

Appendix 2 b

Phase 1 Carer Survey Results

1. This survey was made available to carers via a postal survey, and was also made available online.
2. Respondents were asked to provide their views on current services, to provide any examples of good practice from elsewhere, and were also offered the opportunity to make any other comments that they felt were appropriate.
3. 63 responses were received and a full breakdown of the results is as follows.

Question 1 – Views on current services

NB. Percentage figures are based on the response rate to each question.

Q1. Thinking about the services provided by the Council for people with learning disabilities in Stockton-on-Tees, what do you think currently works well and not so well? Please place a tick in each row below.				
Service	Works well	Doesn't work so well	Don't know	Responses
Location of day centres	66.1%	6.8%	27.1%	59
Type of activities offered as day care	59.3%	16.9%	23.7%	59
Variety of activities offered as day care	57.6%	16.9%	25.4%	59
Day to day opening hours of centres	61%	10.2%	28.8%	59
Seasonal opening hours (eg. during summer period)	53.6%	16.1%	30.4%	56
Transport arrangements for service users	61.4%	7%	31.6%	57
Catering arrangements within day centres and residential	57.4%	1.9%	40.7%	54
Location of residential accommodation	29.4%	9.8%	60.8%	51
Availability residential accommodation	20.4%	16.3%	63.3%	49
Quality of residential accommodation	31.9%	4.3%	63.8%	47
Location of respite care	63%	9.3%	27.8%	54

Availability of respite care	51.9%	23.1%	25%	52
Quality of respite care	66.7%	5.9%	27.5%	51
Location of supported living accommodation	22.9%	2.1%	75%	48
Availability of supported living accommodation	20.8%	8.3%	70.8%	48
Quality of supported living accommodation	25%	-	75%	48
Availability of community support	41.5%	24.3%	34%	53
Quality of community support	49.1%	17%	34%	53
Other	16.7%	-	83.3%	6

Detailed comments are as follows

Q1. Thinking about the services provided by the Council for people with learning disabilities in Stockton-on-Tees, what do you think currently works well and not so well? Please provide brief comments on your answers to the above in the space below.	
1	My daughter is at Brighter Futures which she enjoys immensely. However I do not know what else is available for her if "brighter futures" ceased.
2	I understood that staff were able to take holidays throughout the year, if this is the case I wondered why it was necessary to close centre for 2 half weeks. If not then I can understand closure during holiday season.
3	I am very happy XXXX (my son) is content, happy and getting looked after by supported living.
4	Carer for two people in family but never had respite so cannot answer to certain questions. But have support if needed by telephone or out of reach.
5	Respite care and community support although very good is not readily available and has to be booked a long time in advance.
6	The Services we use seem to run very well, don't agree with all these cuts in services, surely people who use these services were assessed in the first place, and need supporting their every day lives, how can they take that support away, when a lot of people with learning disability need regular routines and don't like changes probably doing them more harm than good also its said its due to government spending cuts I would like to know how much the Council is spending on all these meetings and interviews and time taken to do this.

7	Would be nice to have a week break respite instead of Monday 2 o'clock till Friday 10 o'clock morning for Friday 2 o'clock to Monday 10 o'clock morning as XXX is at home all day.
8	For almost 40 years myself and other carers have highlighted a need for more services for people with learning difficulty it doesn't seem to improve!
9	Not enough places that are suitable for respite and community support has not staff therefore less you down not enough hours available.
10	Want personalisation like Redcar and Cleveland have introduced.
11	My daughter (XXX) doesn't use any of Stockton Services she uses private services in Hartlepool. She lives in her own home with private care supported financially by Stockton Borough Council.
12	Do not know a lot about day centres. My son gets respite care been taken out by carer's using direct payments.
13	I have attended meeting after meeting for the past 30 years as have other before me and the conclusion of all that is that they are a waste of time. Nothing is ever done or changed. All our opinions are ignored. I also find this is the opinion of newcomers to the services.
14	Happy enough with day centre and respite care. Other areas not used.
15	Quality of respite care - Lanark excellent. We have had excellent help and support the only problem finding things to do and places to go when cut with support workers and the cost of petrol for outings it does restrict distances. Would like day centres for activities.
16	My adult son (22 yrs) has learning disabilities however uses your services in a limited capacity but I would like to be kept informed for future reference/uses.
17	I have attended 2 day centres.
18	As my daughter has just returned home from three years study at a residential college in Wakefield we have not had a chance to access the "don't knows".
19	Since the Action Team involvement. Service, especially respite care, excellent.
20	XXX uses creative support for 10 hours per week, but some areas are problematic e.g. transport, carers only willing to do certain things e.g. XXX wanted to go swimming but was told its inappropriate.
21	I have not used them myself but our daughters have.
22	I do not use day care as I do not know what services are provided or where to access this information.
23	[Ticked both 'works well' and 'don't know' for location of day centres and transport arrangement for service users] I would prefer if my daughter could get dropped off from Allensway on a Friday night to my house I'm 62 I shouldn't be walking round to collect her.
24	Catering arrangements within day care centres - NA takes lunch. Availability of respite care - none in area for direct payments. Need to be able to use respite facilities with direct payment - otherwise always have to go out of area.

25	My son attends brighter futures so I can not comment on other services.
26	To support SU transport to day centre's essential - keep good existing transport. Social Services to have ability to offer best and most suitable service to service users and not to fit SU round service.
27	Don't know of any alternative services when day centres are shut. The two week closures seem particularly hard for handicapped people and particularly carers.
28	Location of day centres works well as long as transport provided.
29	Personalisation allows for the client to choose where they want to be, Use Adult Learning courses and have short breaks away from home with carer without using special services.
30	Happy with everything. Everything working very well.
31	Rievaulx Centre works well with continuing changing activities.
32	Seasonal opening hours: August needs changing to June/July!
33	Not sure where day centres are or facilities on offer. Same with respite care and supported living accommodation.
34	I do not abuse the respite care but am very glad it is there as I am 85 and still caring for 42 year old Downs. I am grateful for short breaks. They are happy and do not like change. I am afraid it goes for me too. The community support (Bishopton Lane?) is excellent. He is take out bowling and pictures (he is [eligible] to go and I'm [eligible] to have a rest) centres are a base to be worked round.
35	About Rievaulx and Aysgarth.
36	Is this for XXXX as my dad XXX has passed away in 2010.
37	Have been waiting for supported living accommodation for 2 yrs have only been contacted twice, Would like to have more updates.
38	XXX takes packed lunch daily. Other questions not ticked are not required at present we have never used them so unable to comment.
39	The service we receive at present 2011 works well for us, we hope it will continue.
40	XXX is severely handicapped and need 24hrs full care including toileting. We see services offered to the more able clients and very little to those needing a lot of attention.
41	I found very little after service after a service user turned 19 year old I was given little choice and my son went outside Stockton with a carer to be with him not the day centre.
42	XXX'S DAY AND RESPITE CARE WORKS REALLY WELL AND IS ESSENTIAL FOR HIS AND HIS FAMILIES WELL BEING. HE IS VERY HAPPY AT RIEVAULX AND LANARK.

43	I have only commented on the facilities that concern my son, the others are "don't know". My personal assessment of the facilities and services used by my son are excellent - without fault.
44	Don't know enough about community care to comment on support. Supported living good but not happy with choices "independent choices".
45	If services are still the same as 3yrs ago these are the answers if not please disregard.
46	This is based on our experience. Parents need to know where places are not enough information available i.e. for residential respite. Community support big demand works well when enough staff.
47	XXX lives at home
48	We do not use residential or respite care
49	Everything is good enjoying all of it
50	Everything is good and he enjoys it
51	I am unaware of the daycare services but we did use the respite care when XXX was 17. At 18 no services existed within Stockton however I understand much more independent living has been added.
52	It is difficult to find work due to the day centre my son attends only opening during school hours, I also think more respite care should be offered and more of it made available at short notice, having to book 3 months in advance is sometimes impractical if anything arises that you suddenly need care for.

Question 2 – Examples of good practice

Q2. Are there any examples of good learning disability services provided elsewhere which you think we should take into account as part of this review?	
Yes	22.6%
No	77.4%
Skipped question	10 people

If 'Yes', please tell us the nature of the service and where specifically it is delivered.	
1	My sister XXX uses the services of Stockton Daycare. She is very happy and the variety of training facilities meets XXX's needs perfectly. Thank you. Due to illness and subsequent bereavement in the family XXX is now also in residential care. Again she is happy and secure and has expressed her wishes for this to continue. Unfortunately this does not appear to be straightforward and the procedures which she now needs to go through to finalise her care do not appear to consider XXX's wishes first. The decision making process should be more personal and tailored to the individuals rather than apply the same "blanket policy" to all.

2	Steps. Children and education and social care excellent service
3	As Above. More Short Breaks More Help For Carers
4	Hartlepool pathways to independence take my son out by using direct payments
5	Shaw Trust service is excellent for team building. My daughter goes Shaw Trust 2 days a week and this helps her make friends get up every day she goes and works in a team in the fresh air. So places like that would be excellent if there was more.
6	As far as I can tell Stockton is a good provider in this field.
7	I've looked for relevant services.
8	There should be more jobs available in large stores and local outlets with support to give confidence after all they want to be treated as everyone else without stigma or bullying. Most are able to work and are trustworthy and eager to learn.
9	Cumberland RC Linthorpe Middlesbrough. Building based centre offers small units clean/tidy good location activities in centre and out tailored to suit service user.
10	Previous provision at Newtown. We were very impressed with the provision in the small unit at Newtown and were very disappointed when this facility closed.
11	Autistic Soc areas. The Autistic Soc provides care in various loc within the NE, the quality and type of care given as well as education opportunities are an example of the care needed.
12	My son went to Upsall which is a good service for all disabilities has outdoor and indoor services.
13	Croft Centre, Sunderland are providing excellent facilities for my son, however I also understand the financial side, and realise that similar facilities in our area will benefit all parties (when open).
14	Residential autism/learning/challenging Castlebeck Crook.
15	Shaw Trust/Main Project. Excellent support for special needs clients. Meaningful voluntary employment.
16	Residential care provided by Autism North in the Sunderland area is a model I would hope Stockton could follow.
17	I've only dealt with this area's disability services

Question 3 – Any other comments

Q 3. Would you like to tell us anything else about your thoughts/feelings on the services provided for people with learning disabilities in Stockton-on-Tees and how they could be improved for the people who use/receive them? Please provide brief details below.	
1	I would like to know more about the options/opportunities available to people with learning difficulties...particularly for day services.
2	I am very happy with Elmwood Community Centre and feel they give a good service.
3	Have good relations with doctors for help and support and outreach teams and social services when I've needed to contact them. More money is needed from government to social care to help people who feel left out of society because of their disabilities. It all comes down to finance. MPs should send a petition to parliament on carers behalf. Other than that keep up the good work.
4	More respite places should be available with activities to stimulate people as they are not allowed to go to day services. Blenheim House was perfect for this.
5	As always there is never enough outside activity and never enough staff to take clients to them such as swimming, bowling, parks, seaside especially clients who use wheelchairs and are not as mobile. This has no reflection on the staff who do their best as always it comes down to funds.
6	My son goes to the summer scheme run by Stockton Council it has been a God send this summer. The staff and the way it is run is fantastic I cannot sing its praises enough. My son gets to be with people his own age and gets trips away, and has a great time I think this is a service that cannot be improved on as it is already running great.
7	A lot of facilities are not known about packages of these could be made available to parents and carers.
8	I think personally a day to day place where clients can go all day to provide activities as well as enjoyment things to do. Places like Shaw trust as my daughter has and is getting a lot out of this scheme, Going out with support workers is fine but wandering around finding somewhere and something to do all day can be difficult.
9	As XX only goes to the centre once a week I can't comment on how well the services work for the majority of people.
10	My son is Autistic and has had a plethora of carers, they change rapidly, I would like to see some type of continuity of care implemented enabling a rapport to be built up between carer and client. The service provided by the Shaw Trust 2 days a week is excellent.
11	XXXX is receiving the care and services he needs for his age, over the years he has tried many courses at colleges and elsewhere. He is now content to socialise with his friends. He does not like change and is quite content to remain doing what he already is. Day centres and respite care is essential for the more mature clients.
12	There is not enough information of what is available and not enough for adults over 25 years. Services seem to be only in day care and not enough socially. There should be more in local areas. My daughter is 32 years and both my

	husband and I work. There could be more community centres having courses i.e. cookery, life skills, social events so they can become independent to travel to local places and feel safe in their known areas. ID cards could be a good thing for use on events and days out it would stop a lot of paperwork and looking for benefit forms.
13	My daughter XXXXX is at number one Sycamore Way sometimes she is getting upset when she comes home then she keeps saying packing as thought she wants to go back to Sycamore Way I think she gets a bit bored with herself, I think they do a lot of activities for her. When they take her on holiday abroad with them they say she enjoys the pool a lot she likes water. Mind she is 40 years of age.
14	Not enough activities for adults with multiple disabilities e.g. restricted mobility.
15	I am very happy with the brighter futures service I think it gives a more enabling service to adults with LD who can function independently.
16	A building based service - small units - small groups. To improve and explore using services in next town if suitable and available for service user. A building based centre where indoor activities can be pursued or leave if suitable outside pursuits are arranged. No large group town visits etc. Ability to use services in neighbouring towns if available and they are best for service user.
17	We feel that the services provided at present (day centre 4 days/week and respite care up to 6 weeks/per annum) meet the needs of our relative with learning disabilities. Due to family circumstances we were unfortunately unable to attend the consultation meetings held in August.
18	If people with LD's are already established in services outside of Stockton they should be able to stay in those services until they themselves decide otherwise. Their choice should be acknowledged. New service users should be introduced to facilities in Stockton area and if they fit their needs then they will use them. Remember it is not only the activity that is important e.g. comparable facilities, but being with friends who they have made over the years, they would lose this valuable relationship, stability and continuity if moved against their will.
19	I believe that up to date Stockton have provided a good service for adults with learning problems and I hope it continues. One area of improvement could be to assist Rievaulx to develop satellites for the further advancement of the students.
20	Very approachable and much appreciated that they take XXXX out. It is very beneficial to both of us. Is there anyone who could offer her advice on managing her money?
21	A feeling of unrest is going around with interviews on abilities of own sons with the possibilities of being put out of centre and being paid to do what they want or choose to do etc. It wouldn't work in my case I couldn't get my son from A - B to do what he wanted (which would be wont to ask him for a start). So that would mean stagnation. CIC is running own centre for the moment and achieving good reports working in and with Stockton Council. As in years gone by we have fought for more places and a requisite [sic] which never got off the ground. Hence a back log of children piling up needing help now we are back to square one.
22	Yes sometimes you tell them things but don't pass it on to other staff ps to do and not to do.
23	We are pleased with the services provided by SBC. XXX likes to discuss the

	activities with the instructors and she likes the programmes arranged for her.
24	Regular provision of services with a constant routine is so important to us.
25	Most services and respite and long term care seem to be aimed at the more able. We for instance have had to fight for anything we have received including primary education when XXX was a child. I think the system should look at the clients needs separate to those of the carer and provide targeted services for both. It should be based according to separate needs.
26	I feel once your child turns 19 then there is nothing we are givennot a lot for older adults to do ...there are very few day care for autistic adults.
27	We are very happy with the service provided
28	My son receives excellent support and service from Stockton social services, he attends the croft centre Sunderland where he is making good steady progress, XXX is 20 years of age and is autistic, unable to read, write or talk, he is doubly incontinent, the service provided cannot be praised more by myself, especially since the sudden death of XXX's Mam in December 2010, without the excellent service, my circumstances would be considerably more demanding, I just hope the level of service will continue in order to assist me.
29	My daughter lives supported living which is good. Not enough guidelines giveby [sic] choices. Too much left to the individual to make their own choices - often not good ones - they have to be independent - does this mean do as they like go where they like, tidy up if they want to - do garden etc if want to. Carers can only prompt!!
30	There are not enough small person centred autism specialist places with well trained autism specific carers, in age related groups. When going through the system help was only small and was given by health. Social care couldn't help, no provision for specialist care.
31	Greater flexibility using direct payments grants without having to phone re small changes.
32	The social services help we have received in the past 3 years has been most valuable especially when moving from child to adult services.
33	As I said above more respite care offered and perhaps some later opening times in the day centres for people who wish to work would be helpful.

Demographic Breakdown

4. 63 people responded to the survey. 46 respondents classed themselves as being a carer of a person in receipt of services from Stockton Council, 16 classed themselves as receiving learning disability services from the Council, 3 were staff, and 3 were carers of someone with learning disabilities not in receipt of services from Stockton Council.

(NB. Respondents were able to tick more than one category.)

5. 50 people wanted to keep informed of the EIT review's progress, and 36 wished to take part in Phase 2 of the consultation.

Age	
0-19	-
20-29	-
30-39	1.6%
40-49	25.8%
50-59	27.4%
60-69	30.6%
70-79	8.1%
80-84	3.2%
85+	3.2%
Prefer not to say	-
Skipped question	1 person

Gender	
Male	19%
Female	81%
Skipped question	5 people

Ethnic Origin	
White (British)	95.1%
White (Irish)	1.6%
Prefer not to say	3.3%
All other ethnic groups	-
Skipped question	2 people

6. 39 people provided their country of birth. This was mostly the UK, with 1 person stating 'Ireland', and one person stating 'Kenya'.
7. 41 people stated their nationality. This was either 'English' or 'British' in most cases, with one person stating that they were 'Irish'.

Marital Status	
Single	17.7%
Married	59.0%
Civil Partnership	-
Separated	-
Divorced	6.5%
Widow	8.1%
Widower	6.5%
Civil widow	-
Civil widower	-
Prefer not to say	1.6%
Skipped question	1 person