

West Sussex County Council

Current Services and Comparative Report

May 2016

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1 Understanding current service provision for children and families

1.1 An overview of local services

This report presents data on current service provision and some information about service use, along with comparative data which is primarily provided by schools concerned with SEN. The primary focus is on services for children and young people with disabilities and their families, as there is limited data available specific to adults with lifetime disabilities, as distinct from adults with disabilities in general.

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.

Data issues - Activity is not broken down into Children and Adults across the board and we are not able to identify the cohort within the adults activity of who acquired their disability under the age of 25.

2 Social care

2.1 Looked after children

According to Sloper¹ disabled children in the population of Children Looked After (CLA) are more likely to experience abuse than their non-disabled peers - those with multiple impairments are particularly vulnerable. Disabled children in the CLA population are also more likely to be placed in residential settings.

In West Sussex, there are 129 CLA with a disability, representing 4% of all children looked after by the Council (Table 1). 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).

¹ Sloper T (2003) 'Meeting the needs of Disabled Children' Quality Protects Research Briefings (no 6) Research in Practice Available at:
<http://www.whatworksforchildren.org.uk/docs/Briefings/Disability%20Briefing.pdf>

Table 1: 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
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

Most children in residential care are cared for WSCC's own care homes.

2.2 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).

2.3 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).

Half of all out of county placements (50%) are within five kilometres of the child or young person's home; while about 10% involve journeys of more than 20 kilometres from the family home.

2.4 Children in need

When a child is referred to children's social care, an assessment is carried out to identify if the child is in need of services, which local authorities have an obligation to provide under section 17 of the Children Act 1989. These services can include, for example, family support (to help keep together families experiencing difficulties), leaving care support (to help young people who have left local authority care), adoption support or disabled children's services (including social care, education and health provision).

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 2). 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.

However, the proportion of school age children in need with SEN is higher in West Sussex (64%) than the average for statistical neighbours and for England (Table 3).

Table 2: 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

Table 3: Percentage of school-age Children in Need with SEN

Statistical Neighbours	2012	2013	2014	Change between 2013 and 2014
South Gloucestershire	55.00	46.70	49.50	2.80
Bath and North East Somerset	59.20	54.90	51.60	-3.30
Gloucestershire	65.30	53.70	53.90	0.20
Leicestershire	55.50	66.80	54.50	-12.30
Hampshire	65.20	60.30	56.90	-3.40
Dorset	63.40	58.90	57.00	-1.90
Poole	58.50	58.50	58.50	0.00
Worcestershire	69.50	65.10	60.30	-4.80
North Somerset	62.60	60.40	60.60	0.20
Essex	64.50	64.30	63.20	-1.10
West Sussex	74.80	64.70	64.20	-0.50
Statistical Neighbours	61.87	58.96	56.60	-2.36
England	61.00	57.90	54.70	-3.20

Source: Local authority interactive tool, December 2015

3 Disabled Children's Service

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.

The typical conditions include CYP with a severe learning or significant physical disability, moderate/severe autism with a learning disability, health conditions which are life limiting, degenerative or technology-dependent. In addition to the above, these needs must be complex, linked to the CYP's additional needs and disabilities needs and include the following additional factors:

- Normal daily activities interrupted by frequent health needs, affecting progress in education and independence.
- Needs on-going, intensive support with behaviour to help maintain safe relationships with family and friends².

The services provided include:

- Personal budgets or direct payments to families
- Day-time and overnight short breaks in a Local Authority residential unit
- Tailored packages of support either in the family home or in the local community where the CYP's needs are more complex than can be met by targeted services.

3.1 Personal budgets and direct payments

Families with children and young people who meet the criteria for CDT have the right to request a personal budget and they can take the sum of money identified to meet the outcomes agreed in the child or young person's care plan as a Direct Payment. Direct Payments are paid to parents of disabled children and disabled young people aged (16-17) to arrange their own care and support.

Direct Payments can be used to pay towards support and equipment that the local authority or NHS have agreed is needed following an assessment, e.g. home care, befriender or short breaks services. Parents and young people in receipt of direct payments are responsible for:

- arranging the support they need
- sorting out any problems with the support and who provides it
- evidencing how they use the money
- agreement to spend the money only in ways that keep the child safe and well.

Parents and young people can use the money to employ their own staff. If they choose to employ staff, they have additional responsibilities (eg, legal responsibilities of an employer) and the staff they employ report directly to the parents/young people. Recipients of Direct Payments are signposted to a range of organisations that can offer independent advice and help with direct payments.

² WSCC Short breaks statement

For example, Independent Lives provides support to around 2,000 working age adults with Direct Payments including managed bank account and payroll services in West Sussex. (In Hampshire Independent Lives are involved as partners in an integrated personal commissioning pilot).

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

Table 4: 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

3.2 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 CDPare – 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.

WSSCC launched a Personal Budget Facebook page to connect families together on the bases of shared interests, not just shared disability.

Table 5 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 5: 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

3.3 Short breaks provision

Short breaks provide opportunities for disabled children and young people to spend time away from their primary carers. They provide an opportunity for carers to recharge their batteries and to allow disabled children and young people the experience of new relationships, environments and positive activities. Table 4 indicates that in November 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. The Fun and Breaks Service currently has 90 children on its waiting list. It is not known how this breaks down in terms of length of wait or reason for wait.

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. Families who are in receipt of either the middle or high care component of Disability Living Allowance (DLA), or the standard or enhanced rate of Personal Independence Payment (PIP) for their CYP with additional needs and disabilities will qualify for services automatically. For families who have CYP with similar levels of need, but are not receiving DLA/PIP, short break providers have a simple assessment form to assess eligibility.

In terms of eligibility criteria, all short break referrals come through the Child Disability Social Work teams (and very rarely from non-CDT teams). Threshold criteria for the Child Disability Teams are severe and profound disabilities where the need is for specialist social work intervention.

During 2011, WSSCC went through an open tender process (a legal process for agreeing contracts between organisations and the Council) to deliver short breaks services across West Sussex. There are now 31 contracts in place with 20 different

organisations ranging from small local voluntary groups to larger voluntary sector providers. The contracts run until March 2016.

Three units provide full-time, shared and short breaks care to children aged between approximately 8 and 18 with severe learning disabilities (Cissbury Lodge, Orchard House and High Trees):

- Cissbury Lodge (Worthing) is specifically adapted to meet the needs of young people who have additional physical disabilities and can provide short and long-term care to children with complex health needs.
- Orchard House (Cuckfield) is a fifteen bedded mixed gender unit which offers short breaks and respite for children with learning disabilities aged 12-19 and day service provision for children under the age of 12. Currently 23 children and young people received services at Orchard House.
- High Trees (Crawley and Horsham) is generally for up to 6 children with a significant learning disability and degrees of behaviours that families/carers find challenging.

And also:

- May House (Worthing) provides care for up to three children between 8 and 12 on admission for periods of up to 18 months. The children accessing the service have complex learning disabilities, high levels of challenging and complex needs, and are at risk of exclusion from existing social care and educational resources. A multi-disciplinary team supports them to be able to once again access local services and reduce the risk of needing to be placed in an external, often distant, placement.

In 2015, WSCC funded 21 organisations to deliver 26 Short Break contracts. Funding covers the following four areas:

- After school, weekend and holiday clubs
- Buddy Schemes
- 1:1 (or 2:1 where required) support to enable Disabled Children and Young people to access activities
- Sports, leisure and recreation

An evaluation in January 2014 found that Short Break Providers support nearly 1,500 families.

There are a number of respite services provided by the voluntary sector, for example:

- Chestnut Tree Community Team - Chestnut Tree House near Arundel have a team of nurses and care support workers who provide support to families of children with life limiting or life threatening illnesses at home and in the community. Types of support include at home respite care, clinical nursing care, overnight respite care at the hospice, end of life care, pre and post bereavement support, etc.
- Sussex Snowdrop Trust - provides care at home to children with life threatening or terminal illnesses. The trust's catchment area runs along the coast from Chichester

to Portsmouth and is as far north as Billingshurst. The Care at Home Team is based at the Westhampnett Centre in Chichester. Children are usually referred directly from hospital.

3.4 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. The team visits children in their home, providing support and advice to parents so that you can monitor your child's development. Most referrals come through the health service; however the service also takes referrals from parents, schools and other services that may be involved.

The team covers children within the SEN Pre-School or School Support group and children with a Statement of Special Educational Needs (SEN) or an Education, Health or Care (EHC) Plan who attend a West Sussex-maintained mainstream primary, secondary, or special school, academy or free school.

Any child with a diagnosis of sensory impairment can be referred to the team for support. This includes children whose hearing thresholds are at least in the mild, moderate, severe or profound levels of hearing loss as diagnosed by an audiologist. For children with visual needs, their vision would be less than 6/12, diagnosed by an eye clinic and not correctable by glasses.

Rehabilitation and mobility officers (RMOs) provide specialist input to children with visual impairments focussing on mobility including orientation, long cane skills and route training, as well as independent living skills; anything from pouring drinks, making cakes to dressing and appropriate social skills.

The service holds regular meetings with audiologists, speech and language therapists, paediatricians, orthoptists, portage and social care to ensure that up-to-date information is shared between professionals.

3.5 Community equipment

The Children's Access Point Team can make referrals for specialist equipment for children with hearing impairments. The team support and arrange for specialist equipment to help a child to live safely and independently in their home. The team have the relevant skills and experience to support daily family life, such as giving advice and providing services to children with significant hearing loss.

4 Transitions

The Community Learning Disability Team (CLDT) runs transition for young people with learning disabilities. This is a relatively new team which is well regarded. Transition tracking meetings are held in the north and south of the county. The best route/pathway for children known to the disability teams is discussed at these meetings. However, 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 pathways for that group are perceived to be haphazard.

Currently, there is not a dedicated transition team in WSCC, although the Council is working to ensure that Adult Services comply with the Care Act and the Children and Families Act in relation to transition. As part of Care Act assessment responsibilities, WSCC has wider duties to carry out assessments for young people under 18 years old. 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 Plans.

In Year 9, there are 333 children 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 (in February 2016). The majority are likely to receive information and advice only, but there is a challenge to find out how to contact them, offer assessment and resource it.

5 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 25 or under
- Coastal Enterprise, Worthing - 9 customers 25 or under
- Oaks/Pines, Worthing - 12 customers 25 or under.

In addition, there were 41 people with learning disabilities aged 18-24 in short stay residential care in 2015; 102 receiving Supported Living provision, and 163 receiving day services (aged 18-24).

An update of local data on Adults with a Learning Disability provides a detailed analysis of service level data³.

5.1 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. This represents about 10% of the client group using the service. Across all ages of

³ West Sussex JSNA Update of Local Data, Sept 2015, Adults with a learning disability, WSRU.

people with a learning disability, total numbers appear to have fluctuated considerably over the last three years.

5.2 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 two WTE occupational therapists and 6.5 WTE 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.

5.3 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 Health

6.1 Continuing Care

The National Framework for Children and Young People's Continuing Care sets out an equitable, transparent and timely process for assessing, deciding and agreeing bespoke packages of continuing care for those children and young people under the age of 18 who have continuing care needs that cannot be met by existing universal and specialist services alone. It describes how local organisations, including health and social care, should work together to assess need and put in place packages of continuing care.

In West Sussex, the Continuing Care service provides:

- Continuing care at home - nursing and care support in the home for children with complex health needs
- Health-led Short breaks - nursing and care support away from home at the Cherries for children with complex health needs. The Cherries is a purpose-built, five bedroomed bungalow providing a respite care facility for children aged 0-19 in Chichester and surrounding areas with severe to profound learning difficulties, life threatening illnesses and associated healthcare needs.

All children accessing these services are eligible for NHS Continuing Health Care.

6.2 Speech and language therapy for children

The Speech and Language Therapy service for children in West Sussex is delivered through an Early Years team (0-5 years); School team (5-19 years); and a Complex Needs team. Drop-in clinics based in local Children and Family Centres are also provided. Staff are based in Lancing, Horsham and Chichester.

6.3 Physiotherapy for children service

There are three teams of children's physiotherapists who see patients in a variety of settings including their own homes, mainstream and special schools, and as outpatients covering Worthing, North and West Sussex.

The teams work in the following healthcare areas:

- Musculoskeletal (0-16years)
- Orthopaedics (0-16years) Neuromuscular conditions (0-19years)
- Neurodevelopmental conditions (0-19years)
- DCD
- Hypermobility

These teams are based at the Westhampnett Centre; Hilltop Children's Unit, Horsham Hospital; and Worthing Hospital.

6.4 Occupational therapy for children

Three health OT teams provide assessment and therapy to help children develop life skills and increase their participation in school. They work with children who have a variety of difficulties including children with developmental delay, learning difficulties, physical difficulties, sensory or coordination problems. Children are helped to develop play and self-care skills such as dressing, eating and drinking, washing and toileting, and can help children achieve their potential in school by developing their fine motor and coordination skills.

The teams are based in Chichester, Worthing and the North part of West Sussex (Nightingale, Crawley and Horsham).

6.5 Children's community nursing

There are three teams of specialist community children's nurses and learning disability nurses who provide advice and direct nursing in the community in West Sussex. They provide out of hospital care for children who are ill or who require nursing to enable them to stay at home or school. This includes babies, children and young people who have:

- A long term health condition
- Complex health needs and disability; including requiring continuing care
- A life- limiting and life- threatening illness, including requiring palliative and end of life care

The Crawley team includes Allergy, Diabetes and Cystic Fibrosis Community Nurse Specialists. The Snowdrop Care at Home team is based in Chichester, providing nursing care at home for local children who have a life-threatening illness or who may be terminally ill.

6.6 Complex Behaviour Support Service

The Child and Adolescent Mental Health Service/Child Disability Service (CAMHS /CDS) Complex Behaviour Support Team specialises in working with young people with moderate/severe learning disabilities and behaviours which can be described as presenting a challenge to their families/carers and carers. The team provides two ways of working: network consultations and direct case work.

7 Education and childcare

WSSC's approach to education and childcare for children and young people with disabilities is to promote:

- The view that the majority of children with SEN will be successfully included in settings without special resources or enhanced staffing
- The use of WSSC's website for guidance
- Staff engagement with continuous professional development
- On-going use of assessment and adoption of the graduated approach
- Direct referral to other agencies e.g. Speech and Language Therapy
- The use of all available data on children and families by Early Childhood Service staff to ensure that the right resource is deployed in the most effective way.

The SEND code of practice provides guidance relating to early years children with SEN:

- Providers must have arrangements in place to support children with SEN or disabilities
- Local authorities should ensure that there is sufficient expertise and experience amongst local early years providers to support children with SEN
- Local authorities must ensure that all providers delivering funded early years places meet the needs of children with SEN and disabled children. In order to do this authorities should make sure funding arrangements for early education reflect the need to provide suitable support for these children
- Early years providers should consider how best to use their resources to support children with SEN.

7.1 Early Childhood Service

The Early Childhood Service Inclusion Team offers training and advice to early years and childcare settings in developing inclusive practice.

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

7.2 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.

Each hub hosts a ‘Play and Learn Plus’ parent and child group offering opportunities for children to play and parents and carers to meet each other. 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).

7.3 Playgroups

All playgroups and nurseries are expected to welcome children with special educational needs, but their experience and facilities vary. 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:

- Windmills is a long established charity playgroup run by trustees which has been operating in Burgess Hill since 1984.
- Opportunity Playgroup is a charity pre-school managed by a parent committee, and run by a qualified staff team. The playgroup was founded in 1980 and was primarily for children with Special Educational Needs (SEN) who were unable to access mainstream nursery. The playgroup has since adopted a mainstream status.

Scope run a day nursery in Ingfield in Billingshurst for children from three to five years old with physical impairments and associated learning difficulties.

7.4 Children and family centres (CFC)

There are 48 Children and Family Centres in West Sussex: of which eight are managed by WSCC. It is not known what data the CFCs hold on the number of children with disabilities or families with children with disabilities that use the CFCs.

7.5 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.

8 Information, advice and guidance

Research highlights the needs of parents for information and services, about their child's condition, and about how they can support their child's development. Children also speak of the need for information about their condition, treatment, about how to live with the condition and how to overcome disabling barriers.

Evidence suggests that care co-ordination should ensure that families' needs for information, advice and help are identified and addressed. Particular areas covered should include financial support e.g. help with claiming benefits, aids and equipment, housing adaptations, behaviour problems and support for all family members' needs.

A national exercise carried out with parents identified a three dimensional model of good practice:

- Short directories of local services and support networks, which are regularly updated
- More in-depth and informative booklets covering local and national services.
- Support for locally based facilitators or key workers to guide parents through information.

8.1 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.

8.2 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, which may involve:

- organising additional support to attend visits with you when looking at different childcare options
- making sure that your chosen childcare provider can meet your child's specific needs and give you peace of mind that your child will be looked after by people with the right training and equipment
- putting additional resource in place if necessary so that all children at a nursery, playgroup or childminder can play and learn together.

Additional information is available through Reaching Families. This third sector organisation provides factsheets on different disabilities and these are available on line and at CDCs. They also produce 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). They are in partnership with Amaze to produce more fact sheets.

9 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.

To be eligible for PIP, applicants must:

- Be aged 16-64
- Pass a residence and presence test
- Pass a daily living and/or mobility activities test for a 'qualifying period' of at least three months and be likely to continue to satisfy whichever test applies for a period of at least nine months after that three month period, unless terminally ill.

In July 2015, there were 393 young people aged 16-24 receiving PIP across West Sussex (Table 6). Arun district has the highest number of young people receiving PIP (94) in the county.

Table 6: 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
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.

To be eligible for DLA, applicants must:

- Be under 16
- Pass at least one of the disability tests
- Pass the qualifying period condition
- Pass the residence and presence tests.

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 7) 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 7: 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

DLA was commonly based on self-assessment, whereas eligibility for PIP includes a test carried out by a private company on behalf of the government. Money is allocated according to a points system and eligibility is kept under regular review. 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.

WSSCC 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.

10 Play, sport and leisure activities

Disabled children and young people do not participate in sport and leisure activities as much as non-disabled children. Older children in particular report difficulties accessing social and leisure facilities. A lack of inclusive activities can lead to boredom and loneliness and means that disabled children spend more time at home and more time watching television than non-disabled children⁴. There is a need to engage young disabled people as early as possible whilst they are still in compulsory education, as it becomes much harder to engage with individuals at an older age⁵.

10.1 Play

The third sector plays an important role in providing opportunities for play and other activities for children and young people in West Sussex. For example:

- The Springboard Project is a community based charity that provides inclusive play and leisure opportunities for families with young children and fun short breaks for children and teenagers with disabilities. There are centres in Horsham and Crawley. The centres are accessible with ceiling hoists and changing facilities and the Horsham centre also has a lift.
- PACSO currently supports 150 families who have a child with a disability in the Chichester and Arun districts. They do not require a formal diagnosis, but rather seek to support the individual and varying needs of each family. PACSO currently works with children who are aged between 0 and 19 years who have a disability or additional need. They provide 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. PACSO is based in Chichester (<http://www.pacso.org.uk/localoffer.html>).
- Kangaroos provide short breaks opportunities for children and young people with learning disabilities aged 6-19 years to have fun, interact with their peers, learn new skills and enjoy new experiences independently of their families.

10.2 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. Activities include:

⁴ Sloper T (2003) 'Meeting the needs of Disabled Children', Quality Protects Research Briefings (no 6) Research in Practice.

⁵ NDSOS (undated) Active Beyond Education.

- Out There! West Sussex is a programme of daytime, evening and weekend leisure activities and sports choices for people with learning disabilities, currently running all over West Sussex. Participants are encouraged to become coaches.
- Middleton Sports Club is working hard to be inclusive and accessible for disabled people of all ages. Over the last two years they have been supported by Veolia and West Sussex County Council Short Breaks team and spent over £100,000 to provide better access, permanent ramps, automatic doors, accessible toilets and much more. They are now building on these accessible facilities with new events and participation opportunities for disabled people. Middleton has been holding inclusive sports days, disability cricket matches and wheelchair tennis.
- Cobnor Activities Centre operates a chair boat for children and young people to take part in water-based activities. The Centre also runs other specific activities with students from Chichester University.
- Lodge Hill Park, Pulborough is an outdoor centre which is developing inclusive activities for families with children with a disability.
- South Downs Leisure Centre, Worthing are actively working to provide more opportunities for people with disabilities.

10.3 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 data (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/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. Disability is not recorded.

10.4 Compass Card West Sussex

The Compass card 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. Usually that means they will be eligible for DLA (Disability Living Allowance) or PIP (Personal Independence Payment) and/or have an EHC (Education Health and Care) or Moving On plan.

WSCC has awarded the contract for the card (as well as for a Disability Register) to Amaze and the scheme will be launched in April 2016. Families who register will receive regular newsletters, updates and offers attached to the discount card. The card will provide special deals at many venues.

11 Transport, housing and employment

11.1 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.

There is a gap in information about transport and travel training for children and young people with disabilities.

11.2 Housing

The sorts of problems with housing most frequently reported by families include lack of family space, and lack of space for storing and using therapeutic equipment. Other common problems are difficulties with location and unsuitable or inaccessible kitchens, toilets and bathrooms. Improvements in families' housing situation can lead to increased independence, more confidence and greater self-reliance among disabled children. However, families can experience significant difficulties accessing support and services to help them address the problems with their housing⁶.

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

⁶ Joseph Rowntree Foundation June 2008 Housing and disabled children: round up

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.

11.3 Employment

Young people with disabilities are likely to find it more difficult to obtain employment than other young people. Nationally, the proportion of learning disabled people known to social care who were in paid employment was 7% in 2013-14⁷. 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 8).

Table 8: Number of statemented young people who are also Not in Education, Employment or Training (NEET)

	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. Different schemes have different eligibility criteria and there and support from. The WorkAid scheme delivered by the Aldingbourne Trust 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 set a target to create 40 jobs that are suitable for people with learning disabilities and ASC, which it has now achieved. This includes a pool of

⁷ Department of Health (2014) The Adult Social Care Outcomes Framework 2015/16

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.

Managers were supported to identify jobs that could be 'carved', easy read application forms and an easy read employment handbook were developed. WSCC also prepared staff teams for a team member with a learning disability or ASD. The Council work with WorkAid to promote vacancies and help with induction and training.

Interviews with people who obtained WSCC jobs show that for the individuals concerned, the scheme has been extremely positive. Interviewees talked about enjoying feeling that they were doing something useful and feeling part of a friendly team. Having a job seemed to have a wider positive impact than just being happy in the workplace. People talked about developing better social skills and feeling more confident in their lives in general. Interviewees also liked the extra money that being paid provided and the opportunity that this gave to become more independent.

12 Comparator information

Table 9 presents data on the number of children known to schools with learning disabilities and autism (Note that the dataset uses learning difficulty and learning disability interchangeably).

The proportion of children with profound and multiple learning difficulties is 1.03 per 1,000 pupils compared with the comparator average of 0.95 per 1,000 pupils.

Table 9: Children known to schools, 2013-14, West Sussex and comparators

Authority	Children with autism	Children with learning disabilities	Children with moderate learning difficulties known to schools	Children with severe learning difficulties	Children with profound & multiple learning difficulties
West Sussex	916	2,099	1,601	375	123
Devon	804	-	1,061	352	-
Dorset	725	-	648	124	-
East Sussex	683	-	814	240	-
Essex	1,702	6,542	5,305	1,033	204
Gloucestershire	415	-	879	539	-
Hampshire	886	3,620	2,744	743	133
Hertfordshire	1,477	2,527	1,898	498	131
Kent	3,741	3,613	2,541	789	283
North Yorkshire	679	910	638	194	78

Authority	Children with autism	Children with learning disabilities	Children with moderate learning difficulties known to schools	Children with severe learning difficulties	Children with profound & multiple learning difficulties
Oxfordshire	917	-	2,211	363	-
Staffordshire	1,400	-	2,164	541	-
Suffolk	883	2,074	1,616	368	90
Warwickshire	734	-	1,714	538	-
Worcestershire	687	2,524	2,078	333	113

Source: Public Health England

Blank spaces indicate where values have been suppressed for disclosure control due to small count

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.

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

Authority	Pupils with statements or EHC plans - % of total pupils	Pupils with SEN support – % of total pupils	Total pupils with SEN - % of total pupils
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

Although not directly comparable as the data relate to statistical neighbours rather than comparator authorities, Table 11 indicates how SEN weekly unit costs have changed since 2010-2011. Spending 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. 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 (\$251)	2012-13 (\$251)	2013-14 (\$251)	2014-15 (\$251)	2015-16 (\$251)
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
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>

13 Costs

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

Budget at 1 st 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

Children with disabilities aged 0-16 years old in West Sussex are the fastest growing group amongst the population of people with disabilities. 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. The figures in the Medium Term Financial Strategy explain that based on the current overspending patterns the pressure on this area will increase by £1.4m 2015/16, and an ongoing estimated increase of £0.5m each year thereafter.

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.

According to the national returns on local authority expenditure for 2014-15⁸, the weekly unit costs of long-term care for those aged 18-64 for physical care or sensory support were 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 were 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.

⁸ Personal Social Services: Expenditure and Weekly Unit Costs (£), England - 2014-15, Final Release: Mandatory Activity Data by CASSR - Long Term, NASCIS Online Analytical Processor.