

It has been announced that from the end of 2014, data capture about the multi-faceted needs of all children and young people will be mandated as part of the first iteration of the Children and Young People's Dataset, which is part of the Maternity and Children's Data set. This capability is currently being developed by the team at Health and Social Care Information Centre.

This will allow for the capture of population data about disabled children and young people for the first time across the UK. Every time a child or young person is seen in a non-inpatient setting it will be required that the clinician reports on the diagnoses and terminologies that are applicable for that child or young person. The set of terminologies to be used has been developed by the British Academy of Childhood Disability in collaboration with partners in the National Network of Parent Carer Forums, British Association for Community Child Health, general paediatrics and expert terminologists from the Department of Health.

Dr Karen Horridge, chair of the BACD and consultant paediatrician (disability) in Sunderland said: "Data speak louder than words and more eloquently describe the multi-faceted complexity faced by the disabled children and young people and families that we serve. Data will make those most vulnerable in our society more visible, will inform tariff setting to reflect complexity and will provide a robust foundation for service development and research to improve the evidence-base for clinical practice".

Mary Busk from the National Network of Parent Carer Forums said "It has been an honour to be involved in this work and to co produce it. To have made this achievement in such a relatively short space of time is truly miraculous. As a parent carer, I have fully supported this work because I know, after years of working on health issues, that data is key, not just to being able to commission and plan well for our children and services at a local and national level but also to address some of the practical problems we have in getting consistent, timely and complete diagnoses. Without all that we cannot get better outcomes for our children and young people.

"To have such an intelligent data set, with common descriptors and measures of family and parental satisfaction, will transform lives and for the first time give us all the chance to evidence who our children really are and what is needed to meet their and our needs as families.

"I look forward to taking these messages, with you, to families, children and young people through the National Network of Parent Carer Forums. In my small efforts to promote it to date all the feedback from health professionals and families has been 100% positive.

"I never gave up hope that together we could achieve this and bring the realities of such transformational change to families and our children and young people."

NHS trusts will be mandated to collect this data and should proactively plan how they will set up their systems to collect it. Electronic data capture is established on Meditech Version 6 in Sunderland and developments are underway to set up data capture in System One. Providers who develop electronic data capture systems are encouraged to share via BACD, to reduce the amount of wheel-reinventing that needs to be done.

To find out more contact:

Kelly Robinson
Administrator
British Academy of Childhood Disability
5-11 Theobalds Road
London WC1X 8SH
Email: bacd@rcpch.ac.uk

Ends

Background to the British Academy of Childhood Disability

The British Academy of Childhood Disability (BACD) is the only UK multidisciplinary professional organisation in Childhood disability. It is a specialty group of the Royal College of Paediatrics and Child Health and has membership from paediatric medicine, child and adolescent psychiatry, therapists, allied health professionals, education professionals, representatives from the Departments of Health and Education and from the voluntary sector as well as parents and carers. It works closely with the Council for Disabled Children, Contact a Family and the National Network of Parent Carer Forums, and advises the Department of Health and Department for Education.