

national transition support team

working together to improve transition
for disabled young people

Case Study: Active 8 Gaining Independence

Introduction

**A consultation with 16 to 25 year olds with physical disabilities in Cornwall.
To be read in conjunction with the full report created by Josey Spencer, August 2010.**

Overview

Young people with physical disabilities often miss out on services and the opportunity to input into service design. A comprehensive consultation report produced by Active 8 was commissioned by Cornwall Council to seek the views of 40 young people who have a physical disability, with a particular focus on barriers to independence and their experience of transition.

Main transferable learning points

- Be clear about the language used when seeking to consult with young people. Often they do not see themselves as “disabled”
- Ensure that you have the right environment and support for young people to take part in consultation, be aware of any mobility or personal care needs
- Be clear and honest with young people – they need to know that you will take their views seriously and that they will make a difference
- Use the consultation opportunity to make a difference to individual young people if you can, the young people who took part in the Active 8 consultation were able to try new things and gain confidence

Introduction

This case study summarises the learning from a very detailed piece of consultation work carried out with 40 young people in Cornwall, aged 16-25, with physical disabilities. This summary should be read in conjunction with the full report, produced by Active 8 - a Cornish charity with 20 years experience of working with young people with physical disabilities across the county.

Background

The study was commissioned, by the Transition Lead in Cornwall, from Active 8. It was recognised that the voice of young people with physical disabilities had been absent from previous research and consultation exercises looking at the transition period. The consultation was planned to enable the participants to consider the ways in which they are independent, to understand how that had been achieved and to support others to attain and sustain independence.

Aims and Objectives

The aims of this consultation were:

- For young people to be able to voice their opinions about barriers to independence and possible improvements to the transition process
- Improvement in services for young people in Cornwall with physical impairments and disabilities by demonstrating good practice based on their experiences

- For the young people who participated to be left feeling empowered and positive about their experience

The report was written for the Transition Board. The consultation enabled young people with physical disabilities to express their views, opinions and to influence the development of services and structures within Cornwall.

Approach

Active 8 are very experienced at working with young people in a sensitive and constructive way and they adopted a careful strategy that:

- Agreed the criteria for taking part
- Publicised the request for referrals of young people to take part
- Gave potential participants information about what was involved in the process
- Provided individualised support to enable each young person to fully participate
- Piloted the methodology prior to the main consultation event

Challenges

A number of issues arose as potential barriers to a successful consultation:

- Young people didn't want to offend those who helped them
- Criteria for consultation: ensuring that the young people had a physical disability
- Geography: making it realistically open to everyone
- Time limitations : some young people were unable to attend due to family commitments or personal circumstances and the planning period was not long enough to organise care agency staff to provide personal care
- Use of language: Some people do not identify with the term "disability" or "impairment"
- Not wanting to participate due to "having had enough of talking about it"

- Young people's experience of decision making and knowledge of options available is limited

Mitigating solutions to all of these issues were developed ahead of the consultation event.

Successes

There were a range of successes related to this work. They included:

- Positive Outcomes for the young people who took part -
 - Gaining volunteer roles
 - Being referred to Volunteer Cornwall to gain volunteer placement
 - Agreeing with parents to be able to cook at home
 - Action plan to talk with parents about regaining independence that they had at college
 - Several new friendships made
 - Night clubbing was organised by young people
 - 2 people have tried power chair football with a view to joining the club
 - University design team contacted to design a "fizzy bottle" holder
 - Several people said they were inspired to try more
 - Several reported they hadn't realised how many areas or ways they could be independent
 - Signposting young people on to - Enable, Celtic Storm power chair football, Blind sports groups, driving assessments, Unlocking Cornish Potential
- Young people identified what was important to them in acquiring independence
- Young people developed an understanding of what needed to happen

to become and remain independent

- Young people identified good practice in transition
- Young people identified barriers to independence

Conclusion

This consultation process enabled an under-represented group of young people to articulate their views, to identify barriers and solutions to achieving independence, and to produce a set of recommendations for the Cornwall Transitions Board to consider.

How to...?

There were a number of limitations to this consultation, which Active 8 would like to highlight to help other areas:

- This study does not show, of those who have moved out of the county during the transition period, why they moved
- Participants are not representative of the numbers of people with sensory impairments or disabilities that do not affect their mobility
- The consultation is subjective, giving only the young people's views. There is no comparison with the perceptions of parents or carers
- Comparisons with national data are limited due to budget restraints. The consultation has been subsidised by voluntary efforts and reduced rates from facilities and professionals
- Since completing the consultations, another 10 young people have been identified as suitable to participate in this study

Organisations and Websites / Useful Resources

- <http://www.c4eo.org.uk/themes/disabledchildren/positiveactivities/files>
- <http://www.scie.org.uk/publications/briefings/briefing04/index.asp>

- <http://www.education.gov.uk/research/programmeofresearch/projectinformation.cfm?projectId=15812&type=5&resultspage=1>
- <http://www.education.gov.uk/research/programmeofresearch/projectinformation.cfm?projectId=15811&type=5&resultspage=1>
- National Service Framework for Long Term Conditions
- Better Care – Better Lives
- ACT transition care pathway
- 2005 Improving the life chances of disabled people – Independent review
- 2006 (NSF) Getting it right for young people

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National Transition Support Team (NTST)

NTST is working alongside the National Strategies and the Child Health and Maternity Partnership to coordinate the delivery of the Transition Support Programme.

NTST is based at the Council for Disabled Children (CDC), the umbrella body for the disabled children's sector in England. CDC is hosted by NCB. www.ncb.org.uk/cdc

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