

Best Value Service Review Promotion of Independence Young Disabled Adults 2004

Detailed Report of the Results – Stage 2
Nottinghamshire County Council

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CONTENTS PAGE

	Page Number
EXECUTIVE SUMMARY	i - vi
1.0 RESEARCH BACKGROUND	1 - 2
2.0 RESEARCH OBJECTIVE AND AIMS	3
3.0 METHODOLOGY	4 - 6
3.1 Approach	
3.2 Sample	
4.0 FINDINGS	
4.1 Profile of Respondents	7 – 9
4.2 Weekly Activities	9 - 10
4.3 Leisure and Social Life	10 - 11
4.4 Satisfaction With Leisure and Social Activities	12 - 13
4.5 Perceptions On A Mentoring Scheme	13 - 15
4.6 Education	15
4.7 Support and Satisfaction With Education Provision	15 - 17
4.8 Employment	17
4.9 Advice and Support With Career Development	17 - 18
4.10 Perceptions on Support With Gaining Access to Work	18 - 20
4.11 Profile of Housing and Accommodation	20 - 21
4.12 Satisfaction With Housing Support	21 - 23
4.13 Views on Providing Safety Training	23 - 24
4.14 Perceptions on the Services Provided By Health	24 - 26
4.15 Income and Benefits Including Direct Payments	26
4.16 Service Provided by Social Workers	27
4.17 Service Provided by Social Staff	28
4.18 Thoughts on Transport – Areas For Improvement	28 - 29
4.19 An Individualised Transport Service	29 - 30
4.20 Independence – Support Requirements	30 - 31
4.21 Views on Promoting a Positive Image of Disability	32
4.22 Thoughts On a Cross County Forum	32 - 33
4.23 Additional Comments Including The Parents Perspective	33 - 34
5.0 CONCLUSIONS	35 - 38
6.0 RECOMMENDATIONS	39 - 42
7.0 APPENDICES	
7.1 Questionnaire	
7.2 Topic Guide	

EXECUTIVE SUMMARY

1.0 RESEARCH BACKGROUND

Nottinghamshire County Council, Social Services Department is currently undertaking a Best Value Service Review into the promotion of Independence of Young Disabled Adults to find how successful the County and its partnership agencies are in supporting young disabled adults needs.

The focus of the project is adults aged between sixteen and twenty-five who are likely to be eligible for adult care services under the Department of Health's guidance Fair Access to Care Services (FACS).

One component of the Best Value Review is to undertake research (consultation) with service users to establish their requirements and opinions on the support that they need to become, or remain, independent.

There are two stages to the research, the first to explore underlying issues and the second to determine specific views on services. This report focuses on presenting **the second of the research results**.

An independent research company, Bright Sparks has been commissioned to manage the consultation. This document summarises the findings of the research. A more detailed account of the results is presented in the 'Findings' section of the report.

2.0 RESEARCH OBJECTIVES

The overall objective of the research is to:

- To consult with groups of young disabled people who believe they are losing or not acquiring their independence, in order to understand their needs, knowledge of services and their experience of current services.
- To consult with young disabled adults who feel they have achieved their independence and obtain their opinions on how they have done this.

The aims of the project are to:

- Measure levels of independence.
- Identify needs and expectations.
- Establish where there are gaps in service and support provision.
- Analyse awareness of current services.
- Obtain reaction to proposed service ideas.

- Identify likes and dislikes of the suggested concepts.
- Determine what information and advice is required.
- Investigate the parents' perspective on what services/support is needed as well as their reaction to the proposed ideas.

3.0 RESEARCH METHODOLOGY

Two methodologies were adopted, due to the complex nature of the project:

- Semi-structured interviews with young disabled adults; a questionnaire was used to record and measure opinions.
- Face to face interviews with parents; a topic-guide was used and the discussions recorded on audiotape.

In total twenty interviews were completed with young disabled adults and five with parents.

A cross-section of people have been consulted, in terms of age, type and level of disability, area of location (rural or urban), ethnicity and the housing support received.

The fieldwork was organised and undertaken by Bright Sparks and interviews conducted during June and July 2004.

4.0 SUMMARY OF FINDINGS

The results of the consultation have been aggregated and the findings are summarised below.

1. An equal number of interviews were undertaken with male and female young disabled adults (10 each). The majority of interviews were with young adults who have learning disabilities, (14 out of 20) followed by physical disability, (8) Cerebral Palsy (6) and mental ill-health, (4). Eleven out of the 20 respondents have multiple disabilities.
2. A small proportion of the interviewees, (4) were from Black and ethnic minorities and the same number live in rural areas.
3. Commonality of views existed between the different disability groups and there were no distinct differences in opinion between the different ethnic groups and people who live in rural or urban areas.
4. Attending an education establishment (13 out of 20), followed by a Day Centre (8) and then working (7) were the core activities young adults undertake.
5. Over half of the respondents who do not work (13) would like to work (7 out of 13), one person stated they would like to attend an education establishment but no one aspired to go to a Day Centre.

Best Value Service Review Promotion of Independence - Young Disabled Adults – Report
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6. Parents highlighted a number of problems their son/daughter experienced when after the age of 19 they can no longer study at School. The transition between child and adult education services was perceived to be traumatic and disruptive.
7. Parents who wanted their son/daughter, (usually profoundly disabled) to attend a Day Centre were disappointed with the choice of centres, (in terms of range and availability) and the quality of service provided. Also, there was belief that centres were being shut down and replaced with community provision, which was alarming for some of the parents.
8. Popular activities young disabled adults undertake in their own home are watch TV/Videos, listen to music, look at or read magazines and books, use a computer and listen to the radio.
9. Outside the home the most popular activities are visiting friends and family, going out to pubs and restaurants, going for a walk/journey outdoors, shopping, going to cinema/theatre, watching sport and going for a drive in the car.
10. The amount of activities the young person participates in does seem to depend on the level of involvement they have with their school, centres and social clubs as well as the level of disability they may have, the amount of support they receive from their parents and their geographic location.
11. Over half of the respondents (12 out of 20) were satisfied with the social and leisure activities they can do and 7 were disappointed. A variety of reasons for not being able to participate in social and leisure activities were provided, in particular access, insufficient care and support, health and safety implications, access to transport and lack of awareness/information on what is available.
12. Being able to work, participate in social and leisure pursuits and live in non-parental accommodation are viewed as key elements of being independent. Both parents, on behalf of their son/daughter, and the young adults aspire to achieve some or all of the above dimensions.
13. The majority of the young adults (16 out of 20) and the parents thought that the mentoring service was an excellent proposal. In particular the respondents liked the idea of young disabled people being able to interact and communicate with other individuals who have had similar experiences.
14. The mentoring concept was also developed by a number of the respondents into a befriending service because there is great demand for it. Currently, young adults and their parents do not think they have enough confidants or that they are allowed enough time to spend with them.
15. The majority of the young adults who are studying (13) enjoy learning (12 out of 13) and 10 of the young adults stated that they chose where they wanted to study.

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16. The main support requirements the young learners require when attending their place of study is transport (8 out of 11) and care/teaching assistance (4 out of 11). Over three-quarters of the young learners (10 out of 13) are happy with the amount of support that they receive with their education.
17. Over half of the learners, (8 out of 13) do not think that young disabled adults have a choice over what and where they can study for a variety of reasons. These include availability, access, the negative influence of family and friends, funding and the persons' disability.
18. None of the young adults who work (7 out of 20) are employed full-time. However, 4 work part-time and 3 undertake voluntary work. The majority of the young adults (6 out of 7) enjoy working but half of them need support with undertaking their job, which includes transport, a carer and access.
19. Over half of the young adults (13 out of 20) and all of the parents do not think there are enough jobs available for young disabled adults. Some of the jobs are perceived to be menial or inaccessible. However, it was thought that job opportunities are becoming more available.
20. Just over a third of the young adults (7 out of 20) believe that there is enough careers' advice available. Issues concerned with careers advice were significant, in particular there is very little information available, assumptions are made about what jobs the persons can do and advisors are not fully trained to provide and support young disabled people.
21. The majority of the respondents, (18 out of 20) stressed that the Review Team should recommend setting up a service to assist young disabled people with gaining access to work. The main reasons given are that it will encourage young people to become employed, it will reduce confusion amongst the different support agencies, it will be one source and would provide people with the support that they require.
22. Four-fifths of the young adults (16 out of 20) currently live with their parents and the rest (4) live in sheltered housing e.g. Eden Supported Housing.
23. Parents provide the young adults, who live with them, a substantial amount of support. Five out of the 16 young adults are additionally provided with external support from Social Services and a private care organisation.
24. Parents spoke of the need for an increase in respite care (short breaks) over what is currently available/or on offer to them.
25. The majority of young adults (13 out of 16) who live with their parents aspire to living in their own home. Factors preventing young people from leaving their parental home ranged from lack of confidence, unavailable support, limited choice and waiting lists for accommodation.

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Produced for Nottinghamshire County Council

26. The majority of young adults, (19 out of 20) highlighted the need for the provision of safety training to young disabled people. Parents believe it is a good suggestion because they are concerned that their son/daughter can not recognise danger signs and would flounder if an emergency occurred.
27. The majority of the young adults (17 out of 20) believe that they have access to all of the health services that they require. However, there was considerable concern about the amount of physiotherapy available and that medical staff in hospitals do not know how to deal with people with a disability and stressed that training health staff was a necessity.
28. Just over half of the young adults, (11 out of 20) acknowledged that their doctor/nurse listens and understands their problems, followed by 7 people stating 'sometimes'.
29. The majority of the young adults (17 out of 20) do not see the doctor/nurse on their own and just over half of these (9 out of 17) would prefer to have the support of someone else, other than their parents.
30. Over half of the young adults (12 out of 20) are not responsible for their own money (personal bank account) and their parents typically manage the finances on their behalf.
31. Advice on benefits has been provided to just over half of the young disabled adults, (11 out of 20) and 3 people receive direct payments.
32. There are 16 out of the 20 respondents who have (or recall having) a social worker and half of these (8) see them on their own. Young disabled adults are generally 'satisfied' (8 out of 16) with the service provided by their social worker and 6 said 'very satisfied'.
33. Concern was expressed by parents that social workers can sometimes mislead people about what services they and their son/daughter are entitled to, and what they will be provided with, causing disappointment.
34. Over half of the young adults, (11 out of 20) have a social care worker e.g. a key worker and the majority of these (9 out of 11) are 'very satisfied' with the service provided.
35. A number of the young adults, (17 out of 20) experience problems with using transport and getting out and about. These include problems with access, confusion over paying fares and planning routes, not safe transport, none available in the evenings and at the weekends, and not being able to transport certain equipment for health and safety reasons.
36. Parents are heavily relied upon to provide transport for their son/daughter. However, it is the wish of a number of young adults and their parents for them to organise and access their own transport.
37. The reaction to the individualised transport service was positive with 17 out of 20 young adults and their parents stating it was a good idea. However, there was concern that if the Review recommends providing too much support then it will prevent young disabled people from becoming fully independent.

Best Value Service Review Promotion of Independence - Young Disabled Adults – Report
Produced for Nottinghamshire County Council

38. Just under two-thirds of the young adults (13 out of 20) believe they are “independent”, the main reasons stated being that because they can make decisions and act upon them. Within reason 14 out of the 20 young adults believe that they can do what they like when they like. However, half (10 out of 20) would prefer to have more choice over what they can do.
39. The kinds of additional support the respondents needed (9 out of 20) to help them become more independent is:
- Extra equipment and physiotherapy
 - A befriending service
 - Transport
 - Respite care
 - Accessibility into buildings and facilities
 - Advice and information provision
 - Meeting people of a similar age
40. The majority of the young adults (17 out of 20) and the parents think that the County Council should have a stronger policy on promoting a positive image of disability and that they should be employing more disabled people.
41. The reaction to the proposal of setting up a cross county forum was very positive with 19 out of the 20 young adults and the majority of the parents stating it was a good idea. There was slight concern that the forum may be too broad and would not cover all ranges of disability sufficiently.

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