

**CHILDREN AND YOUNG PEOPLE'S
HEALTH OUTCOMES FORUM**

**CHILDREN AND YOUNG
PEOPLE'S HEALTH OUTCOMES
FORUM – REPORT OF THE LONG
TERM CONDITIONS, DISABILITY
AND PALLIATIVE CARE SUB-
GROUP**

Improving outcomes for children with long-term conditions, disabilities and life threatening conditions

Background

The single largest challenge for this group has been the lack of accurate data in relation to the development of outcomes. This has been a long term challenge and has been repeatedly seen as 'too difficult' by those who have a contribution to make in meeting the needs of this group of children and young people. This has meant that for a group of children who test the interfaces of services and systems there is little currently that records their experiences or challenges and their often poor outcomes. The changes in health, and across the systems given us a real opportunity to tackle these barriers now. This is particularly important against a backdrop of increasing prevalence. Even our partial data shows that the numbers of disabled children and young people are increasing, in part due to better survival rates for low birth weight and improvements in care

Where we do have some data which is regarded as relatively robust it clearly reflects the scale of need for this group of children and young people. A few examples of this type of information covering asthma, diabetes, children with disabilities and palliative care are provided at Annex A.

Complexity

We recognise that this group encompasses a very wide range of conditions that will follow varying courses including:

- lifelong (e.g. Deafness);
- slowly deteriorating (e.g. muscular dystrophy);
- potentially curable (e.g. cancer); and
- variable course (e.g. cystic fibrosis).

There is no consistent relationship between a single diagnosis and impairment, functional need or disability. In addition, for many children with one diagnosis, multiple coexisting conditions—also referred to as comorbidities- will be the rule rather than the exception. For example, a young person with cerebral palsy that affects all four limbs is likely to have speech, eating, chest and gastrointestinal problems as well as being more likely to have intellectual disability, visual impairment and require equipment support for mobility and to enable them to achieve their academic potential.

We agreed that healthcare outcomes for this group of children and young people need to focus not only on the condition and the broader determinants of health (including secondary prevention) but just as importantly on the child's, young person's and family's individual experience and their priorities for care. The single disease model, with its focus on diagnosis and guidelines for care, can

mean that symptoms that are impairing and comorbidities that impact on multiple functions are overlooked. However, it is these that will have a major impact on a child or young person's quality of life and should drive the priorities of need and therefore for care.

Improved outcomes therefore depend on comprehensive quality assessments, access to a range of interventions, well coordinated over time and inclusive of the child's, young person's and family's priorities. Outcome measures therefore need to combine life course outcomes (happiness, family functioning, educational achievement etc) with health service outcomes so that measures reflect changes in the condition, impairment or disability and their impact on the child, young person and their family.

The Approach Taken to Developing Outcomes

We would like to take this opportunity to thank the very many individuals and organisations that submitted such a broad and comprehensive range of comments to the Forum. A summary of the main themes raised are in annex B.

Submissions to the forum from and consultations with children, young people and their families, including members of our group, highlighted the following problems, which are experienced by many children and, young people with a long term condition or disability and their families:

- difficulty accessing the services they need, including obtaining diagnosis and accessing expert assessment;
- inconsistency in the quality and quantity of services, fragmentation of services and particularly, a lack of 'join up' between health, social service and education services;
- delays in provision of services, therapy and equipment;
- boundary disputes over which organisation is responsible for provision of services; and
- the patchiness of good practice, such as the provision of a key worker approach to help with coordination and navigation of the health, education and social care.

Transition to adult services is a particularly difficult time with inconsistencies in age of transfer, decisions made about transfer of clinical or care responsibility not related to need or in some cases no adult service available to transfer to.

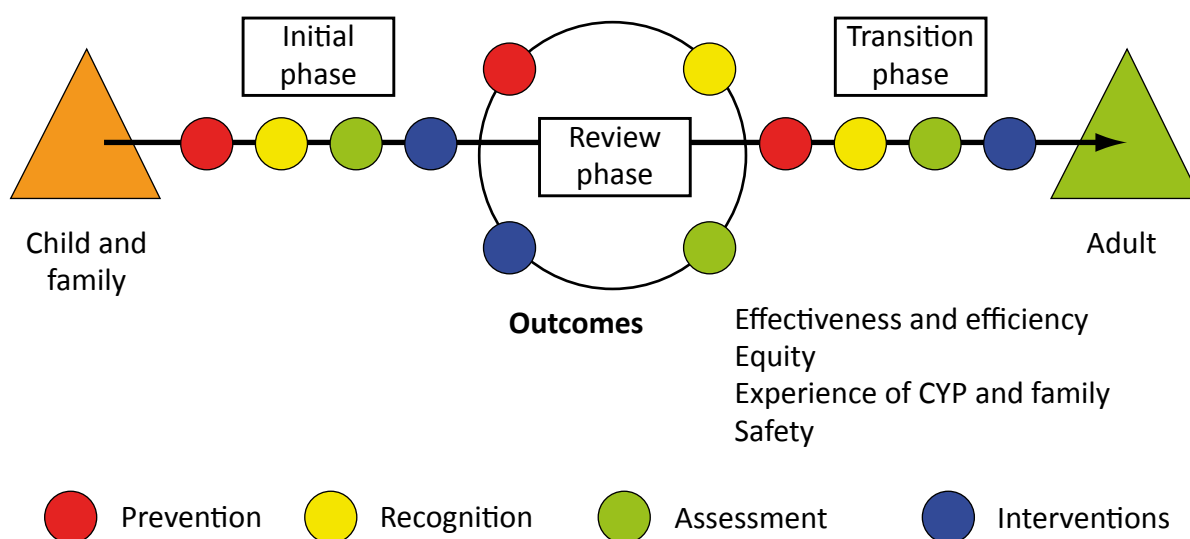
The Green paper, *Support and Aspiration: A New Approach to Special Educational Needs and Disability* published in 2011 articulated the problems outlined above. The Next Steps document published earlier this year sets out how the Government plans to address some of these issues. In our considerations, we took account of these developments, the findings of the experience of children, young people and their families and evidence from clinical experience and research. We were particularly aware of the need to consider the health care of an individual child or young person as embedded in their family and shaped by their experience of education, social care and the wider community.

We aimed to develop proposals on outcomes which would lead to improvement for the individual child or young person and their family in the processes of integrated assessment, care planning and service delivery through a life course approach that placed the child, young person and family at the centre. We recognised that the needs of the child or young person and their family would change over time as they grow and develop, which is why we would want to highlight the importance of undertaking regular and planned reviews at key points of change including transition to adult services.

We were also very aware of the need to work closely with the other theme groups, particularly those covering mental health and health promotion and illness prevention given the need to ensure that children and young people with a long term condition or disability are also able to access holistic, child-friendly mental health and public health services irrespective of their diagnostic label.

Figure 1 summarises the phases of care from prevention (links to the public health outcomes) through the care pathway to adult life

Long term condition pathway
(Simon Lenton)



The Initial phase:

- Improved access into the health system through the development of care pathways;
- Improving the quality of initial assessment; and
- Shortening the time to diagnosis or where a ‘working diagnosis’ is more appropriate because of the age of the child etc, the time to formation of a management and care plan.

The Review phase:

- getting a quality multi-disciplinary assessment that reflects all the child’s or young person’s and their family’s needs; and
- getting a quality package of care (including a health care plan for emergency situations or an end of life care plan where appropriate) fully integrated across health, education and social care with access to key working support, information to enable the child or young person and family to manage the condition and ensure timely provision of equipment to support maximum participation.

The Transition phase:

- ensuring review of the care plan at key points of transition particularly transition to adult life and services.

All phases:

- ensuring that the outcome indicators promote a whole family approach because the health and wellbeing of family (carers) directly impacts on children and young people and their resilience.

We have reviewed the NHS and Public Health Outcomes Framework and the expected commissioning outcomes framework. In developing our outcomes and indicators, we have considered these frameworks and three key tenets that processes and outcomes should reflect and support:

1. Clinical effectiveness;
2. Patient experience; and
3. The potential to facilitate system improvement.

Children and young people with long-term conditions share the same aspirations and life goals as other children and young people, but may need additional help and support to achieve these. One of our key aims is to improve the quality of life and participation for this group of children and young people and their families by reducing school absence, preventing secondary mental and physical health problems, promoting autonomy and involvement in further education and employment.

Where possible, we have supported the use of outcomes applicable to the whole population, but emphasised the need to be able to distinguish this group of children and young people and their families within outcomes such as school attainment and school absence. This will require a shared unique identifier and shared diagnostic categories, that will allow comparison within the locality, across the country and identification of inequalities. In this, we want to cross-refer to wider work of the Forum on inequalities.

The quality of data and information for children and young people with very complex needs is often poor. The group agreed there was a need for accurate data about particular conditions by diagnosis and symptom complexity to enable comparison of outcomes. Condition specific indicators are available for only a very few long-term conditions and disabilities. Where clinical indicators exist, we advocate their use, but for many conditions, robust evidence based indicators of quality clinical care have not been developed. Where available, the group recommended that NICE guidelines and standards should be followed. Where they do not exist, there is a need to develop these

We have made several recommendations for new indicators to be included within the NHS Outcome Frameworks. These include the need to speed up the time from first presentation to the NHS with symptoms to definitive diagnosis for a range of conditions, recognising that this is a serious concern for many children, young people and families and the need to reduce school absence for children with long term conditions. Integrated care and support for children and families was seen as crucial to improve their quality of life. We have recommended the development of a composite measure of effective integrated care.

We concluded that some indicators should be extended to be more relevant for children and young people at different life stages. For example, in domain 1 of the NHS Outcomes Framework there is an indicator relating to reducing infant mortality that we recommend is extended to cover deaths in children and young people of all ages allowing specific analysis of particular conditions.

Group Findings and Recommendations

Getting into the health, education and social care system

The fundamental premise that underpins our recommendations is that there should be an accessible and inclusive service in an appropriate setting (including appropriate provision for out of hours) for all health, education and social care needs as close as possible to the child and young person's home delivered by trained and competent professionals.

The time taken from first raising a concern with a health professional to securing a definitive diagnosis, is a key concern for parents and a particular cause of stress and anxiety. There is evidence that early and prompt diagnosis is key to improving outcomes for children and young people and their families and ensuring that they are able to access appropriate treatments. Early diagnosis often means less intensive intervention as for example with cancer, where also secondary morbidities may not have yet developed. For some conditions, a definite confirmed diagnosis is a clear outcome. However, there will be other conditions, such as autism, where there may well be an emerging diagnosis over a longer period of time. In a situation where a definitive diagnosis is not possible, the key outcome will be access to an assessment that produces a diagnostic formulation and an integrated plan for intervention.

We therefore recommend the inclusion of a new indicator looking at the time to receive a definitive diagnosis from first presentation or contact with NHS services for a set of exemplar conditions starting with cancer, diabetes, meningococcal disease and epilepsy and time from first presentation in the NHS to diagnostic formulation and care plan for autism spectrum disorder.

Getting a quality integrated assessment

We know that parents and children are frustrated by fragmentation and poor coordination between different services and across settings. This can lead to duplication and omission where families are forced into repeating information to different practitioners and services and consequently can be a very stressful experience of care for children and their families. There is a need for assessments to be more holistic and centred around the needs of the child and their family. We support the proposal for a single education, health and care plan, as set out in the SEND Green Paper *Support and aspiration: A new approach to special educational needs and disability*, now being tested in the Green Paper pathfinder sites.

We noted that children's palliative care has developed an integrated multiagency approach with provision based on children's palliative care networks. This approach could be replicated for other long-term conditions.

We therefore recommend that a composite indicator be developed to look at the provision of integrated care for children and young people with a long-term condition or disability.

We also recommend that there should be an indicator in the Commissioning Outcomes Framework, that each child or young person with a long-term condition, disability, or complex special educational need has a coordinated package of care, including a quality assessment, access to the key worker approach and appropriate equipment.

Getting a quality service

Getting a quality service should contribute towards positive physical and mental health and well being in the family. There are several aspects to this:

- children and young people need to **have access** to a comprehensive network of care with staff (including GPs) that are trained and competent and feel confident that they are able to provide a high standard of care. Families want to feel confident that they are receiving the best clinical care in accordance with NICE guidance and other quality standards;
- the child's, young person's and family's **experience of the service**. The service should be child and family centred so that families feel that they are listened to and that their specific needs are reflected in the single plan and the care that they receive. Across the range of settings, they want their care to be delivered in a coordinated way by professionals that are well trained and clinically effective;
- families should have a **good knowledge and understanding of their child's condition** and be confident about how to manage it on a day to day basis. Schools and social care settings should also be trained and have confidence in their management of the medical condition. Where this is the case we would expect to see fewer admissions through A&E; and
- having access to a **key worker approach**.

To ensure a focus on quality of service and the experience of children, young people and their families we strongly support the Forum's recommendation to incorporate the views of children and young people into existing national patient surveys in all settings and to cover the following:

- Young People's experience of transition into adult services (post transition);
- provision of information about their care;
- involvement in decisions about their care;
- timely access to primary care;
- accommodation for families during care where appropriate;
- stigma and discrimination experienced by children in healthcare settings; and
- parental experience of neonatal care.

Additionally, measures of patient experience should include communication about appointments, location of care, suitability of environment for the individual, quality of care and quality of interpersonal communication.

Managing Transition

We want to highlight transition as a key area where there is a particular need for improved services. Adolescence can be a difficult transition for all young people, but there can be specific issues and challenges for young people with a long term condition or disability. Transition needs to promote the aspirations, independence and autonomy of the young person as they move to become a young adult. Outcomes of educational attainment and employment are key- delivered through effective transition planning.

We recommend a new outcome in the NHS Outcomes framework to ensure that effective and healthy transitions between child and adult centred health care take place.

We support the Forum's recommendation that the Royal College of Physicians, working with other colleges and the RCPCH urgently develop a plan to ensure that health outcomes and the experience for transition are improved and that NICE produce a quality standard for age and developmentally appropriate care of teenagers and young adults, including transition.

Family functioning

We also agreed that there should be some measure of family functioning, family stress or parental mental health in order to gauge whether an integrated package of care is improving the quality of life for whole families. We recognised the stress that is frequently placed on siblings and recommend that siblings of a child or young person with a long term condition or disability should be identifiable via school databases to assess outcomes for them compared with the wider population.

Identification of CYPS and their families with long term conditions and disability

We support the recommendation for the addition of identifiers into the pupil database and child health information systems so that they allow subdivision of information by children with long term conditions and long term mental health problems, disability, complex special educational needs and looked after children.

These changes together with the acceptance of the recommendations in this report will support the measurement of the following indicators in the NHS Outcomes framework (table 1 in the main report):

Domain 1 – Time from presentation at NHS setting to definitive diagnosis;

Domain 2 – 2b, 2.1.ii, 2.1.iii, 2.2.ii, 2.3.ii, 2.4.i, 2.4.ii, 2.5.ii;

Domain 4 – 4.6.ii and 4.9.

In the Public Health Outcomes Framework:

Domain 1 – Pupil absence for all children and educational attainment and progress but will allow the separate identification of those with a long term condition or disability.

In the Commissioning Outcomes Framework:

Domain 1 – Childhood mortality for specific conditions including meningococcal, septicaemia, asthma, lower respiratory tract infections.

Domain 2 – Each child with a long term condition, disability or special educational need has a coordinated package of care, any young person in transition from paediatric to adult care has a defined and agreed plan for handover, numbers of children and young people with multi-disciplinary care plans, every child or young person with multiple conditions has an agreed care pathway, number of children and young people with a disability.

A number of specific measures related to the diabetes pathway:

Domain 4 – Numbers of children and young people with end of life plans who die in the place of their choice.

Making the system work

We recognise the importance of alignment **and synergy** at every level in the system including:

- policy development;
- strategic planning;
- commissioning;
- providers/delivery of services;
- data recording; and
- governance/accountability.

We highlight the importance of Health and Wellbeing Boards as the focus for coordination of commissioning (we recognise that children's trust arrangements could be used to support commissioning arrangements for children and young people with a long term condition or disability)); and the vital role of Healthwatch in reflecting the views of children, young people and their families.

Essential to the delivery of improved outcomes for this group of children and young people and their families are the recommendations in the Forum's report for the NHS Commissioning Board that there should be strategic managed networks for children and young people developed at national level, that CCGs develop local networks or formal partnerships and that the NHS Commissioning Board and CCGs must address service configuration to meet the needs of children and young people on a sustainable basis.

In addition, we support the recommendation that the NHS Commissioning Board and Monitor need to prioritise and promote the issue of integrated care provision in their funding, regulatory and performance roles within the NHS; and that DH addresses this issue across government departments for those services that fall within the remit of Local Authorities, education providers or other government departments.

Annex A: Prevalence/Incidence Figures for Long Term Conditions and Disabilities

As this paper made clear at the outset one of the biggest barriers to improving outcomes for this group is a paucity of robust and comprehensive data. Below are a few examples of where data does exist for this group and reflects the scale of the challenge that is faced by many children, young people and their families.

Asthma: 17% among boys and 12% among girls. Current asthma, defined as symptoms in the last 12 months or symptoms controlled by medication for asthma in the last 12 months, was reported by 11% of boys and 8% of girls. Both lifetime and current asthma prevalence increased with age for both sexes. (2010 Health Survey for England)

Diabetes: 23,000 children and young people with diabetes in England, around 209 per 100,000 children aged 0-17 (RCPCH. (2009). Growing up with Diabetes: children and young people with diabetes

Children with Disabilities: the estimated number of children in England with a core disability is estimated to be 700,000. (Hansard Column 358W 28 June 2012)

Palliative Care: approximately 39,000 children under 19 in England are living with a life limiting condition that may require palliative care (Leeds Study: Fraser LK, Parslow RC, McKinney PA, Miller M, Aldridge JM, Hain R, Norman P 2012 Life Limiting and Life Threatening Conditions in children and young people in the United Kingdom: Final Report for Together for Short Lives)).

There are of course many estimates out there regarding the scale of a range of these long term conditions. However, the issue is these cannot in most cases be regarded as sufficiently robust as a basis for use by commissioners, providers and users of services. The purpose of this paper is to set out not only the clear gaps that exist in relation to data but also indicate the benefits that can be accrued right across the spectrum by a focus on increasing the availability of robust information.

Annex B: Summary of comments received

- Poor arrangements for transition
- Better integration of services needed – across health, education and social care, but also community and acute care
- Need for coordinator of care for complex conditions
- Better/quicker access to services needed
- Ongoing support for family needed
- Importance of whole family approach
- Need to emphasise the importance of peer support (ie, from other families)
- Better training needed for doctors and GPs
- Poor provision of therapy services
- HWBs need to be able to hold CCGs to account
- Outcomes frameworks need to help ensure that 'services are delivered in a way that helps disabled children in the context of their family and ordinary lives'
- Waiting and treatment rooms need to be more child/family friendly
- Variability of provision – postcode lottery
- Need to look at the child holistically – focus on what they can do
- Delays/problems in getting a diagnosis
- Treatment of children with a learning difficulty – inappropriate placements, need for access to a learning difficulties nurse on request, professionals don't understand the needs of children
- Support for child centred health plan and personal health budget
- Focus should be on primary care with support from specialist services – not the other way around
- Importance of better management of long term conditions (eg. asthma for school age children)
- Children and young people should be represented on CCGs
- Need for a cultural shift in the way practitioners work with children, young people and families – needs to be more inclusive
- Commissioning/funding arrangement prevent a holistic approach
- Frequent organisational change prevents continuity and forward planning
- Concerns about GP commissioning
- Emotional consequences of LTC/disability
- Need for children to get the right start – better focus on maternity
- Better workforce planning and education
- Better equipment needed
- Problems accessing nursery care – 'child's right to play should be protected'
- Need for improved access to mental health services for children with autism

- Health services not child friendly (eg. eye clinic doesn't understand the needs of a child with Downs Syndrome)
- Support focus on outcomes but some measure of processes needed (eg. safeguarding)
- Need for wellbeing/happiness measure at key developmental points

Theme Group Membership

Colin Green (co-chair)

Gillian Baird (co-chair)

Alan Craft

Anna Gill

Jacqui Double

Michelle Morris

Ruth Owen

Sue Morgan

Tracey Cogan

Simon Lenton

Claire Lemer

Barbara Gelb