University of East Anglia

NHS
Health Education England

Exploring the future needs of Learning Disability Services

To meet the objectives of the NHS Long Term Plan

Phase 1 Report – August 2020

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Executive Summary

Considering the diverse needs and persistent health inequalities experienced by people with a learning disability and autism, the Long Term Plan (NHS England, 2019) has committed to improving the health, wellbeing and treatment of people with learning disabilities and autism as an area of clinical priority. In line with several objectives set out in the Long Term Plan, this review aimed to articulate the (service and service user) needs, and gaps in meeting need, within Learning and Autism Services in England – to explore the applicability, potential and opportunities for new workforce interventions and roles in order to ensure good quality care for people with a learning disability and/or autism.

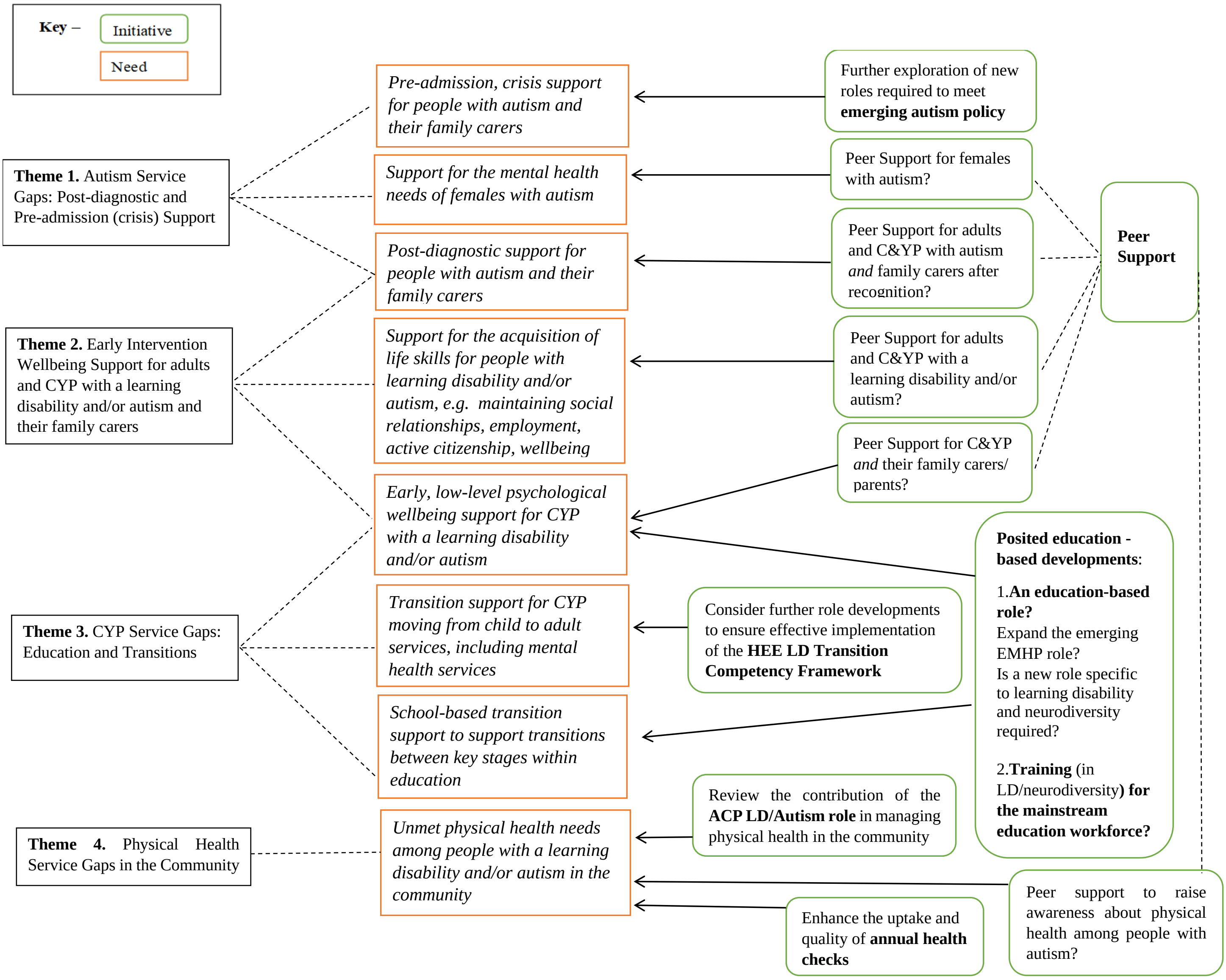
To gather evidence of current (unmet) service and service user needs, this review consulted several sources of intelligence, which are articulated throughout this report. The evidence includes: a review of academic and grey literature, including policy documents; data collected from regional workshops; recommendations and professional input from Expert Reference Group (ERG) contributors; and intelligence from consultations with Health Education England (HEE). As a result of this evidence gathering process, a wide range of suggestions for new and emerging roles (to meet the needs of people with a learning disability and/or autism) emerged. The findings and outcomes of these information-gathering exercises were disseminated at an ERG meeting – feedback from which informed Phase 2 (ongoing) of this review.

Following this process of data collection and analysis, a comprehensive list of service and service user needs was developed – which, subsequently, led to the initiation of a mapping exercise to explore whether there are existing and/or emerging initiatives that can be expected to meet need. Preliminary mapping work identified current gaps (in meeting the need) within existing provision. Considering the corpus of evidence acquired and through consultations with HEE, **four key themes** were identified as **priority areas of unmet need that require further exploration** in Phase 2 of this work, with respect to the development of new workforce interventions/models and roles:

1. **Autism Service Gaps**: Post-diagnosis and Pre-admission (Crisis) Support
2. **Early Intervention, Informal Wellbeing Support** for adults and children and young people with a learning disability and/or autism and their family carers
3. **Children and Young People with Learning Disability and/or Autism Service Gaps**: Transitions and Education
4. **Physical Health Service Gaps in the Community**

These four main themes are displayed in the diagram below (*Figure 3*), which highlights the needs to which they correspond alongside emerging initiatives/roles that substantiate further exploration in respect of meeting need. The present review purports that further work is required to explore how the initiatives identified can contribute to meeting the needs of people with a learning disability and/or autism. The primary focus of this review is to explore the need for new workforce roles to address unmet needs within Learning Disability and Autism Services and, therefore, the upskilling of existing roles in the workforce has not been examined in detail. Although, potential areas in which upskilling (of existing roles) may be useful – and which, therefore, require further exploration to examine whether they can address unmet needs effectively – has been articulated.

Figure 3. Map of Themes and Corresponding Areas of Need, alongside Emerging Initiatives to Meet Need.



Introduction

With the development of the National Plan (NHS England, 2015) and the *Transforming Care* programme (NHS England, 2017), advocating for the reduction in inappropriate hospital admissions and lengths of stay for people with learning disabilities, the aim to support people with a learning disability and/or autism to live within the community became a national priority. The national pledge towards community-based care follows the Winterbourne View scandal in 2011, which uncovered the systematic abuse of people with learning disabilities within an independent sector inpatient unit (Bubb, 2014). Previously, good practice guidance, such as the Mansell report (Department of Health, 1993; 2007), recommended that commissioners develop sufficient local community-based services to support people with a learning disability and/or autism and mental health or challenging behaviour needs – in order to reduce the reliance on out-of-area placements. The efficacy of the *Transforming Care* programme (NHS England, 2017) is contingent upon the development of high quality, specialist community services for people with learning disabilities – to reduce the historical overreliance on inpatient care. As Sandhu and Tomlins (2017) highlight, people with learning disabilities who are admitted to inpatient services often display a multitude of complex physical, behavioural and mental health needs.[1] Therefore, to meet the agenda of *Transforming Care* these interconnected needs must be managed within the community so, consequently, it is vital that community support is developed, strengthened and equipped with the key skills required to manage the complex needs presented by people with learning disabilities and/or autism.

Significantly, it is widely reported that people with a learning disability and/or autism have poorer physical and mental health compared to other people. For instance, a report conducted by Lenehan (2017; '*These are our children*') highlighted that, despite having greater ill-health, people with a learning disability and/or autism often face poorer access to healthcare. Similarly, the Learning Disabilities Mortality Review Programme (LeDeR; NHS England and NHS Improvements, 2019) was set up in response to the premature mortality of people with learning disabilities. Subsequently, the Long Term Plan (NHS England, 2019) has developed a series of objectives focused on improving the health outcomes for people with learning disabilities and autism as clinical priority areas – to ensure they live happier, healthier and longer lives. As will be demonstrated, the present report is aligned with the objectives of the NHS Long Term Plan and the broad aim to improve the health, wellbeing and treatment of people with learning disabilities and autism.

Of concern however, is that the national fragmentation and overall lack of learning disability and/or autism services has been identified across: community learning disability teams (Clare et al., 2017; Clare et al., 2019; Barnoux, 2019); intensive support for children with learning disability and autism (Davison et al., 2015); mental health provision for children and young people (Chester et al., 2019) and adults (Royal College of Psychiatrists, 2020); forensic services (Chaplin and McCarthy, 2015), particularly specialist community-based provision

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[1] While the term 'intellectual disability' is commonly adopted in the literature, the present review will use the recognised term of 'learning disability' widely used in the UK.

(Taylor et al., 2017b; Hindley et al., 2017); and services for people with autism, particularly those *without* a learning disability (Autistica, 2019), including post-diagnostic (Crane et al., 2018) and mental health support (Crane et al., 2019). Considering these concerns, the present review aimed to outline and evaluate current evidence with respect to existing service provision for people with learning disabilities and/or autism in England. The following services will be considered: Community Learning Disability Teams; Intensive Support Teams; Adult and Child and Adolescent Mental Health Services; Forensic Services; and autism-specific service provision.

Informed by evidence relevant to these services, this review will also highlight the shortages and gaps in current service provision; and, where applicable, the outcomes of existing provision for the client group. This will include the identification of wider shortages in meeting key areas of need, for example: with respect to annual health checks, and posit recommendations for future workforce and service development. Relevant grey literature will be incorporated alongside academic research to provide a contextualised understanding of the current state of learning disability and autism services in England. This body of evidence will form the contextual backdrop for the ‘Workshop Headlines’ section, where the new roles/ways of working posited by service staff will be articulated.

Literature Review

To acquire a comprehensive corpus of relevant academic and grey literature, with respect to learning disability and autism services in England, a focussed literature search was conducted between February and April 2020. Multiple search engines were utilised, including: EBSCO databases (The Cumulative Index to Nursing and Allied Health Literature/CINAHL and The Allied and Complementary Medicine Database/AMED); Social Care Online (provided by Social Care Institute for Excellence); PubMed; Google Scholar and UEA's library search engine. To garner recent published evidence with respect to learning disability and autism services, key terms were generated (and grouped – for instance, as MeSH terms) and inputted into the search engines for advanced search building. The following terms were grouped, as the target population: "learning disability/ies"; "intellectual disability/ies"; "pervasive developmental disorder"; "autism"; "autism spectrum"; "autistic"; OR "ASD". These terms were combined with additional relevant terms (using 'all fields' searches) – for example: "service (design; delivery; development; model; structure; provision; needs; challenges; OR outcomes)"; and "workforce (roles; training; specialist skills; OR competencies)". Additional search strategies included hand searches of articles for relevant references and "cited-by" searches to capture the most recent evidence for inclusion. The above search engines were also utilised for direction to relevant grey literature, including published evidence in the form of reports and guidelines. Targeted searches were conducted on specific regulatory and government body websites, including the National Institute for Health and Care Excellence (NICE) Evidence search engine; the Care Quality Commission (CQC) search engine (for national reviews and service-specific inspection reports); the NHS Publications search engine; and the Department of Health and Social Care for England (GOV.uk) website.

Principally, for inclusion, studies had to concentrate on service provision for the learning disabilities and/or autism population group, including commentary on one of the following areas: current service design, delivery, gaps and/or opportunities for future development; existing or emerging service models or workforce roles; or key skills, competencies and training required by the workforce involved in caring for people with a learning disability and/or autism. Studies that explored generic services (such as Child and Adolescent Mental Health Services/CAMHS, which are inclusive of people with a learning disability and/or autism *alongside* non-learning disability/autism service users) were included. Within this population group, adults and children/young people services were included; and studies that did not include the target population were excluded. Searches were limited to articles published in the English language and conducted within the UK. Included studies were published between (January) 2015 and (April) 2020 – to capture the current landscape of learning disability and autism services and the emergence of new roles or ways of working. The structure of this review is aligned to the key areas of service delivery identified from the literature, including: Community Learning Disability Teams; Intensive Support Teams; Adult and Child and Adolescent Mental Health Services; Forensic Services; Autism-specific service provision; and the delivery of annual heath checks. These areas of service delivery also align with several objectives set out in the NHS Long Term Plan (NHS England, 2019), focused on improving health outcomes for people with learning disabilities and autism. These key areas of service delivery will be discussed in turn.

Community Learning Disability Teams

With respect to Community Learning Disability Teams (CLDTs), there is a long-standing corpus of evidence that indicates variability in the structure, size, composition and organisational arrangement of these teams (for example, Clare et al., 2017; Barnoux, 2019; Clare et al., 2019) – even those close in geographic proximity. Although, there appears to be no comprehensive review or typology of CLDT provision in England that outlines the configuration of these services and/or measures outcomes/impact for the population concerned. However, it is recognised that the variation in current community learning disability services can cause difficulty for people with learning disabilities and their families to know what service/s they can access and expect (Clare et al., 2019). At present, CLDTs most typically comprise a multi-agency and multi-disciplinary workforce – including: a consultant psychiatrist specialising in learning disability; community learning disability nurses; psychologists; social workers; occupational therapists; physiotherapists; speech and language therapists – alongside social care workers and administrative staff (Guinn et al., 2016). The aim of CLDTs is to provide focused health support for adults with learning disabilities whose needs cannot be met by mainstream services (White et al., 2019).

Whilst there are these multi professional team structures, there is a growing evidence base highlighting the lack of adequate specialised community service provision for people with learning disabilities and/or autism, in terms of forensic, mental health and crisis response (for example, Barnoux, 2019; Washington et al., 2019; Chester et al., 2019). Consequently, psychiatrists and other Responsible Clinicians have expressed concerns over the lack of a well-resourced community service to provide specialist care to people with learning disabilities and complex needs – a gap that ensued from the rapid and disproportionate closure of inpatient beds, in comparison to the development of community services (Taylor et al., 2017b; Patterson, 2019). For example, from the geographic context of North-East England (Northumberland, Tyne and Wear NHS Foundation Trust), Taylor et al. (2017b) reported that clinical teams were under pressure to discharge patients with forensic needs even though specialist community care was unavailable. Consequently, this resulted in shortened patient rehabilitation programs and led to many individuals leaving inpatient care without being prepared for the challenges of community life. Further adding to this situation and concern for support is the reported lack of specialist community services to meet other complex needs associated with learning disability (Patterson, 2019). For instance, Washington et al. (2019) found that a lack of available and suitable care provision was a significant barrier to discharge from two inpatient Assessment and Treatment Units for people with learning disability and behaviour that challenges, including mental ill health. Therefore, within the context of the *Transforming Care* programme (NHS England, 2017) and the national plan for people with a learning disability and/or autism (NHS England, 2015), the development of community services is still a crucial need in order to try and ensure that appropriate support is available to meet the needs of this diverse population.

Moreover, part of the remit of CLDTs is to support people with learning disabilities who display challenging behaviour, through early identification, assessment and implementation of multidisciplinary interventions (White et al., 2019). In accordance with NICE (2015), a twotiered approach is required: if initial assessment and management by CLDTs has been ineffective, or the person has more complex needs, organisations should ensure that access to specialist assessment, support and intervention services is available – an area of need that, in some cases, is managed by separate Intensive Support Teams (ISTs). As will be articulated in the following section, intensive support is either embedded within CLDTs or delivered as a stand-alone service (Hassiotis et al., 2020) – encompassing a separate workforce and referral pathway. With respect to the latter model, White et al. (2019) report feedback from a service evaluation of working relationships between West Hampshire CLDT and Southampton and Hampshire IST (a stand-alone IST), where a lack of perceived confidence and skill in working with adults with challenging behaviour among CLDT staff was observed. Staff would often make referrals to the IST for functional assessments and Positive Behaviour Support (PBS) planning, which risked deskilling staff within the CLDT and increased referrals for intensive support. Consequently, an 'Inreach model' was piloted, whereby two IST staff (a registered community learning disability nurse and an unregistered assistant psychologist) were based as 'Inreach workers' within the CLDT for six months, one day a week (White et al., 2019:123). They found that IST Inreach had a positive impact on increasing CLDT staff understanding, confidence and use of available resources for working with adults with a learning disability and challenging behaviour. This emerging way of working, which has been extended to all CLDTs within Southern Health Foundation Trust, provides a model for improving coordination between CLDTs and ISTs.

Intensive Support Service Provision

Within the national service model (NHS England, 2015), it is recommended that Intensive/Enhanced[2] services should comprise specialist multi-disciplinary health and social care teams, with intensive support available when required, on a 24/7 basis. Concomitantly, the *Transforming Care* programme (NHS England, 2017) suggests that each team should develop their service(s) to meet the particular care needs of their local population. Intensive services should operate four core functions of support: assessment and treatment for individuals who display challenging behaviour; the delivery of person-specific support and training for other agencies involved in supporting those individuals; supporting the transition out of inpatient care and early discharge; and crisis response (NHS England, 2017:14). According to NICE (2018:25), these services should provide local and personalised intensive behavioural support for children, young people and adults during a crisis. Accordingly, the evidence base regarding what are known as Intensive Support Teams (ISTs) for people with learning disabilities and/or autism will be articulated below.

The most recent comprehensive investigation of intensive support teams for adults with learning disability was initiated by Hassiotis et al. (2020) – who developed a national typology of IST service models, depicting the geographical distribution and core characteristics of ISTs in England. The IST's identified were located across Northern England, Midlands and Eastern England, Southern England and London. A considerable degree of national consistency across IST provision (for adults with learning disability) was observed – for example, most services:

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[2] Referred to hereafter as 'Intensive' services or 'ISTs'.

are funded by the NHS (92%) and comprise a multidisciplinary workforce (89%) that generally includes both health and social care staff, with nursing staff as the most common profession. In addition, most ISTs use PBS as the most common intervention (99%), alongside other psychosocial interventions (93%). Finally, most services do not operate stringent eligibility criteria with respect to adults with a learning disability: individuals who display behaviours that challenge, experience mental ill health or have been in contact with the criminal justice system were accepted (97%). More specifically, by performing a cluster analysis on survey data from 71 ISTs, Hassiotis et al. (2020) found two distinct models of IST provision – namely: *independent* provision (n = 46); and *enhanced* provision (n = 25), centred around a CLDT. These models, outlined below, are consistent with the *Transforming Care* (NHS England, 2017) recommendation that intensive support should either be embedded within existing CLDTs or delivered as a stand-alone service.

Moreover, Hassiotis et al. (2020) report that ISTs with *enhanced* models were more likely to provide longer-term support (above 6 months), accept self-referrals (100%, compared to 35% of independent models); have large case-loads (92%, compared to 33% of independent models) and were less likely to use outcome measures (52%, compared to 89% of independent models). Provision of 24-hour care (Monday to Friday and weekends) was uncommon among both enhanced (only 8%) and independent provision (only 22%). Together, this means around a third of IST's provide intensive 24-hour and weekend support – which highlights a significant consistency gap in meeting the intensive 24/7 care standard outlined in the national service model. Furthermore, Hassiotis et al. (2020) found that just over half of ISTs (52%) reported having a daily helpline operated by health professionals with the capacity to respond to crises immediately. However, from the evidence provided, it is unclear whether these daily helplines operate in the out-of-hours capacity recommended by NICE (2018:25). At present, the available outcomes research into IST provision for people with learning disabilities is localised to specific services. For instance, Fuchs and Ravoux (2019) present the development of the Southwark Enhanced Intervention Service (EIS) in a South London Borough, which has demonstrated good outcomes for a small number of adults with learning disability and complex needs – by supporting them at crisis point locally and preventing hospital admission or referral to restrictive out-of-area placements. The structure of Southwark EIS is further articulated within the *Transforming Care* (2017) agenda as a model case study. Within stage two of their project (ongoing), Hassiotis et al. (2020) aim to report the clinical and cost outcomes of IST provision for people with learning disability across England.

From the above evidence, it seems that there are gaps with respect to existing intensive support provision for people with learning disabilities and/or autism. Previously, Davison et al. (2015) set out to establish the position of specialist 'peripatetic behavioural support teams' (equivalent to intensive support services) for children and adults with learning disabilities and challenging behaviour in England and Scotland. Out of 46 specialist peripatetic teams identified, 20 participated in an online survey and analysis revealed that few services accepted children and young people under the age of 18. As the authors suggested, this raises serious concern regarding the provision of intensive support for children with learning disabilities. It is possible that this shortage in intensive support provision for children and young people with learning disabilities continues to characterise service provision in England: in fact, Hassiotis et al. (2020) found from their study that 81% of ISTs accepted adults *only* (people aged 18 years and above). This is despite some of the aims of the NHS Long Term Plan (2019) to ensure that all children and young people can access crisis care 24 hours a day, seven days a week. Therefore, intensive support for children and young people with learning disability would be expected, and needs, to evolve. Furthermore, the evidence also suggests a potential lack of intensive support for people with autism: only 62.1% of ISTs with enhanced models and 51.1% of ISTs with independent models accepted clients with a neurodevelopmental disorder (Hassiotis et al., 2020). While a paucity of pertinent research makes this difficult to determine, nationally, it is important that future service development plans continue to consider how to meet the intensive support needs of people with autism. From here, we will now turn to another area of particular need by reviewing the current evidence regarding mental health service provision for people with a learning disability and/or autism.

Mental Health Service Provision

The increased prevalence of mental (and physical) disorders among adults, children and young people with learning disabilities, in comparison to the non-learning disability population, is well-documented (for example, Wright et al., 2017; Perera et al., 2020). Similarly, there is a high prevalence of mental health problems (Wigham et al., 2017; Crane et al., 2018) and risk of self-injurious behaviour and suicidality (Camm-Crosbie et al., 2019) among adults and children diagnosed with autism. Despite this, there is a lack of comprehensive research into mental health service provision (in terms of service configuration and clinical/cost outcomes) for the specific client group of people with learning disabilities and/or autism. Previously, Guinn et al. (2016) aimed to articulate the current state of community mental health service models for people with learning disability in England, informed by numerical data gathered from surveys with consultant psychiatrists. They found that the most common model of provision was generic community learning disability teams (84%). This was followed by specialist challenging behaviour services (21%), stand-alone mental health learning disability teams (16%) and services for neurodevelopmental disorders (16%). The remaining ‘other’ services (11%) included two integrated teams, namely: a child and adolescent mental health team; and a specialist epilepsy service. However, these findings may be unrepresentative of current service provision – for only 53 out of 310 consultant psychiatrists fully completed the survey, highlighting a low and unrepresentative response rate of only 21%.

More recently, Perera and Courtenay (2018) provided a short overview of current mental health services for people with learning disabilities across the UK. Broadly, three main models of community mental health services are identified: NHS healthcare teams; social care teams; and integrated teams, encompassing social care and NHS healthcare workers under one management structure. These services vary by locality but are most commonly delivered through a multi-disciplinary workforce of: psychiatrists, psychologists, nurses, occupational therapists, speech and language therapists, physiotherapists, arts therapists and other allied health care staff; and, additionally, integrated teams included social workers and support staff. The authors argue that mental health services (for people with learning disability) are well-developed but face challenges in supporting people to live within the community. Firstly, workforce recruitment, particularly to specialist clinical positions, and training in key skills (particularly for support workers in the community) can amount to shortages in the specialist skills required to support people with learning disabilities. Similarly, Hemm et al. (2015) indicated that staff within mainstream healthcare services (including the mental health workforce) have unmet training needs in terms of the knowledge, skills and attitudes required to support people with learning disability. Secondly, Perera and Courtenay (2018) highlight that local services have not always developed suitable mental health provision for people with complex needs, which has contributed to the problem of (often rural) out-of-area placements. While there is no systematic research into out-of-area placements for people with learning disabilities, local areas have emphasised the difficulties they pose for service users and the receiving services that support them, alongside the considerable cost implications (Shankar, 2015). Therefore, a key challenge is to equip local mental health teams with the specialist key skills required to support the needs of this diverse population within the community.

Furthermore, research indicates that people with learning disabilities and/or autism face an array of barriers when trying to access mental health support. Further to the shortage in specialist skills among the generic mental health workforce, diagnostic overshadowing has been identified as a common barrier to accessing (adult and child/young people) mental health services: whereby symptoms of psychopathology or mental ill health continue to be attributed to the primary diagnosis of learning disability and/or autism (Royal College of Psychiatrists, 2016, 2020; Burke and Hodgson, 2020 (Centre for Mental Health); Autistica, 2019; McNally and McMurray, 2015). In turn, significant mental health needs are mistakenly dismissed as untreatable manifestations of the underlying learning disability and/or autism diagnosis – thereby restricting the individual from accessing mental health services. With respect to service provision for adults with a learning disability, most mental health problems are managed by mainstream services within primary care; and access to specialist (secondary care) mental health support can prove difficult for all patients, but particularly for adults with mild learning disability (Royal College of Psychiatrists, 2020). Often, stringent eligibility/admission criteria can restrict access to mental health provision from specialist services. This is supported by Chinn and Abraham’s (2016) study exploring the barriers and enablers to accessing the Improving Access to Psychological Therapies service (IAPT) in England. They highlight that the ‘stepped-care’ model of IAPT, in which low intensity self-management treatments precede access to more intensive interventions (typically with a cognitive behavioural therapeutic orientation), constituted a ‘managerialist’ approach that emphasised strict eligibility criteria. The need for clearly operationalised guidelines contributed to the exclusion of people with learning disabilities from IAPT. Therefore, the operation of tight eligibility criteria within existing mental health services can act as a significant barrier to adults with a learning disability in need of support.

Moreover, autistic people with mental health issues also face barriers accessing appropriate support to meet their needs. Autistic adults are frequently confined to inpatient generic mental health settings – constituting 10% of the adult inpatient mental health service population – and are often unable to access community mental health support (Autistica, 2019:12). Frequently, people with autism, particularly those with ‘high-functioning’ autism (Barber, 2017) or autistic adults *without* a learning disability (Camm-Crosbie et al., 2019; Autistica, 2019), find themselves within a gap between mental health and learning disability services. According to Davidson et al., (2015), this well-acknowledged gap arises as people with autism are often deemed to have an IQ too high to access learning disability services or do not display significant mental ill health, restricting access to mental health services. This suggests that stringent eligibility criteria can prevent access to suitable provision – to the point where autistic people who display suicidal behaviours have been denied access (Autistica, 2019). Without access to specialist support, mental health problems can escalate to the point of crisis, which can often result in an admission to inpatient services (Crane et al., 2019; Autistica, 2019). Considering these issues, an emergent recommendation has been to develop and strengthen autism treatment pathways within existing mental health services (Camm-Crosbie et al., 2019). More radically, to remove barriers to accessing adequate support, another suggestion is to design services in a way that dissociates autism (and other forms of neurodiversity) from learning disability – due to the diverging profiles of need among these population groups, as suggested by the Centre for Mental Health (Burke and Hodgson, 2020) within the context of (mental health) peer support models.

Overall, what is clear from this corpus of evidence is that meeting the mental health needs of adults with a learning disability and/or autism is generally inadequate and lacking in specialist knowledge and expertise. As will be discussed in the next section, this service deficit also impacts on children and young people with learning disability and/or autism and is of significance given that mental health needs start to develop at a young age.

Children and Young People Services

A significant risk factor associated with mental health problems is being a child with a learning disability (Wright et al., 2017). Mental health services for children and young people with learning disability often vary significantly from service models for the adult population (Royal College of Psychiatrists, 2020). There are two primary models of mental health service delivery available for children and young people with a learning disability: Child and Adolescent Mental Health Services (CAMHS) or CLDTs (Chester et al., 2019). In addition, some services have developed dedicated teams for people with learning disabilities, with a specialist trained workforce integrated into CAMHS (CAMHS-LD/ID) to manage cases with the most complex profile of need. There is considerable variation in the availability of CAMHS across the UK and access is often influenced by age, geography and sub-speciality of the service – for instance, a paucity of low- or medium-secure CAMHS provision for people with learning disabilities (Chester et al., 2019:220) and specific pathways for challenging behaviour or complex physical health needs (Royal College of Psychiatrists, 2020). As Chester et al. (2019) report, there is a distinctive lack of research into the outcomes of those with learning disabilities who have received support from the range of available CAMHS. Previous research has focused on inpatient CAMHS for children and adolescents with and without learning disability, where improved clinical outcomes for both groups have been observed (Chaplin et al, 2015).

Children and young people with a learning disability and/or autism and mental health needs can face barriers accessing suitable provision (Jacobs et al., 2015) – in terms of diagnostic assessment, post-diagnostic support and treatment of comorbid mental health conditions. A report by the Royal College of Psychiatrists (2016) outlines the barriers to mainstream mental health services faced by young people with a learning disability and/or autism. These include: exclusion from CAMHS and learning disability services; exclusion from other tier 2 services (such as school counselling services); difficulties accessing traditional CAMHS due to the presence of physical disability and/or severe challenging behaviour; a lack of awareness about neurodevelopmental disorders within health, social care and education; lack of partnership working between agencies (with respect to eligibility criteria, terminology and provision); and diagnostic overshadowing. Similarly, Autistica (2019) highlight that autistic children are routinely denied access to mental health support due to: diagnostic overshadowing; and CAMHS teams feeling ill-equipped or not being commissioned to support autistic children. Without access to an alternative service, autistic children often do not receive any professional mental health support. This highlights a service gap in mental health support for children and young people with a learning disability and/or autism – due to the inaccessibility of existing CAMHS and, for young people with autism (without a learning disability), the paucity of an alternative mental health service.

Upon accessing CAMHS, children and young people with a learning disability and/or autism often do not have their psychiatric and developmental needs recognised and addressed (Chester et al., 2019). In part, this could be due to a lack of specialist professional input, in terms of expertise and experience in supporting people with a learning disability and/or autism – alongside the lack of resources required to deliver comprehensive assessments and continued management that many patients require (Chester et al., 2019). This is supported by a review of research conducted by Jacobs et al. (2015), where lack of resources and expertise were identified by parents and staff as barriers to mental health services for children/young people with learning disabilities. Similarly, Autistica (2019) report that professionals in mental health services often lack experience and confidence in recognising the subtleties of autistic people’s mental health. This suggests that existing generic mental health services for people with learning disabilities and/or autism – in terms of adult services (as articulated above) and child and young people services (CAMHS) – are lacking in the specialist knowledge and expertise required for meeting the complex needs of this diverse population group.

Finally, researchers and clinicians have frequently highlighted the gap within the transition from child to adult services for young people with autism/neurodevelopmental disorders (Murphy et al., 2016) and learning disabilities – as these services often differ considerably in terms of configuration and the support available. More specifically, this gap characterises the transition from child to adult mental health services, which can be patchy and cause problems for all patients (Paul et al., 2015) – but can be particularly problematic for vulnerable populations, such as young people with a learning disability (Wright et al., 2017) or autism (Crane et al., 2019). A report by the Royal College of Psychiatrists (2016) has shown that the transition from child to adult mental health services runs alongside other difficult transitions – for instance, within education, social service support and changes to community care. Poor planning and lack of support can lead to rushed transition arrangements and, thereby, engender feelings of uncertainty and stress among both the individual transitioning and their families. In summary, within mental health services and beyond, there is no clear pathway that provides a well-planned and informed transition from child to adult services for people with autism (Murphy et al., 2016) and learning disabilities (Royal College of Psychiatrists, 2016). Given these issues, within the context of mental health peer support models, the Centre for Mental Health (Burke and Hodgson, 2020) recommends focusing on young people during transitional phases as the greatest area of need – due to the challenge they pose for the whole family. Therefore, it is essential that future service development plans incorporate support for young people (and their families) transitioning from child to adult services.

Forensic Services

Service provision for people with learning disability who have offended or display challenging behaviour varies across the UK, with respect to the client group and level of security (Chaplin and McCarthy, 2015). This client group can present challenges to the Criminal Justice System and Social Care Services who must assess the level of risk they pose (to themselves and wider society), whilst considering how best to meet their care needs (Perera and Courtenay, 2018). Typically, offenders with learning disability and mental disorders have been cared for in one of three forensic inpatient units, according to the level of security required: high, medium and low secure. These units encompass a multidisciplinary team and provide specialist support, such as adapted treatment programmes for people with learning disability. Historically, the provision of basic community forensic learning disability services has been underdeveloped across the UK (Chaplin and McCarthy, 2015). Within the context of the national plan (NHS England, 2015), Taylor et al. (2017a) highlight that there is little guidance regarding how to facilitate a safe and effective transition from hospital to community services for detained patients with a learning disability and offending histories. This problem prompted the development of a discharge pathway protocol for detained offenders with learning disabilities within a forensic rehabilitation unit (Alnwick Unit) for men in Northeast England – which has seen increased rates of discharge, reduced lengths of stay and lowered readmission rates (Taylor et al., 2017a). Overall, there is limited comprehensive research into the configuration of forensic services for people with learning disabilities across England and the wider UK. Following Morrissey et al's. (2017) systematic review and synthesis of outcome domains for use within forensic services for people with learning disabilities, it is hoped that research into the treatment outcomes of these services will continue to evolve.

The *Transforming Care* programme (NHS England, 2017:25) recognises that people with a learning disability and/or autism who have come into (or are at risk of) contact with the criminal justice system can often 'fall through the gaps' of current provision. This client group are often excluded from mainstream mental health or forensic services due to their leaning disability and/or autism – and from learning disability services as they are deemed 'too able or too high risk' or because they have autism only (NHS England, 2017:25). Considering these gaps in service provision, a framework for specialist community-based forensic support was developed, as part of a community-based health-care service (NHS England, 2017). Wark (2019) conducted a review of six academic papers and found that the need for specialist community-based forensic provision, which employs the least restrictive measures and positive crisis response, is a growing recommendation. These teams are expected to be delivered by (potentially a combination of): existing community mental health forensic teams, including staff with specialist knowledge in learning disability and/or autism; specialist community learning disability/autism teams, with staff who have specialist knowledge in forensic risk; and/or a specialist (tertiary level) forensic learning disability and/or autism service, focused on a sub-set of the population – namely, those with forensic needs which cannot be met by existing local mental health, forensic or learning disability/autism services (NHS England, 2017:35). By strengthening the provision of specialist, forensic community care on a local level, the longstanding problem of out-of-area placements, as identified by Chaplin and McCarthy (2015), may become less pervasive.

With respect to forensic support for young people, Chester et al. (2019) found that antisocial or violent behaviour was first observed in childhood or adolescence for most individuals within an inpatient forensic service for people with learning disabilities. In turn, the authors posit a role for early intervention services to reduce the risk of future offending behaviour and forensic involvement of people with learning disabilities. Around the time of this publication, the NHS (2019) released the ‘Mental Health Implementation Plan’ – which identifies a strategy to roll-out specialist community forensic care, available to children and young people with learning disabilities and/or autism, by 2024. This builds on an earlier note made in the *Transforming Care* programme (NHS England, 2017) – namely: that NHS England will be commissioning forensic CAMHS outreach services aimed at children and young people (under 18 years), which is inclusive of the learning disability and/or autism population. At present, only a small number of areas in England benefit from specialist community forensic CAMHS provision (FCAMHS). These services are inclusive of people with learning disabilities, autism and other forms of neurodiversity and run alongside core service provision for all young people (Hindley et al., 2017). While there is no detailed articulation of what this emerging service will look like, the commitment of NHS England to implement community FCAMHS on a national level is a significant development – and may help address future shortages in early intervention services for young people with a learning disability and/or autism and forensic needs.

Autism-specific Service Provision

Following the release of the Autism Act (2009), the development of health and social care services for people with autism has become a national priority – indicated by the government’s *Think Autism* (Department of Health, 2014) strategy and the plan to roll-out mandatory learning disability and autism training for all healthcare professionals by 2021 (Department of Health and Social Care, 2019; Glasper, 2019). The *Think Autism* strategy focused on the development of provision for the adult population – although, the government has advised that the strategy will soon be extended to children and young people with autism (Parkin et al, 2020). Despite the historical paucity of autism services for adults in the UK, community health and social resources for adults with autism continue to evolve (Murphy et al., 2016). Although, experiential accounts (from autistic adults and professionals working in autism diagnosis) suggest that a lack of appropriate support for adults diagnosed with autism remains (Crane et al., 2018) – a service gap that is echoed by Autistica (2019). In addition, despite the ambitions of the *Transforming Care* agenda, Marshall-Tate et al. (2017) highlight that there is evidence to suggest that the number of people with autism who do not have a learning disability in inpatient assessment and treatment units has increased. More widely, considerable variation in service provision for people with autism remains, in terms of geography and models of service delivery. This variation is characteristic of both diagnostic (Mukherjee et al., 2017) and post-diagnostic (Crane et al., 2018) services.

People with autism face many barriers trying to access diagnostic services, even in the very early stages of the process. Unigwe et al. (2017) collected survey data from 304 GPs in the UK and found that the participants reported modest confidence in their abilities to identify and support autistic patients. Analysis of qualitative survey data revealed that other factors influenced GPs confidence in supporting autistic patients, including: a paucity of services; long delays between referral and diagnosis and, particularly, a lack of clarity surrounding referral and care pathways. Moreover, upon receiving a diagnosis, research has suggested that current post-diagnostic support for people with autism is inadequate. Qualitative data gathered by Crane et al. (2018) indicates that autistic adults, parents of children with autism and professionals involved in autism diagnosis face a lack of appropriate post-diagnostic support: services are only offered at crisis point and, when support is offered, it can be withdrawn due to financial constraints. These experiential accounts also highlight a lack of family support, for example: to support with tensions relating to diagnosis, which was also deemed a barrier to provision by GPs (Unigwe et al., 2017). Currently, the National Autistic Society offers 12-week parental (psychoeducation) training courses (EarlyBird, EarlyBird Plus and Teen Life) delivered by local NHS services – to support the parents of children diagnosed with autism in the UK. Although, further implementation science research has been posited to determine the feasibility and scalability of these programmes (Dawson-Squibb et al., 2019). Finally, a lack of emotional support pre- and post-diagnosis was identified (Crane et al., 2018).

Furthermore, research has identified other demographic factors that should be considered with respect to service provision for people with autism – for instance, to account for the specific needs of females (Mukherjee et al., 2018). Females are often diagnosed with autism later than males and often engage in ‘camouflaging’ behaviours (Hull et al., 2017; Leedham et al., 2020). Currently, services may not adequately recognise or meet the needs of females with autism – particularly their mental health needs considering, for example, the prevalence of eating disorders within this population group (Autistica, 2019). In a small-scale study, Tromans et al. (2019) found that healthcare professionals recommended additional training in recognising, screening and diagnosing autism in female patients specifically. This suggests that improving the knowledge and confidence of the staff within mainstream mental health settings may be a key part of improving the quality of care for females with autism. Therefore, given this existing gap in provision, future service developments should consider how best to identify and meet the needs of females with autism, particularly their mental health needs.

Speculatively, considering these findings in view of the deficit of specialist key skills (Perera and Courtenay, 2018) and perceived unmet training needs (in the knowledge, skills and attitudes for supporting people with learning disability) indicated by staff within mainstream healthcare settings (Hemm et al., 2015), the evidence points to a wider issue regarding a lack of self-efficacy or confidence among the workforce in identifying and meeting the needs of people with a learning disability and/or autism, particularly in terms of mental health. As detailed above, this perceived lack of knowledge and confidence among the mainstream mental health workforce may be particularly pervasive with respect to identifying autism within women (Tromans et al., 2019). Consequently, as part of future service developments (such as the strengthening of pre- and post-diagnostic support for people with autism), it is important to consider how this deficit of specialist knowledge and confidence among the mental health workforce will be addressed.

Annual Health Checks

The Learning Disabilities Health Check Scheme was introduced to encourage practices to identify individuals aged 14 and over with learning disabilities and/or autism and offer them an annual health check. This aligns with a priority target of the NHS Long Term Plan (NHS England, 2019), that is: to increase annual health check compliance for people with learning disabilities and autism – in order to tackle the causes of morbidity and premature deaths among this population group. In partnership with National Institute for Health Research (NIHR), Cantrell et al. (2020) conducted a comprehensive mapping and targeted systematic review into the factors influencing access to primary and community healthcare services for people with learning disabilities. They found that health checks were beneficial in supporting the identification of health needs and to improve the care of long-term conditions for people with learning disabilities. Despite this, research has reported low attendance to, and variable provision of, health checks for people with learning disabilities (Chapman et al., 2018) – consistent with national data indicating that only 55.1% of patients with a learning disability received a health check in 2017-2018 (NHS Digital, 2019). Given the potential benefits that quality health checks can have for people learning disabilities, the shortage in their uptake seems to be a missed opportunity.

Research into initiatives to improve the uptake and delivery of health checks has been limited but seems to be increasing gradually. MacDonald et al. (2018) report qualitative feedback from fifteen practice nurses in GP settings who recommended that mandatory training should be available to practice nurses involved in the completion of health checks. While this research lacks generalisability, it is still important to consider how practice nurses, who are not specialists in learning disability and/or autism, are trained to undertake health checks for this client group in a way that aligns with good practice. Alternatively, other research has reported on initiatives that utilise the specialist knowledge of learning disability nurses to support access to quality health checks. For instance, George et al. (2019) describe the development of the ‘strategic health facilitator (SHF)’ role within Southern Health NHS Foundation Trust (from the geographic context of Hampshire), occupied by a learning disability nurse. Among many other features, part of the remit of the SHF role is to enhance the uptake of health checks – by working in partnership with primary care services and GP practices. Therefore, consideration should be given to whether further workforce training or liaison roles are required to improve access to health checks for people with learning disabilities and/or autism – in order to meet the objectives of the Long Term Plan (NHS England, 2019).

Summary

Considering the above literature, it appears that a series of shortages or gaps characterise current learning disability and autism services.

Firstly, the gaps/shortages with respect to **Community Learning Disability Teams** (CLDTs) can be grouped into two main areas:

- The lack of appropriate, specialist care in the local community for people with learning disabilities and/or autism – which can lead to delays in discharge from inpatient services or patients (e.g. with forensic or other complex needs) being released into the community without the right support in place.
- In cases where CLDTs work in conjunction with stand-alone ISTs, a lack of knowledge or confidence in managing challenging behaviour among CLDT staff can lead to increased referrals to ISTs and, thereby, deskill CLDT staff.

With respect to **Intensive Support Teams (ISTs)**, three mains gaps/shortages in intensive support for people with learning disabilities and/or autism were identified – in terms of:

- The provision of 24/7 crisis (including weekend) support for adults with a learning disability – including the operation of daily intensive support helplines.
- Crisis support for children and young people with learning disabilities.
- Crisis support for people with neurodiversity (for example: autism).

Moreover, the gaps in existing **Mental Health Services** for people with learning disabilities and/or autism can be grouped into four main areas:

- The appropriateness of generic mental health services for people with a learning disability and/or autism: the deficit of specialist skills and expertise within local adult and children/young people mental health services.
- Barriers to accessing mental health services for adults and children/young people with a learning disability and/or autism – for example: stringent eligibility criteria and diagnostic overshadowing.
- Service gaps within the transition between child and adult services, including mental health services.
- The service provision gap between learning disability services and mental health services faced by people with autism (particularly those without a learning disability), which acts as a barrier to mental health support.

With respect to **Forensic Services** for people with learning disabilities and/or autism and forensic needs, three main gaps/shortages in existing provision are identified:

- A historical paucity of forensic support (particularly in the community) for people with learning disabilities across England.

- The lack of early intervention services for young people with learning disabilities and/or autism and forensic needs – although, NHS England (2017) has committed to the national implementation of community forensic CAMHS.
- The absence of a discharge planning protocol in some services to facilitate the transition of offenders with a learning disability from inpatient to community services.

In respect of **Autism-specific services**, four main gaps/shortages in current provision were articulated:

- Barriers accessing autism diagnostic and assessment services.
- The lack of appropriate post-diagnostic support (for adults, in particular) – for example: emotional and family support.
- The lack of specialist skills, expertise and/or confidence among GPs (non-specialists) in identifying and managing people with autism.
- The paucity of support specifically for autistic females.

Finally, the literature identified a key shortage in the uptake of **annual health checks** among people with learning disabilities and/or autism – despite objectives of the Long Term Plan to improve health check compliance for this client group (NHS England, 2019).

Current project scope

Within the context of the above literature review this project aimed to undertake a review of the new role requirements for the National Learning Disabilities and Autism Workforce. The focus of the review was specifically on three segments of the National Learning Disability and Autism workforce as set out below:

1. **Adult Enhanced Community Services.** The workforce that are responsible for the provision of adult community services to people with learning disabilities and/or autism who are in need of enhanced support at the point of crisis or to avert an imminent crisis.
2. **CYP Enhanced Community Services.** The Children's and Young People's specialist Learning Disability community workforce who will deliver enhanced support at the point of crisis or to avert an imminent crisis.
3. **Autism Specific service provision.** The workforce that is involved in a range of autism support from diagnosis through to residential/inpatient care for children and young people and adults.

The aim of this project was to identify service and skills gaps and potential challenges in supply that may require the development of national solutions such as adoption of new and emerging roles to enhance the learning disability and/or autism service provision.

Workshop Methodology

Workshops

Workshops formed the primary information-gathering method: a flyer was disseminated to service managers across England, inviting them to contribute to the project by attending a workshop. Eight workshops were held across what were demarcated the four regions of England, with two taking place in each area – namely, in the North (Leeds), Midlands (Birmingham), South East (London) and West (Bristol).

Secondly, a survey was disseminated to service managers to collect information about their *current service* details (Section A) and design and delivery (Section B). Service staff who were unable to attend a workshop were directed to a further section in the survey (Section C), requesting information and suggestions about the *future design* of their service – in order to meet the objectives of the NHS Long Term Plan. The survey included both quantitative and qualitative questions to gather information about the services relevant to this review. Despite several attempts to promote the survey, the response rate remained considerably low. Moreover, the information that was acquired from the survey did not add to the rich information garnered from the workshops with service staff. Therefore, for the purposes of this report, the results from the survey have not been included.

Workshop Participants

A total of 54 service staff (working within or in conjunction with learning disability and autism services) were present at the workshops (Birmingham: 5; Leeds: 19; London: 13; Bristol: 17), representing a wide range of professional backgrounds (as summarised in the table below).

Table 1. Summary of the Professional Backgrounds/Roles of Workshop Attendees

Profession/Role of Attendee	**Number of Attendees**
Consultant Psychiatrist (adult)	3
Consultant Child Psychiatrist	2
Consultant Clinical Psychologist	2
Speech and Language Therapist	3
Occupational Therapist	1
Learning Disability Nurses and Nurse Consultant	10
Service Managers and Deputy Manager	15
Operational Manager	3
Commissioning and Workforce Manager	5
Medical Specialists and Junior Doctors	2
Workforce Transformation Programme Manager	2
Behaviour Analysts and Mental Health Practitioners	6
Total	**54**

Workshop Headlines: New Roles/Ways of Working

A wide range of suggestions emerged from the workshops with service staff; the new roles/ways of working presented below represent a considered synthesis of these suggestions. These new roles/ways of working were informed by a series of service gaps, as identified by the workshop attendees – and have been grouped into key areas of need, as summarised in the table below.

Table 2. Summary of New Roles/Ways of Working according to Area of Need

Area of Need	New Role/Way of Working
Wellbeing, Mental Health and Community Involvement	• Life Skills Development Coaches • Acute CAMHS Learning Disability and Autism Liaison Role • Specialist Learning Disability and/or Autism CAMHS
Physical Healthcare Support Roles	• Learning Disability and Autism Primary Care/GP Champion • Physician Associates • Non-medical Responsible Clinician
Transitional Roles	• Child-Adult Services Link • Education Transition Support Worker • Community Outreach Link • Complex Discharge Care Coordinator
Education-based Roles	• Education Wellbeing Officer
Family Support	• Family Link/Key Workers
Early Intervention Forensic Support	• FOLS for young people with a learning disability and/or autism • Learning Disability and Autism Forensic Liaison/Support Role
Autism-specific Service Provision	• Intensive Support Team for people with autism • Specialist Inpatient Service for young females with autism
Shortages in Workforce Skills	• Specialist Skills Filtration Model: Assistant Practitioner Roles • Staff Behavioural Skills Coaches

Wellbeing, Mental Health and Community Involvement

Several new roles and ways of working were posited to facilitate access to appropriate mental health and wellbeing support, alongside the acquisition of life skills to enable people with learning disabilities and/or autism to live meaningful lives in the community.

➢ Life Skills Development Coaches

Across all workshops, service staff repeatedly highlighted the lack of provision for the acquisition of life skills among people with learning disabilities and/or autism, for instance: to support community living, emotional wellbeing and employability. This posited new role incorporates three arms of support for: emotional wellbeing and quality of life (using psychoeducation and low-level psychotherapeutic skills); employment support (scoping workplace opportunities with local employers); and community building and social activity coordination (for example: facilitating community-based befriending and social support sessions). The role was suggested as being an enhanced and strengthened reformulation of the existing ‘Support Worker’ role. The branches of support identified are elucidated below:

(a) **Emotional wellbeing and quality of life** –
This branch centres around improving the mental health, emotional wellbeing and quality of life of people with learning disabilities and/or autism within the community. With training in psychoeducation and/or low-level psychotherapeutic skills, such as mindfulness, cognitive-behavioural or dialectical-behavioural therapeutic skills, the posited role can support people with learning disabilities and/or autism to understand their feelings and to develop effective strategies to improve their wellbeing. Some workshop attendees suggested that the role could be organised around the development of each quality of life domain – which could support the tracking of measured outcomes to identify positive changes experienced by the service user and their family. For a model quality of life framework for people with learning disability (developed by Schalock et al., 2005), please see Appendix B.

In addition, the role was envisioned to facilitate group peer support sessions (with ‘experts by experience’) in the community – for example, to deliver bereavement support for those coming to terms with significant loss, which service staff identified as a key area of need. This element of peer support for emotional wellbeing concurs with the recommendations from the **Centre for Mental Health** (Burke and Hodgson, 2020) – with respect to the development of a national mental health peer support network for people from Learning Disability and Neuro Diverse communities. The alignment of the posited role with this project will be further articulated below.

(b) **Employment support** –
This branch aims to support access to employment and the scoping of workplace opportunities for people with learning disabilities and/or autism. Workshop attendees reported that many of their service users desire and are capable of employment, but highlight that workplaces are not always well-adapted or flexible in facilitating the employment of people with learning disabilities and/or autism. Therefore, by working collaboratively with local employers and, potentially, the Job Centre, the posited role supports the development of learning disability- and autism-friendly workplaces.

Examples of the work the role may undertake includes: facilitating reasonable adjustments throughout the recruitment process (e.g. video CVs and providing interview questions beforehand); and flexible job-carving, whereby instead of fitting a person into a rigid pre-existing job description, jobs can be ‘carved’ for people according to the different tasks they can do. This would require the role occupier to work closely with the client to identify their key skills and contribute to their preparation for employment. In addition, it was suggested that experts by experience or peer support workers should be involved in liaising with potential employers and preparing the workplace for people with a learning disability and/or autism.

Moreover, the ‘Life Skills Development Coach’ adopts an advisory role by guiding people with learning disability and/or autism towards training pathways that can lead to paid employment – for example: via the emerging ‘T-levels’ qualification programme, which the government will be gradually rolling-out from September 2020.

A key consideration will be how this branch of support will align with existing provision. For example, as part of the government initiative to increase the number of people with disabilities in employment (Department for Work Pensions and Department of Health and Social Care, 2017), the ‘Disability Employment Adviser Leader’ role was introduced from April 2019 – which works across the Jobcentre Network. Consideration should be given to the part this role plays (now and in the future) in supporting people with learning disability and/or autism in finding suitable employment.

(c) **Community building and social activity coordination** –
The final branch centres around building a welcoming and accessible community that allows people with a learning disability and/or autism to live socially valued and meaningful lives. Workshop attendees highlighted that, despite the national pledge to transition to community-based (rather than inpatient) care, there is a paucity of support for enabling people with a learning disability and/or autism to engage in community life. Resultantly, the posited role supports people with learning disabilities and/or autism to develop the life skills required to engage in the core parts of community life. For instance: social skills for making friends and meeting up in the community, facilitated via a befriending or peer support service; and skills for independent living to enable access to the community, such as how to navigate public transport. As briefly mentioned above, this aligns with the findings from the **Centre for Mental Health** (Burke and Hodgson, 2020) regarding the recommendation for a network of peer support workers – which will be further articulated below.

Concomitantly, it was envisioned that the role would contribute to building a community that is prepared for and welcoming of people with learning disabilities and/or autism. This would involve raising awareness and building networks with local groups and services in the community – to provide safe places and opportunities for people with learning disabilities and/or autism to actively engage and contribute to community life. For example: developing accessible cafes and community centres.

Alignment with Existing Research

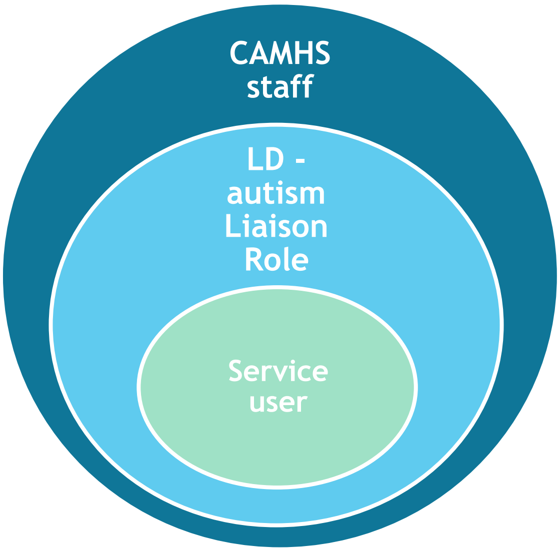
The branches of support posited within this role are consistent with Davies and Matuska’s (2018) findings regarding the key skills and competencies required by the workforce, from the perspective of individuals with a learning disability. In their study, a significant proportion of service users reported a need for what could be broadly understood as support for acquiring life skills, to engage in social activities and independent living. For example: 12-14-year olds reported a need for support to use public transport, manage money, finding the right home and employment. Across several age groups, support for keeping in touch with friends and family, accessing leisure activities, learning to use technology, and being part of the local community were deemed as key skills required by workforce staff. It is these elements of support that constitute the posited ‘Life Skills Development Coach’ role.

Considering the lack of emotional support pre- and post-diagnosis for people with autism (Crane et al., 2018), the ‘Life Skills Development Coach’ role operates an ‘emotional wellbeing and quality of life’ mode of support for people with autism and/or a learning disability. At present, people with learning disabilities and/or autism face barriers accessing even low-level mental health support (Royal College of Psychiatry, 2016; Chinn and Abraham’s, 2016). The mental health/emotional wellbeing support provided by the posited role must be accessible to service users in order to circumvent existing barriers to provision.

Moreover, it is posited that the ‘emotional wellbeing/quality of life’ and ‘community building and social activity coordination’ branches of this role align with the **Centre for Mental Health’s** (Burke and Hodgson, 2020) project into mental health peer support models for people within Learning Disability and Neuro Diverse communities. They recommend the development of a national (mental health) peer support network for the population concerned, which is deemed to require a ‘facilitator’. The posited role (‘Life Skills Development Coach’) has the potential to fulfil this facilitative capacity within a national network, by: contributing to the training/supervision of peer support workers; acting as a moderator for an online platform (acting as a ‘safeguarding lead’); and developing/running group community support sessions, which are guided by those seeking support.

➢ Acute CAMHS Learning Disability and Autism Liaison Role

A recurrent issue raised by service staff was that the mental health needs of people with learning disability and/or autism are often not met within generic Children and Adolescent Mental Health Services (CAMHS) due to: other high-risk populations taking priority (e.g. children with severe eating disorders or those who display suicidal behaviour); and mental health staff lacking specialist knowledge in identifying and supporting the mental health needs of children and young people with a learning disability and/or autism.



Consequently, workshop attendees posited the Acute Learning Disability and Autism Liaison role – situated within generic CAMHS and occupied by a band 5, registered professional with specialist training (for instance, a learning disability nurse). The purpose of the role is to ensure that the needs of individuals with a learning disability and/or autism have their mental health needs recognised, prioritised and addressed. The role can also contribute to the training of fellow CAMHS staff (to increase their knowledge and confidence) in managing the complex mental and physical health needs presented by this diverse population group.

Alignment with Existing Research

Research has indicated that children/young people with a learning disability and/or autism and mental health needs face barriers accessing support from CAMHS (for instance, Jacobs et al., 2015; Royal College of Psychiatrists, 2016). Moreover, Chester et al. (2019) report that this client group often do not have their psychiatric and developmental needs recognised and addressed by CAMHS. In part, this may be due to the lack of experience and confidence among the workforce in recognising the subtleties in mental health needs among people with autism (Autistica, 2019). By providing a layer of specialised support, the posited role ('Learning Disability and Autism Liaison') could facilitate the identification of mental health needs (for entry to CAMHS) and the management of the complex needs presented by people with learning disability and/or autism.

➢ Specialist CAMHS for people with a learning disability and/or autism

Further to the above challenges regarding generic CAMHS, workshop attendees identified stringent eligibility criteria as a barrier to access – which often excludes people with learning disabilities and/or autism (particularly those with mild presentations) from accessing the service. Subsequently, a specialist CAMHS learning disability/autism service, independent of generic CAMHS, was posited – to, firstly, circumvent conflict with other client groups for admission; and, secondly, to ensure the workforce is equipped with the specialist skills required to support the mental health needs of children/young people with learning disability and autism.

Alignment with Existing Research

The development of a specialist CAMHS for people with learning disability and/or autism is an alternative way of working that may help address the problem of unmet mental health needs among the client group within existing generic CAMHS (Chester et al., 2019).

Physical Healthcare Support Roles

A series of modifications to existing roles were posited, in order to meet the physical healthcare needs of people with a learning disability and/or autism – which are outlined below.

➢ Learning Disability and Autism Champion within primary care/GP settings

The deficit in the uptake of annual health checks for people with learning disabilities and/or autism was identified as a significant problem in all workshops. The 'Learning Disability and Autism Champion' role dedicated to supporting access to quality health checks, situated within (or which liaises closely with) primary care and GP settings, was proposed – to meet the objectives of the Long Term Plan (NHS England, 2019). In terms of implementation, the role could constitute an extension to an existing role (for example: a nominated practice nurse receives specialist training) or occupied by a learning disability nurse, who conducts liaison/outreach work with general practice. In addition, increasing awareness about identifying and supporting people with a learning disability and/or autism among GP/primary care service staff was considered by service staff to be a key part of the role.

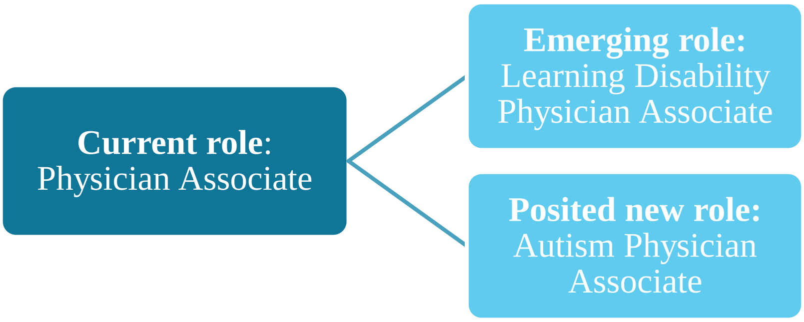
This was a current emerging role identified by workshop attendees within some services/Trusts and, given the perceived positive outcomes it had shown for improving access to annual health checks, it was suggested that the role should be scaled-up across England.

Alignment with Existing Research

Surveys completed by GPs has suggested that a significant proportion report a lack of confidence in supporting and managing autistic patients (Unigwe et al., 2017). A ‘Learning Disability and Autism Champion’ role may be beneficial in supporting GPs, and other service staff, identifying and managing the needs of people with autism during the completion of an annual health check. The posited (emerging) role appears to share similarities with the existing ‘Strategic Health Facilitator’ role, which is typically occupied by a learning disability nurse and currently operates within some localities in England (George et al., 2019).

➢ Physician Associates

Currently, this unregulated role, which is endorsed by the Royal College of Physicians and the Royal College of Psychiatrists, has been implemented in primary care and, more recently, mental health settings. Based on the model of medical training in the Netherlands (where medics can train in the medical specialism of ‘intellectual disability’), a specific ‘Learning Disability Physician Associate’ role or training route has been identified as a potentially beneficial emerging role – to assist with the management of complex physical healthcare needs displayed by people with a learning disability. Further consideration for how this emerging role can be extended to other neuro-diverse conditions, such as autism, is required – for example: whether a new integrated learning disability and autism route is viable, or whether a separate training route specifically for managing the health needs of autistic people is required.



Disclaimer: The Expert Referencre Group advised that the Physician Associate role does not entail medical input or prescribing capacities – and, therefore, cannot contribute to the management of complex and interacting physical health needs displayed by people with learning disability and/or autism. See the 'Expert Reference Group Recommendations' section, where the '**Learning Disability Physician**' (consultant) role is posited as an alternative.

➢ Non-medical Approved Responsible Clinicians

A recommendation that emerged from some of the workshops regards the expansion of the Non-Medical Responsible Clinician role, which allows senior registered learning disability/mental health professionals (e.g. psychologists, occupational therapists and nurses) to occupy a position of leadership whilst continuing to provide clinical input and develop care pathways. Some service staff suggested that current pathways for career development see a reduction in the amount of clinical input provided by senior staff, despite their extensive clinical experience and specialist skills. Therefore, this role was identified as a way of addressing the national shortages in specialist skills (in learning disability and autism) and psychiatrists.

Transitional Roles

Several transitional 'link worker' roles were posited to address long-standing gaps between services and prevent breakdowns in care pathways – which can cause distress for service users and their families. Guided by the suggestions of service staff, four transitional roles are posited below. Although, consideration can be given to a potential synthesis of these roles into a single 'transitional-link' worker role, where there is area of overlap – in order to support service users and their families at various transitional phases.

➢ Child-adult Services Link

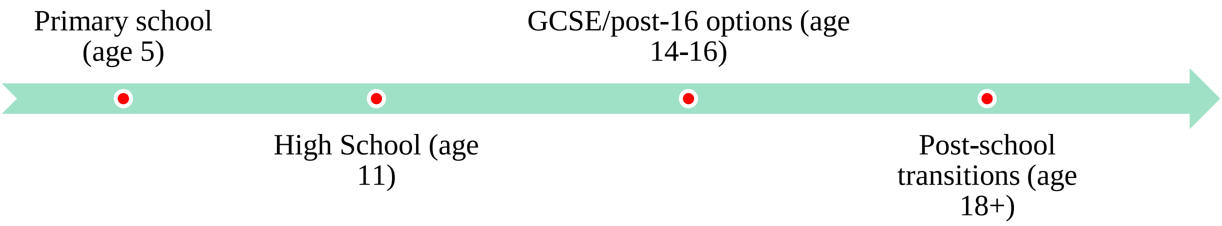
It was recognised that, currently, the transition from child to adult services can be largely unplanned, involving last-minute transition arrangements (which can be disruptive to the service user and their family). The transition also sees the sudden withdrawal of important parts of a client's care package (such as speech and language therapy provision) once they reach the age 18 – which can, therefore, give rise to feelings of distress among service users and their families and lead to unmet needs. Moreover, this transition occurs alongside other difficult transitions (for example, leaving school and changes to the service user's social care support package). Considering this, an emerging consensus was the need for a 'link worker' role to support the service user and their family throughout the transition from child to adult services, as a critical transitional phase. The role can facilitate a fluid transition between child to adult services by beginning transition planning and preparation with the service user and their family at around the age of 14 or 15, continuing to provide support into their 20s.

Alignment with Existing Research

The gap within the transition from child to adult services for young people with autism and/or a learning disability is well-documented (Murphy et al., 2016; Wright et al., 2017; Crane et al., 2019). Moreover, the posited role aligns with the **Centre for Mental Health** (Burke and Hodgson, 2020) which, in the context of peer support models, recommends focusing on young people (from learning disability or neuro-diverse communities) during transitional phases as a key area of need – due to the frustration and crises faced by the whole family. They highlight that when thinking about Learning Disability and Neuro Diverse communities, it is also important to consider the mental health needs of parents and carers. The posited ‘child-adult services link’ would work holistically with the service user and their family to support them during this challenging transitional phase.

Education Transition Support Worker

This posited role focuses on supporting young people during key transitional phases at school and within the education system – for instance: entry into primary school, progression to high school and GCSE years, alongside post-16/school options. These periods of transition can be challenging for young people with a learning disability and/or autism.



Consideration should be given to the similarities between this transition planning role and the ‘Education Wellbeing Officer’ role presented below (see the **‘Education-based Roles**’ sub-section) – and whether it is possible to operationalise a wellbeing-orientated, transitional worker role for young people with learning disabilities and autism in schools.

Community Outreach Link

The shortage of support for the transition from inpatient to community services was widely reported. Recurrently, a ‘Community Outreach Link’ role, that follows the service user through the transition out of inpatient care into the community, was suggested. Through integration planning, the role aims to ensure that a suitable package of community care and support is in place for the individual – for example: by liaising with the housing sector (to ensure suitable housing, such as bungalows) and social services.

Complex Discharge Care Coordinator

Considering the issues detailed above, with respect to discharging patients from inpatient to community services, workshop attendees suggested wide-scale implementation of the ‘Complex Discharge Care Coordinator’ role – an already emerging role within some services/Trusts. This suggestion is informed by the specific challenges faced by inpatient teams trying to discharge patients with the most complex needs.

Alignment with Existing Research

The above two roles, namely: the ‘**Community Outreach Link**’ and the ‘**Complex Discharge Care Coordinator**’, align with existing research that calls for the development of a well-resourced community service for people with learning disabilities and/or autism (Barnoux, 2019; Washington et al., 2019; Chester et al., 2019). Psychiatrists and other Responsible Clinicians have suggested that service users have been discharged from inpatient care into the community without adequate support in place – particularly clients with forensic (Taylor et al., 2017b) and other complex needs (Patterson, 2019). Therefore, a ‘Community Outreach Link’ role could support the development of suitable community care packages (including suitable housing) for service users transitioning out of inpatient care. Similarly, the ‘Complex Discharge Care Coordinator’ can ensure that specialist community support is in place for clients with the most complex needs prior to discharge from inpatient care.

Education-based Roles

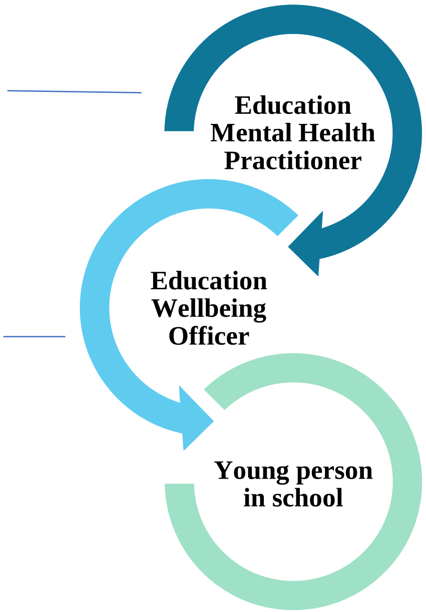
Further to the ‘Education Transition Support Worker’ role (detailed above), workshop attendees highlighted the need for early intervention support for mental and emotional wellbeing for children and young people with a learning disability and/or autism within school settings. As mentioned above, consideration should be given to a possible synthesis of these roles.

➢ Education Wellbeing Officer

As part of an early intervention model, this posited role supports the mental and emotional wellbeing of children and young people with a learning disability and/or autism at critical developmental periods. The role provides a continuum of (low level health and psychological wellbeing) support; facilitate reasonable adjustments; and contribute to teacher training and raising awareness about learning disability and neurodiversity. The outcome of this provision would be to enable young people to acquire skills in identifying and managing their feelings and emotions at an early age – as part of a preventative model of mental health support. As the diagram below suggests, the posited new role could refer onto the existing ‘Education Mental Health Practitioner’ role for specialist interventions – who provides supervisory oversight.

Existing emerging role:
Supervisory oversight and provides specialist interventions

Posited new role:
Refers onto the Education Mental Health Practitioner for specialist support



Family Support

➢ Family Link/Key Worker

The ‘Family Link/Key Worker’ role was posited to work therapeutically with children and families across community and inpatient services, as part of a CAMHS or social care outreach service. The role supports families facing emotional challenges and enables the acquisition of key skills among family carers – for example: by hosting community-based workshops for parents/family carers in the key skills of positive risk-taking, managing challenging behaviour and sleep patterns. This would support the development of family carers' knowledge and confidence in supporting the complex needs of a child/young person with a learning disability and/or autism. Moreover, a further strand of the role is to facilitate the involvement of family carers in the development and implementation of care plans for the service user within inpatient care – for example: by enabling family storytelling, whereby the workforce listens to the family's history and experiences in order to enhance their understanding of the service user and their surrounding network of support.

Alignment with Existing Research

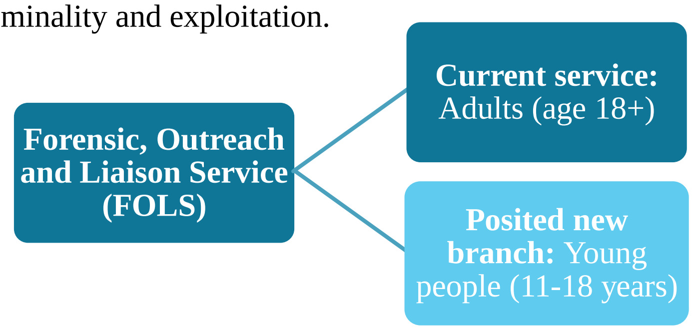
The recommendation for increased family support is consistent with experiential accounts from parent carers and staff (within an autism-diagnostic service), where a paucity of post-diagnostic support for families in understanding an autism diagnosis and its associated tensions was reported (Crane et al., 2018). Furthermore, within the context of peer support models, the **Centre for Mental Health** (Burke and Hodgson, 2020) highlight that it is vital that the mental health needs of parents and family carers are considered – in light of their common experiences of isolation and depression, for example, from concerns over their parenting ability and criticism. They found that parents stressed the positive impact of peer support on their emotional wellbeing and knowledge, particularly at the point of diagnosis. This suggests that extending a national (mental health) peer support network to family carers (as well as people with a learning disability and/or autism, as outlined within the '**Life Skills Development Coach'** role sub-section of this report) may be beneficial. Consideration should be given to the development of a single 'Key Worker/Life Skills Development Coach' role for service users and family carers – to meet these areas of need and facilitate a national network of peer support workers.

Early Intervention Forensic Support

Across the workshops, service staff identified a lack of early intervention forensic support for young people with a learning disability and/or autism – despite their increased vulnerability to forensic involvement and exploitation (for example: sexual abuse, drug use and digital crime).

➢ Forensic, Outreach and Liaison Service (FOLS) for young people

Considering that some localities benefit from adult FOLS, workshop attendees posited the development of a young persons (11-18 years) multi-professional FOLS, inclusive of people with learning disability and/or autism, as a new way of working. This is due to the vulnerability of this client group to criminality and exploitation.



➢ Learning Disability and Autism Forensic Liaison/Support Role

Service staff posited an unregulated 'Learning Disability and Autistic Forensic Liaison' role, which receives specialist forensic training in: the language of digital technology (for example: the "dark web"), risk assessment and identifying signs of abuse. The proposed role liaises with inpatient/community services and the criminal just system/police force, to identify and manage the forensic needs of young people with a learning disability and/or autism. The situation of the role is adaptable: it could be integrated within a newly established FOLS for young people (as outlined above) or within the emerging community forensic Child and Young People's Mental Health Service (FCAMHS), which NHS England (2017) has pledged to implement nationally (Hindley et al., 2017). Alternatively, the role could function as an outreach role independent of forensic services, for instance: based within social care services.

Alignment with Existing Research

The need for early intervention, preventative forensic support for young people with a learning disability is consistent with recommendations within a study conducted by Chester et al. (2019) – where antisocial or violent behaviour was first observed in childhood or adolescence for most individuals within an inpatient learning disability forensic service. In addition, the community-orientated nature of the posited new forensic support role/way of working could help address shortages in community forensic support for people with learning disabilities and/or autism, as highlighted by Chaplin and McCarthy (2015) and Wark (2019).

Autism Service Provision: New Ways of Working

Across all workshops, the shortage of provision for people with autism (*without* a learning disability) was widely reported – due to the inaccessibility of existing services for autistic people (including learning disability and mental health services), alongside an overall lack of appropriate provision specifically for this population group. Therefore, two new ways of working – specific to people with autism – were posited.

➢ Intensive Support Team for people with autism

A considerable proportion of service staff reported a paucity of available intensive support for autistic people reaching crisis point – due to the stringent eligibility criteria of existing ISTs, which often exclude people with autism who do not have a learning disability. Therefore, workshop attendees posited an autism-specific IST, inclusive of all age demographics, to facilitate the assessment and treatment of autistic people reaching crisis. This service could be situated within: existing learning disability ISTs; crisis teams that are equipped with autism intensive support training; or generic CAMHS, via an autism crisis team.

Alignment with Existing Research

Evidence from existing research implies that there is a deficit in intensive support provision for people with neurodiversity (for example, autism): it has been reported that only 62.1% of ISTs (for adults with learning disability) with enhanced models and 51.1% of ISTs with independent models accept clients with a neurodevelopmental disorder (Hassiotis et al., 2020). Therefore, it is important to consider how services can be developed or adapted (for instance, via an autism-only IST) to ensure that intensive support is available for people with 'high-functioning' autism who are experiencing a crisis.

➢ Specialist inpatient service for young females with autism

Some workshop attendees highlight a need for provision specifically for young females with autism. As part of a preventative model, this post-diagnostic inpatient service for young females with autism would offer specialised support to manage the complex needs of this client group – which often differ considerably from males.

Alignment with Existing Research

Research has suggested that females with autism can display complex behaviours and needs that differ from men, for example: autistic females often engage in 'camouflaging' behaviours (Hull et al., 2017; Leedham et al., 2020). Moreover, given the prevalence of eating disorders among females with autism (Autistica, 2019), it is important that future service developments consider how to recognise and meet the needs of females with autism. Therefore, the development of a specialist inpatient service for young females with autism may contribute to meeting the needs of this client group.

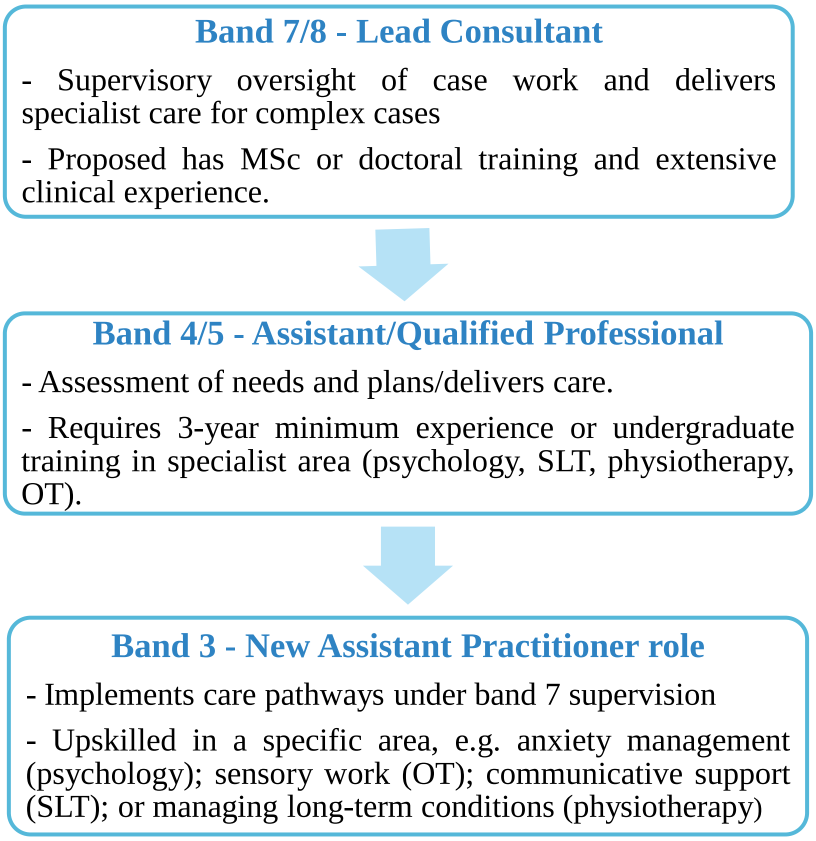
Roles to Address Shortages in Workforce Skills

A recurrent problem identified concerned how to address current shortages in the workforce skills required to deliver high-quality care for people with a learning disability and/or autism. Two ways of bridging this gap in provision were posited, which are articulated below.

➢ Specialist Skills Filtration Model: New Assistant Practitioner Roles

Across all workshops, service staff alluded to a basic framework in which specialist workforce skills are filtered down to a new band 3 role (an 'Assistant Practitioner') that is upskilled and implements care pathways under the supervision of an experienced Lead Consultant (band 7/8). The role occupier is upskilled in a key area of need (e.g. occupational therapy, speech and language therapy, physiotherapy or psychology skills) and provides interim support during the wait for specialist interventions, delivered by a higher-band role. This represents a quick way of addressing shortages in key workforce skills through the provision of interim support in a key area of need. The figure below depicts this 'Specialist Skills Filtration Model', including the posited new 'Assistant Practitioner' role:

Figure 1. Specialist Skills Filtration Model, including a New Assistant Practitioner Role



Band 7/8 - Lead Consultant

- Supervisory oversight of case work and delivers specialist care for complex cases
- Proposed has MSc or doctoral training and extensive clinical experience.

Band 4/5 - Assistant/Qualified Professional

- Assessment of needs and plans/delivers care.
- Requires 3-year minimum experience or undergraduate training in specialist area (psychology, SLT, physiotherapy, OT).

Band 3 - New Assistant Practitioner role

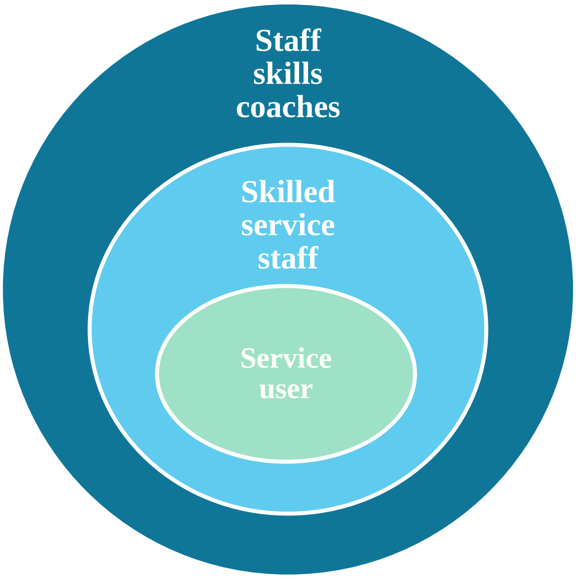
- Implements care pathways under band 7 supervision
- Upskilled in a specific area, e.g. anxiety management (psychology); sensory work (OT); communicative support (SLT); or managing long-term conditions (physiotherapy)

Alignment with Existing Research

Researchers have highlighted the shortage in specialist workforce skills required to meet the needs of people with a learning disability and/or autism. Within mainstream services, healthcare staff have reported perceived unmet training needs in the knowledge, skills and attitudes needed to support this client group (Hemm et al., 2015). Similarly, within the context of mental health services, Perera and Courtenay (2018) identify challenges with workforce recruitment, in terms of appointments to specialist clinical positions, and training in key skills (particularly for community support workers), which can amount to shortages in key skills. The posited new role/way of working provides a model for helping to bridge the deficit in workforce skills – through the recruitment of ‘Assistant Practitioners’ who are upskilled in a key area of need and provide interim support during the wait for specialist interventions.

➢ Staff Behavioural Skills Coaches

Some service staff posited a role to support the acquisition of behavioural skills among the learning disability and autism workforce to enhance their wellbeing and delivery of skilled care. The role could facilitate the training of staff in positive psychological/therapeutic techniques, communication and teaching skills – in order to improve staff wellbeing and prevent staff burnout and, thereby, contributing to improved workforce retention.



Alignment with Existing Research

Guided by the perspectives of people with learning disabilities, Davies and Matuska (2018) highlight the importance of the workforce in being able to teach various new skills to people with learning disabilities – a competency that staff may not routinely have or receive training in. The development of 'Staff Behavioural Skills Coaches' could address this shortage in provision and ensure that the workforce is equipped with key teaching skills.

Expert Reference Group Recommendations

The findings outlined in the previous section were disseminated and presented at a multi-professional Expert Reference Group (ERG) meeting on Thursday 4th June 2020. The outcome of this phase has resulted in a review of the process and focus of Phase 2. Accordingly, based upon feedback from the ERG, the following strands of inquiry/action points were agreed and will be taken into Phase 2 (1st July 2020 – 31st March 2021):

(a) **Determine the areas of, and gaps in meeting, (service and service user) need –** in order to develop a comprehensive evidence base for the development of proposals for modifications to existing roles or the introduction of new roles. The literature review and workshop findings, as articulated in this report (Phase 1), provide a preliminary understanding of (service and service user) needs within Learning Disability and Autism Services. Moving forward, it was agreed that Phase 2 will involve a series of consultations with key stakeholders, as identified by HEE, to further consolidate an understanding of, and evidence base for, needs and areas of unmet need. Iteratively, the list of needs and gaps in meeting need, established during Phase 1, will be expanded upon through consultations with stakeholders involved in other relevant projects and initiatives (for example: NHS Autism Unit and other HEE programmes). This will clarify the areas of need and unmet need – which will inform the subsequent mapping exercise, outlined below.

(b) **Conduct a mapping exercise to identify whether and how needs can be met by existing or emerging roles and initiatives.** It was recommended that, in the first instance, modifications/extensions to *current roles* or initiatives should be prioritised in order to address key areas of need – and, where gaps or continued unmet needs are identified, that is when the introduction of new roles should be considered. To understand what current initiatives and roles are in place, a mapping exercise will be undertaken. This will involve identifying an area of need (established through task (a), detailed above) and determining whether there are new or ongoing initiatives to address these needs and whether they are effective. The exercise will explore whether there are any existing roles in the workforce (including those in adjacent services, such as mental health) that can address the identified need – or whether new ways of working, training or a new role is required. Examples of what the mapping exercise will consider includes: relevant policy documents; the regulatory standards of existing roles; and commissioning/cost factors. Contributing to this mapping exercise, a series of consultations with key stakeholders will be conducted to garner information about existing and emerging initiatives or roles that may be effective in meeting need. This will allow for the development of proposals for modifying or extending existing roles/initiatives in order to suitably meet need.

(c) **Develop an evaluation framework to review the feasibility, viability, effectiveness and acceptability of extensions to existing roles/initiatives and any new role development** (where there are areas of continued unmet need). The aim of this task is to scope an evidence base for any further stages of investment and development, for HEE to consider further. Examples of what this task will consider includes: the training needs of existing or any new posited roles, costs/commissioning factors, role boundaries and processes. It was recognised that it is important to consider existing problems with commissioning when planning for new role development. This activity will allow for the development of proposals for extending existing roles/initiatives or the development of new roles – in order to meet need within Learning Disability and Autism Services.

In addition, ERG contributors highlighted that further consideration should be given to how complex and interacting physical health needs of people with a learning disability and/or autism can be managed. Accordingly, a further consultation was conducted with professional contributors from the ERG, to garner information about enhancing service provision for physical health (see below). The feedback gathered during this consultation will also be taken forward into Phase 2 for further consideration.

Service Provision for Physical Health Needs

Following the ERG meeting, a further consultation was organised with a selection of contributors. The discussion highlighted that the physical health needs of people with a learning disability with complex and multi-morbid physical health problems are often not well-managed within primary and secondary care and, thereby, that greater specialist input and expertise for managing these needs is required. It was reported that this area of need, in terms of physical health inequalities and management of complex comorbidities, is not sufficiently addressed by the NHS Long Term Plan – which focuses predominately on the annual health check to meet the physical health needs of people with learning disability. At present, there is no requirement for NHS England to monitor the uptake and quality of these health checks.

The contributors alluded to existing evidence that GPs lack confidence and have a perceived lack of training in managing people with a learning disability and/or autism. For example, a recent integrative review conducted by Doherty et al. (2020) identified six main themes relating to barriers and facilitators to accessing and utilising primary care (for physical and mental health needs) faced by individuals with learning disability, autism or both. Among the themes identified were: a lack of specialist training among (both primary and acute health care) providers and barriers to this training (such as time constraints, knowledge gaps and uncertainties over specialist help); a lack of understanding, knowledge and awareness about how to support people with a learning disability and autism, which can engender poor attitudes among healthcare and non-health professionals; and inadequate communication, which can result in the wrong diagnosis and inappropriate medication. These findings are consistent with the preliminary evidence garnered about the perceived unmet training needs of GPs (in understanding and managing people with autism), as articulated in the Phase 1 literature review (for example: Unigwe et al., 2017). Furthermore, this evidence aligns with research conducted by Dimensions (2018), which found that 98% of GPs surveyed want more training on meeting the needs of people with learning disabilities and autism.

Moreover, a document shared by the ERG contributors (no author) highlights that continuity and coordination of care for people with learning disabilities is often missing in current service provision. A wide range of health professionals are involved in caring for people with a learning disability who have multiple complex health problems – including multiple professionals in secondary care specialities, where care is frequently provided in tertiary care centres that are geographically remote from home. The contributors highlighted that little consideration is given to the interactions between health conditions or their treatments, with respect to a coordinated and holistic approach. While children and young people (under 18 years) with complex needs can access holistic care from Community Paediatrics, and elderly people with complex needs can access holistic care from elderly care specialists, it was identified that there is no equivalent provision for adults with a learning disability. This suggests that the gap in coordinated care for managing complex physical health needs can be particularly pervasive for the adult population.

Informed by such evidence, the contributors posited the enhancement of specialist input in managing the complex and multi-morbid physical (and often interrelated mental) health needs of people with a learning disability and/or autism, as a key area of need. This will enable greater expertise in understanding, for example, how challenging behaviour can emerge from underlying unmet physical health needs and the impact of prescribing on the physical health of people with a learning disability. Specifically, it was identified that the '**Physician Associate**' role, as posited by the workshop attendees, *cannot* effectively contribute to the improved management of complex and interrelated physical health needs displayed by people with learning disability and/or autism. This is because the role involves assisting GPs (for example, with form-filling and taking medical histories) and does not entail the medical expertise/input and prescribing capacities required to meet this key area of need. Concerns were also reported about how the Physician Associate would be adequately supervised. Alternatively, the contributors advised on the development of a '**Learning Disability Physician**' role – which, practicing at senior consultancy level, may contribute a clinically- and cost-effective way of enhancing the management of complex physical health needs among the population concerned. Drawing upon the documents and feedback shared by the contributors, the 'Learning Disability Physician' role is outlined below.

➢ **Learning Disability Physician** (being considered by another HEE workstream)

The 'Learning Disability Physician' consultant role was posited to enhance the provision of care within Learning Disability Services. The role is based on the existing Learning Disability Physician role in The Netherlands, which has been further adopted in other areas. In England, Hull CCG is beginning a two-year trial of a doctor specialising in treating people with profound and multiple disabilities (PMLD) – following the recovery of a patient (initially on an end of life care pathway) who was treated by a doctor who trained in the area of learning disability. An evaluation of the efficacy and impact of this role could provide a platform for considering further applicability and roll-out of the Learning Disability Physician role more widely.

It was postulated that the development of a Learning Disability Physician could contribute to greater care coordination and holistic care for people with learning disability who have complex health needs – as the role would ensure a high level of liaison and coordination between the multiple specialists involved in caring for the population group. This would engender an understanding about how a person's health conditions and treatments interact. The role would occupy a position of senior medical leadership within a multidisciplinary team, contributing to decision-making, enabling greater care coordination by other members of the multi-disciplinary team, the proper application of reasonable adjustments and the delivery of specialist care. It was anticipated that, in the first instance, the role would be based within secondary care hospitals, working flexibly with and, subsequently, expanding into community teams. The role would input senior specialist medical skills (in managing the complex physical health needs and co-morbidities of people with learning disability) to community teams. It was reported that this could significantly impact the length of stay in hospital and address current physical health inequalities among people with learning disability.

Furthermore, the contributors advised that the role could be included in existing Learning Disability Services in a variety of ways. For example, some learning disability psychiatrists have also received GP training or general medical training and, thus, possess wider physical health management skills. An emerging recommendation is the development of an educational credited programme for the Learning Disability Physician. This was deemed more viable than the creation of an entirely new speciality, due to existing recruitment problems. As an advanced medical professional, the role would support improved expertise among other physical healthcare staff and supervise trainees to acquire the requisite skills to manage the physical health needs of people with learning disability and/or autism. The Learning Disability Physician role is being further considered and reviewed by another HEE workstream.

Summary of the Evidence

This review has consulted several sources of intelligence to acquire evidence of current gaps (in meeting service and service user need) within Learning Disability and Autism Services – in order to garner suggestions for the development of new and emerging roles or ways of working. The present section seeks to synthesise this intelligence and highlight the priority areas of unmet need that require further work in order to be suitably addressed, drawing upon evidence gathered from: the review of academic and grey literature; data collected from regional workshops; the professional input/recommendations obtained from the ERG; and intelligence from consultations with HEE.

The ERG recommended the development of a comprehensive list that details **key areas of service and service user need** (see Appendix D), to inform proposals for modifications to existing roles or, if required, the creation of new roles. A mapping exercise, as recommended by the ERG, has been initiated to identify existing and emerging roles or initiatives that may meet an area of need. This mapping exercise is summarised later in the section. Through deeper analysis of the data and intelligence collated, it became evident that several needs are indicative of wider service-level gaps and these may require further strategic consideration with respect to the operational structures within and the design of Learning Disability and Autism Services, which is outside the scope of this project. These needs are listed in Appendix C.

Mapping of Needs to Existing and/or Emerging Initiatives

In line with recommendations from the ERG, a mapping exercise was initiated to identify ongoing/existing or emerging initiatives that may contribute to addressing key workforce aspects of the (service and service user) needs identified. Preliminary scoping work has highlighted several areas where workforce gaps can be expected to be addressed by ongoing initiatives that are currently in development. These workforce gaps/*needs are expected to be addressed* and are therefore outside the scope of this project. The list of these is contained in Appendix E.

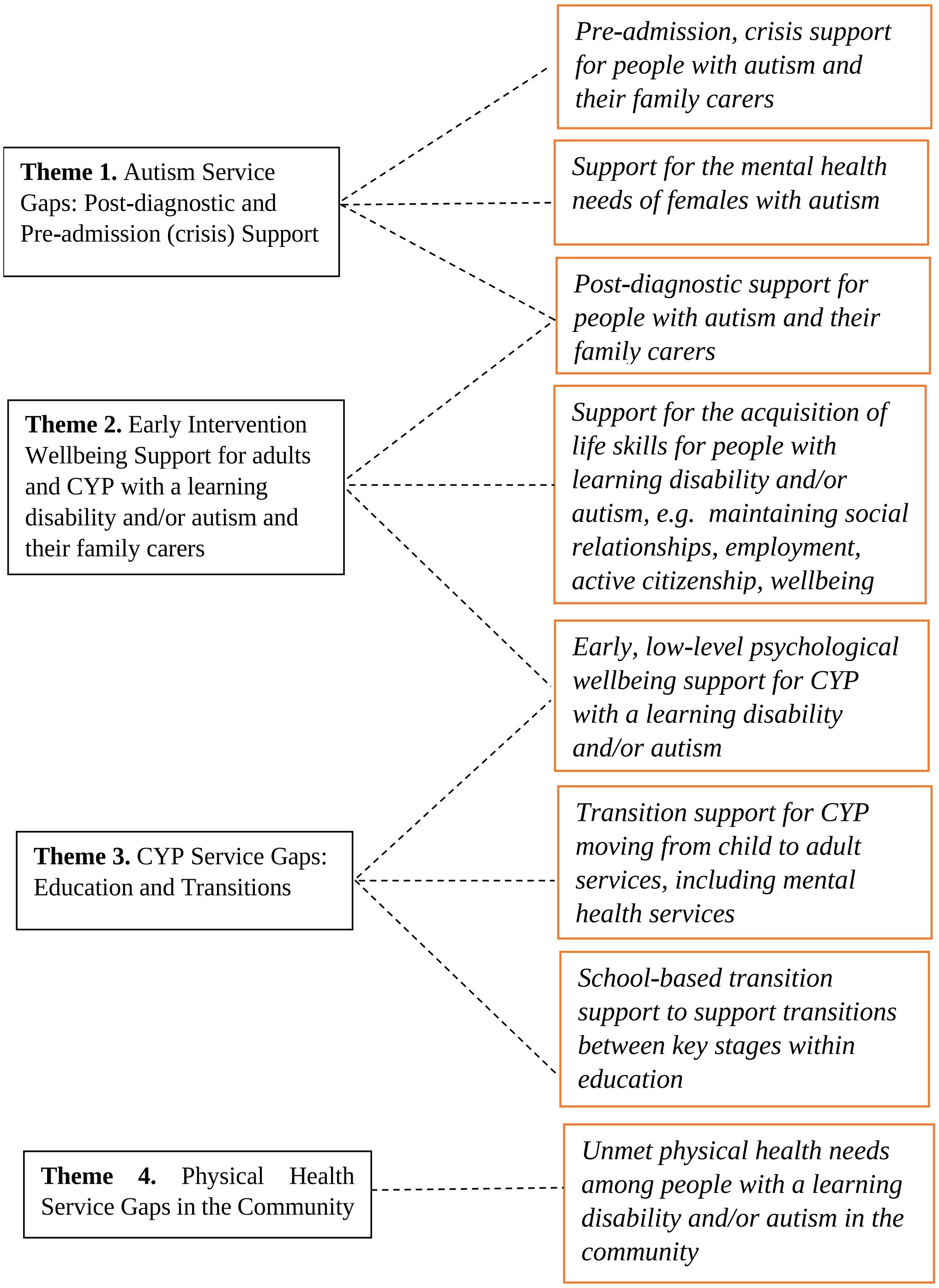
The remaining needs are unlikely to be adequately addressed by ongoing or planned workforce initiatives. In many cases, it was identified that further work is required to build upon and/or extend initiatives that are developing in adjacent services, such as mental health – to suitably meet need within Learning Disability and Autism Services. Considering all sources of intelligence acquired and through consultations with HEE, **four main themes** were identified as key areas for further exploration of new and emerging roles within Learning Disability and Autism Services and will be considered in Phase 2 of this review. These distilled themes are outlined in the following section.

Main Themes for Further Exploration

Through the previously discussed mapping process and further consultations with HEE, four priority themes have been identified for further exploration during Phase 2 with respect to the potential for new and emerging roles – which are summarised in *Figure 2* and further outlined below drawing upon intelligence arising from consultations with HEE.

1. **Workforce Interventions to address known Autism Service Gaps:** Post-diagnosis and Pre-admission (Crisis) Support
2. **Workforce Models to support Early Intervention, Informal Wellbeing Support** for adults and CYP with learning disability and/or autism and their family carers
3. **Workforce Interventions to support C&YP with Learning Disability and/or Autism Service Gaps**: Transitions and Education
4. **Workforce Interventions/Models to address Physical Health Service Gaps in the Community**

Figure 2. Thematic Grouping of Unmet Needs in Learning Disability and Autism Services



Autism Service Gaps: Post-Diagnosis and Pre-Admission (Crisis) Support

The intelligence gathered throughout this review has indicated that there are three main areas of continued *unmet* need in respect of autism. These will be further explored during Phase 2 of this work, include: *reviewing the provision of pre-admission, crisis support for people with autism and their family carers*; *developing immediate, appropriate and effective post-diagnostic support for people with autism and their family carers*; and *developing support for the mental health needs of females with autism*.

Previously, it was identified that the intelligence points to the need to *develop and/or enhance the specialist skills and knowledge among the generic mental health workforce in identifying and managing the mental health needs of adults and children and young people with a learning disability and/or autism*. This is relevant to the present theme given that people with autism often receive support from the mental health workforce which, at present, may be lacking in the requisite skills to support this complex group. It is, however, expected that this area of need will be increasingly met by emerging upskilling initiatives – such as the Oliver McGowan Mandatory Training programme and the Advanced Clinical Practice programme which is in the early stages of development by HEE.

Despite this, it is likely that gaps in post-diagnostic/recognition support for people with autism (and their family carers) will remain. Similarly, further work is required to assess whether the emerging training initiatives (outlined above) will contribute to the identification and management of mental health needs displayed by females with autism, specifically. Peer support has been highlighted as an initiative that could potentially contribute to meeting the early post-diagnostic support needs of people with autism and their family carers, alongside the mental health needs of females with autism. A Peer Support Competency Framework is already in development within adjacent mental health teams. This would require further work to review the reasonable adjustments and/or modifications that are needed in order to ensure that peer support can meet the diverse needs of people with autism and their family carers. As will be demonstrated in the following themes, peer support is a recurring initiative that aligns with several areas of need identified – which, therefore substantiates further exploration.

In line with this, feedback from regional workshops included the suggestion of a ‘Life Skills Development Coach’ role (aligned to the need for post-diagnostic support for people with autism). The role was envisioned to operate an array of functions, including wellbeing support, provision for active citizenship/community involvement and the facilitation of peer support/befriending groups for people with autism and/or a learning disability. The workshop attendees and academic/grey literature both highlighted that informal support for people with autism in this post-diagnostic capacity is significantly lacking. Further work may also be required to establish what this forthcoming autism policy will look like, how it may contribute to addressing these gaps in provision for people with autism and, resultantly, whether any new roles are required to meet the needs of people with autism.

Early Intervention, Informal Wellbeing Support for Adults and CYP with Learning Disability and/or Autism and their Family Carers

The intelligence garnered by this review points to early intervention wellbeing support for people with a learning disability and/ or autism (and their family carers) as a priority area of need that requires further work. This is indicated by the following continued unmet needs: *the development of support for the acquisition of life skills for people with learning disability and/or autism, including for maintaining social relationships, active citizenship/community involvement, employment, and psychological wellbeing*; *the enhancement of early intervention, low-level emotional and psychological wellbeing provision for CYP with a learning disability and/or autism*; and *the development of immediate, appropriate and effective post-diagnostic support for people with autism and their family carers*.

Initial mapping work has identified emerging initiatives that require further work in order to be applicable and extended to people with a learning disability and/or autism, in order to ensure that appropriate and effective early intervention wellbeing support for this population group. **Peer support** is recurrently highlighted as an emerging initiative that, with further work or modifications, could contribute to meeting the needs identified above. At present, a Peer Support Competency Framework is in development within adjacent mental health teams, but this requires extending to meet the needs of people with a learning disability and/or autism. Intelligence from the Centre for Mental Health (Burke and Hodgson, 2020), articulated earlier in this review, reports that peer support is an effective approach from which people from learning disability or neuro diverse communities (and their family carers) could benefit in a multitude of ways. The peer support initiative for people with a learning disability and/or autism was welcomed by ERG contributors and substantiates further consideration.

The benefits of peer support and befriending initiatives for people with learning disability and/or autism (and their family carers) were also identified in regional workshops with service staff – where the posited 'Life Skills Development Coach' role was envisioned to undertake a facilitative role in the provision of peer support groups. This posited role was aligned to the following multi-dimensional need: *the enhancement of support for the acquisition of life skills for people with learning disability and/or autism, including for maintaining social relationships, active citizenship and psychological wellbeing*. Considering the intelligence gathered, Phase 2 of the present review will further explore the role of peer support in meeting the early intervention wellbeing support needs of people with a learning disability and/or autism. The role of peer support within the early intervention space will be discussed in the following subsection (CYP with Learning Disability and/or Autism Service Gaps), along with the Education Mental Health Practitioner (EMHP) role that is in development – which also corresponds to this need.

CYP with Learning Disability and/or Autism Service Gaps: Transitions and Education

The intelligence has pointed to several areas of continued (unmet) need in supporting children and young people with a learning disability and/or autism – including: *the development of transition support for CYP moving from child to adult services, including mental health* *services*; *the enhancement of early intervention, low-level wellbeing support, particularly in school settings*; *and the development of school-based transition support for transitions between key stages within/out of education*.

The sources of intelligence consulted during this review have indicated that support for children and young people moving between child to adult services is a persistent area of need. Despite completed initiatives, such as the HEE Learning Disability Transition Competency Framework, it seems that this area of need is not suitably met, and that further work is required. Previously, another transitional area of need was identified – that is: *the development of transition support that prepares and coordinates the transition from inpatient (such as mental health and forensic) to community services for people with a learning disability and/or autism*. For the child and young person population, an emerging keyworker role is being developed by HEE to support those with complex needs who are admitted, or at risk of being admitted, to Tier 4 inpatient settings (due to their mental health, autism and/or a learning disability). This role emerged from a recommendation in a report by Lenehan (2017) and is expected to contribute to supporting vulnerable children and young people transitioning between services.

As indicated in the above themes, **peer support** has been identified as an emerging initiative (the Peer Support Competency Framework within adjacent mental health teams) that has the potential to positively contribute to meeting the early intervention, low-level emotional and psychological wellbeing needs of young people with a learning disability and/or autism. The development of peer support for this group may also be beneficial for meeting the transitional support needs of young people moving between key stages within education. This aligns with the intelligence acquired from the Centre for Mental Health (Burke and Hodgson, 2020), which recommends focusing on young people (from learning disability and neuro diverse communities) during transitions when developing peer support as the greatest need and gap in service provision – a recommendation that was welcomed by the ERG. Considering this, the present review will further explore the role of peer support in supporting young people with a learning disability and/or neurodiversity (autism) *and* their family carers undertaking challenging transitions and within education.

The unmet transitional and wellbeing support needs of children and young people with a learning disability and/or autism within education were consistency highlighted during the regional workshops and were reiterated by ERG contributors. Consultations with HEE have highlighted further intelligence about current challenges with funding support for children with special educational needs and disabilities (SEND) and upcoming reforms that indicate a likelihood towards increased mainstream schooling for children with a learning disability. A report by the House of Commons Education Select Committee (2019) highlighted concerns with long-term strategic planning and financial prudence in respect of high needs funding. Similarly, a report by the National Audit Office (NAO, 2019) indicates the inconsistency and financial unsustainability of the SEND funding system. The evidence points to (primarily systemic) issues regarding: the unsustainable national funding structure for SEND; poor quality SEND outcomes and lack of rigour in some regions; and a mainstream schooling system that does not serve children and young people with SEND as well as it could, resulting in 50% of all permanent exclusions from schools arising from students with a special educational need in

2017/18 (NAO, 2019). Resultantly, the government has begun a review into SEND funding, which is ongoing.

Considering this evolving evidence, an emerging gap in the capability of the education workforce to support this group to access and sustain a mainstream education has been identified. The likelihood of an imminent increase in the number of children and young people with a (mild) learning disability attending mainstream school may have implications for the skills mix required within mainstream schools. Forethought is needed to consider the implication for the skills teaching and support staff (including SENCO staff and school nurses) may need and how these could be enhanced (for instance, through training via health input). This gap in the capability of the education workforce was alluded to during regional workshops via a posited Education Wellbeing Officer and Education Transition Worker.

Importantly, further consideration should be given to how the education workforce can be supported to become equipped with the necessary skills and competences to support the wellbeing of children and young people with autism. Children and young people spend a significant proportion of their time within education settings and, therefore, it is critical that their experiences and the wellbeing support they receive within this context are made better and maximised. If the experiences of autistic young people at this critical life stage within education are improved, it has the potential to reduce the need for more intensive interventions from health and social care services. As previously stated, the primary focus of this review is to explore the need for new workforce roles to address unmet needs within Learning Disability and Autism Services and, therefore, the upskilling of existing roles in the workforce has not been examined in detail. Considering the above, it is recommended that the possibility and need for upskilling existing roles within the education workforce is further explored by HEE – including, but not limited to, teaching staff, support staff (such as Learning Support Assistants (LSAs) and SENCO), and health staff that support school aged children (such as school nurses, Educational Psychologists, and health visitors).

Moreover, through preliminary mapping work, the Education Mental Health Practitioner (EMHP), emerging out of adjacent mental health teams, has been identified as a current role that warrants further exploration in the context of these needs. Part of the remit of the EMHP is to deliver low-intensity interventions for mild to moderate mental health issues to pupils in school settings and liaise with external specialist services to, for instance, ensure a smooth transition from specialist services. Further work is required to explore how this could be extended/enhanced or duplicated to meet the wellbeing support needs of children and young people with a learning disability and/or autism and the staff that support them. The present review will explore these possibilities of a cross-sector initiative, in order to meet the needs of children and young people with SEND, who are neuro diverse and/or have a learning disability receiving a mainstream education.

Overall, what the corpus of intelligence indicates is that increased support (particularly around wellbeing and transitions) for children and young people with a learning disability and/or autism within mainstream school is required. It is important to further consider how the education workforce can be supported to become equipped with the necessary skills to support the wellbeing of children and young people with autism within mainstream education settings.

Physical Health Service Gaps in the Community

Through further consultations with HEE and ERG contributors, it became apparent that the physical health needs among people with a learning disability and/or autism may not be being adequately addressed within the community. It has been identified that further work is required to develop the provision of specialised physical health care within community teams – in order to achieve the aims of the *Transforming Care* programme (NHS England, 2017) and ensure suitable provision for people with a learning disability and/or autism.

Feedback from regional workshops with service staff highlighted the need for flexibility in the provision of physical health in the community – for example: to allow for practitioners to prescribe and make changes to medication within the community and/or home of someone with a learning disability and/or autism, rather than requiring an admission to inpatient services. This points to a deficit in both the capacity and skills required for community teams to adequately meet the physical health needs of people with a learning disability and/or autism within the community. This area of need was also highlighted by ERG contributors who posited a new 'Learning Disability Physician' role to contribute to the management of complex physical health needs and the role was envisioned to expand into community teams. It is understood that a 'Learning Disability Physician' role could make a significant contribution to meeting physical health needs in the community – and the role is currently be reviewed and considered by another HEE workstream.

Furthermore, further work is required to review what contribution the emerging Advanced Clinical Practice (ACP) qualification/role in Learning Disability and Autism will make to addressing physical health needs in the community. This emerging ACP role is being developed by HEE (early stages of development) and should be explored further to look at how it will (or could be expected to) improve the identification and management of physical health needs in the community. Finally, further consideration should be given to emerging or new initiatives required to enhance the uptake and quality of annual health checks, to contribute to improved physical health within the community.

Conclusion and Recommendations

As demonstrated by the above synthesis and (ongoing) mapping of the intelligence gathered – including from the (academic and grey) literature review, regional workshops, ERG consultations and further consultations with HEE – four themes were identified as requiring further exploration with respect to the development, appropriateness and applicability of new and emerging roles. These are:

1. **Autism Service Gaps:** post-diagnosis and pre-admission (crisis) support

The ERG identified that emerging autism policy developments may require and offer a base for the development of new and emerging roles, in order to meet the pre-admission (crisis) and post-diagnostic needs of people with autism and their family carers. Further work is required to explore what this emerging policy will look like and to determine what new roles may be required to meet need. It has also been demonstrated that emerging training programmes (Oliver McGowen training and HEE's emerging ACP Learning Disability and Autism credential programme) can be expected to contribute to enhanced specialist skills among the mental health workforce – who are often involved in supporting people with autism.

It is likely that gaps with respect to post-diagnostic wellbeing support for people with autism (and their family carers) and support for the mental health needs of females with autism will remain. Initial mapping work has identified peer support as an initiative that may contribute to the effective management of these needs. The potential benefit of peer support in meeting the post-diagnostic needs of people with autism and their family carers was highlighted during regional workshops. This review will undertake further work to review how peer support can contribute to meeting the needs of people with autism and their family carers, whether there are other existing and/or emerging initiatives that, with appropriate modifications, could address autism service gaps – or, moreover, whether other new roles are required.

Roles and/or Initiatives for further consideration:
- Emerging autism policy developments
- Post-diagnostic peer support during for people with autism and their family carers
- Peer support for the mental health needs of females with autism

2. **Early Intervention, Informal Wellbeing Support** for adults and CYP with learning disability and/or autism and their parents/family carers

The intelligence indicated that there are several unmet needs with respect to early intervention wellbeing support for adults and children and young people with a learning disability and/or autism and their families – which require further exploration, including consideration of new and emerging roles. As identified above, initial mapping work has identified peer support as a potentially beneficial emerging initiative for meeting the early and informal wellbeing needs of people with a learning disability and/or autism. Feedback from regional workshops highlighted the gap in provision for the acquisition of life skills for people with a learning disability and/or autism, as indicated by the posited ‘Life Skills Development Coach’. This posited new role was envisioned to provide low-level wellbeing support and operate a peer support/befriending service. Building upon work from the Centre for Mental Health (Burke and Hodgson, 2020), further work is required to explore how peer support could be helpful for people with a learning disability and/or autism and what this service would look like for these diverse groups. Through ongoing mapping work, the review will also acquire intelligence of other existing and/or emerging initiatives that may contribute to meeting this priority area of need.

Roles and/or Initiatives for further consideration:

- Peer support during the early intervention recognition phase (for adults and/or children and young people with a learning disability and/or autism)
- Peer support for parents and family carers

3. **CYP with Learning Disability and/or Autism Service Gaps**: Transitions and education

The intelligence points to several unmet support needs among children and young people with a learning disability, neurodiversity (autism) and/or SEND in respect of transitions and within education. The transition between child to adult services is widely recognised as a challenging time for children, young people and their carers. Previously, HEE developed a Learning Disability Transition Competency Framework to help enable a smooth transition – however, it is unclear how successfully this is being implemented within services. Furthermore, transitions within education and general support for children and young people with a learning disability and/or autism receiving a mainstream education has been identified as a growing area of need – which could be met through extensions to existing, or the introduction of new, education workforce roles.

Intelligence emerging from consultations with HEE around the SEND funding crisis indicates a likelihood towards increased mainstream schooling for children with (mild) learning disability. Resultantly, it is vital that consideration is given to how the skills mix of mainstream schools – including the training required by teaching, support staff, school nurses and SENCO – may change and need enhancing in order to meet need. This was reflected in regional workshops via ‘Education Wellbeing Officer’ and/or ‘Education Transition Worker’ roles and preliminary mapping work has identified the EMHP, within adjacent mental health services, as an emerging role that could be extended or form the basis for the introduction of a new role (specific to learning disability and neurodiversity). Overall, it is important that further consideration is given to how the education workforce can be supported to become equipped with the necessary skills to support the wellbeing of children and young people with autism.

Finally, in line with the other themes, peer support was identified as a beneficial emerging initiative for supporting the transitional and wellbeing needs of young people within school settings and for supporting family carers/parents. This is an area that requires further exploration to understand how peer support may contribute to supporting this population group and how the initiative could involve provision for family carers/parents.

Roles and/or Initiatives for further consideration:

- Peer support for young people from learning disability and/or neuro diverse communities *and* for their family carers/parents
- Extending the EMHP role or further consideration for a new education-based role for children and young people from learning disability and/or neuro diverse communities (for example: Education Neuro Diversity Practitioner/ENDP).
- Provide training to the education workforce to meet the education needs of children and/or young people from learning disability and/or neuro diverse communities

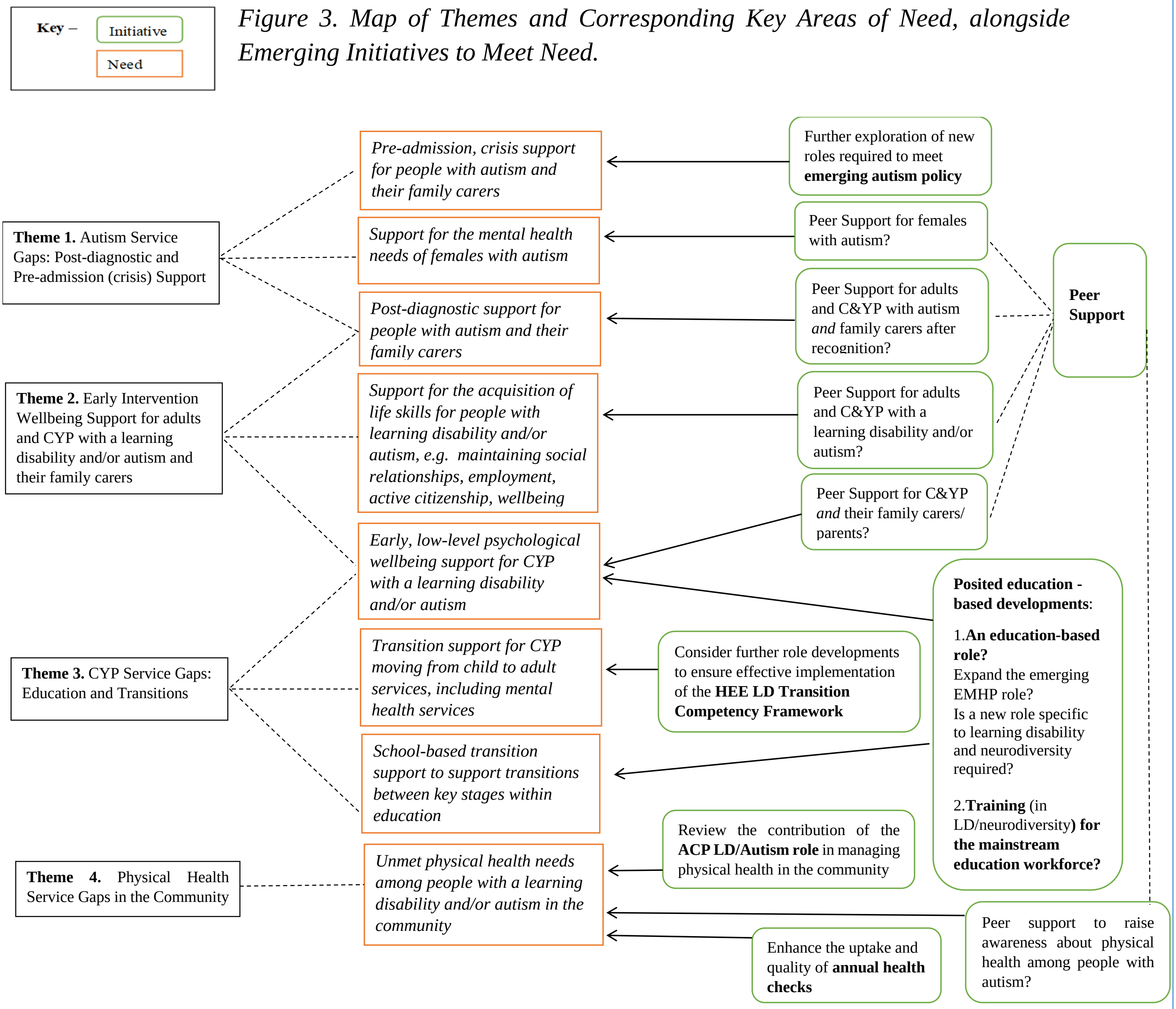
4. Physical Health Service Gaps in the Community

Through further consultations with HEE and ERG contributors, it became more apparent that the physical health needs among people with a learning disability and/or autism are not being adequately addressed within the community. This was corroborated by regional workshop feedback, where greater flexibility within community teams in prescribing medication for physical health was posited. ERG contributors posited the development of a new ‘Learning Disability Physician’ role to contribute to the management of complex physical health needs within the community – which is being reviewed by another HEE workstream. Further work is required to review what contribution the emerging Advanced Clinical Practice (ACP) qualification/role in Learning Disability and Autism will make to addressing physical health needs in the community. This emerging ACP role is being developed by HEE (early stages of development) and should be explored further to look at how it will (or could be expected to) improve the identification and management of physical health needs in the community.

Roles and/or Initiatives for further consideration:

- Consider and review the emerging ACP Learning Disability and Autism qualification/role in managing physical health needs within the community
- Peer support to raise awareness about physical health among people with autism
- Consider emerging or new initiatives required to enhance the uptake and quality of annual health checks

Figure 3. Map of Themes and Corresponding Key Areas of Need, alongside Emerging Initiatives to Meet Need.



Theme 1. Autism Service Gaps: Post-diagnostic and Pre-admission (crisis) Support

Pre-admission, crisis support for people with autism and their family carers

Support for the mental health needs of females with autism

Post-diagnostic support for people with autism and their family carers

Theme 2. Early Intervention Wellbeing Support for adults and CYP with a learning disability and/or autism and their family carers

Support for the acquisition of life skills for people with learning disability and/or autism, e.g. maintaining social relationships, employment, active citizenship, wellbeing

Early, low-level psychological wellbeing support for CYP with a learning disability and/or autism

Theme 3. CYP Service Gaps: Education and Transitions

Transition support for CYP moving from child to adult services, including mental health services

School-based transition support to support transitions between key stages within education

Theme 4. Physical Health Service Gaps in the Community

Unmet physical health needs among people with a learning disability and/or autism in the community

Further exploration of new roles required to meet **emerging autism policy**

Peer Support for females with autism?

Peer Support for adults and C&YP with autism *and* family carers after recognition?

Peer Support for adults and C&YP with a learning disability and/or autism?

Peer Support for C&YP *and* their family carers/ parents?

Peer Support

Posited education - based developments:

1.**An education-based role?** Expand the emerging EMHP role? Is a new role specific to learning disability and neurodiversity required?

2.**Training** (in LD/neurodiversity**) for the mainstream education workforce?**

Consider further role developments to ensure effective implementation of the **HEE LD Transition Competency Framework**

Review the contribution of the **ACP LD/Autism role** in managing physical health in the community

Enhance the uptake and quality of **annual health checks**

Peer support to raise awareness about physical health among people with autism?

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Appendices

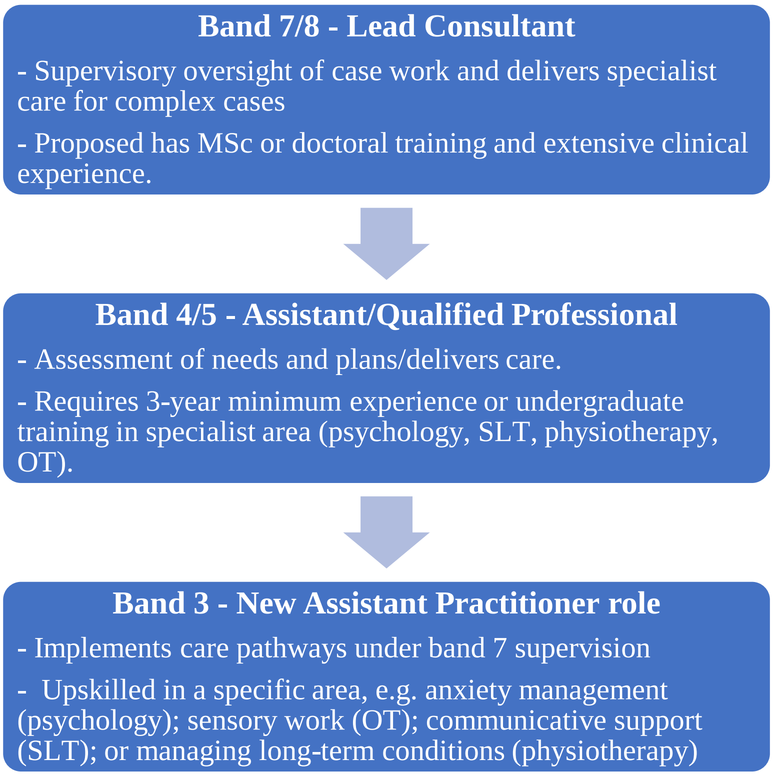
Appendix A

Workshop Headlines Summary with Service/Skill Gap and Theme Frequency

Service/skill gap	New roles/ways of working identified	Role profile (implementation and key skills)	Workshop frequency
Accessing social care provision in the community	**Life Skills Development Coaches**: Situated within health or social care services and enables the development of core life skills and enhanced wellbeing.	Workshops attendees suggested that the role comprises a series of specialist career pathways (see below). Alternatively, the key skills attached to each pathway could form a single role. (a) **Emotional wellbeing/quality of life coaches** – psychotherapeutic techniques (CBT; DBT; mindfulness skills) and bereavement support. (b) **Employment advisors** – scopes workplace opportunities (via the job centre) and facilitates reasonable adjustments (video CV's) and job-carving. (c) **Community social activity coordinators** – enables access to activities and opportunities in the community (e.g. befriending service; accessible cafes; using public transport).	**All** workshops.
Shortages in key workforce skills	**A specialist skills-filtration working model (see the flow chart on the final page of this section)**	Band 3, unregistered "**Assistant Practitioner**" roles to provide interim support during the wait for specialist interventions. The occupier is upskilled in a key area of need (OT; SLT; Physiotherapy; Psychology care provision).	**All** workshops**.**
Physical health care provision: the deficit in health checks and identifying/treating physical health problems.	**(a) GP/Primary Care LD/autism champion:** To ensure the uptake and quality of health checks	Workshop attendees posited two alternate ways in which this role could be implemented: - An **extension of an existing role –** a nominated nurse with specialist training - A **new, specialised role** – with the sole purpose of enabling access to quality health checks	**All** workshops.
	(b) LD/autism Physician Associate Practitioner	Expand the remit of the Physician Associate to encompass a specific LD and autism route/role, based within GP and acute settings. Consideration should be given to flexibility in physical healthcare provision, e.g. a community-based LD Physician Associate.	Leeds and Birmingham
Gaps within and between services	**Transitional roles**: Work across service boundaries to ensure fluid transitions and prevent breakdown in care pathways.	Workshop attendees posited a variety of (unregistered, band 3) transitional roles: (a) **Community outreach link** – follows the service user out of inpatient services into the community. A further "integration planning" branch to liaise with the housing sector. (b) **Child-adult services link** – supports the transition from child to adult services, whereby transition planning/preparation begins with the service user at age 15. (c) **Education-transition support worker** – based within social care and conducts outreach work during key transitional phases in education (at age 5; 11; 15-16; 18).	**All** workshops.

Early intervention, preventative service provision	**Education Wellbeing Officer –** a wellbeing advisory role in schools – as part of a CAMHS or social care outreach service	- Enables reasonable adjustments and neurodiversity awareness among teachers. - Provides a continuum of (lower-level health and psychological wellbeing) support. - Refers those in need of specialist interventions to the **Education Mental Health Practitioner** (an emerging role with a potential for supervisory capacity).	**All** workshops.
Lack of support for families	**Family link/key worker**: Works therapeutically with children and families in the community/inpatient care.	- Supports key skill acquisition of family members (positive risk-taking; managing challenging behaviour and sleep patterns) in the community - Facilitates family storytelling (the workforce listens to the family's history/experiences) within inpatient services	**All** workshops.
Support for individuals with autism *without* a learning disability	**Autism-specific Intensive Support Team (IST) –** for the assessment/treatment of autistic adults and young people reaching crisis or to avert imminent crisis.	An autism IST and a specialist inpatient service for young women with autism. Suggestions regarding the situation of an autism-specific IST included: (a) An autism-specific pathway within existing learning disability IST's (b) Equip crisis teams with intensive autism support training (c) Develop a child/young people autism crisis team with generic CAMHS services	**All** workshops.
Support for people with *mild* learning disability/autism and mental health problems	(a) **A specialist LD/autism mental health CYP service**	A specialist CYP learning disability/autism mental health service, outside of generic CAMHS – to ensure the needs of individuals with mild LD/autism are met. A band 4, registered acute mental health LD/autism liaison role placed in each generic CAMHS service – to ensure that the needs of individuals with LD/autism are recognised and prioritised.	**All** workshops.
	(b) Acute mental health LD/autism liaison role – within CAMHS		Birmingham, London and Leeds.
Supporting young people with forensic needs	**Forensic support liaison role/team** – for young people with a learning disability and/or autism (11-18 years)	A role/team to support young people at risk of offending, with specialist forensic training in the language of digital technology (e.g. "dark web"); risk assessment; and identifying signs of drug use and sexual exploitation. Suggestions included: - A multi-professional Forensic, Outreach and Liaison Service (FOLS) for young people - An unregulated role based within inpatient and community services or the criminal justice system/police force.	Birmingham, London and Leeds.
Workforce retention (high staff turnover)	**Staff behavioural skills coaches**	To equip staff with key skills to enhance their own wellbeing and delivery of quality care (e.g. positive psychological/therapeutic techniques, communication and teaching skills).	Bristol and London.
Shortage of psychiatrists	**Non-medical responsible clinician role**	Scoping opportunities for non-medical staff to occupy Approved Clinician (leadership) roles – while continuing to provide clinical input and develop care pathways of service users.	Birmingham and London.

Discharge delays for complex cases	**Complex discharge care coordinator**	It was suggested that the workforce could benefit from a role with acute inpatient/hospital settings dedicated to discharging patients with complex needs.	Birmingham and London.



Band 7/8 - Lead Consultant

- Supervisory oversight of case work and delivers specialist care for complex cases

- Proposed has MSc or doctoral training and extensive clinical experience.

Band 4/5 - Assistant/Qualified Professional

- Assessment of needs and plans/delivers care.

- Requires 3-year minimum experience or undergraduate training in specialist area (psychology, SLT, physiotherapy, OT).

Band 3 - New Assistant Practitioner role

- Implements care pathways under band 7 supervision

- Upskilled in a specific area, e.g. anxiety management (psychology); sensory work (OT); communicative support (SLT); or managing long-term conditions (physiotherapy)

Appendix B

Quality of Life Framework: The Core Quality of Life Domains (by Shalock et al., 2005)

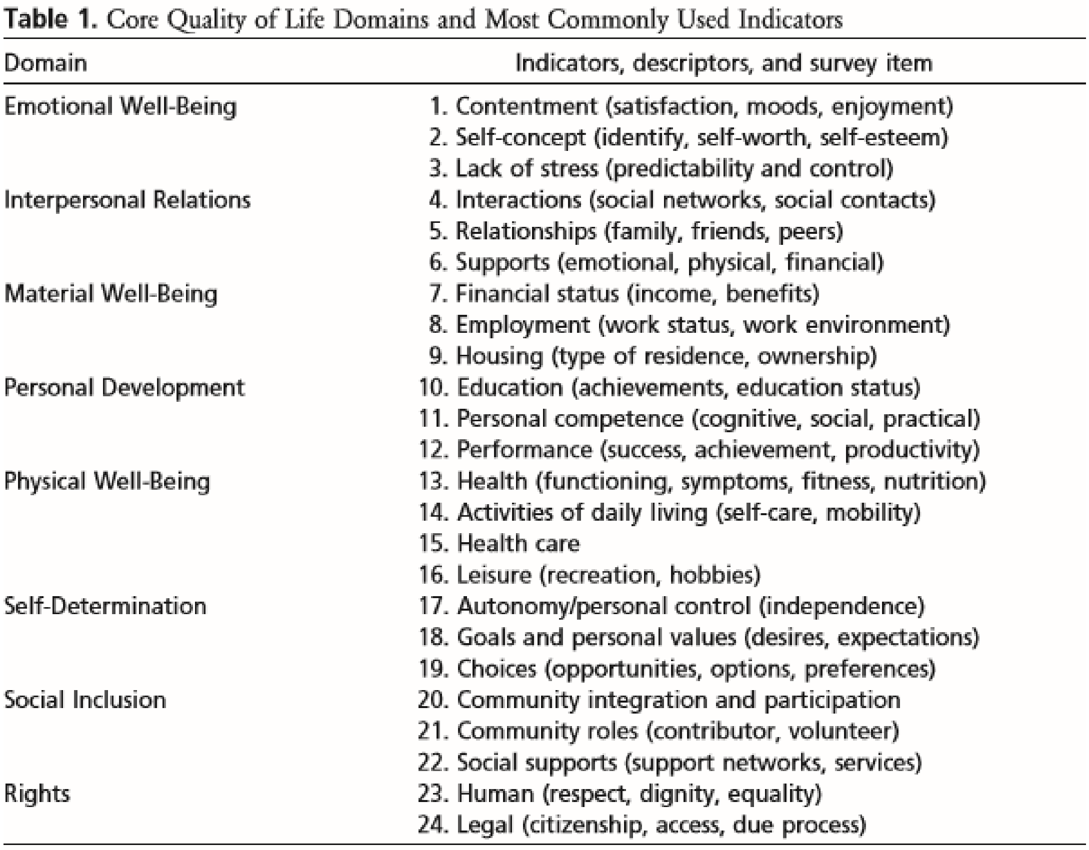


Table 1. Core Quality of Life Domains and Most Commonly Used Indicators

Domain	Indicators, descriptors, and survey item
Emotional Well-Being	1. Contentment (satisfaction, moods, enjoyment)
	2. Self-concept (identify, self-worth, self-esteem)
	3. Lack of stress (predictability and control)
Interpersonal Relations	4. Interactions (social networks, social contacts)
	5. Relationships (family, friends, peers)
	6. Supports (emotional, physical, financial)
Material Well-Being	7. Financial status (income, benefits)
	8. Employment (work status, work environment)
	9. Housing (type of residence, ownership)
Personal Development	10. Education (achievements, education status)
	11. Personal competence (cognitive, social, practical)
	12. Performance (success, achievement, productivity)
Physical Well-Being	13. Health (functioning, symptoms, fitness, nutrition)
	14. Activities of daily living (self-care, mobility)
	15. Health care
	16. Leisure (recreation, hobbies)
Self-Determination	17. Autonomy/personal control (independence)
	18. Goals and personal values (desires, expectations)
	19. Choices (opportunities, options, preferences)
Social Inclusion	20. Community integration and participation
	21. Community roles (contributor, volunteer)
	22. Social supports (support networks, services)
Rights	23. Human (respect, dignity, equality)
	24. Legal (citizenship, access, due process)

Appendix C

List of service-level needs that require further strategic work

Service-level Needs

- Enhance current specialist, local community-based care (multi-disciplinary) or develop this provision where it is unavailable – to circumvent delays in discharges from inpatient services, reduce the risk of readmission and support the continuation of care in the community.
- Review, develop and expand 24/7 intensive support provision for adults with a learning disability at a time of crisis – individuals for whom, without this specialised support in place, may deteriorate or access inappropriate services to meet their needs.
- Review the development of specialist community teams and evaluate the role and outcomes of such teams for delivering intensive support to children and young people with a learning disability and/or autism.
- To identify and overcome the barriers that prevent people with a learning disability and/or autism (including those with profound learning disability; and autism only) from accessing specialist mental health provision – for example: by re-evaluating service eligibility criteria and developing an understanding of the mental health needs of people outside of their learning disability and/or autism diagnosis.
- Expand current community forensic services for people with learning disability and/or autism with forensic needs or develop new means of forensic service provision for the population concerned.
- Identify and overcome the barriers that can prevent people from accessing autism diagnostic and assessment services.
- Identify and overcome barriers that can exclude people with autism (without a learning disability) from accessing provision from Learning Disability Services and Mental Health Services. Consider developing the design and delivery of current provision (including requisite workforce skills) to meet the specific needs of people with autism.
- To review the impact of and possible enhancements to ongoing service developments for children and young people with a learning disability and/autism and forensic (including challenging behaviour) needs (i.e. community FCAMHS) – or to develop early intervention community service provision for young people with a learning disability and/or autism and forensic needs.

Appendix D

List of Needs within Learning Disability and Autism Services

Table 4. Summary of Needs within Learning Disability and Autism Services, informed by the Literature Review and Workshop Feedback

Provision	**Needs**	Literature Review	Workshops
CLDTs	Enhance current specialist, local community-based care (multi-disciplinary) or develop provision where it is unavailable – to circumvent delays in discharges from inpatient services, reduce the risk of readmission and support the continuation of care in the community	✓	✓
	Enhance the requisite specialist skills within the CLDT workforce to facilitate effective and confident management of challenging behaviour and/or complex needs	✓	Low frequency
ISTs and Pre-admission Crisis Prevention	Review, develop and expand 24/7 intensive support provision for adults with a learning disability at a time of crisis – individuals for whom, without this specialised support in place, may deteriorate or access inappropriate services to meet their needs	✓	Low frequency
	Review the development of specialist community teams and evaluate the role and outcomes of such teams for delivering intensive support to C&YP with a learning disability and/or autism	✓	
	Review and consider the provision of pre-admission, crisis support for people with autism – e.g. developing ISTs that are equipped with the requisite skills, training and education so that they can provide effective intensive/crisis support to people with autism	✓	✓
Mental Health and Wellbeing	Develop and/or enhance the specialist skills and knowledge among the generic mental health workforce in identifying and managing the mental health needs of C&YP and adults with a learning disability and/or autism	✓	✓
	To identify and overcome the barriers that prevent people with a learning disability and/or autism (including those with profound learning disability; and autism only) from accessing specialist mental health provision – e.g. by re-evaluating service eligibility criteria and developing an understanding of the mental health needs of people outside of their learning disability and/or autism diagnosis	✓	✓
	The development of transition support that provides planning and preparation to deal with the change in service design and delivery experienced by people with a learning disability and/or autism who are transitioning from child to adult mental health services	✓	✓
	Expand existing and/or develop new provision for supporting people with a learning disability and/or autism to acquire the life skills they may otherwise lack – e.g. for independent living, developing and maintaining social relationships, active citizenship (implementing enablers for community/leisure activities and employment), and psychological wellbeing/ quality of life	Low frequency	✓
	The enhancement of existing or development of new early intervention, low-level emotional and psychological wellbeing provision for C&YP with a learning disability and/or autism – particularly within school settings		✓
Transition	The development of transition support that provides planning and preparation (for people with a learning disability and/or autism) to deal with the change in service design and delivery from child to adult services	✓	✓
	The development of transition support that prepares and coordinates the transition from inpatient (mental health and/or forensic**) to community services for people with a learning disability and/or autism	✓	✓

	The enhancement of school-based transition support for C&YP with a learning disability and/or autism entering each key transitional stage within (and out of) education		✓
Forensic Services	Expand current community forensic services for people with learning disability and/or autism with forensic needs or develop new means of forensic service provision for the population concerned	✓	✓
	To review the impact of and possible enhancements to ongoing service developments for C&YP with a learning disability and/autism and forensic (including challenging behaviour) needs (i.e. community FCAMHS) – or to develop early intervention community service provision for young people with a learning disability and/or autism and forensic needs	✓	✓
	Development of a pathway that facilitates discharge planning for service users moving from forensic inpatient to community services**	✓	
Autism Service Provision	Identify and overcome the barriers that can prevent people from accessing autism diagnostic and assessment services	✓	✓
	Develop and/or expand the provision of immediate, appropriate and effective post-diagnostic emotional and family support for people with autism	✓	✓
	The development of service provision to meet the specific needs of females with autism, particularly in terms of mental health	✓	✓
	Identify and overcome barriers that exclude people with autism (without learning disability) from accessing LD Services and MH Services. Develop the design and delivery of provision (including workforce skills) to meet the needs of people with autism	✓	✓
Physical Healthcare	Improving the uptake of annual health checks and enhancing the quality of annual health checks (NHS LTP)	✓	✓
	Developing specialist skills among primary and secondary care medical staff (particularly GPs) so that they can effectively and confidently manage the complex and interrelated physical health needs (comorbidity and long-term conditions) displayed by people with autism and/or a learning disability	✓	✓
	To ensure that inpatient acute settings can be reasonably adjusted to meet the sensory needs of people with autism		✓
Family Support	To enhance provision for family carers to acquire further key skills and knowledge for supporting someone with a learning disability and/or autism – e.g. how to deal with emotional challenges and manage challenging behaviour		✓
	To review and consider ways in which the involvement of families/family carers in service delivery within inpatient and community services can be facilitated and enhanced, e.g. in designing and implementing care packages		✓
Workforce Skills	Expand and/or review ways in which the following core areas of support can be developed in order to meet need within services: psychological wellbeing and mental health (psychology); activity enablement for daily living (occupational therapy); communication and eating, drinking and swallowing difficulties (speech and language therapy); and managing long-term conditions (physiotherapy)		✓
	To enhance and develop the behavioural skills (e.g. in PBS) among the workforces (particularly social care) involved in caring for people with a learning disability and/or autism – to improve rates of workforce retention, staff wellbeing and the delivery of skilled/robust care		✓
	To review and develop career pathways that enable senior staff, who have acquired vast experience, knowledge and specialist skills, to continue providing clinical input and developing care pathways for the population group – while occupying a position of leadership		✓

Appendix E
Needs that are Expected to be Addressed by Emerging Initiatives

Table 5. Needs to be Addressed by Emerging Initiatives

Needs	**Initiative**	**Status of Initiative**
Enhance the requisite specialist skills within the CLDT workforce to facilitate effective and confident management of challenging behaviour and/or complex needs	Oliver McGowan Mandatory Training	Commissioning stage – HEE LD Programme
	HEE Advanced Clinical Practice (LD & Autism)	Early stages of development – HEE
	LD Forensic Essentials Training Resource for Adult Community Teams	In development – HEE LD Programme
	LD Person Centred Care: Delivering Excellence in Learning Disability Services (training toolkit for Support Workers and Managers)	Resource aimed at support workers in health and social care in development – HEE LD Programme
Develop and/or enhance the specialist skills and knowledge among the generic mental health workforce in identifying and managing the mental health needs of CYP and adults with a learning disability and/or autism	HEE Learning Disability Core Skills Competency Framework	Complete
	Oliver McGowan Mandatory Training	Commissioning stage – HEE LD Programme
	HEE Advanced Clinical Practice (LD & Autism)	Early stages of development within HEE
	LD Tier 4 CYP Inpatient Autism Training	Early stages of development via HEE LD/MH & NHSE programme collaboration
Develop specialist skills among primary and secondary care medical staff (particularly GPs) so that they can effectively and confidently manage the complex and interrelated physical health needs (comorbidity and long-term conditions) displayed by people with autism and/or a learning disability	LD Credential in Primary Health Skills (Medical) for Physicians	Early stages of development – HEE MERP Programme/LD Collaboration
	Posited new role: ‘Learning Disability Physician’ (ERG recommendation)	Being reviewed and taken forward by another HEE workstream
To ensure that inpatient acute settings can be reasonably adjusted to meet the sensory needs of people with autism	Reasonable Adjustments Flag: a digital national record by 2023/24 (NHS LTP)	Post-pilot study planning for national roll-out
To enhance/develop the behavioural skills (e.g. PBS) among workforce staff (particularly within social care) who are involved in caring for people with a learning disability and/or autism – in order to improve rates of workforce retention, staff wellbeing and the delivery of skilled/robust care	HEE PBS Investment in regions	Ongoing
To review and develop career pathways that enable senior staff, who have acquired vast experience, knowledge and specialist skills, to continue providing clinical input and developing care pathways – while occupying a position of leadership	MH/LD Responsible Clinical Training Programme	In development within HEE Mental Health Programme to include LD