



# These are our children

A review by Dame Christine Lenehan  
Director, Council for Disabled Children

Commissioned by the Department of Health

January 2017

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# Introduction

**These are our children and they are known. They occur in every area and they often follow a well-trodden pathway out of their local authority area, never to come back.**



There is a small group of children in every area with significant needs. We know who these children are. We know where they are. They are already in contact with the NHS and Local Authority and there is a broad understanding already of their needs.

This Review was triggered by a small number of individual cases. They focussed public and Ministerial attention on the care, support and treatment provided to the group of children and young people with complex needs (and behaviour that challenges) involving mental health problems and learning disabilities and/ or autism.

Alistair Burt, the then Minister of State for Care and Support, asked in 2016 for a Review to *“take a strategic overview and recommend what practical action can be taken by Government Departments and partners at national level to make the system better able to co-ordinate care, support and treatment for children and young people with complex needs (and behaviour that challenges) involving mental health problems and learning disabilities and/ or autism.”*

The Case Review into the care of one of the individuals that prompted this Review stated that *“There does not need to be another large review to consider how to improve services for children and young people with autism, learning difficulties and or mental health issues.”*

I agree. The failure to deliver appropriate care and support is not to do with activity, or interest or commitment but to do with not giving the necessary outcomes for this group of children. During this Review I have worked with key national leaders, clinicians and managers to understand why the issues in relation to these children remain unresolved.

While this Review is a result of recent cases, it should be noted that this is not a recent issue. Almost 20 years ago a committee of the Mental Health Foundation published *Don't Forget Us, Children with Learning Disabilities and Severe Challenging Behaviour* (Mental Health Foundation, 1997). The report provided a clear overview of the issues and challenges and highlighted the need for children to be viewed as children first. More recently part of my role in the *National Service Framework for Children, Young People and Maternity* (Department for Education and

Skills/Department of Health, 2004)<sup>1</sup> was looking at the needs of this group and understanding how the world of Children and Young People's Mental Health Services (CYPMHS), learning disability services and children's services came together. We didn't get it right then. We haven't got it right now.

When I left practice in 1997, I could walk round my authority looking at small children and knowing that the chances of them going out of the authority area, often to a placement a considerable distance away, aged 11, 12 or 13 was high. Their diagnosis at age two or before was the indicator to the challenges they would face and yet they followed a path which institutionalised them during their teenage years and condemned them to a life hidden from society, away from their families, at huge financial cost to the taxpayer and with very poor outcomes.

That is not to say that all inpatient services are wrong and poor. They are not. Some are exceptional and when they are the right choice for a child at the right time they can make a lifetime of difference. However, when they become a place of last resort they are not being used for assessment or treatment but for warehousing, they act as the long stay hospitals that I thought we had left behind.

So is it too hard? Are they really too complex? Is this the best we can do? It can't be and it isn't. There is enough evidence of good practice in the system to show a different picture. There are too many individuals who want to make a difference for it not to change. This report is about making that change happen everywhere as it is already happening in the best areas, and ensuring that it delivers the best possible benefits for this group of children.

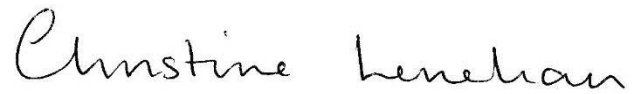
These children are part of our community, not external to it. They are our nieces and nephews, the children of our neighbours and friends. In a very real way they are our children too. We have a responsibility as a community to do the best for these children, to support them in the best possible way in order to allow them to thrive. We need to take that responsibility seriously and believe that our actions can make a difference. One of the things that I feel most strongly about is that at present no one is accountable for this group of children. That is why this report is entitled 'These are our children' and it is why throughout the report I will refer to "our children" not "these children" because it is vital that we all feel responsible for finally bringing them home or supporting them to live lives with their families and communities.

During the course of this Review I received valuable support from officials (Claire Bethel, Karen Gowler, Shain Wells, Gareth James and Colin Startup) at the Department of Health. I would also like to thank all those individuals that gave me their time and shared their experience in assisting me to compile this report. Their names and organisations are listed at Annex B.

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<sup>1</sup> [National Service Framework for Children, Young People and Maternity Services \(2004\).](#)

It was my task to decide on the recommendations that the report would contain. I tried to be pragmatic and selected recommendations that are deliverable and will make a difference. I accept responsibility for the selection of the recommendations and the text in the report.

A handwritten signature in black ink that reads "Christine Lenehan". The script is cursive and fluid, with the first letter of each word being capitalized and larger than the others.

**Dame Christine Lenehan,**  
Director of the Council for Disabled Children

# Setting the Context

1. So who are our children? How many of them are there and what do they need to help them thrive?

## Definitions

### Learning disability and autistic spectrum condition<sup>2</sup>

Learning disability (LD) refers to a significant impairment of general intellectual and adaptive functioning that originates in childhood.

*Early Intervention for Children with learning disabilities whose behaviours challenge, The Challenging Behaviour Foundation, 2014.*

2. A child or young person with a learning disability will find it harder than other children to understand, learn and remember new things. They may need more support with everyday activities such as communicating, keeping safe and managing everyday tasks.

3. Autism is a lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them. A term often used to cover the range of conditions on the autistic spectrum is Autistic Spectrum Conditions (ASC). Other terms sometimes used where children may have a learning disability are “special educational needs”, “developmental delay”, or “complex needs” (where a child also has physical or health needs).

4. Some children have both autism and a learning disability and can therefore need particularly high levels of support.

### Challenging behaviour<sup>3</sup>

“Behaviour can be described as challenging when it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion.”

*Challenging Behaviour: A Unified Approach, 2016*

<sup>2</sup> [Early Intervention for Children with learning disabilities whose behaviours challenge \(CDC / Challenging Behaviour Foundation, 2014\)](#)

<sup>3</sup> [Challenging Behaviour: A Unified Approach \(Learning Disabilities Professional Senate, April 2016\).](#)

5. Most parents and professionals experience behaviours from children which challenge them at times. This is usually a phase which children grow out of as they develop new skills. It is harder for children with learning disabilities or autism to develop the communication and social skills which other children use to get them what they want and need. This may mean that their behaviours are much more challenging and they are unlikely to “grow out” of those behaviours on their own without skilled support to get their needs met in a different way.

6. Other terms sometimes used are “behaviour difficulties”, “behaviour problems” or “behavioural, emotional or social difficulties” This report uses the term “challenging behaviour” when talking about children with learning disabilities and autism, as it is the behaviour which is challenging, not the child.

7. When the system does not meet children’s needs, we know they are at greater risk of social exclusion, prolonged admission to hospital, deprivation, physical harm, abuse, misdiagnosis, exposure to ineffective interventions, and failure to access evidence-based interventions.<sup>4</sup>

8. Our children experience many or all of these. They have a set of needs which has the same effect of their health, happiness and wellbeing as a complex physical health condition and their care and support should reflect that.

## What does the evidence tell us?

9. At least 2.5% of the general UK population has a learning disability that means they will need specialist services at some point in their childhood (Emerson & Hatton, 2008). Nearly 40% of this group will experience significant psychiatric disorder, compared with less than 10% of those without a learning disability (Emerson & Hatton, 2007). This seems to be a consequence of innate factors that confer vulnerability, compounded by a range of external factors

Factors contributing to mental health problems in this population
<ul style="list-style-type: none"><li>• Communication difficulties</li><li>• Limited coping strategies and social skills</li><li>• Coexistent disorders<ul style="list-style-type: none"><li>* Neurodevelopmental disorder – notably ASD and ADHD</li><li>* Psychiatric disorder – emotional disorder and psychosis</li><li>* Physical health problems – epilepsy, immunological difficulties, sleep disorders</li></ul></li><li>• Child abuse (exposure to violence including bullying, abuse and neglect)</li><li>• Out-of-home care (e.g. fostering, institutional placement)</li><li>• Socioeconomic deprivation</li></ul>

<sup>4</sup> [McGill, P., & Poynter, J. \(2012\). High cost residential placements for adults with intellectual disabilities. \*Journal of Applied Research in Intellectual Disabilities\*, 25, 584-587 \(abstract\).](#)



- Inadequate educational provision and supportive services (e.g. a lack of local residential projects, such as respite provision and residential schooling)
- A remote, rural population
- Adverse life events

(Emerson, 2015)

## **Delivering improvements in a time of austerity**

10. The evidence shows us that our group of children tend to be in poorer families and live in challenging circumstances. Even for more affluent and settled families the cuts in local authority support services are biting hard. The loss of local authority early intervention and short breaks services affects our group of children disproportionately. The concurrent pressures on early intervention and particularly prevention services in community health and CYPMHS adds a layer that leads inevitably to higher financial costs and crisis services. This leads to a process where our group of children are escalated through tiers of service as gaps occur and the result is significant pressure on inpatient facilities and a lack of community services for children to return to.

11. Over the course of this Review I have taken repeated evidence of inpatient costs for individual children averaging at £1million per child every three years. Throughout the development of this report I asked each interviewee “What does a post-ATU (Assessment and Treatment Unit) placement look like?” The answer that I got was that they rarely exist and are not being developed, which is one of the reasons that our children can get “stuck” in ATUs. We have created a one way street for children which will mean a lifetime at substantial cost to the taxpayer for some very poor outcomes.

## **Government programmes but no one’s priority**

12. This is not a group of children and young people that is ignored by Government programmes and priorities. The challenge is that everybody’s business becomes no-one’s priority. These children need to become our children.

13. Programmes that cover or are relevant to our group of children and young people include:

- Integrated Personalised Commissioning<sup>5</sup> and personal health budgets;
- Transforming Care;<sup>6</sup>
- Children and Young People’s Mental Health Transformation Programme, which includes the development of a generic pathway for

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<sup>5</sup> [Integrated Personalised Commissioning](#)

<sup>6</sup> [Transforming Care](#)

children and young people's mental health across the spectrum of mental health needs;

- Review of inpatient children and young people's mental health services;
- The commissioning of a children's pathway;
- Challenging Behaviour Foundation (CBF/Council for Disabled Children (CDC) Early Intervention Programme and the Paving the Way website;
- Children's Continuing Care Review;
- *Residential care in England*,<sup>7</sup> Sir Martin Narey's independent review of children's residential care in England; and.
- The SEND (Special Educational Needs and Disabilities) reforms.

14. These programmes build on significant sporadic activity over the years, which has accelerated since the abuse of people with learning disabilities was uncovered at Winterbourne View. All of these activities have investment, energy and creativity attached to them. All of them recognise a problem, but together they have not added up to a definitive strategy. Despite the best endeavours of leaders, clinicians and managers at a range of levels these activities have not been coherent and so have not delivered effective solutions. This report looks at moving forward to a solution that pulls together the parts to form a coherent whole. .

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<sup>7</sup> [Residential Care in England Report of Sir Martin Narey's independent review of children's residential care \(July 2016\)](#)

# Facing the denial of basic children's rights

15. It is important that where we start is with understanding the humanity of the children and young people we deal with.

16. Recent scandals such as Winterbourne View, Mid-Staffordshire, and instances of sustained sexual exploitation of children, have reminded us that when we believe that the people we interact with are less than fully human we build a culture which leads to degradation and abuse. While I do not wish to paint a picture that is worse than it is it's important to remember that many of our group of children remain denied the basic rights of childhood, a loving family environment, a full education, and a right to develop and move towards adulthood within a community, whatever the right community looks like for them. Tackling this denial of rights should be fundamental to our thinking and tested against what action we decide. Otherwise we quickly retreat into deciding a new 'normal', where a different set of values apply, where what is expected for all children is not available for our children, because they are not seen as children any more but as patients, or problems to be solved. This view has to be challenged. We must meet our obligations under the *United Nations Convention on the Rights of the Child*<sup>8</sup> which obligate us to ensure that the best interests of the child are a top priority in all decisions and actions, that every child has the right to the best possible health, and that they develop to their full potential.

## **Recommendation 1: Children's Rights**

**That our children deserve to have their rights promoted, their voices heard and develop to their full potential as per our obligations under the *United Nations Convention on the Rights of the Child*. In order to do this at a national level:**

- a. **The Department of Health should set an example through ensuring that parity of esteem between mental and physical health becomes a reality;**
- b. **NHS England should ensure they are recognised specifically within work on the NHS constitution;**
- c. **Public Health England should ensure they are recognised specifically within work on the review of the *You're Welcome Standards*;**
- d. **The Department for Education should ensure their rights are promoted as part of the Residential Special Schools work and the wider work on vulnerable children; and**
- e. **At a local level, commissioning and delivery of all services for our children should acknowledge and respect their right to a childhood.**

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<sup>8</sup> [United Nations Convention on the Rights of the Child](#)

17. In the course of the Review I heard about young people who had spent the weekend in Accident and Emergency (A&E) following a crisis, because there was no alternative. I heard of a young man spending 6 months in an inpatient unit a long way from home because his local area could not agree a funding package to bring him home. I heard of another young person who spent months living in a single room with no access to toilet or washing facilities because staff did not understand how to work with him. I also heard from hard-pressed managers of services who knew they were not doing their best for young people but didn't know what the alternative was. The few cases that get a national profile are important in that they highlight the sort of difficulties that our group of children and young people encounter, but from what I heard they were not unusual.

18. A senior manager reflected on a panel which had been pleased to agree a solution for an 11 year old which involved him living full time in a residential school a long way from home. "*It can't be right, can it?*", he said and the answer is no, it can't. We wouldn't make that decision for a child without these needs; it would not be seen as acceptable.

### **Recommendation 2: Residential Special Schools and Colleges**

**I recommend that following the concerns raised throughout this Review, a separate piece of work should be undertaken to look at the role of Residential Special Schools and Colleges for this group of children. This Review should be led by the Department for Education but supported by the Department of Health, NHS England and Public Health England.**

### **Recommendation 3: 18-25s in Inpatient Settings**

**I recommend that the Department of Health, Department for Education and NHS England undertake an urgent review into the needs of the young people aged 18-25 covered by the Review currently in inpatient provision (whether they are in acute inpatient, mental health or learning disability beds). The Review should look at numbers, routes of admission and destinations to ensure this group of young people do not face a lifelong future in institutional care and we stop under-18s becoming the next adult inpatient cohort.**

# Articulating the Vision

19. The managers/clinicians I spoke to throughout this Review were passionate, committed and enthusiastic. Their desire to do their best was not in doubt, but it was difficult to see a clearly articulated vision for the outcomes for our group of children's lives and, therefore, the service interventions needed to support those outcomes. We have to build, articulate and test a vision which is about:

- valuing each young person and respecting their right to childhood;
- providing appropriate support at the right stage, at the right level, in order to help them access a full community life;
- understanding children as part of their family and providing support for the whole family; and
- understanding that all children and young people, whatever their level of impairment, communicate and have a right to be heard.

# Delivering a Model of Care

20. At a philosophical level there is a strong degree of consensus as to what a good model of care should look like. A service should provide:

- Early diagnosis;
- Post-diagnosis support including specialist parenting classes;
- Strong early links with education services;
- An agreed CYPMHS (children and Young People's Mental Health Services)/Learning Disability approach which is focussed on prevention/early intervention and which involves schools;
- A Positive Behaviour Support programme which is consistent across settings;
- An early warning system potentially linked to key worker/named clinician models;
- Family support which looks at the whole family;
- Wrap-around support which looks at good multi-agency intervention approaches;
- Education which recognises and understands behaviour as a form of communication and seeks to fully include the child in school life, in the least restrictive way;
- Education, Health and Care (EHC) plans which are a genuine vehicle for bringing "whole child" planning together which take a whole life approach and focus on what matters to the child and their family;
- Good therapeutic short breaks service which provide positive opportunities for young people and support in management to caregivers and others;
- Joint commissioned residential services which should have both health/education and care inputs and serve as an outreach support service.
- An Intensive support service to manage crisis and support community living; and
- An understanding of the additional effective role that inpatient units play.

21. The operationalisation of the model needs more thinking. The issue is that it does not exist in practice except in small parts of individual services.

22. In order to provide the range of support needed there needs to be ownership underpinned by clear joint agency commitment at the highest level with cross-agency agreements on access to the service, costs and funding.

23. I asked staff who ran successful models why those models worked. One service said:

*“Success needs strong commissioning relationships. Key to these is a strong parental engagement and models based on being respectful to families. We work on family partnerships at the heart of our model. We use collaborative practice and then add the technical skills that are needed. We work closely with looked after children’s teams and attachment issues – looking at cross learning. Links with adult mental health are key and often needed to support parents.*

*“Our aim is to keep children at home and in the community. This has to start before school and work through childhood. Commissioning partnerships are key and must be multi agency and involve psychiatry, community nurses, speech and language etc. and it must have a specialist team and family support worker. You have to resource these services to succeed and that means a team big enough to deliver the variety of skills and interventions. The link and partnership with social care is critical. Part of the work is links to adolescence and working closely with the local Safeguarding Board. We need to really understand what supports families and schools to cope.”*

24. There is a real opportunity now to tie some of the development of services into the STP (Sustainability and Transformation Plans) footprints and link the work to what is happening in wider LA footprints such as that in Greater Manchester.

25. The Strategic Director for Children and Adult Services, Salford, which is the lead authority in the Greater Manchester Combined Authority (GMCA), told me:

*“We could look at different commissioning footprints. We are already looking at a LAC sufficiency strategy and this would fit with that alongside a work stream on education and placement planning. There are opportunities as the work develops.”*

#### **Recommendation 4: Model of Care**

**I recommend that NHS England work with the Department for Education, Transforming Care Partnerships, the Association of Directors of Children’s Services, and the Local Government Association to develop an effective model of care for these children and young people, particularly post-ATU (Assessment and Treatment Unit), so that other areas can see what can be achieved and rolled out. This work should include an emphasis on transition both out of the ATU and - where relevant - to adult services.**

# What does it take to make implementation a reality?

## Leadership and accountability

26. There currently appears to be no line of sight for our group of children through the system. The way the system is structured reinforces the status quo. The fragmentation across three statutory agencies builds inertia within them and breeds a lack of ownership. There are perverse incentives built into the system which reinforces agencies to take a partial view. Throughout the Review I was told:

*“There is no one place for support and oversight for this group. There are difficulties in managing cultures/working arrangements to enable a co-ordinated approach.”*

27. In many areas each agency believed that the other should be more engaged, more proactive, more responsible. This was even the case when I spoke to all partners in a locality.

28. Within the NHS or wider system there was no single point of accountability, either at national or local levels. There were both managers and clinicians who believed that they had responsibility but there was no collective ownership. One area brought agencies together to review with the mantra that “these are our children, our collective responsibility”, but this seemed rare.

29. This challenge was reflected in a lack of momentum in the system and no single identifiable focus on the child’s journey throughout it.

30. Our group of children cry out for a cross-government, cross-system approach. They are small in number, easily identifiable and very expensive. They should sit at the heart of joint commissioning and yet they don’t. Why not? The small number in each area means that they never reach a critical mass for commissioning and they are dealt with on an individual basis and placed into a system which has patchy provision, usually a long way from home.

31. If this group are not made a national focus for action and accepted as a cross-government priority then nothing will change. Children with these needs will not go away, and we cannot claim to be effectively planning services based on needs if we pretend they don’t exist just because meeting their needs is hard.



## Accepting professional responsibility

32. The continuing philosophical debates about causation and treatment of challenging behaviour is one of the main reasons that children fall between gaps and fail to get access to appropriate services. The system has a number of built-in barriers which restrict access to supportive interventions. Added to this, our children are complex in their needs and their presentation and they do not always fit individual labels of autism/ learning disability/ neuro developmental disability/challenging behaviour /mental health. It is more likely that they have a combination which does not fit neatly into any one team's existing definitions for service. Furthermore, mental health problems frequently don't manifest themselves until adolescence adding to the difficulties in getting clear diagnosis.

33. As one clinician said:

*"The criteria for community services should be needs-based, not IQ-based."*

34. While the above issues are a challenge, particularly to health, they impact on wider multi-agency activity. Interviewees talked about a lack of mutual respect between education and CYPMHS and a lack of clarity in terms of who does what. A number of social care services have also adopted an "access at diagnosis approach" and this can exclude some of the most complex cases, where diagnosis can take significant time and where a care pathway may not be clear.

35. Case studies from the Challenging Behaviour Foundation/Council for Disabled Children Early Intervention Project provide further information.

36. For example, in one local area even where they have a great positive behaviour support service for children:-

*"The team did not have capacity to support those with less severe levels of challenging behaviour (no early intervention team) and there was nothing for young people with autism but no learning disability. One family of a 13 year old boy with autism were told by Social Services to call the police and although they were reluctant they had to call the police 47 times in 4 years. The GP prescribed liquid diazepam to the child and the family were told there was nothing more they could do and the family were told it was bad parenting. There was no family support, behaviour support, autism or CYPMH specialist support." (CBF/CDC Early Intervention Project)*

37. In another area, *"families explained that children where provision was good in schools were doing OK overall but these tended to be the children "in the middle" – those with more severe learning disabilities (and at risk of later ATU admission) were not able to access good support (except for those who happened to have a paediatrician who took it upon herself to be a key-worker above and beyond what she was required to do) and those with milder learning disabilities (and so at potential risk of encountering the criminal justice system later were similarly lacking support."*

38. Around a quarter of children and young people in custody have learning disabilities (CYP pathway published by NHS England, supported by work from The National Development Team for Inclusion (NDTi) and the Challenging Behaviour Foundation (CBF)). Some children and young people who have learning disabilities and/or autistic spectrum conditions are particularly vulnerable to exploitation by people they perceive as 'mates', or by more defined gangs, and such exploitation may include persuading/coercing the young person to commit crimes. In addition, some young women are highly vulnerable to domestic violence and sexual exploitation and again may be persuaded or coerced into criminal behaviour. Difficulties with understanding cause and effect, managing anger or understanding relationships and intimacy may lead to offending behaviour yet these difficulties are potentially amenable to early intervention.

39. In another area *"they had excellent early years provision for children with autism. Families receiving this were really happy and felt they had family support and behaviour support in place. However, children with learning disabilities were not eligible for this service or any equivalent and were left with nothing, no behaviour support, no family support."*

40. NICE (The National Institute for Health and Care Excellence) has issued guidelines on *Autism Spectrum Disorder in under 19s: support and management*, *Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges*, and *Mental health problems in people with learning disabilities*. These guidelines are all evidence based, all useful but can be a struggle to adapt for children whose needs spread across the boundaries of individual guidelines.

41. As one interviewee said:

*"They are very good, but the system does not 'do' complexity."*

42. We need to get beyond a system which is dependent on diagnosis to one which starts with children's needs and then looks at how and by whom they can best be met. This was clearly spelt out in *Future in mind: "Making multi-agency teams available with flexible acceptance criteria for referrals concerning vulnerable children*

*and young people. These should not be based only on clinical diagnosis, but on the presenting needs of the child or young person and the level of professional or family concern” (Future in mind, DH and NHS England, 2015).*

43. There is also a specific need for clinicians, in particular, to agree ownership and working protocols for our group of children. Too often I was told that this group of children were the poor relations of CYPMHS which themselves are significantly overstretched, currently reaching only 25% of the children who need their services with an aim of reaching 33% by 2020 with the additional money following *Future in mind*.

44. No professional group saw themselves as fully trained in one or more of our group of children’s needs, whether that related to their physical or mental health. The behavioural needs of this group, in addition to their learning disabilities, meant that mainstream child and adolescent services do not feel they have the right skills. There are CYPMHS that literally don’t accept children and young people with learning disabilities as they don’t feel able to offer them any interventions. Meanwhile many paediatric services do not see themselves as mental health professionals. This also means that in some areas neither group believe they are commissioned to deliver the service for this group of children and young people, meaning that yet again these children fall through the gaps.

45. There were some positive stories from specialist clinical psychologists and from psychiatrists with LD/ASD expertise who were managing effective services but these were patchy and often reliant on the particular skills, interest and determination of the clinician involved. Again and again, I heard about the challenges caused by the lack of availability of Learning Disability Nurses.

46. I have asked the Learning Disability Professional Senate to develop a recommendation to challenge this issue and to undertake further work which looks at collective responsibility and which will stop these children “bouncing around the system” and not getting the skill and expertise from health professionals and others that they need.

### **Recommendation 5: Professional Responsibility**

**I recommend that the Royal College of Psychiatrists, the Royal College of Paediatrics and Child Health and the Royal College of General Practitioners working with other relevant Royal Colleges urgently undertake discussions to clarify the responsibility of medical and other professionals for children and young people with a mental health condition, autism, challenging behaviour and/or a learning disability, and develop national jointly owned guidance to ensure respective roles are widely and consistently understood.**

## Supporting parents and families

47. This Review has focused on systemic levers for change rather than child and family experience. However, what is clear is that if professionals find the system a challenge, then it is almost impossible for families to navigate. Professionals talked throughout of the need for a “navigator”, a “keyworker”, a “lead clinician” to stop the child from being lost in the system and to ensure that the parents are informed at all points and able to make genuinely informed choices based on all the available evidence.

48. When children are diagnosed with cancer we rightly assign the child and family a keyworker who stays with them through their journey. If we support that group of children we should be able to do the same for this group. Throughout the Review, the issue of parity of esteem between physical and mental health was repeatedly raised. Our group of children are individuals with a complex condition that need care and treatment. If they had a physical illness, the feeling was that they would have a clear care and treatment plan and would be assigned a lead clinician with full parental engagement. Again *Future in mind* considered the same issue, saying “A designated or lead professional should be identified and their role strengthened – someone who knows the family well – to liaise with all agencies and ensure that services are targeted and delivered in an integrated way” (Future in mind, DH and NHS England, 2015)<sup>9</sup>.

49. Because our children often have more complex needs than a child with a physical illness, the concept of a named lead is even more important, regardless of the fact that it might be more complex to deliver.

50. Lack of communication and support for parents was a key issue raised in the individual case reviews of the young people that prompted this Review. Basic good practice should be to ensure that parents always have a clear point of contact. This should be provided in a way which recognises the needs of the whole family for support. The voice of siblings, for example, is often unheard but the impact on their lives is often significant.

51. One initiative which might be helpful is the work set out in *No voice unheard, no right ignored* (Consultation Paper, DH, March 2015<sup>10</sup> and Government response to Consultation, DH, November 2015)<sup>11</sup> in strengthening the rights and choices for people to live in the community. The Named Social Worker pilot currently applies to

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<sup>9</sup> [Future in mind. Promoting, protecting and improving our children and young people’s mental health and wellbeing \(2015\).](#)

<sup>10</sup> [No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health \(March 2015\).](#)

<sup>11</sup> [Government response to No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions \(November 2015\).](#)

adults but could be extended to this group. It would be particularly valuable for young people in transition.

#### **Recommendation 6: Local Authority role**

I want to see every child getting the level of support that the best parents give their own children. I therefore recommend that **Local Authorities** establish how the right level of commitment and support can be given to children and young people from their area that are placed in inpatient settings (due to their mental health, autism and/or a learning disability) outside their area. There would need to be agreement between the LA in which the setting is located and the home LA on their roles and responsibilities. This would ensure that there is clear accountability for these children and young people and that they are adequately safeguarded and supported. It is also important that **Local Authorities** work in partnership with families where the child is still in contact with them, including where they retain parenting responsibilities.

#### **Recommendation 7: Keyworker/Named Worker**

I further recommend that each child or young person in an inpatient setting (due to their mental health, autism and/or a learning disability) or at **risk** of going into an inpatient setting (due to their mental health, autism and/or a learning disability) who does not already have an individual performing this role should have a keyworker/named worker either from health or local authority services, but in touch with both. This person, based in the child's home area, should have sufficient authority and expertise to support the young person and their family to navigate the system and act as a liaison point for them. Whichever service takes the lead, there should be a named lead in the others.

## Developing coherence within the system

52. Within the system there is money, activity and intent which impacts on this group of children. However, it fails to come together in a single coherent strategy. Transforming Care should provide the vehicle for this and has, this year, included a children-specific focus for delivery but it has struggled to gain cross-system engagement.

53. I was struck throughout the Review by the commitment and determination of staff at all levels to deliver the Transforming Care programme, but also by the complexity and challenge of programme delivery. It is essential that this programme is supported to continue for all age groups. The programme has a children and young people's work stream but it is in its early days. It is also essential that the programme for children is seen as truly multi-agency securing the engagement of the Department for Education (DfE), the Association of Directors of Children's Services (ADCS) and local government as true partners.

54. The adult population targeted through the Transforming Care programme is young, with the majority in NHS commissioned inpatient care being for people between the ages of 18 and 34. Analysis of age on admission/transfer to hospital shows that around 38% of all admissions and transfers are of young people aged between 18 and 25. 21% are young people between 18 and 21 years of age. Many of those transferring into the population will be coming from other residential settings, but nonetheless it is clear that a strong focus on well-planned transition to adult care and support will be required for the Transforming Care Programme to achieve a sustained reduction in the numbers in inpatient settings (NHS Digital, Learning Disability Services Quarterly Statistics: England Commissioner Census (Assuring Transformation) Q2-Q4 15/16)<sup>12</sup>.

55. A much stronger pulling together of initiatives across the system is needed. Key will be bringing together Integrated Personal Commissioning (IPC), where this group of children are already acknowledged as the focus, and an understanding of the contribution of the Special Educational Needs and Disability (SEND) reforms. Expectations of the *Future in mind* strategy for our children need to be made explicit. Mental health and learning disability professionals were concerned that *Future in mind* was passing them by and yet could be a key vehicle for bringing these groups together. There needs to be good links between areas of work and a strong message about their shared outcomes, otherwise we risk them being seen as competing priorities rather than working together.

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<sup>12</sup> [Learning Disability Services Quarterly Statistics - England Commissioner Census \(Assuring Transformation\) – Quarter 4 2015/16, Experimental Statistics](#)

56. The pulling together of programmes nationally needs to be replicated at a local level. Some good local commissioners are pulling strands of the work together but this is instead of a more coherent, systematic approach. Clinical Commissioning Groups (CCGs) are only at the very beginning of their journey for our group of children. Similarly, as already mentioned, the Transforming Care Programme has a children and young people's work stream but it has not been going for long. They need to do key work building preventative services and use data to build dynamic risk registers and children's outreach services. The mandate behind the Transforming Care programme and its level of oversight should be the vehicle which drives this. The vast majority of CCGs currently have nothing in place for our group so are having to start from scratch. CCGs need to have a clear set of expectations in place. The numbers of our group of children at CCG level can be very small, and the costs high, which reinforces the importance of commissioning across wider footprints. There are a lot of good resources for our group including the recent pathway for children and young people commissioned by NHS England but it is difficult to understand the status of these resources, how they are communicated to CCGs and then how they are implemented.

#### **Recommendation 8: National and Local Coherence**

I recommend that the **Department of Health takes the lead in working together with the Department for Education, Department for Communities and Local Government and relevant Arm's Length Bodies** to bring coherence/alignment at a national and local level by the end of the 2016/17 financial year to the initiatives, such as Transforming Care, Integrated Personal Commissioning, Continuing Care, SEND Reforms, Local Transformation Plans/Strategic Transformation Plans for children and young people's mental health services, Mental Health Crisis Care, which impact on services for this group of children and young people. The aim should be for integrated local assessments, plans, decision making and reviews, with local mechanisms for communication and information sharing between teams. Similarly, national and local **commissioners / Health and Wellbeing Boards** should be seeking to consider the needs of all children supported by these different types of commissioning / provision, as a diverse but coherent group – and recognising their overlap with other areas of need, such as community paediatrics, community and school nursing etc. In each area a Senior Responsible Officer (SRO) should be agreed who has the necessary skills and seniority to perform this role.

#### **Recommendation 9: Local Implementation**

I recommend that **NHS England, the Association of Directors of Children's Services and the Local Government Association** support Transforming Care Partnerships in the implementation of the Service Model as it applies to children and young people, by drawing on supplementary guidance issued by

**NHS England and the pathway tools developed in partnership with NDTi and the Challenging Behaviour Foundation.**



# A Focus on Commissioning

## Who commissions commissioners and why don't they commission for this group of young people?

57. The issue about effective commissioning ran through the Review. When I asked commissioners (specialised commissioners and CCGs) why the above was so, their response was

*“the service model for children is written but not well known or understood. There are generally poor levels of awareness of this group of children in services and it is difficult to see an effective commissioning process in practice.”*

58. The challenges in the process start with the ownership of our group of children. As one clinician said:

*“You can only commission into something that exists. If no one owns it it's difficult to commission it.”*

59. This needs to be addressed by the professional groups, as highlighted earlier. However, even when it was owned it wasn't commissioned. There is little evidence of systematic cross-system commissioning with health and local authorities of good early intervention and therapeutic family support/short breaks services. This lack of early intervention can have a significant effect on the need for services further “downstream”.

60. Commissioners were clear that resources have to deliver the mandated Government priorities and other commissioning is at their discretion and should be based on population needs. To ensure that specialised commissioning can better respond to the needs of children and young people with mental health and learning disabilities and/or autism, a recent large-scale service review of inpatient beds for this group was conducted. The outcomes of this review include an understanding that a greater number of inpatient beds for children and young people with a learning disability and/or autism are needed, particularly in the London and the South. Achieving this will ensure that children and young people receive appropriate provision closer to home. The regions are currently working out plans for implementation.

61. Commissioners were worried that there would be high expectations on services but no money to deliver. Commissioners were confused about what was expected of them and what the minimum expectations are (as opposed to the clear expectations

which exist for children with eating disorders for example which has a NHS England programme and separate stream of funding from the Government from the Autumn Statement 2014).

62. The Government's mandate to NHS England sets out objectives with some specific deliverables. Unless the Government makes a specific reference to this group of children in the mandate, which it hasn't done to date, the current situation will not change. However, even if there is no new money available, and that seems the likeliest scenario, we need to understand and work with commissioners on using current money to best value.

63. The other commissioning issue frequently mentioned to me was that you can't commission a service if there is no suitable service to commission. Services tend to be supply-driven in the NHS and if there aren't any suitable providers it is very difficult for commissioners to do their job, however good the specifications they issue.

### **Are we still commissioning for early intervention?**

64. As well as general commissioning issues there were some very specific concerns raised.

65. Interviewees told me that:

*"CYPMHS tenders seem to be about reactive pathways so no early interventions, no early identification, no vision and coherence, no imperative on preventative services."*

66. It reinforced a belief that decisions tend to be made on what we have got to offer in terms of provision, not what we need. The introduction of Integrated Personal Commissioning and personal budgets (health, education and social care) is shifting the focus from what the system can offer to what works for individual children and their families. There is no integrated strategy in place, or prevention, or work with under- 5s. The policy documents produced by Government emphasise the need for these services to be available but in practice they remain largely absent. Do we need to see supporting our group of children as a public health issue and build on a wider set of cross-government activity to reinforce this? For our group of children, school nursing services as commissioned by local authorities can be invaluable for example.

67. It is possible to deliver effective services. This example was collected through the CBF/CDC programme on early identification:

“The Gloucestershire Early Intervention team is a good model – it has a very broad eligibility criteria (but is quickly able to move on those with lower support needs or who may be better supported by another team). This means that families’ first experience is of an open door, rather than another barrier. That approach will cost money and it will cost more for the whole group than a smaller group – but in the long term it really can support children to stay in the community. It would benefit from a full cost benefit evaluation?”

### **Developing a fully-responsive service at crisis point**

68. There is a broad issue with a lack of out of hours provision for children and young people with challenging behaviour, across services. It is clear that there has to be some level of service available out of hours to ensure that children and young people receive appropriate care. I heard regularly of problems when crisis erupts during the evening or at the weekend and where the only available place of safety is the local accident and emergency (A&E) department. This clearly adds strain to the challenges of A&E and does not meet the needs of the young person concerned. The current work in progress through the National Collaborating Centre for Mental Health looking at Achieving Better Access to Emergency Mental Health Care should address this and make clear that children presenting with challenging behaviour should be accepted as having a mental health crisis and that the appropriate pathway should therefore be followed. At a time of crisis, arguments about diagnosis and causation of the presenting problem are extremely unhelpful, and the priority must be ensuring care and support for the child concerned.

### **Places of safety**

69. The current geographical spread of inpatient provision does not represent the population needs both in geography and in capacity. There is no suitable placement available for young people living in London and the South East, or throughout the South West. Distant services are put under pressure and placement decisions will inevitably affect family life.

70. Models of good practice, such as in the West Midlands which links services to specialist children’s homes in the area, illustrate what is possible when provision provides a hub to outreach services, something which is not possible at significant distance. I was cautioned about re-provision. While the geographical challenge is significant, new service configurations are also needed to ensure that they are appropriately staffed and could offer the skilled service that is necessary.

71. I understand that the children and young people's mental health inpatient service review will shortly address many of these issues.

### **Provision for the most complex**

72. There are particular challenges for children and young people with the most complex needs, such as severe autism, severe learning disability and mental health needs. There are few inpatient beds available. Additionally the needs of our group of children have to be balanced against the needs of others and, for fully understandable reasons, units will be reticent about taking children who do not have a placement to return to. Making such an open-ended commitment is very hard for these small units with limited resources.

73. A number of our group of children end up in residential special schools as a last resort and there are real concerns about the level of professional health support available from psychiatrists, psychologists etc. in that setting. Throughout the Review I heard concerns about Residential Special Schools. That is not to say that there are not some very good ones. There are, and they fill an essential role in the system. The concerns arose from placements of children made at crisis point, into services which were not adequately skilled or staffed to effectively meet the level of need. Additionally, concerns were raised around the challenge of admissions from schools into both inpatient children's units and to adult inpatient settings, possibly accounting for the bulge in placements between 18 and 25. The cohort of children currently in 52 week placements (1,129 in 2016: NHS England figures) have a very similar profile of need to those currently in inpatient health settings. The needs and solutions for both groups need to be considered together and full consideration is needed about whether new models of care need to be created.

# Workforce

*“You have to have the right ethos, competency and support and you have to be prepared to work with risk.”* [Quote from a successful service].

74. Throughout the course of the Review I heard about the workforce challenges. There appeared to be problems at all levels of the system leading to services where professionals expressed concerns about either understaffing or inappropriate staffing. At a fundamental level the skills needed for working with our group of children did not seem to be fully recognised, articulated or appropriately valued. There was a very specific set of concerns in relation to the recruitment of Learning Disability Nurses with one service telling us that it was only when they were on shift that care plans for this group were implemented.

75. Conversations about workforce tended to relate to health professionals with little discussion, from any service, about the fact that our group of children are supported in several settings: health, education and care. A multi-agency approach to workforce is key and currently lacking. An example of this is work being undertaken to look at Care and Treatment Review (CTR) processes for children.

76. One interviewee said:

*[The] “process for children works well but would be much better if there were an equivalent team for local authority engagement.”*

77. There is no clear crossover between Care and Treatment Reviews (CTR) and EHC (Education, Health and Care) plans systems but good EHC plans should inform CTRs which could also consider and review EHC plans.

78. A number of interviewees also talked about the importance of ensuring universal services had a greater understanding of children with mental health and learning disabilities. The particular role of GPs was highlighted as was the role of the police as we work towards building a community which accepts and understands the needs of our group of children.

79. Services told us that even where there is money available for recruitment it is difficult to recruit appropriate staff with the right skills. The problem is clearly long-term and needs commitment both in terms of investment and development of the workforce at a strategic level.

## Recommendation 10: Workforce

I recommend that those organisations with responsibility for workforce and training, such as the Health Education England, Skills for Health, Skills for Care, the Department of Health's Mental Health Workforce Board, and the Department for Education with support from providers, commissioners and the Royal Colleges, should identify the staff skill gaps in respect of caring for children and young people with mental health conditions, autism, challenging behaviour and/or a learning disability and take action to address them. This work needs to feed into the workforce strategy that Health Education England are currently working on.

### Incentives and levers

80. One parent said:

*"I've struggled to get £18,000 of care for my son in the community. I can't get any more so he is moving to a placement costing £200,000. What happened to the middle?"*

81. There is something fundamentally wrong with a financial system that appears to reward crisis but disincentives early intervention.

82. One commissioner said:

*"The system is perverse. There is no reward if people respect the needs of children and follow agreed pathways. We have to have some incentives to support people to commission properly."*

83. Another interviewee said

*"There are **perverse financial incentives** in the system. It is just accepted that NHS England specialist commissioning can pay hundreds of thousands of pounds per year to a private provider for a situation which leaves the child and family miserable and outcomes poor. The provider has the incentive of the £, the local area has the incentive that the child is no longer costing their LA/Social Care/CCG very much and the child and family have no say. At least £25m is spent on inpatient costs per year just for 0-18 year olds with a learning disability (not including the larger group of 18-25 year olds)..Surely it cannot be beyond the system to look at how an equivalent sum could be used to set up bespoke packages in the community?"*

84. I realise that the vast majority of those working in the system rightly ignore these perverse financial incentives and are trying to fix them. However, these perverse financial incentives need to be removed from the system altogether. They affect

more than just our group of children. At this stage it is important that it is recognised and that each area of commissioning is tested on whether the financial modelling supports the outcomes we want to achieve.

85. I understand that the New Models of Care Programme in Mental Health is aiming to address this in CYPMHS with integrated primary and acute care system vanguards under way which join up GP, hospital, community and mental health services.

### **Recommendation 11: Financial Incentives**

**I recommend that services (short breaks, intensive support services such as those in Ealing and Bradford) for children and young people with a mental health condition, autism and/or a learning disability, be put forward by the Department of Health to be trialled using Social Impact Bonds (SIBs) as there is the potential to transform services for this group of children and young people and to get the most effective use of the available funding. Given the major local authority interest the Department for Education should also be involved in this initiative. The Departments of Health and Education should seek to involve the leading academic and voluntary and community sector groups working in learning disability and community care with this work.**

### **So if the costs are high, how are placements managed and scrutinised?**

86. Given the significant costs of inpatient and Residential Special School provision there needs to be a clear scrutiny process in the system to ensure outcomes are delivered. There are patches of good practice within the system, and teams are working to improve the delivery of good outcomes but there remains significant scope for improvement. Relevant teams are taking steps in the right direction, by developing stronger incentives around discharge planning, investing in the development of staff involved and working to improve relevant systems.

87. Interviewees told us that they could see no effective assurance or monitoring in the system so our children aren't kept in mind. We were told again and again that once children are in units there are no incentives to discharge them and no focus on outcome planning and no-one in the system that pushes this or looks at next stage provision. Care and Treatment Reviews were designed in part to tackle this lack of focus and momentum but too often run up against the lack of available placements available for individuals to move to. The lack of momentum in the system was frequently commented on. If a young person entering a system for assessment and review, then from the day of admission, stakeholders should be agreeing outcomes for the stay and planning the young person's discharge. This is not yet happening consistently.

88. So whose role is it to maintain momentum and inspect outcomes? One interviewee talked to me about the fact that within schools, Ofsted inspected and understood that some children's needs were not best met but there was nowhere else for them to go. Coupled with the challenges in inpatient units is this the time to start designing a new/different model of support that does meet outcomes?

89. Specialised Commissioners talked about children being placed at times of crisis with individual providers but without an effective framework which then made providers work together to ensure that placements were designed around the needs of the child rather than the providers. We also heard of examples where new providers would open and take the next 10 children referred whether they were suitable or not, as it was the only way of ensuring the financial model of the provision was successful. As one interviewee said, *"it's not that the provision couldn't be successful but it didn't have the time to develop support for each individual child before the next one was placed."*

90. This review has highlighted the need for stronger scrutiny of all commissioning for this group, to ensure that this group of children and young people achieve better outcomes. This is particularly crucial when large amounts of money are involved in their care. As the Director within a voluntary organisation which, rightly, is held to high scrutiny on the spending of public money, it is very difficult to see why these double standards can apply. This is particularly the case, given the vulnerability of our group of children and young people. I can see little evidence that shows me that, our children are safe and having their rights respected. We need to be spending money better, on better outcomes for our children.



# Annex A - Recommendations

## 1. Children's Rights

That our children deserve to have their rights promoted, their voices heard and develop to their full potential as per our obligations under the *United Nations Convention on the Rights of the Child*. In order to do this at a national level:

- (a) Department of Health should set an example through ensuring that parity of esteem between mental and physical health becomes a reality;
- (b) NHS England should ensure they are recognised specifically within work on the NHS constitution and the review of the *You're Welcome* Standards;
- (c) The Department for Education should ensure their rights are promoted as part of the Residential Special Schools work and the wider work on vulnerable children; and
- (d) At a local level, commissioning and delivery of all services for our children should acknowledge and respect their right to a childhood.

## 2. Residential Special Schools and Colleges

I recommend that following the concerns raised throughout this Review, a separate piece of work should be undertaken to look at the role of Residential Special Schools and Colleges for this group of children. This Review should be led by the Department for Education but supported by the Department of Health, NHS England and Public Health England.

## 3. 18-25s in Inpatient Settings

I recommend that the Department of Health, Department for Education and NHS England undertake an urgent review into the needs of the young people aged 18-25 covered by the Review currently in inpatient provision (whether they are in acute inpatient, mental health or LD beds). The Review should look at numbers, routes of admission and destinations to ensure this group of young people do not face a lifelong future in institutional care and we stop under-18s becoming the next Transforming Care cohort.

## 4. Model of Care

I recommend that NHS England work with the Department for Education, Transforming Care Partnerships, the Association of Directors of Children's Services, and the Local Government Association to develop an effective model of care for these children and young people, particularly post-ATU (Assessment and Treatment Unit), so that other areas can see what can be achieved and rolled out. This work should include an emphasis on transition both out of the ATU and - where relevant - to adult services.

## **5. Professional Responsibility**

I recommend that the Royal College of Psychiatrists, the Royal College of Paediatrics and Child Health and the Royal College of General Practitioners working with other relevant Royal Colleges urgently undertake discussions to clarify the responsibility of medical and other professionals for children and young people with a mental health condition, autism, challenging behaviour and/or a learning disability, and develop national jointly owned guidance to ensure respective roles are widely and consistently understood.

## **6. Local Authority role**

I want to see every child getting the level of support that the best parents give their own children. I therefore recommend that Local Authorities establish how the right level of commitment and support can be given to children and young people from their area that are placed in inpatient settings (due to their mental health, autism and/or a learning disability) outside their area. There would need to be agreement between the LA in which the setting is located and the home LA on their roles and responsibilities. This would ensure that there is clear accountability for these children and young people and that they are adequately safeguarded and supported. It is also important that Local Authorities work in partnership with families where the child is still in contact with them, including where they retain parenting responsibilities.

## **7. Keyworker/Named Worker**

I further recommend that each child or young person in an inpatient setting (due to their mental health, autism and/or a learning disability) or at risk of going into an inpatient setting (due to their mental health, autism and/or a learning disability) who does not already have an individual performing this role should have a keyworker/named worker either from health or local authority services, but in touch with both. This person, based in the child's home area, should have sufficient authority and expertise to support the young person and their family to navigate the system and act as a liaison point for them. Whichever service takes the lead, there should be a named lead in the others.

## **8. National and Local Coherence**

I recommend that the Department of Health takes the lead in working together with the Department for Education, Department for Communities and Local Government and relevant Arms' Length Bodies to bring coherence/alignment at a national and local level by the end of the 2016/17 financial year to the initiatives, such as Transforming Care, Integrated Personal Commissioning, Continuing Care, SEND Reforms, Local Transformation Plans/Strategic Transformation Plans for children and young people's mental health services, Mental Health Crisis Care, which impact on services for this group of children and young people. The aim should be for integrated local assessments, plans, decision making and reviews, with local mechanisms for communication and information sharing between teams. Similarly,

national and local commissioners / Health and Wellbeing Boards should be seeking to consider the needs of all children supported by these different types of commissioning / provision, as a diverse but coherent group – and recognising their overlap with other areas of need, such as community paediatrics, community and school nursing etc. In each area a Senior Responsible Officer (SRO) should be agreed who has the necessary skills and seniority to perform this role.

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## **10. Workforce**

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## **11. Financial Incentives**

I recommend that services (short breaks, intensive support services such as those in Ealing and Bradford) for children and young people with a mental health condition, autism and/or a learning disability, be put forward by the Department of Health to be trialled using Social Impact Bonds (SIBs) as there is the potential to transform services for this group of children and young people and to get the most effective use of the available funding. Given the major local authority interest the Department for Education should also be involved in this initiative. The Departments of Health and Education should seek to involve the leading academic and voluntary and community sector groups working in learning disability and community care with this work.

## Annex B: stakeholder discussions

I would like to thank all those individuals that gave me their time and shared their experience in assisting me to compile this report.

- Pru Allington-Smith (Consultant Psychiatrist (Child & LD), Coventry and Warwickshire Partnership NHS Trust)
- Dr Alison Austin (Personalisation Policy Lead, NHS England)
- Professor Dame Sue Bailey (Chair, Academy of Royal Colleges)
- Professor Gillian Baird (Professor of Paediatric Neurodisability, Guy's and St. Thomas')
- Eric Barker (Project Lead, CAMHS LD Project, NHS England)
- Sam Bennett (Head of Integrated Personal Commissioning and Personal Health Budgets, NHS England)
- Laura Bond (Assistant Director, 0-25 Special Educational Needs and Disability Unit, DfE)
- Viv Cooper (Founder, Challenging Behaviour Foundation)
- Dr Jacqueline Cornish (National Clinical Director Children, Young People and Transition to Adulthood, NHS England)
- Dr Andy Cotgrove (Chair, Tier 4 CAMHS CRG)
- Professor Jane Cummings (Chief Nursing Officer, England and Co-Chair, Transforming Care Delivery Board)
- Dr Karen Dodd (Chair, LD Professional Senate)
- Claire Dorer (CEO, NASS)
- Cathy Edwards (Operational Delivery Director, Specialised Commissioning, NHS England)
- Dr Jonathan Fielden (Director Specialised Commissioning, NHS England)
- Nicola Gitsham (Senior Advisor, Integrated Personal Commissioning, NHS England)
- Ann Gross, Director of Special Needs and Children's Services, Department for Education
- Dr Julie Higgins (Director of Transformation and SRO Transforming Care, NHS England)
- Peter Hindley (Chair, Faculty of Child & Adolescent Psychiatry, RCPsych)
- Dr Andre Imich, Special Educational Needs and Disability Professional Adviser, Department for Education
- Dr Hannah Iqbal (Policy Adviser, LD programme, NHS England)
- Ray James (Co-Chair, Transforming Care Delivery Board)
- Anne Longfield (Children's Commissioner for England)
- Victoria Man (Secure Services Commissioning and Programme of Care Lead, NHS England London Region)
- Dr Michael Marsh (Medical Director, NHS England and co-author of MG case review)
- Fiona McMillan-Shields (Head of Transformation and Delivery, Transforming Care, NHS England)
- Simon Medcalf (Head of Mental Health, NHS England)

- Michelle Mello (Deputy Director of Nursing, NHS England)
  - Lorraine Mulroney (Senior Children and Young People and SEND Lead, NHS England)
  - Dr Margaret Murphy (Consultant Child and Adolescent Psychiatrist and National Advisor for in-patient mental health service for children and young people, CQC)
  - Sue North (Social Care and Education Adviser, CYPMH LD Project, NHS England)
  - Hilary Paxton (Assistant Director, Transforming Care, ADASS)
  - Kathryn Pugh (Programme Manager for Children and Young People's Mental Health, NHS England)
  - Charlotte Ramsden (Strategic Director for Children and Adult Services, Salford)
  - Dr Ashok Roy (Consultant in the Psychiatry of Learning Disability, Coventry & Warwickshire Partnership Trust)
  - Jacqui Shurlock (Early Intervention Project Manager, Challenging Behaviour Foundation)
  - Dr Rosey Singh (Clinical Director, Sussex Partnership NHS Foundation Trust)
  - Steve Sylvester (Head of Specialised Commissioning, Bristol, North Somerset, Somerset and S Gloucestershire Area Team, NHS England)
  - Kate Williams (Deputy CEO, NASS)
- 
- Learning Disability Professional Senate meeting
  - Transforming Care Assurance Board – Deep Dive in to the Children and Young People's workstream
  - Group of parents of children and young people with these complex needs

### **About the Council for Disabled Children**

The Council for Disabled Children (CDC) is the **umbrella body for the disabled children's sector and is part of the National Children's Bureau**. We want disabled children and children with special educational needs (SEN) to have full and happy childhoods; fulfil their potential; and be active within the community.

For more information visit [www.councilfordisabledchildren.org.uk](http://www.councilfordisabledchildren.org.uk)

