

The Brecon Group

The Welsh Paediatric Diabetes Interest Group

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Mr Mark Drakeford AM
Chair of the Health and Social Care Committee
National Assembly for Wales
CARDIFF BAY
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Dear Mr Drakeford,

We write on behalf of the Welsh Paediatric Diabetes Interest Group (The Brecon Group). The Brecon Group consists of a group of professionals (doctors, paediatric diabetes nurse specialists and dietitians) with an interest in paediatric diabetes in Wales. Every unit in Wales providing paediatric diabetes care (14 centres in total) actively contributes, and we provide care for a paediatric diabetes population of approximately 1400 children and young people aged 0-17 years.

We understand that the Welsh diabetes plan is being reviewed by the Welsh Government and that you are the chair of a special enquiry of the Health and Social Care Committee. The report your committee prepares will no doubt inform the development of the plan and we are keen that the needs of Children and Young people (CYP) are well represented.

The vast majority (95%) of CYP with diabetes have type 1 diabetes and they, with their families, require a very different care package to that of adults, the vast majority of whom have type 2 diabetes. We believe that paediatric diabetes should be considered in the diabetes plan as a separate disease entity similar to the recognition it now receives in England. In our opinion, previous documents produced by the Welsh Government have

failed to recognise the difference between paediatric and adult diabetes services and as a direct consequence the needs of children with diabetes have not been appropriately prioritised by Local Health Boards.

In type 1 diabetes, over the last decade, there has been a substantial move towards intensification of therapy, including insulin dose adjustment for carbohydrate intake using multiple daily injections and use of insulin pumps. There is a need for continuous structure education programmes, starting at diagnosis and continuing throughout childhood, adolescence and transition into adult services. In addition, an increase in the number of children with type 1 diabetes and the relative increase in the prevalence of diabetes in the under 5 year olds has also led to an increased workload without any new investment in paediatric diabetes services.

As a group we are concerned about some of the outcomes from the National Paediatric Diabetes Audit which, over the last 8 years, have shown very little improvement. Furthermore, there are variations in outcomes between centres in Wales which remain unexplained.

HbA1c (a marker of overall control of diabetes) is often used as one of the most important hard outcome measures, as it is clearly defined with a numerical value and has been shown in numerous studies to be related to lifetime risk of developing complications from diabetes. Most studies would recognise a 37% increased risk of developing microvascular complications (such as kidney, eye and nerve disease) for every 1% rise in HbA1c above the gold standard value of 7.5% (recognised by NICE).

In the 2010/11 National Paediatric Diabetes report, just over 25% of children and young people with diabetes in Wales have an HbA1c of >9.5% which puts them at extremely high risk of developing long term complications, which as you know has a significant impact on the NHS healthcare budget. Furthermore, only 17.5% of children and young people with diabetes reach the gold standard HbA1c of <7.5% in Wales. This is a similar figure to the data for England but much worse than in much of Europe, e.g. in Germany and Austria 35% of children achieve this value. Furthermore only 6% of CYP with diabetes in Wales are receiving all the care processes recommended by NICE as part of their care package. We are extremely concerned about these poor outcomes for children with diabetes in Wales and they cannot be ignored.

In England, where outcomes are of a similarly poor standard, NHS Diabetes (funded by the DoH), has developed new systems of care with the aim of driving up the quality of services for children with diabetes. It has been recognised that most centres are already working at full or above capacity and are substantially under resourced in terms of doctors, specialist paediatric diabetes nurses, specialist paediatric diabetes dieticians and psychologists. In England, this year (2012) has seen the introduction of the Best Practice Diabetes Tariff for paediatric diabetes services¹. Paediatric diabetes is therefore now recognised as a specialist service in its own right. The extra funding is being used to provide increased resource into centres in England. Centres have to comply with a series of standards to receive the Tariff. Furthermore, there is now a Quality Assurance Programme (Peer Review) starting in November 2012, to ensure centres delivering care comply with a series of preset objectives and standards. This allows centres to benchmark themselves against others within their region and nationally and to share experience leading to improved quality and standardisation of care.

The introduction of the diabetes Tariff in England recognises the lack of investment in diabetes services over the last 50 years, and through the resources following the patients will help to address this. There is now quite clearly a divide between the two nations in service provision and concerns have been expressed across Wales from those caring for children with diabetes, that children in Wales are not getting the equivalent recognition when compared to those in England. It is highly likely that this will lead to Wales having poorer outcomes compared to England in the very near future.

Within Wales we have faced the same levels of under investment in services and continue to face lack of resources in our clinics in terms of poor nurse to patient ratios, complete absence of dietetic support in some centres or inadequate dietitian to patient ratios, lack of psychological support etc. Despite this being escalated through the health board structures of diabetes practice and delivery groups, paediatric diabetes services continue to struggle. Indeed paediatric diabetes services are on the critical lists of some health boards due to a lack of personnel, but there appears no mechanism that will successfully change the prioritisation (and therefore the funding) of these services.

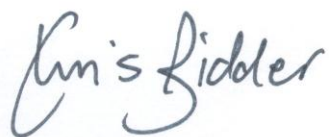
As a group we support the English concepts of network working and the introduction of quality assurance programmes (peer review). However, this system is certainly not cost neutral and has been heavily resourced through NHS Diabetes and the Department of Health in England. Therefore, although we would welcome this process wholeheartedly, it is necessary for it to be a properly costed and funded programme in much the same way as is happening in England. The best solution might be to 'buy in' to the system that already exists in England.

In addition, we have further concerns that, whereas in England, if recommendations are made on the basis of the peer review then there would be funds available through the best practice tariff that could be used to improve services, in Wales no such provision exists. We would anticipate great difficulty in using the information gained from peer review to drive forward service improvements given our previous experience of failure of investment in our services.

In summary, the development of a new diabetes plan presents an opportunity for the specific needs of CYP with diabetes to be recognised, for specific standards of care to be developed and for paediatric diabetes services to be appropriately prioritised and resourced. The current outcomes cannot be ignored and we need to act now if improvements are to be made in the quality of care for CYP with diabetes. Our experience suggests that unless there is a change in prioritisation of paediatric diabetes services that is led centrally by the Welsh Government, that includes the provision of additional funding, then significant quality improvement is unlikely to occur.

The Brecon Group is full of highly motivated and enthusiastic professionals, and there is a lot of good will, but at present all our members are working at or above full capacity and there is very little scope for implementing quality improvement programmes in the current arrangements. We would thus welcome direct liaison with yourself and other relevant staff to highlight the situation to the Welsh Government and to agree how we move forward to meet the needs of children and young people with diabetes in Wales.

Yours sincerely

A handwritten signature in blue ink that reads "Chris Bidder".

Dr Christopher Bidder
Acting Chair of Brecon Group

A handwritten signature in black ink that appears to read "Rebekah Pryce".

Dr Rebekah Pryce
Secretary to Brecon Group

On and behalf of the members of the Brecon Group and children and parents of children
and young people with diabetes in Wales

Reference

1. http://www.diabetes.nhs.uk/networks/paediatric_network/best_practice_tariff_for_paediatric_diabetes/