Kisharon, Langdon and Norwood

Provision and demand for learning disability services in the Jewish community: Executive Summary

February 2020



Thank you

This report would not have been possible without the active co-operation and support of people living and working in the Jewish communities covered by this research. In particular, we would like to thank all the participants who attended the focus groups and shared their insights and experiences as carers. We would also like to thank all the Trustees who contributed their time to this process. Finally, we would like to thank all the staff working across local government, education, day and accommodation services for assisting in the service mapping and providing useful perspectives and understanding.

That this report describes a vibrant, diverse and constantly evolving range of services operating successfully in what is a sometimes highly challenging environment is a credit to everyone involved.

Executive Summary

Introduction

The purpose of this report is to provide an evidenced picture of current and future demand for learning disability services used by members of the Jewish population of London, the South East and Greater Manchester.

This report looks specifically at eighteen local authorities. In London we looked at Barnet, Brent, Camden, City of London, Enfield, Hackney, Haringey, Harrow, Redbridge, Wandsworth and Westminster. In the South East, we looked at Essex, Hertfordshire and Wokingham. These local authorities are mapped in Figure 1.

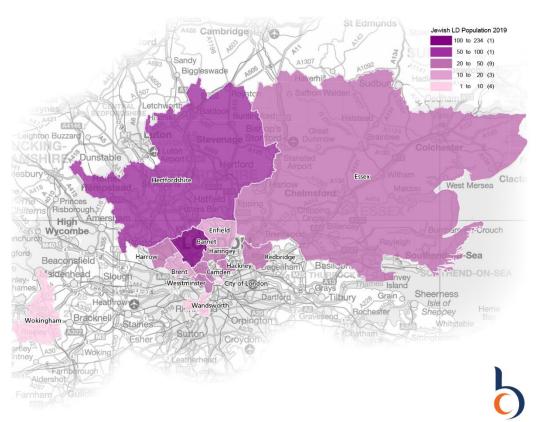


Figure 1: Local authorities included in the South

In the North West we looked at Bury, Manchester, Salford and Stockport. These local authority areas are mapped in Figure 2.

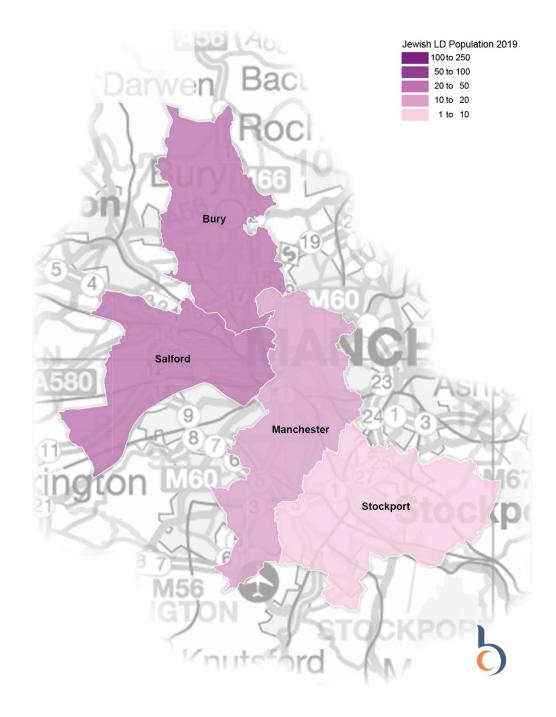


Figure 2: Local authority areas included in the North

This summary explores three main areas:

 Demand for services which is driven by demography, but also by the needs and wishes of families and individuals and the opinions and ideas of commissioners and providers of services.

- Supply of provision in its current form, largely achieved through a service mapping process and interviews with providers.
- How well demand for services aligns with supply now and how it might or might not align in the future, as well as putting this in the context of wider government guidance and recognised best practice.

We recognise that the findings of this report will present some challenges and of necessity they will require organisations and individuals to make choices and decisions about what is done, where and for whom.

Our high-level strategic analysis is covered in this summary. This is based on the evidence in the main sections of the report. These sections are organised by collection methodology and each starts with a key messages or summary section

The nature of the evidence

This report combines data and other evidence from a wide range of sources. There will inevitably be differences of interpretation and some small errors or omissions. Within the structure of this project there is very limited opportunity for validation or audit, sometimes because the data is so large in scale and sourced from central government, or sometimes because the information has been provided directly by providers working across multiple services which we cannot individually inspect and verify.

There are specific examples where even the census data has been questioned in the case of estimating the adult Jewish population living in Hackney. We have tried to draw on multiple sources to arrive at an evidence base that although imperfect is good enough to enable Kisharon, Langdon and Norwood to begin to make credible and authoritative plans for the future.

There may be some evidence that it is worth refining further than we have in this report, but in considering this it is important to reflect on the single strongest message that has come from the people and families that use the services on offer. Families want action and they want change; reflection is important but ultimately it is actions that count the most.

Defining what we mean by learning disability

There is considerable debate about how the population of people with a learning disability can be defined and segmented. There are broadly four main terms used to describe people: mild, moderate, severe and profound. The precise definition of need that sits behind these terms is not agreed. It is generally accepted that there is some link to IQ but that this provides only a partial picture of an individual as there are no consistent or agreed measures of social or

adaptive functioning. In terms of IQ the government in 2001¹ applied the following definition.

Learning disability includes the presence of:

- Significantly reduced ability to understand new or complex information, or to learn new skills
- Impaired intelligence:
 - With a reduced ability to cope independently (impaired social functioning)
 - Which started before adulthood, with a lasting effect on development.

IQ measurement has traditionally been used to define severity:

- A person with an IQ of less than 20 would be described as having a profound learning disability
- A person with an IQ of 20-34, a severe learning disability
- A person with an IQ of 35-49, moderate learning disability
- A person with an IQ of 50-70, mild learning disability.

Defining what we mean by autism

It has long been understood that people who are described as being on the autistic spectrum do not necessarily have a learning disability. Research reported by the National Autistic Society² suggests that around 700,000 people in the UK may be autistic and of this number, somewhere between 44% and 52% may have a learning disability i.e. an IQ measured as being less than 70. However, research also suggests that between 48% and 56% of autistic people do not have a learning disability, i.e. an IQ measured above 70.

There is a growing recognition that there is a significant number of people detained in long stay hospitals and other secure settings funded by the NHS, who were initially thought to have a learning disability when in fact they do not. Their

¹ Department of Health (2001) Valuing People: A new strategy for Learning Disability for the 21st Century.

² National Autistic Society (2019) Available at: https://www.autism.org.uk/about/what-is/myths-facts-stats.aspx) cite the following in their report:

Fombonne et al (2011), in their research review of 14 prevalence studies that mentioned IQ, found a range of 30% to 85.3%, with a mean of 56.1%, of people without learning disabilities, p. 99.

Emerson and Baines (2010) in their meta-analysis of prevalence studies found a range of people with learning disabilities and autism from 15% to 84%, with a mean of 52.6%.

needs stem from their autism and the effect that this had had upon their mental health.

Definitions in the real world

What this means is that most providers of services to people with a learning disability will also be providing some services to people who are autistic as well, and in some instances to people who are only autistic.

The data available for this report does not allow for a very precise demarcation between those people who have a mild learning disability and in some instances autism and those people who only present as having autism but may have additional challenges as well such as anxiety issues, issues of fine motor control etc.

Where it is valuable to differentiate between these different groups of people we have done so, where it is not, we have not.

Demand

We view demand for services in two principle ways, demand that is determined by demography and demand that is about what people want or what they think is needed.

The demography of the Jewish population of the UK is clear: the population will grow in the coming years. While the growth rate will be higher amongst the orthodox community of Hackney, which has a higher than average birth-rate, generally the Jewish population will grow in line with the wider population of the UK.

This in turn means that the numbers of Jewish people with a learning disability will also increase. We are aware of studies suggesting a slightly higher prevalence rate of learning disabilities amongst the Jewish population of the UK, but these studies are open to a range of interpretations, not least of all because they use different definitions of learning disability than those used by the UK government³ and in the absence of definitive evidence we have not attempted to reflect this occasional reported variance in our research⁴.

An overview of the estimated additional number of Jewish adults and children in Jewish schools with a learning disability and/or ASD in the relevant authorities by

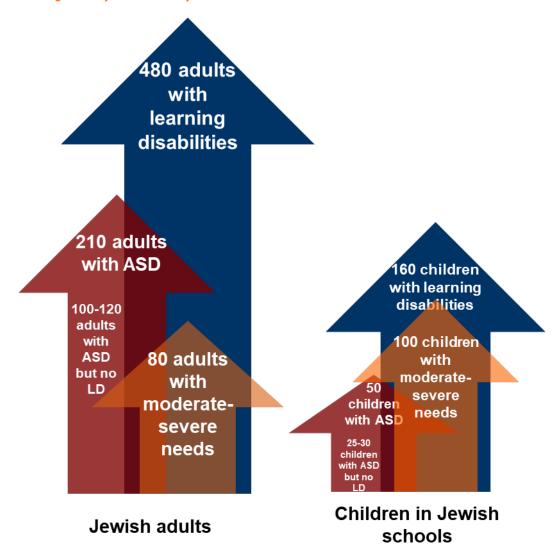
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³ JPR (2013) includes categories such Severe, Light, Moderate and Borderline which do not appear to have a relationship to IQ and which are not included in the UK government definition.

⁴ JPR (2013) National Jewish Community Survey. Cited reports include: The Scottish Census of 2011; a large-scale study of children with special needs in Israel carried out jointly by the National Insurance Institute and the Myers-JDC-Brookdale Institute; the General Practitioners' Patient Survey, conducted among adults in England.

2035, is presented in Figure 3 below. These numbers are discussed in more detail in the following sections.

Figure 3: Estimated **growth** in the number of Jewish adults and children in Jewish schools with a learning disability and/or ASD by 2035



Demography: Adults

In Section 3 of this report we provide a detailed analysis of the current and future demography of likely demand for services for people with a learning disability.

In 2019 we estimate that there are around **186,800** people who would identify as being members of the Jewish community across the 18 local authorities covered

by this research⁵. The largest concentration is in the single borough of Barnet with nearly a third of the population. The second largest population is in Hackney⁶. This skew towards London is set to increase over time. Of this population, we estimate that around **3,700** adults have a learning disability⁷.

Our analysis shows that the Jewish population of adults with learning disabilities and autism will increase over the next 15 years, albeit that we do not expect this to be at a significantly different rate from the general population. An overview of estimated growth is outlined in Figure 4.

By 2035, we estimate that there will be an additional **480** adults with learning disabilities, of which around **80** will present moderate-severe needs. **The largest growth will be seen in the number of people with a learning disability over the age of 65.**

Need	2019 population	2035 population	Change 2019-35	% Change
All learning disabilities	3,727	4,209	+482	+13%
Autism	1,379	1,590	+211	+15%
Moderate- severe learning disabilities	706	785	+79	+11%

It is important to recognise that one of the key challenges of learning disability provision is that relatively small increases in the number of people, particularly with more complex needs can pose a very significant service and funding challenge.

Jewish adults who would be defined as being on the autistic spectrum number around 1,380 across the 18 authorities. As already noted, some of this group will

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⁵ The Jewish population estimate is based on applying the proportion of the population in each local authority reported to be Jewish in the 2011 census, to the Office for National Statistics projected population data for those authorities, for 2019, 2025 and 2035. The full methodology is outlined in Section 3.3 of the report.

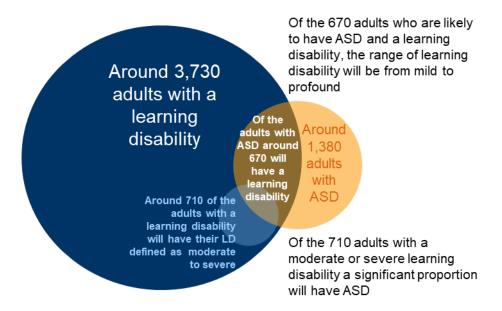
⁶ The configuration of the Hackney population in terms of age is complex, in that the Office for National Statistics (ONS) data appears to under count the proportion of the population that are children. The Interlink (2015) estimate of a 53.5% child population in the Hackney Jewish community has been applied instead, to estimate the adult and child population.

⁷ The learning-disabled population estimate is based on applying the proportion of the population reported to be Jewish in the 18 local authorities in the 2011 census, to the POPPI and PANSI projected learning disability population data for those authorities, for 2019, 2025 and 2035. The full methodology is outlined in Section 3.4 of the report.

also have a learning disability, although there is not clear agreement on the proportions. Based on the NAS research⁸, of a total adult population of around 1,380 members of the Jewish community likely to be autistic in 2019, somewhere between 610 and 720 are likely to have a learning disability, and somewhere between 660 and 770 will not. These numbers are represented in Figure 5 below.

We estimate that the number of Jewish adults with ASD will increase by around 210 by 2035, of which around 100-120 will have no learning disability.

Figure 5: A representation of the estimated number of Jewish adults with a learning disability, a moderate-severe learning disability, and ASD in 2019.



The challenge around adult demography can be summarised in three parts:

- First, there will be growth overall in the numbers of adults with a learning disability and autism and there will be growth of around **80 adults with more significant and complex disabilities** by 2035.
- Secondly, the growth is **skewed towards London** and towards Barnet in particular, where the largest increases in numbers will be seen.
- The third and final point is that the largest rate of growth in numbers will be adults aged 65 and above, which means that service delivery will

⁸ National Autistic Society (2019) https://www.autism.org.uk/about/what-is/myths-facts-stats.aspx

increasingly need to respond to the needs of older adults with autism and a learning disability.

For providers, the difficulty with this final point is that local authorities will increasingly seek to meet the needs of older adults with disabilities as part of their service offer to older adults more generally. The drive for this is the cost difference between funding for a person with a learning disability and funding for an older adult. The variance is normally around 100%. Therefore, a residential placement for an older adult might cost £36,000 per annum, whereas, for a person with a learning disability the average is likely to be closer to £72,000 per annum.

A number of parents expressed concerns in relation to this group, because older adults with a learning disability living with their parents means that they are cared for by people older than them, creating a situation which is not sustainable. There is no reliable data source which scales the number of older people with a learning disability still living with their parents but as the general trend is towards an aging population this will be an increasing number of people. One of the key concerns is that family placements can breakdown suddenly with the death or illness of the parent carer.

Providers may wish to consider how they can work together, both with each other and with other Jewish organisations providing care to the elderly, to ensure that the needs of an ageing learning disabled population are met in the future.

Demography: Children

In order to estimate the demand for learning disability services for children, we have estimated the Jewish child population in each local authority, as well as the number of children attending Jewish schools who are receiving special educational needs (SEN) support

Based on available data, we estimate that in 2019 there are around 47,300 Jewish children aged 0-17 in the 18 local authorities⁹. This calculation accounts for a different estimate of the number of Jewish children in Hackney which appears to broadly tally with the number of Jewish school places in the borough¹⁰.

⁹ The Jewish child population estimate was calculated based on applying the 2011 census Jewish population proportion to the ONS child population data for each local authority area. The full methodology is outlined in Section 3.6.

¹⁰ In Hackney, calculations were made using the Interlink (2015) estimated proportions for the Jewish community in Hackney, which resulted in an estimated Jewish child population of around 9,609 in 2019. This corresponds closely to the 10,034 pupils recorded to be in Jewish schools in Hackney.

Calculations for the number of pupils in Ofsted-registered Jewish schools in the relevant local authorities¹¹ and the number of pupils receiving Special Educational Needs (SEN) are based on data supplied by schools to the Department for Education¹². Some of the data supplied about the number of pupils receiving support was found to be either incomplete or incorrect and the numbers we are using therefore exclude Harrow and Enfield beyond the initial count of Jewish pupils

Around **37,500** students are reported to attend Jewish schools in these areas, representing around 80% of the Jewish child population. Of these students (discounting those in Harrow and Enfield), around **3,360** are reported to receive some level of SEN support and a further **760** have a Statement and/or Educational Health and Care Plan (EHC Plan). Of these 4,140 children, we estimate based on national prevalence¹³ that around **1,320** would be formally described as having some level of learning disability, including **820** whose needs are categorised as moderate-severe. These figures are represented in Figure 6 below.

We have estimated that there may be a further 60 Jewish pupils receiving SEN support in Enfield and Harrow, as well as a further 20 in receipt of an EHC plan¹⁴. These figures have not been included in the totals or the projections due to the different calculation methods used.

¹¹ There are no Ofsted registered Jewish schools in Camden, Essex, Wokingham, or City of London.

¹² Department for Education: Edubase, (2019). Available at: https://get-information-schools.service.gov.uk/Downloads. The full methodology used is outlined in Section 3.7.2.

¹³ This estimated breakdown of need has been calculated by applying the percentage of children in the national DfE data presenting each primary need to the reported population of children in Jewish schools with SEN support and/or an EHC plan. The full methodology is outlined in Section 3.7.3.

¹⁴ The estimated number of children receiving SEN support and an EHC plan in Harrow and Enfield was calculated by applying the proportion of school children in each local authority area who are attending Jewish schools, and applying this to the DfE statistics for the total number of children with SEN in each area. The full methodology is outlined in Section 3.7.2.

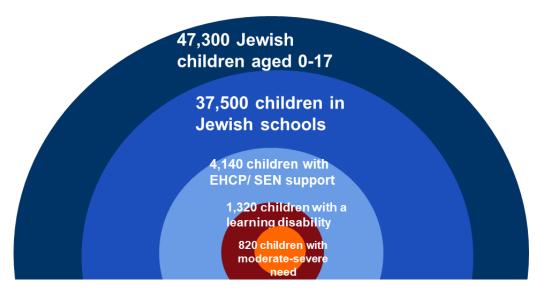


Figure 6: Jewish child population in the 18 local authorities in 2019

By 2035 we estimate that the population of Jewish children will have grown by around **5,500**. We still anticipate that most of these children will be in Jewish schools (although it will require a fairly substantial expansion of places).

The estimated growth in the population of children in Jewish schools with special educational needs is outlined in Figure 7 below. The number of children receiving SEN support or an EHCP will have increased by around **500** by 2035. Of these additional children, the number receiving support for a learning disability in 2035 will have increased by around **160**, including an additional **100** with moderate-severe needs. These numbers are outlined in Figure 7 below.

The number of children receiving support for ASD is expected to increase by around 50 by 2035, of which around 25-30 will have no learning disability.

Figure 7: Jewish child special educational needs population in the 16 local authority areas in 2019-

Need	2019 population	2035 population	Change 2019-35	% Change
Children with SEN support	3,359	3,761	+402	+12%
Children with an EHC plan	775	868	+93	+12%
Children with a learning disability	1,317	1,474	+158	+12%

Need	2019 population	2035 population	Change 2019-35	% Change
Children with a moderate- severe learning disability	823	921	+99	+12%
Children with ASD	441	493	+53	+12%

It is important to recognise that, in practice, different schools appear to make slightly different judgments about levels of need amongst pupils and that without external audit it is impossible to quantify this. As the population of children increases so will the numbers of children who will require a wide range of different levels of types of additional support.

Demography overall

By 2035 the combined population of adults and children in Jewish schools with a learning disability in the 18 local authorities will have risen from around 5,050 to around 5,680. This figure does not include the pupils receiving support for a learning disability in Harrow and Enfield, so is an underestimate.

As a very broad estimate, therefore, the KLN partners would need to consider that the demand for services due to demography is an increase of around 640 people with a learning disability, of which around 180 will have moderate-severe needs.

Those adults and children with a diagnosis of autism (which will also include some people who have a learning disability and some children with SEN and with an EHC Plan) will have risen from around 1,820 to at least 2,080. Although there is no agreement on the proportion of the population with autism who do not have a learning disability, the range is thought to be somewhere between 48% and 56%. On this basis, we estimate that there will be an increase of around 130 to 150 people with autism but no learning disability. A very small number of this group will also present very complex needs.

In summary, by 2035 we estimate that out of the Jewish adults and children in Jewish schools in the 18 local authorities, there will be:

- An additional **640** people with learning disabilities
- Of these, 180 will have moderate-severe needs
- An additional **130-150** people with autism but no learning disability

Although these people will not all present simultaneously or even evenly spaced across the next 15 years, it does mean that on average the growth in demand by people with more complex needs is likely to be around **11 people per year**. While this may not sound like a large increase, if just one of these additional people each year requires a more costly service of £100,000 per year, this alone would amount to an additional **£12million** of cost over the next 15 years.

Needs and wishes of families

The messages in terms of demand were clear and ultimately challenging. There are, not surprisingly, different views about the religiosity of services that are needed. There is a particular challenge from more religious families who feel they may be poorly served and also critically would prefer single sex provision in some instances. However, most parents expressed their desire that services do more to incorporate and promote a culturally Jewish way of life for their children.

Families, unsurprisingly, preferred their son or daughter to be near to them and in practice this means a continuation of the pattern and concentration of provision in London that already exists. That said, sizeable Jewish populations exist in individual local authority areas outside of London, such as South Hertfordshire and Bury, as well as areas outside of this report¹⁵. This creates a challenge for providers seeking to rationalise their services but also hoping to serve the whole community.

Quality of existing provision was seen to be broadly good but concerns about workforce churn were common. As a feature of the social care workforce, this is not surprising or easily addressed.

The dilemma encapsulated by the feedback from families is the need to address a wide range of choice with limited resources, both in terms of money and staff, but also a relatively small number of specialist Jewish providers.

This range of choice reflects the Jewish community in all its diversity of belief and observance and presents a very particular challenge for providers keen to support choice and deliver personalised services, while at the same time operate affordable and sustainable services.

One message that might be easier to respond to is the appetite expressed by families for more opportunities to gather to gain support and exchange experiences and ideas. There is no question that in a world where there is very little likelihood of additional investment in services, the self-reliance of families will continue to be key and anything that can be done to sustain and strengthen this self-reliance must be seen as a priority. One area very clearly identified by

¹⁵ Gateshead South Renfrewshire

families was the need for better access to information about services and advice about how to access them.

Opinions and ideas of commissioners and providers

The views of commissioners do not provide significant insight into the longer-term development of services for the Jewish community. Local authorities have experienced a sustained reduction in funding since 2010 and their capacity and capability to take a strategic approach to service planning and delivery has been reduced.

There will be an ongoing need to try to collaborate, influence and inform the thinking of key local authorities, but it is important that the limitations of this approach are recognised. Local authorities cannot magic up additional resources and going forward they will find it increasingly difficult to meet their statutory obligations. People with a learning disability, although important to local authorities, are just one client group for which they have a duty of care.

Supply

The service mapping, a full analysis of which is presented in Section 5, indicates a rich and varied supply of services for the Jewish community which appears to span the full range of service types.

It is important to stress that the service mapping exercise does not present an exhaustive survey of all available services, or a census of individuals using these services. The exercise relied on self-reporting by services, combined with desk-based research. The wide variety of services covered also means that indicators such as the number of places the service offers may mean very different things. One 'place' in a day service might mean a one-hour art session every week, whereas another may mean full-time support offered within a daycentre. Therefore, these numbers should be taken only as general indicators of the scale and type of available provision.

Adult services

Accommodation for adults

The mapping indicates that there are around **422 places** of accommodation which appear to be specifically targeted at people with a learning disability¹⁶. Figure 8 below shows the breakdown of this accommodation.

¹⁶ There may be some additional nursing places provided by AIHA and by the Federation of Jewish Services, but this is unclear and likely to be a small number as the Care homes with nursing are aimed primarily at older people.

Figure 8: Accommodation provision for adults with a learning disability – data from Cordis Bright service mapping 2019

Type of accommodation	Number of schemes/ homes	Places	Places as % of total
Residential care homes	21	183	43%
Supported living schemes	13	187	44%
Supported housing schemes	12	52	12%
Totals	46	422	100%

To put this into context it suggests that around 11% of the total adult LD population covered by this research are in some form of specialist accommodation. If the population expands to around 4,210 and this proportion is maintained it would require around a further 60 places of accommodation by 2035.

However, we think that demand may be higher than this given that an estimated 140 Jewish adults are currently living in the family home across the 18 authorities¹⁷, some of whom will need or want to move into an accommodation service at some stage. Therefore, we estimate that the community will need to provide at least an **extra 100 places of accommodation** by 2035. At a minimum cost of £180,000 per unit, this represents a capital funding requirement of £18 million.

It is also interesting to note that few of the parents consulted (even when they had their disabled son or daughter living with them) had made plans for what was to happen after they had died.

As might be expected, the residential services tend to provide for higher levels of need. Although there are some examples of services which appear to cater for a particularly broad range of people, with the range described as mild to severe in a single service. As a general comment, the supported living and supported housing is targeted at people who fall into the range of mild to moderate need.

Two residential care services and six supported housing units were identified as single gender provision, providing at least 30 places. No single gender supported

¹⁷ This figure is based on the SALT data supplied by the 18 local authorities, which identify a total of 5,625 adults with a learning disability in settled mainstream housing with family/friends. We have applied the percentage figure for the Jewish population in each area to arrive at the figure of 140 adult living in this type of setting. Available at: https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/social-care-collection-materials-2019

These 140 adults would be included within the total estimated Jewish adult learning disability population.

living units were reported to be available. This may illustrate a gap for more religious members of the community, who expressed a preference for single gender provision for their children.

Home care for adults

There are four domiciliary care schemes which may have supported people with a learning disability, we presume in the family home although some of this support could have been delivered to people living in supported housing schemes. The scale of this operation is not entirely clear but where the number of services users over the last 12 months has been identified it is 37 people.

Day services: not employment for adults

We can identify a range of day services for adults which are not employment, ranging from full-time day centres to weekly sports and arts clubs. While it is difficult to identify the scale of this provision, it would appear to offer around 700+ places, although day to day use would be more variable then this.

Most of these services described the range of needs they serve as mild to severe, which if accurate suggests fairly non-specialist provision.

Day services: employment for adults

There appears to be a fairly good range of employment services, provided by Kisharon, Langdon, Norwood and Misgav, which are a mix of employment support, volunteering and work experience projects. It is worth noting that the issue of employment opportunities came up in the focus groups, with a number of parents keen to see an increase in what is currently available.

The pattern of need for employment services is slightly different to nonemployment-based day services, having on average an identified range of mild to moderate.

Adult services overview

Based on the service mapping data, which does have some gaps in its information, there is a strong alignment between service type and the level of need catered for, i.e. high complexity in residential care, lower in supported living, higher in non-employment focused day services, lower in employment-based day services. Although this pattern is understandable, it does run counter to best practice in service development, which would clearly suggest that level of need should not, for example, be a barrier to accessing supported living or employment services.

The current level of residential care is unlikely to be sustainable in the long term. In the last 10 years, on average the authorities covered by this report have made substantial reductions in the number of beds they buy. On average, out of the 18 local authorities included, the London authorities have reduced the number of

beds by 27%, the home counties by 30% and the Greater Manchester authorities by 10%¹⁸. A shift towards supported living is also in line with best practice in service provision, in encouraging independence for people with learning disabilities, as outlined in Section 1.2.

The three organisations will need to decide what their appetite is for more radical and consistent service development, particularly given a wider commissioning trend of buying less residential care. As the only type of accommodation service offered by Kisharon, Langdon and Norwood, supported living is an area of provision which might benefit from more joined-up working between the partners going forward.

Services for those in transition: aged 16-25

Day services

Three day services were identified as being specifically for people aged 18-25 who are transitioning between children's and adult services.

It is noteworthy that, despite this provision, parents were anxious about the transition process for their children and expressed their desire for more help in preparing for and navigating this period.

Post-16 education

Two co-educational post-16 SEND colleges were identified, provided by Langdon (across two campuses in London and Manchester) and Kisharon. Together, these colleges offer 62 places and have had 45 students attend in the last year.

Both colleges were reported to provide for a wide range of need. As well as those with moderate-severe learning disabilities, Langdon college was reported to support children and young adults with ASD as well as health, speech and language and behavioural needs.

Children's services

Accommodation for children

Unsurprisingly, most Jewish children with a learning disability live at home, which means that the only registered children's homes identified was one delivered by Bayis Sheli and one respite service operated by Norwood.

¹⁸ Analysis of Personal Social Services: Expenditure and Unit Costs 2009/10 – 2014/15 and after this date Short and Long Term Care (SALT) Collection (Activity Data) and Adult Social Care Finance Return (ASC-FR) Collection (Finance and unit costs data)

Home care for children

The service mapping did not reveal any home care specifically for children, although it is possible that the home care services identified cater for a wider age group. Some of the day provision discussed below, however, such as Norwood's Portage Home-Visiting Service, would have some of the characteristics of this type of provision.

Day services for children

This was one of the richest and most varied areas of provision within the service mapping, covering a very wide range of interventions and opportunities. These can be broadly grouped into three main areas: Therapeutic interventions; non-residential respite and leisure and; family support.

Again, as with much of the adult provision, there are a large number of services for which the level of need was described as mild to severe and again, this calls into question how specialist the provision is and how effective it is likely to be at meeting such a breadth of need.

Schools: SEN provision in mainstream Jewish schools

The provision of education is a smaller part of this research, but an important component of a larger picture. We reviewed data from DfE, we interviewed SENCOs and we ran two focus groups with parents of children in school, one specifically in partnership with Gesher School.

The feedback from parents and SENCOs in mainstream Jewish schools was clear. There is a view that a cohort of children, some with ASD, some with a mild learning disability, others with mental health issues or with a less clear diagnosis are struggling, particularly in secondary schools. This is not unique to Jewish secondary education, but perhaps because it is a more discrete range of educational provision it feels more acute.

Parents who were able to get their children into specialist units within mainstream schools were pleased with the service they received, parents who were not were often disappointed by the level of support provided to their child.

The view of SENCOs was that the current arrangements tend to work better for children with more significant disabilities and that it is the children with more mild learning disabilities, ASD etc that tend to get less support.

We think that there is a high degree of alignment in terms of the analysis of the problem, i.e. mainstream Jewish schools struggle to adequately support children and young people at the less severe end of the spectrum of special educational need. This lack of support can often compound and exacerbate problems that are already present.

Accepting that there is agreement about the challenge, there is less agreement about how best to address it.

Broadly there are two approaches, both of which were expressed and supported in the focus groups which we ran:

- On the one hand some parents would like to see specialist secondary provision, possibly along similar lines to the Gesher primary school.
- On the other hand, there are parents who are very clear that they want their child to be in mainstream Jewish education, but with appropriate support in place. They recognise that this might require the creation of a SEN Hub, such as in the case of JCOSS. This would align with the UK policy commitment to 'inclusive education' for children with disabilities in mainstream schools (see Section 1.2).

A third option, and one that did not come up in the focus groups, is to provide interventions in a more targeted manner, possibly away from the mainstream school but clearly intended to facilitate the child's re-integration at a later date.

This range of responses to a broadly agreed challenge reflects the consistent theme of choice and diversity which runs through all our findings. There are no clear answers which garner the majority of support within the community. The service delivery challenge is how within a relatively small community of some 47,300 children, of which around 37,500 attend Jewish schools, the scale of diversity sought is delivered in a cost effective and sustainable manner.

Supply and demand alignment

In terms of service range, there is a fairly good alignment between need and provision. There are, however, a number of key areas where this is less so:

- For children with a mild learning disability or ASD there is a strongly held view by families, echoed by SENCOs, that this group is not consistently supported within mainstream Jewish schools.
- There is a concern held by more orthodox families of adults with disabilities that there are fewer services available which align with their religious beliefs.
- There was a general consensus that families need more support, information and assistance, not least of all in working together and learning from each other.
- There is a longer-term challenge for accommodation-based services in terms of the type of service offered, the level of religiosity desired and the scale of services that will be needed.
- There is a specific challenge around the issue of fairness in terms of where services are developed. The Jewish population is strongly skewed to London,

which is where the greatest growth will occur, but at the same time there are significant populations outside London which will not grow at the same rate.

The challenge of choice and diversity

There is a strong appetite among families to be able to exercise greater choice and control over the nature and content of provision to support their family member. However, the breadth of this diversity is so great that it will be difficult, even for three organisations working collaboratively, to meet it all. There will inevitably be a need to make some difficult and potentially unpopular choices about what can be offered, where it can be offered and the degree of and range to be catered for in terms of need and religiosity.

There were three other factors which are key to thinking about the future of services. These are:

- Funding of services
- Workforce
- Future service planning

Funding of services

There is no political consensus on the long-term funding of social care and publicly funded services more generally. We now know that there is also no plan for how consensus might be achieved or for the ideas which might be explored.

The best that can be expected is a continuation of the additional £1 billion per year in extra funding (most estimates of the required funding would suggest that this falls short by some £2.5 billion to £3 billion per year) and local authorities exercising their right to charge the social care precept.

In the absence of clarity about a longer-term plan or any commitment to ensure sufficiency of funds, combined with the rising demand for services, all providers will need to maximise their efficiency and seek innovative ways of meeting need.

The Jewish community is no different from other communities in this respect, but with two possible exceptions which are the concentration of the community within a relatively discreet group of local authority areas and a long history of selfreliance and philanthropy. These particular characteristics may create some alternative options for how services can be developed, and needs addressed, by capitalising on community assets.

One of the biggest barriers to service innovation is the lack of resource to maintain existing provision while new approaches are developed. It is neither wise nor sustainable to try to fund core service provision on the basis of philanthropy. However, it may be realistic to seek funds of this type to drive

forward innovation, whilst existing provision continues to be supported by public funds.

The delivery of provision is currently focused within a narrow geographic range. In any other context where you had this concentration of activity and you needed to make resources go further, you would seek to rationalise what was delivered. We appreciate that the need for the exercising of choice makes this less practicable. However, it would be worth considering ways in which this concentration could be used to the advantage of the community as a whole. One example might be in the development of a property for supported living services. There is no reason why a single site could not contain accommodation targeted at range of different degrees of religiosity, or why staff training could not be delivered to staff from a range of organisations, or even why out of hours cover could not be provided to a group of organisations. Unfortunately, none of these approaches will be straight forward, but, in a future where funding will continue to be tight, all options are worth consideration.

There is an abundance of voluntary and charitable organisations spanning the entire community in terms of geography, religiosity and need addressed. Clearly smallness of scale reduces the sustainability and robustness of some of these services, but the principle of developing and delivering a solution which is specific to the needs of the Jewish community is well established.

It may be worth considering looking at trying to co-ordinate the efforts of a wider and more diverse group of organisations, through the simple process of coming together, planning together and trying as far as possible to co-ordinate delivery. This will not be easy, but if the concepts of choice and diversity are accepted it will also be necessary to accept that the range of services will encompass many different approaches to provision, not all of which automatically carry the endorsement of all other organisations. The biggest learning point for all providers is that they are not the arbitrators of what should and should not be provided. Their role is to try as best they can to meet some of the specific needs of some of the Jewish community and leave others to address different needs.

Workforce

Now that the United Kingdom has left the European Union, the struggle to secure sufficient staff to deliver services will become harder. The UK will introduce new immigration controls, which will be a points-based system favouring qualified and experienced people wanting to come and work in the UK, most likely in specific technical fields. This type of immigration control does not supply the less skilled and experienced labour generally required by social care. Coupled with the demographic shift of a shrinking working age population and a growing older population requiring care and support as they age, social care is increasingly going to struggle to source the labour needed to provide the care which is required.

We think that this situation will not be a permanent one. Access to the UK labour market will almost certainly form part of any future trade negotiations with other

countries. However, we do think it will be a significant challenge for the next five years and possibly longer.

Any actions to reduce the need for workforce and/or optimise productivity will ultimately be beneficial.

The issue raised by parents of the need for more Jewish carers, and in the case of the Stamford Hill community, specifically Haredi Jewish carers, is a harder one for providers to solve. Providers will need to consider whether they can feasibly hope to create a service acceptable to this more orthodox community, or whether such provision would need to come from within that community itself.

Future service planning

In broad terms, there are five areas of service planning that would benefit from focus, investment and action:

- The three partners need to decide what option they support and intend to promote for children with a mild learning disability or ASD who are struggling in mainstream Jewish schools.
- The three partners could use the service data collected to determine if they want to offer more services to more orthodox families of adults with disabilities. If they accept there is less provision of this type than needed, then they also need to decide if their organisation is the most appropriate to deliver the service.
- The three partners could actively facilitate and support the creation of regular family led support groups. These groups could offer mutual support and learning as well as providing a sounding board for development ideas in the future.
- We are clear that at a minimum an additional 100 units of accommodation will need to be provided by the community in the next 15 to 20 years, at a minimum cost of £18 million. We are also clear that the emphasis should be on the development of supported living services as opposed to registered provision. Just about all the local authorities covered by this research demonstrate a sustained pattern of reducing commissioning of residential care. Most of this accommodation will be needed in London and the South East. The capital value of this accommodation will be substantial and we do not think that there will be any single source of supply. This may be another area where the combined efforts of the community are able to deliver what a single organisation working alone cannot. There is a longer-term challenge for accommodation-based services, both in terms of the type of service offered, the level of religiosity desired and the scale of services that will be needed.
- The location of future services is a challenge and one which will become more acute overtime. The largest growth in absolute numbers will be in Barnet and

other London boroughs. The fastest rate of growth will be in Hackney. We think that it will not be practical to try to 'even out' development across all locations, but having said that it would be sensible to look at the work we have undertaken on current service distribution compared with population and consider if further developments would be more appropriately located in other areas such as South Hertfordshire.

It is far from clear that there is significant duplication of service activity between the three organisations. Families did not perceive this and in fact valued the differences between Kisharon, Langdon and Norwood. Local authority commissioners did not raise this as an issue and neither did the service mapping show this.

Providers will need to consider how to balance the need for cooperation and more joined up working between organisations with the need to maintain each organisation's distinctive ethos and service offer with regard to religious observance, need and age group of focus.



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