

It's MY Journey

following on



2009

“I’m at college now. On Mondays I do social activities, Tuesdays holiday planning and Thursday IT. I get on fine at college. I get the bus in and I manage to find my way about fine.”

“In the future I want it just now going along as it is. I would like to do more art. In the long term the aim is to live independently, in a flat.”

Introduction

This report is a follow up to 'It's My Journey' (Highland Children's Forum 2007) which was produced from a consultation with 44 young people with a range of support needs who were somewhere in the transition process from children's services to adult services. The consultation was an early stage in a multi-agency project, a 'Vision for Transition' (Highland Council 2006), which sought to develop policy, procedure, guidance and tools to improve the experience of transition in to adult services for young people with additional support needs. The consultation report, 'It's My Journey' (2007), ensured that the voice and experience of young people with additional support needs was the foundation for the development of the rest of the 'Vision for Transition'. In fact the report not only influenced the development of policy and guidance but a range of other outcomes as well. The good practice of this multi-agency young person centred approach has been acknowledged with a Highland Council Innovation Reward (2009) as well as receiving national and international attention. This report will briefly describe how the voice of the young people was able to contribute to these outcomes.

It was recognised that transition in to adult services was not a one off event that occurred on leaving school, but actually was a process over a number of years. The young people who took part in 'It's My Journey' were asked when giving consent if they could be visited at a later date to find out how well they had made that transition in to adulthood. It was not possible to contact all 44 young people but those who could be contacted were interviewed to find out about their lives now. One or two individuals who had not been involved directly in the original project but who had shown interest in it were also able to contribute their experience. This report tells their story.

“I am now in first year of an HNC in child care. I am also working as a care assistant. I qualified as a care assistant.

I left school early and it didn't really help. But my youth worker helped me get in to college.”

“On Wednesday night we go to a club at Glachbeg Farm. We are talking about recycling and composting and stuff and we do games and baking and we have had two bands playing for us.”

Key Issues Raised

- Most young people had moved on to be active and involved in something, no one was still at home with nothing to do.
- Those who had been contactable in the More Choices, More Chances group had made a successful transition.
- Young people with learning difficulty were frequently only in part time education or activities and without future planning for work or volunteer placement.
- Almost all young people aspired to independent living but only one young person had achieved this.
- Social opportunities for those with learning difficulty or significant physical disability were often limited to specialist groups.
- The young people knew what the health messages are but did not always choose to follow them.
- Young people were able to access a GP service if needed.
- Young people were not always able or willing to access a dental service.
- The loss of physiotherapy in particular and other allied health services was a substantial loss to young people with significant disability and was a cause of anxiety for them.
- Training of carers in the personal care, medical care and communication needs of the young person is essential.
- There is a limited range of options for young people with significant learning or disability issues; this is worse in the more rural areas.
- For young people with significant needs the lack of respite in adult services (sometimes a year or two without any break) is difficult. As the young person is often also at home more during the day this can be even more stressful.

“I am happy just the way I am and just enjoying my life.”

“My mum and Granny showed me how to grow up.”

“I’d like to learn about being a mum and adults things.”

“I could do with more help to plan, someone from college maybe, I can’t remember their name. I am planning with people [at the club] to do forestry things, planting things. I would like more help from people like the Shirlie Project. If I needed help I’d probably ask my mum.”

The Vision for Transition

The post of Transition Co-ordinator was set up in 2006 by Highland Council, with the role of co-ordinating efforts to develop Guidelines, Policy and Procedure and also interactive tools to assist the process of transition for children and young people with additional support needs.

A multi agency group was set up to steer the post of Transition Co-ordinator and they developed the 'Vision for Transition'.

From the beginning the importance of listening to young people with additional support needs who were either currently experiencing transitions planning or who had recently gone through transitions was recognised as essential to inform the development of all other aspects of the 'Vision'.

'It's My Journey' (2007) drew key factors from the testimony of the young people about what had helped them, what had not been so helpful and what they thought would have helped them. This was shaped in to advice which was used in the development of the Joint Transitions Policy and Procedure (2007) and the Transitions Guide (2007) which provided both guidance to parents and practitioners as well as practical tools to help young people be involved in their own transitions planning process. The publication, 'It's My Choice' (CHIP+2004) which provided information about opportunities and services available to young people with learning difficulties was updated and expanded to include information for a wider range of young people. (It's My Choice 2007).

However, beyond the initial 'vision' young peoples' experiences also indicated other specific needs of particular groups of young people. This led to the development of a number of different transitions supports as listed below:

- My Learning Record (an initial curricular transfer record for mobile Travelling children)
- Initial Rapid Assessment Guide (used in conjunction with the My Learning Record for out of school settings)
- Going places (to design an individual intervention for teenagers on the Autism spectrum who have little or no experience of independent travel)
- Work Experience for Young People who have Autism Spectrum Disorder (to more effectively prepare pupils with ASD for work experience and to prepare the employer for receiving the young person with ASD on placement)

“But I have been getting down about friends around here. I joined the church and some of my friends think it is gay and they don’t know why I go. I get made fun of. In the past I said a lot of things, that is what has brought it about. I’ve forgotten about the past it’s the future I care about.”

About a transitions fair:

“Yes coz u would need you know.”

“I would like to know more about jobs.”

“I would like to know more about money.”

- Transitions Bridge (a tool for use in the transition process to support an information bridge between the GIRFEC Child's Plan and the Adult Personal Plan)
- Tool Box (an online resource with a range of material including practical tools to promote the involvement of children and young people in their personal planning as well as in service evaluation and policy making)
- Developmental Coordination Difficulties Primary to Secondary School transitions (a pack to assist young people in moving from primary to secondary education when Developmental Disorder is seen to be a challenging factor)
- Transitions Fair (an annual fair providing information about opportunities and services for young people in transitions, now held in two areas in Highland)
- Transitions pathways in health services (a plan to improve the transition of young people from children's to adult's health services)

The combined work involved a range of young people, parent carers, agencies, professionals and practitioners across Highland. This coordinated approach was recognised in the awarding of the Highland Council's 'Innovation of the Year' Award 2009. The combined work of 'It's My Journey' and the rest of the 'Vision' has also been viewed as an example of good practice nationally by 'Partnership Matters' looking at the support for young people going on to college or higher education and by educational psychologists at their national conference. The methodology of the consultation process and its consequent findings are under consideration for an international academic publication.

Currently the online toolbox is under development to enable the tools in the young person's transitions guide to be used interactively online. There will also be an online resource of information for young people in the transition process.

The Vision for Transition always recognised the need to follow up young people who had taken part to find out how their transition had panned out after the initial consultation had taken place.

This follow up report describes the young peoples' stories of how things have worked out for them out of school and what they hope will come about in the future.

*“I work in a supermakret now, full time. I am a parent. I have a wee boy, 8 weeks old, he was a happy accident. Before him I couldn’t give a s*** but now I know I need to work to support him for the next 16 years.”*

“Where they proposed to put [my daughter] at transition was completely unsuitable. The speech therapist and physio visited and said it was not suitable. There is a facility in the area for young people with behavioural problems but not for those with a disability, they have no where to go.”

Young people's Stories

Young people who were willing to be visited for a follow up interview were asked to tell their stories about what is happening in their lives just now, in terms of their access to training, employment or other facilities, where they are living and who they are living with, where they socialise or spend their spare time. They were also asked about their planning after school, how they plan for subsequent transitions. Young people were also asked about where they saw their life after school going, what were their hopes for the future. It was recognised that in 'It's My Journey' the transition through health services had not been fully addressed and so young people were asked more specifically about their experience of health services. (Further consultation on health was also carried out by the Interagency Nurse Consultant.) Finally young people were asked to consider the process of transition and to reflect on how well it had met their needs.

12 of the original 44 participants were able to provide their own follow up stories in personal or phone interviews, 2 from the "More choices, more chances" group and 10 from those with learning or physical disability and/or communication difficulties. One of the original participants from this group is now in prison and not able to be contacted. The two parents who had participated on behalf of their son/daughter in 'It's My Journey' provided follow up stories. 4 different young people from the Gypsy Traveller community took part through a focus group activity. Follow up contact details were not available for the participants with autistic spectrum disorder and so they could not be contacted. The staff who had involved the participants who were in the 'through care after care' system had moved on and so these young people were not contactable either. One young man who had not wanted to participate in the original consultation asked to be involved this time. One parent in a more rural area wanted to contribute the story for her daughter who has complex needs because she felt opportunities were lacking in rural areas. The original project had failed to involve anyone with vision impairment but one participant came forward for this report.

The initial project had been restricted to the Dingwall and Inverness area. It was recognised that this would not represent experience elsewhere. It's My Journey had a questionnaire at the back which it was hoped young people might use if their experience was very different. Only one parent of a young woman with complex and profound needs living in a rural area requested to describe her daughter's experience.

“I left college to do part time landscaping. They asked me to do more and now I am full time. I use maths at work, when making patios. I plant trees and shrubs, mow the grass. I get myself up with my alarm clock and get the bus to work.”

“I’m at Nansen Highland four and a half days. Saturday and Sunday I’m volunteering at the pub on pub duty. Nothing has really changed in the last year or so. Still living at home with my brother. Social life is the same. I go to YOFI when I can get the transport.”

What young people are doing now:

From the “More choices, More Chances” group, one young person has gone on to qualify as a care assistant which she still does part time while also studying for the first year of an HNC course in child care. One young man was now in full time employment and had recently become a parent. This had had a huge affect on him and although previously he had not really cared about what he was doing or where he was going, he was now very focussed, recognising he had his son to support for years to come. He hoped to access an apprenticeship or do other training in the future to improve his job prospects.

Only two of the young people with learning difficulty were occupied full time, one young lady who has complex and profound disability attends a day centre five days a week and one young man had successfully landed a full time job. All of the others had a range of activities they accessed on different days but all had days or half days at home without anything to do. Most of these young people accessed college one or two half day sessions a week, but there did not seem to be much choice available in terms of the subjects they were taking. It was also not clear if these courses were to prepare young people for a job, to widen their life skills or just an ‘out of school’ leisure activity with no particular purpose or hoped for outcome. It seemed that young people would return to college and choose to do one or two of the available subjects year after year with no end destination in sight.

Some young people accessed specialist placements (such as the Nansen Project or Cantray Bridge) and reported enjoying these. Some attended day centres (such as the Isobel Rhind Centre or Cheshire House) these were not as acceptable to the young people. The activities on offer did not seem to hold the same appeal.

Some young people had taken on volunteer placements hoping that it would lead to employment, but this had not happened.

For those young people who had significant needs and who required personal care, getting the right sort of care package had been difficult. This sometimes restricted the hours they could access college if toileting was required. Sometimes there were not the facilities for personal care or the medical care needed by some (for example, those with epilepsy).

All but one of the young people still lived at home. The young man who

“I am no longer at the Blitz, my time there finished. I am not doing anything else just now but have moved in to my own flat; getting set up here was hard work. My family and friends call round all the time. Some of them help me as carers, cleaning and that. I have to manage my money.”

“I keep in touch with other people through Bebo. Quite a few girls on my Bebo page are upset or sad. I give them advice. I get replies in capitals saying ‘YES IT WORKS’. I am a love counsellor, I’m good at helping with that. Even though I have never had a girlfriend myself, I can help others.”

had moved in to independent accommodation had found that process demanding of his time and energy and he had not managed to apply for college or look for any other placement while he had been moving. He was now managing in his own house with support from carers. He could cook himself but tended to opt for microwave meals. He is regularly visited by friends and family members. Once he is settled he hopes to apply for college next session.

Socially, some young people went out with friends; some were involved in a church. One young man volunteered at a local hotel as a security person. Most of the young people who had complex needs and or mobility issues had one or more sessions a week with a carer who could take them out somewhere or help access hobbies or other activities. This might be a pub lunch or the chance to go shopping or something.

Most of the young people with learning issues socialised within their own specialist youth groups. Some young people had tried the leisure groups offered to adults with learning difficulties such as drama groups. The proportion of much older people at these clubs had been off putting and all 3 of those spoken to had withdrawn.

The Plus One scheme which allows a carer to go free when accessing council facilities, such as the swimming pool, is helpful.

One young man whose social life was restricted not just by his own additional support needs but because of other caring issues at home, had made friends through social network sites. He had been able to interact with others on these sites and even offered people advice when they were feeling low or struggling with relationships, even though the young man himself has never had a girlfriend. People had responded positively to his comments and seemed to appreciate having someone caring listen to them.

The young man who had left school and whose parents had accessed Independent Living Fund and Direct payments to plan a busy week of learning, volunteering and other activities for him was continuing as before.

“There are no plans to follow up the childcare things I wanted at school. No one helps me plan now. Hopefully I’ll go back to college again next year. In our courses you can go as long as you want. I would like to get a job.”

“Life is OK. I’m happy at home just now but maybe later I will live somewhere else, a flat or something with helpers. No one is helping me make plans for next year or after that. I will wait till the end of the year. I don’t have any other ideas.”

Planning

In It's My Journey some people had left school without a plan and sometimes had nothing to do during the day. However, each had some support making plans later and are now accessing college or other placements. Support had come from someone such as a social worker, community nurse or youth worker or from voluntary organisations such as the Shirlie Project.

Some young people had not had support to do any further planning after the initial plan for the year after school. This was sometimes due to a change in social worker or a gap between social workers.

For those young people with learning difficulty or complex disability, it was not clear if anyone was supporting these young people look at a future further than the next year. Young people still held other aspirations about work or volunteering (things like child care/security/office or shop work) or to develop hobbies such as dance or film making or travel but did not seem to know how they could progress those aspirations.

Most young people did have an aspiration to live independently at some stage but did not seem clear when this would be likely to happen or who would help them move towards this independence.

Involving young people with communication needs in their own planning was sometimes hindered either because a parent/carer spoke for the person or where the young person did not have experience to understand the choices offered.

In planning it is really important that new carers have the right information and training to both communicate with the young person and meet their medical and personal care needs. One agency trained 15 of its workers in both the communication method and medical needs of the young person before taking that young person on. Other services have not had that foresight and there have been difficulties for the young person as a result including one case where the young person is tube fed and someone tried to feed her causing her to choke.

“I have not had a social worker for five months. Mum gets no help with forms and benefits. It is hard to manage. Planning is just not happening. The Community Nurse changed. The other one moved things on a bit but not this one.”

“I never got any physio at all after I left school. I got it 4 times a week before. It helped with muscle relaxant and body relaxant. It made me feel great. It makes me sad. I think the health board are going to have to spend a lot more money on operations for my contractures. My muscles are tight and painful.”

Funding

Getting the right benefits and managing money were issues raised. Some young people managed their own money, paid their own digs, and even if living at home bought their own food and paid their own transport and other costs. Others had no experience or limited experience in managing money.

There had been challenges in getting Independent Living Fund or Direct Payments for those young people with significant support needs. This seemed to be dependent on having a parent willing and able to get the forms and complete the application. The long term employer's liability involved in Direct Payments was a disincentive.

Health

Young people were asked about how they managed their own health. Alcohol was one aspect mentioned by most of the young people taking part. Some chose not to have any alcohol at all, one or two reported taking an occasional drink. One young lady admitted to having had a problem with drink which she had got help with and was now managing.

All of the young people recognised the health benefits of regular exercise and a healthy diet, but most admitted to opting out of this from time to time or even most of the time.

Almost all of the young people accessed a GP service when needed, although some of the young people with learning difficulty were not sure if they would be able to do it themselves or if they would ask their parents to do it for them.

Only a few young people listed the dentist as a health service they accessed. When asked some could not remember the last time they went to a dentist, some did not choose to go because they didn't like the dentist and one had been trying to access a dentist and had been unable to do so.

The allied health professionals, physiotherapy in particular, seemed to vanish after school. For those young people whose disability this leaves them vulnerable to contractures, which is a great worry to them. They know from past experience that this can lead to painful operations. The

“I have not been able to get a dentist. I asked my social worker about the dentist, she is looking for me now. I was on a waiting list I think but my social worker changed. I would go to my doctor if I needed to.”

“Sometimes I don't sleep as the voices I hear trouble me. If I get up in the night to eat something they trouble me, try to get me to do something. I ignore them. Then I need to sleep in the morning. I hadn't seen my GP in a while but the Community Nurse came to see me and made an appointment with the GP. I haven't seen my dentist in ages.”

parents and carers are given exercises to do with them but young people still feel that there had been deterioration without physiotherapy sessions. One mother had fought on behalf of her daughter and managed to get a physiotherapist. One young man had had an operation on his foot which had given him a few weeks of physiotherapy which he had felt enormously beneficial. One young man pointed out that the cost of future operations to correct contractures would be greater than the intervention of physiotherapy now.

Sessions at the swimming pool was seen to be helpful in preventing contractures, but sometimes this could not be accessed as the young person required a second carer to be safe swimming or because there was not a suitable hoist available.

For some young people with significant health issues the handover to the adult service had been well managed and they had established a good working relationship with the adult consultant. No one reported the handover to be difficult, but for some people the specialist consultant meant that other health needs were not being addressed. For example one young woman has a consultant for her epilepsy but is not under a consultant for her recurrent chest infections which cause her to require hospitalisation from time to time.

One young person had mental health needs as well as physical health needs. He was not always able to judge when he needed help. There is now a community nurse visiting him from time to time who is able to help him access other health services when he needs them and to give him advice about his health. When this advice does not appeal to him he tends to ignore it.

“I’d like to go to college to study first aid. I’d like to do something about security, I don’t know if there is a course. Nansen will help. I told them what I wanted and they are looking in to it now.”

“Key Housing took 15 people and got them trained both medical training and Makaton. They did it straight away but no one in school has done it yet. For first time in years [my daughter] has gone out and when they take her out I can trust them and relax.”

Conclusion

It was a great pleasure to meet up with young people two years after the initial project. It was wonderful to see that even those who had endured a difficult and stressful time after leaving school without any plan or without a funding support package in place and had each moved on to find work or training or to have some sort of supported activity during the week. It is frustrating that this journey was made more difficult by the gap they encountered on leaving school. The young people's resilience, flexibility and optimism were evident in their stories. It was especially heartening that those young people in need of "More choices, More chances" had gone on to find work or training.

However, the additional support needs of some of the young people, especially those with learning difficulty, clearly restricted the choices available to them. Many young people seemed to be fitting in to the support services available rather than realising their own aspirations and potential. There seemed to be a revolving circle where young people continued year on year in part time college or other placements without any future destination in sight. The aspirations of these young people are not so far fetched. Person centred planning might allow these dreams to be realised. The young woman who had wanted to do child care, while perhaps not able to count in terms of adult numbers, would none the less be a real asset as a volunteer in a childcare setting. The young man who was interested in security already volunteers at a pub and may well manage a more regular security role.

For those with significant personal and medical care needs the funding for support packages and the lack of suitable opportunities continue to limit the possibilities for these young people. The lack of respite adds to the strain for young people and their parent carers. The best outcome seemed to be when well trained support workers who understood the needs and could engage with the young person could take them out and help them manage some of the activities they wanted (such as swimming, shopping, enjoying outdoors). The loss of physiotherapy and other allied health services after school was a real problem and cause of anxiety for those young people who feel they are in need of these services.

The number of young people no longer accessing a dentist is something that has been taken on board by the dental services and they are seeking to ensure that in future dental care is considered in transitions planning.

Overall, the most positive resource available to young people with additional needs is themselves. They have shown a remarkable determination to meet adulthood and move forward in to it with hope for independence in the future. Service providers should be moving towards person centred planning which should build on that optimism and allow young people to achieve their potential.

“I left school suddenly before the end of term and didn’t have a plan. I wish I had stayed. The teacher at school was helping me. I do stay in touch with her.”

“I was volunteering at the COOP for a trial period; but they didn’t take me on. My job is my first priority, I don’t want to be thinking about anything else. My social worker has helped me and my foster family. One day I would like to live on my own but not yet.”

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