

Appendix 2

Phase 1 Consultation – Outcomes and Opinion

Background

1. The Phase 1 consultation to support the EIT review of Learning Disability Services has been conducted to seek as wide a range of opinion as possible on services as they are now.
2. It is proposed that a Phase II will be conducted during the autumn of 2011 which will reflect back on the feedback from Phase 1 consultation and begin to discuss how services might change in the future.

The Phase 1 Consultation

3. The Phase 1 Consultation has been conducted with the help and support of a number of partners, namely:-
 - Stockton Helps All
 - The George Hardwick Foundation
 - Abbey Hill School
4. Stockton Helps All (SHA) are an independent organisation set up to facilitate self advocacy for people with learning difficulties within the Borough. Stockton Helps All were commissioned to seek the opinion of service, their work was conducted in group and individual sessions in day centres, residential homes, private homes at a specific event held at ARC and two specific events held at Abbey Hill School.
5. The George Hardwick Foundation is the Borough's central support organisation for carers. The Foundation's support has been invaluable throughout this process and two specific sessions were held at their Stockton town centre premises.
6. Abbey Hill School hosted four sessions for year 12 and 13 pupils approaching the transition from children's to adult services and provided a venue for sessions attended by parents to share their hopes and aspirations for their children's futures.

The Opinions Shared by Adult Service Users

7. The Stockton Helps All Staff during the summer months captured the opinion of 125 individual service users:-
 - 65 adults in day services
 - 20 adults in residential settings
 - 40 young people at Abbey Hill School
8. The questions put to service users were:-
 - What is good about the services you use?
 - What is bad about the services you use
 - What would you like to change?
9. ***What's good about your services?*** - The response to this question on the whole was positive, people liked the day services that they attended, and they also liked the chance to see their friends and to take part in the activities that were on offer. People also liked the physical environment of the buildings and felt that it offered them a safe place to be. People also liked the relationships that they had developed with staff and felt that staff provided them with the right level of support and understood their needs and were able to meet these needs.
10. ***What's bad about your services?***- People felt that there were still incidents of bullying going on in the day service and on the fleet transport; some people did not like the fact that they had to spend a long time on the bus to travel to the day service and the transport was too inflexible. Some people felt that there were not always enough to do and also not always enough staff on to meet their needs.
11. Some people felt that the day service was too noisy and too big and there was not sufficient space for people to be quiet, when they wanted to spend some time away from other people.
12. Some people also felt that staff were not always meeting their needs and sometimes staff could be short tempered and shout at them which they did not like. Some people also felt that the day service was not open long enough and should be open later at night and at weekends for them to go and do things. Some people felt that they had little choice about what they did or always did the same thing each time they went to the day service. Some people also felt that people with more complex needs got all the attention from staff and they were ignored as a result.
13. ***What would you like to change?***- People all felt that whilst they enjoyed going to the day service they would like to be involved in more things in the community, people wanted to be more involved in sport and leisure activities and they were able to give a number of examples

for the things they would like to do: for example, go to a snooker club and organise a snooker tournament of people with learning disabilities, people would like to join a walking group, other people wanted to be part of a mini football league, people also wanted to go to the gym and go swimming and be able to meet up with friends to go bowling or to the cinema.

14. People also said that they would like to have paid employment, some had had this in the past but this had stopped when the financial crisis meant services were cut. Other people said that they should be paid for all the work they do at the day service rather than just be seen as volunteers. People also wanted to know more about their benefits and money. People said that there was not enough information or support around getting a job.
15. The other area that people wanted to change was having more to do on a weekend and in the evening; they also wanted to learn to be more independent in terms of travelling and to be given more choice about the things they like to do. People said that this was a big barrier in their lives and stopped them being part of the community.
16. **Other issues for change** – service users would like more information about what goes on locally; a men's group; freedom to discuss emotions and relationships; stop feelings of being rushed; time to make their own decisions; over protective attitudes from paid carers and families.

The Opinions Shared by Young Service Users

17. The 40 young people taking part in the consultation were asked two main questions:-
 - What do you want to do with your life?
 - What support do you think you will need to achieve this?
18. **What do you want to do with your life** - Young people said that what was important to them was to be able to have a job and a career, some people felt that they would need more support than others and the support they would need would include job coaching to prepare them for work. They also wanted a chance to learn the job properly so that they didn't make any mistakes and also they wanted information about the tasks they had to complete at work in a way that they were able to follow and understand.
19. A number of the young people had very definite ideas about the careers they would want to follow, some wanted to go on from college to university and some wanted to join the armed forces or the police.

20. All the young people that we consulted with felt that they would need some support to achieve these ambitions, but it was not impossible to do them. Again all the young people said that they need to be supported so that they can go at a pace they feel confident with, with any support should be tailored to their individual needs.
21. We also asked if any of them would consider going to a day service instead of working and all agreed that this was not something that they would consider as going to work was of primary importance and part of what people did.
22. All the young people we consulted with wanted at some point to be able to live independently from their families. Some wanted to live with their friends in a house or a flat, some wanted to live with either their boyfriend or girl friend and others wanted to get married and have a family. All agreed that they would need some support to be able to do this and it was also important to maintain contact with their families.
21. All the young people wanted to be able to meet with their friend to go out and do all the things that other people of their age are able to do. The clear message that came across from all the young people was that they did not see their lives and futures as being any different from anyone else; they have the same dreams and aspirations to be independent and to determine their own lives.
22. ***What support you need to do this*** - All young people agreed that the main barriers to them achieving what they wanted from their lives was not being able to travel independently to see their friends and having to rely on the family to take them to places. Lots of young people wanted to be able to learn to drive a car or to use public transport. A number people gave the example of only being able to see their friend at college because they live in different parts of town and cannot travel to see them or to meet up in town.
23. Families not giving them enough choices about what they want to do and spending too much time worrying about them, so not giving them the chance to take risks and to enjoy new things. Money was seen as a big problem, partly because they did not have any experience of handling money especially large amounts. People also felt that they needed support to be able to budget and to pay bills and also to be able to open bank accounts and manage their own money. Many of the young people receive DLA payments but were not sure how much or what they could use it for. Also young people wanted to know more about the benefits they could claim and felt that one of the main barriers to this was having to fill-in very long and complicated forms.
24. All the young people saw themselves as young adults, but felt that too often they are treated as children; they felt uncomfortable in some situations because people only see their disability, they felt that much

more needed to be done to educate the wider public about disability to break some of these barriers down.

25. Many of the young people felt that they did not get the respect they deserve because of their disability and this excludes them from being active members of society.
26. Some young people felt that a lot more could be done to make places more accessible for them. Where young people had a bad experience this put them off going again and also had a knock on effect on their confidence. One young person gave the example of wanting to go to the sports centre but was told he couldn't attend because he had epilepsy and they could not take the risk if he wasn't well.
27. Most young people said that there wasn't enough to do at the weekend or on an evening and college finished early, they would like to have more places to go after college and thought that college should be open longer and also at weekends for them to meet their friends and do other things. They also wanted to do more activities independently and thought that having someone who organised them would be good, rather than having to fit in with what the family wanted to do.
28. Some young people were members of clubs and other groups and were able to get out more and felt that because of this they were more part of their community. This also gave them the opportunity to meet with other young people and helped to break down some of the barriers they felt because of their disability.

The Opinions Shared by Carers at Facilitated Sessions

29. Opinion was sought from carers in two principal ways, by holding six facilitated consultations and the use of a postal questionnaire, backed up by an online questionnaire.
30. Again the three key questions were asked of those attending the facilitated sessions:-
 - What is good about the services you use?
 - What is bad about the services you use
 - What would you like to change?
31. A document listing all the comments shared at the six events is attached as **Appendix 2a** to this report, whilst below is a summary of the key issues and themes emerging: -

What is good about existing services?

- Staff providing services are on the whole supportive and caring

- An open mindedness about quality services provided outside Stockton being replicated within the Borough, as long as the quality is sustained
- A variety of day services provide good quality meaningful days for service users
- Respite is invaluable for the whole family but concerns over availability
- General provision of educational and leisure facilities.

32. ***What is bad about existing services?***

- Unfulfilled promises made at re-organisation from County
- Repeated lack of response to carer's opinion
- Out of Borough placements due to lack of provision in Stockton – especially Autism services
- Lack of support for carers
- One size fits all approach within day centres
- Limited availability of respite care
- Summer closure of services
- Confusion over direct payments and personal budgets
- Transitions support
- Repetition of training offered to service users

33. ***What is missing from existing services?***

- Provision of autism services in the Tees Valley
- Opportunity for carers and clients to influence the choice of services and service providers
- Carer of advocate support at Assessment Panel
- Adequate meaningful choices and activities during the day
- Personal development and life skills training
- Better preparation for transitions
- Community bridge building opportunities
- Better use of assistive technologies
- Support for community enterprise and community business development.

Opinions Shared via the Questionnaire

34. In an attempt to broaden the range of opinion gathered, acknowledging that the facilitated events took place during the peak summer holiday period a postal questionnaire was mailed to registered carers. The questionnaire was also available on line, the deadline for the return on on-line and postal questionnaires was September 9th. In total 63 questionnaires were returned of which 61 were postal.

35. A detailed breakdown of the Carer Survey including individual comments can be found at **Appendix 2b**.
36. In the questionnaire to be consistent with the other opinion gathering methods respondents were asked what is working well and not working so well with existing services.
37. The questionnaire sought opinion on 18 service specific prompts concerning services ranging from the location of day centres, opening hours, transport arrangements, quality of residential accommodation to the availability of community support, as set out below:-

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

38. As illustrated above there were six prompts concerning day care provision, which provoked an average 58 responses from the 63 surveys returned. This group of prompts raises questions concerning the appropriateness of seasonal closures of centres and the Variety of activities offered as day care.
39. The three questions concerning residential accommodation provoked a high return of don't know answers, reflecting that this questionnaire reached the carers of clients who are not in residential accommodation.
40. With regard to the responses on respite care the fact that a quarter of respondents don't have an opinion raises questions about the equality of access to this service for carers and service users alike.
41. Similarly the three questions seeking opinion on supported living returned a very high proportion of don't know responses again suggesting a lack of awareness of supported living as a viable option for consideration.
42. Amongst the comments received in the free text areas the availability of respite care was a concern for respondents along with the summer closure of day centres. A number of respondents complained about not having enough information on services generally to make informed decisions about their sons/daughters/wards care.
43. In addition the software package used to manage the data returned can produce a graphic representation of the key words used in the free comments boxes, producing "word clouds", these are attached as **Appendix 2c** to this report, the larger the text in the "word cloud", the more frequently it was used in the return.

44. **Recurring Themes** - A number of recurring themes are consistent throughout all the attempts to gather opinion from both carers and service users themselves:-
- More respite care is required, specifically respite that is more flexible and more readily available;
 - Autism specific services must be provided more locally;
 - Community Bridge Building-type opportunities are increasingly an aspiration of all;
 - A review of day centre seasonal and daily opening hours;
 - More support for carers;
 - More variety in training, activity and opportunity for day care service users;
 - Additional College Provision.