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Children's Services to Adult Services understand
the process and what their choices are?

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The reports were completed between September 2009 and February 2010 and apply a wide range of research methodologies. They are not intended to be longitudinal research reports but they provide a snapshot of the views and opinions of the groups consulted as part of the studies. As these projects were time limited, the evidence base can be used to inform planning but should not be generalised across the wider population.

These reports reflect the views of the practitioners that undertook the research. The views and opinions of the authors should not be taken as representative of CWDC.

A new UK Government took office on 11 May. As a result the content in this report may not reflect current Government policy.

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ABSTRACT

This project research examines the understanding that young people who receive services from North Yorkshire Children's Social Care Disabled Children's teams, have of the process of transition to Adult and Community Services.

Young people who have been through the system and now use an independence group explained that the relationship they had with their social services transitions worker was of great importance and helped develop the questions asked to the interviewees.

A sample of young people were identified by their workers for the research and most were happy to share their experiences. Some of their carers acted as interpreters and all gave their views of the process.

The report highlights that many of the young people had no relationship with their transitions worker and indicates that parents are also often unable to identify a person to allay fears about the move to Adult and Community Services.

The report highlights the failure of both Adult and Community Services and Children's Social Care services to develop a meaningful relationship with service users so that they can participate in the planning process.

The report discusses the different needs of young people and their families whilst focusing on how to involve the recipients of services in the planning process, the majority of the young people interviewed did not know who their Adult and Community Services Transitions worker was nor did they have any clear idea of any choices they might have.

Other agencies (such as Education) seem better able to engage with the young people. Young people can take a meaningful part in planning for their own future, but need to build a relationship with the transitions worker before they can do so.

Young people with additional learning needs may need intensive or regular sessions with a worker in order to make sense of the system and participate in any meaningful way.

INTRODUCTION

Over recent years there has been growing evidence about poor transition planning and outcomes for disabled young people in particular which has led to the issue becoming an increasing priority on the government's agenda.

Aiming High for Disabled Children (AHDC), launched in May 2007, is the government's guidance for disabled children's services in England. One of the issues identified in AHDC was the need for agencies to work together in careful and coordinated planning to improve the transition processes and the experience of being transferred from children's to adult services for disabled teenagers.

To facilitate this, the Government announced the Transition Support Programme backed by £19 million over a three year period (2008 – 2011) (DSCF 2007) which would aim to raise the standards of transition in all local areas.

AIMS OF RESEARCH PROJECT

Existing research emphasises that transitions planning and processes are characterised by the inadequacies and inconsistencies of agencies, and research reports and journal articles frequently stress the need for an increase in multi agency collaboration and person centred planning around young people. However, repeated research over the last fifteen years appears to make similar recommendations, as it would appear that concerns continue to be raised by young people and their families about short timescales, and inconsistencies in planning for transition to adulthood for teenagers with health and support needs. These findings mirror those which examine the involvement of disabled young people in decision making in their lives (Mitchell, 2007)

The government's AHDC project was launched in 2007, built upon both The National Service Framework (2004) and Children act (2004) and is designed to improve service provision across the country. This research proposal aims to identify progress made locally over the first two years of Aiming High. This research will attempt to ascertain how a sample of young people and their carers are experiencing their own individual transition process and to reflect upon how planning for transition between Children's Social Care and Adult and Community services could be improved to facilitate a more positive process for disabled teenagers. It is this aspect of transitions which is explored in this research.

It is hoped that practical outcomes will be developed from the project, specifically to feed the views of young people and their carers directly into the local Transitions Support Programme and to inform the development of the new transitions protocol and action planning.

CONTEXT

There is a wealth of research which has been carried out around disabled young people with varying needs and the transitions process from child to adult hood. The research explored for the purpose of this review varied in its dates, in some cases back to the 1990's to the present day. However, what quickly becomes apparent is that the issues and recommendations

continue to be the same, which would seem to show that lessons continue to go unlearnt from this research.

In 1995, Tutt in 'Transitions - Children with a disability and their passage in to adult hood' looked at a consultancy with Essex SSD and concluded that Social Services needed to review their internal procedures and practices to 'ensure that young people with a disability receive a consistent and reliable service as they pass through the transition from child to adulthood'.

Nine years later a SCIE research briefing entitled 'Transition of young people with physical disabilities or chronic illnesses from child to adult service' repeated these findings. It stated that 'young people and their families must be involved at all stages of transitions and offered support, choice and information' and this must also focus upon the young persons strengths. It stated that it is vital that any plan is centred on the views, wishes and aspirations for the future of the young person, and that services and support provided at the time of transition should be seamless and enable the young person to go on to achieve greater independence. The work of Franklin and Sloper (2006) reinforces this in emphasising the need for involvement of young people at all stages of the process.

Franklin and Sloper (2006) showed that common concerns around the transitions process were the apprehension of young disabled people as they approach transition, the changing roles of family and carers, difficulties in securing employment, and the failure of agencies to work together to plan services and that there is a need for time scales and services to be tailored to the individual. It was also felt that an appropriate assessment of young peoples needs before and during the transitions process was missing followed by a shortage of appropriate services once they reach adulthood.

Caton and Kagan (2007) examined the transition experiences of young people with moderate learning disabilities, and concluded that these young people often had less fulfilled and optimistic experiences than their non-disabled peers who had a wide breadth of knowledge about the choices available to them. They also stated that in previous research it has been more common to assess the transition experiences of those with severe learning disabilities, and that this research found that despite the assistance provided to these young people from 'transitions teams' the experiences of these young people were disadvantaged, with low levels of unemployment, poor social integration and low levels of independence.

A general theme of all the research appears to be the need for agencies to work together in a timely way to provide a holistic approach where the young persons aspirations can be supported to ensure that their needs are met in an appropriate way, making sure that they are included and understand what is happening at every stage of the transitions planning process.

'A Transition Guide For All Our Services' published by the DoH in 2007 states that it provides key information for professionals about the transitions process for disabled young people, and tries to look at how best the 'most appropriate people' can be brought together to plan, agree and implement a local strategic transition protocol and identifies some of the difficulties in doing this. It states that the absence of this protocol is a '*key problem leading to the lack of continuity in provision across transition systems*'.

However, this research focused on the theory that the '*most appropriate people*' (young disabled people and their families) are frequently not the ones most included and informed

around the process, and that whilst it may be hard for them to have a positive experience of the transitions process with the best outcomes, we must all find a way to achieve this.

At present transition's workers where this research took place are based in Adult and Community Services teams. The effectiveness is considered within this research.

METHODOLOGY

The aim of this project was to inform discussion for local services and improve the experience of the transition process for service users and their families.

As the focus of this study is the experience of Transition from Children's Social Care to Adult and Community Services for young people in receipt of services from North Yorkshire Disabled Children's teams, we felt it was appropriate to involve young people from the beginning of the research.

We initially approached a group of young people with disabilities who attend a local independence group and have experienced the transitions process to tell us what they felt were the key questions which young people should be asked with regard to transitions. Four volunteers helped suggest questions based on this framework. These were then reduced after discussions to a set of six open questions focusing what the young people felt were the key issues of the transitions process.

Permissions documents and an information leaflet were designed in both word and symbol format to ensure that informed consent was obtained. A form was then provided to ensure reassurances for the young people about issues of ethics and confidentiality.

To find our research sample we approached workers from the three North Yorkshire Disabled Children's teams for introductions to young people in receipt of services who had been referred to Adult and Community Services Transitions workers.

The intention was to have a sample of three young people in each of the last three school years leading up to their eighteenth birthday. Three researchers, who work for the Disabled Children's Teams were to interview young people from an area other than the one in which they worked to reduce interviewer bias. The plan for the research was then forwarded to the Local Authority ethics committee who agreed with the proposal.

Two young people from the researchers' own caseload then took part in a pilot study, and the process and questions were modified slightly in response to this.

Certain external issues, including that a disproportionate element of the interview group were at the older end of the age group, resulted in the interviews being delayed. For the research a group of nine people eventually were interviewed consisting of four males and five females and a range of disabilities ranging from those who could verbalise clearly their views to two young people with profound disabilities who required carers to communicate for them.

Communication with the young people was facilitated by the carers. For some young people a simple explanation of the body language and young person's individual communication style was all that was needed whilst for others carers explained what the young person may have

meant. This of course had its own implications as the parent may have had their own agenda, conscious or otherwise.

All of the young people interviewed had their parents or carers present. This posed a number of issues. Some parents were extremely dissatisfied with the service provided by the transitions process, all parent / carers prompted the young people and filled in gaps as they felt fit. Ideally, all the interviews would have been taped but due to malfunctioning equipment, some of the interviews were taped, in others the researcher made notes and all were then transcribed for analysis. All information was kept safely, with hard copies and tapes locked away and electronically recorded information password protected.

A meeting of the researchers and a facilitator was then held and the information divided into quantitative and qualitative data.

All the young people who have helped with the project have been recompensed for their time with gift tokens.

FINDINGS FROM THE RESEARCH

The story boxes below give brief summaries of three of the interviewed young people's views whilst the response to individual questions gives a more qualitative analysis.

Story Box Adelle

Adelle aged 16, thought the questions were too hard; she could talk about the Connexions service and people she saw at her independence group, but had no idea about any body from Adult and Community services. Mum did not really mind the lack of involvement; she said that Adelle may need things explaining to her many times over a number of weeks before she fully understood it, Mum felt that the workers would have too big caseloads to devote that time to an individual.

Story Box Timothy

Timothy is fourteen and is on the Autistic Spectrum, his school invited the Connexion's worker to talk about his transition, Timothy thought he would have to leave school immediately and became upset. The Connexion's worker made a separate appointment with Mum and explained to her so she could then let Timothy know what his options were in a way he could manage. Neither Timothy nor Mum has met anyone from Social Care who talked about transitions.

Story Box Jane

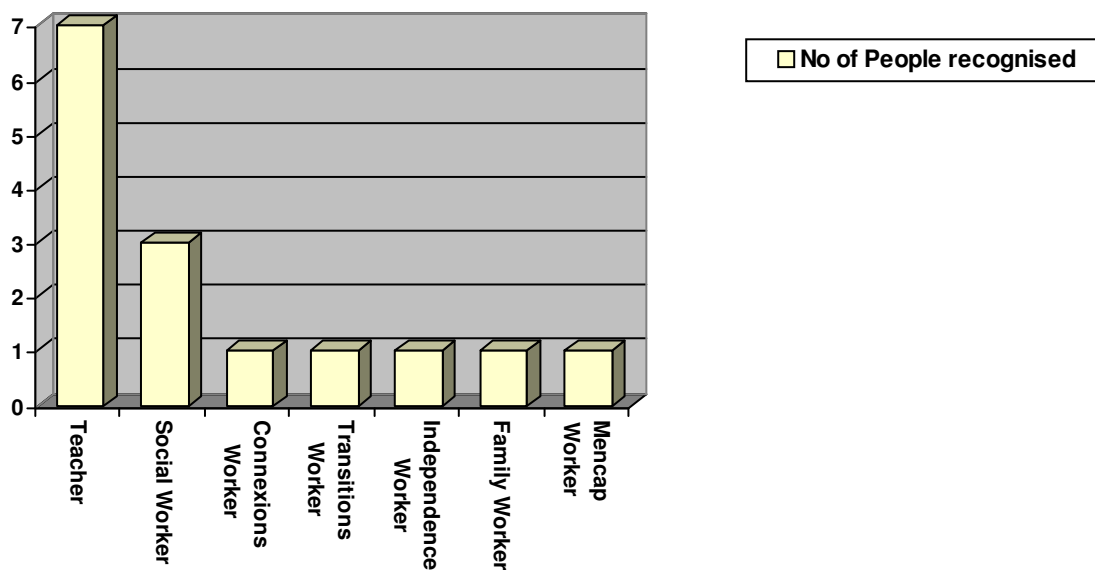
Jane will leave school this year, Jane says she does not know her Transitions worker, but that she will go to college, and then live at home. Jane's parents have had a house built for her; they have been helped to choose a college for Jane by the Connexions worker. They have met the Transition's worker twice, and asked about direct payments for Jane in October, four months later Jane and her family are still waiting for their worker to be trained in direct payments. Although Jane has a place at the college and believes she will attend, her family are waiting for a decision on funding as Jane's care needs are high. They are upset by the delay and uncertainty.

Some key areas have been identified as being important to transitions and were central to the questions asked in this research.

A total of nine young people were interviewed and the findings below identify their qualitative and quantitative responses to the questions asked in this research. Many needed prompting from a carer to respond.

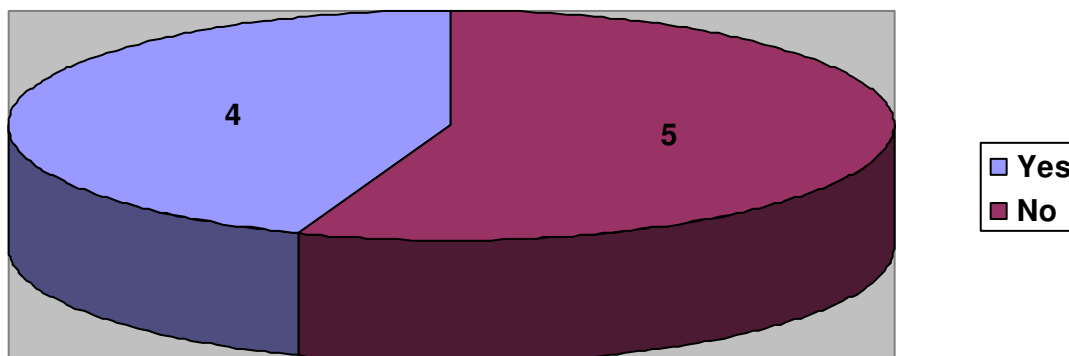
Question 1. Can you name the people who work with you?

Of the nine young people interviewed two said they could not name any worker. Of the remainder, the following responses were received as outlined in the graph below.



Question 2. Have you heard about transitions?

Number of young people who had heard/not heard about transitions.

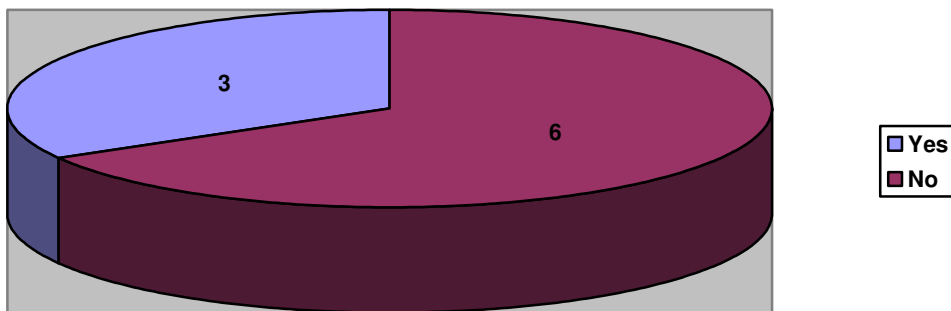


Many of the young people needed prompting but the feedback was by no means universally positive. One mother, referring to services received said “We are not offered a great service”. This parent had only met the worker once and had been left to draw her own conclusions that somebody would contact them in the near future. Another mother of a young person said that they had heard about a transitions event at school but had not been invited to attend.

A sixteen year old female respondent indicated that the transitions worker had attended her school review. Another however highlighted one of the complexities of the role when reflecting that her son felt that he had to leave school immediately in response to transitions being discussed. A sixteen year old male respondent said that he had never even heard of the word transitions.

Question 3. Do you know what a transitions plan is?

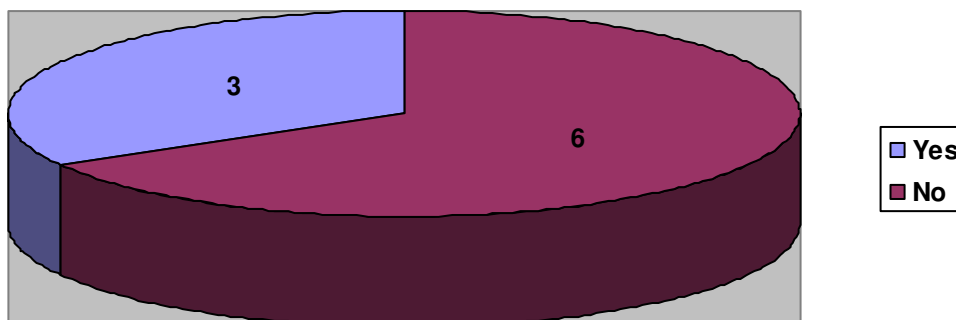
Number of young people knowing/not knowing what a transitions plan is:



Knowledge of this was minimal. The young people who did say that they knew what this was did not appear willing to expand upon this. When placed in the context of the transitions worker, one young person was able to state which school he wanted to go to displaying an understanding of the subject, if not the term, “transitions plans”.

Question 4. Were you involved in making your plan?

Number of young people who were involved/not involved in making their plan:



An informative comment came from a carer who said that information regarding options for the future tended to be given to parents rather than young people.

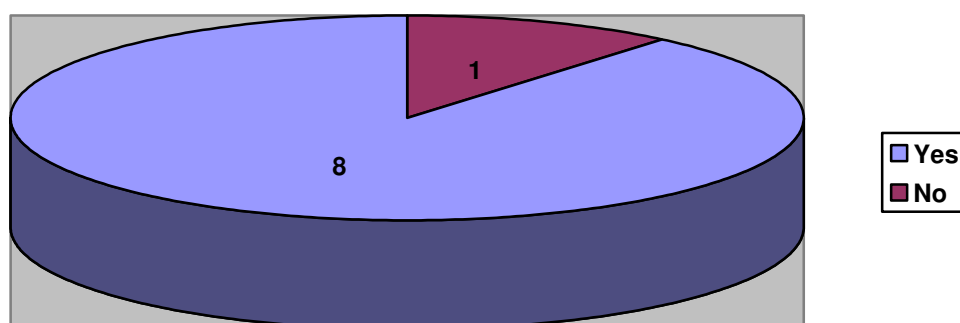
Some of the “no” responses to these questions however were not reflected in an underlying involvement of the young person which they do not appear to have understood.

One young person in this context had been involved in a trial stay over of one night at a potential future home for her. She did however understand that if she was unhappy with this she would not have to go and live there. This indicated some involvement of the young person in the plan.

Various people including Connexions had been involved in the plan, but not the young person. It appears that this was reflected in the experience of other young people. While they did not directly communicate that they were involved, their response to visits etc influenced their plan. One other young person appeared very clear about what they wanted following the transitions period.

Question 5. Do you know what you can do when you leave school?

Number of people who know/did not know what they could do when they left school:

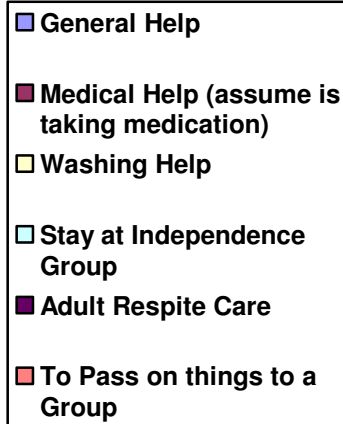
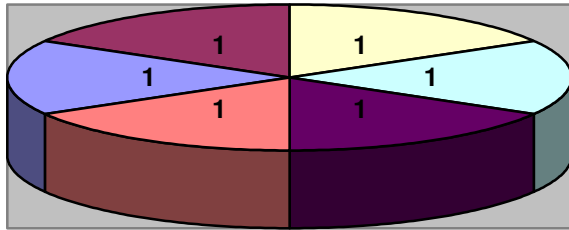


It appears that all the young people had a clear view about what they wanted to do when they left school. Seven of the eight who responded positively indicated that they wished to go to college, although it appears that several of them were very influenced by the prompting of their carers. One young person said that whilst foster carers were fully informed they did not have any direct information regarding living arrangements/accommodation options into adulthood. A mother commented that she did not know how long her son was entitled to stay at school.

While the young people seem to know overall where they wanted to go after leaving school they appeared unclear about either the process or their rights with regard to this.

Question 6. What services would you need at age 18?

Services needed at age 18;



The nature of the young people's response indicated a different awareness of their needs in comparison with what carers or workers might view as their needs. Continuing practical/care help was obviously key to several of the young people, but support groups were mentioned by two of them.

IMPLICATIONS FOR PRACTICE

Whilst transitions is now firmly on the Government's agenda and new initiatives continue to be introduced in a bid to improve the experiences of disabled young people facing the move into adulthood, there is an ongoing need for close monitoring and evaluation of the progress of these initiatives to assess their effectiveness.

This research highlights that the transition period for disabled teenagers remains problematic and it outlines just some of the difficulties that disabled young people and their parents continue to face whilst identifying that preparation for the process of transition could be greatly improved. The following factors appear particularly relevant:

The timeliness of provision of information

A recurring theme throughout our findings is that if accurate information regarding available options was given to the teenagers earlier in their lives they would feel there were choices available to them.

Who information is provided for

There is a need for practitioners to ensure that crucial information be given directly to young people rather than exclusively to their parents. Young people continue not to be actively involved or consulted regarding the options available to them when they leave school and decisions are being made by parents, at times contrary to the wishes of the school leavers themselves.

Who provides the information

It has also become apparent that the work of the transitions service is often being undertaken by other professionals working in children's social care or education and in external agencies such as Connexions. This needs to be clarified in order for consistency of service.

Young peoples understanding of information provided

It is clear from the research that young people in this sample struggled to comprehend the meaning or concept of many of the terms used regarding transitions. More work needs to go into ensuring that this occurs.

Other Areas and Issues

One key area highlighted by the interviewer was that young people received little or no information regarding their options for post-college. The majority of information about this appeared to come from Education Services. This view was backed up by another interviewer who commented "any plans young people are aware of, seem to be purely educational orientated".

Another important issue to place these responses in context is that it often appears difficult for a young person with a disability to see beyond the school world, and that in this context the term transitions means little in contrast to something more solid such as "leaving school".

For one interviewer in particular, much of the positive learning for young people about transitions came from knowledge of others such as brothers/friends who had gone through the same process. This might indicate the potential of introducing a peer mentoring scheme.

Conclusions

From this research we are able to tentatively highlight a number of areas for change, which would help improve young people's experience of the transitions process. Given the small size of the sample and the complexities of interviewing the subject group, a further exploration of the issues with a larger group would be needed before these conclusions may be viewed as definitive.

The very word 'Transitions' is in itself problematic. It is a concept, and can mean many things to many people, factor in that a number of the young people who were interviewed had additional communication needs and it becomes a word with no obvious meaning for many young people. By changing the name to such as 'Moving on' may make the whole concept more realistic for young people.

The young people interviewed appeared to have a better relationship with their Connexions advisors than their transitions workers. More needs to be done to look at these relationships to see what those in social care can take from this. It is also vital that the two services work better together, as education post 18 and adult social care are not mutually exclusive.

A major finding of this research is the poor relationship between the young person and their families and the transitions workers. It is vital that the young people are engaged in the transitions process and are able to play a meaningful part in the planning of services which will

have a huge impact upon the rest of their lives. In order to achieve this, a good, trusting relationship needs to be built up by the professionals involved. As the research shows, it may take a number of meetings for the young person to understand the process, and this can only be made easier if they are able to communicate easily with their worker.

The need for this long term relationship could be argued as one of the reasons that it would be beneficial for the transitions planning process to be led by Children's services. The workers there may have known the families for a number of years, and given that transitions is known to be a stressful time, it might feel more comfortable for families to have a familiar face to approach for information, than to introduce new workers at this already difficult time.

One way in which the methodology of this research could have been improved would have been to spend more time getting to know the young people, to be better able to understand their methods of communication. The researchers were very reliant upon others advocating and communicating for the children. At times it was difficult to tell whether these were truly their views or that of a frustrated parent which clearly inhibited the validity of the research.

Whilst the Government appears to be putting transitions planning high on their agenda alongside 'Aiming High for Disabled Children' a commitment also needs to be made to putting in place increased staffing to reduce case loads which would enable workers to form a relationship with the young people they are working with. Without this, the ability to communicate with young people will be inhibited and in many cases the concept of transitions, according to the findings within this research remain meaningless to disabled teenagers.

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