People with Learning Disabilities in Suffolk (age 14 and over)

Health and Social Needs Assessment

Dr Mashbileg Maidrag, Public Health Consultant
Ian Diley, Specialty Registrar in Public Health
Julie Ghurtskaia, Health and Care Programme Manager

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EXEcutive Summary

This needs assessment aims to identify the key needs of people with learning disabilities in Suffolk aged fourteen years and over.

Estimated number of people with LD in Suffolk

There are an estimated 13,700 people in Suffolk with a mild, moderate or severe learning disability and this is projected to rise by (5%) to around 15,000 by 2030. Of this, there are an estimated 2,800 people with complex or severe learning disabilities. However, less than 2,000 people are formally registered as having a learning disability on either Suffolk County Council (SCC) or NHS Primary Care LD registers. This difficulty in calculating an accurate county LD population reflects similar difficulties nationally. The gap in numbers between estimated prevalence and the registered population suggests a significant amount of unidentified and unmet need. It may be that there is as much as 80-85% of the LD population does not receive specialist LD support.

Inequalities

As a population, people with learning disabilities (LD) face considerable health and social inequalities. This population experiences significantly shorter life expectancy and significantly poorer physical and mental health than the general population. This is partly due to genetic factors in certain LD groups, poorer outcomes for the social determinants of health, and poorer access to health services.

Nationally, the median age at death for men with LD is 65 years and for women with LD it is 63 years. This is significantly lower than the life expectancy for men (78 years) and women (83 years) in the general population. A recent national study of LD mortality found that over 20% of people with a learning disability died before the age of fifty, compared with only 3-5% of the general population. This decreased life expectancy applies across people with moderate learning disability as well as more severe conditions. Most concerning was the fact that this study suggested that 38% of deaths to people with LD were amenable to change through good quality healthcare compared with only 9% of deaths in the general population study control group. Most common causes of deaths were heart (22%) and circulatory diseases (20%) at much younger age than those with general population which may relate to lifestyle issues and later detection.

Compared with general population, people with LD experience higher prevalence of epilepsy, respiratory disease, mental health disorder, dementia, sensory impairment, osteoporosis, obesity and higher incidence of accidental injury. Additionally, people with LD have lower rates of access to certain types of health service such as health screening, immunisation, and oral healthcare, which present huge potential to improve health and reduce inequalities in this group. It shows a potential for improvements in this area through improved access to health care through GP engagement, carer education and tailored communications (easy read documents, teletext etc). However, in terms proportion of emergency admissions and admission rate for non-
ambulatory conditions Suffolk is low in line with these comparator counties.

v. In terms of social outcomes, people with LD experience increased levels of inequity in relation to paid employment, stable accommodation, educational attainment and social inclusion. Each of these factors are significant determinants of health. In Suffolk in 2013, only 31% of people with LD were recorded as being in settled accommodation (markedly lower than for statistical neighbours 65-79%) and accommodation status was not known for 55% of LD population. The Care First system enables accommodation status to be recorded and this suggests that this higher proportion of unsettled accommodation could be due to recording practice.

Suffolk services for people with learning disabilities

vi. Suffolk provides an extensive variety and volume of services to meet the specific needs of people with learning disabilities and to provide both generic and specific care. These services are commissioned by both social services (SCC) and the NHS (the three Suffolk Clinical Commissioning Groups (CCGs)).

vii. A service mapping exercise was conducted as a part of this needs assessment for the 407 providers commissioned by SCC. A comprehensive map of services could not be completed due to a lack of response from a number of providers. However, there has been a transformation in the range of service types in recent years to meet the best practice requirements of Valuing People and Transforming Care, with services moving from residential settings to day services and community-based care. In Suffolk, the priority is now to move people from day services to community-based services that will enable maximisation of independence.

viii. The SCC strategy for implementation of Supporting Lives, Connecting Communities (SLCC) and personalisation is designed to provide services more effectively and efficiently while putting control of choice in the hands of LD service users. It is clear that the comparatively strong uptake of direct payment demonstrates good progress towards meeting these objectives. The common needs of the LD population reflect the chronic nature of many LD conditions and the intensity of support that can be required. As such, a large proportion of the interventions provided to people with learning disability in Suffolk is long-term Tier 3 provision, and consequently can be highly resource intensive. Comparatively low uptake of LD specific annual health checks may be hampering ability to identify serious or chronic illness at an early stage in development, increasing the risk of health inequities for this population.

ix. CCGs in Suffolk commission a range of specialist services for people with Learning Disabilities and generic services used by people with LD. These include specialist community support for learning disabled adults across Integrated Delivery Teams and specialist in-patient assessment and treatment beds for children, young people and adults with learning disabilities. Most NHS services are based in the community and there has been a move since 2009 to move the majority of service users out of
Norfolk Suffolk Foundation Trust (NSFT) inpatient or residential settings. Additionally, this needs assessment examined access to generic primary and secondary care for people with LD. Since 2011/12, there has been an increase in the number of people with a primary diagnosis of a learning disability admitted to hospital care.

In response to the findings of the Winterbourne View enquiry, the Department of Health published recommendations for changes to commissioning and providing practice for people with learning disabilities in its report, Transforming Care (2012). This required that placements for all people with LD be reviewed and everyone placed inappropriately in an inpatient setting be moved to community-based support no later than June 2014. There has been a dramatic reduction in the number of people with LD placed in inpatient settings in Suffolk in the past three years, as required by these recommendations.

Additionally, Public Health England’s Improving Health and Lives (IHaL) initiative for LD provides further best practice guidance for commissioners. Among the many recommendations it provides across primary care, acute care, specialist services, and wider health issues, Suffolk is performing comparatively poorly in certain specific areas. The proportion of people with LD accessing annual health checks (19% in the last Suffolk LD profile, 2013) is well below regional and statistical neighbours. For health screening access, while Suffolk figures are similar to many other areas, the proportion of people with LD accessing screening programmes is well below that of the general population. This could be due to reporting issues. Further, IHaL stresses the importance of ensuring adequate training for staff in acute healthcare services in effectively working with people with LD. Responses from stakeholders suggest that people do not think that staff working in generic health services are in fact adequately trained to work with this particular population.

The IHaL guidance for commissioners also notes the importance of good coordination between health commissioners and social care commissioners. The stakeholder survey highlighted concerns from both carers and staff members that such co-ordination was not always there in terms of support plans or communication between agencies.

Conclusions

There may be significant areas of unmet need for Suffolk’s LD population. The county strategy for providing support to this population needs to prioritise improved access to healthcare services such as annual health checks and health screening programmes.

The key area of unmet need for the county’s LD population may be the large number of individuals who are either identified as having a learning disability late, or never identified at all. The gap between estimated prevalence and registered population is large. There is likely to be a large population who could benefit from Tier 1 to 3 social care support or through supported access to healthcare who may never receive this assistance.

Further, this needs assessment has identified areas for data recording
improvement, identifying a lack of centralised detailed service provider information and a lack of consistency in the approach to provider performance management. Improving access to information about available services and offers and the level of care quality, would support both the process of personalisation and commissioners’ ability to monitor provider performance.

xvi. Despite these areas of potential unmet need, this assessment has found areas of good practice with evidence of good progress towards local policy objectives of moving services from residential and day settings to community-based settings and increasing personalisation. Further, responses to the stakeholder survey suggest high levels of confidence in the ability of services to meet the social education and safety needs of the LD population. Service users have also reported how the care and support they have received has enabled them to integrate better in their communities and improve their life skills and opportunities.

Recommendations

**Recommendation 1** – Local authority and health care commissioners in Suffolk to ensure that data recording practices/systems facilitate and require recording of social circumstances (including accommodation status) of its LD service users. This will address a significant information gap not present in regional and statistical neighbour counties.

**Recommendation 2** – Systems for recording safeguarding referrals, alerts and action plans should be amended to ensure that data on people with learning disability can be disaggregated from data for other service users.

**Recommendation 3** – The Suffolk Learning Disability Partnership/Mental Health and Learning Disabilities Joint Commissioning Group should consider the appropriate use of the Health Equalities Framework in assessing the level of health inequalities in the county’s LD population as part of the development of its LD strategy. This development work should enable improvements in processes for completion of the Self-Assessment Framework.

**Recommendation 4** – The Suffolk Learning Disability Partnership/Mental Health and Learning Disabilities Joint Commissioning Group should consider the appropriate use of the Quality of Life Standards in guiding expectations for care/support quality in service contracts and in personal care plans, assessments and reviews.

**Recommendation 5** – Both health and social care commissioners should consider requiring all LD service providers to participate in a service mapping exercise to collate information on access arrangements, intervention types available, and target populations. This will facilitate performance monitoring, commissioning processes, and service user/carer provider choice.

**Recommendation 6** - Suffolk CCGs should consider undertaking an audit of a representative sample of screening appointment invitations to people with LD to assess frequency of use of appropriate communication methods such as easy read documentation. The objective of this audit would be to determine whether
improvements could be made to the screening appointment invitation process for this population to help increase screening uptake.

**Recommendation 7** – Health and Social Care Commissioners and Public Health should continue prioritising and co-ordinating efforts to increase uptake of LD annual health checks. This should enable improvements in identification of health issues at an early stage for people with LD and improve uptake of screening. Methods for improving uptake of health checks could include ensuring that information materials are accessible to the LD population and appropriate communication support is provided. This should include support for carers as they provide a vital role in facilitating service user access to health checks.

**Recommendation 8** – Commissioners to undertake a pilot audit of a representative sample of LD service users to assess process and outcomes for support plans and interventions in relation to Quality of Life Standards. This will enable commissioners to better understand the effectiveness of current services in complying with agreed support plans and meeting service user life objectives.

**Recommendation 9** - Social care commissioners to consider options for ensuring a practical, regularised framework for contract performance monitoring across all LD service providers is developed and implemented. This should include assurance that a set of SMART performance indicators linked to best practice standards (such as Quality of Life Standards) are included in all contracts and that the process for monitoring relates directly to these performance indicators. Schedules and forums/methods for review should be explicitly recorded in contracts and compliance with the review system monitored.

**Recommendation 10** – Health and Social Care commissioners should continue to prioritise the development of a standard integrated transition process for CYP involving education, health, and care with a focus on a person centred approach. This development process should consider stakeholder involvement, identification of named co-ordinating individuals, improved recording/tracking systems, and liaison across geographical boundaries.

**Recommendation 11** – Health and social care service commissioners to consider how current systems for supporting clients' health service referral and social care service purchase can be improved to ameliorate co-ordination between agencies. This could include identifying named care co-ordinators for service users able to liaise across organisational boundaries.
MAIN REPORT

1.0 INTRODUCTION

This needs assessment aims to identify the key needs of people with learning disabilities in Suffolk aged fourteen years and over. It provides an assessment of how well services are currently addressing these needs. Where unmet need or gaps in knowledge are identified, recommendations are provided for commissioners to consider.

The needs assessment was planned through an expert steering group comprising key stakeholders from within health and social care commissioning organisations. The steering group was chaired by representatives from Public Health Suffolk who have authored the final report.

Data were collated from publicly available routine health and social care data sources, organisational activity and cost data sources, key commissioner, provider and user/carer stakeholders, and from peer-reviewed research evidence and grey literature.

The needs assessment relates to the Suffolk resident learning disability population covered by Suffolk County Council and the West Suffolk, Ipswich and East Suffolk, and the Great Yarmouth and Waveney Clinical Commissioning Groups. It specifically relates to the population aged 14 and above population.

1.1 Methods

1.1.1 This needs assessment follows a framework which amalgamates three distinct approaches to assessment:
- Epidemiological assessment
- Corporate assessment
- Comparative assessment

The epidemiological approach to a LD needs assessment involves collation and analysis of data relating to time, person and place: i.e. who in a population is more likely to have (or be at risk of having) learning disabilities, where in a geographical area is prevalence more or less frequent, and how this prevalence has changed over time. The epidemiological approach also assesses the effectiveness of particular interventions for the population that has been identified. The corporate approach emphasises the systematic collection of the knowledge and views of stakeholders on services and needs. This allows for qualitative analysis of both the impact of conditions on lives and health and the effectiveness of services currently in place. The comparative approach examines the extent to which local services meet the needs of their population in relation to the performance/quality of services in other areas.

1.1.2 Epidemiological assessment

Data was collated using national sources of routine data (e.g. IHaL, PANSI, POPPI) to establish synthetic estimates of the LD population and local LD registers (held by Suffolk County Council and NHS GP practices) to determine numbers of individuals formally identified as having a learning disability. Additionally, validated national sources of best practice were identified to provide recommendations for evidence-based interventions and quality standards (e.g. NICE, Royal Colleges, Public Health England).
1.1.3 Corporate assessment
Existing sources of stakeholder feedback were identified through colleagues in Adult Social Care services and through service user advocacy agencies to assist with qualitative assessment of the extent to which needs are being met. In addition, a bespoke web-based survey was developed and implemented to seek responses to specific questions agreed by the needs assessment steering group.

1.1.4 Comparative assessment
In order to identify the scope and volume of support services for the LD population in Suffolk, a service mapping exercise was conducted in July and August 2014.

1.1.5 Progress of the needs assessment was monitored and guided by a task-specific steering group comprising representatives from Public Health, Adult Social Care Services, and CCG commissioners.

1.1.6 Drafts of the needs assessment report were provided to key stakeholder groups (including the Learning Disability Partnership) for consultation prior to the report’s finalisation. Comments from these key stakeholder groups were considered and addressed as appropriate.

1.2 Service mapping exercise
1.2.1 The main aim of this exercise was to get a clear picture on current health and care provision for this group of population. Information was collected in the following areas:
- Locations of services
- Tier of service provided
- Service setting (community, day care, residential etc)
- Types of intervention provided
- Age groups supported
- Client groups supported (by severity of learning disability)
- Access information (opening hours, out of hours access, transport links, provision of LD appropriate client information)

1.2.2 Initially the identification of current services was sought via evaluation of the current provider contracts. However, these contracts are not held in a centrally located database and do not contain a level of detail to identify the specific services being provided to the LD population. Therefore, providers’ responses to the authors’ information outreach exercise has served as the basis for mapping current services.

1.2.3 The authors identified differing sources of information from which to develop a definitive list of service providers. These consisted of ACS finance department lists, Care Quality Commission (CQC) registers, and the Suffolk local offer website. The amalgamated list for the needs assessment was then used as a basis for the service mapping and providers were then contacted with a view to requesting the information noted in 1.2.1

1.2.4 Outreach by phone, face-to-face meeting, or email was achieved with 247 providers across the service type categories. Final responses were received from only 60 providers by the end of this process. This may reflect a lack of engagement with the mapping process by providers or potentially a lack of clarity within provider services over definitions of intervention types and target populations. The results of the exercise are provided in Appendix 5.
1.2.5 In addition, service activity and performance was assessed in relation to that of regional neighbours and statistical neighbours through the IHaL learning disability profiles and the annual Self-Assessment Framework results for 2013.

1.3 Limitations
Several areas of limitation were encountered in the development of this needs assessment. As noted above, the response from several providers to the service mapping exercise was limited meaning a comprehensive list of service providers and of the interventions available was not available. This hampers the authors’ ability to identify certain areas of unmet need. Additionally, numbers of people formally registered as having a learning disability in Suffolk are significantly lower than synthetic estimates for the county’s LD population. This is a problem that has been encountered nationally. While this means that accurate prevalence figures are difficult to acquire, it does point to significant unmet need where individuals with a learning disability may be missing out on support that may make a beneficial impact on their lives.

2.0 WHAT ARE THE PRIORITIES AND FOCUS OF THIS NEEDS ASSESSMENT?

2.1 Objectives
The objectives of this needs assessment are as follows:
- Identify the prevalence of learning disabilities in the Suffolk population aged fourteen years and over and project their future growth
- Identify risk factors for learning disabilities and specific population groups in at high risk of a learning disabilities diagnosis
- Assessment of inequalities in terms of health and social outcomes
- Map out current service provision to assess whether it meets the need of this group effectively in terms of availability, accessibility and acceptability whilst identifying areas for potential improvements
- Assess the performance of services for learning disabilities against national standards
- Provide recommendations for local commissioners to inform the planning and decision making process

2.2 Local priorities
Suffolk has defined its current strategy for adult care in its Supporting Lives, Connecting Communities (SLCC) approach (1). This approach is structured around the principles of prevention, integration, personalisation, community response, simplification of response, and promotion of independence for providing support and care to adults in need. The operating model for SLCC is based on three offers to the community: help to help yourself, help when you need it, and on-going support for those who need it.

2.3 This needs assessment seeks to identify the scope and extent of health and social care needs of people with learning disabilities in Suffolk and assess how well care and support provision can meet these needs in relation to the SLCC approach.

2.4 During the implementation of SLCC, it will be key to ensure that expert knowledge held for individuals by clinicians is not lost through changes to care access arrangements:
“...where one used to have a named physio, OT, SALT, Consultant Neurologist, Community Nurse and Community Paediatrician, social worker – for example – who knew the case, kept the files and was quickly available in emergency, one now has to take the lengthy route of reapplication via the GP/Customer First for every need.”

(Carer)

2.5 Additionally, NHS commissioning services have identified provision and take-up of annual health checks for people with learning disabilities as a key priority for analysis as part of this needs assessment. GP practice managers have reported to Public Health Suffolk that although LD patients are invited to attend for a GP health check, many do not come because their carers do not support it, through concern at its relevance and usefulness. This issue is being addressed as a recommendation for a carer education intervention arising from health and social care integration work that is currently ongoing.

3.0 WHAT IS THE ISSUE AND WHY IS IT IMPORTANT FOR SUFFOLK?

3.1 As a population, people with learning disabilities face considerable health and social inequalities. This population experiences significantly higher rates of mortality and morbidity, significantly poorer outcomes for social determinants of health, and increased levels of unmet health need in comparison to non-learning disabled peers.

3.2 A significant proportion of this excess mortality and morbidity is avoidable. Much of the increased risk of negative physical and mental health outcomes in this population can be attributed to socio-economic factors and to barriers to health service access. Assertive support to vulnerable groups, effective health promotion, early diagnosis and high quality care and treatment can ameliorate these risks.

3.3 There are a number of national policy and strategy documents to guide supporting people with learning disabilities in England:

i. Key among them is *Valuing People Now* (2009) (2), which aims to address the needs identified by people with learning disabilities within the framework of current government priorities and in relation to the recommendations for improved access to healthcare identified in *Healthcare for All* (2008) (3). *Valuing People Now* relates primarily to the health needs of people with learning disabilities and sets out expectations against four key principles: rights, independent living, control, and inclusion.

ii. The *Health Equalities Framework* (HEF) and commissioning guide (2013) (4) provides a framework for assessing the effectiveness of service provision for learning disability support in terms of equality of access and outcomes. It is based on assessment of the determinants of health inequality and enables commissioners to assess the impact of commissioning decisions on the health of people with learning disabilities. The Improving Health and Lives observatory for learning disabilities (IHaL) has developed a further guide for commissioners (5) in conjunction with the Royal College of General Practitioners and the Royal College of Psychiatrists.

iii. The review into abuse of people with learning disabilities and autism at the Winterbourne View care home led to set of recommendations and a programme of action designed to ensure that this population are cared for and supported in line with national best practice and their individual needs and that their wishes and the wishes of their families are appropriately acknowledged and prioritised in planning and
delivering their care (6). Further best practice guidance is set out in the Mansell Report of 2007 (7) and by the Royal College of General Practitioners in relation to access to annual health checks in primary care (8).

iv. The National Institute for Health and Care Excellence (NICE) have developed a clinical guideline for autism (9), and are currently in the process of developing clinical guidelines for challenging behaviour and learning disabilities (due May 2015) and mental health problems in people with learning disability (due 2016). In addition, there are ancillary advice documents and technology appraisals for a range of specific learning disability diagnoses and treatments.

3.4 The public sector Equality Duty of the Equality Act (2010) requires that public bodies must consider all individuals when developing policy, delivering services and in recruiting and employing staff. This encompasses eliminating discrimination, advancing equality of opportunity and fostering good relations between different people while pursuing their activities (10). There is strong evidence to suggest that general programmes to reduce inequalities in health may not be effective for people with learning disabilities and that specific programmes may need to be developed to ease inequalities in this population.

3.5 The population of Suffolk (over 14 years) is projected to increase by 7% to around 644,000 by 2021 (11). This increase in population size, added to improved survival rates for pre-term birth babies and changes to diagnostic practice could see increases in both the proportion of the population and the total number for people diagnosed with a learning disability.

4.0 WHICH POPULATION IS THIS NEEDS ASSESSMENT ABOUT?

4.1 The needs assessment will identify needs in people aged fourteen years and over. This enables the needs of individuals in transition between children and young people’s services and adults services to be assessed along with adults of all ages. A needs assessment for children and young people with learning disabilities has recently been completed by Public Health Suffolk and can be accessed through the Healthy Suffolk and Suffolk Observatory websites (12).

4.2 Geographically, this will cover residents of Suffolk county, including those whose care services are supplied outside of the county’s borders (e.g. where an individual’s residential placement is outside of the county). Activity and cost data are examined at county level, district level, CCG level and Office for National Statistics output area level where this is available.

4.3 IHaL provides useful definitions of a person with a learning disability for both children and adults. In their terms, adults will be considered to have a learning disability if any of the following conditions are met (13):

i. When a child they were identified within education services as having a Special Educational Need (SEN)¹ associated with ‘moderate learning difficulty’, ‘severe learning difficulty’ or ‘profound multiple learning difficulty’;

ii. They attended a special school or unit for children with ‘moderate learning difficulty (or mental handicap)’, ‘severe learning difficulty (or mental handicap)’ or ‘profound multiple learning difficulty (or mental handicap)’;

¹ Or Special Educational Need and Disability (SEND) from 1st September 2014
iii. When a child they typically scored lower than two standard deviations below the mean on a validated test of general cognitive functioning (equivalent to an IQ score of less than 70);

iv. As an adult they scored lower than two standard deviations below the mean on a validated test of general cognitive functioning and there is good evidence to suggest that they have had difficulties in learning since childhood. Care should, however, be taken when considering the results of tests carried out in English on adults for whom English is not their first language, or where the person is experiencing disrupted mental health at the time of the test;

v. They have been identified as having learning disabilities on locally held disability registers (including registers held by GP practices or Primary Care Trusts) or by relevant Read Codes in health information systems;

vi. They report having significant difficulties in literacy and numeracy and there is good evidence to suggest that they have had these difficulties since childhood;

vii. They screen positive for learning disabilities using a validated screening test;

viii. In response to survey questions, they identify themselves (or a carer identifies them) as having a long-term illness, health condition or disability associated with ‘learning disabilities’ (or equivalent term) and have low educational attainment (equivalent to no GCSEs at grade C or above). This criterion is only likely to be used by the Observatory, and only when working with the results of large-scale social or health surveys that have already been completed;

4.4 IHaL uses Department for Education categorisations of level of learning disability in its definition (14). These definitions are provided below and are useful categorisations of need for the purposes of this needs assessment. They relate explicitly to children in terms of the Department of Education can be used to cover any point in the life course:

**Moderate learning difficulties:** People with moderate learning difficulties find it hard to attempt new tasks alone and require individual support. This often stems from a lack of self-esteem and confidence in their own abilities;

**Severe learning difficulties:** People with severe learning difficulties experience significant intellectual cognitive impairment requiring a high level of support in educational, social or work environments;

**Profound or multiple learning difficulties:** People with profound and multiple learning difficulties may often also have physical or sensory disabilities and will have significant problems with learning.

4.5 IHaL reports that the prevalence of mild disabilities in populations is often most markedly underestimated. These are disabilities that may not manifest clearly enough to enable identification and diagnosis and allow for needs to be assessed and addressed.

“There are a lot of people with mild learning disabilities who are struggling to cope without support. People often come to our groups with letters that need reading and explaining and questions about their support. Our services are used as a safety net for people with mild learning disabilities”

(Provider member of staff)
4.6 The National Autistic Society define autism as “a lifelong developmental disability that affects how a person communicates with, and relates to, other people… [the society notes] It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways.” (15)

NHS Choices adds that the term “neurodiverse” is also used to describe the condition and note that the main features of autistic spectrum disorder (ASD) usually develop in childhood although their impact may not be felt until the individual experiences a significant life change (such as a change of school) (16). NHS Choices estimate that there is a UK prevalence of one per 100 people in the general population.

4.7 Asperger’s syndrome is a form of autism where individuals experience difficulties in social communication, social interaction and social imagination (17). While similar to autism, people with Asperger’s Syndrome experience fewer difficulties with speech and are frequently of average or above average intelligence.

4.8 The ICD-10\(^2\) diagnostic codes for learning disabilities including ASD and Asperger’s Syndrome are grouped under the heading “Disorders of Psychological Development” and are identified as codes F80 to F89 with ASD noted as codes F84.0 and F84.1 and Asperger’s Syndrome as F84.5. These codes are used in the diagnosis and identification of people with learning disabilities in the NHS and are used in this needs assessment to identify people with learning disabilities in Suffolk who access NHS health care.

4.9 Additionally, this group of population is projected to increase by 8.5% by 2030 which will increase demand on local system.

5.0 ESTIMATING PREVALENCE OF LEARNING DISABILITIES IN SUFFOLK

5.1 There are acknowledged difficulties in estimating the prevalence of learning disabilities in geographic and social populations. Learning disabilities are not always diagnosed by health, social care or education agencies. While there are recognised systems for identifying potential learning disabilities symptoms or attributes in the school population, any methods for identification are less systematised in the adult population unless individuals or their carers actively seek support. Where a learning disability has been identified, there is no consistency in recording or registering this fact across health services and social care services, or between children’s’ services and adult services.

5.2 Synthetic estimate
IHaL estimated in 2004 that while there were approximately 224,000 people with learning disabilities known to services in England, there was an estimated population of 985,000 people with learning disabilities in England of all ages (18). This estimate took into account hidden numbers of people with mild disabilities following a model reflecting expected prevalence. In 2014, IHaL estimates that the number of adults aged 18 and over with learning disabilities in Suffolk identified at GP level is 4.5 per 1,000 population. This estimate drops to 4.3 per 1,000 for adults identified by local authorities. When this is applied to Suffolk age stratified population numbers, this would suggest an estimate of around 2,900 people over the age of 14 known to health or social care services in the county.

\(^2\) International Statistical Classification of Diseases and Related Health Problems 10\(^{th}\) Revision.
However, if the ratio of identified need to hidden need estimated by IHaL is correct, we can estimate that there are more likely to be around 13,000 people over the age of 14 with mild to profound learning disabilities (including ASD and Asperger’s). However, these estimates are subject to significant potential inaccuracy and this caveat highlights the need to improve processes for identification, diagnosis and recording of learning disabilities in the adult population.

Example comments from provider service stakeholders reflect the perceived gap between identified and unidentified need:

“National data from the Improving Health and Lives Team has highlighted that there is a huge discrepancy between those identified and those who remain unidentified by services. This is certainly reflected within this organisation, especially those with mild learning disability.”

(Provider service staff member)

The following provides a LD population estimation for specific age ranges for Suffolk.

Table 1: Estimated potential prevalence of learning disabilities (including autistic spectrum disorders and Asperger’s Syndrome) for Suffolk by age range using IHaL estimated prevalence

<table>
<thead>
<tr>
<th>Age range</th>
<th>Estimated LD population known to services</th>
<th>Estimated total LD population</th>
</tr>
</thead>
<tbody>
<tr>
<td>14-18 years</td>
<td>190</td>
<td>850</td>
</tr>
<tr>
<td>14-25 years</td>
<td>370</td>
<td>1,650</td>
</tr>
<tr>
<td>18+ years</td>
<td>2,750</td>
<td>12,100</td>
</tr>
<tr>
<td>25+ years</td>
<td>2,560</td>
<td>11,250</td>
</tr>
</tbody>
</table>

Source data: Office for National Statistics and IHaL

5.3 The Institute of Public Care provides population projection calculations for local authority planners and commissioners through its Projecting Adult Needs and Service Information system (PANSI) (19) and its Projecting Older People Population Information System (POPPI) (20). It estimates that there are 13,664 people over the age of 18 in Suffolk with a learning disability of any type; of these, 2,801 having a disability categorised as moderate or severe (rather than mild). It is this estimated prevalence that will be used throughout this needs assessment.

As a comparison with other types of disability, PANSI estimates that there are just over 53,000 people with moderate or severe physical disabilities and around 81,000 people with a common mental health disorder in the county. Many individuals are likely to have more than one type of disability; learning disability, physical disability and/or mental health disability.

5.4 The National Centre for Social Research estimated in 2007 that around one per cent of the adult population of England has an autistic spectrum disorder (21). Their study estimated that prevalence in males was higher than in females (1.8% compared with 0.2%). If this is the case, it would suggest that there are around 6,000 adults with autism in the county. PANSI estimates that there are 4,255 people aged over 18 with an autistic spectrum disorder in Suffolk (19).

5.5 Learning disabilities are an integral attribute of Down’s Syndrome. The prevalence of Down’s Syndrome in the UK is estimated to be around 6.3 per 10,000 population

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3 Of the c10,000 people with learning disabilities.
(19). Using prevalence estimates, PANSI estimates that there are 266 people with Down’s Syndrome in Suffolk.

5.6 PANSI and POPPI provide projections of population size and prevalence for learning disability, physical disability and mental ill health from 2015 up to 2030. For Suffolk as a whole, it projects that by 2030, the county’s total LD population will be 14,949 (an increase of 8.5% from the estimate of 13,664 in 2014). For moderate or severe learning disabilities, the population size is projected to be 2,942 by 2030 (an increase of 5% from 2,801 in 2014). These population level increases are predicted through predicted increases in LD prevalence and changes in population size and structure in the county. The LD population is projected to increase in the age groups 35-44, 55-64, and over 65s.

5.7 Prevalence comparison within Suffolk

5.7.1 The table below provides estimates of current numbers of people with a learning disability now and by 2030 for each district in Suffolk.

Table 2: Learning disability baseline estimates by age for Suffolk districts: 2014 and 2030

<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>18-24</td>
<td>146/134</td>
<td>162/188</td>
<td>352/357</td>
<td>171/164</td>
<td>228/223</td>
<td>203/185</td>
<td>225/207</td>
</tr>
<tr>
<td>25-34</td>
<td>197/182</td>
<td>266/261</td>
<td>533/508</td>
<td>242/227</td>
<td>359/319</td>
<td>261/249</td>
<td>294/279</td>
</tr>
<tr>
<td>45-54</td>
<td>310/244</td>
<td>175/178</td>
<td>415/408</td>
<td>350/287</td>
<td>373/320</td>
<td>436/344</td>
<td>371/297</td>
</tr>
<tr>
<td>55-64</td>
<td>270/304</td>
<td>147/180</td>
<td>331/389</td>
<td>306/354</td>
<td>295/348</td>
<td>397/441</td>
<td>335/370</td>
</tr>
<tr>
<td>Total</td>
<td>1178/1103</td>
<td>933/1037</td>
<td>2075/2159</td>
<td>1350/1319</td>
<td>1595/1561</td>
<td>1636/1548</td>
<td>1534/1477</td>
</tr>
</tbody>
</table>

* 2030 estimates indicated in blue

Data source: PANSI

5.7.2 It is clear that across Suffolk, PANSI predict the numbers of young adults (18-34) with a learning disability will decrease over the period while the numbers of people with LD aged over 55 will increase. This change in predicted prevalence relates primarily to changes in the demographics of the Suffolk population rather than changes in prevalence rates for each age range. Districts with larger urban areas (Ipswich, St Edmundsbury and Waveney) all show projected increases for the LD population in the 35-44 year age range. This information could be used to inform planning for services such as those helping people with LD into employment.

5.8 Prevalence comparison with statistical neighbours

5.8.1 The Office for National Statistics (ONS) note four statistical neighbours for Suffolk arising from analysis of the 2001 Census. Prevalence estimates and projections for each of these counties are provided below.

Table 3: Learning disability baseline estimates by age for Suffolk’s statistical neighbours: 2014 and 2030

<table>
<thead>
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<tbody>
<tr>
<td>18-24</td>
<td>1487/1460</td>
<td>1644/1638</td>
<td>1335/1344</td>
<td>615/547</td>
<td>1049/1010</td>
</tr>
<tr>
<td>25-34</td>
<td>2154/2022</td>
<td>1912/1840</td>
<td>1738/1701</td>
<td>819/757</td>
<td>1404/1365</td>
</tr>
<tr>
<td>35-44</td>
<td>2148/2258</td>
<td>2045/2223</td>
<td>1858/1966</td>
<td>881/922</td>
<td>1495/1609</td>
</tr>
<tr>
<td>45-54</td>
<td>2432/2075</td>
<td>2543/2135</td>
<td>2133/1821</td>
<td>1094/859</td>
<td>1845/1509</td>
</tr>
<tr>
<td>55-64</td>
<td>2085/2388</td>
<td>2316/2526</td>
<td>1724/1998</td>
<td>929/1047</td>
<td>1627/1795</td>
</tr>
<tr>
<td>Total</td>
<td>10306/10203</td>
<td>10460/10362</td>
<td>8789/8829</td>
<td>4339/4132</td>
<td>7420/7287</td>
</tr>
</tbody>
</table>

Data source: PANSI
5.8.2 For counties for whom Suffolk is usually measured against, the nearest comparator is Devon in terms of numbers and patterns of age related increase and decrease. This is useful in relation to comparison of service provision and service use. There is a consistent increase in prevalence for those aged over 35 for all neighbours.

5.9 Summary
There are major difficulties in calculating accurate numbers for learning disability populations in Suffolk and across the United Kingdom. In all regions, there is predicted to be a large proportion of the LD population who do not present to health or social care services until late in life and for whom identification of need and potential support is problematic. PANSI and POPPI estimate that there are over 13,600 people over the age of eighteen with one or more learning disabilities in Suffolk. This is projected to rise to 15,000 by 2030.

6.0 **RISK FACTORS FOR LEARNING DISABILITIES**
Specific risk factors can be identified for the development/presence of learning disabilities in children and adults. Information about these risk factors is provided below:

6.1 **Down's Syndrome (and other congenital disorders)**

6.1.1 Down's Syndrome is a genetic condition that produces a characteristic range of physical features and learning disabilities. All children born with Down's Syndrome have some degree of learning disability and delayed development but the extent of disability and developmental delay varies from child to child (20). Down's Syndrome is one of the most common genetic causes of learning disability, with around 750 babies born with the condition in the UK each year. It is caused by the presence of an extra copy of Chromosome 21 in a baby's cells and the chances of having a baby born with Down's Syndrome increases with maternal age. There is no evidence that anything can be done to prevent Down's Syndrome during pregnancy beyond reducing risk through earlier age at maternity. Screening for Down's Syndrome is universally offered as part of the national antenatal screening programme with additional targeted tests available for high risk groups.

6.1.2 In addition to learning disabilities, many children and adults with Down's Syndrome have associated health conditions such as (20):
- Heart disorders,
- Bowel abnormalities,
- Digestive problems,
- Hearing and vision impairments,
- Thyroid dysfunctions,
- Infections,
- Cervical spine dislocation,
- Blood disorders

While all healthcare services should be equipped and trained to enable equity of access to care for people with Down's Syndrome or any other source of learning disability, it is particularly important that healthcare services make reasonable adjustments to their provision to serve people with these conditions.

6.2 **Pre-term birth and low birth-weight babies**

6.2.1 Although the majority of children born pre-term do not develop major impairments, more pre-term children than full-term children develop cerebral palsy and/or other
cognitive impairments, and the risk increases with decreasing gestational age (23). There is also evidence that pre-term birth increases the additional risk of more subtle impairments of attention, executive function, language, visual-perceptual abilities, and fine motor function that may influence the ability of a child to function at school and in home life (23). Studies have suggested that the prevalence of these lower severity dysfunctions and of associated ADHD is increasing and that they may occur in as many as 50-70% of very low birth-weight babies (<1,500g) (24). It is estimated that the incidence of learning disability in pre-term babies born before 26 weeks of pregnancy is 4 per 10 births (25).

6.3 Events during birth

6.3.1 A learning disability may be caused by an interruption in a baby’s oxygen supply for a significant period of time. There is a risk of this occurrence during the birthing process. There is no available incidence data on the numbers of children with learning disabilities caused through this route.

6.4 Head injury

6.4.1 Head or brain injury is a rare causative factor for learning disabilities. It is also potentially a factor in worsening a learning disability in people with an existing LD condition. Common risk factors for brain injury include falls and road traffic accidents, for which preventative measures such as stair-gates, seat belts, cycle helmets and 20mph road zones are based on relatively strong evidence bases. Such brain injury is more likely to be a causative factor in learning disability for infants and children as it may disrupt brain development. There is evidence that head injury in adulthood is more associated with potential mental illness such as depression and schizophrenia.

6.5 Infection

6.5.1 Some childhood infections can affect the brain, potentially leading to learning disabilities. The most common LD associated infections are encephalitis and meningitis. Infections leading to LD can occur in the antenatal, perinatal and postnatal period (26):

- **Antenatal**:
  - Rubella can cause learning disabilities when acquired in utero, and is more severely damaging the earlier the infection occurs in pregnancy,
  - HIV, Toxoplasmosis and Cytomegalovirus can all also lead to the development of learning disabilities in the antenatal period,
- **Perinatal**
  - In the perinatal period (24 weeks pregnancy to 7 days post-birth), infection with Herpes Simplex can lead to the development of LD,
- **Postnatal**
  - Infection with meningitis or encephalitis causing agents or with common childhood diseases such as measles or pertussis (whooping cough) may lead to the development of a learning disability.
7.0 MORTALITY AND MORBIDITY AND FEATURES OF THE POPULATION

7.1 Mortality

7.1.1 It is acknowledged that people with learning disabilities have poorer physical and mental health and die younger than the general population. A national Confidential Inquiry into the deaths of People with Learning Disabilities (CIPOLD) has been instigated to investigate the avoidable or premature deaths of people with learning disabilities in England. Between 2010 and 2012, the deaths of 247 people with learning disabilities were reviewed and compared with a non-learning disability control sample of people dying in the period (27).

7.1.2 CIPOLD found that the median age of death for the learning disability cohort was 65 years for men and 63 years for women. This is significantly lower than the life expectancy for men (78 years) and women (83 years) in the general population. Around 22% of the members of the learning disability cohort died before the age of fifty. This compares with 5.4% of men in the general population and 3.3% of women (25). This difference in age at time of death is illustrated in Figure 1.

Figure 1: Age at time of death of people with learning disabilities compared with the population of England and Wales:

![Age at death graph]

Source: CIPOLD, 2013

7.1.3 Around 70% of the learning disability cohort in CIPOLD had either a mild or moderate learning disability, suggesting that premature death is not solely a risk for those with severe or profound learning disabilities. As with the general population, the most common underlying causes of death were heart and circulatory disorders (22%) and cancer (20%). However, the proportion of people with learning disabilities dying with cancer or heart and circulatory disease was lower than for the general population. Additionally, people with LD who died of cancer or heart/circulatory disease, on average died at a younger age than those with similar disease in the general population which may relate to later detection of disease. Uptake of cancer screening is lower in the LD population than the general population. Deaths from diseases of the nervous system and those relating to congenital or chromosomal disorders were of much greater prevalence in the LD cohort, reflecting the link between chromosomal disorders such as Down’s Syndrome and learning disabilities.
7.1.4 CIPOLD applied Office for National Statistics (ONS) definitions for deaths that were amenable to change or preventable. The inquiry found that while 25% of deaths in the control group were preventable by public health intervention (e.g. smoking cessation), only 17% of deaths in the LD cohort were preventable. However, while 9% of deaths in the control group were amenable to change through good quality healthcare, this compared to 38% of deaths in the LD group. This suggests that a large proportion of deaths for people with learning disabilities occurred earlier than they might have done because of delays or problems with diagnosis or treatment, problems with identifying need, and difficulties in providing appropriate care in response to changing needs (27). It also suggests that this proportion is higher than that for the general population. As such, this is a significant modifiable area of health inequality for people with learning disabilities.

7.1.5 Additionally, fewer deaths of people with learning disabilities were reported to the coroner than for the general population (38% compared with 46%). The CIPOLD panel identified several deaths in the LD cohort where the coroner should have been notified but was not. CIPOLD make no comment as to why this may have been the case. Further, the review noted that less than a quarter of the deaths in the LD cohort had an LD diagnosis recorded on the death certificate. This suggests that routine data sources for measuring mortality and causes of mortality in people with learning disabilities are likely to be missing significant amounts of data.

7.1.6 The CIPOLD review report (2013) concluded that there was a need for healthcare services to improve identification of people with learning disabilities, record and communicate this information, implement reasonable adjustments to care in light of this population’s needs, and audit this provision. The panel also concluded that ill-informed assumptions had often be made by clinicians about quality of life of LD patients and the appropriateness of medical or social interventions. In several cases, people having problems using recognised care pathways were not referred to specialist services. Additionally, CIPOLD recommended that a named health professional be identified to co-ordinate care for people with multiple health conditions and that their health records should be held by the patient or carer to aid multi-agency working.

7.1.7 Further research by IHaL suggests that there are two specific causes of death in LD populations that are both frequently cited on death certificates and clearly preventable (28):

- Lung problems caused by solids or liquids going down the wrong way (14% of deaths);
- Epilepsy or convulsions (13% of deaths);
This supports the CIPOLD finding that the most frequently cited direct cause of death was a respiratory problem. Movement of learning disability support from residential services and day services to community services requires the consideration of systems for mitigation of health risks relating to these particular concerns. Community based support may provide reduced scope for risk assessment review and clinical supervision.

7.1.8 There is a consensus across the wider evidence base that people with learning disabilities experience reduced life expectancy in comparison to the general population. Predictors of mortality include the severity of the learning disability, reduced mobility, difficulties with feeding such as dysphagia, and chromosomal co-morbidities such as Down’s Syndrome (29). However, there is a trend for increasing life expectancy in the LD population. Research has suggested that this increase may be due to greater support for community lifestyle, improvements to person-centred
care and support, and improved access to healthcare interventions such as antibiotic treatment for chest infections and cardiac surgery for congenital heart disorders (30). This potential increase in life expectancy may increase the prevalence of LD in Suffolk’s population and also increase the number of people with multiple conditions alongside learning disabilities. This would raise the demand for service provision.

7.2 Morbidity
Provided below is information about the symptoms and attributes of learning disabilities. Information on Suffolk prevalence for each of these specific symptoms/attributes was not available for use in this needs assessment.

7.2.1 Symptoms/attributes prevalence
Learning disabilities are disorders where one or more of the processes involved in understanding and using language are hindered leading to difficulties in listening, thinking, speaking, reading, writing, or performing mental arithmetic. Specific conditions within the umbrella term of learning disabilities include dyslexia, dyspraxia, Attention Deficit Disorder (ADHD), dysphasia, autism and Asperger’s Syndrome.

7.2.2 Dyslexia:
Dyslexia is a learning difficulty that affects the ability to read and spell with accuracy and fluency. It occurs across the full range of intellectual ability. Dyslexia is thought to be around four times as common in males as in females with an estimated upper limit of prevalence of around 10% of the population for mild to severe forms of the condition. Many people with the condition develop adaptive strategies to work with the lifelong disorder and ameliorate its effects (31).

7.2.3 Dyspraxia:
Dyspraxia is a developmental disorder affecting fine or gross motor co-ordination in people of all ages. It can also affect people’s speech. It is a lifelong condition that varies in severity of presentation and varies in the level of impact on daily activities. Many people with dyspraxia may experience difficulties in educational activities and when driving a car, for instance, in adulthood. Common co-conditions include social and emotional difficulties, difficulties with personal organisation, and difficulties with memory, perception and mental processing (32). Research suggests that prevalence of the condition is around 6% in the United States, with 2% of the population experiencing severe symptoms (33).

7.2.4 Dysphasia (Dysarthria):
Dysphasia is an impairment of language while dysarthria is a speech disorder caused by disturbance of muscular control in the mouth. Both conditions often co-exist. Both conditions are caused by physical damage/deterioration to the brain and can arise from space-occupying lesion, head injury or dementia. Both conditions can be treated by speech and language therapy, where patients are taught techniques to improve speech clarity and assisted with alternative methods of communication. These conditions may have a severe, debilitating effect on the everyday life of patients but the prognosis for recovery is better where the disorder arose from traumatic injury than when it arose after stroke, for instance. Cumulatively, the two conditions are classed as rare with less than one case per 2,000 people (34).

7.2.5 Attention Deficit hyperactivity disorder (ADHD):
ADHD is an umbrella term for a group of developmental disorders including inattentiveness, hyperactivity and impulsiveness. Common symptoms include short attention span, restlessness, and over-activity. It can occur across the full range of intellectual ability and can often co-exist with sleep and anxiety disorders. Most cases
are diagnosed in childhood and symptoms often improve with age. Risk factors for ADHD include pre-term birth, low birth-weight and maternal use of alcohol or smoking during pregnancy. The estimated prevalence of ADHD in the UK is between 2 and 5% in childhood and young adulthood and is more common in males than females (35).

7.2.6 Autistic Spectrum Disorders (ASD) including Asperger’s Syndrome:
ASD is a condition that affects social interaction, communication, and behaviour. Common symptoms include problems understanding other people’s emotions, delayed language development, and difficulty participating in conversation. Additionally, people with ASD often make repetitive physical movements and can become upset if repetitive physical routines are disrupted. ASD often co-exists with mental health conditions. It is thought that the disorder is caused by an interaction between genetic and environmental factors. The condition is frequently diagnosed during childhood rather than later in life but can often become apparent during a significant change in a person’s life, such as the move from primary to secondary education. Some adults with the condition may experience difficulty in finding and maintain employment because of the social demands and disturbance to set routines that may be required. Symptoms can be ameliorated through education and behavioural support; through social learning programmes, leisure activity programmes, or skills for daily living programmes. Prevalence in the UK is estimated to be around 1%, equating to an ASD population of around 700,000. This estimated prevalence has risen since the 1990’s which may be due to changes in diagnostic processes (16).

7.3 The health of people with learning disabilities
The health impacts of learning disability diagnoses can be considered in two ways: firstly, there are physical health conditions that can be causative for learning disabilities; and secondly, the presence of learning disabilities can be a risk factor for physical and mental health conditions.

7.4 Associated co-morbidities
7.4.1 Epilepsy
Epilepsy is a condition relating to electrical activity in the brain. It can cause seizures where uncontrolled electrical activity disrupts the brain’s normal processes for a short period of time. Epilepsy is frequently caused by brain damage during birth or by head injury (36) which is also associated with learning disabilities. There have been no recent studies of the prognosis of epilepsies in the overall learning disability population although studies relating to specific syndromes suggest that seizure control in patients with LD is generally poorer than the for non-LD patients (37). Mortality in patients with epilepsy is higher than that in the general population and higher in patients with a dual diagnosis of LD and epilepsy than with epilepsy alone. A Swedish study found the standardised mortality ratio for people with epilepsy was 160 (60% higher than the general population) and for patients with LD and epilepsy it was 500 (five times higher than the general population) (37). Patients with LD and severe epilepsy are at particular risk of sudden death (37).

7.4.2 There is a strong association between diagnoses of learning disabilities and epilepsy. NICE suggests that the prevalence of epilepsy is estimated to be between 15 and 30% among people with learning disabilities compared to around 1% in the general population (38). Additionally, research suggests that up to a quarter of people with epilepsy have learning disabilities. NICE and the Scottish Intercollegiate Guidelines Network (SIGN) note the following considerations that should be made by services and clinicians in working with people with an epilepsy and LD dual diagnosis (37):
• allow time for longer consultation times – consider double appointments;
• consider home visits for those who might be distressed by attending a practice;
• ensure that the patient is accompanied by a carer who knows the patient and who can bring information about seizure type and frequency, possible side-effects of medication, compliance and concordance, and general health and behavior;
• provide information in an accessible format;
• enable people with learning disabilities and their carers to take an active part in developing their care plan where appropriate: this may include primary care led coordination of community care. Speech therapists can also be of help;
• ensure that possibilities of adverse cognitive and behavioral effects of AED therapies are recorded and the patient is referred to their epilepsy specialist for a treatment review;
• discuss the higher risk of mortality for people with learning disabilities and epilepsy with the patient and their family/carers;
• ensure a risk assessment has been carried out, including risk of bathing and showering, preparing food, using electrical equipment, managing prolonged or serial seizures, social impact, SUEP and suitability of independent living. Some learning disability teams have occupational therapists to assist here;
• ensure healthcare teams are aware of the interactions between AEDs and antipsychotics, which are often used in this population, and the inappropriate use of rescue medication;
• establish a multidisciplinary approach to care that is delivered by professionals with an expertise in epilepsy. Community learning disability nurses have an important role in liaising between the specialist services and patients and carers;
• ensure the person is transferred to a transitional care team at the appropriate time. In some trusts, young people with learning disabilities enter the transitional care pathway later than their peers.

7.4.3 Coronary heart disease (CHD)
CHD is a leading cause of death among the adult learning disabilities population. Between 14% and 20% of deaths in people with LD have a primary cause of CHD. This is similar to the rate in the general population. Around half of all people with Down’s Syndrome are affected by congenital heart defects (39). Additionally, some children with congenital heart disease may develop learning disabilities due to poor oxygen supply during early life (40).

7.4.4 Respiratory disease (including dysphagia)
Respiratory disease is the leading primary cause of death in adults with LD, contributing to between 46% and 52% of deaths. This compares with only 15% to 17% in the general population (39). A study in the United States found that morbidity and mortality rates for asthma were higher in LD populations than in the general population and that there was a strong association between asthma in people with LD and both smoking and obesity (41). Further risks for respiratory disease are difficulties with eating, drinking and swallowing (dysphagia). A small-scale UK study found that almost the entire LD study cohort had some elements of dysphagia (42). Around 40% of people with dysphagia experience recurrent respiratory tract infections and can experience asphyxia, dehydration and poor nutritional status (39).

7.4.5 Mental health and challenging behaviour
Around one third of children with learning disabilities also have mental health disorders. This compares with 8% of the general child population. Children with
autistic spectrum disorders (ASD) are around 33 times more likely to have a mental health disorder than a child without ASD. This high prevalence continues into adulthood for those where a learning disability has been identified by a GP (39). Studies suggest that the prevalence of anxiety and depression are higher in those with Down’s Syndrome than in the general population and that people with LD may be up to three times more likely to experience schizophrenia (39). Positive health outcomes and life expectancy have been shown to be significantly reduced for people with either a learning disability or a mental health disorder. The risks of mortality inherent in elements of many learning disability diagnoses or associated chromosomal conditions may be exacerbated by the presence of a mental illness.

7.4.6 Challenging behaviours (aggression, self-injury and others) are shown in between 10% and 15% of people with LD with prevalence being particularly high between the ages of 20 and 49 (39). These behaviours may stem from pain associated with physical health problems which may take longer to diagnose than in people without learning disabilities (21).

7.4.7 Dementia
The prevalence of dementia is nearly four times higher in older adults (65+) with learning disabilities than in the general older adult population (22% vs 6%). Additionally, people with Down’s Syndrome are at particular risk of developing dementia at a younger age than the general population with average age of onset being 30 to 40 years younger (39).

7.4.8 Sensory impairments
People of all ages with learning disabilities are significantly more likely to have a sensory impairment than the general population. Prevalence studies have suggested an increased risk of up to 200 times for visual impairment and estimated that up to 40% of people with LD have a hearing impairment. People with Down’s Syndrome are at particularly high risk of developing vision and hearing loss (39). Access to eye examination has been shown to be significantly less likely for those people with LD who are living independently or with family than those living with paid support staff. The Annual Health Check for people with learning disabilities should include an eye and ear examination (43). In an area such as Suffolk where take up of health checks is low, this may impact unfavourably on the ability to identify sensory impairment need.

7.4.9 Physical impairments
Lack of personal mobility has been shown to increase mortality risk among adults with learning disabilities. Being non-mobile increases mortality risk by seven times and partial mobility is associated with a twofold increase in such risk. A large-scale Dutch study found that people with learning disabilities were 14 times more likely to have musculoskeletal impairments than the general population (39).

7.4.10 Oral health
Oral health problems are particularly common for people with Down’s Syndrome. Four out of five adults with Down’s syndrome have tooth decay and/or gum disease, with adults living with families having more untreated decay and poorer oral hygiene and adults living in residential services having more missing teeth (39). IHaL suggest that one in three adults with learning disabilities have oral health problems which is a similar rate to that for the general population as noted in the NHSIC Adult Dental Health Survey of 2009 (44).
7.4.11 Diabetes
While IHaL states that there have been no recent large-scale studies of diabetes prevalence in the UK learning disabilities population, the 2010 health inequalities report does note a Dutch population-based study showing that people with LD do have increased rates of diabetes. This study suggested that in the Netherlands there was a prevalence of 112 people per 1,000 learning disabilities population with a diagnosis of diabetes mellitus compared with 62 per 1,000 in the general population (45).

7.4.12 Osteoporosis
There is evidence to suggest that adults with learning disabilities have increased risk of osteoporosis and low bone density due to lack of weight-bearing exercise, delayed puberty, early menopause, poor nutrition and being underweight. This increases the risk of fractures from minor injury (39). When this increased risk is coupled with a higher prevalence of accidental injury and falls for the LD population (39), it is clear that hazards associated with post-operative periods and reduced mobility can be a particular problem for people with learning disabilities.

7.4.13 Injuries, accidents and falls
People with diagnoses within the wide category of learning disabilities have been shown in studies outside the UK to have higher rates of accidents and injuries than the general population. In addition, these accidental injuries more frequently lead to death in the LD population (39). Studies in childhood have shown that children with autism, attention deficit disorders (ADD) all have a particular statistically significant increased risk for accidental injury compared to other groups (46) although this is contradicted by other studies in adults suggesting both autism and Down’s Syndrome were protective factors (47). This study found that epilepsy was a key risk factor and this may be a confounding element in the raised incidence of accidental injury in people with LD.

7.5 Lifestyle issues

7.5.1 Obesity
People with a learning disability are more likely than the general population to be overweight or underweight (48). Individuals with a severe or profound learning disability are at higher than average risk of being underweight or malnourished due to problems with feeding or dysphagia (swallowing difficulties). Others with learning disabilities are at higher risk of obesity due to lack of support or knowledge relating to health affecting lifestyle factors. Additionally, LD associated conditions such as Down’s Syndrome increase the risk of obesity. A 2005 study in of supported accommodation in Northern England suggested that the prevalence of obesity in the LD population was markedly higher in women than men, and higher across all age ranges in women with LD than women without LD (49). Regarding prevalence of underweight, the proportion of people with a BMI less than 20 was higher for all age ranges in both genders in the LD population than the general population. As many as 30% of men aged 16-24 with LD had a BMI less than 20 (compared to 16% of non-LD peers). The same study found that at least 83% of people with LD across all age ranges were physically inactive. This was significantly higher than the non-LD control group.

7.5.2 NHS Choices advises carers of people with LD to provide support with food shopping, cooking, healthy snack choice and healthy menu choice when eating out and provides age-based physical activity guidelines. Additionally, the LD annual health
check can provide monitoring of weight and health advice/planning for managing weight, underlining the importance of increasing health check uptake in the county.

7.5.3 IHaL suggests that smoking prevalence is lower among adults in contact with learning disability services than the general population but that the opposite is true in adolescents (39). Further studies suggest that adolescents with mild learning disabilities were more likely to smoke than adolescents with no learning disability and the risk was particularly high for adolescents with ADD (50). This finding is contradicted by a British study of attendees at learning disability specific Social Education Centres which found a very low smoking prevalence (51). Unfortunately, studies in this area have been small scale to date meaning definitive answers on prevalence are not currently available.

7.5.4 There is little research information available for prevalence of substance misuse in the LD population. Evidence from small scale studies suggests that prevalence is lower in people with LD than in the general population. A literature review in 2003 (52) suggested that the prevalence of alcohol misuse in the LD population lay between 0.5% and 2%, compared with prevalence of around 6% for alcohol dependence in the UK population (53). The available evidence also suggests that prevalence of misuse of other substances is lower in the LD population than the general population. Where there is substance misuse, this is associated with location of residence, ethnicity, age and available role models (54).

8.0 SOCIAL CARE NEEDS

8.1 Social care determinants of need
An individual’s health status depends upon many genetic, environmental, and behavioural factors. The interplay between these factors can determine the health and emotional well-being of an individual across the life course. Key social determinants of health include education, employment, and accommodation. The Improving Health and Lives annual learning disability profiles assess social determinants and health service access and outcomes for English local authorities and counties.

8.2 Social care indicator comparison: National and regional

8.2.1 In terms of social care activity and outcomes, the national and regional comparison for Suffolk from the 2013 profile is shown in figure 2. Areas where Suffolk is performing better than average are, paradoxically, numbers of people living in non-settled accommodation and provision of direct payments. Recording of accommodation status and absence of settled accommodation for people with LD are both identified as areas of concern for Suffolk. In each case, performance in the county is significantly worse than the national average and worse than regional neighbours. Additionally, the number of adults with LD using community services is significantly lower than the national average and the majority of regional neighbours.
Figure 2: National and regional comparison\(^4\) of social care indicators in the 2013 Learning Disability Profile: Suffolk

<table>
<thead>
<tr>
<th></th>
<th>Suffolk</th>
<th>Cambridgeshire</th>
<th>Essex</th>
<th>Norfolk</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living in settled accommodation</td>
<td>31%</td>
<td>75%</td>
<td>69%</td>
<td>72%</td>
<td>69%</td>
</tr>
<tr>
<td>Living in non-settled accommodation</td>
<td>15%</td>
<td>21%</td>
<td>30%</td>
<td>26%</td>
<td>22%</td>
</tr>
<tr>
<td>Accommodation status unknown to LA</td>
<td>55%</td>
<td>5%</td>
<td>1%</td>
<td>0.2%</td>
<td>9%</td>
</tr>
<tr>
<td>Accommodation severely unsatisfactory</td>
<td>0.3%</td>
<td>0</td>
<td>0</td>
<td>0.2%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Adults (age 18-64) using day services</td>
<td>349</td>
<td>318</td>
<td>223</td>
<td>446</td>
<td>347</td>
</tr>
<tr>
<td>Adults (age 18-64) using community services</td>
<td>687</td>
<td>774</td>
<td>811</td>
<td>638</td>
<td>750</td>
</tr>
<tr>
<td>Adults with learning disability in paid employment</td>
<td>5%</td>
<td>6%</td>
<td>9%</td>
<td>5%</td>
<td>6%</td>
</tr>
<tr>
<td>Adults (age 18-64) receiving direct payments</td>
<td>36%</td>
<td>30%</td>
<td>28%</td>
<td>37%</td>
<td>-</td>
</tr>
<tr>
<td>Gross current expenditure for residential personal social services per 1,000 people known to LAs with LD</td>
<td>27</td>
<td>24</td>
<td>22</td>
<td>29</td>
<td>22</td>
</tr>
<tr>
<td>Rates of referral for abuse of vulnerable person</td>
<td>298</td>
<td>29</td>
<td>123</td>
<td>47</td>
<td>112</td>
</tr>
</tbody>
</table>

Source data: Suffolk Learning Disability Profile, 2013; IHaL

8.2.2 The performance results for the social care element of the 2013 profile suggest that there is a major gap in knowledge around accommodation status for the county’s LD population. The Care First system enables accommodation status to be recorded and this suggests that this is a problem with recording practice rather than the data software.

**Recommendation 1**

- Local authority and health care commissioners in Suffolk to ensure that data recording practices/systems facilitate and require recording of social circumstances (including accommodation status) of its LD service users. This will address a significant information gap not present in regional and statistical neighbour counties.

8.3 Learning disability profiles – statistical neighbours

8.3.1 Provided below (figure 3) is a similar comparison of Suffolk and its statistical neighbours in terms of the social care indicators included in the IHaL learning disability profiles, 2013.

\(^4\) Selected regional neighbours
Figure 3: Comparison of statistical neighbours for social care indicators in the 2013 Learning Disability Profile

<table>
<thead>
<tr>
<th></th>
<th>Suffolk</th>
<th>Devon</th>
<th>Gloucestershire</th>
<th>Shropshire</th>
<th>Somerset</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living in settled accommodation</td>
<td>31%</td>
<td>68%</td>
<td>65%</td>
<td>78%</td>
<td>79%</td>
</tr>
<tr>
<td>Living in non-settled accommodation</td>
<td>15%</td>
<td>25%</td>
<td>26%</td>
<td>22%</td>
<td>20%</td>
</tr>
<tr>
<td>Accommodation status unknown to LA</td>
<td>55%</td>
<td>7%</td>
<td>9%</td>
<td>0</td>
<td>0.3%</td>
</tr>
<tr>
<td>Accommodation severely unsatisfactory</td>
<td>0.3%</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0.3%</td>
</tr>
<tr>
<td>Adults (age 18-64) using day services</td>
<td>349</td>
<td>527</td>
<td>235</td>
<td>506</td>
<td>239</td>
</tr>
<tr>
<td>Adults (age 18-64) using community services</td>
<td>687</td>
<td>739</td>
<td>672</td>
<td>890</td>
<td>840</td>
</tr>
<tr>
<td>Adults with learning disability in paid employment</td>
<td>5%</td>
<td>6%</td>
<td>6%</td>
<td>10%</td>
<td>1%</td>
</tr>
<tr>
<td>Adults (age 18-64) receiving direct payments</td>
<td>36%</td>
<td>23%</td>
<td>17%</td>
<td>21%</td>
<td>17%</td>
</tr>
<tr>
<td>Gross current expenditure for residential personal social services per 1,000 people known to LAs with LD</td>
<td>27</td>
<td>12</td>
<td>21</td>
<td>20</td>
<td>10</td>
</tr>
<tr>
<td>Rates of referral for abuse of vulnerable person</td>
<td>298</td>
<td>40</td>
<td>81</td>
<td>97</td>
<td>135</td>
</tr>
</tbody>
</table>

Source data: Learning Disability Profiles, 2013; IHaL

8.3.2 It is clear that the concern with accommodation for Suffolk shown in regional comparison is also reflected in comparison with statistical neighbours. However, the county is outperforming its statistical neighbours in terms of proportion of people with LD receiving direct payments. In terms of safeguarding, rates of referral for abuse of vulnerable people are significantly higher than comparators, suggesting that systems for identifying and acting on suspected abuse are more robust than other comparable counties.

8.4 Learning Disability Self-Assessment Framework 2013: Social care indicators

8.4.1 A summary of the 2013 SAF submission for social care indicators relevant to adults with LD is provided below.

8.4.2 Assessment and provision of social care:

How many people with learning disability received the following between 1st April 2012 and 31st March 2013?

<table>
<thead>
<tr>
<th>Description</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Received a statutory assessment or reassessment of their social care need whose primary client type was learning disability</td>
<td>956</td>
</tr>
<tr>
<td>Received community-based services whose primary client type was learning disabilities</td>
<td>1,295</td>
</tr>
<tr>
<td>Received residential care whose primary client type was learning disabilities</td>
<td>418</td>
</tr>
<tr>
<td>Received nursing care whose primary client type was learning disabilities</td>
<td>19</td>
</tr>
</tbody>
</table>

Source: Self-Assessment Framework submission (Suffolk), 2013
These figures suggest that over 750\(^5\) LD social care service users did not have an assessment or review of their care in this twelve month period. This has been raised as an area of concern by carers’ representatives in Suffolk.

8.4.3 Employment and voluntary work:

*As at 31st March 2013*

<table>
<thead>
<tr>
<th>Description</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>How many people with learning disabilities in paid employment (including self-employed known to Local Authorities)?</td>
<td>98</td>
</tr>
<tr>
<td>How many people with learning disabilities as a paid employee or self-employed (less than 16 hours per week) and not in unpaid voluntary work?</td>
<td>43</td>
</tr>
<tr>
<td>How many people with learning disabilities as a paid employee or self-employed (16 hours + per week) and not in unpaid voluntary work?</td>
<td>55</td>
</tr>
<tr>
<td>How many people with learning disabilities as a paid employee or self-employed and in unpaid voluntary work?</td>
<td>9</td>
</tr>
<tr>
<td>How many people with learning disabilities in unpaid voluntary work only?</td>
<td>162</td>
</tr>
</tbody>
</table>

Source: Self-Assessment Framework submission (Suffolk), 2013

Suffolk self-rated as Amber for this key area. This was the most common rating for Partnerships nationally (53%). If we accept that there are around 2,700 people with LD known to health or social care services in Suffolk, having fewer than 100 people recorded as being in paid employment suggests that barriers to such employment remain significant.

8.4.4 Reviews of health and social care packages:

The Self-Assessment Framework examines performance against the expectation that a local authority and CCG know of all funded individual health and social care packages for people with learning disabilities across all life stages and have mechanisms for on-going placement monitoring and individual reviews. The 2013 Suffolk submission was rated as Red. This is due to the fact that only specific groups of service users (those in transition, those relevant to Winterbourne View recommendations, those in supported living developed since 2008, and those in out of county health care placements) are covered by mechanisms for such regular review. 40% of local authorities rated themselves as red for this indicator which points to a huge potential for improvements.

9.0 SAFEGUARDING

9.1 Safeguarding and people with learning disabilities

People with learning disabilities are frequently vulnerable to health inequalities, neglect, exploitation and abuse. They can experience such harms both in residential institutions and in the community and the perpetrators can be strangers or known to the victim. Health and social care organisations must play a significant role in safeguarding the learning disability population. Safeguarding encompasses six key concepts: empowerment, protection, prevention, proportionate responses, partnership, and accountability (55).

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\(^5\) These figures suggest that 956 of 1,732 people received an annual assessment
9.2  Adult safeguarding in Suffolk

9.2.1  Adult safeguarding in the county is co-ordinated through the Suffolk Safeguarding Adults Board (SAB). It is a multiagency body promoting the development of safeguarding work throughout Suffolk. The Board consists of senior officer nominated by each of the main agencies responsible for inter-agency protocols and members have sufficient delegated authority to represent their agency and make decisions on the agency's behalf. These agencies include Suffolk County Council, CCGs, NHS acute hospitals, the East of England Ambulance Service, the Church of England, Advocacy organisations, the voluntary sector, and the emergency services. As of 2014, it is responsible for producing an annual Safeguarding Report and this is due to be published in October 2014.

9.2.2  SAB is in the process of developing a county wide strategy for 2014 onwards. The 2013 Strategy sets out the responsibilities of organisations and staff members in commissioning, providing or inspecting services (56). It sets out a list of abuse types for vulnerable people including people with learning disabilities:

- Physical abuse
- Sexual abuse
- Financial abuse
- Neglect
- Psychological abuse
- Discrimination
- Institutional abuse

The strategy also sets out risk factors for abuse or neglect including a recent increase in level of dependency, disturbance of carers at night, a lack of purposeful activity, exhibition of unusual behaviour, lack of co-operation with carers, and difficulty in communication. Additionally, risk factors for abusers include substance misuse, history of mental illness, history of abuse as a victim, and dependency for accommodation on the person for whom they are caring. Finally, the strategy sets out processes to follow for reporting safeguarding issues.

9.2.3  An Adult Safeguarding Referral form has been developed for completion by staff who hear about or suspect abuse. This should be completed and returned to ACS Customer First. Additionally, reports can be made to the manager of a staff member's manager, the CQC, and/or the police. Once a referral is made, a strategy meeting is convened to agree a plan for proceeding with the alert or referral. This meeting is held to ensure that steps have been taken to safeguard the vulnerable adult, reach a consensus view about the incident(s), and outline and agree timings/responsibilities for actions. An investigation should then be planned including any required interviews, evidence examination, and medical examination. An appropriate Adult Safeguarding Plan should then be implemented for all the individuals involved.

9.2.4  A Strategic Work Plan was in place for 2013/14 which set out positive outcomes for adults at risk and indicators for measuring the extent of their achievement. Performance against these outcomes/measures will be included in a further iteration of this needs assessment once available.

9.3  Safeguarding activity for people with learning disabilities

9.3.1  Full data on numbers of safeguarding referrals/alerts for the Suffolk LD population is expected to be available by the publication of the Annual Report in October 2014. The annual Self-Assessment Framework for learning disabilities submission for 2014 requires reports on numbers of safeguarding referrals and the proportion of referrals
escalated to alert, and the number of in county and out of county placements visited for unannounced inspection. The 2013 submission, stated that there were 593 adults with LD in the year to 31st March.

The inability to report on other questions of safeguarding stems from an inability to disaggregate learning disability service users from other users in the safeguarding data. Action to ameliorate this was noted as being a high priority in the SAF action plan.

9.3.2 The IHaL Learning Disability profile for Suffolk (2013) includes the indicator, *Rates of referral for abuse of vulnerable person*. For Suffolk, the rate was significantly higher than the national or regional average for 2010/11 and 2011/12, being at 244 (per 1,000 population) in 10/11 and 298 (per 1,000 population) in 11/12. While no judgement is made by IHaL over whether a high referral rate is a positive or a negative outcome, it can be viewed as suggesting processes may be more sensitive or robust than neighbouring areas reducing the risk of hidden harms.

9.3.3 Sexual abuse can be referred and reported to the Suffolk Sexual Assault Referral Centre (SARC). SARC have provided figures on numbers of referrals for individuals with recorded vulnerabilities for the total period April 2011 to September 2014. In this three and a half year period, a total of 174 referrals have been made with a logged vulnerability. 38 of these referrals recorded learning disability as being the sole vulnerability or a co-vulnerability to physical disability, mental disability, or sex worker status. From a total of 800 referrals, 22% involved a person with a known vulnerability and 5% involved a victim with a learning disability.

9.3.4 The Suffolk Hate Crime Service (SHCS) is a partnership between Suffolk County Council and Suffolk Police. It employs Hate Crime Officers to support people and families who experience or witness hate crime in the county. The service can be contacted by telephone in normal office hours. There is no out of hours service. SHCS’ aims are to provide advice and information, provide inter-agency liaison (police, schools, housing services etc), increase awareness of hate crime and its effects, and respond to the needs of local communities in reducing hate crime. Activity information for hate crime/incidents reported to SHCS are provided below. Unfortunately, the data does not discriminate between types of disability.

### Table 4: Numbers of reported hate crimes/incidents in Suffolk: by month, 2014

<table>
<thead>
<tr>
<th></th>
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<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Hate crimes (total)</td>
<td>33</td>
<td>26</td>
<td>32</td>
<td>33</td>
<td>32</td>
<td>43</td>
<td>30</td>
<td>45</td>
<td>40</td>
<td>47</td>
<td>41</td>
<td>53</td>
</tr>
<tr>
<td>Hate crimes (disability)</td>
<td>4</td>
<td>4</td>
<td>6</td>
<td>6</td>
<td>10</td>
<td>6</td>
<td>8</td>
<td>9</td>
<td>7</td>
<td>10</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>Hate non-crimes (total)</td>
<td>15</td>
<td>15</td>
<td>15</td>
<td>16</td>
<td>21</td>
<td>21</td>
<td>17</td>
<td>11</td>
<td>14</td>
<td>21</td>
<td>18</td>
<td></td>
</tr>
<tr>
<td>Hate non-crimes (disability)</td>
<td>3</td>
<td>3</td>
<td>2</td>
<td>4</td>
<td>4</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>3</td>
<td>3</td>
<td>5</td>
<td>5</td>
</tr>
</tbody>
</table>

Source data: Suffolk Hate Crime Service; [http://www.suffolkhatecrime.org.uk/](http://www.suffolkhatecrime.org.uk/)

9.3.5 Over the 12 months to July 2014, the proportion of hate crimes where disability was an aggravating factor was 21% with the proportion appearing to rise in the last six months of reporting. The overall monthly number of hate crimes increased over the
period and over one quarter of such incidents per month related to disability by the year end. Where incidents categorised as non-crime are included, there were 126 incidents recorded against people with a disability in the twelve months to 31st July 2014.

9.4 Self-Assessment Framework 2013: Safeguarding

The Self-Assessment Framework submission noted that the SCC Adult and Community Services (ACS) Care Quality Monitoring Team carried out 180 safeguarding visits but were unable to provide a breakdown by specific customer group for the submission. This meant that SCC was unable to answer questions relating to numbers of safeguarding referrals or alerts for this population. However, Suffolk self-rated as Amber for this indicator. Nationally, only one Partnership Board rated itself as Red and around half were able to self-rate as Green.

10.0 SUMMARY OF NEEDS

10.1 The number of people who experience learning disabilities in Suffolk

10.1.1 Estimating the prevalence of learning disabilities in any geographical area is difficult. While systems are in place to identify children with LD needs in schools, need is not always identified for those individuals with mild to moderate disabilities. Additionally, it is estimated that large numbers of adults live with learning disabilities with the informal support of family and friends only. Often, individuals are only identified at moments of crisis, such as hospital admission or the death of primary carers.

10.1.2 As such, while figures indicate that 1,735 people received a Tier 2 or 3 service from SCC commissioned services in 2012/13 and 978 people (aged over 14) were registered by GPs as having LD, prevalence estimates for Suffolk by PANSI and POPPI suggest that 2,800 people have a moderate or severe learning disability in the county and 13,600 have an LD of any severity. Further, if IHaL potential estimates for true prevalence of LD are correct, there may be as many as 20,000 people with a learning disability of any severity.

10.2 How this may change

10.2.1 Research evidence suggests that the prevalence of learning disabilities will increase in the UK population due primarily to increased survival rates of pre-term infants and increases in life expectancy for people with LD. PANSI and POPPI estimate that the number of people with any level of learning disability in Suffolk will increase by 8.5% by 2030 to just under 15,000.

10.3 Health inequalities

10.3.1 People with learning disabilities are at increased risk of a series of co-morbidities and of mortality across all ages up to average life expectancy. CIPOLD found that the median age of death for men with learning disability was 65 compared with 78 years in the general population and for women with LD the difference was even larger (63 years compared with 83 in the general population). Over one fifth of people with LD die before the age of 50. Many more deaths in the LD population are amenable to change through good quality healthcare than for the general population. Much of this difference is suggested to be due to delays or problems in diagnosis and treatment and problems with identifying need.
10.3.2 People with LD experience higher prevalence of epilepsy, respiratory disease, mental health disorder, dementia, sensory impairment, osteoporosis, obesity and higher incidence of accidental injury. Additionally, people with LD have lower rates of access to certain types of health service such as health screening, immunisation, and oral healthcare.

10.3.3 Interventions to reduce such health inequalities have been made at a national level. One such initiative is the introduction of annual health checks for people aged over 18 with learning disabilities. However, uptake of these health checks in Suffolk is at a significantly lower level than statistical or regional neighbours or the national average for England. Encouraging an increase in uptake has been acknowledged as a priority by health and social care commissioners.

10.4 Accommodation

10.4.1 The national strategy and local strategy for supporting people with learning disabilities has been to move from long-term residential campus accommodation and care to maximising independence in the community. This has shifted the types of need experienced by this population to needs relating to increasing social participation in the community and maintenance of tenancies. The IHaL profile for Suffolk for 2013 suggested that a much lower proportion of people with LD in Suffolk were in settled accommodation than the national average or the average for statistical neighbours and a greater proportion of individuals had their accommodation status unrecorded.

10.4.2 The use of day services, domiciliary care and specialist housing interventions has increased in Suffolk since 2009 in order to support the move from residential care to care in a community setting which is designed to facilitate maximisation of independence for clients. To the same end, NHS secondary care services have greatly decreased inpatient/residential care provision for people with a dual diagnosis of learning disability and mental ill health.

10.5 Employment

10.5.1 The IHaL profile suggests that only 5% of people registered as having a learning disability by SCC are in paid employment. While this is a similar figure to most regional and statistical neighbours, it is worth noting that the proportion is twice as high in the statistical neighbour Shropshire. Paid employment is a significant factor in maximising an individual’s independence due to the security and opportunity afforded by an increased income. It is also accepted that paid employment is associated with improved health outcomes.

10.6 Regular review

10.6.1 Concern has been expressed from some stakeholders that assessments and reviews are not always undertaken within an appropriate timescale. This view is potentially supported by the most recent Suffolk submission for the national Self-Assessment Framework. The figures suggested that as many as 750 people receiving LD support (45%) had not had an assessment or review in the preceding 12 months (April 2012 to March 2013). The county self-assessed with a “red” rating for this area of work.
10.7 Safeguarding

It is clear that learning disabilities increase the risk of people being vulnerable to abuse, neglect, or exploitation. Disabilities of all type are a common factor in reported hate crime and sexual assault. In comparison to national and regional figures, Suffolk has a significantly higher rate of safeguarding referral than comparable areas which suggests that systems and processes for raising awareness of safeguarding issues and reporting safeguarding incidents and concerns are relatively robust and effective. However, accessibility to data for national submissions on safeguarding and learning disabilities could be improved through amendments to recording systems.

**Recommendation 2**

- Systems for recording safeguarding referrals, alerts and action plans should be amended to ensure that data on people with learning disability can be disaggregated from data for other service users.

11.0 BEST PRACTICE IN SUPPORTING PEOPLE WITH LEARNING DISABILITIES

Review of the best practice of the national guidelines and research evidence identified the following key areas (detailed review is provided below):

- Annual health checks for people with LD
- Safe and appropriate transfer of people with LD from residential care settings to community-based accommodation
- Outcome-based assessment
- Emergency response services for LD care
- Increased provision of Direct Payments
- Job coaching during transition from CYP services to adult services
- Improved access to disease prevention interventions
- Effective partnership working between CCGs and local authorities
- Involvement of service users and carers in care planning

11.1 Valuing People Now (2009)

11.1.1 This is the current government strategy aimed at maximising the independence and life experience of all people with a learning disability, their carers and their families (2). First developed in 2001, a further three year strategy was then published in 2009 and the strategic direction set out in that document still applies. The original strategy was built on four key principles: rights; independence; choice; and inclusion. In 2010, the Department of Health published a national summary report of progress against the implementation of the strategy. Its findings were categorised in the following areas:

- Health
  - Increasing uptake of specific annual health checks for people with LD although over half of eligible individuals were still not receiving them
- Housing
Although progress had been made in transferring people from health/social care campus accommodation to independent living, there remain a substantial number of people with LD living inappropriately in residential care settings

- **Employment**
  The employment rate of people with LD in contact with social services remained low at 6.4%

- **Inclusion**
  The summary report presents best practice for encouraging inclusion across varying severity levels of learning disabilities, ethnicities and support roles to ensure communication is facilitated and opportunities to contribute to policy and strategy are promoted and enabled. These interventions include:
  - Development worker posts for linking with BME communities
  - Champions for autism and people with challenging behaviour
  - Outcome-based carers assessment tools and emergency response services
  - Assistive communication technology for those with complex needs (e.g. communication passports on digital key rings)

- **Personalisation**
  Further implementation of personalisation and direct payments was encouraged with best practice examples of Jobs First and Getting a life pilots demonstrating how the use of direct payments and other appropriate funding can be used to maintain independence and prioritise employment objectives for individuals

- **Transition**
  Only 42% of partnership boards reported that person-centred client reviews at transition addressed paid employment as an outcome
  Areas of best practice used job coaching at this stage to help people find jobs suited to their skills and abilities and support to develop their own business

- **Hate crime**
  The report outlined best practice interventions for tackling hate crime including:
  - Third party crime reporting services enabling people with LD to report crime without going to the police themselves
  - Educational materials for schools
  - Identification of safe places with shops identifying themselves as such with window stickers

- **Advocacy**
  Self-advocacy advice has been produced through the Staying Strong toolkit and employment advocates have been identified by some local authorities to challenge myths and preconceptions about employing an individual with LD with local employers

### 11.2 Health Equalities Framework (HEF)

11.2.1 The HEF is an outcomes framework based around the determinants of health inequality and is designed to help commissioners determine the impact and effectiveness of the services they are commissioning for people with learning disabilities (4). The framework has been produced by the National Development
Team for Inclusion and IHaL. It is built around five determinants of health outcomes: social, genetic and biological, behavioural, communication, and health literacy.

11.2.2 The framework focuses on the prevention and reduction of the determinants of health inequalities and provides tools for measuring such inequalities and outcomes, and a mechanism for monitoring the impact of mitigating actions. Where the HEF is used, commissioned services are expected to demonstrate how they are adopting their approach to identifying, measuring and addressing health inequalities for people with learning disabilities.

Recommenbation 3

• The Suffolk Learning Disability Partnership/Mental Health and Learning Disabilities Joint Commissioning Group should consider the appropriate use of the Health Equalities Framework in assessing the level of health inequalities in the county’s LD population as part of the development of its LD strategy. This development work should enable improvements in processes for completion of the Self-Assessment Framework.

11.3 Improving the health and wellbeing of people with learning disabilities: an evidence-based commissioning guide for clinical commissioning groups (2012)

11.3.1 This good practice guide for commissioners on reducing health inequalities in the LD population was produced by IHaL in 2012 (5). It was designed to assist CCGs to:

- Commission high quality, cost effective general and specialist health services for people with learning disabilities
- Jointly commission services for people who challenge services and those with complex needs
- Work with local authorities and others to address the social factors which adversely affect the health of people with learning disabilities

11.3.2 It recommends specific commissioning actions for CCGs to ensure the following interventions are effectively implemented:

Primary care

- QOF registers for learning disabilities and Down’s Syndrome
- Annual learning disability health checks
- Reasonable adjustments in place including a mechanism for notifying providers
- Improving access to/uptake of disease prevention interventions (e.g. vaccination)
- Health Action Plans being in place

Acute care

- Mechanisms in place to identify patients in place with LD services and to make reasonable adjustments
- Support for family carers
• Training for staff in effectively working with patients with LD
• Effective patient involvement in deciding care plans
• Effective LD liaison function

Specialist LD services
• Effective partnership working between CCGs and local authorities
• Ensuring people with learning disabilities in the justice system have access to full healthcare provision
• Ensuring shared knowledge of care packages and pathways
• Involvement of service users and their families/carers in planning and decision-making about treatment/support

Wider health, wellbeing, and public health issues
• Access to health promotion and screening
• Well-functioning partnership arrangements

Transition from CYP to adult services
• Ensuring avoidance of crisis and smooth planning in the transition process

11.4 Quality of Life Standards

11.4.1 In June 2014, the Government launched the Quality of Life Standards for people with learning disabilities (57). These standards are designed to cover all areas of a person’s life including employment and equality within the community and are intended to raise aspirations of people with LD and their families. There are three fundamental principles underpinning the standards:
• Equal citizenship and integration into the community
• Personalisation to facilitate person-centred care and living
• Support quality

The standards were written in conjunction with 650 adults and young people with learning disabilities and are expected to be used by commissioners to guide quality assurance in service contracts and quality assurance in personal care plans. The three principles support ten categories of expectations that people with learning disabilities should have for their life chances and support services:
• Being in control of my own life
• My voice
• Staying safe
• Personal care
• Having a full life
• My home
• Employment
• Buying my own support
• Short breaks
• The way people work with me
11.5 Transforming care

11.5.1 This is the Department of Health response to the findings of the Winterbourne View enquiry (6). The report aimed to develop mechanisms to respond to the safeguarding failings at Winterbourne View Hospital through strengthening the regulatory framework for care organisations and tightening accountability structures for management and corporate boards. A summary of required actions for care organisations is provided below:

- all current placements will be reviewed by 1 June 2013 and everyone inappropriately in hospital will move to community-based support as quickly as possible, and no later than 1 June 2014
- by April 2014 each area will have a locally agreed joint plan to ensure high quality care and support services for all children, young people and adults with learning disabilities or autism and mental health conditions or behaviour described as challenging
- as a consequence, there will be a dramatic reduction in hospital placements for this group of people and the closure of large hospitals
- a new NHS and local government-led joint improvement team, with funding from the Department of Health, will be created to lead and support this transformation
- we will strengthen accountability of Boards of Directors and Managers for the safety and quality of care which their organisations provide, setting out proposals during Spring 2013 to close this gap
- CQC will strengthen inspections and regulation of hospitals and care homes for this group of people. This will include unannounced inspections involving people who use services and their families, and steps to ensure that services are in line with the agreed model of care; and
- with the improvement team we will monitor and report on progress nationally

11.6 Mansell Report

11.6.1 This report was published in 2007 under the leadership of Professor J Mansell on behalf of the Department of Health (7). It examined the provision of services for people with both learning disabilities and challenging behaviour or mental health needs. It provides best practice guidance for both commissioner and provider organisations in relation to service models and service commissioning development.

11.6.2 In terms of service models, the report’s recommendations focused on replacing large regionally centralised services (distant from users’ residences) with smaller, more localised services better able to tailor support to individual’s needs. It encouraged the
extended use of direct payments and personalisation and encouraged the development of alternative day services equipped specifically to provide for those with challenging behaviours who have been excluded from traditional services. It further encouraged localities to develop models of supported access to further education and employment. The report also recommended the provision of 24 hour emergency support for this specific population. The incomplete response to the service mapping exercise for this needs assessment does not enable us to accurately assess whether this element of best practice is comprehensively in place across all relevant services.

11.6.3 In terms of commissioning for service development, it recommended that LD partnership boards monitor the effectiveness of inter-agency collaboration in supporting people with challenging behaviour and strengthen the commissioning process through combining expertise, undertaking shared audit, and conducting needs assessment. Additionally, the report recommended funding independent advocacy to ensure person-centred planning for all users, effective resource/needs forecasting, and prioritising support for those with greatest need and where positive outcomes can most effectively be achieved.

11.6.4 Additionally, NHS specific recommendations were made, primarily focused on ensuring that any specialist psychiatric treatment is provided as part of a wider integrated pathway of care (aimed at supporting an individual back into the community) and that people in this population have fair access to generic health services.

11.7 Royal Colleges guidelines

11.7.1 The Royal Colleges of Nursing and of Psychiatrists provide best practice guidance for clinicians, service users and carers on care and support for people with learning disabilities. For people with learning disabilities and their families, the Royal College of Psychiatrists (RCPsych) provide Books Beyond Words designed to help with understanding their health and wellbeing, health screening, lifestyle and using care services and the criminal justice system (58). Additionally, the RCPsych produces guidance for people with LD on mental health disorders, dementia and epilepsy. The Royal College of Nursing (RCN) provides links to guidelines for clinicians relating to agencies and communities, good practice examples, and social exclusion policies (59). Several of these links are to initiatives noted above. Summaries of additional best practice noted by RCN are provided below:

Joseph Rowntree Foundation
In its report, Perspectives on ageing with a learning disability (60), the JRF recommended that:

- services work to better identify older people with LD and their families in the community as part of their JSNA
- services invest in planning for the future needs in a person-centred way for families growing older together and older people in supported living or residential care
• commissioners join up practice initiatives across learning disability and older people’s services
• services equip the workforce to be aware of age-related needs of people with learning disability and to make adjustments to make their practice to meet them
• services continue to listen and learn from what older people with learning disabilities and their families have to say

MENCAP and British Institute of Learning Disabilities
This organisational partnership has produced the *Involve Me* guide to help clinical staff, families and policy makers enable people with learning disabilities to be involved in decision making and consultation (61). This guidance can be summarised in eight key points:

• Ensure services know the service user as well as possible
• Ensure key people from services spend significant quality time with the service user
• Ensure services do not make assumptions about people with LD
• Ensure services are responsive to the shared experiences of people with LD, communicating them widely
• Ensure services are creative in developing novel routes for LD service users to contribute to decision making and consultation
• Ensure services learn from what LD service users tell them – treat LD service users as experts in their own lives
• Ensure that services facilitate LD service users to gain community based experiences in line with their life preferences
• Ensure services facilitate LD service users to use recollections and memories to help others understand their preferences

11.8 NICE guidelines in development

11.8.1 The National Institute for Health and Care Excellence (NICE) is currently developing a clinical guideline for challenging behaviour and learning disabilities. It will cover both prevention and support interventions and is scheduled to be published in May 2015.

11.9 Practice in other counties

11.9.1 Suffolk has taken account of the model developed in Hampshire for its transition pathway for children and young people services and adult services. This pathway is designed to ensure that assessments for facilitating transition between services at this key time are harmonised and simplified, that reviews are fully person-centred from the ages of 14 to 19 (and that these reviews are at the core of the transition process and inform commissioning), and that there are increases in uptake of post 16 education and employment and direct payments. See section 14 for further information about this pathway.

11.9.2 As noted above, the difficulties that many people with learning disability face in accessing healthcare services and communicating their needs can contribute to health inequity for this population. An attempt to mitigate this risk has been made in
Humberside and East Yorkshire through the introduction of a patient passport. This is carried by the patient in a CD:ROM and carries information on the specific needs of the individual, the information that they and their families can provide, and lets clinicians know how the person is when well to reduce diagnostic overshadowing (62).

11.9.3 In Oxfordshire, an intervention was developed for people with learning disabilities who are parents (63). It aims to support parents who have contact with child protection agencies as they may be at increased risk of having their children removed where this might be avoidable due to inability to understand what is asked of them by the agencies. It recognises the right to be a parent and aims to ensure people with LD have the best opportunity of meeting child protection requirements and keeping children safe. While objective evidence of the impact of this intervention is limited, the participants have reported increased feelings of involvement in child protection processes and satisfaction in the support process.

11.9.4 Two councils in the English Midlands (Nottingham and Lincolnshire) have implemented a project to facilitate and increase the use of assistive technology to help people with LD live in the community rather than residential services (63). Telecare and Assistive Technology Support Workers have been employed within Community LD Teams in Nottingham to encourage creative and flexible thinking about the use of assistive technology. The council estimates overall cost savings approaching £1 million over a five year period. In Lincolnshire, telecare is being used to support step-down care from institutions to fully independent living. The business case estimates savings of over £350,000 annually once the system is fully implemented.

11.9.5 In North Lancashire, a project driven by the self-advocate Chair of the LD Partnership Board has been developed to facilitate relationship building among people with learning disabilities (63). The project has developed training groups and a training pack entitled “Friendship matters” to help build relationship skills in this population. Further work based on development of social capital and social networking has delivered reported reduction in isolation, development of long-term personal partnerships and cascaded learning across the northwest region.

11.9.6 Primary Care Link Workers
There are no studies available on the effect of placing secondary care or link workers in primary care settings specifically for learning disability care. However, there have been a number of studies examining this for mental health NHS trusts which provide care for patients with a dual diagnosis of mental illness and learning disability.

While there is some evidence of positive outcomes from link working in terms of service user and clinician satisfaction, the evidence for preferential changes in activity or costs is equivocal. While reductions in waiting times and length of treatment have been reported, studies have not suggested that link workers have helped reduce referrals/admissions to secondary care or reduced overall care costs.
12.0 EXISTING SERVICES

It is essential in a needs assessment to acquire a clear understanding of the service provision available for your population. This allows for identification of potential areas of unmet need at a broad, strategic level.

12.1 Local commissioned services

12.1.1 Local authority commissioned services

Local authority commissioned services are categorised in terms of tiers of service provision\textsuperscript{6}. It is important to note that the tier system refers to the duration and rationale of service not the needs or diagnoses of individuals with learning disabilities. The specific circumstances of the individual at any one time might necessitate the provision of a Tier 2 or Tier 3 services by ACS or alternatively a mixture of a Tier 3 service and Tier 2 services (such as assistive technology) and potentially Tier 1 services provided through non-ACS funding. Additionally, tiers are not defined by service type. Service types such as residential care can fit into Tier 2 if provided on a short term basis.

12.1.2 However, for practicality of reporting, service types have been assigned to tiers for the monthly ACS senior management team performance report process (known as NORM). Work in 2014 on HASC\textsuperscript{7} modelling used a different allocation of service types to tiers. Appendix 7 provides a table of service agreement codes with description of service and the tier it is designated to sit within in relation to the NORM performance reports and indicates where that allocation differed in the HASC\textsuperscript{7} modelling work.

12.2 Service mapping: local authority commissioned services

12.2.1 Suffolk ACS identified 407 local authority funded providers of social care services to people with learning disabilities in the county. Many of these providers are connected as constituent parts of a wider provider organisation. These services can be grouped into the following categories with numbers of providers annotated in (*):

\textbf{Tier 1} - This is described as helping people to help themselves and comprises universal services (for anyone in Suffolk). The key objectives of Tier 1 services are to enable people to live independently, enable people to live as long as possible without formal care, and to encourage people to be as active as possible in their communities. Tier 1 services are designed to meet these objectives through provision of information and assistive technology.

\textbf{Tier 2} - This is described as providing help to people when needed as a short term measure. The key objectives are to help people regain independence, respond to people at risk of losing independence (in particular people at risk of being unable to live in their own homes), and to do all this on a time limited basis. Services are designed to meet these objectives through swift appropriate response, supporting family carers and using occupational therapy (OT) and assistive equipment/technology. Tier 2 services should be delivered in partnership with health services where appropriate and be delivered through a care co-ordinator in line with a reablement plan.

\textbf{Tier 3} - This is described as providing ongoing support for those who need it. The key objectives are to ensure that preventative or reablement support is offered before Tier 3 support is considered, that support plans are tailored to meeting specific outcomes relating to a person's individual circumstances, that the support offer will be clear and unambiguous and be provided through direct payments, and that people will be able to create and amend their own support plans. Tier 3 services can be co-ordinated through external support planning organisations. As with Tier 2 services, Tier 3 provision should be delivered in partnership with health services where appropriate.

\textsuperscript{6} Tier 1 - This is described as helping people to help themselves and comprises universal services (for anyone in Suffolk). The key objectives of Tier 1 services are to enable people to live independently, enable people to live as long as possible without formal care, and to encourage people to be as active as possible in their communities. Tier 1 services are designed to meet these objectives through provision of information and assistive technology.

\textsuperscript{7} Health and Social Care Integration
There are likely to be other types of service provided by these organisations that fall outside these descriptive categories. The full scope of services provided has not always been made clear during the service mapping exercise. Additionally, it was identified during the mapping exercise that singular providers may exist in various locations under different names; however this was not easily verified and no metadata exists for the provider lists.

12.3 Leading Lives

12.3.1 Leading Lives is a contracted ACS service provider for Suffolk County. They provide a suite of services across numerous county locations (see Appendix 3)\(^8\). They are highlighted here specifically in this needs assessment report as they are the largest single LD provider organisation commissioned by Suffolk County Council. Leading Lives services are primarily located in the following geographic locations across the county: Ipswich, Stowmarket, Felixstowe, Saxmundham, Lowestoft, Haverhill, Newmarket, Sudbury, Bury St Edmunds, Mildenhall and Hadleigh.

The services are largely grouped into the following categories which reflect the national guidance and policy direction for maximising independence and moving LD clients from residential campus accommodation to support in the community:

- Supported Living
- Community Support
- Short Breaks
- Community Hubs

Estimated numbers of users of Leading Lives services were provided from ACS (which year):

- 404 individuals in day services
- 63 individuals in supported living
- 270 individuals utilising respite services

During the development of this needs assessment, Adult Care Services in Suffolk stated the policy direction of moving services wherever possible from day service settings to community-based settings. The number of service users utilising Leading Lives day services suggests that a re-focusing of provision may be needed to meet this policy.

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\(^8\) Also note the Leading Lives website for further details http://www.leadinglives.org.uk/
12.3.2 Appendix 4 provides a template support plan used by Leading Lives for its Learning Disability service users. It is produced in easy read format and is indicative of the personalised approach to care, enabling service users to determine the objectives they wish to achieve in their life and in their care partnership with the provider.

12.3.3 Service user demographic, activity and outcome information was limited in its availability for the needs assessment meaning there are difficulties in determining service gaps with the provider. Ongoing service review will provide more meaningful information on Leading Lives.

12.4 NHS commissioned services

12.4.1 Suffolk Community Care

As with local authority commissioned services, responses to outreach were not received from all services so the ability of this needs assessment to provide a full service map was limited. Suffolk Community Care and Specialist Community Learning Disability Child Nurses are contracted to provide care up to the age of 19. Under the requirements of the Care Act (2014), the remit of these services will extend to the age of 25. Currently the process for implementation of the service expansion has not been identified to the service providers, therefore at the time of writing the services continue to cease at age 19. Suffolk Community Care provides services as part of the Integrated Community Paediatric Community Services involving the following services being delivered to individuals across Suffolk County:

- Paediatric Medical Team- consisting of paediatricians, speciality doctors, specialist nurses, and associated administrative support staff
- Paediatric Physiotherapy Team
- Paediatric Occupational Therapy Team
- Paediatric Speech and Language Therapy Team
- Children’s Community Nursing Team
- Community Audiology and Newborn Hearing Screening
- Community Clinical Psychological Therapy Team
- Child Health and Administration

The Suffolk Community Care Services encompass coverage for the entire LD population with the exception of the Waveney area. This provider identified that whilst they have limited capacity for providing services, they were not turning referrals away nor was there a waiting list for services to the LD population they serve. This was similar for the LD specialist nurse services, too. Specific activity data was not available to review for these services.

12.5 Norfolk and Suffolk NHS Foundation Trust

The Norfolk and Suffolk NHS Foundation Trust provide inpatient and community-based care for people with a dual diagnosis of learning disabilities and mental ill-health. The Trust has established policies for assessing and monitoring their patients’ physical health and these are currently in the process of further development.

12.5.1 Inpatient care

Trust policy requires that every patient admitted to inpatient care is offered a physical health assessment, including patients admitted to specialist learning disability inpatient care. At the Walker Close facility, this assessment is conducted by Trust
nursing staff but at the Airey Close facility, the patient’s GP is retained as responsible clinician for physical health assessment and they are expected to undertake this assessment at time of admission.

12.5.2 Risk assessment on admission (and at appropriate points during the inpatient stay) examines physical health issues relating to smoking, alcohol use, substance misuse, nutrition (through the Malnutrition Universal Screening Tool), falls risk and pressure ulcer risk. Needs relating to dental care are also included in the risk assessment process although this relates more to emergency dental treatment rather than ensuring attendance at routine dental check-up appointments.

12.5.3 People using any of these services may be admitted and detained under a Section of the Mental Health Act. Inpatient services comprise of a 4 bed Assessment and Treatment unit near Lowestoft, for young people aged 12–18, two six bed Assessment and Treatment units, one for males and one for females, for adults with learning disabilities in Ipswich and a five bed rehabilitation ‘step down’ service near Lowestoft, for adults with learning disabilities who have been detained in secure accommodation.

There are currently problems with providing annual health checks for long-term inpatients in terms of identifying when these assessments are due to take place. The Trust is examining systems to flag this requirement through their patient administration system.

12.5.4 The Trust employs two physical health care nurses (one based in Suffolk). These nurses are able to work with inpatients to ensure need for access to screening programmes is identified and patients are facilitated to attend such appointments. Information about the benefits and risks of physical health screening programmes and processes is provided to patients with learning disabilities in easy read format.

12.5.5 Community-based care
Support to patients is provided through the recovery model of care. This prioritises the principle of patients owning their own care plan and working to live effectively and comfortably with their diagnosis. All patients (including patients with learning disabilities) are encouraged to complete a physical health tool developed by the Rethink charity called My physical health. This is completed by the patient who can ask staff to work through it with them if necessary. The tool includes self-assessment of medical conditions and family history; history of health check attendance; medications and immunisations received; problems with dental care, podiatry, eyesight, hearing, continence and dysphagia; lifestyle concerns around diet, smoking, alcohol, substance misuse and inactivity; and sexual health. The findings of this tool are then addressed in the patient’s care/support plan. While this tool is available in easy read format, the Trust is currently investigating whether further modification for patients with a learning disability is required.

12.5.6 For patients in the community, the Trust perspective is that responsibility for physical health care lies with the patients’ GP. Trust policy is to facilitate access to a patient’s GP and assist in registering with a GP practice if there is no registration in place. The same follows for attendance and registration with dental practices. If there remains an issue with GP attendance for the patient, the Trust is able to conduct a community based physical health assessment through Trust employed nursing staff. The Trust acknowledges the importance of working with GP practices to ensure that patients with a learning disability that has been identified in secondary care are included on GP learning disability registers.
12.5.7 For community-based patients, the Trust health and social care assessment includes assessment of lifestyle physical health issues such as nutrition, smoking, alcohol and substance misuse and sexual health. It also includes assessment of significant medical history.

12.5.8 Child and Adolescent Mental Health Services (CAMHS) and LD nurses provide services to people aged 0-18 years with a requirement to extend this to the age of 25. Currently, this service is provided to 68 individuals with learning disabilities and is limited by the staffing establishment of 2 nurses and a psychologist covering a county-wide area. Further, NSFT provides an autism diagnostic service for children aged 11 and for adults aged 18 and over on pilot two year pilot basis (64). The multi-disciplinary team deliver pre-diagnostic counselling for people who may be on the autistic spectrum disorder and a diagnostic service. Referral is through a patient’s GP. Services are provided in-hours. Monday to Friday.

12.6 Secondary Health Care Services
12.6.1 There are three acute foundation trusts located in Suffolk: James Paget Hospital, Ipswich Hospital and West Suffolk Hospital. These organisations provide hospital based care for the LD population of Suffolk. Currently both hospitals employ LD Health Liaison nurses which help facilitate the care of LD individuals when they access hospital based services. A comprehensive list of specific services and any gaps around services located within these facilities was not available during the time of this JSNA. The LD liaison nurses noted that as long as an LD individual is flagged for ‘reasonable adjustment’ needs in their data intelligence system then further assistance can be provided, however they further identified that many LD individuals are not ‘flagged’ in their systems. Often individuals are self-identifying for LD ‘reasonable adjustment’ flags or acute encounters result in this happening. The problem with this process as identified by the nurse is that it results in lack of awareness of hospital staff with regards to the individual’s needs which often causes added difficulties in their health care plan. These nurses noted numerous ‘work-arounds’ they undertake to try and facilitate ‘reasonable adjustment’ flags, as well as, receiving new cases daily that may not necessarily meet the ‘criteria’ for a flag. The process described was seemingly grounded in a historic approach; however the current delivery model has been adapted to meet the demand being presented. This is noteworthy in relation to the findings of the national CIPOLD enquiry and its findings in relation to acute hospital care. There is a need to ensure that people with learning disabilities are facilitated to communicate their needs and changes in their circumstances clearly and effectively (see section 5.1).

12.6.2 In relation to integration between health and social care services, a project is currently in place to ameliorate data exchange between the two acute hospitals and social care in the county. Any move to facilitate this may help mitigate the heightened risks experienced by people with learning disabilities in emergency healthcare situations.

12.7 Service gaps
Assessment of service gaps in this needs assessment was hampered by a lack of service provider responses to outreach work. Future comprehensive completion of a service mapping exercise would enable a central, care-focused dataset of providers to be developed and maintained which would in turn improve the ability of commissioners to implement SLCC and personalisation.
12.8 CQC registered Learning Disability service locations

12.8.1 All health and social care providers in England are required to register each of their operating locations with the CQC if they provide any one of 15 regulated activities (65). These regulated activities include treatment of disease, disorder or injury, assessment or medical treatment for persons detailed under the Mental Health Act, and diagnostic and screening procedures, each of which are activities that would be expected to be undertaken in hospital, residential or community based LD services. Registered services are expected to work to a set of essential standards and a monitoring and assessment regimen is in place to ensure the care provided reflects these recognised standards.

12.8.2 The CQC provides a directory of places where CQC regulated care is provided in England on its website. As at 1st August 2014, there were 135 service provider locations registered in Suffolk as providing such regulated care activities to people with LD in Suffolk:

- 6 community services
- 9 dental services
- 1 diagnostic and screening service
- 75 homecare agencies
- 2 mental health hospitals
- 1 nursing home
- 38 residential homes
- 5 locations providing supported living.

Twelve of these locations are registered to Leading Lives as a provider and eight are registered to Suffolk County Council. Other providers also hold multiple registered locations. Figure 4 provides a map showing registered locations for hospital, residential, nursing home and community located providers.

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9 This recommendation follows the example of Suffolk Children’s Services publishing Suffolk’s local offer
12.8.3 Additionally, a further CQC database is publicly available which categorises provider organisations by health or social care designation. This database can be filtered by service user band, with one band categorised as “Learning disabilities or autistic spectrum disorders”. This database notes that there are:

- 2 NHS healthcare locations (provided by Norfolk and Suffolk NHS Foundation Trust)
- 3 Independent healthcare locations (providing care to people with learning disability, as well as mental health care and substance misuse care)
- 121 social care organisations
- 9 primary dental care locations

12.8.4 The CQC assesses and reports on quality performance of registered provider services against its essential standards. A summary of recent performance reviews for multi-location provider organisations can be found in Appendix 9 of this needs assessment. While services are assessed by the CQC relatively infrequently, this is an important source of both factual and evaluative information which commissioners could consider systematic referral to in their quality monitoring processes.

12.9 Advocacy Services

12.9.1 ACE Anglia is an independent advocacy organisation with a regional agency based in Suffolk. It is a user led organisation that aims to support people with learning disabilities to be in control of their lives and the support they receive. Ace provides group advocacy through People First groups which meet in a variety of locations across Suffolk on a monthly basis. They also provide drop in sessions, again in a range of locations. The organisation can support and encourage self- advocacy for individuals and groups but can also support LD service users to access formal advocacy through Total Voice Suffolk (TVS). Additionally, ACE acts as a third party reporting centre for the Suffolk Hate Crime Service.
12.9.2 ACE directly provides the following areas of advocacy:

- Formal advocacy
- Generic learning disability advocacy
- Art advocacy, supporting individuals to move on from residential settings
- Child protection advocacy
- NHS complaints advocacy

The organisation also supports people with learning disabilities to self-advocate on the LD Partnership Core Group, the Adult Safeguarding Board People’s Panel, and the Suffolk Coalition of Disabled People Steering Group.

12.9.3 Figures for the TVS advocacy service for Quarter 1 2014/15 (1st April 2014 to 31st March 2014) suggest that of 480 people helped with advocacy issues, learning disability was the primary need for 121 of them (25%). This, along with mental health, was the most frequent primary need for people requiring advocacy. There were 45 new referrals for people with learning disability while the service was able to close 32 referrals. The most common reason for advocacy request (across all need groups) was for housing and accommodation issues.

13.0 ACTIVITY, COST AND OUTCOMES

13.1 Local authority commissioned services activity information

13.1.1 Activity and cost information for local authority commissioned services for adults (18+) in the period April 2009 to March 2013 is provided below. The available information for Tier 3 services was relatively complete. Only 3% of records were excluded from this data report due to missing data. However, data quality for Tier 2 services was much lower. 44% of records were excluded due to lack of information about cost or about length/frequency of service. This omission is a concern in terms of the ability of this report to accurately assess the level of need and for local authority commissioners to understand the demand and the resource supplied at Tier 2 level.

Tier 1 services

13.1.2 A Tier 1 service relates to a service that helps clients to help themselves. The service provided generally relates to information provision and signposting to individuals from the whole community and data on access to such signposting is not regularly recorded. As such, no activity data for utilisation of Tier 1 advice services by individuals with LD is available.

Tier 2 services

13.1.3 Data provided by Suffolk County Council, Adult Community Services, suggested that between 157 and 236 people per year had received a Tier 2 service between 2009 and 2013. Estimated annual total spend varied between £394,440 and £570,710. This is very likely to be below the real figure. In terms of spend, for instance, no information on cost was provided for Adult Placement Schemes which may relate to their provision by in house teams rather than externally commissioned services. The data provided for Tier 2 services to date show very small numbers of people receiving only Tier 2 interventions, for instance, 33 in 2012/13. Recorded numbers of people receiving both Tier 2 and 3 interventions are much higher (203 in 2012/13). The great majority of clients of ACS services would be expected to receive ongoing, long-term Tier 3 services rather than the time limited Tier 2 services.
13.1.4 Over the period April 2009 to March 2013, 2004 people aged 18 and over received at least one tier 3 intervention. The total cost of all tier 3 interventions for this period was £178,631,360 which is a mean cost of £89,140 per service user for this period. In 2012/13, spend on Tier 3 service provision was £48,377,930, an increase of over 20% on the £38,316,570 spent in 2009/10. Part of this difference can be explained by changes in recording practices with the movement of some care from in-house SCC services to external services where further itemisation of cost has been necessary.

13.1.5 Table 5 shows the numbers of service starters (new users) and existing service users (18 and over) of learning disability Tier 3 services provided between April 2009 and March 2013. Between 7% and 10% of service users per year are accessing a learning disability service for the first time. There is no particular trend of increase or decrease. Overall numbers of service users has increased by around 8% while numbers of new users have not. Such a trend over a longer period might indicate increased time limited (Tier 2) SCC service provision or increased use of non-SCC commissioned services.

Table 5: New and existing users of Adult Social Care Learning Disability Tier 3 services

<table>
<thead>
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<th></th>
<th>2009/10</th>
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<th>2011/12</th>
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<td></td>
</tr>
<tr>
<td><strong>Total aged 18 and over</strong></td>
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<td><strong>1666</strong></td>
<td><strong>1662</strong></td>
<td><strong>1735</strong></td>
<td></td>
</tr>
</tbody>
</table>

Data source: Suffolk County Council

13.1.6 Figure 5 shows the numbers of users of SCC commissioned Tier 3 learning disability services by age group over the same period. Peaks of activity occur between the ages of 18 and 24, and then between the ages of 40 and 45. Numbers of service users decline from 55 onwards, potentially reflecting the reduced life expectancy associated with the learning disability population. Use of services in the age group 18-24 has increased as a proportion of the total consistently over the period 2009-2013 (13.7% to 16.7%). This may reflect an increase in LD diagnoses in childhood, however, SCC data on service use does not include diagnostic information so it is not possible to identify which particular diagnoses are receiving which services.

Figure 5: Tier 3 learning disability service use by age group
13.1.7 Figure 6 shows the numbers of different type Tier 3 LD interventions in the period and the total cost for each intervention type. It is clear and well understood that interventions based in the service user’s home or in a day care setting are significantly less expensive than those requiring long-term residential care support. Similarly, the cost for direct payments appears to be a lower cost per unit than other interventions. However, unit cost for residential respite care appears comparatively low. Use of this intervention reduced dramatically between 2011/12 and 2012/13 and commissioners should ensure that reduced use of this resource does not hamper the ability of service users and carers to maintain or increase levels of independence. It will be important to ensure that analysis of service user outcomes per intervention is made a routine part of activity and cost reporting to ensure that where objectives for reducing SCC resource use are met, that objectives for maintaining care support quality are also achieved.

Figure 6: Tier 3 learning disability service use by intervention type

13.1.8 There has been significant variation in the proportion of total interventions that each intervention type constitutes over the period. This fluctuation is shown in figure 9. Provision by Direct Payment has more than doubled over the four year period and there is a commitment in SCC to further increase the proportion of services provided this way. Use of day services and domiciliary care has significantly increased (by 33% and 67% respectively. Use of specialist housing has increased by over 300% in one 12 month period (2011/12 to 2012/13) while use of residential respite care has reduced by 73% in the same period. It is clear that significant change has taken place in SCC learning disability service provision in 2012/13 with use of services provided in the home and community increasing at the expense of residential respite

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10 SPCAP relates to services provided through the supporting people programme.
care and an increase in the previously low frequency use of specialist housing (67 interventions to 202 interventions p.a.). Use of SPCAP services has reduced in the time period as the Supporting People programme ceased in Suffolk in 2012 and services are being transferred to ACS.

13.1.9 The reason for the reduction in recorded use of residential respite care relates to inconsistencies in data recording. There was a period of between nine and twelve months where there was a lack of clarity between two administrative teams over responsibility for this area of data recording. This led to significant information gaps. This issue was resolved during 2013/14 but retrospective correction of data has not been undertaken.

13.1.10 The apparent increase in use of specialist housing is explained by ACS as improved data recording. Previously, a significant proportion of supported housing was recorded as a domiciliary care service due to limitations in the categories available in the ACS client data system. The introduction of a specific category for specialist housing on the system has enabled more accurate recording and a process of gradual movement of data between the proxy category and the new category has taken place in the last two years. Additionally, the use of specialist housing has increased to some degree over the period also although it is difficult to ascertain how much of the increase is due to data reconciliation or genuine practice change. Further, it remains the case that a number of specialist housing providers have not been registered on the ACS data system and there is still a problem with recording ascertainment.

Figure 7: Tier 3 learning disability interventions by change in use

Data source: Suffolk County Council

13.2 NHS commissioned service activity

13.2.1 Norfolk and Suffolk NHS Foundation Trust (NSFT):
NSFT provides both inpatient and community based services for people in Suffolk with a dual diagnosis of learning disabilities and mental ill health. Data on inpatient admissions and community caseloads is provided below for the five year period from April 2009 to March 2014.

Table 6: Inpatient/residential admissions and community caseload figures for people with a learning disability diagnosis at Norfolk and Suffolk NHS Foundation Trust: April 2009 to March 2014

<table>
<thead>
<tr>
<th></th>
<th>2009/10</th>
<th>2010/11</th>
<th>2011/12</th>
<th>2012/13</th>
<th>2013/14</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of admissions</td>
<td>664</td>
<td>242</td>
<td>77</td>
<td>77</td>
<td>54</td>
</tr>
<tr>
<td>Community caseload as at 31st March</td>
<td>1,195</td>
<td>1,228</td>
<td>1,171</td>
<td>1,177</td>
<td>1,036</td>
</tr>
</tbody>
</table>

Source data: Norfolk and Norwich NHS Foundation Trust

13.2.2 The dramatic reduction in the number of inpatient/residential admissions to the Trust for people with learning disabilities reflects the re-provision of residential services for this patient group at the three campus sites in Ipswich, Lowestoft and Kedington between 2009 and 2011.

13.3 Primary healthcare activity

13.3.1 As noted in section 4, estimating the prevalence of learning disabilities in the Suffolk population is problematic. Part of this is due to a concern over lack of completeness in local authority or primary care registers. The Quality and Outcomes Framework (QOF) register for April 2012 to March 2013 show the following number of people registered as having a learning disability within Suffolk CCGs:

- NHS Great Yarmouth and Waveney – 1,091
- NHS Ipswich and East Suffolk – 1,319
- NHS West Suffolk – 871

This suggests a prevalence of between 0.4 and 0.6% which is significantly below the synthetic estimated prevalence for the 14+ population and even for the 18+ population.

13.3.2 Research evidence suggests that learning disabilities are associated with health attributes and conditions such as obesity, diabetes and epilepsy. Unfortunately, the data to cross reference inclusion on one or more QOF register is not available for the 2013/14 period. The 2013 Self-Assessment Framework provides data for the QOF registered prevalence in the LD population for the following ambulatory conditions:

<table>
<thead>
<tr>
<th>Condition</th>
<th>Number of People</th>
</tr>
</thead>
<tbody>
<tr>
<td>How many people with learning disabilities are there aged 18 and over who have a BMI in the obese range?</td>
<td>262 (of 649 with a BMI record)</td>
</tr>
<tr>
<td>How many people with learning disabilities are there aged 18 and over who have a BMI in the underweight range?</td>
<td>1</td>
</tr>
<tr>
<td>How many people with learning disabilities aged 18 and over are known to their doctor to have a coronary heart disease?</td>
<td>11</td>
</tr>
<tr>
<td>How many people with learning disabilities of any age are known to their doctor to have diabetes</td>
<td>68</td>
</tr>
<tr>
<td>How many people with learning disabilities of any age are known to their doctor to have asthma</td>
<td>93</td>
</tr>
<tr>
<td>How many people with learning disabilities of any age are known to their doctor to have dysphagia</td>
<td>34</td>
</tr>
<tr>
<td>How many people with learning disabilities of any age are known to their doctor to have epilepsy</td>
<td>162</td>
</tr>
</tbody>
</table>

11 Note, these figures are for West Suffolk CCG, Ipswich and East Suffolk CCG and Great Yarmouth and Waveney CCG. They include Norfolk residents of Great Yarmouth and Waveney CCG.
Without more accurate baseline data on learning disability prevalence, it is difficult to determine whether prevalence of such chronic disorders in the Suffolk LD population is different to what might be expected.

13.4  Suffolk Learning Disabilities Profile 2013 (healthcare)

13.4.1  As noted above, the Learning Disability Self-Assessment Framework process requires local authorities and CCGs to provide a data submission covering a wide range of service activity and outcomes. A summary of the 2013 submission for health care indicators relevant to adults with LD is provided below. It is worth noting that the submission asks for the number of people listed on GP QOF\(^{12}\) registers as having moderate, complex, or profound learning disabilities. The 2013 submission was only able to access information for 29 out of 67 practices and constitutes less than 50% of the county population. These figures are not included here.

13.4.2  Screening:

How many women are there eligible for cervical cancer screening?

<table>
<thead>
<tr>
<th>Description</th>
<th>Count (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of total eligible population</td>
<td>47,225</td>
</tr>
<tr>
<td>Number of total eligible population who had a cervical smear test</td>
<td>29,529 (63%)</td>
</tr>
<tr>
<td>Number of eligible population with learning disabilities</td>
<td>276</td>
</tr>
<tr>
<td>Number of eligible population with learning disabilities who had a cervical smear test</td>
<td>61 (22%)</td>
</tr>
</tbody>
</table>

Source: Self-Assessment Framework submission (Suffolk), 2013

13.4.3  How many women are eligible for breast cancer screening?

<table>
<thead>
<tr>
<th>Description</th>
<th>Count (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of total eligible population</td>
<td>26,700</td>
</tr>
<tr>
<td>Number of total eligible population who had mammographic screening in the last 3 years</td>
<td>18,818 (70%)</td>
</tr>
<tr>
<td>Number of eligible population with learning disabilities</td>
<td>78</td>
</tr>
<tr>
<td>Number of eligible population with learning disabilities who had mammographic screening in the last 3 years</td>
<td>44 (56%)</td>
</tr>
</tbody>
</table>

Source: Self-Assessment Framework submission (Suffolk), 2013

13.4.4  How many people are eligible for bowel cancer screening?

<table>
<thead>
<tr>
<th>Description</th>
<th>Count (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of total eligible population</td>
<td>26,285</td>
</tr>
<tr>
<td>Number of total eligible population who completed bowel cancer screening in the last 2 years</td>
<td>16,582 (63%)</td>
</tr>
<tr>
<td>Number of eligible population with learning disabilities</td>
<td>80</td>
</tr>
<tr>
<td>Number of eligible population with learning disabilities who completed bowel cancer screening in the last 2 years</td>
<td>39 (49%)</td>
</tr>
</tbody>
</table>

Source: Self-Assessment Framework submission (Suffolk), 2013

The proportion of LD individuals eligible for national screening programme tests who took up the offer of screening is significantly below that of the general eligible population. Suffolk self-rated as Amber for this indicator. This was the most common self-rating nationally. Barriers to access for services such as cancer screening contribute to health inequities for the LD population. During the development of this needs assessment, health service representatives suggested that improvements should be made to systems of communication inviting people with LD to screening appointments. Where systems for providing appropriate communication are in place, it is vital that systems for identification and registration of people with LD are...
effective. Documents should be provided in easy-read format along with greater awareness of health care appointments including health checks among carers and family members.

**Recommendation 6**

- Suffolk CCGs should consider undertaking an audit of a representative sample of screening appointment invitations to people with LD to assess frequency of use of appropriate communication methods such as easy read documentation. The objective of this audit would be to determine whether improvements could be made to the screening appointment invitation process for this population to help increase screening uptake.

13.5 Learning Disability profile: Health indicators

13.5.1 IHaL produces annual LD profiles for county’s and local authorities on behalf of Public Health England. They are designed to support and inform health service planning. The most recent report (2013) has been used to inform LD prevalence estimates for this needs assessment in section 4 (66). It also provides information on health and social care service activity for the period and allows Suffolk to be compared with national performance and regional partners.

13.5.2 In terms of health service activity and outcomes, the national and regional comparison for Suffolk from the 2013 profile is shown in figure 8. While admissions of people with LD diagnoses contribute a smaller proportion of all admissions than the national average or regional neighbours, performance in relation to LD specific GP health checks is poor with by far the lowest rate of uptake in the East of England region. Additionally, the difference in recorded prevalence between local authority register and QOF register in Suffolk is 18% which is significantly greater than the national average or most regional neighbours. This suggests a lower level of information co-ordination between health and social care providers than for comparable areas.

**Figure 8: National and regional comparison of health indicators in the 2013 Learning Disability Profile: Suffolk**

<table>
<thead>
<tr>
<th></th>
<th>Suffolk</th>
<th>Cambrid</th>
<th>Essex</th>
<th>Norfolk</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proportion of eligible adults with a learning disability having a GP health check</td>
<td>19%</td>
<td>73%</td>
<td>47%</td>
<td>64%</td>
<td>53%</td>
</tr>
<tr>
<td>Median age at death</td>
<td>57</td>
<td>56</td>
<td>60</td>
<td>59</td>
<td>56</td>
</tr>
<tr>
<td>Emergency hospital admissions as % of total</td>
<td>40%</td>
<td>53%</td>
<td>51%</td>
<td>25%</td>
<td>50%</td>
</tr>
<tr>
<td>Admission rate for non-psychiatric ambulatory care sensitive conditions in people with LD (per 1,000)</td>
<td>15</td>
<td>24</td>
<td>19</td>
<td>12</td>
<td>23</td>
</tr>
<tr>
<td>Identifying people with learning disability in general hospital statistics (per 1,000)</td>
<td>29</td>
<td>29</td>
<td>30</td>
<td>25</td>
<td>27</td>
</tr>
</tbody>
</table>

**Source data:** Suffolk Learning Disability Profile, 2013; IHaL
13.5.3 Provided below (Fig 9) is a similar comparison of Suffolk and its statistical neighbours in terms of the healthcare measures included in the IHaL learning disability profiles, 2013.

Figure 9: Comparison of statistical neighbours for health care indicators in the 2013 Learning Disability Profile

<table>
<thead>
<tr>
<th>Measure</th>
<th>Suffolk</th>
<th>Devon</th>
<th>Gloucestershire</th>
<th>Shropshire</th>
<th>Somerset</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proportion of eligible adults with a learning disability having a GP health check</td>
<td>19%</td>
<td>72%</td>
<td>73%</td>
<td>53%</td>
<td>71%</td>
</tr>
<tr>
<td>Median age at death</td>
<td>57</td>
<td>58</td>
<td>57</td>
<td>54</td>
<td>61</td>
</tr>
<tr>
<td>Emergency hospital admissions as % of total</td>
<td>40%</td>
<td>50%</td>
<td>29%</td>
<td>57%</td>
<td>56%</td>
</tr>
<tr>
<td>Admission rate for non-psychiatric ambulatory care sensitive conditions in people with LD (per 1,000)</td>
<td>15</td>
<td>15</td>
<td>13</td>
<td>11</td>
<td>24</td>
</tr>
<tr>
<td>Identifying people with learning disability in general hospital statistics (per 1,000)</td>
<td>29</td>
<td>25</td>
<td>25</td>
<td>30</td>
<td>30</td>
</tr>
</tbody>
</table>

Source data: Learning Disability Profiles, 2013; IHaL

13.5.4 Suffolk performs poorly in comparison to statistical neighbours in only one area; that of GP health check uptake (see above, sections 7.4.8 and 16.15). However, the proportion of emergency hospital admissions that are people with LD is comparatively low, and the admission rate for ambulatory conditions is low in line with these comparator counties.

13.5.5 For health service planning, the 2013 profile for Suffolk suggests that the prioritisation of annual health check uptake, acknowledged by CCGs in the county, is justified (see below). Similarly, it may be beneficial for primary care services and social services to develop improved systems of liaison and notification to help align identification of individual need on its learning disability registers.

13.6 Annual Health Checks for people with Learning Disabilities

13.6.1 In line with national policy, all adults with a moderate or severe learning disability or who have a mild learning disability and other complex health needs, should be offered an annual health check by their Suffolk GP. As noted above, people with LD may have difficulty in recognising illness, communicating their needs and accessing and using health services. The rationale for annual health checks is to ensure that treatable health concerns are identified and addressed and that people with LD become more used to attending and using health services, reducing any fear they may have. All people registered as having a learning disability with Suffolk Social Services and who are registered with a GP should be invited by their GP to an annual health check. This highlights the importance of accuracy in learning disability registers and in ensuring systems for identifying people with LD are robust.

13.6.2 The health check consists of the following elements (67):

- general physical health examination, including weight, heart rate, blood pressure, and taking blood and urine samples
- assessment of patient behaviour, including lifestyle and mental health
- check for epilepsy
check of prescribed medication
- check for management of any chronic illness such as asthma or diabetes
- review of arrangements with other health professionals such as physiotherapists or speech and language therapists

13.6.3 **How many people with a learning disability aged 18 and over had an Annual Health Check under the Directed Enhanced Scheme in Suffolk**

<table>
<thead>
<tr>
<th>Description</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>How many people were agreed as eligible for an Annual Health Check?</td>
<td>1,201</td>
</tr>
<tr>
<td>How many people received an Annual Health Check?</td>
<td>433 (36%)</td>
</tr>
<tr>
<td>How many people were agreed as eligible for a Health Action Plan?</td>
<td>937</td>
</tr>
<tr>
<td>How many people had a Health Action Plan completed</td>
<td>266 (28%)</td>
</tr>
</tbody>
</table>

Source: Self-Assessment Framework submission (Suffolk), 2013

13.6.4 Uptake of LD annual health checks has been limited in Suffolk to date. The 2013 IHaL LD profile for Suffolk suggests that as few as 19% of eligible people with LD took up the opportunity to have an annual health check. The annual LD Self-Assessment Framework submission for 2013 suggested that this had risen to 36%. This compares with figures of 70%+ in statistical neighbour counties of Devon, Gloucestershire and Somerset, and regional neighbours such as Cambridgeshire.

The low uptake of annual health checks is concerning as the checks are provided as a method of early identification for health problems in a population where there have been traditional barriers to healthcare access. A key intervention area for improving uptake of health checks (as well as screening) is through carer education. There is concern from carer feedback elsewhere that the relevance and usefulness of health checks is frequently questioned and that certain screening programmes (such as cervical screening) is of less relevance for people with LD than their peers.

**Recommendation 7**

- Health and Social Care Commissioners and Public Health should continue prioritising and co-ordinating efforts to increase uptake of LD annual health checks. This should enable improvements in identification of health issues at an early stage for people with LD and improve uptake of screening. Methods for improving uptake of health checks could include ensuring that information materials are accessible to the LD population and appropriate communication support is provided. This should include support for carers as they provide a vital role in facilitating service user access to health checks.

13.7 Secondary healthcare activity

13.7.1 Access to healthcare services is a recognised area of health inequality (as noted in section 9). The CIPOLD review in 2013 found that 42% of deaths in the LD cohort were premature and the most common reasons for premature death were delays or problems with diagnosis or treatment, problems with identifying need, or problems providing appropriate care in response to changing need (21). These delays and problems are likely to be caused in part by an inability in services to facilitate LD appropriate care in non-LD specific health services.

13.7.2 Common health problems among people with learning disabilities include (25):
- Respiratory disease (adults);
- Coronary heart disease (adults);
- Physical impairment with associated risk of postural distortion, hip dislocation, chest infections, eating and swallowing problems, gastro-oesophageal reflux, constipation and incontinence (all ages);
- Underweight (all ages);
- Obesity (all ages);
- Mental health problems (including dementia) (all ages);
- Epilepsy (all ages);
- Sensory impairments (all ages);

In each of these conditions or groups of conditions, prevalence in people with LD is significantly higher than the prevalence in the general population (25). Additionally, while some of these conditions may be ambulatory in nature, difficulties in accessing appropriate primary care services can lead to potentially avoidable inpatient admission.

13.7.3 Numbers of admissions to secondary care of people with a recorded learning disability diagnosis in Suffolk CCGs are provided in Figure 10. For all combined ages, there has been a slight annual increase between April 2011 and March 2014 with the largest increase being seen in childhood groups (0-14)\textsuperscript{13}. For people over the age of 14, numbers have remained similar over the three year period with a sum of between 877 and 945 admissions per year. Numbers of admissions in males are markedly higher than in females (76\% higher). This reflects the higher prevalence of learning disabilities in males than females. The difference is most pronounced in the 0-14 age group where there was twice the number of admissions (1,051 boys, 518 girls).

Figure 10: Number of admissions by age (all ages): April 2011 to March 2014

<table>
<thead>
<tr>
<th>Age</th>
<th>2011/12</th>
<th>2012/13</th>
<th>2013/14</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>0-14</td>
<td>289</td>
<td>156</td>
<td>354</td>
</tr>
<tr>
<td>15-24</td>
<td>208</td>
<td>128</td>
<td>210</td>
</tr>
<tr>
<td>25-44</td>
<td>135</td>
<td>91</td>
<td>136</td>
</tr>
<tr>
<td>45-64</td>
<td>100</td>
<td>90</td>
<td>121</td>
</tr>
<tr>
<td>65+</td>
<td>80</td>
<td>45</td>
<td>73</td>
</tr>
<tr>
<td>Sub-total</td>
<td>812</td>
<td>510</td>
<td>894</td>
</tr>
</tbody>
</table>

\textsuperscript{13} Note, these figures are for West Suffolk CCG, Ipswich and East Suffolk CCG and Great Yarmouth and Waveney CCG. They include Norfolk residents of Great Yarmouth and Waveney CCG.
13.7.5 The most frequent ICD10 chapter reason for admission in the period was factors influencing health status (see Figure 11). This chapter includes admission for investigative care such as examination and observation, health hazards relating to socioeconomic and psychosocial circumstances (including education and literacy), and health hazards related to family history affecting health status. High frequency admission causes (those contributing more than 5% of admissions) are:

- Factors influencing health status (684 admissions);
- Diseases of the digestive system (580);
- Symptoms and signs, not elsewhere classified\(^\text{14}\) (477);
- Diseases of the nervous system (443);
- Mental and behavioural disorders (310);
- Diseases of the respiratory system (303);
- Injury and poisoning (247);

The ICD-10 chapters, factors influencing health status and symptoms and signs, not elsewhere classified both include diagnostic codes for symptoms or attributes commonly associated with specific learning disabilities or with chromosomal disorders associated with learning disabilities. However, diseases of the respiratory system and injury and poisoning may be more avoidable through prevention interventions or improvements in healthcare access or practice.

13.7.6 These figures show the high volume of hospital admissions per year for patients of Suffolk CCGs with an underlying learning disability (1,400 on average). It is clear that secondary care services require clinical and non-clinical staff, and facilities to be adequately trained and adapted to ensure equality of access, care quality and service liaison for patients with learning disabilities. While many admissions will relate primarily to the learning disability itself or to the physical condition underlying a learning disability, there are many admissions for conditions ancillary to these disabilities and all staff, regardless of specialty, require the training to work effectively with this population.

13.7.7 The 2013 Self-Assessment Framework submission for Suffolk stated that there were 1,364 attendances at Accident and Emergency services in 2013, with 146 people attending on more than three occasions. Emergency care often requires rapid appraisal of conditions, clinical histories and standing care liaison arrangements for patients. For frequent attendance of patients with LD, emergency department staff require strong LD specific skills in communication.

\(^{14}\) This category includes symptoms relating to cognition, perception, emotional state, behaviour, speech and language, and respiratory systems
13.8 Autism Diagnostic Service

13.8.1 The Norfolk and Suffolk NHS Foundation Trust provides an autism diagnostic service for individuals aged 11 and over (64). There is no upper age limit. The multi-disciplinary team delivers pre-diagnosis counselling, a diagnostic service, and post-diagnosis counselling and onward referral to appropriate services.

13.8.2 Referral and outcome information for the adult service is provided below. In the period August 2013 to August 2014, the service received between 9 and 26 referrals per month (mean = 14 per month). The great majority of these referrals were for males (70%) which is roughly indicative of estimated prevalence of ASD by gender in the UK population. For post-teenage clients, the service received more than twice as many referrals (n=70) for the 20-29 year age group than for any other age group. However, referrals continue to be made to the team for people up to and beyond the age of 60. The great majority of service users are referred by GP although referrals are made by a large range of different health and social care professionals. Asperger’s Syndrome was the most frequent diagnostic outcome (60% of diagnoses) while 18% of referrals were deemed to be inappropriate.

13.8.3 The Youth service sees clients aged between 11 and 17 years. Figures for number of referral have been provided from January 2014 to August 2014 (different to the time period provided for the Adult Service). 107 referrals were received in that time with the largest number of referrals being made for 11 year olds (n=29). There is a linear negative correlation between number of referrals and age with consistently fewer referrals as child age rises. This would be predicted by the research evidence that suggests ASD symptoms often become pronounced at times of major life change.
such as the move between primary and secondary education at age 11. No data has been provided by the service for diagnostic outcome but as with adult services, the great majority of referrals originate from GPs. These pilot services will be evaluated by Public Health Suffolk in due course.

13.8.4 The numbers of referrals to the adult service for all ages show that early identification and intervention for ASD is problematic. As a developmental disorder, ASD is a condition arising in early years but it may be decades before it is diagnosed or brought to the attention of health and social care services. This may be due to individuals being well supported by families and networks who do not feel that state support is needed. Alternatively, identification may arise due to contact with services for other health concerns. Where parental support has been able to reduce the need for access to services for people with ASD, carer health concerns can impact the ability of families to cope. Early identification of ASD may enable services to better monitor the ability of carers to provide support and help service mitigate the problems arising with carer illness.

14.0 EFFECTIVENESS OF SERVICES

14.1 Provided below is a summary of the status in Suffolk in relation to national best practice guidance:

Table 7: Status of care/support for people with learning disabilities in Suffolk in relation to identified key areas from national best practice guidance

<table>
<thead>
<tr>
<th>Best practice</th>
<th>Suffolk status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provision of annual health checks for people with LD</td>
<td>Uptake of health checks in Suffolk is currently below the national average and below uptake in statistical neighbour counties</td>
</tr>
<tr>
<td>Transfer of care/support from residential settings to community settings</td>
<td>Significant reduction in the number of people supported in healthcare residential settings since 2010. SCC data does not suggest a significant change in the numbers of residential social care packages for LD service users in the same period.</td>
</tr>
<tr>
<td>24 hour LD emergency response services for LD service users</td>
<td>The incomplete response from providers to the service mapping exercise undertaken for this needs assessment did not enable a full evaluation of the availability of this service for people with LD.</td>
</tr>
<tr>
<td>Increased provision of Direct Payments (DP)</td>
<td>Provision of DPs in Suffolk is higher than the national average and higher than statistical neighbours.</td>
</tr>
<tr>
<td>Improve access to disease prevention interventions</td>
<td>In addition to comparatively low levels of uptake for annual health checks, access of screening programmes is significantly lower for the registered LD population than it is for the general population.</td>
</tr>
<tr>
<td>Effective partnership working between health services and social care services</td>
<td>Several responses to the stakeholder survey suggested that there should be more co-ordination between providers of health care and providers of social care. Concern was raised at the lack of a single care co-ordinator who can ensure that health services and social care services work efficiently with his/her LD client.</td>
</tr>
<tr>
<td>Effective involvement of service users/carers in care planning</td>
<td>Responses from the stakeholder survey suggest that this works relatively well for most people.</td>
</tr>
<tr>
<td>Effective identification of individuals with learning disabilities in primary and secondary care</td>
<td>Comments from carer and staff responders to the stakeholder survey suggest that systems for identifying people with LD work well. However, the gap between people with LD receiving a care service and the estimated prevalence of LD remains wide.</td>
</tr>
<tr>
<td>Outcome based assessment tools</td>
<td>Systems for routine monitoring of outcomes for individual LD service users receiving social care are not in place.</td>
</tr>
</tbody>
</table>
14.2 CQC quality review of Suffolk services

14.2.1 The CQC has a remit to quality assess, report upon and request remedial action for all services registered as providing health and social care in England. As at 1st August 2014, 135 learning disability care provider locations were registered with the CQC. A summary of recent quality review reports for organisations with multiple service locations is provided below in Appendix 9. The majority of locations were meeting all essential standards. Where standards were not being met, the most frequent reasons related to not treating people with respect or involving them in their care, staffing problems, or quality and suitability of management.

14.3 Clinical/care quality outcomes

14.3.1 The Care Quality Commission assesses care quality at the organisational level and seeks to ensure that process and safety standards are met across service caseloads. In addition to this national quality assurance process, it is beneficial to assess processes and outcomes on a regular basis at the local level.

14.3.2 Information on outcomes linked to activity is difficult to acquire. There is currently no routine quality audit programme or evaluation system to review measurable outcomes for learning disability service users. It would be valuable for commissioners and providers of services to receive regular outcome data to help inform the successful implementation of SLCC and personalisation.

“Care plans are fine however applying the plans [is] difficult”. (Carer)

**Recommendation 8**

*Commissioners to undertake a pilot audit of a representative sample of LD service users to assess process and outcomes for support plans and interventions in relation to Quality of Life Standards. This will enable commissioners to better understand the effectiveness of current services in complying with agreed support plans and meeting service user life objectives.*

14.4 Social care contract monitoring

14.4.1 Effective contract monitoring is a key aspect of a successful commissioning process. After assessment of needs and procurement of services to meet those needs, it is important to develop robust systems to ensure the requirements of contracts are met.

14.4.2 SCC uses agreed standard template designs for contracts that can be amended to suit the particular situations of the required service. Example contract templates are publicly available on the Suffolk County Council website. The content requirements for these contracts include systems for contract monitoring and sets of broad performance standards are included in service specification documents.

14.4.3 Arrangements for contract performance review differ across service types. The largest single provider organisation, Leading Lives, has a specific performance monitoring regime with meetings of a Contract Board. For supported housing,
contracts require meetings of a Joint Advisory Group (JAG) to be held for each provider at least three times per year. Key stakeholders (including service users and carers) are invited to these meetings to discuss service performance. However, while there are key indicators noted in contracts and target/expected outcomes for care, there is no strong evidence that these indicators form the basis for discussion of performance at the JAG meetings. Additionally, in a sample of live contracts assessed as part of this needs assessment work, there may be scope for bringing extra clarity to indicators and expected outcomes through set targets and clearer data collation requirements. However, the sample indicator sets do include measures across structures, processes, outputs and outcomes which follow Donabedian good practice (68).

14.4.4 For domiciliary care services, there is no requirement for JAG meetings and the authors were unable to identify a standard performance monitoring process across services. In the absence of implementation of a set monitoring process and schedule, exception reporting is relied upon to identify service weaknesses and failure.

14.4.5 For Supported People interventions/services, contracts were previously measured against the Supported People Quality Assessment Framework through self-assessment with some external validation. This work ceased with the disbanding of the SCC Supported People Team. There are benefits in monitoring performance or quality against clearly defined set standards in terms of consistency, relevance and comparability.

14.4.6 Quality assessment of SCC service providers is co-ordinated by the Quality Improvement Team (QIT). This team undertakes unannounced assessment visits based on a risk scoring system to determine frequency of assessment. Any quality issues identified here or by the Safeguarding Team can be fed back to the contract management team for potential action. There is, however, no explicit set of validated standards for the QIT to assess quality against on these inspection visits. Adoption of such a set of standards may enhance the team’s ability to make consistent, evidence-based judgements across services.

14.4.7 The standard contract template sets out the sanctions that are available for failure to provide adequate service. Initially, SCC accreditation of the service can be suspended for a set period of time to enable a recovery plan to be developed and implemented. This recovery plan is designed to enable service providers to rectify the problems with the service and allow it to meet the expectations set out in the contract. During this period, no new service users are placed with the provider but the existing service users will receive their existing service. There is a risk in this approach that current service users may receive a sub-standard service or be at risk of harm if the amelioration process is not sufficiently supervised or swiftly completed. Alternatively, provision of service can be moved to another organisation for the period of recovery with excess costs to the Council borne by the original provider. Lastly, termination of contract can take place immediately on suspension of accreditation.

14.4.8 In the Self-Assessment Framework submission for 2013, Suffolk rated itself as Red for contract compliance assurance, stating that “contract compliance is not fully proactive as a scrutiny and assurance method. Good practice is being developed with large externalised service providers”. Three quarters of Partnership Boards nationally were able to assess themselves as amber or green.
15.0 INFORMATION GAPS

15.1 This needs assessment notes the following gaps and limitations to available information where access may have improved the accuracy or extent of the assessment.

15.2 Learning Disability registration:
While stakeholder feedback suggests that there is a high level of satisfaction with systems for identifying individuals with learning disability in the county, at a national level there is concern that numbers of registrations on social services registers and QOF registers are well below estimated prevalence levels. While it is estimated that there are around 13,000 people aged 18 and over in Suffolk with any level of learning disability, further research suggests that this figure could be as high as 23,000 when hidden need is taken into account. This suggests that the numbers of registrations in Suffolk are also significantly below expected prevalence. While evidence-based synthetic estimates suggest there is a gap in known and unknown need, it is difficult to determine an accurate figure for this difference.

15.3 Service provision information:
The service mapping exercise undertaken as part of this needs assessment has pulled together additional information for target populations, support options available, and access information for provider services in Suffolk. However, the response from service providers was not comprehensive. Should a comprehensive response be received by Public Health Suffolk, it would be possible to produce a centralised database of service providers by service type, intervention types, and target populations for learning disability service users. The exercise has also identified potential additions to current contract monitoring processes that may enhance the ability of commissioning services to monitor performance of service providers, and consequently support the effective implementation of SLCC and personalisation.

15.4 Safeguarding:
The 2013 Self-Assessment Framework submission for Suffolk was unable to provide learning disability specific information for numbers of referrals escalated to alerts and numbers of unannounced inspection visits to providers. This was due to an inability to disaggregate information for people with learning disabilities from information for other services users for these specific questions. Amelioration of this issue was included in the priorities for action from the 2013 data submission process so it is expected that this data be included in the 2014 submission to be completed at the end of 2014.

15.5 Outcome data:
In order to assess the effectiveness of support and treatment for people with learning disabilities, it is ideal to have access to results for structural measures, process measures, output measures, and outcome measures (68). In this needs assessment, there has been only limited availability of outcome data. The outcome data available has been either corporate level quality assessment by the Care Quality Commission, or qualitative experiential data from service users and carers. The introduction of routine quality audit of individual service users’ care, could support the successful implementation and monitoring of Supporting Lives, Connecting Communities (SLCC) and personalisation of care. Should such an audit programme be introduced, it would benefit from examination of process measures (development of appropriate support plans), of output measures (implementation of support plan actions), and
outcome measures (achievement of stated objectives). It would also benefit from linkage to the national Quality of Life Standards.

16.0 SERVICE PROVISION SUMMARY

16.1 Suffolk County Council commissions services using a three tiered approach to service categorisation. Tier 1 relates to services designed to help people help themselves. This primarily equates to providing advice on where and how to access non-SCC funded care and support. Tier 2 relates to providing help to people when needed, as a short-term measure. This equates to time-limited support for specific needs that can be addressed fully within a set timeframe. Tier 3 relates to provision of on-going support for those who need it and where Tier 2 support alone is judged to be insufficient. As LD is most often a chronic condition, the majority of LD service users require Tier 3 support.

16.2 The service mapping exercise undertaken for this needs assessment identified 407 providers of social care services for people with LD in Suffolk providing support in residential, day, and community based settings or providing logistical support with transportation or communication. A lack of responses from providers hampers the ability of Public Health Suffolk and Suffolk commissioners to fully identify areas if unmet need in the population in relation to recognised best practice and national guidance.

16.3 NHS services provide generic and specialist healthcare for people with learning disabilities in the county and are commissioned by three separate Clinical Commissioning Groups (West Suffolk, Ipswich and East Suffolk, and Great Yarmouth and Waveney). Specialist services are provided in the community by Suffolk Community Care and Norfolk and Suffolk NHS Foundation Trust (NSFT). NSFT also provide inpatient/residential specialist LD services.

16.4 In recent years, both social and health care commissioners have had a strategy in place to move people from residential settings and day service settings to community-based settings. This follows national policy arising from Valuing People and Transforming Care.

16.5 In order to successfully implement SLCC and personalisation, it is important for there to be robust and comprehensive information to be available for service users and their SCC commissioning agents. Quality and performance information collated, analysed and presented by the CQC and by commissioning bodies in Suffolk will enable potential clients of LD care services in the county to make decisions that are right for them. There is scope for commissioners to further improve the decision making process for clients by adding more clarity to the performance assessment process through renewed expectations for agreement of key indicators, methods of assessment, frequency of assessment, and validated standards against which assessment will be made. A regularised approach to presenting performance and quality information on potential providers will allow clients to make fully informed decisions on how their personal budget can be spent.
16.6 Over the course of 2012/13, 1,735 people with LD received a Tier 3 social care service in Suffolk. This is an increase of nearly 8% on the figure for 2009/10. The cost of these services was £48.4 million. This is an increase of around 20% on the spend figure for 2009/10. Part of this difference can be explained by changes in recording practices with the movement of some care from in-house SCC services to external services where further itemisation of cost has been necessary. Between 7-10% of LD social care service users are accessing services for the first time each year.

16.7 In the period 2009/10 and 2012/13, between 157 and 236 people with LD per year received a Tier 2 social care service. The disparity in demand between Tier 2 and Tier 3 service can be explained by the nature of most learning disabilities being chronic conditions requiring on-going support. Only 33 people received a Tier 2 service and no Tier 3 service in 2012/13.

16.8 There are three high volume social care service types in Suffolk: residential respite care, day services, and domiciliary care (each of whom having had over 5,500 episodes agreed between 2009/10 and 2012/13). Residential care has the highest spend due to the high unit cost. Around £70 million has been spent on interventions in this category in the four years between 2009/10 and 2012/13 while a further £55 million has been used for domiciliary care. National and local policy movement towards community-based rather than residential care should reduce reliance on high cost residential services, however, figures over the four years between 2009/10 and 2012/13 do not suggest a significant change in residential social care use.

16.9 In terms of age groups, peaks of LD social care activity occur between the ages of 18-24, and 40-50 years. Numbers of service users decline after the age of 55, potentially reflecting reduced life expectancy. Use of services in the age group 18-24 has increased as a proportion of the total consistently over the period 2009-2013 (13.7% to 16.7%). This may reflect an increase in LD diagnoses in childhood. The higher number of service users in the 40-50 year age bracket than in the 25-39 age bracket may be indicative of people seeking social care support when their family support network may break down.

16.10 For NHS care, the number of people receiving residential/inpatient care from NSFT has reduced markedly in the past five years. While in 2009/10 664 people received residential/inpatient care, this had dropped to 54 people in 2013/14. As noted above, this reflects national policy in the period. The number of people receiving community-
based care from NSFT has remained stable in the same period (1,195 in 2009/10 and 1,036 in 2013/14).

16.11 In terms of secondary NHS care, over the five year period 2009/10 to 2013/14 numbers of admissions were relatively stable (between 877 and 945 admissions annually). A high proportion of admissions related to the chromosomal disorders often associated with learning disabilities. The high volume diagnostic areas most amenable to preventative interventions or improvements to healthcare access or practice were diseases of the respiratory system and injuries and poisoning.

16.12 Despite this increased risk of physical and mental health disorder, access to screening and health check services for people with LD is markedly lower than for the general population. The 2013 Suffolk Learning Disability profile suggests that in comparison to the general population, uptake of cervical screening in people with LD is 41% lower than for peers without LD, and for breast cancer and bowel cancer screening it is 14% lower. Additionally, the 2013 Self-Assessment Framework submission suggests that only 36% of people who were eligible attended their GP for a LD annual health check.

16.13 However, the 2013 Suffolk LD Profile does suggest that people with LD make up a lower proportion of emergency secondary care admissions than the national average and comparator counties. The rate of admission in the LD population for ambulatory care sensitive conditions is also lower than the national average.

16.14 It is clear that while there are mechanisms in place to try and address health inequities for the LD population, uptake in Suffolk can be improved. While mortality rates for cancer are similar in the LD population and the general population, people who die of cancer die younger when they have a learning disability co-morbidity. Initiatives such as screening and health checks should enable earlier detection of conditions such as cancer so it is vital that access is better facilitated for people with LD.

16.15 Uptake of the annual health check for people with learning disabilities is markedly lower in Suffolk than in statistical neighbour counties. Where the IHaL LD profile suggested as few as 19% of eligible individuals had a health check and the 2013 SAF submission suggested that the figure had risen to 36%, statistical neighbours reported figures of 70% plus. Improving the uptake of this intervention may help address health inequities in this population in terms of treating illness earlier.

17.0 TRANSITION OF CARE BETWEEN CYP SERVICES AND ADULT SERVICES

17.1 Definition
For the purposes of this needs assessment, transition is the term used to define the process of moving from Children’s and Young People’s (CYP) services to Adult services. While in many areas of care, the age of 18 is a threshold for service responsibility from children’s’ services to adults’ services, this arbitrary milestone can produce difficulties and risks for service users with disorders such as those found within the learning disability categorisation. The introduction of the Children and Families Act (2014) in April 2014, moved expectations for beginning the transition process for children forward from the age of 16 to 14. This Act also introduced a system designed to ensure that children with special educational needs (SEN) can have their needs supported in through CYP service input up to the age of 25.

17.2 Current transition population and projection
As at the end of August 2014, Suffolk had 303 individuals with learning disabilities who are being tracked for transition. With the current approach to transitioning starting around age 16 years and the incoming Children and Families Act identifying age 14 years as the point to initiate transition, one would project a shift in the number of individuals with LD being assisted and tracked. The data projection for all young people with special educational need, or disability (SEND) for the period 8th September 2014 to 7th September 2015 is that there are 85 young people in transition. Current projected estimates indicate that there will be between 80 and 110 people in transition in future years beyond 2015. Tracking meetings will be used to revise these projection estimates as required. Currently, the number of young people in transition with learning disabilities cannot be separated from the total figure for SEND. It is expected that this disaggregation will be possible for future projections.

17.3 Current transition process
As noted above, the current process is in the process of review and amendment. A standard approach to Transition does not currently exist across all Health and Care services. From 1st September 2014, all young people will attend a review designed to assess preparation for adulthood in Year 9 of school. This will be led by the school and involve all relevant practitioners. During the production of this needs assessment, it was noted in many encounters with those involved in the transition process that age 14-18 years was the start for the process; however it was also noted that this could get missed and transition might start later at times such as at age 16 years when a child is leaving school. In general the education system will continue to be the catalyst for the occurrence of transition events. When a child leaves school there has been increased risk identified for failure for continued transition into adulthood as previous resource availability has historically ended at age 18 years. However with the 2014 Care Act requirements and SEN Reform, this drop-off in services at age 18 changes. No specific guidance on how this will happen has yet been identified. In the interim, the former process continues to be utilised. Those service providers involved are generally aware that the SEN Reform will expand the services from 18 years up to 25 years but again the means to makes this happen remains unclear at the time of writing.

17.4 It is noted that there is limited transition planning prior to age 14 years if a child is in mainstream school and any planning that seems to be occurring may be limited to children located in specialty schools where the focus is more specific to the LD population. The specific involvement of health and social care in the transition process is unclear in Suffolk. In general it is reported that when transition review meetings occur that usually health and care are present to provide input. The current pathway was developed around involvement of both; however again this is not the process which is currently implemented. Health services for the LD population appear to be working independently of social care services and there is a lack of clarity over joint planning and information exchange during transition from the CYP population into ACS.

17.5 Best practice

17.5.1 Suffolk County has invested in a system to record and share information about the services available to young people under SEND known as Local Offer. This provides service-mapping information for young people with learning disabilities and could act as a suitable model for mapping and communicating services for adult users.

17.5.2 Suffolk County is in the process of identifying the best practice for transition in the LD population and as such they are undergoing an evolution of the process. It is noted that Suffolk is looking at other local authorities for best practice such as Hampshire.
County Council’s Transition Pathway, which clearly defines Years 9-12 (ages 14 years and up) and the associated actions as each step of the pathway. Currently in Suffolk, there is engagement in Transition Group meetings to help develop best practice with the plan for a published document defining the process. Furthermore, a conference sponsored by the CCGs was recently held to examine transition as part of the health review for transition. Transition processes in Cambridgeshire and South Hampton were identified as models of best practice and include the following elements:

- Initiate planning for the whole population at age 14 years with GP involvement
- Person centred approach
- Identified/named integrated health & care lead professional for the plan
- Plan has established outcomes
- Individual is in the agreed upon integrated database with access to those involved
- Transition review dates are established and individual, families/carers aware early in process
- Properly skilled/trained workforce is involved with the process
- Individual/family/carer participate in the process
- A clear plan for those who may no longer meet certain resource eligibility criteria

17.5.3 The iHaL commissioning guide for learning disabilities notes that transition is often not started early enough and there is insufficient information on the needs of young people to adequately inform planning of services (5). It provides the following best practice guidance for designing the local transition process:

- Transition planning for individuals should be tailored to that individual’s needs and should include health, independent living, employment and social inclusion;
- Any plan pertaining specifically to health should ensure that,
  - The young person’s aspirations are understood and accounted for
  - Standing plans for the management of specific issues are accounted for, and
  - Details of the professional and/or agency lead for each aspect of support management are included
- The single assessment process and plan for education, health and care support outlined by the Department of Health in 2012 in its document, Support and aspiration: a new approach to special educational needs. Progress and next steps (69), needs to be adopted to provide planning that emphasises the long term and a child-centred process;
- A care co-ordinator should be identified and provided to help a service user, carers and the multidisciplinary team implement a support plan effectively;
- There must be effective two way communication between child/carers and services to ensure the young person’s wishes and aspirations are understood and they are helped with self-efficacy to work towards these aspirations;
- Appropriate and accessible information and advice must be provided to enable young people to exercise choice effectively and participate fully in the transition process;
- Commissioners must focus as much as possible on outcomes and improve joint commissioning to promote flexible services based on developmental needs

17.6 The Suffolk Transition Pathway document (2013) provides guidance for services and families for this crucial process. However, the Care Act (2014) requires amendments to the pathway to meet this new legislation. Review of the 2013 Transition Pathway document identified that the pathway had not been fully implemented and
development input from commissioners had been limited. Therefore, evidence of implementation of the 2013 Transition Pathway process throughout Suffolk is inconsistent. This creates difficulties in assessing how well current transition services meet the needs of the LD population. In the summer of 2014, a consultant was engaged by the CCGs in Suffolk to review the transition process in light of the requirements of the Care Act and of reported inconsistencies in pathway implementation. This review is ongoing at time of writing.

17.7 Summary
Currently Suffolk does not have a documented Transition Pathway/Plan in place that is reflective of current legislative requirements or have commissioner involvement in the process. There is wide-scale fragmentation in education, health, and social care as a result of the lack of a process. Additionally there is a need for integration across the services in the process to achieve a whole person approach to the development of the required Education, Health, and Care plan (EHC). There are significant gaps between the current Suffolk processes when compared to potential best practices. Currently none of the previously noted best practices are implemented in Suffolk.

Recommendation

10

• Health and Social Care commissioners should continue to prioritise the development of a standard integrated transition process for CYP involving education, health, and care with a focus on a person centred approach. This development process should consider stakeholder involvement, identification of named co-ordinating individuals, improved recording/tracking systems, and liaison across geographical boundaries.

18.0 STAKEHOLDER EXPERIENCE

18.1 Introduction

18.1.1 Quantitative information on activity, outcomes and cost can tell us a great deal about the quality and extent of service delivery but it is vital to ensure that qualitative information about stakeholder experience of services is also sought. There is a wide range of stakeholders for this needs assessment that can be broadly categorised as:
• Users of services
• Carers of users of services
• Staff working in service providers
• Commissioners of services

18.1.2 The views of stakeholders were sought for this needs assessment through face to face meetings and telephone meetings with key individuals, through accessing sources of existing stakeholder feedback, and through the undertaking of a bespoke online survey. A copy of the online survey tool and the quantitative results are included as Appendix 8. This survey received 100 responses across carers, provider staff, and commissioning staff. The survey was not designed for completion by service users as the method was not thought to be appropriate for a significant proportion of the service user population.
18.1.3 The survey findings were mixed in terms of satisfaction with current services and confidence in the ability to meet increased future demand. While the majority of respondents felt that systems for identifying people in the county with LD need were working well, there were key areas where respondents felt that identified need was unaddressed. Concern was particularly acute relating to support for co-morbidities, transition of care between CYP and adult services, and co-ordination between health and social care services.

18.1.4. For respondents to the survey, the great majority (73%) suggested that Suffolk LD services usually worked well in meeting the needs of their service users. However, of carer responders, only 38% felt this to be the case.

Areas of broadly positive feedback were:
- Ability to identify people with LD in Suffolk;
- Ability to meet LD service users’ needs in the areas of social skills, safety, healthy living support, education, and access to leisure;
- Care/support plans accurately identifying and proposing interventions for meeting LD service user needs.

Areas for improvements were:
- Ability to meet services users’ needs in the areas of mental health, sexual health and relationship building, and employment;
- Co-ordination between health services and social care services;
- Skills training provision for generic staff in caring for people with LD;
- Transition of services between CYP and adult social care’

The following section provides detailed information on stakeholders’ views and comments.

18.2 Service users’ experience

18.2.1 The web-based stakeholder survey was judged to be an inappropriate vehicle for collection of service user qualitative data. Existing sources of service user views and narratives were sought from SCC’s advocacy partners.

18.2.2 The ACE People First Groups and the quarterly county-wide group meetings provide feedback from users for their hopes for the care services they would like to receive and comments on how they would like to make their voice heard.

- A consultation exercise at the end of 2013 found a wide spread of opinion from LD service users on how they would like to share their comments and concerns with advocates (70). While the most popular method was through group meetings (22% of respondents preferred this method), there were significant proportions of respondents whose preferred of self-advocacy was through one-to-one meetings, telephone consultations, online systems or through easy read pro-formas
- An ACE consultation exercise in November 2013 asked LD service users to rate the advocacy they had received (71). The attendees reported on the positive and negative experiences they had had in using the advocacy service:

  Positive experience:
  - Having advocates attend review meetings
  - Support from advocates in getting independent accommodation
  - Advocacy increased service user confidence in communicating with strangers
  - Advocacy supported service users in saying things they found hard to say before
People First events enable users to build social relationships with peers
Advocacy supported users in getting employment
Advocacy supported users in talking to the police

Negative experience:
Communication difficulties experienced where advocates were not able to use sign language and Makaton
Infrequent access to advocates
Need for hospital based advocates when an LD patient is admitted
Lack of access to People First Groups due to other commitments
Difficulty with handling bad memories and negative emotions raised through advocacy once a person is back with their family
Difficulties communicating with advocates when not in face-to-face meetings
Use of jargon during advocacy meetings
Lack of contact with peers in between People First meeting dates

• ACE facilitated LD service users to contribute to the Suffolk Self-Assessment Framework in 2013 (72). The following comments were received to specific questions relating to health assessment and health care:
  Was the information (about health checks) easy to read?
  o “No, mum had to explain it to me.”
  o “Staff had to support me to read it. Pictures would be better so I can understand it better.”
  o “It’s better if someone calls me (and explains things).”
  Did the health professional support you to feel comfortable?
  o “Kind of, the doctor looked through my notes and saw that I had a learning disability and ADHD.”
  At the chemist, do the staff make it clear?
  o “My mum goes for me.”
  o “They say things so quick, and staff do my medication.”
  o “I don’t like taking my medication. The staff at the XXXX put the tablet in my yoghurt so I don’t get anxious about taking the tablet.”
  Do you feel there is enough in Suffolk to keep people’s minds active and healthy?
  o “No, there’s nothing to do in Suffolk.”
  o “There should be more things to do. At night time.”
  o “We would like something to do in the evenings, music or drama.”
  Do you feel like there are good employment services in Suffolk?
  o “I need to write a CV, but need support to do it. I’ve asked my support worker to help but they said I need to do it myself.”

At the county wide Advisory Group meeting the following month, the comments on key issues collated from previous meetings were analysed with prioritisation of issues agreed. The attendees across the People First groups identified health, housing and benefits to be the three key issues of concern for people with LD in the county. Further common issues where service users wanted advocacy help were relationships, online and community safety, direct payments, deaf/blind awareness, employment, and recycling.

18.2.3 Self-Assessment Framework:
The national annual learning disabilities Self-Assessment Framework report requires local authorities to provide a data submission for their population covering a range of
health and social care issues. The submission requires RAG rated\textsuperscript{15} assessment of key areas with user reported examples to provide evidence for the judgement. Examples of this user experience evidence are provided below:

- B has severe epilepsy and has to have regular check-ups at the hospital. He gets a letter sent to him through the post which his mother reads to him. The letters use technical language so difficult to understand. B normally sees the same nurse who knows him and understands him. B is able to communicate with that nurse but if he gets a different nurse he feels agitated and frustrated as they do not always understand him. Continuity is important to him;
- While in hospital, C was very distressed as she did not have her glasses with her. Her bed was positioned in such a way that she was always in direct sunlight. Nurses unable to communicate with her. C had a collapsed lung. Hospital initially unaware of this as ward had not communicated with Learning Disability Liaison Nurse;
- A, a physically and learning disabled customer had been receiving regular podiatry treatments. He was informed that he is not within the group defined as in most urgent medical need, based on the opinion of the podiatry team, without reference back to his GP. A has severely malformed feet, wears surgical boots, and callipers and has severe difficulty walking. He also suffers from lymphedema and cellulitis, his walking immobility is severe, and he is in almost constant pain and discomfort. Failure to have regular podiatry treatment causes him to suffer even more and could cause him to have total immobility. The decision to remove him from regular treatment was reversed because of the confidence and determination of his carers in arguing on his behalf;
- F requires sedation in order for her teeth to be effectively examined and, if necessary, treated and referred to a Special Care dental team. The team have been excellent carrying out normal examinations and also restoration of her accidentally damaged tooth (under GA). However, the availability of dental sedation in Suffolk is unclear - different providers provide different types of sedation and the availability of a two-stage process is not always possible. The position needs to be clarified to ensure appropriate access for all, including for those with behavioural issues;
- F had been suffering discomfort from gagging and began to display uncharacteristically aggressive behaviour. It took nearly a year to stabilise F’s condition ns the slow and lengthy diagnosis process included an internal examination under general anaesthetic which was disconcerting, inconclusive and unnecessary. In addition to the challenging behaviour towards her carers F also became detached from involvement in activities at her resource centre resulting in changes having to be made to her care plan. When the diagnosis was eventually made, chiefly through the excellent support from the Speech and Language Therapy team with the LD Community Services, it became apparent that F’s was a relatively common condition. A key learning point for the Acute Health Services is that there should be improvements in access to diagnostic information relating to common issues occurring in specific health conditions;
- C was a discharged from Paediatric SALT services and should have been referred directly to the adult assessment and treatment service for people with learning disabilities. This route was temporarily closed until C’s mother eventually tracked down the progress of her referral. C has been able to benefit from the advances in AAC (Augmentative and Alternative Communication.) Without this tool she reverts to meltdowns, rages due to understandable frustration and unresolved fears. C is a success story partly due to her mother’s drive and

\textsuperscript{15} RAG rating is a traffic light rating scheme; Red, Amber, or Green
creative input but mainly due to the Speech and Language Therapy she has enjoyed to date combined with the provision of technical practical help from the Suffolk Communication Aid Resource Centre which had to discharge her when she reached 19;

- F is on the waiting list for Supported Housing. During most of the past year there has been excellent support of a Community Care Practitioner and from Suffolk Family Carers. F has been offered a number of potential placements. Some of these have been visited; however with all of the unsuccessful ones, the placement has been deemed inappropriate due to incompatibility with the existing tenants – the incompatibilities in every case were as a result of discussions with key professionals involved in the support of the existing clients and F – a process which the parents had encouraged. It is clear that these incompatibilities could, and should, have been identified before the parents were advised of the potential placement – thus avoiding the misplaced optimism;

It is clear that in many examples where experience of care has included negative elements, that problems with interagency and provider-user communication has been a major contributory factor. It is also often the case that breakthroughs in access to treatments and interventions are brought about through strong carer advocacy.

The Suffolk Self- Assessment Framework submission for 2013 was also able to highlight positive outcomes and experiences of care for learning disability service users.

- J is a young man with autism in his early 20’s. He recently finished attending college and he volunteers at the local museum two days a week. He wanted to do different things in his community. The Opportunities Team have supported him with travel training to access a horticulture project. J is now more confident accessing public transport and is using local buses two days a week independently;
- T is a man in his 20’s with learning disabilities who lives with his parents expressed an interest in volunteering opportunities. He has been supported to visit and join the local library. He is also working as a volunteer at a local drop-in activity once a week where he is learning new skills and socialising with peers, gaining in confidence;

18.3 Carers of service users

18.3.1 Eighteen carers of LD service users responded to the needs assessment online survey. A summary of the quantitative findings is provided below:

Positive comments:
- 36% of 18 carers felt that systems for identifying people with learning disabilities in Suffolk worked well, this happened most of the time and 82% felt it worked well some or most of the time
- 72% of them felt that support/care plans address the needs of people with LD some or most of the time
- Respondents were also generally positive about services’ ability to meet the needs of people with LD in the areas of social skills, safety, and education

Additionally, some of the qualitative, free text responses spoke of good experiences of LD support:
“My experience [of transition of services] was totally positive”;
“My daughter will always need 24 hour care and support but within that need/support, she is developing independence under supervision which is truly life enhancing. Thank you Suffolk and Mencap!”

Areas for improvements:
- Where respondents were able to judge, 60% did not feel that service prioritised maximisation of independence highly enough
- 66% felt that health services and social care services seldom or never co-ordinated their services well in identifying people with LD, and 80% felt they were not well co-ordinated in implementing support/care plans
- 64% felt that transition of support from CYP services to adult services seldom or never worked well
- Areas of need where respondents were less positive about services’ ability to provide effective support were physical health, mental health, communication, and family resilience

Additionally, some of the qualitative, free text responses spoke of specific concerns with LD services:
- “Social services do not seem to understand the real problems [encountered] by LD folk or their parents”
- “…where one used to have a named physio, OT, SALT, Consultant Neurologist, Community Nurse and Community Paediatrician, social worker – for example – who knew the case, kept the files and was quickly available in emergency, one now has to take the lengthy route of reapplication via the GP/Customer First for every need”
- “It seems that health services are denied my daughter now she has turned 19”
- “[Health services and social care services] need to have an open dialogue and not use people as human shuttlecocks to be batted from one agency to another. No-one is willing to take overall responsibility”
- “As my daughter’s transition was some 7 years ago I hope it has improved. I was reduced to tears on more than one occasion and left in limbo, not knowing if I was going to be left to care for an autistic [daughter] with sometimes challenging behaviour 24/7 and have to give up my job”
- “Care plans are fine however applying the plans [is] difficult”

Further comments:
- “Often some people in Health Service only see people with LD when they are ill – useful to see them when well – this is happening in some places (e.g. visits by staff from Ipswich Hospital to day services etc.)”
- “The vulnerability of service users needs to be taken into account, alongside the need for independence”
- “Independence is often restricted by factors such as availability (and costs) of transport…”
- “It is wonderful to have [X] as a nurse for learning disabilities and liaison in Ipswich Hospital. But she is a drop in the ocean”
- “My daughter’s particular supported living service is well funded and the residents well matched and therefore it is able to implement her support/care plan well. Although it still requires vigilance on my part to ensure some of the details of her complex needs are understood and carried over between the frequent staff turnovers”
Additionally, discussion of the stakeholder survey results with the lead carers’ representative in the Learning Disability Partnership produced the following points:

- The learning disability health and social care community in Suffolk should ensure that the LD Partnership plays a central role in commissioning services (defining need, procuring services, monitoring delivery). Members of the Partnership hold specific skills and expertise that can be invaluable in maximising the effectiveness of the commissioning process;
- Services and commissioners need to ensure that person centred plans for users of services and their carers remain live and viable through the continual effective review of progress and relevance. Valuing People Now set out a standard that plans should be reviewed at least annually;
- Commissioners and service providers should ensure that person-centred plans seek to meet the standards set out in the Quality of Life standards;
- For people with LD in the transition age groups (14-25) and earlier, there may be disincentives for schools to identify certain types of learning disability (dyslexia being given as an example) if this diagnosis does not meet the threshold/criteria for financial support for the school.

**Recommendation 11**

- Health and social care service commissioners to consider how current systems for supporting clients’ health service referral and social care service purchase can be improved to ameliorate co-ordination between agencies. This could include identifying named care co-ordinators for service users able to liaise across organisational boundaries

18.4 Service providers

18.4.1 64 people from service providers responded to the online survey. A summary of the quantitative findings is provided below:

Positive findings:
- 92% of respondents felt that systems for identifying people with learning disabilities in the county worked well most or some of the time;
- 60% of respondents felt that support/care plans addressed the needs of people with LD all or most of time. Only 9% felt that this was seldom the case;
- Respondents were also generally positive about services’ ability to meet the needs of people with LD in the areas of physical health needs and communication (contrary to the reported experience of carers – see 16.3.1), social skills, safety, health living support, and access to leisure.

Additionally, some of the qualitative, free text responses spoke of good experiences of LD support:
- I know the befriending Scheme works hard to promote independence. The people that use our services value the opportunity to have choice and to be encouraged to learn new skills and have new experiences. It enables them to feel valued and boosts their confidence;
- As an organisation we always involve people in whatever way they want and feel comfortable with;
• Within Mencap people are fully involved on developing their plans or their loved ones (at their request);
• I feel there has been great improvement over the past few years;
• For core needs [the service works well] but others which turn existence into life can be overlooked in a difficult financial climate

Areas for improvements
• 58% of respondents felt that maximisation of independence was not prioritised highly enough by LD services and commissioners;
• 38% of respondents felt that health services and social care services were not usually well co-ordinated;
• 83% of respondents felt there was inadequate skills training provision for staff working with people with LD (in non-LD specific services);
• Areas of need where respondents were less positive about services’ ability to provide effective support were mental health, sexual health and relationship building, and employment

Additionally, some of the qualitative, free text responses spoke of specific concerns with LD services:
• The assessments carried out by health and social care professionals often don’t look at independence and personalisation in enough depth. There is little advice about transitional plans and different service pathways including personal budgets;
• In many circumstances people are not given the right support when they require it and are left to be too ‘independent’ which can compromise their health;
• Health and social care always seem to have challenges working in partnership and using joint funding stream. There is confusion over diagnosis and responsibility, particularly with people who have a learning difficulty and mental health problems;
• The role of specialist LD community nurse no longer exists to joint work with community support services to support people with LD living independently. This has had a big impact in individuals and increased the demand for community support services to try and deal with health-related issues outside their area of expertise. The needs of people who have LD and mental health issues are currently not being met;
• The creation of the support plan is usually well coordinated, however the monitoring once it is up and running is poor. There doesn’t seem to be a trail of accountability to ensure it is followed as it should be;
• Time is very limited to plan and share information. Often transition plans aren’t in place. Young people and families often aren’t aware of their rights and entitlements or the support services available;
• There are a lot of people with mild learning disabilities who are struggling to cope without support. People often come to our groups with letters that need reading and explaining and questions about their support. Our services are used as a safety net for people with mild learning disabilities;
• It feels as though provision post College is very poor and where support is in place it is very limited which is demotivating for the individuals but also impacts on the lives of the Carers who are then unable to do anything for themselves;
• In the past value was put on social activities and developing friendships, it seems that now the majority of funding is for care so little is left for other things.
Further comments:

- Maximisation for independence of service user should be given the highest of priorities as there is a shortage of help and support with funding for some to access the support they need;
- We need to consider the views of the person as the priority particularly in relation to the recent rulings re Mental Capacity Act/Deprivation of Liberty;
- Community Support services primarily deal with crisis. Prevention and early intervention is wrongly seen as an unnecessary cost but investment in this would ultimately make savings and prevent costly crisis management, misery for the individual and often a move to supported housing;
- People who are living independently who are in debt or facing eviction often resist support and may not initially engage in support planning;
- Commissioners should ask providers to contribute to the cost of independent advocacy for people using the service;
- There needs to be a shift in thinking to provide opportunities that are person-focused and not disability labelled;
- [Teams] are taking on more roles as colleagues depart seeking increased opportunities in other areas/agencies. Caseloads increase and it becomes harder to take up training and development opportunities that are available to teams across the council;
- [We] still come across prejudice often - two people we support were refused to stay at a hotel recently as the owner deemed they may upset other guests;
- There needs to be input available from health representatives for people with LD living independently in their own home which co-ordinates with input from community support services;
- [The] division between a "health need" and a "social need" is not helpful to people with a learning disability or their carers. Usually there are elements of both in any person's care and putting the person at the centre of care should be the first consideration;
- Training for staff with a non LD background, so they have a true understanding of how to treat the individuals with dignity and respect, for example giving them extra time at appointments (this rarely happens);

18.5 Overall findings

18.5.1 From the 13 carer respondents who answered the final question, “how well do you feel that health and social care services are able to meet the needs of people with learning disabilities in Suffolk?”:
- 5 felt that services usually worked well to meet LD needs
- 7 felt that this was seldom the case
- 1 felt that this was never the case

18.5.2 From the 43 staff respondents who answered the final question, “how well do you feel that health and social care services are able to meet the needs of people with learning disabilities in Suffolk?”:
- 36 felt that services usually worked well to meet LD needs,
- 7 felt that this was seldom the case;

19.0 CONCLUSIONS

19.1 Nationally, the LD population is at high risk of experiencing health inequalities. These health inequalities can arise from barriers to accessing health services, increased levels of physical and mental health co-morbidities, and negative outcomes for the
social determinants of health such as education, accommodation, and community integration.

19.2 The median age at death for people with learning disabilities, while similar to other LD populations nationally, is significantly lower than the life expectancy for the general Suffolk population. Additionally, a larger proportion of hospital admissions and Accident and Emergency attendances are experienced by the LD population in Suffolk than the population size might expect.

19.3 People with learning disabilities in Suffolk need to be assured that the health and social care staff providing their routine and urgent care are trained and equipped to facilitate access to assessment and treatment/support so they are not disadvantaged in comparison with their non-LD peers.

19.4 Suffolk provides an extensive variety and volume of services to meet the specific needs of people with learning disabilities and to provide both generic and specific care. There has been a transformation in the range of service types in recent years to meet the best practice requirements of Valuing People and Transforming Care, with services moving from residential settings to day services and community-based care. In Suffolk, the priority is now to move people from day services to community-based services that will enable maximisation of independence.

19.5 The service mapping exercise undertaken in this needs assessment was limited in its ability to identify service gaps due to the lack of information returned by service providers.

19.6 Quality assessment of service providers suggests areas where Suffolk services are performing better than regional and statistical neighbours. One such area is provision of direct payment which suggests that efforts to meet a major SCC commissioning priority are meeting success. However, the comparatively low uptake of LD specific annual health checks may be hampering ability to identify serious or chronic illness at an early stage in development, increasing the risk of health inequities for this population.

19.7 The strategy for implementation of Supporting Lives, Connecting Communities (SLCC) and personalisation is designed to provide services more effectively and efficiently while putting control of choice in the hands of LD service users. It is clear that the comparatively strong uptake of direct payment demonstrates good progress towards meeting these objectives. The common needs of the LD population reflect the chronic nature of many LD conditions and the intensity of support that can be required. As such, a large proportion of the interventions provided to people with learning disability in Suffolk is long-term Tier 3 provision, and consequently can be highly resource intensive.

19.8 The nature of SLCC and the move to personalisation means that choice and flexibility can be a key benefit to service users. However, in order to exercise choice, it is vital that the information available to clients on service providers is extensive, contemporary and high quality.

19.9 Currently, there are areas of information provision where there is potential for rationalisation and extension. Where service users are able to refer to performance management and quality assessment information for a range of services, they have the ability to make informed choices about how they spend their personal budget. Further examination of systems of performance and quality assessment may be beneficial in identifying potential amendments. The linking of monitoring to validated
quality standards would provide further assurance that services are providing high quality care as per best practice.

19.10 Stakeholder views on services for the LD population in Suffolk cover the full range of satisfaction. There is a good deal of positivity from providers and carers in relation to the ability of systems in the county to identify people in need. Carers were positive in their opinion of services’ ability to meet the needs of service users, particularly in the areas of social support, education and safety. Service users have reported how the care and support received has enabled them to integrate better in their communities and improve their life skills and opportunities. Provider staff was often positive about improvements in services and assured about the ability of support teams to deliver the agreed objectives in care plans.

19.11 However, stakeholders across all areas were able to identify aspects of care and systems where improvements could be made. Particular areas of concern related to lack of co-ordination between health and social care and concerns about provision for physical and mental health. For provider staff, there was significant concern either that the maximisation of independence was not prioritised highly enough, or that the balance between independence and safety was not always correct.

19.12 This needs assessment has identified areas where systems can be improved to help the implementation of the SLCC strategy and reduce potential for health inequities for this vulnerable population. These areas relate primarily to strengthening systems for information recording and sharing, and quality and performance assurance. Section 20 provides a summary of recommendations arising from this needs assessment.

20.0 RECOMMENDATIONS

Recommendation 1 – Local authority and health care commissioners in Suffolk to ensure that data recording practices/systems facilitate and require recording of social circumstances (including accommodation status) of its LD service users. This will address a significant information gap not present in regional and statistical neighbour counties.

Recommendation 2 – Systems for recording safeguarding referrals, alerts and action plans should be amended to ensure that data on people with learning disability can be disaggregated from data for other service users.

Recommendation 3 – The Suffolk Learning Disability Partnership/Mental Health and Learning Disabilities Joint Commissioning Group should consider the appropriate use of the Health Equalities Framework in assessing the level of health inequalities in the county’s LD population as part of the development of its LD strategy. This development work should enable improvements in processes for completion of the Self-Assessment Framework.

Recommendation 4 – The Suffolk Learning Disability Partnership/Mental Health and Learning Disabilities Joint Commissioning Group should consider the appropriate use of the Quality of Life Standards in guiding expectations for care/support quality in service contracts and in personal care plans, assessments and reviews.

Recommendation 5 – Both health and social care commissioners should consider requiring all LD service providers to participate in a service mapping exercise to collate information on access arrangements, intervention types available, and target populations. This will facilitate performance monitoring, commissioning processes, and service user(carer) provider choice.
Recommendation 6 – Suffolk CCGs should consider undertaking an audit of a representative sample of screening appointment invitations to people with LD to assess frequency of use of appropriate communication methods such as easy read documentation. The objective of this audit would be to determine whether improvements could be made to the screening appointment invitation process for this population to help increase screening uptake.

Recommendation 7 – Health and Social Care Commissioners and Public Health should continue prioritising and co-ordinating efforts to increase uptake of LD annual health checks. This should enable improvements in identification of health issues at an early stage for people with LD and improve uptake of screening. Methods for improving uptake of health checks could include ensuring that information materials are accessible to the LD population and appropriate communication support is provided. This should include support for carers as they provide a vital role in facilitating service user access to health checks.

Recommendation 8 – Commissioners to undertake a pilot audit of a representative sample of LD service users to assess process and outcomes for support plans and interventions in relation to Quality of Life Standards. This will enable commissioners to better understand the effectiveness of current services in complying with agreed support plans and meeting service user life objectives.

Recommendation 9 - Social care commissioners to consider options for ensuring a practical, regularised framework for contract performance monitoring across all LD service providers is developed and implemented. This should include assurance that a set of SMART performance indicators linked to best practice standards (such as Quality of Life Standards) are included in all contracts and that the process for monitoring relates directly to these performance indicators. Schedules and forums/methods for review should be explicitly recorded in contracts and compliance with the review system monitored.

Recommendation 10 – Health and Social Care commissioners should continue to prioritise the development of a standard integrated transition process for CYP involving education, health, and care with a focus on a person centred approach. This development process should consider stakeholder involvement, identification of named co-ordinating individuals, improved recording/tracking systems, and liaison across geographical boundaries.

Recommendation 11 – Health and social care service commissioners to consider how current systems for supporting clients’ health service referral and social care service purchase can be improved to ameliorate co-ordination between agencies. This could include identifying named care co-ordinators for service users able to liaise across organisational boundaries.
### Glossary

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ACS</td>
<td>Adult and community services</td>
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<tr>
<td>ASD</td>
<td>Autistic Spectrum Disorder</td>
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<td>CAF</td>
<td>Common Assessment Framework</td>
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<td>CCG</td>
<td>Clinical Commissioning Group</td>
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<tr>
<td>CAMHS</td>
<td>Child and Adolescent Mental Health Service</td>
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<tr>
<td>CIFOLD</td>
<td>Confidential into premature deaths of people with learning disabilities</td>
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<tr>
<td>CYP</td>
<td>Children and Young People</td>
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<td>DES</td>
<td>Direct Enhanced Service</td>
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<tr>
<td>EHC Plans</td>
<td>Education Health and Care Plans</td>
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<tr>
<td>GY&amp;W</td>
<td>Great Yarmouth and Waveney</td>
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<tr>
<td>IAPT</td>
<td>Improving Access to Psychological Therapies</td>
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<tr>
<td>IHaL</td>
<td>Improving Health and Lives Learning Disability Observatory (Public Health England)</td>
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<tr>
<td>LD</td>
<td>Learning disability(ies)</td>
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<tr>
<td>LEA</td>
<td>Local Education authority</td>
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<td>LES</td>
<td>Local enhanced service</td>
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<td>LO</td>
<td>Local Offer</td>
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<tr>
<td>MLD</td>
<td>Moderate learning disability</td>
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<tr>
<td>NSFT</td>
<td>Norfolk and Suffolk Foundation Trust</td>
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<tr>
<td>P&amp;MLD</td>
<td>Profound and Multiple Learning Disability</td>
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<td>QOF</td>
<td>Quality and Outcome Framework</td>
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<td>SAF</td>
<td>Self-assessment framework</td>
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<td>SCC</td>
<td>Suffolk County Council</td>
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<tr>
<td>SEN</td>
<td>Special Educational Need</td>
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<td>SEND</td>
<td>Special Educational Need and Disability</td>
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<tr>
<td>SLD</td>
<td>Severe Learning Difficulty</td>
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22.0 REFERENCES


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APPENDIX 1: CAUSES OF LEARNING DIFFICULTIES (AETIOLOGY)

Rees\textsuperscript{28} describes how the aetiology of learning disabilities can be subdivided into conditions that arise at conception (therefore whose prevention lies before conception) and those that arise during pregnancy, labour and after birth (see table 4.7). No aetiological cause is found in about 30\% of cases of mild or severe learning disabilities. Aetiological agents fall into three main categories: genetic, infective and environmental.

Table 1: Aetiology of learning difficulties from Rees et al.\textsuperscript{28}

<table>
<thead>
<tr>
<th>Aetiological factor</th>
<th>Timing of injury/exposure</th>
<th>Antenatal</th>
<th>Perinatal</th>
<th>Postnatal</th>
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<tr>
<td>Genetic</td>
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<tr>
<td>Trisomies:</td>
<td>Secondary neurological damage</td>
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<tr>
<td>21 Downs Syndrome</td>
<td>e.g. phenylketonuria</td>
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<td>18 Edwards Syndrome</td>
<td>Lipid metabolism e.g.</td>
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<td>Syndrome</td>
<td>Tay-Sachs</td>
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<td>13 Patou Syndrome</td>
<td>Carbohydrate</td>
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<td>Syndrome</td>
<td>metabolism</td>
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<tr>
<td>Genetic</td>
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<tr>
<td>Chromosome aberrations</td>
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<tr>
<td>Rubella, with more severe damage the earlier in pregnancy</td>
<td>Secondary</td>
<td>Herpes Simplex</td>
<td>Meningitis</td>
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<td>HIV</td>
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<td>Cytomegalovirus</td>
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<td>Infective</td>
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<td>Encephalitis</td>
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<td>Encephalopathy</td>
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<td>Rhesus Incompatibility</td>
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<td>Drugs/alcohol</td>
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Genetic Factors

Internationally, iodine deficiency is the most common cause of severe learning disabilities. In the U.K. the most common causes are related to genetic factors. Non-inherited Down’s syndrome causes about 30\% of cases at birth. The second most common known causes are X-linked disorders, most commonly fragile X syndrome. Other single gene disorders, of which more than 200 have been identified, account for 12\% of cases. Known genetic disorders cause only 5-10\% of cases of mild learning disabilities, although more are being identified.\textsuperscript{28}
Non-genetic factors – infective and environmental

25% of severe learning difficulties which result from non-genetic causes are related to infection, non-accidental injury and accidents. A further 10% are caused by obstetric complications and injuries at birth. This may account for observed associations between learning disabilities and factors such as epilepsy and cerebral palsy. Infective causes are uncommon and the outcome is variable. Rubella infection in early pregnancy, for example, severely affects the development of those who survive; later infection tends to be less damaging.

Some causes of learning disabilities are socially determined or influenced, for example in the social gradient in the harm caused by alcohol, exposure to pollutants (including lead) and poor maternal and infant nutrition. Dietary folate deficiency is associated with an increased risk of neural-tube defects which are associated with learning disabilities. There is however little evidence that socio-economic background affects severe learning disabilities.
### 1. Awareness and Empowerment - People in Suffolk know what to do if abuse* happens

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Measures</th>
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| - Local people, councillors, volunteers, service users and family carers say they know how to recognise and report abuse.  
- People with care and support needs and those concerned for their welfare say they know how to share concerns about possible abuse. | - There will be an increase in appropriate referrals from members of the public.  
- There will be an increase in referrals from customers.  
- There will be an increase in referrals from family carers.  
- Visits to the Safeguarding Adults Board’s (SAB) website increases each year from the July 2013 baseline. |

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<thead>
<tr>
<th>Actions</th>
<th>Lead</th>
<th>Timescale</th>
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<tbody>
<tr>
<td>Development of communications strategy to include review of referral system and methods of communication for those without internet access.</td>
<td>SAB Communication Sub-Group</td>
<td>To be confirmed</td>
</tr>
<tr>
<td>Explore feasibility of establishing a service user reference group for the SAB.</td>
<td>SAB Task and finish group</td>
<td>Group reports by April 2014</td>
</tr>
<tr>
<td>Periodic surveys of members of the public’s views includes questions regarding safeguarding awareness</td>
<td>ACS Quality &amp; Improvement Team (Q&amp;I Team) in liaison with SCC Communications team.</td>
<td>Annual Survey – date to be agreed</td>
</tr>
</tbody>
</table>

### 2. Prevention and Risk Management - Abuse of adults at risk of harm is prevented whenever possible.

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>- An increased percentage of people with care and support needs say they feel confident about their ability to look</td>
<td>- Create a baseline of periodic audits which confirm the right support from our information or advocacy is</td>
</tr>
</tbody>
</table>

*Disclaimer: The text has been adjusted to remove any sensitive or specific information that might cause privacy concerns.
after themselves.

- Local people with care and support needs and those concerned for their welfare say they are confident that “it’s OK to share concerns”
- Organisations in Suffolk reduce the risk of abuse by helping people stay independent and safe in their own homes and engaged in the community.
- A safer recruitment policy and procedure to ensure people are vetted and safe to work with vulnerable adults is in place across all agencies and providers

available and received from partners to reduce harm.

- Create a baseline of the percentage of people with care or support needs who feel that “it’s OK to share concerns”
- Increased participation in the GEM awards
- Increase in the number of green rated providers (previously rated by Dignity and Safeguarding ambassadors)
- Successful management in the reduction of repeat referrals.
- Audits provide reasonable assurance of safer recruitment policy and practice.

<table>
<thead>
<tr>
<th>Actions</th>
<th>Lead</th>
<th>Timescale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Development of Serious Case Review (SCR) Sub Group to look at lessons learnt locally and nationally for example from SCR’s and Serious Incidents</td>
<td>Suffolk Constabulary to chair</td>
<td>April 2014</td>
</tr>
<tr>
<td>Review of SCR policy &amp; procedure</td>
<td>Head of Adult Safeguarding</td>
<td>September 2013 COMPLETE</td>
</tr>
<tr>
<td>Roll out of GEM awards (Going the Extra Mile) to domiciliary care and supported housing providers</td>
<td>APT and Dignity and Quality Advisor</td>
<td>Await Section 256 funding decision.</td>
</tr>
<tr>
<td>Roll out of My Home Life</td>
<td>Q&amp;I Team</td>
<td>July 2013-July 2014</td>
</tr>
<tr>
<td>SAB to develop risk register</td>
<td>Performance and Quality Sub Group</td>
<td>To be confirmed</td>
</tr>
<tr>
<td>Risk assessment tool to be developed in line with Multi Agency Safeguarding Hub (MASH) and Adult Protection Team (APT)</td>
<td>MASH operational group</td>
<td>March 2014</td>
</tr>
<tr>
<td>Develop further customer led outcomes e.g. use of restorative justice</td>
<td>APT &amp; Suffolk Constabulary</td>
<td>Full menu implemented by August 2014</td>
</tr>
<tr>
<td>Periodic retrospective audits of customer experience</td>
<td>Performance and Quality Sub Group supported by Q&amp;I Team</td>
<td>Frequency determined by Performance and Quality Sub Group but at least annually.</td>
</tr>
<tr>
<td>APT is aligned with the principles of Supporting Lives Connecting Communities</td>
<td>APT</td>
<td>Teams in place by May 2014</td>
</tr>
<tr>
<td>(SLCC)</td>
<td>Commissioning services to include clear expectations of safeguarding policies and procedures including whistleblowing policy.</td>
<td>SCC and Clinical Commissioning Groups Contracts Teams</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Secure improved housing representation on SAB</td>
<td>SAB Business Management Group</td>
<td>December 2013</td>
</tr>
<tr>
<td>Improve links with hate crime/mate crime service, stay safe cards and Care Aware.</td>
<td>SAB Business Management Group</td>
<td>December 2013</td>
</tr>
<tr>
<td>Training to be delivered with Trading Standards.</td>
<td>LSCB &amp; SAB Training &amp; Development Sub Group</td>
<td>June 2014</td>
</tr>
</tbody>
</table>

### 3. Protection - Adults at risk are protected from harm when they need to be.

**Outcomes**

- Action in response to an alert is always personalised to the person at risk and proportionate to the level of risk.
- People with care and support needs at risk of harm say they had a real say in their safeguarding investigation and comment positively on outcomes.
- People with care and support needs who are abused have access to justice.
- Owners and managers of contracted services understand benefits of engaging with safeguarding services.

**Measures**

- The percentage of investigations completed within agreed timescales each year is stable or increasing on 2012 baselines.
- Audits show that over 95% of investigations were progressed in a timely and consistent way with proportionate action to protect the person at risk of harm.
- Following a safeguarding investigation, an increasing percentage of people with care and support needs using a 2013 baseline say they:
  - Were listened to
  - Agreed with the outcome
  - Had access to justice
- Decrease in the number of repeat referrals

<table>
<thead>
<tr>
<th>Actions</th>
<th>Lead</th>
<th>Timescale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Develop a joint approach with Children and Young People Services (CYP) to ensure that the Mental Capacity Act is fully implemented within CYP processes</td>
<td>Professional Adviser, DOLs, MCA and Safeguarding</td>
<td>December 2013</td>
</tr>
</tbody>
</table>
Develop a strong relationship with the Crown Prosecution Service to enable a single point of contact within the Criminal Justice System to ensure a consistent approach.

Develop person centred protection plans for customers.

Review of SAB Safeguarding Policy to include person centred practice guidance.

Annual independent care sector conference always includes “key messages from” SAB

Undertake qualitative random retrospective interviews.

Regional Care Contract review reflects requirement of Safeguarding responsibilities.

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. Compassionate, Proportionate and Skilled - Skilled staff and volunteers from partner agencies recognise abuse and neglect and take timely, compassionate and proportionate action to ensure protection.</td>
<td></td>
</tr>
<tr>
<td>All partners have learning and development programmes in place for all relevant staff and volunteers to use the agreed national safeguarding adults’ competency framework.</td>
<td>Each partner of SAB demonstrates an increasing percentage of people who went on awareness or other learning know how to recognise abuse and what action to take using the baseline for 2013.</td>
</tr>
<tr>
<td>The percentage (85%) of staff and volunteers across the partnership expected to have given levels of competency</td>
<td>An increasing percentage of staff and volunteers surveyed using 2013 baseline, report that they have the</td>
</tr>
</tbody>
</table>
in safeguarding is met each year.

- All those leading and managing safeguarding investigations can evidence:
  - They have appropriate and accredited skills and competences.
  - Can take timely, proportionate and personalised action to protect people with care and support needs from harm and risk of further harm.
- People working within care and support services understand what whistleblowing is and feel confident to raise concerns.
- Partner organisations have appropriate structures to support staff regarding safeguarding processes.

right knowledge, skills and support, including professional supervision to:
- Recognise and report abuse when necessary;
- Meet the requirements of local policies and procedures;
- Respond consistently, competently and in a compassionate way when someone tells them about abuse.
- Offer effective supervision and support to staff and volunteers
- Oversee safeguarding investigations effectively

- Feedback from customers confirms staff are compassionate proportionate and skilled.
- Care Quality Commission (CQC) report an increase in numbers of whistle blowers in Suffolk.
- SAB member’s report 85% of relevant staff receive mandatory safeguarding training.
- Feedback from staff confirms appropriate management support regarding safeguarding.

<table>
<thead>
<tr>
<th>Actions</th>
<th>Lead</th>
<th>Timescale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Development of core APT to ensure consistency and quality</td>
<td>Head of Adult Safeguarding</td>
<td>Recruitment in place by February 2014 Teams in place by May 2014</td>
</tr>
<tr>
<td>Periodic Audits to be undertaken by safeguarding team to ensure Suffolk County Council (SCC) data recording is of a high standard.</td>
<td>Area Safeguarding Managers</td>
<td>Commenced July 2013 and on-going</td>
</tr>
<tr>
<td>Audit to be explored through Performance and Quality Sub Group to examine themes and trends such as repeat referrals. Develop and monitor improvement plans.</td>
<td>Performance &amp; Quality Sub Group</td>
<td>Commenced July 2013 and on going</td>
</tr>
<tr>
<td>Ensure training and development programme adheres to Bournemouth competencies to embed a standardised framework.</td>
<td>Training &amp; Development Sub Group</td>
<td>To be confirmed</td>
</tr>
<tr>
<td>Task</td>
<td>Responsible Party</td>
<td>Date</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>------------------------------------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>Develop a SAB audit template and implement audit programme of key partner agencies.</td>
<td>P&amp;Q Sub Group</td>
<td>February 2014</td>
</tr>
<tr>
<td>Quality Assurance Sub Group to develop a benchmarking survey which all parties implement.</td>
<td>P&amp;Q Sub Group</td>
<td>May 2014</td>
</tr>
<tr>
<td>Ensure whistleblowing information and guidance is displayed on SAB website.</td>
<td>APT</td>
<td>December 2013</td>
</tr>
<tr>
<td>All Health and Social Care contracts should include section on whistleblowing policy.</td>
<td>SCC &amp; CCG Contracts Teams</td>
<td>June 2014</td>
</tr>
<tr>
<td>Carry out audit that customers receiving a personalised health budget are DBS checked.</td>
<td>Health Sub Group</td>
<td>June 2014</td>
</tr>
<tr>
<td>SAB to develop baseline percentage for staff who can recognise and report abuse.</td>
<td>P &amp; Q Sub Group</td>
<td>Annual Audit – completed by July 2014</td>
</tr>
<tr>
<td>Key partners to audit staff to ensure supportive and appropriate management is in place for safeguarding.</td>
<td>P &amp; Q Sub Group</td>
<td>Annual Audit – completed by July 2014</td>
</tr>
<tr>
<td>Develop training workplan that ensures awareness raising and how to report is delivered to key identified groups.</td>
<td>Local Children Safeguarding Board (LSCB) &amp; SAB Training &amp; Development Sub Group</td>
<td>March 2014</td>
</tr>
<tr>
<td>Develop links with University Campus Suffolk regarding social work curriculum.</td>
<td>APT</td>
<td>June 2014</td>
</tr>
<tr>
<td>All partner agencies develop and share their own agency training plans.</td>
<td>SAB partners</td>
<td>March 2014</td>
</tr>
</tbody>
</table>

5. Effective Partnership - Partners work together and link well with others.

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Each partner organisation is clear about its role and responsibility in safeguarding adults and meets national and local standards.</td>
<td>• Audits completed by partner organisations confirm an increasing understanding of roles and achievement of progress against agreed safeguarding standards on the 2013-14 baseline.</td>
</tr>
<tr>
<td>• Service users and family carers are involved in the work of the board and subgroups.</td>
<td>• Service users and family carers say they feel they are</td>
</tr>
</tbody>
</table>
- The standards and requirements of the Partnership Agreement are met.
- Involved appropriately in the work of the board and in shaping what it does.
- A summary of board discussions and decisions is publicly available within three months of each board.
- In an annual development day the board reviews its success against partnership agreement and the relevant Work Plan for that year.

<table>
<thead>
<tr>
<th>Actions</th>
<th>Lead</th>
<th>Timescale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual review of partnership agreement at annual development day</td>
<td>SAB</td>
<td>September 2013 &amp; September 2014</td>
</tr>
<tr>
<td>Attendance register</td>
<td>SAB</td>
<td>Commence September 2013</td>
</tr>
<tr>
<td>Chairs of Sub Groups to review Terms of Reference and membership and develop action plans.</td>
<td>Sub Group Chairs</td>
<td>Review of Terms of Reference By November 2013 Action plans signed off by January 2014</td>
</tr>
<tr>
<td>Develop Communication and SCR sub groups</td>
<td>SAB</td>
<td>SCR by December 2014, Communication to be confirmed</td>
</tr>
<tr>
<td>Review and re-launch Performance and Quality sub group enhanced membership</td>
<td>SAB</td>
<td>October 2014</td>
</tr>
<tr>
<td>Review partner agencies financial contributions in line with Part 9 Care and Support Bill statutory footing.</td>
<td>Director of Adult and Community Services and Assistant Director, Personalisation, Quality and Safeguarding</td>
<td>Initial discussions by November 2013. Agreement by September 2014</td>
</tr>
<tr>
<td>Put resources/post in place to support SAB</td>
<td>Head of Adult Safeguarding</td>
<td>February 2014</td>
</tr>
<tr>
<td>Create Post of Board Coordinator</td>
<td>Head of Adult Safeguarding</td>
<td>February 2014</td>
</tr>
<tr>
<td>Board to develop comprehensive quality assurance framework</td>
<td>P&amp;Q Sub Group</td>
<td>Commence September 2013 in place by January 2014</td>
</tr>
<tr>
<td>MASH to develop and agree a local multi-agency info sharing protocol</td>
<td>Mash Operational &amp; Strategic Groups</td>
<td>On-going – by April 2014</td>
</tr>
<tr>
<td>Improve joint working with CYP by members of both SAB and Local Safeguarding Children Board (LSCB)</td>
<td>SAB &amp; LSCB</td>
<td>July 2013</td>
</tr>
</tbody>
</table>

6. **Accountable Policy and Procedures** - Safeguarding Adults policies and procedures work well for local people.
<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Local policies and procedures enable practitioners to focus on making a difference to people’s lives.</td>
<td>• The percentage (90%) of staff and volunteers who say that policies and procedures are easy to find and to follow increases year on year on 2013 baseline.</td>
</tr>
<tr>
<td>• Local safeguarding policies and procedures are clear, accessible, up to date, known and followed consistently.</td>
<td>• There are no reported concerns about information sharing between partners that is essential to prevention and protection of people from harm.</td>
</tr>
<tr>
<td>• All requests for serious case reviews are dealt with in a timely way and responded to in line with agreed local policy and procedure.</td>
<td>• Local policies and procedures are consistent with national and other guidance.</td>
</tr>
<tr>
<td>• Local boards and partners can evidence that they work together and share information appropriately and in a timely way</td>
<td></td>
</tr>
<tr>
<td>• The partnership has agreed a framework on how and when personal or sensitive information is shared to prevent risk of harm or respond to abuse.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Actions</th>
<th>Lead</th>
<th>Timescale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual development day, board to be proactive in design</td>
<td>SAB Chair</td>
<td>September 2013 &amp; September 2014</td>
</tr>
<tr>
<td>Review policies and develop additional practice guidance to ensure they are easy to read and person centred.</td>
<td>Head of Adult Safeguarding &amp; APT</td>
<td>On going</td>
</tr>
<tr>
<td>Practice auditing. Confirm adherence to policy and procedures</td>
<td>APT and Personalisation and Quality sub group</td>
<td>Personalisation and Quality sub group to confirm audit programme</td>
</tr>
<tr>
<td>Develop innovative methods of seeking feedback on effectiveness and accuracy of policy and procedures</td>
<td>Q&amp;I Team with APT</td>
<td>Annual Survey July 2014</td>
</tr>
<tr>
<td>Information Protocols are in place</td>
<td>MASH operational and strategic groups</td>
<td>May 2014</td>
</tr>
</tbody>
</table>

* Abuse includes neglect as defined under No Secrets 2000.
APPENDIX 5: SERVICE MAPPING RESULTS
APPENDIX 6: 2013 TRANSITION PATHWAY
### Appendix 7: Suffolk ACS Service Agreement Codes for Care First 6

<table>
<thead>
<tr>
<th>CODE</th>
<th>FULL TITLE</th>
<th>DESCRIPTION</th>
<th>Indicative Tier as Used in Norm</th>
<th>Indicative Tier as Used in Hasci</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADPLASCH</td>
<td>Adult Placement Scheme</td>
<td>This is like Foster Care but for adults. i.e the young person stays with another family either on a semi-permanent basis but more likely as a respite service (i.e one day a night or a fortnight) to give their parents a break from caring. This is support to an individual to help them live independently but does not involve personal care tasks. So it will include things like, help to pay bills, help with shopping and preparing healthy food, help with maintaining a property, writing letters etc.</td>
<td>Tier 2</td>
<td>Tier 3</td>
</tr>
<tr>
<td>COMSUP</td>
<td>Community Support</td>
<td>Day centres where customers go to learn skills for independence and an opportunity to undertake everyday activities in the community e.g leisure opportunities</td>
<td>Tier 2</td>
<td>Tier 3</td>
</tr>
<tr>
<td>DLYLIVING</td>
<td>Daily Living</td>
<td>This service agreement seems to be used for people accessing the RNIB talking book service. There are very few of these service agreements Also called Homecare – this is when carers help individuals with personal care tasks – getting up, dressed, help to the toilet, bathing etc.</td>
<td>Tier 2</td>
<td>Tier 3</td>
</tr>
<tr>
<td>DOMCARE</td>
<td>Domiciliary Care</td>
<td>Also called Homecare – this is when carers help individuals with personal care tasks – getting up, dressed, help to the toilet, bathing etc. Also called Homecare – this is when carers help individuals with personal care tasks – getting up, dressed, help to the toilet, bathing etc.</td>
<td>Tier 2</td>
<td>Tier 3</td>
</tr>
<tr>
<td>EDTRAIN</td>
<td>Education and Training</td>
<td>This is used when someone is supported into education or training</td>
<td>Tier 2</td>
<td>Tier 3</td>
</tr>
<tr>
<td>EMPSERV</td>
<td>Employment services</td>
<td>This is used when someone is supported into employment</td>
<td>Tier 2</td>
<td>Tier 3</td>
</tr>
<tr>
<td>FINANCE</td>
<td>Direct Payments</td>
<td>An agreed weekly sum of money paid to the individual or into an account (which they can control) in lieu of care services arranged by ACS. The money must be spent on services that meet the persons assessed social care needs</td>
<td>Tier 3</td>
<td>Tier 3</td>
</tr>
<tr>
<td>INTTRANS</td>
<td>Interpreters/Translators</td>
<td>This service agreement is used when an interpreter or translator is required to help communicate with the customer/their family a delivery of a hot meal from the WRVS</td>
<td>Tier 2</td>
<td>Tier 3</td>
</tr>
<tr>
<td>MEALSERV</td>
<td>Meal services</td>
<td></td>
<td>Tier 2</td>
<td>Tier 3</td>
</tr>
<tr>
<td>NRSECARE</td>
<td>Nursing Care</td>
<td>This is a Care home placement where the customer receives both Nursing Care as well as general personal care</td>
<td>Tier 3</td>
<td>Tier 3</td>
</tr>
<tr>
<td>RESCARE</td>
<td>Residential Care</td>
<td>This is a care home placement where the customer will receive general personal care</td>
<td>Tier 3</td>
<td>Tier 3</td>
</tr>
<tr>
<td>RESCARE - RESPITE</td>
<td>Residential Care respite</td>
<td>This is when a customer goes into a residential care placement for a short period only (i.e usually only a night or two) to give their family carer a break from their caring role.</td>
<td>Tier 3</td>
<td>Tier 3</td>
</tr>
<tr>
<td>SPCHOUSE</td>
<td>Specialist Housing</td>
<td>This service agreement is used when a customer is living in ‘Supported accommodation’ i.e the</td>
<td>Tier 3</td>
<td>Tier 3</td>
</tr>
</tbody>
</table>
property is owned by a registered social landlord. In addition to providing the accommodation the landlord will also provide a domiciliary support service to all of the residents within the home. Some individuals will need a lot of support and some will only require minimal support. The information recorded in the SPCHOUSE service agreement relates to the amount of domiciliary care support each individual receives. The type of services provided to customers may include personal care, support to live independently e.g paying bills etc, support during the night

<table>
<thead>
<tr>
<th>SPCAP</th>
<th>SPCAP</th>
<th>Tier 3</th>
<th>Tier 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>SUPPSERV</td>
<td>Support service</td>
<td>I think this is basically the same as Community Service</td>
<td>Tier 2</td>
</tr>
<tr>
<td>TRANSERV</td>
<td>Transport service</td>
<td>Cost of transport to and from other services e.g someone attending a day service may also require help with transport costs to get to the day service</td>
<td>Tier 2</td>
</tr>
</tbody>
</table>

It is only in the last year or so that ACS have really started to use the SPCHOUSE service agreement on CF6. In earlier years the type of support provided to someone in supported accommodation was recorded either as SPCAP or under a Domcare agreement.
APPENDIX 8: STAKEHOLDER FEEDBACK — ONLINE SURVEY

Issues of independence

1. How highly do you think that maximisation for independence of users of services should be prioritised by services supporting people with a learning disability?
   - Highest priority
   - One of the highest priorities
   - Medium priority
   - Low priority
   - Don't know

If you have any additional comments, please add them here:

2. Do you think that services supporting people with learning disabilities in Suffolk appropriately prioritise maximisation of independence?
   - Yes
   - No, too highly prioritised
   - No, not prioritised enough
   - Don't know

Additional comments:
3. Overall, do you think services supporting people with learning disabilities in Suffolk help their clients maximise their independence?

- Yes, all the time
- Yes, most of the time
- Yes, some of the time
- Seldom
- Never
- Don’t know

Additional comments:

4. How often are users of support services for people with learning disabilities able to appropriately input to the development of their support/care plan?

- Always
- Usually
- Sometimes
- Seldom
- Never
- Don’t know

Additional comments:
Integration of health services and social care services

5. How well do health services and social care services work together to identify the needs of people seeking support for their learning disabilities?

- Well co-ordinated, all the time
- Well co-ordinated, most of the time
- Well co-ordinated, some of the time
- Seldom well co-ordinated
- Never well co-ordinated
- Don't know

Additional comments

6. How well do health services and social care services work together to implement the support plans of people with learning disabilities?

- Well co-ordinated, all the time
- Well co-ordinated, most of the time
- Well co-ordinated, some of the time
- Not usually co-ordinated
- Never well co-ordinated
- Don't know

Additional comments
7. Do you feel that there is adequate skills training provision for working with people with learning disabilities for non-LD specific services?

- Yes
- No
- Don't know

If no, how do you think this could be improved?

8. Do you have any suggestions for ways in which health services and social care services can better integrate their support for people with learning disabilities?
Transition between services for children and young people and services for...

9. In your experience, how often does the transition of support/care from CYP services to adult services work well for people with learning disabilities?

- Always
- Usually
- Sometimes
- Seldom
- Never
- Don't know

Additional comments
Outcomes for people with learning disabilities

10. Overall, how well do systems work for identifying individuals with learning disabilities in Suffolk?
   - They work well, all of the time
   - They work well, most of the time
   - They work well, some of the time
   - They seldom work well
   - They never work well
   - Don't know

   Additional comments

11. Overall, how well do support/care plans address the needs of people with learning disabilities in Suffolk?
   - They address needs well, all the time
   - They address needs well, most of the time
   - They address needs well, some of the time
   - They seldom address needs well
   - They never address needs well
   - Don't know

   Additional comments
12. In your experience, how well are support services for people with learning disabilities able to implement support/care plans?

- Always able to fully implement support/care plans
- Usually able to fully implement support/care plans
- Sometimes able to fully implement support/care plans
- Seldom able to fully implement support/care plans
- Never able to fully implement support/care plans
- Don't know

Additional comments

13. How often are services supporting people with learning disabilities in Suffolk able to help clients meet their objectives as identified in support/care plans?

- Always
- Usually
- Some of the time
- Seldom
- Never
- Don't know

Additional comments
14. How often are support services for people with learning disabilities in Suffolk able to address the following specific areas of need:

<table>
<thead>
<tr>
<th>Area</th>
<th>Always</th>
<th>Usually</th>
<th>Sometimes</th>
<th>Seldom</th>
<th>Never</th>
<th>Don't know</th>
</tr>
</thead>
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<td>Physical health</td>
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<td>Mental health</td>
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<td>Communication</td>
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<td>Sexual health/relationship</td>
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<td>building</td>
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<td>Family resilience</td>
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<td>Healthy living support</td>
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<td>Employment</td>
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<td>Financial management</td>
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Additional comments

15. Overall, how well do you feel that health and social care services are able to meet the needs of people with learning disabilities in Suffolk?

- Always well
- Usually well
- Seldom well
- Never well

Additional comments
## APPENDIX 9: SUMMARY OF CQC QUALITY ASSESSMENT OF MULTIPLE-LOCATION LD SERVICE PROVIDERS IN SUFFOLK

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Type of service*</th>
<th>Most recent assessment date for locations</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ambercare East Anglia</td>
<td>Care Homes x3</td>
<td>August 2013, May 2014, July 2014</td>
<td>All expected standards met in two locations. One standard (Respect and involvement) not met in one location.</td>
</tr>
<tr>
<td>Consensus Support Services Ltd</td>
<td>Care homes x2</td>
<td>January 2014, July 2014</td>
<td>One expected standard not met in one location (staffing). One location had all standards met.</td>
</tr>
<tr>
<td>Crossroads Care East Anglia Ltd</td>
<td>Homecare agencies x2</td>
<td>Not yet assessed</td>
<td>One standard not met in one location (quality of management). All standards met in other location. Many locations nationally, action being taken by CQC in one location outside Suffolk.</td>
</tr>
<tr>
<td>Housing and Care 21</td>
<td>Homecare agencies, supported housing and supported living x2</td>
<td>February 2014, July 2014</td>
<td>One standard not met in one location (quality of management). All standards met in other location. Many locations nationally, action being taken by CQC in one location outside Suffolk.</td>
</tr>
<tr>
<td>Inroads (Essex) Ltd</td>
<td>Residential homes x3</td>
<td>March 2014, August 2014, One location not yet assessed</td>
<td>All standards met in each location.</td>
</tr>
<tr>
<td>Leading Lives</td>
<td>Residential homes x6, Supported living x6, Homecare agencies x1</td>
<td>Most recent assessments between December 2013 and August 2014 (two locations not yet assessed)</td>
<td>Eight locations met all expected standards. One location failed to meet standards for staffing. One location failed to meet standards for both respect and involvement, and quality of management.</td>
</tr>
<tr>
<td>National Autistic Society</td>
<td>Residential homes x2, Homecare agencies x1</td>
<td>January 2014, March 2014</td>
<td>Two locations met all expected standards. One location (a residential home) failed to meet three standards (caring for people safely, staffing, and quality of management)</td>
</tr>
<tr>
<td>Norfolk &amp; Suffolk NHS FT</td>
<td>One location providing community services LD and hospital services for mental health, One location providing services as above plus community services for mental health and substance misuse</td>
<td>April 2012, November 2013</td>
<td>One location met all expected standards. The other location failed to meet standards for respect and involvement.</td>
</tr>
<tr>
<td>Organization</td>
<td>Types of Services</td>
<td>Inspection Dates</td>
<td>Summary</td>
</tr>
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<tr>
<td>Orwell Housing Association Ltd</td>
<td>Homecare agencies x2, Supported housing x1</td>
<td>September 2013, December 2013</td>
<td>All expected standards met in each location</td>
</tr>
<tr>
<td>Royal Mencap Society</td>
<td>Homecare Agencies x3, Residential homes x2</td>
<td>February 2014, August 2013, December 2013, January 2014</td>
<td>All expected standards were met in three locations. One location failed to meet standards for respect and involvement and quality of management</td>
</tr>
<tr>
<td>Suffolk County Council</td>
<td>Homecare agencies x7, Community services (healthcare) x1</td>
<td>August 2013, September 2013, January 2014, February 2014, March 2014 x4</td>
<td>Two locations last assessed in autumn 2013 both failed standards for staffing and quality of management. All other locations met all expected standards All Staff/mgt x2</td>
</tr>
<tr>
<td>The Papworth Trust</td>
<td>Homecare agencies x3, Supported living x2</td>
<td>June 2013, July 2013, December 2013</td>
<td>All expected standards were met across all locations</td>
</tr>
<tr>
<td>The Regard Partnership</td>
<td>Residential homes x2, Homecare agencies x1, Supported living x1</td>
<td>July 2014 x2, August 2014</td>
<td>All expected standards were met at the two residential homes. The location providing homecare agency and supported living failed to meet standards on providing care that meets patient needs and quality of management.</td>
</tr>
</tbody>
</table>

Source data: CQC (http://www.cqc.org.uk/providers)

* the number of locations per location type is indicated (e.g. x3 for 3 locations)