London South Bank University

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A WORKFORCE DEVELOPMENT PROJECT

Working with Children and Young People with Learning Disabilities and Comorbid Mental Health/Autism/Challenging Behaviour Conditions

On behalf of the:

The Tavistock and Portman NHS
NHS Foundation Trust

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Executive Summary

London South Bank University (LSBU) are pleased to submit the programme of work presented below for Health Education England in response to the Working with Children and Young People with Learning Disabilities and Comorbid Mental Health/Autism/Challenging Behaviour Conditions' scoping review.

The Report findings are presented as outcomes and consequences. These can then inform an ongoing expert stakeholder review group project to identify workforce development needs suitable to deliver high quality, family centred care packages, sustained across integrated health and social care services, in order to provide care closer to home for Children and Young People (CYP) living with complex needs including Intellectual/Learning Disabilities (ID/LD), Mental Health (MH) and Challenging Behaviours (CB).

Children and Young People (CYP) with LD comprise a heterogeneous group who cover a vast range of abilities and who have varying support needs. Whether diagnosed or not the number of CYP that will come into contact with LD services is significant. All will need 24 hour support to some degree, whether at home with parents/family and/or unpaid volunteers or require a full time placement that can meet their individual complex needs.

The recent report by Dame Christine Lenehan[1] identified significant system failings in the way the NHS and social care services support children with complex comorbid learning disability and mental health conditions. These children, the report suggests, receive sub-standard services delivered in a poorly coordinated way at an unnecessary cost to the tax-payer. A system wide collaborative has been convened to address the issues identified within this report, of which one is the development of the workforce.

In the absence of complete education and health pathways, solutions have been sought to try and

[1]https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/585376/Lenehan_Review_Report.pdf

maintain equity of provision, however much of this has failed in terms of other philosophical underpinnings that guide provision such as least restrictive practice and care close to home e.g. an over reliance on long term residential placements and secure services, in many cases miles from home. This type of scenario is a reality for many. This is in spite of person centred care being at the centre of policy and guidance since the start of the century.

A quality workforce with specialist skills were identified as necessary to achieve the complex requirements of children and young people (CYP) with learning disabilities, mental health and behaviour that challenges, as a population with demands that infiltrate across health, education, social and judicial workforce roles. Providing high quality provision equates directly to a skilled and compassionate workforce who can form positive working relationships with the CYP and their family, plus working across the health and social care economy.

Personalised, family centred care packages should anticipate future support needs for the child's wellbeing both immediate and in the long term, whether this is educational, physical or mental/psychological. This requires a life-course approach and joining up of services between disciplines and specialities to ease different transition stages during childhood into adult services.

The lack of local LD friendly pathways into education and physical and mental health care in the local community has meant the current system has become the norm for commissioner's local authorities and health services and disillusioned many front line workers unable to get appropriate services for their clients. To address this one solution is the introduction of Sustainability and Transformation plan leads to examine the current situation with stakeholders across services.

For the most complex presentations requiring forensic service, it remains to be seen if it is still the case that these services are commissioned across greater geographical areas e.g. regional. For many it will be structure rather than security that may negate their risk to the community, whatever model is used it is important that local pathways into services should be aware of the workforce requirements needed if more is done to meet the needs of this group locally or when this group will return to their local area so they receive a multi-agency package within TC Partnership.

The FYFV identified services for the 1.5m people with learning disabilities (LD) as requiring

increased focus. The learning disability workforce programme will ensure the workforce has the education, skills, values and behaviours it needs to help service users lead better, more independent lives. Though yet to happen everywhere, LD services must be delivered through integrated, community based services. The LD workforce needs to change as more services are moved into the community to improve the quality of care.

Project Brief

The National Workforce Skills Development Unit (The Unit) wished to commission a literature review to provide information for 'Our Children's Workforce Project', which is a Workforce Development Project focusing on 'Working with Children and Young People with Learning Disabilities and Comorbid Mental Health/Autism/Challenging Behaviour Conditions'.

After the publication of 'Transforming Care' and 'Building the Right Support[2]' by NHS England, the Local Government Association (LGA) and the Association of Directors of Adult Social Services (ADASS) supported the creation of 48 transforming care partnerships (TCPs). The 48 TCPs have been working on their plans to change services in a way that will make a real difference to the lives of children, young people and adults with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition. Plans include aims of improving community services so that people can live near their family and friends, and making sure that the right staff with the right skills are in place to support and care for people with a learning disability and/or autism.

The recent report by Dame Christine Lenehan[3] identified significant system failings in the way the NHS and social care services support children with complex comorbid learning disability and mental health conditions. These children, the report suggests, receive sub-standard services delivered in a poorly coordinated way at an unnecessary cost to the tax-payer. A system wide collaborative has been convened to address the issues identified within this report, of which one is the development of the workforce.

A national strategic work plan has been established across the Department of Health, the Department for Education, the Department for Social Care and Local Authorities aligned with the Transforming Care Partnerships programme. This programme has high level professional and political impact.

The Tavistock and Portman NHS Foundation Trust (The Trust)

The Trust is a specialist Mental Health Trust with a focus on education and training alongside a range of mental health services and psychological therapies. The Trust has a long-established history of integrating service and education provision through our clinician-tutor

[2] https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf

[3] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/585376/Lenehan_Review_Report.pdf

model, ensuring education is embedded within, and founded upon, best clinical practice. The Trust is committed to improving mental health and emotional wellbeing for individuals within society. The Trust is committed to developing new training initiatives to meet the needs of a modern health and social care sector, responding to policy and initiatives from government and other relevant agencies.

The National Workforce Skills Development Unit (The Unit)

The Trust makes a significant contribution to the mental health education agenda through its National Training Contract with Health Education England (HEE). The Trust, in collaboration with HEE, created a national body for the development of strategic educational and workforce development activities to support enhanced mental health capability across England. This body is known as the National Workforce Skills Development Unit.

In its first year, The Unit have agreed a number of specific areas of work to support the delivery of mental health priorities for the NHS. The Unit will aim to identify the workforce development needs of this workforce to address the policy needs and new workforce models as identified by the 'Transforming Care Delivery Board' and develop an educational mechanism to support workforce development.

A Project Report

Working with Children and Young People with Learning Disabilities Comorbid Mental Health/Autism/Challenging Behaviour Conditions.

Issues of service transformation and workforce development

Authors: Professor Sally Hardy, Associate Professor Eddie Chaplin and Associate Professor Barry Tolchard. Mental Health and Intellectual Disabilities Research Informed Policy Unit, School of Health and Social Care, London South Bank University.

This report has been commissioned by the Tavistock and Portman NHS Trust to examine real and perceived barriers to providing high quality care closer to home for children and young people (CYP) (>25 years) living with learning disabilities (LD) who have complex care needs and co existing conditions such as neurodevelopmental disorders (such as autism or attention deficit hyperactivity disorder (ADHD)), mental health problems and behaviour that challenges.

The context of this report will largely focus on workforce and workforce development in the context of current service provision, whilst examining solutions that have already been put forward to address issues of workforce development planning. Although the intention is to define the group requiring specialist services, often working definitions can change between services and can be problematic for people trying to access services.

Working Definitions

This report uses the following definitions as published in '*Supporting people with a learning disability and/or autism who display behaviour that challenges including those with a mental health condition'*,

Learning disability

Individuals with a learning disability (internationally referred to as individuals with an intellectual disability) are those who have:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence)
- a significantly reduced ability to cope independently (impaired adaptive and/or social functioning)

and

- is apparent before adulthood is reached and has a lasting effect on development.

Autism

Also referred to as Autistic Spectrum Disorder (ASD) or Autistic Spectrum Condition (ASC).
Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people.

The three main areas of difficulty, which all people with autism share, are known as the 'triad of impairments'. They are difficulties with:

- social communication (e.g. problems using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice)
- social interaction (e.g. problems in recognising and understanding other people's feelings and managing their own)
- social imagination (e.g. problems in understanding and predicting other people's intentions and behaviour and imagining situations outside their own routine).

Behaviour that challenges

"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." LGA, ADASS, NHS England (2015)

Children and Young People

The age range for children and young people included in this literature review scoping exercise has been identified as ranging between 0-25 years. This is because of the complex developmental needs associated with the study population and different eligibility criteria within services and who are considered CYP.

According to the NICE guidelines for transitioning children to adult services (NICE, 2016), transition planning should take into account each young person's individual capabilities, needs and hopes for the future, therefore point of transfer should not be based on a rigid age threshold, only taking place at a period of relative stability in the young person's life course.

Background

People with learning disabilities make up a significant proportion of the population. In the UK it is estimated that 2.5% of the population will have LD, (Emerson and Hatton, 2008) there are an estimated 65,000 children with severe and profound learning, where many are living longer and more CYP are being identified from BAME communities (Department of Health (DH), 2009). NHS Digital have started collecting data from January 2016 onwards. The Mental Health Services Data Set (MHSDS) contains record-level data about the care of children, young people and adults who are in contact with mental health, learning disabilities or autism spectrum disorder services initial figures indicate:

- 57,608 people were in contact with LD Services in January 2016 as per the new MHSDS collection
- Aged under 18
- Of admissions/transfers in the year, 280 were under 18 years old at the time of admission;
- Of discharges/transfers in the year, 235 were under 18 years old at the time of discharge;
- Of those who were under 18 years old on admission 10 patients were recorded as receiving continuous inpatient care for over 5 years.

CYP with LD comprise a heterogeneous group who cover a vast range of abilities and who have varying support needs. Whether diagnosed or not the number of CYP that will come into contact with LD services is significant. All will need 24 hour support to some degree, whether at home with parents/family and/or unpaid volunteers or require a full time placement that can meet their individual complex needs.

People with LD in general are four times more likely to experience mental health problems, which may go undiagnosed or attributed to their LD, due to a lack of mental health awareness in this group from carers and services. This is further confounded by co existing neurodevelopmental disorders such as ADHD and Autism, physical health problems and a number of cognitive and social deficits, such as communication difficulties, limited coping and communication strategies and/or problem solving skills, poor socio economic status living in poorer areas; are more likely to be subject to poor schooling, bullying,

exclusions, experience poor education provision and a lack of appropriate residential, respite and care services close to home.

Support for CYP in general can therefore be in itself complex, given interfaces with education, health and local authority plus interfaces with the third sector. For those with LD the right to equitable education and health can be compromised for a number of reasons such as a general lack of awareness of the needs of this group and also the need for specialist input to deliver highly skilled and resource intensive education, health and social care support and programmes. The need for services is often dictated by levels of ability, with more input required the less able a person is. Delivering appropriate and consistent models of care and care pathways that have capacity to meet local need has been a challenge following de-institutionalisation.

The closure of an over reliance on institutionalised care provision was to be accompanied by a new mind set and philosophy with people with LD as equal citizens was rightly adopted. Part of the problems of inclusion was a lack of awareness from society on having an LD, which was also accompanied by a hangover of attitudinal personal stereotypes to the lifestyles of people with LD, having little or no due regard to what was achievable in meeting the aspirations of CYP.

Institutional care was seen largely as a process of 'warehousing' people, providing a one stop shop for the persons needs not only in childhood but across the lifespan. Since this period of time the key issue has often been seen as relating to; what services do we need for these CYP's and considered separately, whereas a better way may be to look at the needs of all CYP per se and then focus on where and what special provision is required and how that can be delivered to maintain equity in terms of a right to education and healthcare.

Currently there is an absence of person and family centred services being available across the country for all CYP. Current provision has come under scrutiny in terms of delivery of appropriate high quality services that meet a complex range of health, education and social care needs. Among the issues discussed and barriers cited includes: workforce skills, recruitment, responsibility for care, fragmented pathways, over exclusive eligibility criteria to services, lack of referral to specialist services and long waiting times.

In the absence of complete education and health pathways, solutions have been sought to try and maintain equity of provision, however much of this has failed in terms of other philosophical underpinnings that guide provision such as least restrictive practice and care close to home e.g. an over reliance on long term residential placements and secure services, in many cases miles from home. This type of scenario is a reality for many. This is in spite of person centred care being at the centre of policy and guidance since the start of the century.

Policy

The 2001 White Paper, Valuing People set out a vision for people with LD being part of society and aspirations of how this would be achieved. It commented on previous policy and proposed models of care to ensure a workforce and wider community based service provision that was able and skilled to meet the needs of CYP with LD.

The foreword by the then Prime Minister Tony Blair to the White Paper, Valuing People: Valuing People: A New Strategy for Learning Disability for the 21st Century stated:

> *'…. a real cause for concern and anxiety is that many parents of learning disabled children face difficulties in finding the right care, health services, education and leisure opportunities for their sons and daughters. At best, they can feel obstacles are constantly put in their way by society. At worst, they feel abandoned by the rest of us'* (DH 2001, p1).

At the time £60m was promised to provide support, with the Government aim to provide new opportunities for CYP with LD and their families to live full and independent lives as part of their local communities. To achieve this and ensure a workforce fit for purpose, the White Paper advocated a person-centred approach and planning across agencies as essential to deliver real change in the lives of people with LD. Person-centred planning using a single, multi-agency mechanism was put forward to achieve this, with guidance to follow on its implementation through the Learning Disability Development Fund. In terms of solutions to how children were to be supported the issues stated were similar if not the same as those faced today by children and

their families i.e. need for appropriate services and to reduce the number of hospital places for children, increase inclusion stating higher costs incurred by families and decreased employment prospects, respite and joined up services that are fit for purpose to be provided by Education, Health and Social Care, a clear transition strategy for children. The best place to be? Policy, practice and the experiences of residential school placements for disabled children (Abbott et al, 2001) articulated the problem specifically to CYP and how the current system was failing them.

> *Despite increasing policy commitment by government to the inclusion of children with special educational needs in mainstream services, significant numbers of disabled children remain in specialist boarding schools and placements continue to be made. This is an area of public policy and expenditure characterised by a lack of knowledge and understanding. We do not have a clear national picture about the numbers or needs of the children concerned; there is inadequate evidence about why such placements are made and whether they are in fact the best way to meet children's needs; and there is confusion over the implementation of local authorities' statutory duties towards them.* (Abbott et al, 2001, p1)

Although policy and guidance set out a vision in reality there was great disparity in how regions implemented this and what they implemented, examples of good practice that were put forward were often isolated and not adopted by others

By 2009 the update Valuing People Now (DH 2009) reiterated the aspirations from 2001 and prior to this Aiming High for Disabled Children: Better Support for Families (HM Treasury, 2007), was published outlining how local areas would be supported to improve transition arrangements across children's health and social care, using and improving upon person centred approaches, access and empowerment, responsive services and timely support, and improving quality and capacity. Fast forward and still there are a regular stream of reports that highlight the gap in achieving equity and access to appropriate healthcare services (e.g. *Death by Indifference (MENCAP 2007, 2012a,b), Healthcare for all* and Michaels, (2008) these issues once again come into focus and led to many using these two poor examples of institutionalised abuse to illustrate the complexity and nature of generic and specialist services.

The overriding philosophy currently is that people with LD access and have the right to the same services as the remainder of the population. 'Death by Indifference' however revealed that in general people were not confident and had a generalised poor level of awareness about issues relating to LD, such as common comorbidities, communication etc. This lack of awareness contributed to a series of avoidable deaths. Whereas at 'Winterbourne[4]' revelations of how a specialist care pathway that supposedly linked mainstream psychiatric services to secure services for those with mental health problems was failing CYP with LD. The assessment and treatment services, identified that what was being offered was a dubious demand for institutionalised care provision, rather than repatriate CYP with LD. Many local areas started to use out of area placements to once again 'warehouse' people for whom local specialist residential provision was unavailable.

Transforming Care: A national response to Winterbourne View Hospital: Department of Health Review Final Report (2012) was published both to look at the antecedents and to ensure that this 'scandal' would not happen again. The report built on the models proposed in the Mansell Reports (DH 1993 and 2007) which had highlighted what good services looked like. Although mainly focussed on adult services it did include transition plans from child to adult services.

The Mansell Report (s) emphasised

- the responsibility of commissioners to ensure that services meet the needs of individuals, their families and carers
- a focus on personalisation and prevention in social care
- commissioners should ensure services can deliver a high level of support and care to people with complex needs/challenging behaviour
- services and support should be provided locally where possible.

(DH, 2012, Annex A p50)

Mansell (DH, 2007) in his report on services for adults with learning disabilities challenging behaviours and mental health problems, highlighted how challenging behaviour was an issue across the lifespan and the continued use of residential special schools away from people's homes needed to be re-examined.

[4] For a timeline examining Winterbourne and Transforming Care see http://www.bild.org.uk/resources/winterbourne-view/

The Mansell Reports (DH, 1993 & 2007) unfortunately is still current with the advent of Transforming Care committed to 'closing inappropriate and outmoded inpatient facilities' in order to establish stronger support in the community.

Both reports put forward key principles that advocate the delivery of person centred care which is the least restrictive and grounded in local communities. To support workforce transformation and minimise restrictive interventions, Skills for Care and Skills for new programme Positive and Safe was launched by the Department of Health. In Winterbourne View - A Time for Change (Bubb, 2014) the government drew up what at the time seemed an ambitious timetable to initiate a move for 3,250 children and adults in assessment and treatment units (ATUs) back to their local communities by 1st June 2014. However, it appears that rates of secure bed occupants remain the same with some reports suggesting numbers have increased particularly for those with more complex presentations the more complex groups (Mencap & the Challenging Behaviour Foundation (2008) and Marshall-Tate *et al* 2017).

NHS England data for between September 2013 and March 2014 reported 200 people more were admitted to units than were discharged, with 90% of the thousands of people in units have no set date when they will leave. To help understand the policy landscape a list of some of the key policies this century is presented below with particular reference to workforce issues, planning and development.

Documentary Analysis

Identifying workforce issues

Prior to the main review, available policy and guidance was searched and of 40considered, 19 were identified as relevant to the project specification specifically for their workforce related issues. Each of the 19 are summarised in table 1 below.

Each document was reviewed for workforce related information specifically relevant to:

a) workforce needs/planning
b) training requirements and skill developments
c) competencies and
d) requirements needed to influence innovation across service integration models

A quality workforce with specialist skills were identified as necessary to achieve the complex requirements of children and young people (CYP) with learning disabilities, mental health and behaviour that challenges, as a population with demands that infiltrate across health, education, social and judicial workforce roles. Providing high quality provision equates directly to a skilled and compassionate workforce who can form positive working relationships with the CYP and their family, plus working across the health and social care economy.

Published DATE	**DOCUMENT SOURCE**	**WORKFORCE ISSUES**	**RECOMMENDATIONS**
2001	***Valuing People:*** Summary identifying key tasks and activities and a short audit tool.	Objective 4: Supporting Carers Objective 10 Workforce training and Planning	Carers as partners: Local authorities include carers in local action plans. Local councils offer training to Carers to develop their skills as a training resource. Learning Disabilities Awards Framework (LDAF) DOH to explore links Leadership: partnership working Local Workforce Plans: resourcing and training Person centred plans

			Local Partnership Boards- Learning Disability Development Fund
2007	***Death by Indifference***: MENCAP	Many health care professionals do not understand much about learning disabilities; risk of diagnostic overshadowing Many health care professionals of not properly consulting and involving families and carers Many staff do not understand the law on capacity and consent to treatment.	All NHS staff require training on Learning disability Address health inequalities, attitudes and access to services for people with learning disability
2010	***Short Breaks:*** Statutory guidance on how to safeguard and promote the welfare of disabled children using short breaks Department for Children, Schools and	Practitioners and families will be aware of particular vulnerability of disabled children. While the needs may be met in different settings with necessary differences in regulation, it will be helpful to providers, commissioners and families for short	Short break carers need to be able to undertake risk assessment in moving and handling, behaviour management, and specific training about certain clinical procedures, plus detailed information about the child's preferences, to meet the child's needs effectively, and help the child adapt quickly to being away from home and parents. Disabled children use a range of communication methods, it is essential to have staff skilled in different methods of communication to ensure that the child's

	Families	breaks to be viewed as one coherent package of family support, planned and reviewed as a whole. There is no requirements for agencies to register with Ofsted or CQC if they provide services to support 'disabled' children in the community, unless they provide personal care.	voice is central to the process of assessment, planning and review Visits should be from a qualified social worker, and a person with the skills and experience to communicate effectively with the child, representatives of the placing authority, the child's parents and the child's Independent Reviewing Officer (IRO) (p 15). It is not recommended practice to place with childminders, who are not approved foster carers. The British Associate of Adoption and Fostering (BAAF) form F has been used to effectively assess applicants for fostering. Approval is gained through an appropriate manager – not the fostering panel (p 28)
2011	***Support and aspiration: a new approach to special educational needs and disability.*** A consultation. Department of Education	To transfer power to professionals on the front line and to local communities – to strip away bureaucracy so that professionals can innovate and use their judgement to establish clear systems from different services to work together, to give parents and communities more influence over local services (pg 5 item 7)	Teachers and other staff are well trained and confident to: identify and overcome a range of barriers to learning, manage challenging behaviour, address bullying and intervene early when a problem emerges. SENs – provide a national banded framework for funding provision for CYP with SEN, or who are disabled could improve transparency Talented support workers in class to develop relationships with CYP and families with special needs.

		Schools and Collages play a key role in helping children transition into adulthood.	Developing high quality speech and language therapy workforce (section 5.40: pg 103) Educational Psychologists – can make a significant difference to CYP and Families – currently varies between local authorities. Commissioning process Consider a national banded framework (funding and training) set out high level descriptions of the different types of provision needed for CYP with severe and complex needs (item 5.65: pg 111)
2013	***The National Health Visitor Plan***: Progress to date and implementation 2013 onwards	Department of health commitment to increase health visitor workforce and transform the health visiting service by 2015. Workforce expansion to 4,200 by 2015	Building Community Capacity work based e learning module. For wider community impact locally. Maternal mental health framework Establishing the Institute for Health visiting www.ihv.org.uk
2014	***From the Pond into the Sea*** Children's transition to adult health services CQC	Section 7: Training for Professionals Key findings: Adult and children's healthcare professionals felt competent to meet the specific clinical needs that they are trained for, and young people	Transition can begin when child is 14, lack of staff understanding and knowledge, and lack of expert knowledge in specific conditions. Some children's community nurses had started working on joint clinics and handover arrangements for young people with health care needs: endocrinology,

		and parents agreed. But professionals did not feel equipped to manage the transition process, as they lacked knowledge about age specific needs in relation to their complex needs.	rheumatology, and oncology.
2014	***Special Education needs and disability***: A guide for parents and carers	Education, Health and Care needs assessment and plans Transferring CYP with statements and LDAs to EHC plans	Services that provide help for your child, need to work with each other to benefit your child. Local Offer: local authority, local people Education Health and Care Plan (EHC) Preparing for adulthood: assessment
2015	***Care services for people with learning disabilities and challenging behaviour*** National Audit Office	No detailed analysis of cost of expanding community services, to provide places for all those to be transferred from hospital. Not assessment the availability of skilled staff or the tailored accommodation require to support community placements.	Low confidence in placement management and sustainability Suitably skilled and experienced staff to respond to the person's needs – especially when in crisis Quality standards of community service providers Risk management Discharge planning Preventing hospital readmission through clinical and trained care staff Lack of capacity to deliver and fund care packaged for people with challenging

			behaviour Degree of development between community and health service partnership working: shared culture, joined up health and social care management and commissioning structure that has pooled budget.
2015	***Building the Right Support***: A national plan to develop community services and close inpatient facilities for people with a Learning disability and or autism who display behaviour that challenged, including those with a mental health condition. NHS England, ADASS, LGA	Workforce Development Annex b	HEE, Skills for Health and Skills for Care will collaborate to support the development of appropriately skilled workforce to build the capacity to support people in the community Equip commissioners with tools and confidence to commission for workforce skills and competencies. Working with existing service providers to review the skills and competencies within their existing workforce to identify education and training needs, and facilitate transition to a new way of working Ensure the education and training to enable the wider workforce is able to meet the needs of people with learning disabilities in all care settings. Developing leadership capability across the system, including commissioners, service providers and carers, to promote innovation, and change services to focus on people's needs.

2015	***Transforming Care for People with Learning Disabilities*** – next steps	Skills for Health, HEE and Skills for Care, work in partnership to develop a workforce to deliver and support people with LD in the community	Page 22: Using the same approach to the dementia strategy: three tiered approach. 1: Awareness raising 2: Detailed learning 3: Expertise and leadership
2015	***Workforce Development for People with Intellectual disability***: Report of the KSS ID Workforce Scoping Project	To create a sustainable and secure workforce supply for people that have ID, who require support from and /or access to services across Kent Surrey and Sussex pg 7	Recommendations: 1: workforce planning and education commissioning 2: Secondment opportunities 3: Location of and access to pre reg. nursing education 4: Provide involvement in pre reg. nursing education 5: Recruitment to Pre Reg. nursing 6: Promotion of LD nursing careers 7: Developing the current learning disability nursing workforce 8: Developing current non registered workforce 9: Equitable access to KSS leadership collaborative 10: Communication and sustainability
2016	***Residential Care in England*** Report of Sir Martin Narey's independent review of children's residential care	We must have a confident and competent workforce, but this does not necessarily mean graduates. Best staff are ones who can make a good relationship with troubled and	Level 3 Diploma for residential childcare Many staff need further training, particularly those working therapeutically. CPD: team based training required Managers Pay and recruitment

		challenging children	Social Workers Recommendations page 61
2016	***National Framework for CYP 's Continuing Care*** Department of Health	Covers CYP up to their 18th birthday: requires multi-agency working Three core phases • Assessment • Decision Making • Package of Care	Workforce skill requirements: Holistic assessment process Evidence Based Professional judgements - to inform continuing care package Multi-agency working/ Sharing information across IT systems Funding streams and Commissioning Ongoing re-assessment and evaluation of care pathway Inclusion of family and CYP Managing disputes Arrangements for reciprocal assessors working out of area
2016	***Centre for the Advancement of Positive Behavioural Support Organisation and workforce Development*** Skills for Health et al… HEE	Positive Behavioural Support blends person centred values with evidence based understanding of how behaviour is learned and maintained. Requires a range of supports and approaches reducing negative impact on people's lives.	Training for three tier Positive Behavioural Support Prevention (as for Dementia) tailored to different roles Competencies based framework 1. Awareness 2. Foundation level 3. Practitioner level 4. Coaching 5. Advanced/Consultant level
2016	**Sustainable safe staffing:** A report of mixed methods systematic	Summarise the best evidence on sustainable safe staffing levels of multi-disciplinary learning	No empirical evidence for safe staffing Three Findings: • Service Models: implementing service changes, professional roles,

	review of literature University of West London and NHS Improvement	disability teams	collaboration for integration • Standards of Care: effective care delivering, communication, quality delivery • Resources: professional competence, values and retention Recommendations Hub and Spoke model of service provision for people with LD Hospital communication Passports – help with tracking patients transitioning across services Pre, post and mandatory training
2016	***Safe, sustainable and productive staffing:*** an improvement resource for learning disability services National Qualify Board	NHS Improvements, improve and measure approach for community and inpatient learning disability services Sustainable safe staffing must take into account the complex nature of LD care models and the number and skill mix of professionals and agencies involved in meeting the needs of people with complex needs	*Traditionally Learning disability teams have comprised, nurses, speech and language therapy, psychiatry, psychological therapies, occupational therapy, and physiotherapy. Some integrated teams include social workers and other therapist roles, such as audiology, podiatry and dietetics. New health care models, utilise emerging roles, such as advanced practitioners, apprenticeships, associate roles, care navigators, experts by experience, peer workers, non-medical prescribing roles and professional leaders who can work across services, facilitating values based elements of transforming service delivery models (p4-6)* Right staff: Emerging roles (assistant practitioners etc.) Workforce planning

			Unplanned intensive care Community learning disability teams Liaison roles Specialist intervention roles Right skills: Professional, education, non-clinical, quality assurance Right place – right time: Managing, prevention, cost efficiency, technology
2017	***Local support for people with a learning disability***	Partnerships have not produced workforce plans for community provision (pg 3). Workforce plans are not being developed until 2019 leaving no time for recruitment and training to provide community support. Discharging people from hospital is not taking place due to high numbers of cancellations due to changes in available clinical staff. P 35	To bring forward timetables for workforce development plans Local delivery plans rely on having health and social care teams who work together and understand local needs and constraints. (P 28) Workforce Planning (P 43) Care Workers, Specialist learning disability nurses, and psychiatrists.
2017	***Health Visiting, and School Nursing Partnership –***	Lack of training opportunities and an ageing workforce: addressed through the	Sets out partnership pathways to achieve seamless support and care, working with children 0-19.

	pathways for supporting HV and SN interface and improved partnership working Wendy Nicholson, Lead Nurse CYP and Families, Public Health England, Pauline Watts, Lead Nurse, PHE Fiona Hill, Project support officer, CYP and Families, PHE	identification of joint training opportunities, and greater visibility of health visiting and school nurse careers. Ensure aligned training for assessment between health professionals and educational providers. Joint training and supervision Improving skill mix and team working	**Universal Plus**: for supported CYP and Families, tailored to family needs, early identification and timely responses/interventions **Universal partnership plus**: Seamless multiagency support for complex needs, safeguarding referrals/vulnerable families
2017	***These are our Children*** A review by Dame Christine Lenehan Director, Council for Disabled Children. DOH	Workforce page 28 A multi-agency approach is essential, and currently lacking. Lack of understanding of Universal Plans for CYP with MH and LD	Retention and recruitment needs long term strategic level support Need to identify the skills gap
2017	***Facing the Facts, Shaping the Future:*** a draft health and	To plan for the future workforce requires adequate knowledge of service delivery models	The six principles are: **1. Securing the supply of staff** that the health and care system needs to deliver high quality care in the future. Since the

	care workforce strategy for England 2027 NHS HEE	and commissioning intentions. *The Five Year Forward View* described service transformation plans in a number of priority areas, from which we have been able to produce service specific workforce plans, the first time the health service has produced a strategic workforce response to defined future service delivery models. One of the areas in which we are seeking your views is the introduction of a '**Workforce Impact Assessment'** for new best practice or service redesign recommendations, ensuring that workforce competencies, skills and training as well as numbers are considered early in the planning phase.	NHS began patients have been well served by staff from around the world. However, maximising the self-supply of our workforce is critical. It cannot be right for the NHS to draw staff from other countries in large numbers just because we have failed to plan and invest. **2. Enabling a flexible and adaptable workforce through our investment in educating and training new and current staff.** Individual NHS professions have distinct roles but there is scope for more blending of clinical responsibilities between professions. This flexibility is rewarding for staff and can provide the NHS with more choice in how we organise our services. **3. Providing broad pathways for careers in the NHS,** and the opportunity for staff to contribute more, and earn more, by developing their skills and experience. Structured career opportunities which enable staff to progress both within and between professions will enhance retention and make the health and care system more resilient and attractive in the face of changing demands from staff. **4. Widening participation in NHS jobs so that people from all backgrounds have the opportunity to contribute and benefit from public investment in our healthcare.** This enshrines the public duty to provide equal opportunity for all and will ensure the NHS workforce of the future more

			closely reflects the populations it serves. If delivered successfully it will increase the pool of people available to be recruited into the NHS.

Table 1: Documentary analysis of workforce issues relating to CYP with Intellectual disability, mental health and challenging behaviour[5]

Reviewing all the documents, a central tenet to the developing of services and workforce capacity for CYP and LD, there is a recognised need to have an overarching philosophy which dictates decision making i.e., one where the CYP and family are at the centre of decision making and that services are built or allocated around them, at home or close to home, according to need.

Personalised, family centred care packages should anticipate future support needs for the child's wellbeing both immediate and in the long term, whether this is educational, physical or mental/psychological. This requires a life-course approach and joining up of services between disciplines and specialities to ease different transition stages during childhood into adult services.

The issues that currently remain as a barrier to this are many and include

- Lack of joined up services
- Lack of a defined skilled workforce i.e. who makes up the workforce and who regulates it
- Lack of strategies for the training and recruitment of the workforce
- National guidelines on acceptable levels of services
- Bottlenecks, this can lead to a lack of meaningful reviews where recommendations can be actioned
- An end to perverse incentives
- Scrutiny of commissioning across children's services from community groups and to ensure better outcomes.

Central to the provision of high quality services is safety, choice, inclusion, compassion, dignity and respect.

[5] Hyperlinks to the documents in the table are provided following the references

The Lenehan Report (2017) examined issues around current children's provision, providing a review on care and support for CYP with complex needs involving mental health, learning disabilities and/or autism, that reiterated that children's LD services were 'everyone's concern but no one's priority' (pp. 8-9). This impasse or attitude has had serious ramifications for workforce development and capacity building.

A number of key policy areas are currently not being fully implemented, such as:

- Integrated personal commissioning and personal health budgets
- Transforming Care
- Children's and Young People's Mental Health Transformation programme (including Generic Pathways)
- Children's and Young People's Mental Health across the spectrum of need
- Review of inpatient Children's and Young People's Mental Health
- The commissioning of a children's pathway

The Lenahan (2017) review has also highlighted the need for stronger scrutiny of commissioning across children's services to ensure better outcomes.

Health Education England (HEE) produced Guidance for the production of a Transforming Care Partnership Workforce Plan see https://hee.nhs.uk/sites/default/files/documents/Transforming%20Care%20Partnership%20workforce%20plan%20guidance_FINAL.pdf. This resource was designed to help Transforming Care Partnerships (TCP) to develop service models, providing examples of existing models. This built upon the earlier Skills for Health's six steps model. The TCP are responsible for a wide and diverse range of needs of CYP, particularly those with additional comorbidities such as other neurodevelopmental disorders such as autism or ADHD, mental health problems and behaviour that challenges.

The following groups were identified as those who come under the remit of the TCP:

1. Children and young people with a learning disability, autism or both who have or are at risk of developing a mental health condition such as anxiety, depression, or a psychotic illness, and those with personality disorders, which may result in them displaying behaviour that challenges.

2. Children or young people with an (often severe) learning disability, autism or both who display or are at risk of developing self-injurious or aggressive behaviour, not related to severe mental ill health. Some of

whom will have a specific neuro-developmental syndrome and where there may be an increased likelihood of developing behaviour that challenges.

3. Children or young people with a learning disability, autism or both who display or are at risk of developing, risky behaviours which may put themselves or others at risk and which could lead to contact with the criminal justice system (this could include things like fire-setting, abusive or aggressive or sexually inappropriate behaviour).

4. Children or young people with a learning disability, autism or both, often with lower level support needs and who may not traditionally be known to health and social care services, from disadvantaged backgrounds (e.g. social disadvantage, substance misuse, troubled family backgrounds) who display or are at risk of developing, behaviour that challenges, including behaviours which may lead to contact with the criminal justice system.

Local Government Association (2017, pp.6-7)

The current consultation *Facing the Facts, Shaping the Future: A draft health and care workforce strategy for England to 2027* (Public Health England, PHE, 2017) puts forward potential solutions and observations on aligning and developing the workforce and services. It outlines where progress has already been seen to have been made (e.g., introduction of competency frameworks, workforce planning, new roles and leadership). Looking at national standards a new PBS alliance has been proposed to manage risk for a number of emerging threats such as graduate pre-registration nursing, special interest LD GP fellows, LD children and young people Improving Access to Psychological Therapies (IAPT) and pilot media campaigns.

Workforce planning is part of a wider government strategy to ensure appropriate children's services can be delivered closer to home. Although a plethora of guidance has been produced to what good services look like and the skills needed to staff them, implementation has been slow and a variety of models have emerged which have been implemented with varying quality. For many Local Authorities and health and social services, a total reallocation of resources is required to provide appropriate local services, as many examples of availability appear to have been forced into placing children out of areas or in 52 week residential placements to keep within budgets or there is not to the energy or resources available to develop transformation required to provide modern more person and family centred commissioning strategies.

The aspiration is a new generation of community based services. This requires cultural, society and service changes and shifting finances from inpatient service to community with the target currently set at 50% for the next 3 years (2015-2018). According to the CQC, the closure of large mental health institutions was one source of funding release that just has not been achieved in time to reallocate resources into community based provision (CQC, 2014 & 2017)

Transforming care partnerships will need to base their plans on a strong understanding of: the population they are seeking to achieve better outcomes for (both current inpatients and those in the community at risk of admission without the right support); how much money CCGs, local authorities and NHS England specialised commissioners are currently spending on health and care for that population; which providers are delivering what services for that spend; and how the system is currently performing, its strengths and weaknesses. The principle of equitable treatment and access to opportunity for all children is enshrined in the Children's and Families Act 2014. In March 2017 the Care and Treatment Review policy was revised to include an annex specifically for children, which provides specific guidance for professionals and a national framework for Care and Education Treatment Reviews. These focus on some of the most vulnerable who have been in, currently in or at risk of admission to specialist mental health or learning disability hospitals in the NHS or independent Sector.

There are various strategies being put forward as least restrictive, one example is Integrated Personal Commissioning (IPC) which allows the person and their families to develop the skills to self-manage and control available resources and take charge of their own care through building. This is designed to bring together traditional stakeholders like health and social care with the Voluntary Community and Social Enterprise (VCSE) sector. This is outlined by the Local Government Association publication Developing support and services for children and young people with a learning disability, autism or both in the diagram below:

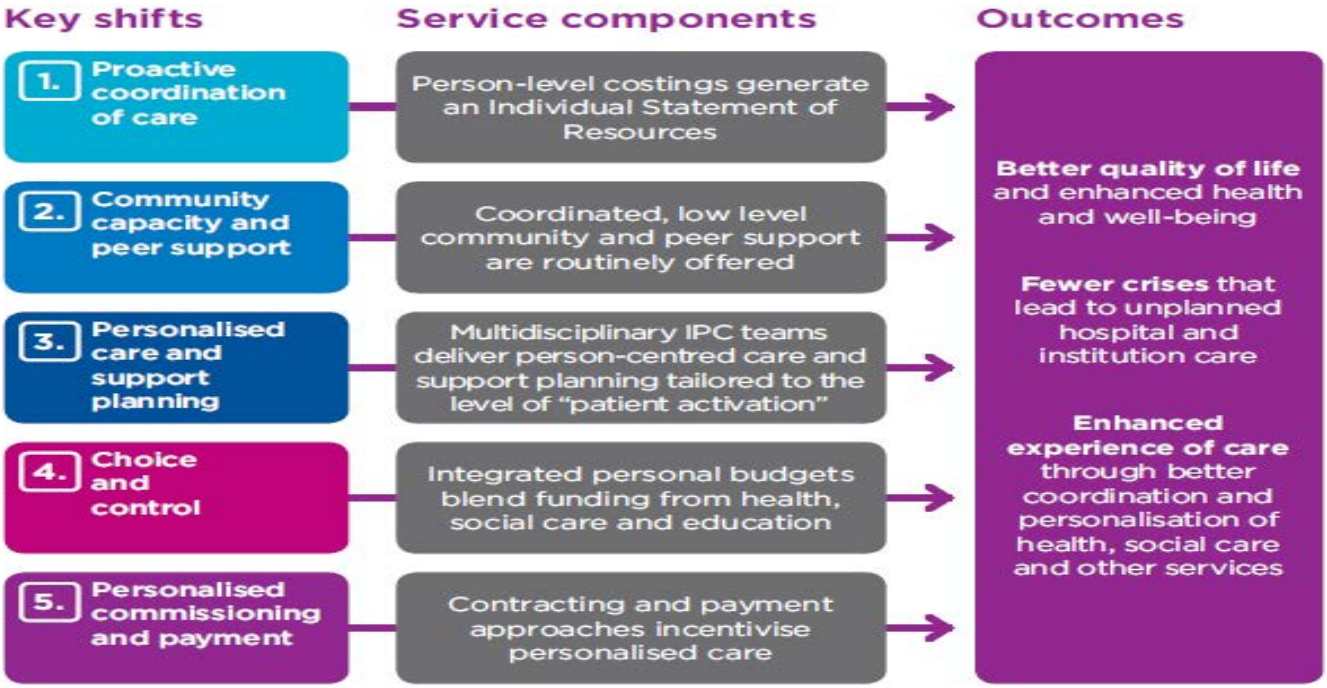


Figure 1: Local Government Association (2017) Developing support and services for children and young people with a learning disability, autism or both p.33

In the absence of a strategic overview existing services can become muddled and become characterised by reactive short-term decision making, dictated by crises by existing roles. Given there is a blueprint as to what service should look like the pitfalls are financing and maintaining support has services transition and services close whilst others open causing issues such as capacity of and availability of a skilled workforce with the right skills mix, estates to ensure services are within the local community to serve the local population.

A lack of education placements has seen a rise in home education as a makeshift solution. This not only places more stress on families the specialist input required to help children meet their full potential is unlikely to be available. The lack of local LD friendly pathways into education and physical and mental health care in the local community has meant the current system has become the norm for commissioner's local authorities and health services and disillusioned many front line workers unable to get appropriate services for their clients. To address this one solution is the introduction of Sustainability and Transformation plan leads to examine the current situation with stakeholders across services. For the most complex presentations requiring forensic services we need to see if it is still the case that these services are commissioned across greater geographical areas e.g. regional. For many it will be structure

rather than security that may negate their risk to the community, whatever model is used it is important that local pathways into services should be aware of the workforce requirements needed if more is done to meet the needs of this group locally or when this group will return to their local area so they receive a multi-agency package within TC Partnership.

Scoping Review Process

To examine the current barriers to providing CYP LD services fit for the future and that fit with current policy a review of current academic and grey literature, which mainly consists of commentary and expert opinion has been included. We have also courted expert opinion through seeking the views of a small number of stakeholders.

Stakeholder Review

In order to ensure the scoping review process was including the views and opinions of those with an interest in the transitioning of CYP with LD and complex needs the team approached several volunteer stakeholders to include their comments and views in the report as a first step to member checking findings.

The following semi structured interview informed stakeholder involvement and was emailed out to several members of the identified expert reference group who had given permission to be approached at this early stage of the project.

From your experience of CYP with MH and ID/Challenging behaviours, please provide comments on the following issues that are emerging from our scoping exercise:

WORKFORCE ROLES	SERVICE MODELS	Other
• What do you consider to be the existing workforce engaged with this client group? • What are the different roles you are aware of? • Where are there gaps in terms of skills or specialist roles? • What training and education is required to address any gaps?	• What's your understanding of the commissioning of services? • Are there any data sets/statistics you are aware of in your geographical area or nationally? • Are there any case scenarios you can share with us of when things went well or even went wrong for this client group and their families?	• Is there any other information you wish to share with us that will help inform any recommendations? • Please forward any information you feel relevant

Figure 2: Semi structured interview for stakeholder interaction

Responses included the following information across the three areas as outlined above. Owing to time limits the data is presented in unrefined way, and is often a precis of a far longer discussion. Quotations are provided as close to the conversation and words used by participants as possible without losing meaning and are presented in italics.

The over-riding outcome of stakeholder participation is that people have a depth of information and a variety of detailed stories and are more than willing to share their experiences in order to improve service experiences for others, as well as help them understand and continue to manage their own situations and circumstances.

1: Workforce Roles:

Stakeholders identified workforce staff ranging across Health, Education, Social Care, plus included external organisations staff, identified as relevant wherever the CYP meet and interacted with people within their care context (e.g. Leisure centres, Shops etc.). The range of people involved with a person appears to entirely depend on the range of their health needs. Therefore a complex referral process ensues, depending on the health and care needs the CYP presents with. Some stakeholders also mentioned the Police and other emergency service contacts, with examples given as, 'for those who run away', or those who come into contact with criminal justice system.

Roles made specific reference to are (recognised to be a non- exhaustive list):

- *Health Roles*

  Health Visitors, GPs, School nurses (immunisations etc), Paediatricians (different types in different settings), Occupational therapists, Speech and Language, Physiotherapists, Clinical Psychologists (different types in different settings), phlebotomists, anaesthetists, ENT consultants, Dentists, Optometrists, Dieticians, X ray staff, A&E staff, Other health consultant specialists (eg gastroenterology), administrators, reception staff, inpatient staff (not elsewhere mentioned).LD nurses, other nurses, (e.g. adult, child or mental health), Psychotherapist, IAPT, pharmacist, community LD team staff.

- *Education Roles*

Education psychologists, Head teachers, SENCOs, class teachers, teaching support assistants, SEND staff in local authority

- *Social Care Roles*

Social workers social work assistants, trainee social workers, social care providers (many types), domiciliary staff, Heads of Care, Managers and Care staff (residential settings), foster carers, childminders, play therapist, short break residential care staff, host families .

- *Criminal Justice Roles*

Police, probation staff, liaison, judges, solicitors, administration staff, reception, appropriate adults, advocates etc…

Where are there gaps in terms of skills or specialist roles?

There is lack of agreement and understanding as to the needs and prevalence of issues among this group. There is also a gap in what is understood to be best practice for how their needs and emerging complex needs are best managed (and for example the need for an ongoing role of lead professionals to ensure health needs are met).

There are gaps in different approaches to pathways and therefore a lottery as to what help and services will be forthcoming in each local area.

There is lack of skill in making and understanding how services should work together to ensure these CYP and their families have good lives.

There is a different language set used between health, education and care for the same group. Therefore education and care staff are less likely to understand the needs of this group in terms of the specific impact and health staff may also lack skills and knowledge and feel they are not commissioned to help.)

There is a lack of understanding of quality for this group and families and they get passed from pillar to post.

Our CYP can scare people including all professionals and our own families and there can be little empathy. They are not always seen as human.

Psychologists have not clear training in this area – its interest driven, same for Psychiatry, they tend to come via adult or child training, or dual, with a bit of LD. The Royal College of Psychiatrists is looking at credentially ID Psychiatry, but very early days.

LD and MH nurse training has been badly effected, particularly with the bursary being taken away as these were an older demographic that conventional school leavers who come into nursing, and they just cannot take on a loan when they have families and mortgages to pay. This has had a major impact on recruitment into these specialist fields of nursing.

What training and education is required to address any gaps?

There needs to be national agreement as to the needs and prevalence of this group and their full range of possible needs.

They are not always seen and understood as complex neurodisabilities and can be mislabelled as poor parenting or social emotional needs, reflecting different approaches to the use of language across education, health and care.-

There is also a lack of understanding of their personalised needs such as environmental factors, space, the personal needs of this group (e.g. they can sense fear and know when people do not link them and this will make them upset) and so on.

All staff need to be trained with this background as well as managing behaviours such as PBS.

Social care, education and other support staff have to be funded and trained to provide high levels of care, not babysitting so that these CYP can lead full lives not being contained at home, in residential settings or hospitals

What does genuine coproduction means for this group?

There needs to be training for local staff groups and programme for parents, not the incredible year, but have modified incredible years for LD and getting access to some of these resources

ACAM has an offer of masterclasses and interclasses on challenging behaviour, it's a two day conference

CYP IAPT is being developed at UCL, although not published yet, linking to the first course of its kind at the Anna Freud centre, LD ASD KCL, if you do a search their course comes up.

There is definitely more need for advanced practitioner programmes like the CYP IAPT

Predominantly training is geared towards CAMHS, but we need more expert CAMHS, more awareness raising and modifying of practice.

There are workforce deficits in educational psychologists and underfunding. Health then will only be picked up on so it's hard to work out a diagnosis and clarify the maladaptive behaviours to get the right help to families and the child.

2: Service Models

What's your understanding of the commissioning of services?

Fragmented, no sense of understanding of the needs at all and crisis management. Making families fight until they become exhausted.

Good experiences tend to be down to committed people trying to do their best to help families and the CYP

Not listening to children or families.

In an ideal world there would be ring fencing of funding to make a real difference.

Without a really good team of people we just wouldn't be able to function in the way we do, and the only alternative is that all the children would end up on lots of medication.

When it works well it's because of a good established team working alongside a functioning multi-agency settings, in particular social care disabilities teams, with good education settings that can meet the needs of children, then you can keep them out of hospital, and off medication

We need really good parameters, so that the team know what they can put through and refer on, but people get re-referred.

If we had a residential school in my area, we could keep people local, but we don't so cannot do this, so if you don't have a good commissioning to provide expertise and resources then you get a knock on effect in the system where other children are sometimes pushed away at lower levels so they have to hit a higher threshold where the team do not have the skills to deal with this, so this effects other areas, as staff get moved about to other areas, or they get escalated rapidly to inpatient areas out of area.

It is important to assess people in their local area, otherwise you can push out another 10, 20, 30 other families into a crisis, as they are not getting their time out, so there is a knock on effect of poor commissioning and shuffling people out of local area.

However, there is a flip side, where there are children with higher needs who do need residential or inpatient settings which can form the base plan to make that happen.

There is some innovative stuff going on in Bradford for example. David Simms at Field Head House, a social innovation is being funded allowing things to be done differently and involving industry partners. There is also the Leicester model, keeping children locally and going into generic units, but staff go with them, so wherever the child is their team goes with them, whether a respite unit, or into general services, also in Dorset, and there's some forward thinking in Birmingham.

Private providers, it gets all very messy again and very difficult to know how to monitor these services.

Are there any data sets/statistics you are aware of in your geographical area or nationally?

http://www.bacdis.org.uk/policy/dataset.htm

The data is mixed and murky as it's often a subset of a subset from other data, which makes it hard to pull out what is adult and what is children.

You might get some learning disabilities nursing data, but you cannot always see where they are working as so many no longer work in the NHS, so no data being gathered on them and their qualifications

Royal Colleges might have some data – Royal College of Psychiatrists, Royal College of Nursing

MIND ED website

Disability Matters website

CAMHS as a subset of workforce in general

There is a report coming out in the New Year from HEE, might be willing to share an early draft of the report.

I can send you what I have….

Are there any case scenarios you can share with us of when things went well or even went wrong for this client group and their families?

Positive: Early Intervention works as do short breaks and this can keep people in their communities.

Negative: too much fighting to have needs identified and met, crises, ATUs, Winterbourne View, poor transitions, people dying from neglect

For example my son (who has a severe learning disability, autism and complex language and communication needs) was refused access to a Feeding and Eating Disorders Service when young (too disabled - we successfully appealed under the Equality Act), has been refused blood tests (too difficult) and thrown out of hospital and refused anaesthetic (as a health and safety risk), been wrongly diagnosed by his GP recently (I challenge for him as he has no voice himself) and told that he cannot feel pain over and over again (because he cannot say ouch or indicate in a way "professionals" recognise and understand)!

My brother who has a learning difficulty took some persuading but went to see his GP wanting to give up smoking, as I had encouraged him to do this, and he got told they wanted to review his medication first. I was outraged and it's put him back as he didn't need any medication changes, he knows what he takes so changing his meds makes him really anxious. He went seeking help to stop smoking, not to get a medication review. So typical of professionals thinking they know what's best for the person all the time. Just didn't listen or see his side at all.

3: Any other information

Is there any other information you wish to share with us that will help inform any recommendations?

Yes the enclosed paper was submitted initially and families like it as it raises the issues they want to see considered.

For children and young people with learning disabilities the health inequalities start young leading to earlier and avoidable deaths. This is part of the story too. See slides enclosed from Kevin Elliott from the Improving Health and Quality Team.

Our children are not seen as human and cannot access basic good quality health services or are denied it because of their disability.

There are no people in Iceland with Downs Syndrome as the screening process gives parents choice to not have the baby which then starts to alter the international data across the globe.

If you take a person with learning disabilities, and place the PD concept on top, with the emotionally unstable elements that can fit with CYPS who are susceptible, so this muddies a diagnosis, and therefore service provision required.

WE need a clearer breakdown of the adult, child workforce and what is needed

ONS Statistics are not great for these groups as parents tend to overestimate, so it looks like 5-6% of children in my area have a learning disability. Whereas its 1-5% of the population depending on where you look and whose data you have looked at.

Academic Literature Search

The academic literature was characterised by commentaries, observational accounts, expert opinion, reviews and service evaluations. Where there was more robust methodology used this often didn't extend to children. One of the most serious issues is that of health inequalities. The literature suggests that often a lack of basic awareness about the needs of people with LD can have catastrophic consequences. As mentioned earlier people with LD experience elevated rates of mental and poor physical health and reduced outcomes (Koskentausta et al., 2007; Trollor *et al.*, 2016). Compared with the general population the rates on common mental health problems is two-four times higher (Einfeld et al., 2011). In a cohort study, only 10% of children and adolescents with a mental health problem received treatment (Einfeld et al, 2006). Common conditions in many people with LD such as Epilepsy, are mismanaged, often due to support workers having little or no training (Pointu & Cole, 2005). Iacono *et al.* (2014) in a systematic review concluded that hospital care for people including children with LD was inadequate, citing poor knowledge and skills of the workforce.

Often there is a lack of, or poor training available. In Australia, Weise *et al*. (2016) using a modified Delphi approach identified the skills required of primary care and mental health providers in recognising and manage common mental health problems in people with LD. While some of these were specific to Australian culture, most could be transferable across boundaries. They identified 11 workforce domains in

three core areas; working with people with LD, clinical competencies and quality improvement and professional development. In spite increased awareness of the problem, a recent systematic review concluded that despite efforts by governments and health professionals' people with LD continue to have poor hospital experiences (Iacono et al., 2014). This review did not specifically identify experiences of children and adolescents.

Workforce & Services

Although innovative service models and care pathways have been put forward; in reality workforce planning has largely focussed on a maintenance model around the current workforce with a particular emphasis on staff competency particularly in areas of safety. Evidence from the UK and overseas indicates there is need of a skilled and stable workforce and one that would match population and geographical variations (Dowse et al., 2016). This is particularly highlighted in, the *'London Workforce Strategic Framework'* (2016). The current workforce consists of a number of disciplines with specialist educated nurses in LD providing the large proportion of current roles. It has been consistently reported over the past decade that the numbers of LD nurses are on the decline and with recent changes to funding of courses this is likely to worsen. While there is reported declines in nursing numbers the shift from traditional National Health Service (NHS) settings to independent and third sector care has meant they are not appearing in standard statistics. To gain a better understand of the nursing workforce, an urgent redesign is needed (Gates & Statham, 2013; Glover & Emerson, 2012). One approach suggested is to refocus learning disability nurse training into a regional model where, perhaps Health Education Providers provide joint programs (Gates & Statham, 2013).

Central to any workforce redesign is for both intra and inter agency collaboration. Such collaboration is necessary to ensure the complex and multiple support needs for children and adolescents with learning disabilities are managed in a proactive manner. This then takes into account, not just the specific individual needing support, but the family and local community from which that child or adolescent lives. Therefore, an agreed philosophy and shared principles are identified across all sectors (Dowse et al, 2016). This is summed in box one below.

Box one: The coordination of case management for children or adolescents with a learning disability should include;

a) coordinate the use of specialist services as necessary;
b) maintain and extend natural supports as appropriate;
c) refer to and support the transition to mainstream services as appropriate;
d) assist with capacity building of mainstream services and the community's natural supports; and
e) be responsive during inevitable periods of high support; the provision of specialist mental health, positive behaviour, and trauma support; training, mentorship, and supervision of the direct support personnel and families expected to translate often complex plans to practice in the field.

Source: Dowse, L., Wiese, M., Dew, A., Smith, L., Collings, S., & Didi, A. (2016). More, better, or different? NDIS workforce planning for people with intellectual disability and complex support needs. Journal of Intellectual and Developmental Disability, 41(1), 81-84.

The lack of co-ordination between agencies and absence of involvement of the young people, their families and carers in all stages of planning is frequently cited as a problem (Tarleton & Ward, 2005). An example of good collaboration was reported by Pointu et al, (2005) where a focused educational programme for epilepsy was successful due to consistent cross agency working and involvement of family and cares at all stages. This programme ensured all whom came into contact with the child or adolescent understood what was required when they were confronted with seizures and other problems associated with epilepsy. This ensured there was a translation of the agreed principles.

Many children and adolescents with learning disabilities continue to be cared for by specialist services. There are wide variations across the UK in terms of the frequency and scope of specialist services. The rates vary between 4.8 per 100 000 in Scotland to 7.8 per 100 000 in Northern Ireland. This includes 5.5% of children and adolescents in specialist services (Hatton, 2016). Hallawell (2001) reported almost all children in residential care are outside their home area. In this same study, a quarter of the sample continued to live in multiple occupancy housing. Managing children & adolescents in out of area placements are expensive and ineffective in meeting the specific needs of the individual. Those most likely out of area tend to have histories of challenging behaviour, detention under the mental health act and a diagnosis of Autism (Allen *et al.,* 2007). Caregivers report difficulty engaging local services and experience negative impacts from continuing to support their child or adolescent out of area leading to severe financial and relationship burdens. Caregivers of children & adolescents with Autism compared to

those with other learning or developmental problems are affected most (Vohra *et al.,* 2014; Zablotsky *et al.,* 2015).

While much of the care given is within specialist services there is need to appraise the benefits of interventions non-specialist community settings. Skills training for the individual and parental awareness and support are shown to be most effective in non-specialist settings in improving a combination of outcomes (Reichow *et al.,* 2013). Ensuring gaps are identified for people with a learning disabilities in mainstream services is a priority. Liaison roles help bridge such gaps between specialist and mainstream services. MacArthur *et al.,* (2015) examined the facilitation role of learning disability liaison nurses (LDLN) to enable people with learning disabilities including those under 25 access to general hospital services. They identified seven areas fulfilled by LDLNs (Box two). Similarly links between current mental health services and gaps for young people with learning disabilities is poorly understood. The UK government initiative "*Valuing People Now: A New Three-year Strategy for People with Learning Disabilities"* resulted in specialist learning disability child and adolescent mental health services (Department of Health, 2009). This was in response to findings that a lack of engagement by mental health professionals contributed to significant service gaps (Kaehne, 2011). In an evaluation of one such service it was recommended changes to staff skills in dealing with children and adolescents with learning disabilities include a) appropriate communication, b) a welcoming approach, c) an open approach and, d) choice of location (Boyden, Muniz & Laxton-Kane, 2013). This is supported by findings from a number of services where problems with communication lead to poor healthcare for children and adolescents (Gowland, 2011); Lennox *et al.,* 2012).

Box two: Facilitation of adjustments for people with learning disabilities;

a) access to information;
b) adjustments to care;
c) appropriate environment of care;
d) ensuring equitable care;
e) identifying patient need;
f) meeting patient needs; and
g) specialist tools/resources

Source: MacArthur, J., Brown, M., McKechanie, A., Mack, S., Hayes, M., & Fletcher, J. (2015). Making reasonable and achievable adjustments: the contributions of learning disability liaison nurses in 'Getting it right' for people with learning disabilities receiving general hospitals care. *Journal of advanced nursing, 71*(7), 1552-1563.

There is growing evidence supporting person-centred approaches that take into account individual planning. Important to this shift in practice is ensuring the person's voice is heard, funding arrangements meet the individual need and there is provision for workforce training and supervision (Mansell & Beadle-Brown, 2004). In their study of LDLNs, MacArthur and colleagues (2015) found that ensuring reasonable adjustments for people with learning disabilities including under 18s in general settings promotes person-centred care and leads to equal health outcomes. In response to changes in disability support, Australia has moved towards a national payment scheme similar to the UK NHS and Social Care provisions for the disabled (Dowse *et at*, 2016). The inclusion of learning or intellectual disabilities into this scheme has led to a raised awareness of the gaps and provisions for such a population. Deficits in both skill level and quality of education are barriers to an effective workforce. This affects those encountering children & adolescents with learning disabilities at all levels of care, from primary services, specialist disability programmes and co-morbid provision (Gowland, 2011); Trollor et al., 2016).

The transition from adolescence to young adulthood is greater problem for young people with a learning disability and this is especially so when transitioning into adult services (Hudson, 2003). All too often individual needs are poorly met or not met at all. There are issues of different age limits, disconnected referral processes, a lack of opportunities to attend services in the local area and lack of knowledge and education of all involved including the person, family, care givers and service providers. Such transitions are complex and poorly understood (Hudson, 2006).

The person in transition quite naturally experiences anxiety and apprehension with family, carers and specialist support staff being ill prepared to deal with this. Adolescents with a learning disability in transitioning to adulthood are often a) socially marginalised, b) more dependent on family, and c) have fewer education and work options (Forte, Jahoda & Dagnan, 2011). In a systematic review it was found that many young people with a learning disability identified more specific issues within the three areas described above and include under **social marginalisation** – safety, healthy living, having fun; music; sport; helping others, friends; sex and relationships; **family** - living independently, being in charge of their life and where to live; **education and career** – college and money (Tarleton & Ward, 2005).

It is suggested transition planning start by mapping all of the systems encountered by the child or adolescent. This would ensure areas of strength are identified to assist the transition process while those

not meeting needs be prioritised to ensure they are not failing the person (Small, Raghavan & Pawson, 2013). There have been several papers examining the aspects that make good transition. Barron & Hassiotis (2008) in a policy review summarised good transition (Box three).

Box three. Elements that contribute to experience of good transition

Heslop *et al* (2002)	**Deb *et al* (2006)**	**Viner (2008)**
a) Co-ordination: inter-agency working b) Comprehensive and effective transition plan for all young people c) Continuity of key workers; a seamless transition from children's to adult services d) Choice: more and better involvement of young people and their families in the transition process e) Communication between agencies, and between agencies and families f) Independent advocacy for young people.	a) Transition planning b) Transition co-ordination, use of a transition co-ordinator c) Service user involvement d) Needs assessment e) Identify needs of clients, incorporate the views of carers and the other professional bodies f) Use of health action plans and person-centred planning	a) Preparing the young person and their families for transition b) Preparing the adult services c) Listening to the needs of young people

To ensure transitions are effective protocols that aim to identify the principles of partnership working and determine processes need to be in place. Transition protocols are developed through partnerships between service providers, voluntary sectors and local authorities vary widely in practice. Many of the protocols contain some or all of the elements outlined in Box three above. However, in a study of protocols in Wales the involvement of the individual was cited most as not happening as well as disorganised person centred transition planning meetings and limited agreement on pooled funding (Kaehne, 2010). The inclusion of the individual in their transition planning and ensuring services are tailored is key to positive outcomes (Kaehne & Beyer, 2014).

Grey Literature Search

Although there was some overlap with the academic literature search a number of themes within the literature and interviews were highlighted as barriers to providing quality services that are fit for purpose

and allow children with LD the same rights and opportunities afforded them as is offered to other children. These ranged from ethos to developments and current issues that are preventing current best practice being implemented. In this review ten themes were identified which are listed below. The themes highlight perceived areas where intervention is required or systems need to be put in place so it is possible to provide service that are in line with current guidance and best practice :

- Philosophy
- Reducing Admissions
- Commissioning
- Experience of services
- Service Delivery
- Services
- Workforce capacity
- Workforce fragmentations
- Lack of available data
- Referrals

Philosophy

In principle there is an agreed philosophy and shared principles, however the translation of accepted or agree principles is not always smooth e.g. differences in the schools of thought such as labelling has produced strong emotive arguments on both sides. Labelling is thought of by many as stigmatising and alienating individuals from society, whereas in the current set up there are many that agree with this sentiment that still advocate for it as it is necessary to access services or benefits and provides a common language at transition.

Reducing Admissions

CTRs were developed to reduce admissions to unnecessary hospital placements, restrictive interventions long stays out of area in the absence of local services. As well as adults CTRs refer to children and young people with learning disabilities, autism or both.

Given the different policies and needs of children the process was renamed 'Care, Education and Treatment Reviews' (CETRs) to reflect the role of education, and educational placements. Currently there is a lack of resource to evaluate CETRs and guidance has been produced by the Local Government Association (2017) Developing support and services for children and young people with a learning disability, autism or both, but again like guidance before it is aspirational highlighting rather than offer guidance on how to implement best practice.

Commissioning

In spite of a plethora of information on what good commissioning looks like (DH, 1993. 2007 etc. Many regions still full back on traditional models of commissioning that maintain the current situations such as the use of out of are placements, a lack of joined up working between adult and children's services. Part of this may not be entirely the fault of commissioners but fragmented service models, lack of data, lack of expertise in knowing what highly specialist placements look like and contingencies to manage difficult situations where someone's behaviour or mental health may worsen. This is in a servicer backdrop where there can be *perverse incentives* to move people on. (McGill et al 2010). For some families often their relationship is fraught with local services due to persistent failure to provide adequate services and often as a result some will feel there is no alternative but to look for flagship services out of area. Competing eligibility criteria and budget restraints however may mean alternatives are offered not meeting expectations or need. Moving between services was also an issue whether during transition or moving to a different level of service as often there had been little in the way of case review where all key stakeholders attend with no sanction for not attending from adult services, it may be that many do not feel this to be their core business or priority. Currently there is a disparate range and coverage of service in regions across different levels of need. Exacerbating this is there is no clear statement on pathways of what a child should expect.

Experience of Services

Although there is little in the way of published research into the LD child workforce specifically, reports and consultations such as Lenehan (2017) and McGill et al, (2010) have provided us with the issues faced by parents and children in trying to access services. There are a number of common themes that are consistently voiced by families. The lack of local services often meant that families reached crisis due to poor response for referrals or services for children whose behaviour was challenging, as well as a lack of provision there was also no support or strategies to help families manage. This not only meant a

deterioration in health for the child but also the family. Although there was a better response to crisis solutions were not always person centred relying on long term residential and/or out of area placements. A lack of services has meant more and more families are

Service Delivery

The configuration of services are a major issue. As well as a number of independent providers, services within local authority education and health and social care are also compromised between the lack of joined up working and systems. This can include electronic records or the fact that with competitive tendering adult and children services, serving the same location maybe in different Trusts. This both confuses pathways and reporting as for some quality objectives more than one organisation could have responsibility. The use of the independent sector often means that the market for the least complex presentations is catered for whilst those often needing more intensive input not provided within the local area.

Workforce Capacity

In terms of delivery there are no minimum standards on the professional make-up of services and where the provision of key health disciplines are required such as nursing, OT, Psychology or psychiatry. Neither is there an indication that who should lead and regulate different groups of support workers. Skills and competencies are defined to some degree but how courses are delivered and quality of induction can vary greatly and not prepare inexperienced care staff for a range of necessary duties for example like a specialist nurse might carry out. It is also the case that as a result there is a lack of meaningful training and supervision on the job, and roles are assigned outside individual levels of competence. There is a need for new standards and new roles supervised by existing professional group's e.g. Nurse Associates or apprentices. However the decrease in LD nurses and use of cheaper alternative as led to a critical shortfall where a strategy has to be put agreed to increase supply and the training of nurses and support staff.

Workforce Fragmentation

Currently there is guidance and published resources on how to maintain and enhance staffing (National Quality Board, 2016). However like other guidance it is good at articulating the challenges and providing part of the context but with no clear direction of how to navigate the problem. This approach leads to

commissioners developing their own models according to supply of the workforce. Currently there is no clear data on the attrition of a number of professional disciplines providing child LD care such as learning disability nurses (Council of Deans, 2017) and Special Education Teachers (McLesky et al, 2004). It is estimated that the learning disability nursing workforce has fallen by a third – 1,700 posts and there is a lack of data to inform service development, improvement and demand (RCN, 2016 & 2017). This is acknowledged in the recent consultation paper which highlights professions were numbers are failing, including 1,674 fewer district nurses (26.1%), and 842 fewer learning disability nurses (36.5%) and a fall in GP numbers of approximately 1% since 2012**.** In the absence of a national strategy to provide a LD workforce fit for purpose it is left to local providers to establish staff working models without levels of expertise to support them or to ensure adequate training and quality. It is acknowledged that developing and defining the workforce is a challenge. In 2015/15 HEE Commissions 664 Learning disability Nurses – 95 Learning Disability Psychiatrists (higher specialist training) * 52 Clinical Psychologists * 608 Speech & Language Therapists * 1543 Physiotherapists (*Not LD specialist programmes). However there is great variation in England on education frameworks and strategies (Lisa Bayliss- Pratt Director of Nursing-Health Education England http://www.challengingbehaviour.org.uk/learning-disability-files/11-03-15-Lisa-B-P.pdf). Varied education frameworks employed across England have often not taken into account or placed enough emphasis on the requirement to develop and grow LD services. This lack of attention is characterised in difficulty in recruiting and running LD nursing programmes, where we are now seeing courses cancelled (Merrifield & Stephenson, 2017) and a lack of support staff to staff local services. The move to nurse associates and nurse apprenticeships are welcome but the main discussion on how these will underpin the current workforce has largely focused on other fields of nursing. To go forward the current workforce needs to be mapped against an agreed future model so a strategy can be put in place to achieve a fit and competent workforce that affords access to quality education and healthcare for children with LD. that will need to be mapped. There should be a high-profile national recruitment campaign, across education establishments, supported by national bodies including HEFCE and Health Education England. Part of this will be to ensure key professional disciplines such as learning disability nurses are central to Health Education England's future workforce as recommended by the Council of Deans of Health (2017).

Referrals

The issue of referral of CYO with LD to appropriate education and health services varies widely across the country for a number of reasons:

- Current service configurations and care pathways
- Types of services available
- Eligibility criteria

In many areas there are deficits within pathways and a lack of services to meet need. Often parents whose children would benefit from certain interventions or placements are not referred if they are seen as too able and this fail to meet eligibility criteria, for some services this might be IQ, current support or the need is not seen severe enough to warrant intervention. Other concerns that have been raised as well are lack of referral to appropriate service or long waiting times to be referred and that referral might be a holding referral to ensure waiting times are met. Another issue is that often now treatment is measured in episodes so there is a risk of no support or service being available following referral.

SUMMARY: A Way Forward

A number of issues that affect the provision of equitable services and experiences have been highlighted within this report. The FYFV identified services for the 1.5m people with LD as requiring increased focus. The learning disability workforce programme will ensure the workforce has the education, skills, values and behaviours it needs to help service users lead better, more independent lives.

Though yet to happen everywhere LD services must be delivered through integrated, community based services. The LD workforce needs to change as more services are moved into the community to improve the quality of care. Social care is expected to employ an additional 7,500 staff with community support requiring 1,000 workers. Around 2,750 inpatient staff need to transfer their skills and knowledge to community settings. Staff in the community require competencies in positive behavioural approaches (PBS), mental, physical and forensic interventions.

The current phase is focused on aligning and developing the workforce and services with significant progress in competency frameworks, workforce planning, new roles and leadership. As provision is commissioned the effort will shift to service providers.

A new PBS alliance will find the best way of ensuring standards as steps are taken to address emerging risks such as; graduate pre-registration nursing, special interest LD GP fellows, LD children and young people Improving Access to Psychological Therapies (IAPT) and pilot media campaigns.

The next phase will ensure sustainability including the supply and development of key professionals through apprenticeships and HEE, with partners, will review the future staffing and skill mix required for the new LD services.

The overall aim of the documentary review process was to identify any workforce issues relating to providing a workforce able to achieve seamless care for CYP with ID/MH/CB as they transition into adulthood, taking into account the complex needs, family and person centred preferences. 19 of the 40 papers identified in relation to the sample population had a specific reference to workforce issues.

A variety of workforce roles were specifically mentioned, as the CYP with LD/MH and CB often has complex needs that translate across health, education and social care sectors. By consequence, the workforce issues address the need for a skilled person needed to undertake a holistic assessment that will then feed into the complex commissioning and associate funding arising from delivering on care packages that may include out of local area service needs, particularly at a time of unplanned crisis, or respite/short breaks. However, it was also recognised that not everyone involved in the person's care package will need to be a specialist practitioner.

The three tiered model, as used in Dementia Care Training is identified as a potential model that could translate well into the CYP with ID/MH/CB workforce education and training requirements and follows a similar approach used in positive behaviour change training models (c.f. Transforming Care, 2015).

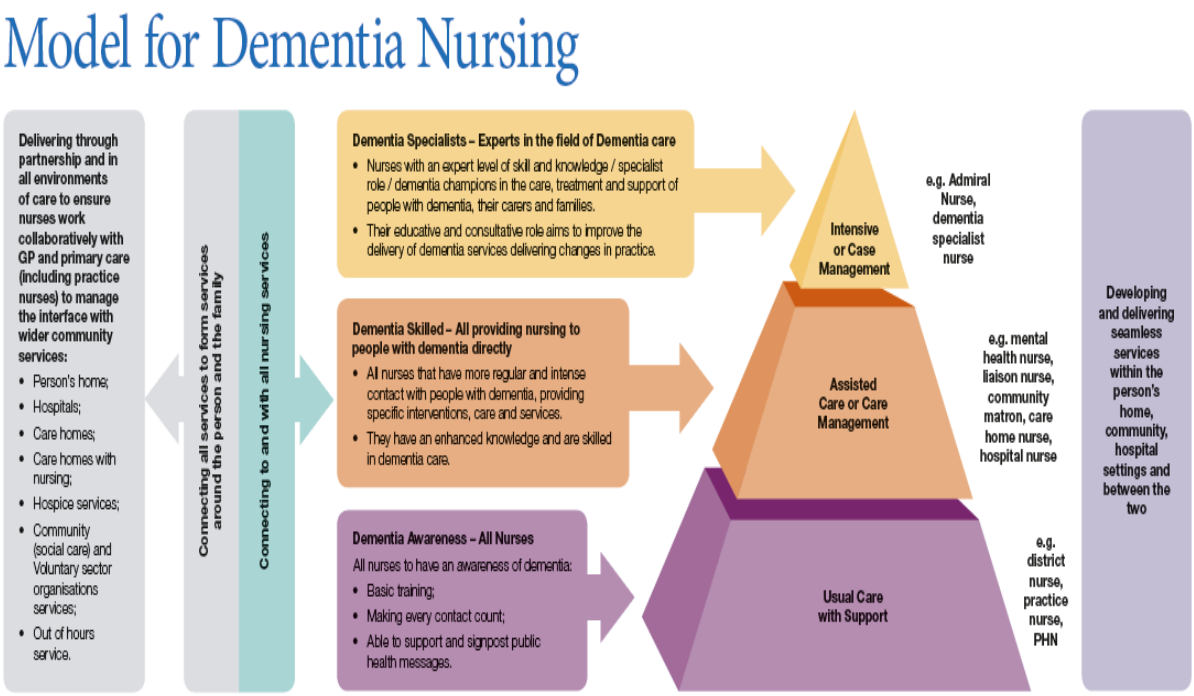


Figure 4: A model for Dementia Nurse Training Tiered Approach

The Facing the Facts, Shaping the Future: A draft health and care workforce strategy for England, 2027 has just been published by Public Health England, (December, 2017) and outlines the issues of workforce demands against the changing service models across health and social care. It tackles issues of workforce supply, retention and recruitment patterns and future education and training models against a changing backdrop across health and social care and changing socio economic environments. The **six principles** underpinning the review are identified on page 18 as:

1. Securing the supply of staff that the health and care system needs to deliver high quality care in the future. Since the NHS began patients have been well served by staff from around the world. However, maximising the self-supply of our workforce is critical. It cannot be right for the NHS to draw staff from other countries in large numbers just because we have failed to plan and invest.

2. Enabling a flexible and adaptable workforce through our investment in educating and training new and current staff. Individual NHS professions have distinct roles but there is scope for more blending of clinical responsibilities between professions. This flexibility is rewarding for staff and can provide the NHS with more choice in how we organise our services.

3. Providing broad pathways for careers in the NHS, and the opportunity for staff to contribute more, and earn more, by developing their skills and experience. Structured career opportunities which enable staff to progress both within and between professions will enhance retention and make the health and care system more resilient and attractive in the face of changing demands from staff.

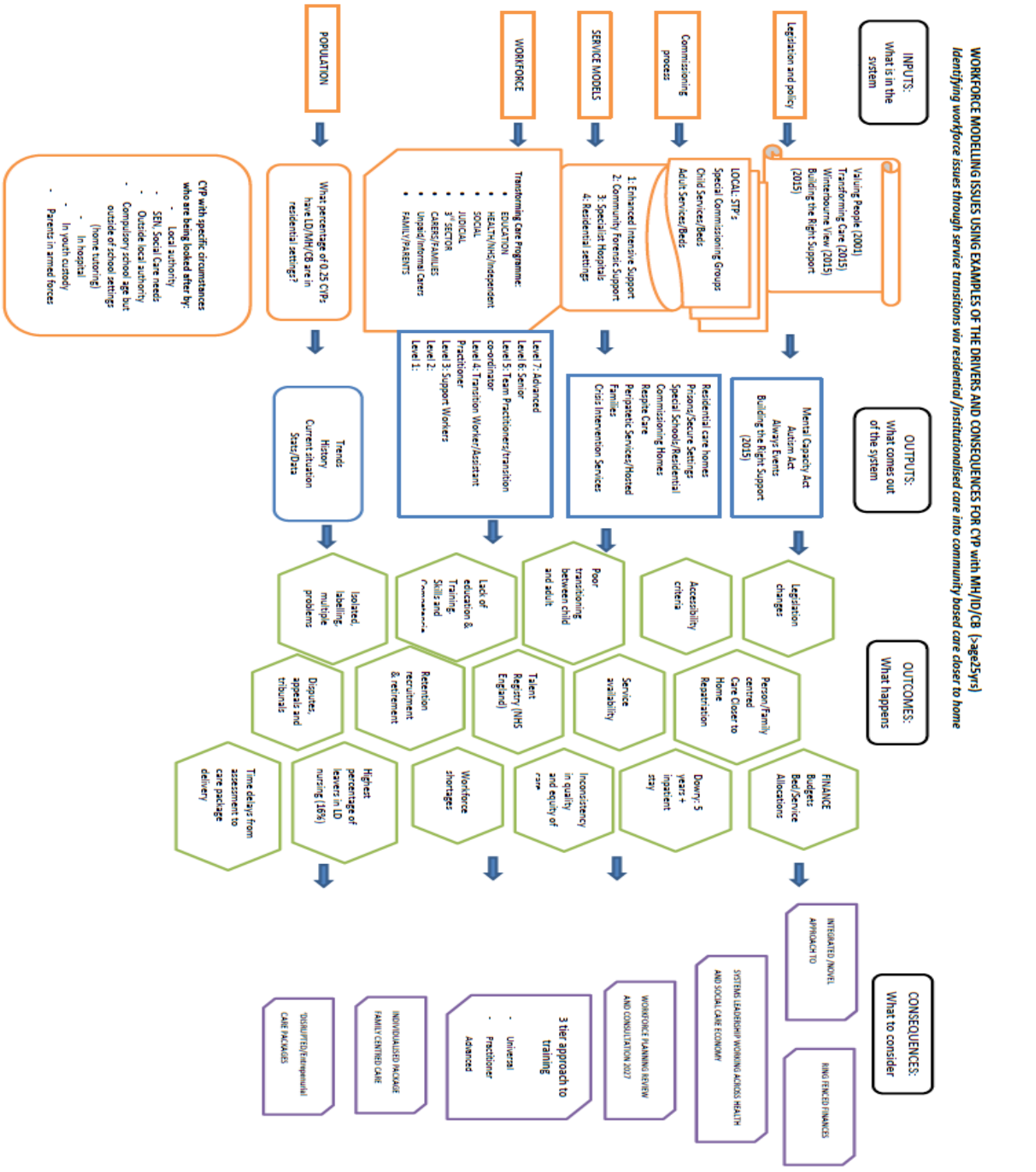
4. Widening participation in NHS jobs so that people from all backgrounds have the opportunity to contribute and benefit from public investment in our healthcare.
This enshrines the public duty to provide equal opportunity for all and will ensure the
NHS workforce of the future more closely reflects the populations it serves. If delivered successfully it will increase the pool of people available to be recruited into the NHS.

The percentage of vacancies as at March 2017 by profession identifies learning disability nursing as the highest percentage (16.3%), learning disabilities was identified as a focused/priority workforce group, within integrated services and professional networks needed to provide effective care and deliver the Service Transformation Plans (STPs) Locally. The report also identified the need to upskill the workforce, and improve skill mix including advanced clinical practice, through increasing a modern flexible workforce and credentialing. Further representation from carers during this consultation to understand their role and unrealistic expectations placed on them from time to time.

Next Steps

The final part of this report see Figure 3 provides indication for aspects relevant to creating a logic model for CYP with MH/ID/CB to inform workforce planning. It may be a good starting point for the expert reference group to also help identify core elements of discussion and potential ways forward in areas for further consideration to improve access, equity by recognising areas for improvement to affect change in a systematic way to remove barriers.

Figure 3: Examples of the drivers and consequences for CYP with ID/MH/CB (>25 yrs) service transitioning via institutionalised, residential, towards community provision care closer to home.



References and Reading List

Abbott, D., Morris, J & Ward L (2001) *The best place to be? Policy, practice and the experiences of residential school placements for disabled children,* York, Joseph Rowntree Foundation

Allen, D. G., Lowe, K., Moore, K., & Brophy, S. (2007) Predictors, costs and characteristics of out of area placement for people with intellectual disability and challenging behaviour. Journal of Intellectual Disability Research, 51(6), 409-416.

Barron, D & Hassiotis, A., (2008) Good practice in transition services for young people with learning disabilities: a review. Advances in Mental Health and Learning Disabilities, 2(3), pp.18-22.

Boyden, P., Muniz, M., & Laxton-Kane, M. (2013) Listening to the views of children with learning disabilities: An evaluation of a learning disability CAMHS service. Journal of Intellectual Disabilities, 17(1), 51-63.

Bubb, S (2014) Winterbourne View-Time for Change Transforming the commissioning of services for people with learning disabilities and/or autism, A report by the Transforming Care and Commissioning Steering Group, chaired by Sir Stephen Bubb – 2014

Care Quality Commission (2017) The state of care in mental health services 2014 to 2017 Findings from CQC's programme of comprehensive inspections of specialist mental health services, Newcastle, CQC,

Care Quality Commission (2014) From the pond into the sea Children's transition to adult health services Newcastle, CQC,

Council of Deans of Health (2017) Learning Disability nursing meeting report (16th November 2017)

Deb S., LeMesurier N. & Bathia N. (2006) Guidelines for services for young people (14-25 years) with learning difficulties/ disabilities and mental health problems/ challenging behaviours: Quick Reference Guide (QRG). *University of Birmingham*, Birmingham, UK. www.ldtransitionguide.bham.ac.uk

Department of Health (1993) 'Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs'. London, UK: The Stationery Office. The Mansell Report

Department of Health, (2001) Valuing People: A New Strategy for Learning Disability for the 21st Century London, UK: The Stationery Office.

Department of Health, (2007) Services for people with learning disabilities and challenging behaviour or mental health needs (Revised Edition) London, UK: The Stationery Office. The Mansell Report (revised)

Department of Health (2009) *Valuing People Now: A New Three-Year Strategy for People with Learning Disabilities*. London, UK: The Stationery Office.

Department of Health (2012) Transforming Care: A national response to Winterbourne View Hospital: Review Final Report, London, UK: The Stationery Office

Dowse, L., Wiese, M., Dew, A., Smith, L., Collings, S., & Didi, A. (2016) More, better, or different? NDIS workforce planning for people with intellectual disability and complex support needs. Journal of Intellectual and Developmental Disability, 41(1), 81-84.

Emerson, E. and Hatton, C., (2008). CEDR Research Report (2008) (1): People with Learning Disabilities in England.

Einfeld, S. L., Ellis, L. A., & Emerson, E. (2011) Comorbidity of intellectual disability and mental disorder in children and adolescents: A systematic review. Journal of Intellectual and Developmental Disability, 36(2), 137-143.

Einfeld, S.L., Piccinin, A.M., Mackinnon, A., Hofer, S.M., Taffe, J., Gray, K.M., Bontempo, D.E., Hoffman, L.R., Parmenter, T & Tonge, B.J., (2006) Psychopathology in young people with intellectual disability. JAMA: The Journal of the American Medical Association, 296(16), pp.1981-1989.

Forte, M., Jahoda, A., & Dagnan, D. (2011) An anxious time? Exploring the nature of worries experienced by young people with a mild to moderate intellectual disability as they make the transition to adulthood. British Journal of Clinical Psychology, 50(4), 398-411.

Gates, R., (2009) The valued people project: report of a strategic review of educational commissioning and workforce planning in learning disabilities.

Gates, B., & Statham, M. (2013) Lecturers and students as stakeholders for education commissioning for learning disability nursing: Focus group findings from a multiple method study. Nurse education today, 33(10), 1119-1123.

Glover, G., & Emerson, E. (2012) Patterns of decline in numbers of learning disability nurses employed by the English National Health Service. Tizard Learning Disability Review, 17(4), 194-198.

Gowland, S. (2011) Enabling people to give feedback about their health care: Finding out what patients think about their treatment is notoriously difficult. Learning Disability Practice, 14(8), 32-36.

Hallawell, B. (2001) Issues emerging from the London learning disability plan. British Journal of Nursing, 10(3), 173-178.

Hassiotis, A., & Turk, J. (2012) Mental health needs in adolescents with intellectual disabilities: Cross-sectional survey of a service sample. Journal of Applied Research in Intellectual Disabilities, 25(3), 252-261.

Hatton, C. (2016) Specialist inpatient services for people with learning disabilities across the four countries of the UK. Tizard Learning Disability Review, 21(4), 220-225

Heslop P., Mallett R., Simons K. & Ward L. (2002) Bridging the Divide at Transition: What Happens for Young People with Learning Difficulties and Their Families. BILD, Kidderminster.

HM Treasury/Department for education and skills (2007) Aiming High for Disabled Children: Better Support for Families,

Hudson, B. (2003). From adolescence to young adulthood: the partnership challenge for learning disability services in England. Disability & Society, 18(3), 259-276.

Hudson, B. (2006) Making and missing connections: learning disability services and the transition from adolescence to adulthood. Disability & Society, 21(1), 47-60.

Hurst, K., (2010). Evaluating the strengths and weaknesses of NHS workforce planning methods. *Nursing*.

Iacono, T., Bigby, C., Unsworth, C., Douglas, J., & Fitzpatrick, P. (2014) A systematic review of hospital experiences of people with intellectual disability. *BMC health services research*, *14*, 505-505.

Kaehne, A. (2010) Multiagency protocols in intellectual disabilities transition partnerships: A survey of local authorities in Wales. Journal of Policy and Practice in Intellectual Disabilities, 7(3), 182-188.

Kaehne, A. (2011) Transition from children and adolescent to adult mental health services for young people with intellectual disabilities: a scoping study of service organisation problems. Advances in Mental Health and Intellectual Disabilities, 5(1), 9-16.

Kaehne, A., & Beyer, S. (2014) Person-centred reviews as a mechanism for planning the post-school transition of young people with intellectual disability.n Journal of Intellectual Disability Research, 58(7), 603-613.

Koskentausta, T., Iivanainen, M., & Almqvist, F. (2007) Risk factors for psychiatric disturbance in children with intellectual disability. Journal of Intellectual Disability Research, 51(1), 43-53.

Lenehan, C (2017) These are our children: a review by Dame Christine Lenehan, Commissioned by the Department of Health

Lennox, N., Ware, R., Carrington, S., O'Callaghan, M., Williams, G., McPherson, L., & Bain, C. (2012) Ask: a health advocacy program for adolescents with an intellectual disability: a cluster randomised controlled trial. BMC Public Health, 12(1), 750.

Local Government Association (2017) Developing support and services for children and young people with a learning disability, autism or both p.6-7

Local Government Association, Association of Directors of Adult Social Services, NHS England (2015) Buildng the Right Support A national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition

MacArthur, J., Brown, M., McKechanie, A., Mack, S., Hayes, M., & Fletcher, J. (2015) Making reasonable and achievable adjustments: the contributions of learning disability liaison nurses in 'Getting it right'for people with learning disabilities receiving general hospitals care. Journal of Advanced Nursing, 71(7), 1552-1563.

Mansell, J., & Beadle-Brown, J. (2004) Person-centred planning or person-centred action? Policy and practice in intellectual disability services. Journal of Applied Research in Intellectual Disabilities, 17(1), 1-9.

Marshall-Tate, K., Chaplin, E., & McCarthy, J., (2017) Is "transforming care" failing people with autism? Advances in Autism, 3(2), pp.59-65

McLeskey, J., Tyler, N.C & Saunders Flippin, S., (2004) The supply of and demand for special education teachers: A review of research regarding the chronic shortage of special education teachers. The Journal of Special Education, 38(1), pp.5-21.

Merrifield, N & Stephenson, J (2017) Exclusive: University cancels learning disability course in wake of bursary removal, Nursing Times https://www.nursingtimes.net/news/education/exclusive-university-cancels-learning-disability-course-in-wake-of-bursary-removal/7021567.article?search=https%3a%2f%2fwww.nursingtimes.net%2fsearcharticles%3fqsearch%3d1%26keywords%3dturner Accessed on 25th December 2017

McGill, P., Cooper, V. & Honeyman, G. (2010) Developing better commissioning for individuals with behaviour that challenges services – a scoping exercise. Canterbury/Chatham: Tizard Centre/Challenging Behaviour Foundation.

MENCAP (2007) Death by indifference, London, MENCAP

MENCAP (2012) Death by indifference: 74 deaths and counting A progress report 5 years on, London, MENCAP

MENCAP & Challenging Behaviour Foundation (2012) Out of Sight, Stopping the neglect and abuse of people with a learning disability

Michael, J (2008) Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities. London: Department of Health.

National Institute of Clinical Excellence (2016) Transition from children's to adults' services for young people using health or social care services, NICE guideline [NG43] Published date: February 2016

National Quality Board, (2016) National Quality Board guidance on Safe Staffing,

Noyes, J & Lewis, M., (2007) Compiling, costing and funding complex packages of home-based health care. Paediatric nursing, 19(5), pp.28-32.

Pointu, A., & Cole, C. (2005) An education programme for social care staff: improving the health of people who have a learning disability and epilepsy. British Journal of Learning Disabilities, 33(1), 39-43.

Public Health England, (2017) Facing the Facts, Shaping the Future: A draft health and care workforce strategy for England to 2027, London, PHE

Reichow, B., Servili, C., Yasamy, M. T., Barbui, C., & Saxena, S. (2013) Non-specialist psychosocial interventions for children and adolescents with intellectual disability or lower-functioning autism spectrum disorders: a systematic review. PLoS medicine, 10(12), e1001572.

Royal College of Nursing (2016) Connect for Change: an update on learning disability services in England, London, RCN

Royal College of Nursing (2017) Safe and Effective Staffing: Nursing Against the Odds, London, RCN

Small, N., Raghavan, R., & Pawson, N. (2013). An ecological approach to seeking and utilising the views of young people with intellectual disabilities in transition planning. Journal of intellectual disabilities, 17(4), 283-300.

Tarleton, B., & Ward, L. (2005). Changes and choices: finding out what information young people with learning disabilities, their parents and supporters need at transition. British Journal of Learning Disabilities, 33(2), 70-76.

Trollor, J. N., Eagleson, C., Turner, B., Salomon, C., Cashin, A., Iacono, T & Lennox, N. (2016). Intellectual disability health content within nursing curriculum: An audit of what our future nurses are taught. Nurse education today, 45, 72-79.

Vohra, R., Madhavan, S., Sambamoorthi, U., & St Peter, C. (2014). Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions. Autism, 18(7), 815-826.

Weise, J., Fisher, K. R & Trollor, J. (2016). Utility of a Modified Online Delphi Method to Define Workforce Competencies: Lessons from the Intellectual Disability Mental Health Core Competencies Project. Journal of Policy and Practice in Intellectual Disabilities, 13(1), 15-22.\

Viner, R.M., (2008) Transition of care from paediatric to adult services: one part of improved health services for adolescents. *Archives of Disease in Childhood*, *93*(2), pp.160-163.

Wright, B., Williams, C. & Richardson, G., 2008. Services for children with learning disabilities.

Zablotsky, B., Pringle, B. A., Colpe, L. J., Kogan, M. D., Rice, C., & Blumberg, S. J. (2015). Service and treatment use among children diagnosed with autism spectrum disorders. Journal of developmental and behavioral pediatrics: JDBP, 36(2), 98.

Hyperlinks to reports contained in 'Documentary analysis of workforce issues relating to CYP with Intellectual disability, mental health and challenging behaviour' figure.

Valuing People
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf

Death by Indifference: MENCAP
https://www.mencap.org.uk/sites/default/files/2016-06/DBIreport.pdf

Short Breaks: Statutory guidance on how to safeguard and promote the welfare of disabled children using short breaks
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/271205/Short_breaks_-_how_to_safeguard_and_promote_the_welfare_of_disabled_children.pdf

Support and aspiration: a new approach to special educational needs and disability. A consultation.
http://www.educationengland.org.uk/documents/pdfs/2011-green-paper-sen.pdf

The National Health Visitor Plan: Progress to date and implementation 2013 onwards
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/208960/Implementing_the_Health_Visitor_Vision.pdf

From the Pond into the Sea Children's transition to adult health services
https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report_Summary_lores.pdf

Special Education needs and disability: A guide for parents and carers
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/417435/Special_educational_needs_and_disabilites_guide_for_parents_and_carers.pdf

Care services for people with learning disabilities and challenging behaviour
https://www.nao.org.uk/wp-content/uploads/2015/02/Care-services-for-people-with-learning-disabilities-and-challenging-behaviour.pdf

Building the Right Support: A national plan to develop community services and close inpatient facilities for people with a Learning disability and or autism who display behaviour that challenged, including those with a mental health condition.
https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf

Transforming Care for People with Learning Disabilities – next steps
https://www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-nxt-stps.pdf

Workforce Development for People with Intellectual disability: Report of the KSS ID Workforce Scoping Project
https://www.hee.nhs.uk/sites/default/files/documents/FULL%20REPORT%20-%20PWID%20Workforce%20Development%20report.pdf

Report of Sir Martin Narey's independent review of children's residential care

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/534560/Residential-Care-in-England-Sir-Martin-Narey-July-2016.pdf

National Framework for CYP 's Continuing Care
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/499611/children_s_continuing_care_Fe_16.pdf

Centre for the Advancement of Positive Behavioural Support Organisation and workforce Development
https://www.hee.nhs.uk/sites/default/files/documents/CAPBS%20Organisational%20and%20Workforce%20Development%20Framework_0.pdf

Sustainable safe staffing: A report of mixed methods systematic review of literature
https://improvement.nhs.uk/uploads/documents/LD_evidence_review.pdf

Safe, sustainable and productive staffing: an improvement resource for learning disability services
https://improvement.nhs.uk/uploads/documents/Adult_in-patient_safe__sustainable_staffing.pdf

Local support for people with a learning disability
https://www.nao.org.uk/wp-content/uploads/2017/03/Local-support-for-people-with-a-learning-disability.pdf

Health Visiting, and School Nursing Partnership –pathways for supporting HV and SN interface and improved partnership working
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/465412/2903820_PHE_School_Nursing_Accessible.pdf

These are our Children A review by Dame Christine Lenehan
https://www.ncb.org.uk/sites/default/files/field/attachment/These%20are%20Our%20CHildren_Lenehan_Review_Report.pdf

Facing the Facts, Shaping the Future: a draft health and care workforce strategy for England 2027https://www.hee.nhs.uk/sites/default/files/documents/Facing%20the%20Facts%20Shaping%20the%20Future%20a%20draft%20health%20and%20care%20workforce%20strategy%20for%20England%20to%202027_0.pdf

Project Report/ Plain English

INTRODUCTION

London South Bank University (LSBU) are pleased to present a project report for Health Education England on the staffing needs for Children and Young People with a learning disability, mental health problem and challenging behaviours.

Many families have complained about poor services. People have told us about:

- Poor access and referral to services
- A lack of awareness by staff of the things that matter to people with learning disability
- Not getting the right support
- Having services not near to where we live
- People being sent to hospital or long term residential services

This project report talks about who are the most suitable staff needed to help to improve services to offer high quality, family centred care packages, working across health and social care services. The aims is to provide the right care for Children and Young People (CYP) closer to their homes and families.

The information was collected from looking at published reports and hearing about people's experiences of service changes taking place today.

The report will be shared with the group who will make recommendations for better services to the Government.

BACKGROUND

Children and Young People (CYP) with LD cover a range of abilities and have may different support needs. Significant number of CYPP come into contact with services, whether or not they have been diagnosed.

People with LD are four times more likely to have poor mental health. All children need 24 hour support to some degree, whether living at home (with parents/family and/or unpaid volunteers) or living at a full time placement that can meet their specific personal needs.

The recent report by Dame Christine Lenehan[6] identified problems in the way the NHS and social care services support CYP. These children, the report suggests, receive poor services that are not organised and which cost more to provide .

There are many CYP being cared for in long term residential care homes, miles away from their home and family. This is why we need to think differently about what is needed and who are the best people to deliver person centred care.

WORKFORCE: THE PEOPLE WHO CARE

The key people in the workforce we were told about includes health, education, social and legal staff (for example Police, Judges, Solicitors).

A workforce that knows about learning disability and the skills and the right attitude is needed to achieve all of the requirements to support CYP.

[6]https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/585376/Lenehan_Review_Report.pdf

We know good services will have a skilled and caring workforce. These are people who can work well with others, have good relationships with the CYP and their families, as well as other staff groups.

What families think is best, is what is often called a Personal Family Centred Care Package. This includes what future support might be needed for the child's wellbeing both now and in the future This will include education, physical or emotional/ psychological support.

Different services need to work together to help children growing up, through their childhood and when they move into adult services.

It is important that services should be aware of what types of staff (e.g. Nurses, Speech Therapist, Behaviour support etc) are needed to meet the needs of CYP locally.

Transforming Care Report tells us about why we need local services. For people who receive services away from home. Local commissioners should be looking at when children will be able to return to their local area to receive services.

Summary

To get better services we need to:

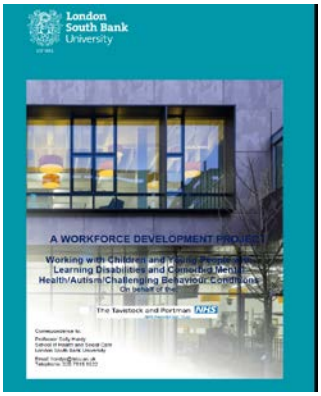
- ensure the workforce has the education, skills, values and behaviours it needs to help people lead better, more independent lives.

- services can be delivered in local communities by people who know about learning disabilities and what needs to go into a family care package .
- The LD workforce needs to change with the times, as more services are provided in the community to improve the quality of care.
- More people need to be trained to understand and work with CYP with a learning disability
- What might work is using the same model of three staff training levels, as used for Dementia Care

What we need to do next is discuss these findings further.

Working with the expert reference group the next steps will be to advise government on how the education and health services can continue to be improved for CYP and their families.

Project Report: Easy Access



London South Bank University wrote a report about how we can get the best people to work with and support people with learning disability and make services better

We looked at many reports which told us how people with learning disability find it difficult to get the healthcare and support they need.

People with learning disability are 4 times more likely to have poor mental health. For some people this means getting help, like education or treatment far away from home.

Talking to people we found out problems people with learning disability were having with education and health services included:

A Bad Experience of Services.

This meant waiting a long time to be referred.

Being refused services.

Or staff not knowing enough about learning disability. Being sent away from home to get help.

The next step is to invite people to talk about the report. This will include talking about how we get good staff who know about living with a learning disability.

After our talks our group will advise the Government on how to make educaiton and health services better for people with learning disability.

Key Contacts and Validity

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Appendices

Profile of London South Bank University

London South Bank University is one of London's largest and oldest universities. We owe our origins to those far sighted people who created the Borough Polytechnic in 1892, an institution that was greatly admired and successful in delivering life enhancing education relevant to employment. We have inherited, and cherish, the role of welcoming students with potential from whatever background and helping them achieve career success. This mission is central to the University and we remain true to it. Since our inception, we've been providing vocationally-relevant, accredited and professionally recognised education.

We're a cosmopolitan university with over 25,000 students drawn from over 130 countries. We received the highest possible rating for the quality of our education from the independent Quality Assurance Agency (QAA).

Research plays a crucial role at LSBU. As well as addressing the challenging issues faced by society today, our applied research seeks to provide solutions to the business world and beyond. We feel justifiably proud of our researchers' achievements as well as their success in attracting external financial support for their research ideas. Each of our Schools is involved in a wide range of research projects, many involving collaborations with business.

Profile of the School of Health and Social Care

The School of Health and Social Care (HSC) is made up of the following:

- Department of Primary and Social Care
- Department of Adult Nursing and Midwifery
- Department of Children’s Nursing
- Department of Mental Health and Learning Disabilities
- Department of Allied Health Sciences

- Institute of Vocational Learning
- Institute of Medical and Dental Education

Across these departments, we work in partnership with a large number of NHS organisations in London and beyond, providing training and education for a wide variety of healthcare workers. Ranging from one-day workshops through to full-time undergraduate and postgraduate degrees, the school has developed an excellent and well-deserved reputation. School staff members are highly experienced, registered healthcare professionals who deliver highly flexible, innovative and contemporary courses. All of our courses have a key focus on inter-professional working, supporting the integration agenda of wider healthcare services. LSBU is proud to be the largest provider of CPPD for the health and social care workforce in the South East of England and in the recent Quality Contract Performance Monitoring was RAG rated Green.

The School of Health and Social Care has extensive facilities across two campuses; Southwark and Havering. Both campuses offer a range of facilities including our state of the art interactive clinical skill laboratories which provide simulation of the highest quality.

Research in the School of Health and Social Care

The School of Health and Social Care is a leading centre in London for research in nursing, midwifery, allied health professions, public health and social care. 97% of its research was internationally recognised or better in the 2014 Research Excellence Framework. Top ratings of 'world leading research' or 'internationally excellent' (4* or 3*) were achieved for 80% of our research impact and for 66% of our publications. Our research is broken down in to 4 broad themes, described in more detail below.

Children, young people and families

This theme aims to promote understanding of children and young people’s experiences of illness, health, disability and those in disadvantaged circumstances through a user-centred, integrated programme of research, service evaluation and consultation. By using a broad range of innovative but robust research techniques of engagement with children, young people and families the aims are to build an evidence

base to influence both policy and practice that is locally relevant and applicable nationally and internationally.

Health and Social Care Delivery

Health and social care is delivered in the context of a changing and dynamic service provision for diverse populations across varied care settings. Many people have long-term health conditions and, increasingly, those accessing health and social care are older and with complex needs. Care delivery should be person-centred and collaborative and maximise opportunities for service user engagement and empowerment, as well as promoting shared responsibility for health. This research theme focuses on the development and evaluation of novel approaches to care delivery that improve quality of experience as health and social care services move towards greater integration, innovation and flexibility. Complementary approaches to healthcare are included within this theme, in particular the study of Chinese medicine and self-help techniques, as they are part of integrative and person-centred care.

Community and Public Health

The Community and Public Health theme has a broad and integrated programme of research that is locally relevant and applicable nationally and internationally. Issues concerned with the health and wellbeing status and behaviour of individuals, groups and communities are addressed. The work is informed by a desire to build an evidence base of what works and for whom and the translation of research findings to inform education and practice development and service effectiveness.

Workforce Innovation, Education and Development

All health and social care is underpinned by the quality of its workforce and there is an on-going need to identify and develop flexible ways of responding to dynamic and ever changing policy and care environments. Embedded within one of the largest providers of health and social care education in London, this research theme is about developing the research base to support innovation in health and social care roles and the ways we deliver education to the health and social care workforce at all levels, from pre- and post-registration to leadership and organisational development. It is fundamentally important that any changes in how care staff are educated or deployed is based on the highest quality research evidence.