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West Sussex County Council

Comprehensive Needs Assessment of the Life Pathway for People with Disabilities

Final Report

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1 Introduction

This report brings together four different elements of the comprehensive needs assessment of the life pathway for people with disabilities, completed by the Institute of Public Care at Oxford Brookes University for West Sussex County Council. Four component reports have been completed which cover:

- Policy, literature and good practice
- Epidemiology
- Service information including comparative data
- Qualitative feedback from commissioners, service providers, and the children and families of people with disabilities living in West Sussex.

This final report includes an executive summary, an overall report which brings together the main findings from the needs assessment, and a set of recommendations. A number of methods were used to obtain a qualitative assessment of the needs of people with disabilities across the life pathway, including workshops, interviews, and surveys of both staff and families.

2 Executive Summary

As part of the ‘discover’ phase of a longer-term project to redesign of services over the next 3 - 5 years, the comprehensive needs assessment of the life pathway for people with disabilities in West Sussex aimed to:

- Review evidence on good practice
- Describe and map current pathways
- Assess what is working well and what needs improvement
- Gather and review existing stakeholder views
- Gather information on support services, e.g. transport, community provision
- Compare West Sussex with other local authorities

The project was carried out in five stages: epidemiological analysis, evidence review, mapping of current needs and services, comparison with other local authorities, and the preparation of this final report and recommendations.

In terms of the population, three key trends were identified: an increase of 8.6% in the total number of children and young people with disabilities in the county over the next 20 years; an increase in the number of children and young people with ASD; and increase in the number of children and young people with complex needs.

Children and young people with disabilities have poorer outcomes than their peers in many areas of life. In their health, housing, education, economic, employment and social outcomes, they are likely to do less well than the general population, underlining the ongoing need for commissioners to seek ways to improve these outcomes.

Stakeholder engagement indicated that WSCC is doing well in a number of areas in relation to the life pathway of people with disabilities:

- Development of the Local Offer
- Short Breaks Service
- Community Learning Disability team
- Effective Parent and Carer forum
- Welfare benefits advice
- Sports development

Key areas of concern to parents and young people were:

- A directory of services, easily accessible needs to be made available to all parents/carers/young people
- Too often, too many parents are left in ‘information vacuums’ not knowing what to do next and who best to ask
- It’s not always about money; it’s often about the ‘attitude’ of ‘the system’.

Key areas of concern to staff and professionals were:

- Lack of consistency around transition and a need for earlier and improved planning for adulthood.
- The challenge of achieving coherence and joined up services.
- Waiting times and accessibility – especially for CAMHS, OTs, SALTs, and qualified social workers.
- The impact of rurality and geography exacerbated by limited transport services.
- Lack of housing options both in terms of the existing and new housing stock.
- Lack of support to help young people with disabilities into employment and training.
- The need for an extended short breaks and respite service to cover those outside the 5-18 age range.
- Growing pressure on specialist welfare benefits advice due to welfare reforms and changes in disability benefits.

The needs assessment exercise also identified issues of concern in terms of recruitment and retention of care staff, particularly around Gatwick; the need for improved data quality and flexibility; and difficulties in engaging health staff in the needs assessment exercise.

In comparison with other local authorities, West Sussex does not appear to be significantly different from its comparators, except in terms of: the apparently low proportions of adults with learning disabilities in employment, and in stable accommodation; and relatively high weekly unit costs of long-term in-house residential provision and nursing provision for learning disability support.

Different pathways are presented which offer a useful means to developing a holistic approach to services for people with disabilities along the life pathway. Evidence on pathway design indicates that they should:

- Be negotiable, workable and understandable
- Have multiple points of entry
- Be integrated to remove barriers to movement
- Minimise the need for transition between services or providers
- Enable services to be built around the pathway… not the pathway around services
- Be family focused
- Use a project team
- Engage staff groups in consensus building
- Ensure learning and change
- Optimise and recalibrate resources to needs.

Based on the needs assessment, a number of specific recommendations have been made as to measures that would improve the outcomes for people with disabilities along the life pathway.

The completion of the needs assessment provides an opportunity for WSCC to build on the momentum and energy which the process has generated, and to work with parents and young people to explore the options for service redesign.

3 Recommendations

3.1 Earlier identification and planning for move into adulthood

Develop arrangements to facilitate earlier identification of children and young people with disabilities approaching the transition to adulthood, particularly those with physical disabilities, Children who are Looked After, and those returning from out of county placements funded by education.

3.2 Strengthen coordination and coherence both within WSCC and with other organisations

Develop arrangements to reduce the fragmentation within WSCC and between WSCC and other organisations, including schools, NHS, housing, training and employment providers.

3.3 Improved information and guidance for parents and families around diagnosis

Strengthen coordination with health to ensure appropriate information and guidance is available to parents and families around the time of diagnosis of disability.

3.4 Address delays in access to CAMHS, OTs, SALT and qualified social workers

Explore ways to address delays in access to CAMHS, OT, SALT services and qualified social workers. Possible approaches include changes to recruitment and pay parity with neighbouring local authorities.

3.5 Develop housing options and support to adapt existing homes

Work pro-actively with planners and housing providers to widen the range of housing options for young people with disabilities across the social and private sector, both in new and existing housing, for example, models similar to extra care housing, Shared Lives schemes, wheelchair accessible housing/Lifetime Homes requirements in new developments, promotion of Disabled Facilities Grants to families with a disabled child or young person.

3.6 Strengthen employment and training support

Work pro-actively with Job Centres, FE Colleges, and local employers to strengthen employment and training support for young people with disabilities.

3.7 Additional resource for welfare benefits advice

Increase resources for specialist welfare benefits advice and advocacy in order to ensure that young people with disabilities are able to get the full financial support to which they are entitled.

3.8 Extend short breaks beyond 5-18 age groups

Extend the coverage of the short breaks service and respite care to a wider age group and in terms of those with complex needs and working parents.

3.9 Improve data recording and data quality

Review current data recording of disability information and data quality, including NASCIS data based on WSCC returns.

4 Policy, literature and good practice

4.1 Policy and legislation

The Care Act 2014, the Children and Families Act 2014, and the Special Educational Needs and Disability Code of Practice: 0 to 25 years, 2015 create a new comprehensive legislative framework for transition focussed on personalised, outcome-based approaches with a new focus on carers that recognises the role of families in the process of transition to adulthood.

The Children and Families Act 2014 and the Special Educational Needs and Disability Code of Practice: 0 to 25 years, 2015 introduced a system of support extending from birth to 25 years of age. This includes:

- Children, young people and their families must be involved in discussions and decisions about their individual support and local provision.
- The right to make requests and decisions under the Act will apply directly to disabled young people and those with SEN over compulsory school age rather than to their parents.
- New Education, Health and Care Plans (EHC) for 0-25 years, replace the current system of Statements and Learning Difficulty Assessments, which reflect the child or young person’s aspirations for the future, as well as their current needs.
- Integration of education, health and care to promote well-being and joint commissioning arrangements to secure provision set out in EHC plans.
- Young people have the right to request an (education) personal budget as part of the EHC planning process.
- The EHC planning process requires preparation for adulthood to begin at 14 years (school year 9) with a clear focus on life outcomes.
- A Local Offer of support including information and advice available to children and young people with SEN or disabilities to help them to prepare for adulthood.

NICE has also produced guidelines on transition which includes a series of recommendations linked to the existing legislation and guidance (NICE, 2016). These cover overarching principles for good transition, planning transition, support before and after transfer, and the supporting infrastructure for transition and emphasise that: *Health and social care service managers in children's and adults' services should work together in an integrated way to ensure a smooth and gradual transition for young people*.

4.2 Research

Much of the research on children and young people with disabilities has focused on the transition to adulthood. There is now considerable evidence to point to the importance of the transition experience in terms of immediate and longer-term life outcomes. Poor transitions are likely to be a key contributor to poor outcomes. Young people who are already vulnerable in terms of complexity of needs and/or circumstances are at greater risk of marginalisation during the transition process. The importance of the process of transition to adulthood has been repeatedly emphasised within the literature.

However, research indicates that for most disabled young people the process of transition from child to adult services is problematic, both in terms of services and in terms of giving young people the level of autonomy and control they desire. Researchers have found that the experience of transition to adulthood for many individual young people remains unacceptable; and parents also identify transition to be one of the most stressful periods, with difficulties experienced around coordination, availability, sufficiency and appropriateness of services.
While there is considerable diversity within transition services in terms of their structure, organisation, and funding arrangements, there are some common features associated with better outcomes in the transition process including:

- A written transition plan.
- Continuity 'beyond transition' of designated lead professionals or key workers who are able to coordinate support to the young person, parent or carer.
- Transition service managers having strategic level involvement (e.g. as 'champions').
- Transition workers setting up the adult care package for young people, negotiating funding for it and supporting them until they are settled in adult services.
- Use of person-centred planning.
- User involvement in oversight and development groups.

So far as the structure of services is concerned, the following features seem especially important:

- Transition workers and transition teams who identify and facilitate coordination of support packages and cooperation between providers.
- Services that 'narrow the gap' by providing a bridge between child and adult provision with a focus on preparing the child and family for adulthood.
- Formal intra and inter-agency liaison and agreements, strategic transition protocols and pathways to foster improved communication, co-operation or collaboration.
- Arrangements that promote accessibility of services, including support available from universal services.

Alongside the availability of appropriate provision, a successful transition to adulthood depends on early and effective planning, and putting the young person at the centre of the process to help them prepare for transfer to adult services. The process of transition should start early and while the young person is still in contact with children's services. Organisations need to ensure that they have ways of measuring outcomes for young people at the transition stage and that these are used in commissioning for choice and improvement of services.

4.3 Models

The Department of Health's best practice guidance, Pathways to Getting a Life: transition planning for full lives, (2011) identified key pathways into adult life for young people with learning disabilities. The guidance states that it is relevant to *all* young people with additional needs (for example, children and young people with other disabilities).

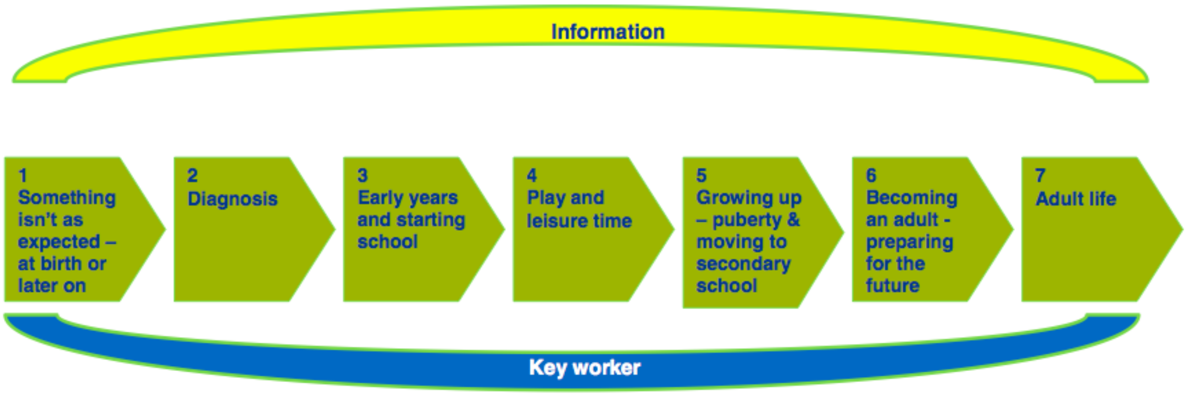
The pathways approach focuses on outcomes rather than services, on the basis that this generates more creative approaches. The approach focuses on the outcomes of: employment, housing, health, and community participation and developing friends and relationships from school year 9.

Apart from Pathways to Getting a Life, there is a lack of literature on the life pathways approach in relation to children and young people with disabilities. However, some broad principles emerge from a review of the current literature on care pathways:

- Pathways should be:
    - Workable and understandable for individuals, their families, partners and carers, and professionals.
    - Accessible and acceptable to all people in need of the services served by the pathway.
    - Responsive to the needs of individuals, their families, partners and carers.
    - Integrated so that there are no barriers to movement between different services and levels of the pathway.
    - Outcomes-focused (including measures of quality, service user experience and harm).
- Pathways should minimise the need for movement between different services or providers; allow services to be built around the pathway and not the pathway around the services; establish clear links (including access and entry points) to other care pathways; and ideally have designated staff responsible for the coordination of people's engagement with the pathway.
- Developing a focus on the family as a whole means that a wider network of services is likely to be involved in the pathway than has conventionally been the case.
- Specific consideration needs to be given to variance reporting and pathway review as these consistently appear as areas of weakness in operation.
- Pathways need to be locally scoped and owned and to reflect local contexts, histories and circumstances.
- A balance is needed between comprehensiveness of scope and manageability, suggesting that pathway development should be an incremental process with an initial focus on high-level mapping and detailed work within identified areas of change that are likely to make the most difference in terms of improving outcomes for families.
- Supporting guidance for professionals, children and young people and families' needs to reconcile comprehensiveness of detail with usefulness and usability.
- Information generated by pathways should not be simply confined to reviewing the operation of the pathway itself, but be utilised to inform broader commissioning activities.
- Pathways need to accommodate and support multiple points of entry to services.
- Shared documents, such as single assessment and family-based plans can serve as useful and powerful vehicles for integration as they draw the perspectives and contributions of many stakeholders into one coherent record.
- Developing and implementing pathways will involve change management activity. The amount of time that is required to support this kind of implementation through change management cannot be underestimated.

- Early support and intervention objectives also have implications for the skills base and workload pressures for key professional groups particularly within universal services. Training programmes designed to support implementation of a new pathway need to take account of this and to address identified deficits. In addition, a realistic assessment of the impact of new roles on workload pressures within key staff groups needs to be undertaken and made subject to routine review.

IPC developed a Family Support Pathway model for children and young people with disabilities. The pathway shows the journey of a child and family over time, from the family's point of view. It is grouped into a series of stages. The pathway tells everyone involved what should be happening, and it can help families and professionals make sense of a complex world.



Each pathway stage in this document describes the following:

- **Event** - A period of time or key event in the life of the family, eg diagnosis.
- **People involved with families -** Which professionals should be involved with parents/carers and children and young people. To provide holistic services, multi-agency working will need to be a key part of this process.
- **Where -** things should happen.
- **When -** At what point in time should things happen. For example the length of time to wait for a service.
- **What can we expect? -** What should happen, i.e. a list for the family and the professionals to check whether the right things have happened.

The model family support pathway is centred around a series of 7 'events' representing key events, or periods of time, for children and young people with disabilities and their families.

The model pathway emphasises the importance of information and the role of the key worker: '*The right information, given at the right time, at every stage, is very important for parents*'. Types of information needed include:

- Information about the process of support and care, including what will happen next and what is due to happen when.
- Information about the disability including diagnosis and how it will/may change over time, plus trusted and reliable websites.
- Health care arrangements.
- Services available, including entitlement to services and waiting times.
- Support options including short breaks, counselling and support groups.
- Play, sport and leisure opportunities.
- Financial information.

Key workers have responsibility for working together with the family and with professionals, and for ensuring delivery of an inter-agency care plan for the child and family.

4.4 Examples

A number of local authorities have introduced 0-25 years' services for children and young people with disabilities. Three examples are presented below. It is understood that these services have not yet been evaluated.

4.4.1 South Gloucestershire - 0-25 Years Service

South Gloucestershire Council has established an integrated 0-25 service for children and young people with disabilities which aims to provide a seamless service. The service is composed of Portage, Early Years Worker, SEN Service, Disability Social Work Service, Occupational Therapist, Adult Disability, and Travel Trainers. The team is made up of Team Managers, Senior Practitioners, Lead Professionals, Lead Workers and Assessment Coordinators. They are split into two geographical teams.

First Point is the 'single front door' to all children and young people's services in South Gloucestershire, including the new 0-25 service. 'Needs Indicators' have been developed by the service in consultation with parents, children/young people. These are used as a guide by staff in First Point to help them screen requests for a referral to the new 0-25 service and signpost to what's available in the Local Offer.

Every referral accepted by the 0-25 service is allocated a Lead Worker/Lead Professional. The first stage involves the Lead Worker/Lead Professional working closely with the child/young person and their family to gather and review evidence to decide whether to do a 'needs assessment'. The Lead Worker/Lead Professional is supported by their manager and a multi-agency panel. The aim is that their expertise matches the needs of the child or young person.

If the decision at this stage is that the child/young person's needs would be better met via the Local Offer, then the Lead Worker/Lead Professional provides advice and support on how to access those local services. If the decision is to do a 'needs assessment', then the Lead Worker/Lead Professional contacts other relevant services, and together with the parents, as the Team around the Child (TAC) they work with the child/young person to find out their needs and personal goals and how the plan of support can help them achieve those goals and reach their potential. The aim is to develop a one-stop approach.

The local Parent Forum was actively involved in the development of the service. Questionnaires, focus groups and forums were used to engage and consult parents and young people.

4.5 Essex County Council – 0-25 Years Service

Essex County Council introduced a service to support children and young people with disabilities from 0-25 years old in July 2014. After consultation with staff and the public, four geographical teams were set up with each one incorporating the following functions:

- Children with disabilities team – supporting 0-15/16
- Young people with disabilities team supporting 16-25
- Occupational therapy – supporting 0-25
- Information, advice and guidance (IAG) – supporting 14-25
- Family and child support – supporting children with disabilities teams but due to be reviewed.

A Central team covers:

- Communication and engagement
- Service development
- Contracting and administration of the High Needs Funding budget
- Management and oversight of the IAG function
- Management and oversight of the OT function.

The structure is perceived to benefit from ensuring all teams have a dedicated team manager, providing a more local and integrated sensory service, a strengthened OT service with a reduction in waiting times, a removal of the need for a formal referral, and co-location which will enable more joined up working.

Essex has established a transition protocol which sets out the criteria for a young person to move to an adult social care team which covers education, accommodation, employment, and support.

4.6 Leeds City Council Complex Needs Service

Leeds complex needs service is for children and young people from 0 to 25 years old with complex learning difficulties and disabilities, and their families. It aims to ensure that every Leeds child with a significant learning difficulty or disability will benefit from child-centred, high quality, flexible and responsive services that help them to live a successful and fulfilling life.

There are three area based complex needs teams: East North East, West North West and South. Each team works closely with families, schools and other learning providers to deliver strong support services which are coordinated around the needs of the child or young person (0-25 years) and their family.

The five main professional areas within the complex needs service are:

- Special educational needs statutory assessment and provision service (SENSAP)
- Special educational needs inclusion team (SENIT)
- Educational psychology
- Sensory service
- Child health and disability (CHAD) including social work teams, occupational therapy and the regional specialist paediatric team.

5 Epidemiology

Children, young people and adults with a lifelong disability are a diverse group. Some will have highly complex needs requiring multi-agency support across health, social services and education, while others will require substantially less (if any) support.

5.1 Data and definitions

Attempts to provide accurate estimates of disability in children, young people and adults are hampered by the range of definitions in use. For example, the Census uses the following definition of disability: '*A long-term health problem or disability that limits a person's day-to-day activities, and has lasted, or is expected to last, at least 12 months*'; while the Family Resources Survey (FRS) uses a different definition: '*a long-standing illness, disability or impairment which causes substantial difficulty with day-to-day activities*'.

Routine data are collected by local authorities on children with statements of Special Educational Needs/ EHC Plans, but this does not reflect the spectrum of disability, and is a weak proxy measure for severity. However, the data do indicate demand and how it is changing over time. West Sussex County Council does not currently have a Disability Register.

Thus, different sources of data provide different information on the needs of children, young people, and also adults with a disability. In some cases they are not directly comparable, as some indicate prevalence, while others reflect expressed demand for services; age ranges may also vary. As long as these differences are taken into account when making conclusions, each data source provides an insight into numbers of people with lifelong disabilities that this needs assessment aims to study.

5.2 Disability

Using FRS age-related prevalence rates, there are estimated to be nearly 15,100 children and young people with a disability aged 0-24 years in West Sussex in 2015, projected to increase to 16,400 (8.6%) in the next 20 years (Table 1). The increase in numbers aged 10-14 and 15-19 years old is projected to be the greatest (17% and 13% respectively).

Table 1: Children and young people aged 0-24 in West Sussex projected to have a disability by age, 2015-2035

Age quintile	2015	2020	2025	2030	2035	2015-35 % change
0-4	1,400	1,400	1,400	1,400	1,400	-2.5%
5-9	3,300	3,500	3,400	3,400	3,400	1.2%
10-14	3,500	4,000	4,200	4,200	4,100	16.8%
15-19	3,200	3,000	3,500	3,600	3,600	12.6%
20-24	3,600	3,400	3,300	3,700	3,900	8.3%
Total	**15,100**	**15,400**	**15,800**	**16,300**	**16,400**	**8.6%**

Figures calculated using prevalence rates of 3% for age 0-4, 7% for 5-10, 8% for 11-14, 7% for 15-19 and 9% for 20-24 from FRS 2011/12.

There are significant differences in the estimates for the numbers of children and young people with severe disabilities in West Sussex. While one source estimates that there are 131 children and young people living with a severe longstanding illness or disability aged 0-19 years old[1]; another generates an estimate of 862 with a severe learning difficulty aged 0-19 years old and 212 with a profound and multiple learning difficulty aged 0-19 years old[2]. This is likely to reflect different approaches to definition and classification.

5.3 Physical disabilities

Based on data from the Department for Education, there were 509 children and young people across the school system whose primary need was physical disability. In addition, 2,337 people aged 18-24 are estimated to have a moderate physical disability, and 456 people aged 18-24 to have a serious physical disability in West Sussex.

5.4 Visual and hearing impairment

Over 450 children and young people are estimated to have some level of visual impairment in West Sussex: 113 children aged 0-16 years are estimated to be severely sight impaired or blind, and 37 young people aged 18-24 are predicted to have a severe visual impairment[3]. This compares with 129 school pupils in West Sussex in January 2015 with a visual impairment (across primary, secondary and special schools by primary type of need).

There are an estimated 20 children aged 0-17 who are registered as hard of hearing (and this will rise to 22 in 2035) and 54 who are registered deaf in 2015. There were 83

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[1] ONS/Family Fund Trust/ChiMat

[2] Emerson and Hatton's Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England (2008)

[3] http://www.pansi.org.uk/

young people aged 18-24 predicted to have a moderate or severe hearing impairment according to PANSI. This compares with 237 school pupils in West Sussex in January 2015 with a hearing impairment (across primary, secondary and special schools by primary type of need). This indicates that not all children and young people with a hearing impairment are registered as deaf or hard of hearing.

5.5 Autism Spectrum Disorder (ASD)

Based on National Autistic Society data, there are an estimated 2,622 children and young people aged 0-24 years with autism in West Sussex in 2015, rising to 2,796 by 2030. In contrast, two different sources of administrative data indicate either 759 or 1,025 school pupils in West Sussex in January 2015 with ASD. This indicates that not all children and young people with ASD have a statement or EHC plan, and that some children may be misdiagnosed or undiagnosed.

The available data indicate that the numbers of children and young people with ASD is increasing which may reflect better diagnosis due to increased public and medical awareness, rather than an actual increase in prevalence.

5.6 Down's Syndrome

There are an estimated 120 people with Down's Syndrome aged 0-24 years old in the county. Numbers are not projected to increase greatly in future years.

5.7 Challenging behaviour

It is estimated that there are 80 children and young people with a learning disability predicted to display challenging behaviour in West Sussex in 2015. Numbers are not projected to increase greatly in future years.

5.8 Overall trends

While there may be some variation in the estimates of numbers, it is clear that numbers will increase at least in line with the overall 7% projected increase in the population aged 0-24 years old in the next 20 years[4]. In addition, continuing developments in medical technology mean that the number of children living through birth and early years is increasing, resulting in a growing number with complex needs. This not only means that there is a greater number of children and young people with disabilities who are in need of a social care intervention, but also that the complexity of the care need is greater. This will put greater pressure on services for more intensive support. Numbers are also increasing as a result of better diagnosis of conditions such as autism.

5.9 EHC Plans and SEN

Administrative data provides another method of identifying the numbers of children and young people (CYP) with disabilities. In January 2015, there were 20,656 school pupils with statements or EHC plans or SEN support in West Sussex.

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[4] Based on ONS population projections which correspond with WSCC population projections.

In terms of school pupils with special educational needs in West Sussex in January 2015, by primary type of need, there were:

- 3,781 with speech, language and communication needs
- 3,210 with a moderate learning difficulty
- 3,091 with a specific learning difficulty
- 120 with a profound and multiple learning difficulty
- 509 with a physical disability.

Table 2 presents the number of pupils with SEN in primary, secondary and special schools across West Sussex by primary type of need in January 2015.

Table 2: All school pupils in West Sussex with special educational needs by primary type of need, January 2015

Primary type of need	Primary school	Secondary school	Special school	All schools
Specific learning difficulty	1,323	1,752	16	3,091
Moderate learning difficulty	1,552	1,345	313	3,210
Severe learning difficulty	36	22	333	391
Profound and multiple learning difficulty	12	5	103	120
Social, emotional and mental health	1,197	1,234	205	1,440
Speech, language and communications needs	2,511	1,088	182	3,781
Hearing impairment	108	122	7	237
Visual impairment	60	66	3	129
Multi-sensory impairment	17	6	0	23
Physical disability	232	186	91	509
Autistic spectrum disorder	355	291	379	1,025
Other difficulty/disability	398	536	43	977
SEN support but no specialist assessment of type of need	173	182	0	355
Total	**7,974**	**6,835**	**1,677**	**16,486**

Source: Department for Education

5.10 Evidence on outcomes

National research evidence on the outcomes of children and young people with disabilities clearly indicates that along the life pathway they experience poorer outcomes than the general population. In terms of their health, housing, economic, employment and social outcomes, children and young people with disabilities have poorer outcomes than their peers. Some of these areas are amenable to change by WSCC, while others are less amenable to the county council's influence, such as health and housing. A fuller picture is provided in the epidemiological report.

6 Service information including comparative data

West Sussex County Council offers a range of services to children, young people and families affected by disability. Services range from universal services available to all, to those that are very specialist, offering support and interventions to children and young people with complex disabilities and care needs.

6.1 Social care

6.1.1 Looked after children

In West Sussex, there are 129 Children Looked After (CLA) with a disability, representing 4% of all children looked after by the Council (Table 3). The largest group are those with social, emotional and behavioural difficulties (41), followed by those with ASD (27) and those with speech, language and communication difficulties (21).

Table 3: Numbers of Children Looked After (CLA) and Children with a Child Protection Plan with a disability, 2015

	Number of Children Looked After with a disability	Number of children with a Child Protection Plan with a disability	Number of out of county placements
General learning difficulty	0	1	1
Moderate learning difficulties	12	2	29
Severe learning difficulties	13	2	18
Profound and multiple learning difficulties	1	0	4
Autism Spectrum Disorder	27	4	85
Physical difficulties	7	2	60
Hearing impaired	1	1	19
Visually impaired	1	0	4
Speech, language and communication difficulties	21	9	61

	Number of Children Looked After with a disability	Number of children with a Child Protection Plan with a disability	Number of out of county placements
Social and emotional and behavioural difficulties	41	4	105
Specific learning difficulties, eg, dyslexia	5	0	21
Total	**129**	**25**	**407**

Source: SEND data from Business Support, WSCC

6.1.2 Children subject to a child protection plan

There are 25 children with a disability who are subject to a Child Protection Plan in West Sussex. The largest group are those with speech, language and communication difficulties (9), followed by social, emotional and behavioural difficulties (4) and ASD (4).

6.1.3 Out of county placements

In 2015, there were 407 children and young people in out of county placements, having risen steadily from 351 in 2011. The largest group are those with social, emotional and behavioural difficulties (105), followed by those with ASD (85), speech, language and communication difficulties (61) and physical difficulties (60) – possibly reflecting a lack of availability of placements in-county for these groups of children and young people.

The number of children with speech, language and communication difficulties placed out of county has increased steadily from 39 in 2011 to 61 in 2015; and the number with ASD as a primary need placed out of county has grown from 68 to 85 over the same period of time (equivalent to a 25% increase).

6.1.4 Children in need

At 31st March 2015, 656 children were identified as ‘in need’ in West Sussex with child’s disability or illness as the primary need at assessment (equivalent to 13.8% of the total number of children in need in West Sussex) (Table 4). Rates of behaviour and mobility disabilities appear to be particularly low in comparison with the regional and national rates, while rates of autism/Asperger Syndrome and learning disability are above the regional and national rates. Rates of other disabilities are closer to regional and national rates.

Table 4: Number of children in need at 31 March 2015 with breakdown of disabilities

Area	Number of children in need at 31 March 2015	Number of whom have a disability recorded	Percentage having a disability recorded	Percentage of children reported with a disability who report the following disabilities											
				Autism/ Asperger Syndrome	Behaviour	Communication	Consciousness	Hand Function	Hearing	Incontinence	Learning	Mobility	Personal Care	Vision	Other Disability
West Sussex	4,766	656	13.8	*41.6*	*13.4*	*17.7*	*7.9*	*10.2*	*3.4*	*11.0*	*51.1*	*13.9*	*9.9*	*7.0*	*2.0*
South East	53,900	8,100	15.1	*33.3*	*20.5*	*21.2*	*6.8*	*4.8*	*5.2*	*6.1*	*48.0*	*21.5*	*9.5*	*9.1*	*10.5*
England	391,000	50,800	13.0	*30.5*	*23.0*	*23.7*	*5.3*	*5.1*	*5.6*	*8.9*	*45.7*	*21.5*	*13.7*	*8.8*	*20.1*

Source: https://www.gov.uk/government/statistics/characteristics-of-children-in-need-2014-to-2015
Note: Rows add up to more than 100 as children may be reported with more than one disability

6.2 Disabled Children's Service

6.2.1 Child Disability Teams

The Child Disability Teams (CDT) focus on that group of CYP with severe or profound disabilities and complex health needs where the needs specifically relate to the CYP's disability or health condition.

In November 2015, there were 431 disabled children receiving a Direct Payment in West Sussex (Table 5). Direct Payments are received by parents on the child's behalf.

Table 5: Disabled children in receipt of Direct Payments, residential, foster care and short breaks services (November 2015)

Age	No. of Disabled Children receiving a Direct Payment	No. of Disabled CLA in agency residential care	No. of Disabled not CLA in agency residential care	No. of Disabled Children in Foster Care	No. of Disabled Children in in-house residential care	No. of placements in Short Breaks
0-4	10	0	2	0	0	2
5-9	120	3	10	1	0	219
10-14	184	7	14	3	14	397
15-16	62	3	6	0	6	145
17-18	34	7	6	0	4	114
19-25	21	0	0	0	0	12
Total	431	20	38	4	24	889

Source: WSCC

6.2.2 Personal budgets

Personal budgets are available through Health, Social Care and Education. Some young people are receiving all three and each request is considered on an individual basis. The criterion for a personal health budget is that the patient must meet eligibility for NHS funded children's continuing healthcare.

The following number of people aged 0-25 years receiving a personal budget:

- Education – 9 agreed and 1 being considered
- Continuing Health Care – 22 agreed including 6 that are jointly funded by Social Care
- Social care – 239 active personal budgets, of which 170 come through the Children with Disabilities Team rather than the SEND EHC process.

Personal budgets within education may be used to pay for specific types of therapeutic educational approaches, while social care personal budgets may cover activities such as swimming lessons, attending groups and clubs, communications aids and other equipment.

Table 6 shows the number of children and young people with an EHC Plan in West Sussex. Between January and October 2015, 390 EHC Plans were issued to under 16 year olds and 273 to those aged 16 and over.

Table 6: EHC Plans - Jan-October 2015

	Number
EHC Needs Assessment requests received	370
Draft EHC Plans issued	360
Final EHC Plans (SSEN) issued	342
Final conversion EHC Plans issued (under 16 transfers)	390
Final conversion EHC Plans issued (post 16 transfers)	273

Source: SENAT Business Plan Monitoring 2015-2016

6.2.3 Short breaks provision

The Short Breaks services are available for children and young people (CYP) with additional needs and disabilities who live in West Sussex and who are aged between 0-18 years old. In November 2015, there were 889 short break placements in West Sussex for children and young people aged between 0 and 25 years old, with 69% of placements for those aged between 5 and 14 years old.

6.2.4 West Sussex Sensory Support Service

The West Sussex Sensory Support Team (SST) supports children and young people aged between 0-19 years who have a sensory need - hearing, visual or multi-sensory impairment.

6.2.5 Community equipment

The Children's Access Point Team can make referrals for specialist equipment for children with hearing impairments.

6.3 Transitions

The Community Learning Disability Team (CLDT) runs transition for young people with learning disabilities. A significant number of young people with learning disabilities and their families receive a social care service at age 18 who have not been previously been known to Childrens' social care services. A significant proportion come from the CLA team or residential placements fully funded by education.

The CLDT is also working with Children's Services to develop effective protocols, and with mental health, continuing health care and physical health partners and education services around EHC Needs Assessments and EHC Plans.

In February 2016, there were 333 children in Year 9 with a SEN statement, and of these 81 are known by Social Services, leaving 265 who have a SEN statement but are not known to Children's Services and are entitled to assessment. Although the majority of these unidentified children are likely to receive information and advice only, finding out how to contact them, offering them an assessment and resourcing it is challenging. Better information sharing and communication between education and social services may help to address this.

6.4 In-house services for adults with learning disabilities

In 2015, there were 379 people with learning disabilities aged 18-24 receiving a service from WSCC, including 41 people with learning disabilities aged 18-24 in short stay residential care; 102 receiving supported living provision, and 163 receiving day services. It should be noted that although WSCC provide at least 50% of day services, WSCC is not the main provider of residential care and provides no supported living services.

West Sussex CC provides seven in-house day services and five residential homes for adults with learning disabilities. These are located along the coast and in Chichester, Burgess Hill and near Horsham. A number of customers are aged 25 or below:

- Chichester - 11 customers aged 25 or under
- Coastal Enterprise, Worthing - 9 customers aged 25 or under
- Oaks/Pines, Worthing - 12 customers aged 25 or under.

6.4.1 Shared Lives

Shared Lives provides care for up to three people with a learning disability in a private home. This can provide long-term accommodation or short term breaks. In 2015, there were 40 people with learning disabilities aged 18-24 using this service in West Sussex.

6.4.2 Independent Living Service

The Independent Living service is funded through the Better Care Fund. It provides Carepoint (the access point to adult social care), reablement services, six locality teams which offer occupational therapy to adults and children (including occupational therapists and senior practitioner OTs), community equipment, rehabilitation services to the visually impaired, and a Blue Badge service. The most recently available data indicate there are 36 children on the locality team waiting lists: 16 of whom are in the Horsham and Mid Sussex locality.

The Community Equipment service is joint-funded by the NHS. In October-December 2015, it provided equipment to 8,277 people. However, the data are not broken down by age.

6.4.3 Prevention and Assessment Teams

The PAT teams are multi-disciplinary teams delivering a preventive service to around 200 people with lower level needs, about 45% are people with autism. They provide information, advice and support.

6.5 Health

There are a range of health services for disabled children and young people in West Sussex. These include:

- Continuing care at home
- Health-led short breaks
- Speech and language therapy for children
- Physiotherapy for children
- Occupational therapy for children
- Children's community nursing
- Complex Behaviour Support team working with the CAMHS/Child Disability Services.

Data on service use was not available.

6.6 Education and childcare

6.6.1 Early Childhood Service

A range of services are provided for children with a disability or additional needs:

Providers	Number receiving service
Breakfast Club	57
Child minder	579
Crèche	12
Day Nursery	334
Child minder offering free entitlement (FE)	230
Holiday scheme	71
Infant School	40
Out of school care	78
Pre-School Playgroup	96
Primary School	180

Source: Health and Social Care Directorate presentation, WSCC

6.6.2 Under-5s – Early Years Hubs

WSCC provide Early Years Hubs to make it easier for families with children under 5 with SEND to access advice, guidance, services and activities at a convenient location. Sensory play equipment is available during the sessions and many have a sensory room. Staff can help with information about local services and activities for parents of children with disabilities or additional needs, access specialist toys through our sensory toy libraries and give advice on benefits. In some hubs specialist therapies offered by health partners may be available. Some have hearing loops and all are wheelchair accessible. There are hubs in Bognor Regis, Boundstone (Lancing), Chichester, Durrington, East Preston, Horsham, Langley Green and Ifield (Crawley), and Sidney West (Burgess Hill).

6.6.3 Playgroups

All playgroups and nurseries are expected to welcome children with special educational needs. In addition, there are two "opportunity" playgroups in Burgess Hill and East Grinstead which although mainstream nurseries, actively invite and include children with special needs. Scope run a day nursery in Ingfield in Billingshurst for children from three to five years old with physical impairments and associated learning difficulties.

6.6.4 Children and family centres (CFC)

There are 48 Children and Family Centres in West Sussex: of which eight are managed by WSCC.

6.6.5 Special schools

WSCC currently has contracts for 361 children placed in 76 different schools, including approximately: 75 children with dyslexia. Of the total, 114 are funded through Direct Payments.

6.7 Information, advice and guidance

6.7.1 The Local Offer

Information and advice for children and young people, their family and carers is available through the Local Offer; the Information, Advice and Support Service; Carers Support West Sussex. The Local Offer is a web-based resource which brings together information about the help and support available for children and young people with special educational needs and/or disabilities (SEND) and their families.

6.7.2 Family Information Service

The Family Information Service can provide support for parents and carers looking for childcare for a child with a disability or additional needs. Additional information is available through Reaching Families, a third sector organisation which provides factsheets on different disabilities, a handbook for parents of children with special needs and disabilities in West Sussex (Making Sense of it All), and a handbook on transition (Making Sense of Adult Life).

6.8 Welfare benefits

Personal Independent Payment (PIP) is a benefit for people who need help taking part in everyday life or who find it difficult to get around. It replaces Disability Living Allowance for people between the ages of 16 and 64 inclusive. In July 2015, there were 393 young people aged 16-24 receiving PIP across West Sussex (Table 7). Arun district has the highest number of young people receiving PIP (94) in the county.

Table 7: PIP Claims in Payment by age and district – July 2015

Local Authority	Age 16 to 17 years	Age 18 to 24 years	Total
Adur	5	27	30
Arun	22	75	94
Chichester	16	40	54

Local Authority	Age 16 to 17 years	Age 18 to 24 years	Total
Crawley	10	44	59
Horsham	5	49	53
Mid Sussex	5	40	45
Worthing	12	44	63
West Sussex	**75**	**318**	**393**

Source: DWP Stat-Explore

Disability Living Allowance (DLA) is available to children and young people under 16 who are disabled and need extra help to look after themselves or have difficulty walking or getting around. DLA is not means tested. There are two components to DLA: the care component, which has three rates of payment and the mobility component, which has two rates of payment. There were 4,170 children and young people claiming DLA in May 2015, and 2,520 aged 16-24 (who will eventually be moved over to PIP) (Table 8) in West Sussex. In total, the largest number were in Arun district, however the largest number under 16 were in Crawley. As people are still moving across from DLA to PIP, it is not possible to identify the impact of the change in West Sussex or compare numbers across time.

Table 8: Disability Living Allowance Claimants by age and district at May 2015

Local authority	Under 16	16-24	Total
Adur	415	250	665
Arun	645	530	1,175
Chichester	490	290	780
Crawley	780	390	1,170
Horsham	500	345	845
Mid Sussex	675	360	1,035
Worthing	665	355	1,020
West Sussex	**4,170**	**2,520**	**6,690**

Source: DWP Neighbourhood Statistics Data

The criteria for PIP are stricter than for DLA - for example, in the past someone was considered to be "virtually unable to walk", and therefore eligible, if they could not walk more than about 50 metres. Under PIP, that was dropped to 20 metres, excluding, at the government's estimate, more than 420,000 people across the UK.

WSCC employs a benefits adviser for families with children with a disability. Face to face services were provided to 237 people in 2015, in addition to drop-in sessions in family centres, specialist schools, colleges and other venues. Advice and support includes attending tribunals with families. This is becoming a growing part of the role with the introduction of the Personal Independence Payment.

6.9 Play, sport and leisure activities

6.9.1 Play

The third sector plays an important in providing opportunities for play and other activities for children and young people in West Sussex. For example: PACSO currently provides After School Clubs, Saturday morning creative clubs, Saturday afternoon sports clubs, East fun days, Christmas play days, Summer play scheme and Monthly coffee mornings for parents/carers to 150 families who have a child with a disability in the Chichester and Arun districts; the Springboard Project provides inclusive play and leisure opportunities for families with young children and fun short breaks for children and teenagers with disabilities in Horsham and Crawley; and Kangaroos provide short breaks opportunities for children and young people with learning disabilities aged 6-19.

6.9.2 Sport

There is a range of sport and leisure based activities open to children and young people with disabilities. The Sussex Disability Sports Network is currently made up of over 150 members. Active Sussex leads the Sussex Disability Sports Network – supporting the development and provision of disability sport in Sussex. The Network is developing an action plan and works with a range of organisations, for example, with leisure centres to organise disabled access days and help pools to become more inclusive. A range of organisations are working to make their facilities more accessible and developing opportunities for children and young people with disabilities including: Out There! West Sussex - a programme of daytime, evening and weekend leisure activities and sports choices for people with learning disabilities; Middleton Sports Club; Cobnor Activities Centre; Lodge Hill Park, Pulborough; and South Down Leisure Centre, Worthing.

6.9.3 Leisure

There are a limited number of youth clubs for young people with disabilities in West Sussex. WSCC currently run two M8s youth clubs for young people with learning difficulties or additional needs: one in the Coastal area and one in the Northern area.

The most recent attendance in November 2015 was:

Area	Age 11-14	Age 15-16	Age 17-18	Age 19-26	Total
Coastal	4	4	2		10
Northern	2	7	5	8	22

In 2015, a total of 23 different clients attended the Coastal club and 37 different clients the Northern club. Attendance at the clubs is relatively constant varying by not much more than 2 above, and below, the attendance figures quoted above. During October 2015, 90 young people with a Statement of SEN had contact with the M8s service (56 males and 34 females) indicating that there may be more interest than spaces on the projects.

6.9.4 Compass Card West Sussex

The Compass card (launched in April 2016) is a discount card for young people aged 0-25 years old which is available to a child or young person living or going to school or college in West Sussex, or being ‘looked after’ by West Sussex County Council, with a disability or special educational need that has a significant effect on their daily living.

WSCC has awarded the contract for the card (as well as for a Disability Register) to Amaze. The card will provide special deals at many venues.

6.10 Transport

Transport is often an issue identified by children, young people and their families. A lack of 'door to door' transport, either through school transport services or public transport can be a key barrier to participation in out of school opportunities and activities. Information about transport for children and young people with disabilities and travel training was not obtained.

6.11 Housing

There is no specialist supported housing for young people with disabilities aged 16-25, apart from a scheme in Worthing (Fethneys) run by Leonard Cheshire which provides accommodation for up to 10 physically disabled adults with the aim of training them to live independently over a two year period. General supported housing, such as foyers and short stay supported lodgings, is not considered particularly suitable for young people with disabilities. WSCC is currently working with Livability to develop an extra care housing scheme suitable for up to 9 young people with disabilities in Bognor.

There is limited accommodation provision for adults with physical disabilities. For example, wheelchair accessible provision of supported housing is understood to be almost negligible.

There are over 450 supported living placements for adults with learning disabilities, and a further 700 plus in other non-residential settings, family homes etc. There are many partnerships between independent sector care providers and landlords that have created opportunities for supported living either in shared houses or self-contained units. Following the learning disability campus closure in 2010, 41 units of specialist housing were developed.

Southdown Housing provides some supported housing in West Sussex, particularly for people with learning disabilities. They provide accommodation, care and support for over 220 adults with learning and physical disabilities in 26 supported living services across Sussex. Ability Housing has a small stock of adapted housing but turnover is limited.

According to the Adult Social Care Outcomes Framework data, there is a lack of suitable accommodation for people with learning disabilities. This appears to indicate that WSCC is well below the average for similar local authorities. However, it is understood that this reflects a recording issue and poor review performance.

Disabled Facilities Grant provides a mechanism for improving access to the existing housing stock and making adaptation. However, the age profile and disability profile of grant recipients is not known. This is part of a wider gap in information about housing for children, young people and adults with disabilities and their families and carers.

6.12 Employment

Nationally, the proportion of learning disabled people known to social care who were in paid employment was 7% in 2013-14[5]. The number of young people with statements of SEN who are not in education, employment or training has risen from 100 in 2013 to 241 in 2015, equivalent to a 141% increase (see Table 9).

Table 9: Number of statemented young people who are also Not in Education, Employment or Training (NEET) in West Sussex

	2013	2014	2015
No. of Statemented Cohort who are also NEET (April except 2013 (July))	100	174	241

Source: WSCC SEND data

Data from the Adult Social Care Outcomes Framework indicate that the percentage of adults with learning disabilities in employment in West Sussex is less than a third of the average for similar local authorities. However, as with the data on settled accommodation for adults with learning disabilities, it is understood that the data are not robust and reflect recording issues and poor review performance. Information on people with physical disabilities was not available.

There are a limited number of supported employment schemes in West Sussex, for example, the WorkAid scheme delivered by the Aldingbourne Trust which aims to match adults with learning disabilities with suitable work placements and includes help for employers. Participants work through a tailored programme to prepare them for work, including skills training, assistance with job applications and supported inductions with employers. Independent Lives has recently established a volunteering programme for people with disabilities. WSCC has also been proactive in developing opportunities for people with disabilities in the authority itself. WSCC has created 40 jobs that are suitable for people with learning disabilities and ASD, which it has now achieved. This includes a pool of seven event assistants. At present most of the people employed have a mild learning disability or Asperger's, as the jobs that have been created are not considered that suitable for people who are less able.

6.13 Comparator information

The total percentage of pupils with SEN in West Sussex is the fourth highest among the comparator group authorities (Table 10). It should be noted that both these tables reflect what schools have reported and may therefore underestimate the numbers. Equally, they will include a number of children with learning difficulties which would not necessarily constitute a disability, for example, dyslexia.

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[5] Department of Health (2014) The Adult Social Care Outcomes Framework 2015/16

Table 10: All schools – Number of pupils with special educational needs (SEN), based on where pupil attends school

Authority	Pupils with statements or EHC plans - % of total pupils	Pupils with SEN support – % of total pupils	Total pupils with SEN - %of total pupils
West Sussex	**2.9**	**14.2**	**17.2**
Devon	3.5	14.6	18.1
Dorset	2.5	15.7	18.2
East Sussex	3.8	11.2	15.0
Essex	3.3	10.8	14.2
Gloucestershire	2.8	12.7	15.4
Hampshire	2.7	12.0	14.7
Hertfordshire	1.9	11.9	13.8
Kent	2.9	11.3	14.2
North Yorkshire	2.2	10.2	12.4
Oxfordshire	2.2	12.6	14.8
Staffordshire	3.0	10.8	13.8
Suffolk	2.6	10.8	13.5
Warwickshire	3.1	11.4	14.6
Worcestershire	3.0	14.3	17.3

Source: School Census SFR25-2015_TABLES_LA Table 16 – January 2015

Spending on SEN in West Sussex is below that of statistical neighbours and the average for England. Unit costs in West Sussex appear to have doubled since 2010-11, while average unit costs in the statistical neighbours and in England have been falling over the same period. However, it should be noted however that other authorities started from a much higher base. It is possible that the data reflect poor recording in the past.

Table 11: SEN - S251/Outturn weekly unit costs (£) (approximate)

Statistical Neighbours	2011-12 (S251)	2012-13 (S251)	2013-14 (S251)	2014-15 (S251)	2015-16 (S251)
West Sussex	40.00	50.00	80.00	90.00	80.00
Bath and North East Somerset	220.00	135.00	80.00	75.00	25.00
South Gloucestershire	80.00	95.00	80.00	70.00	50.00
Worcestershire	90.00	75.00	75.00	70.00	70.00
Poole	125.00	135.00	95.00	80.00	75.00

Statistical Neighbours	**2011-12 (S251)**	**2012-13 (S251)**	**2013-14 (S251)**	**2014-15 (S251)**	**2015-16 (S251)**
Hampshire	125.00	120.00	90.00	90.00	85.00
Essex	95.00	90.00	85.00	85.00	85.00
Leicestershire	110.00	105.00	90.00	90.00	85.00
Gloucestershire	120.00	150.00	100.00	100.00	100.00
North Somerset	140.00	215.00	140.00	140.00	140.00
Dorset	130.00	160.00	135.00	125.00	140.00
Statistical Neighbours	123.50	128.00	97.00	92.50	85.50
England	105.00	115.00	95.00	95.00	95.00

Source: Local Authority Interactive Tool
https://www.gov.uk/government/publications/local-authority-interactive-tool-lait

6.14 Costs

Based on information from April 2015, WSCC's current pathways budget for child disability and special educational needs is composed in the following way:

Budget at 1st April 2015	**Expenditure**	**Child Disability - £000s**	**Special Educational Needs - £000s**
Residential and foster care	External commissioned	3,054	0
WSCC residential homes	In-house	5,174	0
Other budgets	External commissioned	0	0
	In-house	0	2,145
CDT Care management team	In-house	1,315	
Family support		800	
Direct Payments		2,640	
Short Breaks, Short Breaks Transport & Parent Carer Training		1,933	
Foster care allowances		151	

Source:WSCC SEN Contract and Placements data

The most costly group in terms of the total cost of residential placements are:

- 83 children and young people with ASD (£3.8 million)

- 105 children and young people with social, emotional and behavioural difficulties (£3.5 million)
- 66 children and young people with speech, language and communication difficulties (£2.3 million)
- 55 children and young people with physical difficulties (£2.3 million)

The most costly placements are in independent and non-maintained special schools (INMSS). However, placements in INMSS may not actually be much higher when the full cost of therapeutic support, transport and specialist equipment is taken into account. There are sometimes complex reasons why children are placed in INMSS due to a combination of their social care and education needs. West Sussex special school placements are the next most costly followed by West Sussex special and academy support units with mainstream schools and academies costing less.

The most expensive individual packages of care are weekly and termly residential placements for 2 children and young people with severe learning difficulties costing over £115,000 per annum, followed by yearly residential placements for 8 children and young people with ASD costing over £100,000 per annum, and yearly residential placements for children and young people with physical disabilities costing over £65,000 per annum.

Over the past ten years there has been a significant increase in the number of children with complex health needs which has affected the budget pressure on this area. Given the projected increase in the number children and young people with disabilities of 8.6% over the next twenty years, placements of children and young people with ASD in INMSS will increase further, and the cost of care for this group will increase if the level and type of service remains unchanged. According to the Medium Term Financial Strategy, spending is projected to increase by £1.4m 2015/16, and an ongoing estimated increase of £0.5m each year thereafter.

6.14.1 Comparative unit costs for adults with disabilities

The comparative unit costs of services for adults with disabilities indicate that while the weekly unit costs of long-term care for those aged 18-64 for physical care or sensory support are around the average for comparator authorities, the weekly unit costs of long-term in-house residential provision and nursing provision for learning disability support are significantly above the comparator average of £558 and £587 respectively.

According to the national returns on local authority expenditure for 2014-15[6], the weekly unit costs of long-term care for those aged 18-64 for physical care or sensory support are around the average for comparator authorities. However, the weekly unit costs of long-term in-house residential provision and nursing provision for learning disability support are significantly above the comparator average of £558 and £587 respectively. However, the data do not appear entirely credible (for example a significantly higher weekly spend on long-term residential care for those aged 18-64 requiring physical support than the spend on nursing care for the same category of people) and further analysis of recording issues is needed.

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[6] Personal Social Services: Expenditure and Weekly Unit Costs (£), England - 2014-15, Final Release: Mandatory Activity Data by CASSR - Long Term, NASCIS Online Analytical Processor.

7 Feedback from commissioners, service providers, and the children and families of people with disabilities

As part of the Needs Assessment, a number of methods were used to obtain a qualitative assessment of the needs of people with disabilities across the life pathway. These included:

- Two interactive stakeholder workshops with professionals to map services and explore needs
- A range of interviews with parents by phone and in group settings via West Sussex Parent/carer forum, The Pines and PACSO Go Club (see appendix 1)
- A range of interviews with young people individually and in groups via The Pines/Oaks Community Project and PACSO Go Club – (see appendix 1)
- A survey of stakeholders both WSCC and others which obtained 82 responses
- Telephone interviews with a range of stakeholders commissioning and providing services to children, young people and adults with disabilities in West Sussex.
- A review of the results of a 2015 survey of parents and carers of children with special educational needs (SEN) and disabilities by WSCC, which obtained 557 responses.

7.1 Overview

Overall, the 2015 survey of parents and carers of children with SEN and disabilities indicated a good level of satisfaction with social care and family support services – the average rating on a scale of 0-10 was 6.9. According to the most recent data from NASCIS on parental experience of services provided to disabled children, West Sussex scored 61% in terms of satisfaction. Professional stakeholders thought that the quality of services in WSCC was generally high and there was a good range of provision for children and young people with disabilities.

In terms of engagement, professionals considered that there is a strong parents' voice and consultation in WSCC, particularly through the Parent and Carer Forum which is active. The 2015 survey of parents and carers of children with SEN and disabilities found high levels of satisfaction in their involvement in planning for any changes in their children's live (an average rating of 7.4 out of 10) and good levels for their child's involvement in planning changes (average 6.8 out of 10).

A range of areas and services were mentioned by those contacted as part of the needs assessment. These are presented below.

7.1.1 Transition

Although the extension of transition is viewed as a positive development and there were perceived to be good working practices and relationships between services for children and the Community Working Age Adults Learning Disability Team, there were a number of areas where improvements were suggested, including:

- Greater consistency for all groups of children and young people in transition, such as those with physical disabilities where there is not necessarily an educational need, Children who are Looked After and those returning from out of county residential placements funded by education.

- The need for earlier and improved planning in the preparation for the transition to adulthood was echoed by both parents and professionals: '*It would be helpful if adult's teams could get involved earlier in the process of transition',* and similarly, '*They need to be drawn in earlier to allow more time to plan and prepare*'.
- Comments from parents reflected a need for more information to parents and young people along the pathway to adulthood. Peer mentors or buddies were suggested as a helpful way to support parents and young people through the transition to adulthood.
- More information would help to address another issue frequently mentioned by professional stakeholders: managing parental expectations in recognition of the different ethos, and more limited care packages available to adults with disabilities compared with children and young people, and the different levels of resources in adult services.

7.2 Coherence and coordination

Delivering joined up services in a two tier authority with three Clinical Commissioning Groups was recognised as a challenge by many stakeholders. However, a number of professionals mentioned the need for more joined up services between health, social care and education, particularly in terms of the processes and procedures around the transition to adulthood in order to develop a seamless pathway from children's to adults services, suggesting the development of one pathway with permeable boundaries.

Stakeholders identified a need for more partnership working with other organisations but also less fragmentation and better coordination within WSCC. Even professional stakeholders found that it was often difficult to find the right person to deal with in WSCC. This would contribute to a stronger strategic direction for the Council.

Better communication and information sharing between (and within) health and social care and other services, to share good practice, provide holistic services and reduce barriers was recommended by a number of stakeholders. For example: '*We wish services would talk to each other and share information*' (2015 survey comment).

7.3 Waiting times and accessibility

A number of areas emerge as concerns in relation to waiting times and accessibility of services. In particular, stakeholders mentioned difficulties in accessing:

- CAMHS services
- Occupational therapy
- Social workers, and
- Speech and language therapy.

Professional stakeholders frequently mentioned that while services were generally good, they could be patchy, and the quality of access to services depended on location and disability. For example, there was perceived to be limited assessment, advice and provision within the county for young children with physical disabilities.

7.4 Transport

Concerns about transport in terms of availability and cost, particularly for those in rural areas, were mentioned by both professional stakeholders and families. For example, one professional stakeholder survey respondent commented on '*poor and expensive services from public transport*'. A need for travel training was mentioned by workshop participants.

7.5 Housing

There was a view among professional stakeholders of the need to identify who has strategic responsibility for housing for people with physical disabilities and the lack of a mechanism for influencing the range of accommodation options for people with lifetime disabilities. A number of professional stakeholders mentioned the current lack of housing provision for young adults with disabilities, and the need for better forward planning in relation to housing: '*Lack of new housing developments for people with disabilities, particularly learning disabilities*'. This appeared to relate to both those who met the criteria for local authority funded accommodation services and those who do not. Although there is some supported housing for young people with additional support needs, such as foyers; these are not perceived as suitable for young people with disabilities. They also may need support to develop independent living skills.

There was also felt to be a need to increase adaptations in the family home to support children and young people to live independently in their accommodation: '*there is a long wait for housing adaptations for children and young people with disabilities*'.

7.6 Training and employment

Professional stakeholders commented on the lack of support into employment and training for young people and adults with disabilities, including those with mild learning disabilities. For example, '*Accessing training and employment for young people post 16 with learning difficulties is practically impossible and there are no effective services offering appropriate support'*. Some stakeholder survey respondents were critical of Work Aid: '*Workaid just doesn't work (except for a limited few)*' and support from Job Centres for young people and adults with disabilities was described by one survey respondent as 'pretty woeful'. There was felt to be a need for specific support for specific abilities, for example, a lack of tailored services to help people with learning disabilities into employment. It was suggested that there was a need to provide a dedicated employment support service for young people and adults with disabilities and learning difficulties who want to work. There were also concerns about opportunities for training and employment among the adult population of people with learning disabilities.

7.7 Leisure activities and sport

Stakeholders identified a range of sport and leisure activities for children and young people with disabilities. The popularity of swimming was highlighted. Survey respondents commented that limited resources meant that it was difficult to provide ongoing, regular and affordable activities. Transport and access were also identified as barriers to taking part in sport, particularly in rural areas.

Reductions in the number of youth clubs have affected young people with disabilities, and workshop participants mentioned a gap in youth provision. However, the Compass Card was seen as potentially providing access to more activities, such as bowling.

7.8 Health

Professional stakeholder survey respondents highlighted concerns around access to continuing health care provision, and the need for greater awareness among generic health professionals about learning disability, some of whom were felt to lack understanding. A number of health-led services were mentioned by stakeholders at difficult to access including:

- Occupational therapy
- Speech and Language Therapy
- CAMHS - including services for children and young people with autism and their parents; challenging behaviour; and specialist services for children with physical disabilities.

Waiting time for a social care assessment by CAMHS was reported to be over 12 months. More resources were felt to be needed to work with families, for example, to help them learn sustainable strategies for managing behaviour and understand communication.

7.9 Short breaks and respite

Stakeholders considered that the development of short breaks services had been very positive. Professional stakeholders highlighted good work by the Short Breaks Team as one of the strengths of WSCC's services for children and young people with disabilities. Commissioning of Short Breaks activities were noted for involving parents/carers and young people. However, gaps were mentioned in relation to holiday playschemes, respite services in and out of the home, and respite for complex needs. In addition, more short breaks for children under 5 years old and young people aged 18 an above were felt to be needed.

7.10 Welfare benefits

Professional stakeholders mentioned the specialist benefits advice available to families of children with disabilities as a good service. However, welfare reforms were felt to have made it more difficult to claim benefits and placed additional demands on the service which is struggling to meet demand. It was felt that the welfare reforms were having a significant impact on those with lower level needs.

7.11 Advice and information and the Local Offer

A 2011 West Sussex County Council survey of almost 600 parent-carers demonstrated that information is the biggest barrier to them accessing services and support. Since then, the Local Offer has been introduced in West Sussex. There were mixed views about the Local Offer. Although the website was seen by some stakeholders to be a very good source of information, some professionals thought it was still relatively new and people were not yet engaging with it. For example: '*Local offer starting to be more* *effective - still gaps but work happening to fill them and parents feedback if received will be valuable*' (Professional stakeholder survey).

Although the Local Offer was widely perceived as improving access to information about available services, parents and professionals commented on the difficulty of finding out what help and support is available (including welfare benefits). For example, '*I have generally found it hard to find information, eg, direct payments, or about the one-off carers' grant for a break. It was only through friends that I found out.*' (2015 survey comment) and similarly: '*Can be difficult to find out information unless families know where to look for it*' (Professional stakeholder survey). There was perceived to be a need for better signposting.

7.12 Workforce

Professional stakeholder survey respondents were asked how easy or difficult it was to recruit and retain staff. Forty per cent reported that it was difficult to recruit staff and nearly one-third (32%) reported that it was difficult to retain staff.

Answer Options	Very easy	Easy	Neutral	Difficult	Very difficult	Response Count
Recruit staff	3%	27%	30%	33%	7%	30
Retain staff	6%	41%	22%	19%	13%	32

Source: IPC Survey

Survey respondents mentioned high turnover and relatively low salaries as concerns. Specific skill shortages were mentioned including Occupational Therapists, Speech and Language Therapists, and Level 3 qualified staff. For example: '*Shortage of qualified occupational therapists and WSCC salary scale is less than surrounding organisations*' and '*Occupational Therapists can earn more in adjacent counties and in the NHS*'. Opportunities for career progression were seen as problematic. Providers mentioned difficulties in recruiting and retaining staff, particularly in Horsham and Crawley, in the north of the county, and in the very rural areas.

7.13 Other points

A number of other points were made in feedback on current services and future needs:

- IT issues were mentioned by one professional stakeholder as a potential problem in developing a more joined up understanding of needs – across housing, health and social care. For example, EHC plans are currently not on the Framework-i system.
- Participants in the professional stakeholder workshops mentioned a need for more support to the siblings of children and young people with disabilities, echoing a parent's comment: '*I would like to see more support for siblings of disabled children*' (2015 survey comment).
- There was little mention of hard to reach groups in the various engagement exercises undertaken as part of this needs assessment. However, a couple of stakeholder survey respondents did comment that language was a barrier to accessing existing services for some groups, (particularly in the Crawley area).

- There was some concern about the availability of services for children below the threshold of support for Child Disability Team with lower level needs and the availability of suitable support from Family Support social workers.
- One stakeholder survey respondent identified a general gap in services for 18-25 year olds with a disability. This could include participation in leisure and social activities such as clubs.
- Provision for children with behaviour difficulties was mentioned as a gap by one stakeholder survey respondent.
- One professional stakeholder identified a lack of fully accessible facilities in the County which needs to be considered in the future planning of all provision.

7.14 Life pathway

Professional stakeholders were asked for their views about the life pathway approach. Respondents emphasised the need for a smoother, more joined up transition to adulthood. A range of suggestions to improve the pathway to adulthood included:

- A dedicated team of staff supporting people with disabilities from birth to adulthood;
- The first person involved with the child or young person taking on the role of key worker to plan and provide support along the pathway;
- Stronger integration with a multi-disciplinary team working together to create joint goals and enabling fluid pathways.

7.15 Summary of engagement with parents and young people with disabilities

The interviews conducted individually and in groups with parents and young people reinforce the key findings noted above. A number of questionnaires were also completed, the comments from which further underline a picture of what parents and young people feel would improve the quality of service delivery and provision at a strategic level by West Sussex County Council which include the following:

- Making sure that the views of children, young people and families are listened to.
- Overcoming the organisational and cultural differences between services.
- Building a picture of services/interventions/support that people will need over the course of their lives – the life pathway.
- Ensure you have appropriate and clear transition arrangements. These include transition between services or systems not directly under the council’s control.
- Develop relationships with key partners to ensure there is a range of learning, work, and leisure opportunities to meet local need.
- Ensuring there are ways of measuring outcomes for young people at the transition stage and that these are used in commissioning for choice and improvement of services.
- Encouraging an integrated approach to direct payments and personal budgets to support transitions from children’s to adults’ services.

8 Conclusions

The comprehensive needs assessment brings together a wide range of data and information related to people with disabilities and the life pathway from birth to adulthood. The results of the needs assessment provide an estimate of current and future need, and highlight a number of gaps and areas for development in current services.

Estimates of the current and future numbers of children and young people with disabilities indicate that although there are over 15,000 children and young people in West Sussex with a long-standing illness or impairment which causes substantial difficulty with day-to-day activities, the number with needs which will require a care service is much lower. Depending on the approach and definition used, this may range from between 131 children and young people living with a severe longstanding illness or disability aged 0-19 years old[7] and 862 with a severe learning difficulty aged 0-19 years old and 212 with a profound and multiple learning difficulty aged 0-19 years old[8].

The number of children and young people with a disability aged 0-24 years in West Sussex is projected to increase by 8.6% in the next 20 years, concealing increases of 17% for those aged 10-14 and 13% for those aged 15-19 years old. In addition to the overall increase in numbers, continuing developments in medical technology will result in a growing number of children and young people with complex needs, while improvements in diagnosis and growing awareness of ASD will also result in growth above the trend. This is likely to put greater pressure on services, particularly those for more intensive support.

There appear to be a large number of children and young people in out of county placements in independent and non-maintained special schools (INMSS) – possibly reflecting a lack of availability of placements in-county for these groups of children and young people. The most costly group in terms of the total cost of residential placements are: 83 children and young people with ASD; followed by 105 with social, emotional and behavioural difficulties; 66 with speech, language and communication difficulties; and 55 with physical difficulties. Given the projected increase in the number children and young people with disabilities of 8.6% over the next twenty years, placements of children and young people with ASD in INMSS will increase further, and the cost of care for this group will increase, if the level and type of service remains unchanged.

In terms of the life pathway and transition to adulthood, there are a number of areas where improvements appear to be needed. There appears to be a gap in information and guidance for parents and families around the time of diagnosis of disability. There is also a need for better coordination and information to enable WSCC to identify, prepare, and plan for young people with disabilities as they move towards adulthood: out of 333 children in Year 9 with a SEN statement, only 81 were known to social services.

Linked to this is an apparent need for greater consistency for all groups of children and young people in transition, such as those with physical disabilities where there is not necessarily an educational need, Children who are Looked After and those returning

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[7] ONS/Family Fund Trust/ChiMat
[8] Emerson and Hatton's Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England (2008)

from out of county residential placements funded by education. Current arrangements appear to be patchy.

More information for parents would help to address the issue of managing parental expectations as young people move into adulthood. There is a large difference perceived between what is available to children and young people with disabilities, and what is provided to support adults with disabilities. This is illustrated in the differences between the personal budgets available at the different points on the pathway. Peer mentors or buddies were suggested as a helpful way to support parents and young people through the transition to adulthood.

However, more work is also needed on how to develop a seamless service which will include closer partnership working between social care, health, education in particular, but also housing, training and employment, leisure and transport services. The need for better coordination within WSCC has emerged in order to deliver a more joined up service (and illustrated in the development of the needs assessment).

As part of improving the life pathway for people with disabilities, there is a need to develop more housing opportunities for young people with disabilities, both through new developments and through adapting existing homes to make them more accessible and appropriate to their needs.

Equally, there appears to be a gap in training and employment support for young people and adults with disabilities in West Sussex which is illustrated by the comparatively poor employment outcomes for adults with learning disabilities in the national ASCOF data.

Changes in welfare benefits are likely to affect many children, young people and adults with disabilities, particularly those with lower level needs. Current specialist benefits advice is stretched and there is a perceived need to provide more resources for this service, given recent and ongoing welfare reforms which are affecting people with disabilities.

There were perceived gaps in the availability of particular services for children and young people with disabilities. These were identified as the CAMHS service, Occupational Therapy, Speech and Language Therapy, Qualified Social Workers. This may reflect wider issues around the recruitment and retention of appropriate staff. Difficulties appear to reflect competition from better paid posts in neighbouring authorities (for occupational therapy) and in areas of high employment such as near Gatwick (for carers).

The rurality of some parts of the county affects the level of service provision and the accessibility of services. Much of current provision is along the coastal fringe and in the northern part of West Sussex. Given the rurality of the county, the cost, reliability and regularity of transport are a concern for those in rural areas and small towns. Lack of transport for children, young people and adults with disabilities may contribute to social isolation.

Conducting the needs assessment indicated some gaps in information and data in relation to children, young people and adults with disabilities. In particular, the age and nature of disability of people receiving a service were not always known or easy to establish. There was little information available related to health, housing, and transport, and there were also concerns about data quality which were highlighted by some of the data obtained through NASCIS.

This needs assessment was part of the ‘discover phase’ of a longer term project to support the redesign of services over the next three to five years. With the results of this phase of the work, it is recommend that WSCC now moves on to explore the options which would best address the needs identified and help to improve the outcomes along the life pathway of children and young people with disabilities.