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West Sussex County Council

Qualitative Report

Report

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Qualitative Report

1 Qualitative results

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.

A full list of those taking part in the workshops and interviews is provided at the end of the report.

The findings from the qualitative work are presented thematically reflecting the range of areas where needs were identified.

2 Findings

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.

As part of the survey of stakeholders, respondents were asked '*How well or poorly do you think the needs of children and young people/adults with disabilities in West Sussex are met in terms of..*' key elements of the life pathway for people with disabilities. Survey responses, although relatively small in number, indicate a concern about how well WSCC is meeting the needs of children, young people and adults with disabilities, particularly in terms of housing, transport, training and employment and social care (Table 1). Health, advice and information, and social and community activities elicited a more positive response. However, many respondents were neutral in their response.

Table 1: How well or poorly do you think the needs of children and young people/adults with disabilities in West Sussex are met in terms of...?

Answer Options		Very well	Well	Neutral	Poorly	Very poorly	Response Count
Social care	Children and young people	2%	42%	38%	16%	2%	45
	Adults	6%	46%	11%	29%	9%	35
Health care	Children and young people	2%	50%	34%	11%	2%	44
	Adults	3%	37%	37%	20%	3%	35
Training and employment	Children and young people	0%	16%	66%	16%	2%	44
	Adults	0%	17%	46%	29%	9%	35
Housing	Children and young people	0%	18%	56%	24%	2%	45
	Adults	0%	26%	44%	18%	12%	34
Social and community activities	Children and young people	7%	40%	40%	9%	4%	45
	Adults	0%	37%	40%	14%	9%	35
Transport	Children and young people	0%	25%	57%	14%	5%	44
	Adults	3%	20%	60%	9%	9%	35
Advice and information	Children and young people	4%	40%	44%	9%	2%	45
	Adults	3%	42%	42%	9%	3%	33
Other	Children and young people	7%	22%	63%	7%	0%	27
	Adults	5%	14%	62%	10%	10%	21

Source: IPC Survey

2.1 Engagement of families and carers in shaping services

Professionals considered that there is a strong parents' voice and consultation in WSCC, particularly through the Parent and Carer Forum which is active.

However, as part of the stakeholder survey, respondents were asked: 'In West Sussex, how well or poorly do you think children and young people/adults with disabilities and their families/carers are engaged in shaping the way services are commissioned and delivered. The responses indicate that about one-third of stakeholders think WSCC engages well with children and young people with disabilities in shaping the way their services are commissioned and delivered, compared with 18% who thought that WSCC engages poorly (Table 2).

Table 2: In West Sussex, how well or poorly do you think…..?

Answer Options	Very well	Well	Neutral	Poorly	Very poorly	Response Count
Children and young people with disabilities and their families/carers are engaged in shaping the way services are commissioned and delivered	2%	31%	50%	11%	6%	36
Adults with disabilities and their carers are engaged in shaping the way services are commissioned and delivered	0%	12%	70%	12%	6%	33

Source: IPC Survey

2.2 Person-centred planning

In the 2015 survey of parents and carers of children with SEN and disabilities, parents and carers reported 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).

As part of the stakeholder survey, respondents were asked: 'In West Sussex, how well or poorly do you think person-centred planning for children and young people/adults with disabilities and their families/carers is addressed?'. The responses indicate that a greater proportion of professional stakeholders think that person-centred planning is being addressed well (than poorly), although the maximum is only 50% in relation to children and young people (Table 3).

Table 3: In West Sussex, how well or poorly do you think…..?

Answer Options	Very well	Well	Neutral	Poorly	Very poorly	Response Count
Person-centred planning for children and young people with disabilities and their families/carers is addressed	6%	44%	33%	14%	3%	36
Person-centred planning for adults with disabilities is addressed	3%	44%	34%	6%	9%	32

Source: IPC Survey

Stakeholder survey respondents highlighted a number of service areas which they considered to be operating in a very person-centred and outcomes focused way, including the integrated Community Learning Disability Team, Adults with Autism, Portage, Educational Psychology, Sports Disability Team, and Occupational Therapy services.

2.3 Transition

In the workshops for professional stakeholders, participants commented on the benefits of the extension of transition as a positive development with good working practices and relationships between services for children and the Community Working Age Adults Learning Disability Team.

However, professional stakeholders commented on a lack of consistency around transition. For example, there were concerns about transition for young people with physical disabilities. Workshop participants commented on gaps in terms of physical disability pathways which can be disjointed, particularly in relation to health, and where there is not necessarily an educational need.

A significant number of young people who do not meet learning disability criteria are not known to the Children with Disabilities team – a significant proportion come from the CLA team or residential placements fully funded by education. One professional stakeholder observed that young people with highly complex needs in expensive out of county education provision often come into the system '*at the last minute*'. The transition pathways for these children and young people are perceived to be haphazard.

One interviewee highlighted concerns about the lack of support for young people with autism moving into adulthood, who may not require adult mental health services but will have a care and support need, even if it is only for information and advice. There were also concerns that young people moving into adulthood with a continuing health care need received a Care Act compliant assessment.

The need for earlier and improved planning in the preparation for the transition to adulthood was echoed by in the professional stakeholder workshops: '*It would be helpful if adult's teams could get involved earlier in the process of transition but would require more resources. Need a young person team working with 14+ to handle transition more easily – but should it be in children's or adults?*' and similarly, '*They need to be drawn in earlier to allow more time to plan and prepare*'.

> '*Help in advance with post-16 – help with thinking in advance what decisions need to be made regarding adulthood*.'
> (2015 survey comment)

The idea of a key worker was mentioned by one respondent to the 2015 survey:

> '*Having one person responsible for telling me what is available and how to access it. Also one person responsible for my child to ensure nothing falls down between the cracks*.'
> (2015 survey comment)

Comments from respondents to the 2015 survey indicate the need for more information to parents and young people along the pathway to adulthood.

> ‘*Also, as parents, you don't know what services or set-ups will be available when child comes "of age" – i.e. in 3 years’ time. So next step isn't clear-cut. I know my child will need 24 hour supervision of some kind so how will this happen? I don't want to do it for rest of my life. A one-on-one information session with someone "in the know" would be helpful and to go through your options at first time. How can you know your options if you don't know what’s out there*.’
> (2015 survey comment)

> ‘*Frustrated by the lack of knowledge and info from my son's social worker on how his transfer to Adult Social Care Services would look*.’
> (2015 survey comment)

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 lower level of resourcing in adult services. For example, a survey respondent commented: ‘*Better information given to families about care options as an adult - expectations are not currently managed well due to misconceptions*’.

Communication with parents around the time of transition was also mentioned by several respondents to the 2015 survey:

> ‘*Much more information about choices for when my son finishes school – more input from social services and regular updates.*’
> (2015 survey comment)

Peer mentoring or buddying was suggested as a helpful way to prepare families in thinking about the process and the decisions to be made:

> ‘*There needs to be much more support for these children, particularly in the teens and through transition into adulthood. A mentorship programme and community network to give them a presence, value and advice*.’
> (2015 survey comment)

> ‘*A parent who had already been through the transition process and had a positive outlook would have been extremely helpful/useful to talk before the process began 18 months ago*.’
> (2015 survey comment)

One professional interviewee expressed concern that there was not a full appreciation that the Mental Capacity Act applies to those aged 16+ and that this has implications for the transition to adulthood.

2.4 Coherence

As a two-tier authority with seven districts and three Clinical Commissioning Groups, developing coherent, joined-up services is recognised as a challenge by professional stakeholders, particularly around the transition to adulthood. They 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. One interviewee commented: '*Transition just isn't working – there is no defined role around who does transition plans in the county. The hard work done by the voluntary sector falls apart at 18*'.

Workshop participants emphasised the priority for more joined up services to enable a seamless pathway from children's to adults services, suggesting the development of one pathway with permeable boundaries.

Stakeholders mentioned a need for more partnership working with other organisations but also less fragmentation within WSCC. Internal coordination was perceived by some professional stakeholders to be fragmented and lacking strategic direction. Even professional stakeholders found that it was often difficult to find the right person to deal with in WSCC.

One interviewee cited an example of the difficulty of getting three way personal budget to work well for a young person due to IT issues and different approaches to budget setting across education, health and social care. More flexibility around pooling service budgets was seen as potentially useful.

For adults with physical disabilities, a professional stakeholder survey respondent commented on the lack of synergy between health and social care.

The need for greater strategic coherence to avoid duplication was mentioned by a number of professional stakeholders.

2.5 EHC Plans

A couple of stakeholder survey respondents mentioned difficulties in getting an EHC Plan completed and the need for: '*more support with EHCP the process, schooling options and help when things go wrong*'.

One stakeholder survey respondent thought that there was a need for '*EHCPs to be in place earlier for young children, to allow settings to access funding to support children and improve outcomes before starting school. This would also mean a fairer way of allocating school spaces in special provision*'.

2.6 Waiting times and accessibility

A number of areas emerge as concerns in relation to waiting times and accessibility of services. In particular, respondents in the 2015 survey mentioned difficulties in accessing CAMHS services, occupational therapy, social workers, and speech and language therapy.

A number of parents in the 2015 survey mentioned general difficulty in accessing support, for example:

> '*When you have a disabled child everything is a battle! You have to find your way around the system, what you are entitled to, etc.*'

> (2015 survey comment)
>
> ‘*You always seem to have to fight for things. Chase things up. I don't think we should have to have that worry and concern especially when we are looking after a child with severe disabilities.*’
> (2015 survey comment)

Professional stakeholders were asked how easy or difficult it was for children, young people and adults with disabilities to access their services. The majority said that it was easy, with one-sixth saying that it was difficult, due mainly to lack of transport or a waiting list. Particular concern was expressed in relation to people with a sight impairment.

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.

> ‘*I believe this is hit a miss for some it is very good, but other may not reach the criteria for support as their needs are not seen as complex enough, at the same time other may not receive a service because their needs are so complex all funding is paid for by education, and there are not given an assessment, which could neglect other needs*’.
> (2016 professional stakeholder survey comment)

For adults with disabilities, some professional stakeholder survey respondents commented on the difficulty of obtaining an assessment by a social worker, ‘*unless the situation is dire*’.

There was perceived to be limited assessment, advice and provision within the county for young children with physical disabilities.

2.7 Geography and rurality

Some parts of the county are perceived as having more limited service provision than others, often due to the rurality of the area.

> ‘*It seems that because of my geographical location, on the edge of the county, it appears difficult for me to access services – particularly carers, I think people living on the edge of the county are being let down*.’
> (2015 survey comment)
>
> ‘*Most services are Chichester-based, way out of our area*.’
> (2015 survey comment)
>
> ‘*We also attend the over 12s group at Felpham one Saturday a month and the after school club held there – this is only available once a fortnight on a Monday, unfortunately. This has highlighted a huge gap in the area of afterschool care for the over 12s with special needs*.’
> (2015 survey comment)

> ‘*There is a need for a local Horsham group for teens with Asperger’s to be able to form friendships...*’
> (2015 survey comment)

One professional stakeholder observed that ‘*big towns get lots of services but smaller towns and villages do not get as much and families end up doing a lot of travelling*’.

Professional stakeholders thought that those living in rural locations were more vulnerable to isolation due to the greater difficulty of accessing services. Areas that were mentioned as having gaps in services were Billingshurst, Midhurst, Petworth, Henfield and Steyning.

2.8 Transport

Concerns about transport are linked to the geography of the county and were mentioned by both professional stakeholders and families.

> ‘*The transport we use is West Sussex-based. It is always organised very last minute – this quite stressful for family and especially for child as they need the security of a routine or person involved in their care. This would be an area for improvement*.’
> (2015 survey comment)

> ‘*Transport to get to school holiday clubs as he isn’t always comfortable on public transport – would to be happy to contribute financially*.’
> (2015 survey comment)

A professional stakeholder survey respondent commented: ‘*Transport seems more problematic when transferring to adult services - leading to isolation. More of a problem when the person's needs are more complex’*.

One professional stakeholder survey respondent commented on ‘*poor and expensive services from public transport*’. However, another reported very good transport links in the Worthing area, though less so in other areas (eg, Burgess Hill).

A need for travel training was mentioned by workshop participants.

2.9 Housing

Stakeholders commented on the limited housing options available to young people in general. For example, ‘*social housing is under tremendous pressure and therefore waiting times are very lengthy*’. 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.

A number of professional stakeholders mentioned the 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*'. Where young people come from schools or residential care, there was felt to be a lack of advance warning for accommodation providers.

Lack of awareness of the needs of the visually impaired in relation to housing was mentioned by one professional stakeholder.

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*'. Another respondent commented: '*lots of families in unsuitable housing - more focussed support needed via children and family centres on local support and processes. Nobody seems to have responsibility for this area on behalf of families*'.

The last comment echoes a wider perception 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.

2.10 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. 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.

Stakeholder survey comments underlined the lack of opportunities both for young people and adults with disabilities:

> '*Unless it is sheltered employment, very little help is available*'.
>
> '*Accessing training and employment for young people post 16 with learning difficulties is practically impossible and there are no effective services offering appropriate support*'.
>
> '*I think children and young people with disabilities have good access to training whilst they remain in formal education, but limited access to training once they leave college, and poor access to employment other than voluntary work. This is arguably a national issue rather than a local one*'.

Support from Job Centres for young people and adults with disabilities was described by one survey respondent as 'pretty woeful', and there were concerns that welfare reforms were having a significant impact on those with lower level needs. Some stakeholder survey respondents were critical of Work Aid: '*Workaid just doesn't work (except for a limited few)*'. There were particular concerns about opportunities for training and employment among the adult population of people with learning disabilities:

> ‘*Employment support for adults with disabilities is very poor. I have had numerous customers reported the job centre have advised they continue with benefits as this is an easier option 'why would you work if you don’t have to*'.
>
> ‘*I do not think that there are enough opportunities for disabled people in terms of employers and not enough advice and support in place for employers*’.

2.11 Leisure activities and sport

Stakeholders identified a range of sport and leisure activities for children and young people with disabilities but one commented that there could be more variety, for example, drama and IT related activities. The popularity of swimming was highlighted. Active Sussex is working to increase swimming provision and has also identified a need to work with more coaches to give them the confidence to work with children, young people and adults with disabilities.
Responses to the 2015 survey indicate the demand for swimming provision and other activities for children and young people with disabilities.

> ‘*More 1:1 swimming lessons. More holiday play schemes for children and their siblings*.’
> (2015 survey comment)
>
> ‘*We need swimming lessons for SEND and sport and after school activities*.’
> (2015 survey comment)
>
> ‘*More activities for severely disabled children in wheelchairs. A lot of activities are aimed at mobile children*.’
> (2015 survey comment)
>
> ‘*Weekends are a struggle to find activities – more sporting activities, clubs where we can meet up.*’
> (2015 survey comment)

One interviewee said that disabled sports sessions are not as frequent or consistent as they could be because people cannot afford to go regularly. Survey respondents commented that limited resources meant that it was difficult to provide ongoing, regular and affordable activities:

> ‘*There are some short term activities but nothing seems to provide ongoing support*’.

Transport and access were identified as barriers to taking part in sport, particularly in rural areas. Rural facilities are often not accessible and reasonable adjustments were understood to be needed for existing facilities, while new provision needs to consider accessibility thoroughly.

One professional stakeholder highlighted the issue of how to reach young people when they turn 18 years old with information about sport and leisure, because once they are out of education, they can get lost unless they have pro-active parents or carers.

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 providing access to other activities, such as bowling.

One stakeholder survey respondent thought that while '*Local communities in West Sussex are developing their support networks,.. the infrastructure is currently not as inclusive as it could be. There is potential for community development work and raising awareness*'.

2.12 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.

Difficulties in accessing OT and SALT services have already been mentioned in this report.

Transition was also identified as an issue on health services, for example, one survey respondent stated that there was '*poor transition from child to adult health services - ie hospital and core NHS professionals (NOT including CHC which is working well in WSx)*'.

2.13 CAMHS

Consultation with parents as part of the WSCC mental health needs assessment for children and young people in 2014 highlighted a number of gaps, including services for children and young people with autism and their parents; and specialist services for children with physical disabilities. Professionals considered that commissioned services for those with learning disabilities or autism were insufficient.

Professional stakeholders considered that there was inadequate support for families of children and young people with challenging behaviour due to the CAMHS service being '*full up*'. 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.

One stakeholder survey respondent commented: '*Thresholds at CAMHS exclude young people with emotional wellbeing needs from effective interventions e.g. trauma, attachment, neglect, learning difficulties*.'

Another commented that: '*CAMHS is under resourced and is only able to provide low level support to those in most need*'. In addition, waiting time for a social care assessment by CAMHS was reported to be over 12 months.

2.14 Short breaks and respite

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.

Stakeholders considered that the development of short breaks services had been very positive. However, gaps were mentioned by individual stakeholder survey respondents in playschemes, respite services in and out of the home, and respite for complex needs. Respondents' comments in the 2015 survey also indicate some gaps.

> '*We desperately need short break facilities for children with medical and physical needs in Chichester*.'
> (2015 survey comment)
>
> '*Short breaks: Useful to consider better provision of activities in the north of the county. This seems to be improving. And to consider provision for profoundly disabled children, eg. sensory activities, music therapy*.'
> (2015 survey comment)

Professionals also mentioned a need for year-round short breaks for children and young people, and the potential benefit of providing more skilled outreach in the home could have a long-term impact.

> '*Increased child-care available for children with disabilities in the holiday. Whilst PACSO are excellent, the hours provided don't allow both parents to work (even part-time) on a long-term basis, keeping one parent trapped in a carer role*.'
> (2015 survey comment)

Short breaks services are mainly for those aged 5-18 and some professionals noted a need to provide them for younger and older groups with disabilities. For example, one stakeholder survey respondent commented on the '*need for more activities for children aged under 5 to attend with their parents respite care to give parents a break from caring even for few hours a week*'.

2.15 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.

2.16 Siblings and the wider family

In the 2015 survey of parents and carers of children with SEN and disabilities, satisfaction with the social care and support services provided to other members of the family averaged 6.2 on a scale of 0-10.

> '*I would like to see more support for siblings of disabled children*'.
> (2015 survey comment)

This was echoed by participants in the professional stakeholder workshops

2.17 Workforce

Some of those responding to the 2015 survey commented on staff shortages which were perceived to be due to lack of funding. Staff turnover was also mentioned by respondents as a factor contributing to a lack of continuity – for example, one respondent had seen nine different OTs in four years.

Stakeholder survey respondents were asked how easy or difficult it was to recruit and retain staff (Table 4). Forty per cent reported that it was difficult to recruit staff and nearly one-third (32%) reported that it was difficult to retain staff.

Table 4: How easy or difficult is it to…..?

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. They cited competition from Gatwick, and from supermarkets such as ALDI and LIDL which pay above the Living Wage.

Another survey respondent commented: ‘*A workforce crisis in West Sussex at the moment, which will only get worse*’.

2.18 Communication and information sharing

Professional stakeholders and workshop participants mentioned the need for better communication and information sharing between health and social care and other services, to share good practice, provide holistic services and reduce barriers.

Communication between services and departments was mentioned by a number of respondents in the 2015 survey.

> ‘*Sometimes the communication between the depts. will be very poor that we have to repeat same things about the kids over and over again.*’
> (2015 survey comment)
>
> ‘*We wish services would talk to each other and share information*’.
> (2015 survey comment)

2.19 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. In all but one district of the county, information was ranked as the number one service priority (in the others it was ranked second). More than three-fifths (62%) of parents said not knowing about services was the greatest obstacle to accessing them.
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.

> '*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).

> '*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)

There was perceived to be a need for better signposting. Respondents to the professional stakeholder survey commented:

> '*Advice and information is sorely lacking - where do parents go for support, again, only those with the highest need are offered support, the rest are left to cope*'.
>
> '*Can be difficult to find out information unless families know where to look for it*'.

2.20 IT

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 not on the Framework-i system.

2.21 Hard to reach groups

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):

> '*I feel than unless a family is able to fight they get missed. In our area we have a large amount of parents where English is a second language and so their understanding of what there is available to them is not conveyed to them so they do not seek help until the child enters into an early years setting and then now*

> *that FIRST has changed it takes too long before support is given to either the child / family and setting*.'

2.22 Low level needs

Parents of children with lower level needs also expressed dissatisfaction with access to services. Professional stakeholders also expressed concern about 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 commented: '*the preventative support services for adults (and young people) who do not quite meet the eligibility criteria of Adult Social Care (including the Community Learning Disability Team) are not robust enough. I think these adults and young people are in some ways more vulnerable than those who do meet eligibility criteria, as they have presenting needs but are not eligible for a funded service*'.

Professional stakeholders commented that some needs could increase once a young person with a disability has left education.

2.23 18+

Management of the transition to adulthood was mentioned by many, and of particular concern for those aged 18 and above. One professional stakeholder commented that people could fall through the gaps after leaving further or higher education.

> '*Short breaks funding stops on a young person's 18th birthday. A young person with a learning disability doesn't understand why they can't go to their club anymore*.'
> (2015 survey comment)

One stakeholder survey respondent identified a general gap in services for 18-25 year olds with a disability.

2.24 Other points

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

- Professional stakeholders mentioned good support in getting children and young people with disabilities into universal services. However, one stakeholder survey respondent thought that this has become harder to access for children with significant additional needs and workshop participants mentioned a need to increase the understanding of the needs of disabled children and young people among universal service providers.
- The work of the Aldingbourne Trust was valued by a number of professional stakeholders. Springboard's peer mentoring/buddying by young people was also highlighted.
- There is very little support for parents who work full time for their child care needs. When they find a setting prepared to support them, it is perceived that the setting has to fight to get support from WSCC.

- Provision for children with behaviour difficulties was mentioned as a gap by one stakeholder survey respondent.
- There is a lack of fully accessible facilities in the County which needs to be considered in the future planning of all provision.

2.25 Life pathway

The survey of stakeholders asked for their views on how the life pathway for children and young people with disabilities and their families could be improved. Individual respondents emphasised the need for work around transition:

Better work around transition from children to adults services. Better communication between staff/ services. Time to do more joint working.
Provide ongoing support through the transition from children's to adult services.
Transition period needs to be longer. People find it difficult as children get more services provided and when they reach adulthood the level of services and support is dramatically reduced.
Smoother transition process. More joined up working. Less difference in funding from childhood to adulthood.
Working with families to plan for the future rather than just looking at today.
I believe the pathway for some is probably good, for others there needs to be more support and the ability given for families to encourage them and help themselves.
A more holistic approach between adult and child service providers. For example a parent with mental health issues receiving support from adult services - there is no info sharing to children services so our service is not informed of this to enable support for the family as a whole and the children within those families.
Provide quicker assessments and interventions for children and adults with mental or physical health needs. Agencies to communicate better with each other. Services to communicate better with parents and be contactable'.
Services need to be better co-ordinated, more equitable and proactive.
It would be helpful to establish a dedicated team of staff supported from birth through to adulthood. This could incorporate customer engagement, needs assessment, support planning, commissioning, review. An all age strategy clarifying the strategic direction would be informative to all parties and needs to be based on a comprehensive needs assessment.
First person involved takes responsibility to set up early help plan, provide core information around emotional/financial/practical support and/or refer to appropriate service as soon as possible.
Greater MDT team working together to create joint goals. Fluidity in pathways. Access to working and newer resources/technology, integrated notes and access to joint therapy. Increased staffing and funding. Better accommodation/sites fit for purpose and access to these.
Greater integration of services across early years and education - closer

alignment of children with disabilities team in Children's Services with the SEN Assessment team in Education and Skills. More capacity in educational psychology to be funded through schools commissioning the service.

3 Data availability and quality

A number of interviewees commented on issues of data availability and quality. In particular, there is limited data available broken down by age which hampers WSCC’s ability to plan for the numbers of young people with disabilities moving into adulthood. It was also observed that some databases did not always tally with each other.

4 In summary

The interviews conducted individually and in groups (see appendix 1) with parents, young people and key support/commissioning staff all 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 and 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.

Interviewees and workshop participants

Aaron Gain - CAMHS
Alan Alvis – CCS Tenders, Core Assets – Children’s Services
Amanda Brewis - Contracts & Commissioning Manager SEN/CwD & Lead for DPS
Ani Beams - SEND Post 16 Development Officer
Carl Burton - Principal Manager, Young People's Service
Charlie Connor - Personal Budgets Commissioning Manager, SEND Commisioning Team, Family Operations Care, Wellbeing and Education
Charlotte Smith – SEND Local Offer Officer: Information Advice & Support Services
Chris Hughes – Community Connector: The Pines and Oaks Community Project
Chris Lewis - Educational Psychologist
Daniel Cheeseman – SEND Commissioning Manager
Debbie Buckwell – Commissioning Manager SEND Commissioning Team, Child Disability Team
Deborah Allsop – Day Care Manager: Wrenford Centre
Dympna Miles – Day Care Manager: Pines & Oaks Community Project
Elizabeth Flegg - Employment & Skills Consultant, WSCC
Emma Kennedy – PACSO: Go Club
Emily Griffiths – Short Breaks Manager
Fiona Morris - Principal Finance and Assurance Officer, WSCC
Gemma Finlay – NGB Development Manager, Active Sussex
Gráinne Saunders – Health Representative: West Sussex Parent Carer Forum (WSPCF)
Heather Mooney - Lead Nurse for Children's Continuing Healthcare
Helen Dunkley – National Autistic Society
Ivan Western- Housing / Supported Housing
Jacqueline ? – SEND Information and Advice Young People’s Adviser
Jane Walker - Operations Manager, Independent Living
Jenni Herret – Projects and Funding Manager, Kangaroos
Joanna Earl - Education Policy Adviser, WSCC
Jolene Marchant – Community Connector: The Pines and Oaks Community Project
Jo Roberston – Children’s Commissioning Manager, NHS/WSCC
Julie Carter - Housing, Health and Social Care Co ordinator
Julie Lawrence – Service Finance Manager supporting Health & Social Care Commissioning
Leo – Community Connector: Wrenford Centre
Lesley Durbin – Impact Advocacy Services
Liz Deans – WSCC
Nik Demetriades – Chief Executive, 4Sight
Nigel Scott Dickeson – CEO Springboard Project
Nigel Street - Service Finance Manager
Paul Morrison – SEND Post-16
Philip Allen - Children’s Homes Service Manager
Philippa Thompson - Chief Executive, Independent Lives
Robert Hayes - SEND benefits advice
Sarah Burling – Chair of West Sussex Parents Carer Forum
Sarah West - SEND Data and Research Officer
Simon Starns - Service Development Manager, Adults Provider Services
Sue Coldham - Operations Manager, Learning Disabilities
Tim Martin – Research Officer

Toby Hewson – Independent Disability Awareness Consultant
Tom Elsam - Service Development Worker, Transition & Partnerships - Care, Wellbeing and Education