

# Reflections on the caseload in Leeds and the implications for future working practice

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## Article points

1. Cases of both type 1 and type 2 diabetes are increasing in children and they need intensive support.
2. The author examined the paediatric diabetes caseload in Leeds.
3. An important factor when considering the caseload in Leeds is the level of deprivation of vulnerable children.
4. The assessment highlighted the need to plan ahead for future workforce.

## Key words

- Caseload profile
- Diversity
- Future planning
- Sustainable service
- Workforce planning

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This article considers the children and young people with diabetes who attend the Leeds Children's Diabetes Service. It discusses the scale of the condition, the diversity of the caseload, the mix of skills delivering the service and future workforce planning. The article concludes that in order to provide a sustainable service for the future, investment is required now. Failure to do so is likely to lead to a most costly future.

Diabetes is one of the greatest health threats of the 21st century, affecting 2.2 million people in the UK (NHS Information Centre, 2011).

There has been a significant increase in children developing the condition, with 98.4% having type 1 diabetes and 1.6% with type 2 (NHS Information Centre, 2011). In the UK, diabetes has a prevalence of 1 in 700–1000 children and an estimated 25 000 with the condition (Department of Health [DH] Diabetes Policy Team, 2007).

If the present trend continues, it is predicted that new cases of type 1 diabetes in European children younger than 5 years will double between 2005 and 2020, and the prevalence in children aged under 15 years will rise by 70% (Patterson et al, 2009).

On average, life-expectancy is reduced by 23 years for young people with type 1 diabetes and by 10 years for those with type 2 (DH Diabetes Policy Team, 2007). Moreover, it is estimated that the NHS spends £25 million

each day treating people with diabetes – around 10 per cent of the NHS budget (Diabetes UK, 2010a).

## Caseload profile

In June 2011 an examination of the caseload in Leeds was undertaken to assess the current patient population. The total caseload comprised 345 children and young people with diabetes cared for by a multidisciplinary team. The team included 0.8 whole time equivalent (WTE) dietitian, 0.4 WTE psychologist, 1.2 WTE consultant paediatricians with a particular interest in diabetes and 4.61 WTE children's diabetes nurse specialists (CDNS) with an availability of 4.15 WTE clinical hours.

There are currently 83 patients per 1 WTE CDNS, which is significantly more than the Royal College of Nursing (RCN) recommended ratio of 1 WTE for every 70 patients (RCN, 2006). It must also be remembered that the RCN recommendations

Page points

1. The management of children under the age of 5 years is particularly challenging because they require intensive support and care.
2. An important factor when considering the caseload in Leeds is the level of deprivation.
3. Vulnerable children living in areas of social deprivation need to receive coordinated, high-quality child- and family-centred services based on assessed needs.

were based on the diabetes care available at the time. Since then, intensive insulin regimens and insulin pump therapy have become standard treatment as the EDIC (Epidemiology of Diabetes Interventions and Complications) study demonstrated the importance of intensive treatment in achieving good glycaemic control soon after diagnosis (EDIC, 2005). These intensive regimens need intensive support so it would seem timely for the RCN's recommendation to be revised.

Over the past 3 years, the number of newly diagnosed children attending the service in Leeds has increased, with 23 in 2009, 43 in 2010 and 37 diagnosed in 2011 to date, with 16 since the profile was undertaken in June. This, at a local level, is clear evidence of the rising numbers of children being diagnosed.

It is also worth noting that a number of these children, 11 in total this year, are under the age of 5 years. This is particularly challenging for their families and for the diabetes team. They require intensive support and care, often using an insulin pump and continuous glucose monitoring. As diabetes-related complications become more likely with increasing age and duration of diabetes (NHS Information Centre, 2011), these children are at the greatest risk and therefore require the greatest care and support.

Currently, there are eight cases of type 2 diabetes, around 2% of the caseload. Children have been referred to the team from the existing obesity services in the community such as the WATCH IT programme (Rudolf, et al, 2006). If the present obesity levels continue to increase, we can expect to follow the American pattern and see an estimated 8–45% of referrals having type 2 diabetes (Fagot-Camagna, 2000).

Around 12% of the total caseload is made up of ethnic minority groups; these children have particular problems with a higher incidence of type 2 diabetes and poorer diabetes control (NHS Information Centre, 2011). Thompson et al (2011) suggest that ethnicity plays an important role in determining HbA<sub>1c</sub> and that health-related beliefs, rather than deprivation, among these

populations may be involved. In addition, these children and their families may not have the language skills to facilitate their understanding of the condition and staff need to account for their language and cultural needs when caring for them. There have been five children diagnosed since June 2011 for whom this is the case.

### Deprivation

Another important factor when considering the caseload in Leeds are the Indices of Deprivation. This is an important tool for identifying areas of greatest need and looks at seven domains of deprivation: income, employment, health, education, housing, environment and crime (Leeds City Council, 2010). The indices assign a score and a rank to each of the 32 482 lower level Super Output Areas in England. Super Output Areas are a geographical hierarchy designed to improve the reporting of small area statistics (NHS, 2010). A rank of 1 indicates the most deprived within the measure and a score of 32 482 the least.

If we consider the caseload in Leeds based upon the Indices of Deprivation scores, then 23.1% of the caseload have a score of 1, which puts them in the top 3% of the most deprived council wards in the country. A further 25.5% score 2, putting them among the 10% most deprived, and 8.9% score 3, thus making them among the top 20% most deprived wards in the country. Worryingly this means that over half the caseload lives in an area of high deprivation. This is a significant factor as social deprivation is associated with higher risk of poor blood glucose control (NHS Information Centre, 2011).

Improved diabetes management and control can reduce the incidence and delay the impact of diabetes-related complications (DH, 2007). This clearly has implications on how to ensure that vulnerable children living in areas of social deprivation receive coordinated, high-quality child- and family-centred services based on assessed needs, which promote social inclusion (DH, 2004).

Children with diabetes live within their

community and are affected by their circumstances. Those born into the most disadvantaged backgrounds are adversely affected in terms of socioeconomic position and health (Graham and Power, 2004). Thus the diagnosis of diabetes is an additional burden to the struggle of daily living. People with a higher socioeconomic position have a greater array of life chances and better health (Marmot, 2010). In this situation, people are equipped with more skills to manage their condition and it is noticed that on average their diabetes control is better (NHS Information Centre, 2011). If, as Marmot (2010) says in his review, inequalities are tackled by employing “proportionate universalism” – that is, having actions of a scale and intensity that is proportionate to the level of disadvantage – then this would benefit patients and society as a whole. One of the policy objectives Marmot describes is in strengthening the role and impact of ill health prevention. Attention to health at this strategic level will certainly have a positive impact on the diabetes population and will allow services to be directed accordingly.

Since 2009, patients have had the legal right to choose the hospital in which they would wish to receive care (NHS Choices, 2011). The service in Leeds has received a number of referrals from out of the region (four in 2010 and six in 2011), with some children and families travelling a great distance for their care. This brings unique challenges. Caring for people from outside the region requires clear communication with the local team and the family, agreeing responsibilities and the services that can or cannot be provided. For example, Leeds staff cannot visit the child’s school due to the distance. Occasionally difficulties have arisen when the family has chosen not to avail themselves of shared care, something that is strongly advised. This leads to poor communication and problems with support in school and access to local diabetes care when needed.

Regional patients account for 17.3% of the caseload, a significant impact on the service provided by the team. Although the trust

is remunerated for these referrals, none of this money has been invested in the current diabetes service provision. One could argue that this income helps ensure posts in other areas of the organisation are saved. However, wouldn’t a business reinvest in the department providing the service? After all, NHS staff are always encouraged to be financially aware and develop a more businesslike approach.

At any one time less than 1% of the caseload is in hospital. This is often at diagnosis, but other reasons may be due to poor adherence to treatment regimens, particularly prevalent during adolescence (Taddeo et al, 2008), intercurrent illness or a planned admission for surgery or re-education. Diabetic ketoacidosis at diagnosis, which may be a result of missed diagnosis (Bui et al, 2010), may delay the start of education and thus delay discharge. Other factors that may delay discharge are language barriers that hinder education, and poor social circumstances. Other children whose primary diagnosis is not diabetes are referred to the service also, for example children with cystic fibrosis-related diabetes, and steroid-induced hyperglycaemia. There have been eight such referrals in 2011.

### Workforce

The DH Diabetes Policy Team (2007) highlighted that caring for children with diabetes is fundamentally different to caring for adults with the condition, involving a complex working partnership with children and families. It states that the workforce must be commissioned as part of the local model of care to ensure that diabetes care for children and young people is a priority and can be delivered effectively. However, service provision in the UK still lags behind much of Europe (Danne, et al, 2001)

It is recognised that the role of the clinical nurse specialist is one of the successes of modern healthcare. As Young et al (2010) state: “They bring a high degree of clinical expertise, innovation, leadership and continuity of care. They are committed to clinical governance, audit and meticulous documentation.”

### Page points

1. Those born into the most disadvantaged backgrounds are adversely affected in terms of health.
2. Since the introduction of Choose and Book, the service in Leeds has received a number of referrals from out of the region.
3. Caring for people from outside the region requires clear communication with the local team and the family, agreeing responsibilities and the services that can be provided.

Page points

1. The assessment highlighted the need to plan ahead for the future workforce. Recruitment needs to begin now to identify the nurses who would welcome a developmental role in their existing post.
2. The depth and range of skills of a specialist nurse working with children and young people are vital to ensure that children can optimise control of their diabetes.
3. Caring for children requires a team approach; an area that requires investment for Leeds team is in social support.

The Children's Diabetes Nursing Team in Leeds can be counted among these specialist nurses. Over the past 10 years team members have taken on nurse-led clinics, prescribing, treatment decision-making, mentoring and education for other clinical and professional staff. This has been done with no extra financial reward or incentive.

Nationally, 43% of DSN posts are unfilled as a result of cost-saving initiatives and, according to the Diabetes UK workforce survey, one in five specialist nurses will retire by 2016 with large spikes in retirement every 5 years (Diabetes UK, 2010b; Hicks, 2011). This will certainly be the case for the service in Leeds, which is becoming a more experienced and senior workforce with staff who have remained in post for over 10 years – two members for over 15 years. Therefore, it is essential to plan ahead for the future workforce. Recruitment needs to begin now to identify the nurses who would welcome a developmental role in their existing post. This will ensure that there is a career structure for nurses coming into the role from beginner to proficient to expert, as described in the RCN document *Specialist Nursing Services for Children and Young People with Diabetes* (RCN, 2006). In the current climate, it is extremely concerning to note that as patient numbers increase, the number of DSNs is decreasing (Hicks, 2011). With children in particular, this is unsatisfactory.

The latest National Diabetes Audit (NHS Information Centre, 2011) highlighted that only 14.5% of children with an HbA<sub>1c</sub> measurement achieved the recommended NICE target (NICE, 2004). The DCCT (Diabetes Control and Complications Trial) Research Group (1993) found strong evidence that life-expectancy can be increased, illness and disability reduced, and inequalities tackled by having good diabetes control. The depth and range of skills of a specialist nurse working with children and young people are vital to ensure that children can optimise control of their diabetes (TREND-UK, 2011). The CDNS provides value for money as high-quality, cost-effective care is provided which

saves unnecessary hospital admissions and generates income (Hicks, 2011)

Caring for children requires a team approach; an area that requires investment for the Leeds team is in social support. Given that a significant number of patients live in the poorest areas, then having a social worker with an understanding of diabetes as a member of the multidisciplinary team is essential. This would allow children and families to receive the social support they require in a timely manner and would release time to care for the specialist nurse (NHS Institute for Innovation and Improvement, 2010).

Releasing time to care for the CDNS would allow the team to provide more systematic and proactive management of this chronic condition (Imison et al, 2011). It would also allow time for more programmes of structured education to be developed in order that children and families may learn self-care in an appropriate environment.

### Conclusion

Assessing the profile of the caseload is a useful way of highlighting the needs of the patient population. It ensures that the caseload for each staff member has a mixture of the patients attending the service based on age and geographical location, and that the very poorest wards are shared so that no one caseload consists of all very young children, ethnic minorities or social deprivation. This profile has highlighted that more social support for patients is required in Leeds because a significant amount of specialist nursing time is taken up with social issues that would best utilise the skills of a social worker.

As staff are becoming more senior, there needs to be a recruitment of new junior specialist nurses so that they may learn and develop to ensure there is a clear career pathway for new staff members, continued provision of coordinated high-quality child- and family-centred care, and a sustainable diabetes service in Leeds for the future. The diabetes team of the future will need to be able to utilise its resources in much more creative and innovative ways and the introduction of

the best practice tariff (Anderson, 2010) may allow this to happen.

The Leeds Children's Diabetes Team sees the best practice tariff as an opportunity and has put forward a 5-year strategic plan. One area being discussed within Children's Services is the development of four band five rotational posts. Staff with a keen interest in diabetes and aspirations for a nurse specialist post in the future would be recruited from the ward. This would ensure 24-hour cover, provide expertise within the ward environment and pave the way for a career pathway.

Doing nothing and maintaining the status quo is not an option; with no action, the cost of treating diabetes-related complications in the future is likely to be even higher. In 2006, treatment for diabetes accounted for 5% of national health spending (Diabetes UK, 2006) – it now accounts for around 10% (Diabetes UK, 2010a). If the service does not receive investment, despite these challenging financial times, then the future will indeed be costly. ■

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*“Assessing the profile of the caseload is a useful way of highlighting the needs of the patient population we serve. This profile has highlighted that we definitely need more social support for our patients because a significant amount of specialist nursing time is taken up with social issues that would best utilise the skills of a social worker.”*