell on the negatives (the HbA1c result) at every appointment. Many of them appreciated that young people found clinic stressful.

I know a lot of young people have said to me it's like going to get your exam results when you go to get your HbA1c result and we know getting exam results is a stressful time for young people

It was rare for a psychologist to be in attendance at clinics, largely because few sites had a designated psychologist. In terms of dietetic support all teams included a dietitian with varying hours, but they were not always available for every clinic. Nevertheless, the diabetes teams thought it was important for a dietitian to be present at clinic to provide education and to show children and young people that they were part of the team. Some sites were unable to provide a dietitian in the adult clinics. This meant that young adults with type 1 diabetes had no dietetic input whatsoever when they attended clinic.

As far as the management of clinic sessions was concerned, different ways of working and combinations of staff were utilised within the different teams, ranging from all professionals being present in one room for each consultation to professionals occupying separate rooms for each consultation. Regardless of the approach adopted, the message seemed to be the same, that the

diabetes teams were constantly evaluating their clinic procedures and looking for ways in which to improve their service for families. No site reported having achieved the ideal clinic scenario, although there were particular clinic attributes that were deemed more successful than others. These included:

- longer clinic appointments, for example, up to 1 hour
- continuity of care and ensuring children, young people and parents saw the same professional(s) at successive appointments
- having a link person/diabetes educator to control the flow of children, young people and parents through clinic
- age-banding clinics and scheduling appointments for adolescents and young adults after school/work hours
- creating a one-stop shop with all professionals in attendance so care was more individualised and children, young people and parents had greater control in terms of who they needed/wanted to see
- ensuring children, young people and parents had the dates of their four clinic appointments for the year at the start of the year, thereby allowing them to plan ahead
- introducing automated texting as a clinic reminder
- aiming to ensure the child or young person felt more important in the consultation by involving them in decision-making and collaboratively agreeing targets and goals
- providing resources for children, young people and parents in the waiting area, for example, information on carbohydrate counting
- following up every clinic session with a staff meeting in order to review and discuss each child or young person
- moving away from the medical target of HbA1c towards a more holistic approach and, in particular, incorporating lifestyle changes.

I think if we had more time and resources we could use our clinic in a more imaginative way ... a clinic that is quite holistic in what it's offering and not necessarily seen by a doctor, a nurse or a dietitian but the families and the children can choose what they need

All the diabetes teams raised the issue of those children and young people who persistently did not attend clinic (DNAs). This was identified as a major concern in some areas, to the extent that DNAs were referred to social services because the teams felt safeguarding issues needed to be considered.

## Education

In general, education across all the sites was ongoing, and provided predominantly on a one-to-one basis rather than in structured group sessions. The diabetes teams felt that education should be tailored to each child, young person and their parents and given at the 'right' time.

It's more about getting the families to talk about what they want rather than telling them what to do and when to do it

Education began as soon as a child or young person was admitted to hospital, although in the initial stages this was usually in the form of basic information, akin to a 'survival guide', as the diabetes specialist nurses felt it was important not to overload children, young people and parents with too much information at what was generally a very stressful time. Some sites had measures in place to ensure every child or young person and their parents received certain information: for example, a checklist of education that had to be completed and signed off by the person delivering the education before the child or young person could leave hospital. In most cases the diabetes

specialist nurses provided the bulk of the education, although dietitians normally saw the child or young person on the ward when they were first diagnosed and before they were discharged. In those sites where there was a diabetes educator they worked with the rest of the team to deliver appropriate education and support children, young people and their parents, especially in the early stages following diagnosis. Some diabetes teams referred to the benefit of keeping a child or young person in hospital longer for education purposes. Being 'on site' had its advantages as this meant children, young people and their parents were accessible from an educational and learning point of view. Most importantly, education could be delivered over a few days rather than all at once; key points could be reinforced and particular aspects of diabetes management could be addressed according to the needs of individuals.

... we can do the education over a few days and they actually hopefully retain it rather than being bombarded ... some are able to retain it better than others ... you do have to reiterate things and it's fine because they're there and you can do

However, facilitating education in bite-size chunks over a period of time was not possible for some teams as the current layout of the hospital and/or the location of the diabetes teams meant that, logistically, education could only be delivered at designated times.

Whilst all the professionals recognised that they were able successfully to deliver appropriate education at diagnosis and on an ad hoc basis, they acknowledged that they were often not in a position to reinforce particular aspects of education.

I think we're really good at diagnosis with support and education but something we're not good at is re-educating

All the professionals were aware of the need to deliver a structured education programme that catered for the changing needs of children and young people at different ages. Although they regarded this as an important component of diabetes management, both in the short and long term, time and a lack of resources were the main reasons preventing staff from delivering structured education. Professionals commented on the fact that there was a lack of age-appropriate literature available explaining various issues, for example, diabetes complications. Group sessions on pump education and carbohydrate counting were the main ones currently organised within paediatric services, and sessions on DAFNE for the young adults within adult services. The various diabetes teams commented on how they would like the opportunity to extend their education provision.

It would be absolutely fantastic to have a rolling programme where we had more staff so we could keep these going; at the moment it's a bit ad hoc, it's where we can fit it in

Many of the professionals organised camps for the children and young people. The diabetes teams commented on how useful these were, in terms of providing an opportunity to deliver specific education sessions and for allowing the children and young people to learn amongst others with the same condition. In some cases the adult team, as well as the paediatric team, attended the camps. This enabled the children and young people to get to know the adult diabetes team prior to the transition process. In addition, some paediatric teams were trying to implement a yearly plan that could be introduced for those who were newly diagnosed. This would include a curriculum with learning outcomes that addressed specific topics: for example, exercise, alcohol and sexual health. The main advantage of implementing a plan was that individuals would embark on it as soon as they were diagnosed, which would help structured education to become part of the norm. Attendance at organised group education sessions was a significant problem across all sites and every diabetes team commented on poor attendance.

The major difficulty is getting the people to the education sessions ... it's the ones you really need to target that don't come

The healthcare professionals also reiterated there was only so much that they were able to do. They could arrange and advertise the education sessions, but currently individuals and families could not be made to attend. One suggestion put forward to address this issue was for a mainstreamed, standardised education programme across the region, which would ensure consistency and also send out the message that structured education was an important part of diabetes management.

## Psychological support

All the diabetes teams were in agreement that there was an acute lack of psychological support available for children and young people with diabetes. In most cases there was no psychologist attached to the diabetes teams and in the few instances where a psychologist was available this was only for a limited number of hours per week.

It's very difficult for us to be able to access psychological support in a timely manner for our patients and that's being polite about it

In a few sites psychological support was available for young adults who were in the transition process, but many professionals identified a specific gap in service provision for those young people aged 16–18, despite this being a difficult time.

Consequently, the diabetes nurses provided what support they could in the form of extra appointments and home visits, but they felt there was a limit to what they could do.

It's usually at crisis point, it's not prevention ... or an automatic post diagnosis ... you discuss how they're feeling but it's not structured

Many diabetes specialist nurses stated they lacked the training to be able to deal with psychological issues and, in the majority of cases, they only felt comfortable listening to families and talking through their concerns rather than anything more specialised, although the time available to do this was becoming less and less.

We pick up the pieces and we know our limitations; we're not trained psychologists, but we will endeavour to do the best we can so I think psychology with any long term condition should be across the board

In those sites where there was psychological provision the psychologist offered advice and basic training for the diabetes specialist nurses to help them support families. The psychologists believed the nurses were well equipped and had enough knowledge to be able to give initial low key support, which was extremely important.

I think they sometimes underestimate the work they do themselves, particularly the DSN [diabetes specialist nurse] who is there on the phone for families ... she does a lot of low key psychological support day in day out

However, some diabetes specialist nurses thought that by providing psychological support the boundaries of their role were becoming increasingly blurred and this was a concern.

The diabetes teams stated that having a psychologist as part of the team would be the ideal scenario, in particular a health psychologist who was able to attend clinic, as well as undertake more supportive and preventive work. Most importantly, such a person would be readily accessible for families as a routine aspect of diabetes care. Furthermore, if a psychologist were to be introduced as part of the team at diagnosis and everyone was more open about the need for

psychological support, the professionals thought this would endorse the importance of it, as well as remove the stigma associated with psychological services. The general feeling amongst most professionals was that psychology was thought of as being predominantly associated with mental health problems and young people did not want to be labelled as having a mental health problem. Therefore, families were often reluctant to pursue psychological support because of the implications. This issue was further complicated by the fact that if families required any psychological input often the only option available to them was the Child and Adolescent Mental Health Services (CAMHS), but referrals could be difficult to obtain because CAMHS was for mental health issues and diabetes did not fall within its remit.

... supporting newly diagnosed families isn't necessarily a mental health issue because newly diagnosed families will be going through all sorts of emotional experiences ... it's a normal process to be going through

There's a lot less time for providing psychological help and each of us knows our limits; there's a time for referring on but there is no one to refer to

In cases where CAMHS was deemed to be inappropriate, many families were left without any support until a situation reached crisis point. Many professionals acknowledged that rather than psychological support being part of normal service provision it was restricted to crisis management, by which time it was often too late.

The only time you can get an emergency CAMHS appointment ... if a child is sick enough to be admitted with an attempt at self-harm. If they come into clinic and tell you they're going to top themselves this evening that won't count

Professionals identified further areas where they thought additional input was required. First, they recognised that disordered eating was a problem and, increasingly, a psychologist was needed to help address this. Second, professionals thought there was an increasing need for social service support to tackle the social issues that affected young people's diabetes and which they, as diabetes specialist nurses, did not have the time or expertise to deal with. Professionals commented on the process of applying for Disability Living Allowance (DLA). Although the diabetes specialist nurses currently helped families complete the necessary forms they thought this was something that was more appropriate for a social worker or diabetes educator to undertake. Third, professionals identified a need for local support groups, to provide young people and parents with someone to talk to. Finally, some professionals raised the idea of a befriender role or educator, which already existed in some sites. This individual would be able to listen to young people and parents and talk through their concerns, thereby freeing up the diabetes specialist nurses to deal with clinical issues.

Last, an important issue raised by the professionals was the provision of psychological support for staff. Professionals acknowledged their role was becoming increasingly difficult from a mental health and emotional well-being perspective.

I do think a psychologist would help to support the staff because sometimes the staff have problems ... you get to the end of a clinic and you have all these problems and you do feel a bit low and you think gosh, where am I going, what am I doing, am I doing things right?

## School/college

Consistency was the main issue regarding schools and colleges and their management of children and young people with diabetes. In general, primary schools seemed to be more interested in



managing children with diabetes than secondary schools and colleges, although this was not universally the case. Regardless of the type of school, some were simply more helpful and willing than others.

Some schools will be very enthusiastic and say we will take on whatever the child needs, other schools will not take on as much so then you have to adjust the care that the child gets to accommodate what the school will take on

The diabetes specialist nurses identified an issue regarding whose remit it was to provide support to schools, as there seemed to be a lack of clarity between the roles of the diabetes specialist nurse and the school nurse and, in particular, whose responsibility it was to facilitate diabetes care within schools. Predominantly, it was the diabetes specialist nurse or the diabetes educator who provided the initial training for school staff when a new diagnosis was made. However, this was unsustainable with the ever-increasing numbers of children and young people diagnosed with type 1 diabetes. The workload continued to increase.

We are overwhelmed now with what is required by schools because there's only so many nurses and we have ... schools that need training

A member of the diabetes team always went into schools when a new diagnosis was made, even if a school had a child or young person with diabetes already, as each person was regarded as an individual with separate needs. A care plan was drawn up for the school, parents, professional and child, if they were old enough, which included specific information pertaining to the individual child or young person. In terms of refresher training and updates for school staff, it was difficult for the diabetes teams to manage this aspect of their role largely because of a lack of time and resources. Some schools did invite diabetes specialist nurses to staff meetings or training days, and sessions were given by dietitians in some instances, and had proven useful. In an attempt to manage time and resources more effectively some sites had introduced group sessions where several schools in an area were invited to attend a workshop, the aim of which was to increase awareness, provide basic training and, importantly, motivate and prepare school staff for managing children and young people with diabetes.

In general, most diabetes teams reported having a good relationship with school staff.

Schools know that if you can't contact the parents you contact DSNs and if you can't contact us then you contact the ward ... I think we're very good with schools really ... we do above and beyond with schools with training

Clearly, there were occasions when problems had occurred in relation to the care of children and young people with diabetes in schools and these had been dealt with on a case-by-case basis. However, what concerned the diabetes specialist nurses the most were the instances where children and young people were left vulnerable: for example, school staff refusing to administer insulin or do a finger prick for a young child because of worries about insurance and liability. In addition, the diabetes teams highlighted the involvement of parents in schools and, in particular, the issue of over-demanding and protective parents. They reported having to deal sensitively with both parents' and the school's expectations in order to work out the best solution for the child or young person.

I would like to be able to walk into a school and say this child needs this, this and this and get it without question ... very often it depends on the relationship the school's got with the mum to the level of care the child gets!

## Transition

Transition differed in each site, in terms of the length of the process and the age at which a young person moved through transition. Professionals stressed two key points in relation to transition. First, transition should be focused on the individual and be a flexible process, necessarily dependent on the age and maturity of the young person concerned.

[transition] is quite fluid which is fine because again it's responding to the needs of the individual so the children's clinic would start to think about moving children up into our young adult clinic as and when they are ready, but it wouldn't be a one off conversation

Second, communication between the paediatric and adult diabetes services, and involving the young person and their family, should be maintained to ensure as efficient a process as possible. Most of the paediatric and adult diabetes teams thought that they had a good relationship with one another and that their transition process was well managed, although they recognised there was room for improvement. Normally, diabetes services started the transition process at around 16 years of age, with transition lasting approximately 2 years and young people moving up into adult services at 18, although there were exceptions. Many of the teams thought the issue of transition needed to be raised with the young people and their parents at an earlier age than at present: for example, when young people moved into the teenage or adolescent clinic at approximately age 13 or 14.

Perhaps we don't start the conversation early enough, usually it is 'oh, you're nearly 16, this is what's going to happen next'

In some sites both the paediatric and adult diabetes teams were actively trying to use the teenage clinics as preparation for transition. Young people were encouraged to see their paediatric consultant and/or diabetes specialist nurse by themselves and be more independent from their parents, although the professionals acknowledged this could be difficult for both the young people and the parents.

I think it can be intimidating ... where we encourage young people to come in on their own ... we are consciously always trying to direct questions to the young people rather than the parent so we are trying to get them to answer the questions

In addition, some diabetes teams had implemented a specific pre-transition plan agreed through joint consultation between the young people and themselves. Furthermore, the diabetes teams tried to schedule the teenage and adolescent clinics for late afternoon and evenings, in order to avoid a conflict of time with school and college, although this was not always possible and depended on time and resources.

Transition itself normally involved young people attending six transition clinics over the 2-year period at which members from both the paediatric and adult diabetes teams were present, including consultants, diabetes specialist nurses and, where possible, dietitians. Some sites had also introduced targeted group education sessions at the beginning of the transition clinics based on what the young people had said they wanted, including information on carbohydrate counting, footcare, driving and alcohol. The professionals recognised that transition could be an anxious time for many young people and once they moved into adult services the difference in the approach to care could be quite daunting. Some paediatric diabetes teams admitted that they nurtured their young people, others used the term mollycoddled which, they acknowledged, meant that they 'held onto' their young people for longer than they should. In adult services the young people were rightly encouraged to be more independent, but the consequence of this was that there were more DNAs. The paediatric diabetes teams stated that they worried about the young people not being

able to adjust easily to their new care regimen because, compared with the paediatric diabetes service, the adult process could seem chaotic.

... there is a lot of 'failure to attends' because sometimes it's difficult to make that change

In most sites, at the end of the 2-year transition period there was a formal handover to minimise confusion and to ensure that the young people and their parents were clear about which service was responsible for managing their care. One major weakness that was highlighted in several sites was the difference in record-keeping between the paediatric and adult diabetes services. This had important implications for the handover process. Diabetes teams stated that the handover could be very difficult because of the difference in systems.

I suppose that's our biggest downfall in the handover procedure because all our notes are paper based and the adult service is computer based so you're sort of photocopying and scanning it

The consequence of this was there was a lack of continuity and a young person's diabetes history could potentially be disregarded.

... we could have a young person on our case load for nearly 18 years and when they move to adult services their notes don't follow so all that vital history and information is not used as both services work on different databases

# Section 5 Conclusions

The conclusions are divided into two sections: first, those arising from the views of children, young people and parents; and second, those arising from the views of professionals. All the key findings explained below represent areas for future improvement in the diabetes care provision for children and young people.

## Children, young people and parents

### Diabetes care

In general, participants who attended the paediatric diabetes service were happy with the care they received, although they recognised that some aspects needed to improve, especially in relation to clinic and diabetes education. Young people wanted to take on more responsibility for their care and be actively involved in decision-making. Young people who accessed the young adult diabetes service were less positive about their care. Staff attendance at clinic and discontinuity in care were the main concerns raised. Participants accessing both services thought the annual assessment process should be reviewed, including the monitoring of complications. In addition, they thought that ward staff needed more education in relation to children's and young people's diabetes management. Participants thought there needed to be increased awareness amongst GPs.

### Psychological support

Few individuals and families had access to any kind of support, including psychological support, but they would talk to a psychologist or counsellor if available. Participants thought psychological support was a necessary component of effective diabetes management and essential to remaining healthy. The majority of young people and parents had no one to talk to about the impact of type 1 diabetes on their lives apart from each other and their diabetes specialist nurses. Young adults in particular thought that more consultants needed to understand the full implications of managing diabetes and demonstrate greater empathy and understanding.

### Education

A lack of awareness of type 1 diabetes among GPs as well as a lack of understanding among ward staff regarding the treatment of diabetes were highlighted as major concerns. Whilst some participants were given information on healthy eating, physical activity and sexual health, this was not routine. Very few participants had attended a structured education course and most parents and young adults found out the majority of what they needed to know through the internet.

### School/college

Diabetes management in schools and the quality of care varied enormously, particularly between primary and secondary schools. Parents and younger children relied heavily on the goodwill of a school volunteer to oversee care. While diabetes specialist nurses attended school when a child was newly diagnosed to agree a care plan, parents felt the majority of ongoing education was left to them. Participants thought there needed to be increased awareness of type 1 diabetes among all school staff and pupils within schools and a designated member of staff should be assigned the responsibility for those pupils with long-term conditions. Participants emphasised the need for

consistency in terms of policies and practices within schools and colleges: for example, policies relating to classroom management, the storage of insulin/medical kits and the provision of a safe place for children and young people to take their insulin.

## **Transition**

Participants needed to be better informed of the transition process; communication between young people, parents, paediatric and adult diabetes teams was regarded as essential. Participants did not necessarily know what transition meant and when they were in transition they were often unaware of what was happening and why. Transition was regarded as a vital time in a young person's diabetes journey and had important implications for the ways in which young people continued to manage their diabetes.

## **Inconsistencies**

Inconsistencies were evident both between and within diabetes services. Young people and parents received conflicting information from consultants and diabetes specialist nurses when attending clinic and from ward staff. The use of pump therapy, care received in clinic and the type and amount of diabetes education varied across the region. In general, psychological support was severely lacking; while some diabetes services had the support of a psychologist for a set number of hours, others had no psychological support whatsoever. There was a huge difference in diabetes care between paediatric and adult services. The management of young people's diabetes in schools varied, particularly between primary and secondary schools.

## **Professionals**

### **Resources**

There were too few staff and resources across all the diabetes sites, which had important implications for the care provision available to children, young people and parents. In particular, insufficient diabetes specialist nurses and administrators, a lack of dietetic and psychological support and inadequate staff training procedures were highlighted as major concerns. A lack of time negatively impacted on clinic appointments, the level of support provided and the ability of diabetes specialists to deliver structured education.

### **Diabetes care**

There were differences relating to the management of newly diagnosed patients across the region, in particular the length of hospital stay as well as the care provided during that time, and the 24-hour on-call service. Access to 24-hour diabetes specialist care was not always available. Following discharge from hospital similar procedures were adopted by all paediatric diabetes teams with home visits and regular telephone communication being an integral part of continuing care and diabetes management.

### **Clinic**

Allocated clinic sessions and appointments were often too short. There was a recognised need to improve clinic and many diabetes teams had already taken the initial steps to do this. There were particular clinic attributes deemed to be more successful than others. Many aspects of clinic organisation were beyond the control of the diabetes teams. High DNA rates were a major concern across all young adult clinics.

## Education

Structured education and the continuous reinforcement of education were regarded as important components of diabetes management, but time and lack of resources were the main reasons preventing staff from delivering both aspects. In general, paediatric diabetes education across the region was ongoing, provided on a tailored one-to-one basis and delivered at the most appropriate time for the individual. DAFNE courses were available for young adults. Children and young people benefited from attending diabetes camps, but poor attendance at group education sessions organised as part of paediatric care was a significant problem across the whole region.

## Psychological support

All professionals acknowledged an acute lack of psychological support across the region; it was rare for a psychologist to be attached to individual diabetes teams. There was a specific gap in service provision for those young people aged 16 to 18 in transition. Professionals identified a clear need for a health psychologist as an integral member of the diabetes team to reinforce the importance of psychological health and reduce the stigma associated with psychological services. Often the only option open to individuals and families was CAMHS, which was not always appropriate. Professionals highlighted the need for psychological support to be available for diabetes specialists.

## School/college

A lack of consistency was the main issue identified by professionals in terms of the management of children and young people with diabetes in schools. The care of a child or young person with diabetes often depended on the willingness of individual staff to assume responsibility. An increasing number of staff refused to take on this responsibility because of concerns relating to insurance and liability. The diabetes teams had good relationships with school staff and were instrumental in drawing up care plans for newly diagnosed children and young people. Increasingly, professionals found training updates in schools difficult to manage because of a lack of resources and escalating workloads and had, therefore, introduced group staff training sessions.

## Transition

Transition differed across the region, in terms of the length of transition and the age at which a young person moved through transition. Key aspects relating to communication, individual targets and flexibility were emphasised as being essential for ensuring an efficient transition process. Paediatric and adult diabetes teams were actively trying to use the adolescent clinics as preparation for transition and some had implemented a specific pre-transition plan agreed through joint consultation between the young people and themselves. Professionals recognised that transition was an anxious time for many young people because the approach to care was different in adult services. Discrepancies in record-keeping between paediatric and adult diabetes services across the region was highlighted as a major concern because of the implications this had for continuity of care.

# Section 6 Areas for improvement

1. Staff training
2. Structured education
3. Psychological support
4. Transition
5. Young adult diabetes care
6. Staffing levels
7. Clinic
8. Annual assessment and monitoring of complications
9. 24-hour on-call provision
10. Record-keeping
11. GP and public awareness of type 1 diabetes
12. Care provision and type 1 diabetes education within schools

# Section 7 Recommendations

The following recommendations are based on the research findings. They are important in terms of the ways in which current practice needs to change to improve the care and support of children, young people and families with type 1 diabetes in the Yorkshire and the Humber region.

## Resources

Every paediatric and adult diabetes team needs to include, as a minimum, a consultant, diabetes specialist nurse, dietitian, psychologist and administrator. Ideally, a diabetes educator and social worker need to be part of the team. There needs to be an appropriate number of diabetes specialist staff within every team, in order to ensure children, young people and parents across the whole region receive the care and support they are entitled to. Staff should be appropriately trained and enabled to attend courses as part of their continued professional development. A standardised, formalised staff training programme needs to be in place and all ward staff should be trained in diabetes care. Record-keeping processes need to be such that they facilitate diabetes care rather than hinder it. A universal computer system across all diabetes sites, including both paediatric and adult services, would enable this.

## Diabetes care

Young people and families should have access to the same standard of care regardless of which hospital they attend and whether they use the paediatric or adult diabetes service. Young people and families need to be actively involved in care planning and discussions around treatment regimens. Too much emphasis is placed on the medical aspects of diabetes, particularly HbA<sub>1c</sub>. Instead, a holistic approach to diabetes care needs to occur centred on the lifestyles of individuals and their families, and incorporate glycaemic control. The annual assessment process and monitoring of complications need to be reviewed, in order to ensure consistency in terms of practice across all diabetes teams region-wide. Procedures need to be instigated to ensure young adult diabetes care provision is comparable with that in paediatric services, in particular regarding consultant continuity and clinic appointments. It has been suggested that a region-wide 24-hour on-call system should be introduced to manage the after-hours diabetes care provision.

## Transition

Transition needs to be a planned process carefully worked out through joint consultation between young people and professionals. It should not simply be a transfer from paediatric to adult services. Ideally, the transition process should be managed over at least 1 year, with both the paediatric and young adult diabetes teams involved. Young people and their parents need to be properly informed about the transition process well in advance and there should be clear communication at all times and between all parties, including young people, parents, paediatric and adult diabetes teams. At the end of the transition process there needs to be an explicit handover, which includes the transfer of patient records, in order to ensure continuity of care. It has been suggested that a transition nurse should be appointed to oversee care and provide support through transition.

## Education

A mainstreamed, standardised structured education programme needs to be implemented within all diabetes services across the region, in order to ensure consistency and to send out a clear message that structured education is an important and integral component of diabetes care. This will complement the ongoing one-to-one education that individuals and families currently receive. Education needs to be age appropriate and include advice relating to sexual health, healthy eating, physical activity and alcohol. Awareness of type 1 diabetes amongst GPs, and the difference between type 1 and type 2 diabetes amongst both professionals and the public needs to improve.

## School/college

A standardised, formalised protocol in respect of diabetes management within schools needs to be introduced to ensure consistency. This needs to be enforced through a joined-up approach between the education authority, health and social services that involves diabetes specialist nurses, dietitians, health psychologists, social workers, school nurses and children, young people and parents. Awareness of type 1 diabetes amongst all school staff and pupils within schools needs to improve. There is an urgent need for more diabetes specialist nurses to support children, young people and parents in schools.

## Psychological support

Every diabetes team should have a designated health psychologist working as part of the team. The psychologist should be available to undertake supportive and preventive work with individuals and families. This needs to be a routine aspect of diabetes care in paediatric and adult services.



# Section 8 Reference

Department of Health (2007) Making Every Young Person with Diabetes Matter: Report of the Children and Young People with Diabetes Working Group. The Stationery Office, London.