A MULTI-AGENCY CONSULTATION PROJECT WITH YOUNG PEOPLE WITH SUPPORT NEEDS AT THE TRANSITION BETWEEN CHILDREN’S AND ADULT’S SERVICES

Gillian Newman, Sam Collyer, Marea Foulis and Simon Webster
The Highland Children’s Forum

Abstract
This study involved 49 young people with a range of support needs who told the story of their transition from secondary school to adult services. A range of media was used by the young people to tell their story including oral, video, writing and photographs. Researchers used a set of topics such as outcomes and meetings, to facilitate this process. The young peoples’ stories were analysed to look for themes that identify good practice which supports transition, the barriers young people face and strategies young people say would improve transition. This consultation study contributed to the development of new Transitions Policy (The Highland Council, (THC), 2008a), Transition Procedures (THC, 2008b) and Transition Guidelines (THC, 2007) in Highland. The young peoples’ transitions stories and the key points raised were also published in a report called “It’s My Journey” (Highland Children’s Forum (HCF), 2007a; 2007b.).

Introduction
There has been growing acknowledgement of young people’s right to be consulted with and included in any decision making that affects them. This right to be consulted has increasingly been reflected in legislation, in Scotland legislation such as The Education (Additional Support for Learning) (Scotland) Act 2004 (Scottish Executive, 2004) which introduced a duty on Local Authorities to provide transition planning support for all young people with additional support needs. The Children’s (Scotland) Act (United Kingdom Government, 1995) places a duty on service providers to listen to the views of children and young people when taking decisions which affect them. An important recent driver that has contributed to increased involvement of young people at the level of local authority decision making has been the introduction of a less prescriptive structure through which Scottish Government funds Local Government: the Concordat (Scottish Executive, 2007). National Government has set outcomes in the Concordat for local authorities, which also require evidence of consulting young people to identify if the outcomes have been achieved. Within this context the Highland Council employed a Transitions Coordinator to assist with the preparation of a new transitions policy and procedure and accompanying guidelines. The Transitions Coordinator met with a number of professionals working with young people and also with the Highland Children’s Forum, a charity whose aim is to ensure that children and young people in need are listened to and represented. The Highland Children’s Forum had the issue of transition raised to them by young people and were keen to research this further. This multi-agency group decided that a consultation with young people with a range of transition support needs about their experience of planning for adulthood would be conducted. The primary aim of which was to inform the development of new transitions guidance for professionals but also contribute to the small but growing literature on consulting with young people with additional support needs about the services they receive. (See Woolfson, Harker, Lowe, Shields, Banks, Campbell & Ferguson, 2006, for a summary of current literature).

Professionals in different agencies were asked to consult with young people they support. This ensured that consultation with young people was undertaken by professionals with whom the young people had a trusting relationship and the professional had an understanding of the young person’s specific abilities and challenges.
The resulting stories expressed through various media were analysed using inductive thematic analysis. Common themes that emerged from and among the young people's stories were identified. Where a particular young person's story was significant for highlighting specific good practice or gaps and barriers to service those issues were also included. The consultation topics provided a degree of structure that framed the analysis. The advice gathered has informed a formal report and steered the development of new joint Education, Social Work and Health Services transitions policy, procedure and guidelines (THC, 2007; 2008a;2008b) in Highland. The consultation is also informing the development of a transition protocol (THC, 2008c) dealing specifically with transition within health services.

The project

The main condition for selection for the project was that the young person should have been involved in some form of planning for adulthood during the past 3 years.

Participants

Forty-nine young people aged 14 to 25 years of age with a range of support needs participated. Twenty-three young people who ‘need more choices and chances’ took part. This group includes young people who persistently truant, young people with mental health problems, young people with low attainment, young people with offending behaviour, young parents, young people with drug or alcohol problems and young people who are not in (or have recently been out of) education, employment or training (Scottish Executive, 2006). Twelve were male, 11 were female and they ranged in age from 15 to 18 years with one participant in their early twenties. Sixteen young people (9 male, 7 female; 16 to 24 years of age) ‘with disability’ including those with learning disability, communication difficulty, hearing impairment, physical disability and complex and profound disability participated and also 6 young people had autism spectrum disorder. Two young people from the ‘Gypsy and Traveller community’ and two ‘Looked After/Leaving Care’ young people also took part; one of the young people with disability was also ‘Looked After/Leaving Care’.

Where the learning support needs of an individual meant that informed consent was not possible, or they were under 16 years of age, consent was sought from parents who answered for the young person if they were unable to answer for themselves. Two young people with profound learning and communication difficulties were represented by their parents.

Data collection

It was decided to offer a range of different media for young people to tell their story, as they had a range of learning and communication needs. This reflects the Mosaic Approach (Clark & Moss, 2001), which suggests that when you are involving children (or in this case young people with some learning and communication challenges) a much fuller picture can be obtained by enabling participants to choose the media to express themselves. Consultation topics (Appendix 1) were agreed between the agencies. Topics included: outcomes, understanding of transition planning, meetings, information and ‘ownership’ of the planning process. In practice, questions could not be asked of all young people on all topics.

Each professional working with young people adapted the questions to the needs of the young person involved and used a slightly different method or offered different media to suit the participant. These included face to face interviews, video or photo diaries, and for one participant an interview over MSN messenger. For example, interviews were used with young
people who ‘need more choices and chances’, and questionnaires were used to gather the views of the young people who were looked after or from the Gypsy and Traveller community.

For young people with disability, three special needs schools, two special needs leisure clubs, the Vision Impairment Service and the Deaf Education Service were all approached along with members of the Highland Children’s Forum to identify possible participants. Potential participants attended a face to face interview in order to explain the project and ensure understanding for informed consent to be given. These young people were offered the opportunity to take part by telling their story, based on the consultation framework, in writing, by being interviewed, by making a video or by using a disposable camera and commenting on the photographs. The mother of one of these young people said that he liked video and had enjoyed being in a video previously, and when asked he agreed to a video being made of his story. Two young people chose to make a video together. Three other young people made an individual video each. Two young people chose to do a joint slide show from the photographs they had taken, and also participated in an interview each. Six other young people chose to do an interview, and four of these planned to use photographs as well but did not return the disposable cameras. Of those young people who chose to be interviewed, one was visited at school, one at the local leisure centre, four at a specialist youth club and two were interviewed at home. One young person chose to type up her own story around the consultation framework.

One young man expressed an interest in being involved in the filming and editing of his video. This young man is severely disabled and had left school with no support package or planned activities. Funding was sought from the transitions budget to acquire adapted equipment and involve this young man in the filming and editing of all the videos for this project. Training was also given to him.

Those participants who had chosen video were helped to plan a story board using the consultation framework. Arrangements were then made to visit them in their chosen locations and film there. Those young people who wished to make a slide show were also helped to plan what they wanted to take photographs of within the consultation framework. They were then given a note of this and given two disposable cameras each. Only two young people returned the cameras and chose to make a slide show together.

The Transitions Coordinator was also able to arrange a weekend in an activity centre for five of the young people, where discussion groups around transition took place along with activities. This weekend was filmed and the video is included with the other videos on the “It’s My Journey” DVD (HCF, 2007b). The transcribed discussions from this weekend were analysed with the other results to look for common themes.

Analysis

The stories of the young people were transformed into a narrative and taken back to the young people for their approval and changes were made when requested.

There was considerable overlap between ‘understanding transitions planning’ and ‘feeling ownership’ of the process. Responses to these were amalgamated in a new theme: ‘getting the right support’.

The main points were summarised for each theme under the headings “What does help”, “What is not so helpful” and “What could help”. Responses to each theme were further grouped by additional support needs to see if the issues for young people varied with the type
of support need. Where a young person had more than one support need, the response was attributed to the support need deemed most relevant to the comment.

Responses are summarised below. Fuller details are available in the report “It’s My Journey” (HCF, 2007a).

Findings
The findings are outlined below under each of the consultation topics.

Outcomes
The young person’s own confidence and ability to influence decisions and their understanding of their additional support needs seemed to affect their personal outcomes. Those who were able to make clear what they wanted were more likely to achieve these than those who needed support or were not sure of what they wanted or needed. Some young people’s additional support needs severely limited the choices in training, employment or even in social opportunities after Children’s Services; this was especially true of young people with complex needs. Young people were disappointed when an expected outcome, described in a plan, did not work out. Some young people left school with no plan in place, being left at home every day for a period of time. These young people were well known to services, often from birth, and so this delay in planning is difficult to justify.

Young people felt work experience was hugely important in helping them develop confidence and be sure of decisions. There was a feeling expressed that there should be more work experience available. Young people also expressed the need for more practice and experience in learning life skills especially managing money. An example of good practice cited by the young people is a leavers’ programme in one of the specialist schools where young people had the opportunity to try out a range of work and social experiences.

Social opportunities can drop off after Children’s Services for those with the more complex needs. Transport and lack of funding contribute to this difficulty.

Good practice identified by the young people for health service transitions was when the adult consultant/health professional had seen the young person while they were still seeing their paediatrician, so that the change was not abrupt. Several barriers to a smooth health transition were raised. For example, some of the Allied Health Services such as physiotherapy ceased abruptly when the young person left school; some medical equipment, even when made to measure, was reclaimed by children’s services. It was suggested that medical equipment should follow the young person and that a service deemed necessary for a child should only cease in adult services if the assessment of the young person’s health needs change.

Meetings
Young people had been involved in different types of planning meetings. They reported that they generally preferred to be actively involved in their own planning. Person-centred planning meetings where the young person is able to make and express their own choices and hopes are preferred by those with experience of these meetings. They want to be able to invite people to the meetings and feel they need to be better prepared for meetings in advance.
Information

Some young people did not seem to get very much information or support through the transitions process. Some did not have access at home to the phone or a computer and saw this as a disadvantage. Information about the support available in higher and further education does not seem to be easily available to young people with particular needs such as signing for someone with hearing impairment. Parents were not always aware of changes in benefits at transition or other changes such as the need to return medical equipment or apply for legal guardianship. Some young people felt they needed guidance to find their way through the information.

The booklet ‘It’s My Choice’ (Chip Plus, 2007) was produced (replacing ‘It’s My Choice’, 2005) as a response to this consultation and provides fairly comprehensive information about opportunities available, in an accessible format.

Getting the right support

For some young people, decisions seem to be taken for them or they feel forced out of school or in to something different. Some young people felt the choices made for them were good but others did not think so. Choices seemed to be limited especially for those with more profound disability.

A number of young people, mainly those who had been or were not in education employment or training after leaving school, found having one consistent support worker throughout beneficial. The key worker from the careers service provided support for planning, in organising and completing applications, and even in some cases transport to training.

For some individuals who require a complex care package, lack of funding can be a barrier to needs being met. The failure of adult social workers to attend future needs meetings early enough was seen as contributing to this problem. Lack of suitable respite was also a problem for some young people and their families. A young person on Direct Payments and Independent Living Fund seemed to have the best package of support, although it involved considerable work for his parents.

Transition through health services

Transition through health services was a specific issue which came up for those young people who had significant health needs as noted in the Outcomes section of these findings. Not being able to keep valued medical equipment caused significant anxiety for young people and their families. For one young person with complex needs, her parents had not realised that the medical equipment their daughter used would have to go back to Children’s Services and be reapplied for from adult services. For example, her gait trainer, which was made to measure and would be unlikely to fit anyone else, belonged to Children’s Services and had to remain at the school. Other equipment, including an ear thermometer, had to go back to the children’s ward. It was not clear if this equipment would be replaced from adult services.

For another young person, communication equipment had been provided, but he had insufficient training before leaving school to use it effectively. On entering adult services his needs were reassessed and a new communication aid was put in place. He reported finding the new tool ‘sort of better’ but found his experience with the previous aid frustrating. A young person with a physical disability had been well supported throughout school and had received regular physiotherapist sessions and appropriate equipment but these services stopped as he
had transitioned to adult services. He was concerned that without physiotherapist input the issues he had with his legs would return.

Another anxiety was in accessing adult medical services. The parents of a young woman with a degenerative condition and profound and multiple disability had good links with the children’s ward at hospital, however to access a similar adult service required a referral from her general practitioner. The parents felt this was an unnecessary complexity considering the changing and degenerative nature of their daughter’s condition.

Changes to consent and communication issues concerned some young people and their carers. One young person had felt professionals were still not including him fully in conversations about him; his mother felt that this was because professionals find it hard to understand him. For the parents of a young girl who was unable to make decisions for herself, her parents had to go through the court process to gain the right to take medical decisions for her. They felt this was an upsetting and unnecessary complication.

Where communication between adult and paediatric services was strong this helped the transition. One young person’s family valued having a joint meeting with his paediatric consultant and new adult services consultant in their home.

Discussion

The main points from the young people are summarised in Table 1 for each theme under the headings ‘What does help?’ and outlines existing practices they valued; ‘What is not so helpful?’ which highlights barriers to a successful transition; and ‘What could help?’ - the young peoples’ recommendations for improving transition planning in Highland.

The overall message coming from young people is that to get transition right we need to listen to young people, whatever their communication needs, and ensure they are central to the planning process. Transitions planning needs to begin early so there is time to offer opportunities for young people to practice life skills, such as making choices or managing money and opportunities for social and work experience.

Information needs to be widely available and in different formats; someone needs to check a young person has access to communication tools such as the phone and the internet and provide guidance through the information if necessary. Parents of young people also need information early about the changes in benefit, services and respite transition into adult services will bring for their son/daughter.

Currently there is not equity in accessing leisure, education and work for young people with additional support needs and there are gaps in support from social care and health services. Lack of funding from central government is a major barrier to young people with complex needs achieving their goals. Without enough money, adequate resources and support structures cannot be created. This means young people move from school into unsuitable, inadequate opportunities where they are unable to fulfil their potential. In order for young people to become valued and responsible citizens we have to get better at creating opportunities that leave no young person unable to fulfil any of their hopes and dreams.

There needs to be a standard approach to the transition process which focuses on the individual, considering strengths as well as needs, and services need to become creative in overcoming barriers to enable hopes to be realised. Young people need to be given ownership of their planning so they are in control, working in partnership rather than pushed through a process. The transitions guidelines (THC, 2007) produced as a result of this consultation aim to meet these needs.
These conclusions are similar to those of Craig (2009) and Mallinson (2009), which focus on improved communication and effective and early planning and preparation.

### Table 1 What helps, what is not so helpful and what could help

<table>
<thead>
<tr>
<th>Topic</th>
<th>What does help?</th>
<th>What is not so helpful</th>
<th>What could help</th>
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</thead>
<tbody>
<tr>
<td><strong>Transition journey</strong></td>
<td>When people listen to you</td>
<td>Unrealistic expectations of what might be possible</td>
<td>More work experience</td>
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<td></td>
<td>Having confidence to argue your case</td>
<td>Few choices</td>
<td>Skills practice – making choices, managing money</td>
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<td></td>
<td>Decisions and plans leading to actions</td>
<td>Things left too late</td>
<td>Back-up plan</td>
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<td></td>
<td>Being heard whatever the communication needs</td>
<td>Being moved on before you are ready</td>
<td>Guidance as well as information and help to find information</td>
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<td></td>
<td></td>
<td></td>
<td>Creative ideas</td>
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<td></td>
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<td></td>
<td>Focus on strengths of YP not deficits</td>
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<td><strong>Meetings</strong></td>
<td>People listening to you</td>
<td>Too many people in suits</td>
<td>Being better prepared</td>
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<td></td>
<td>Choices about who to ask and where to hold meeting</td>
<td>Making plans which depend on funding which might not happen</td>
<td>Making a backup plan</td>
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<td></td>
<td>Being prepared for the meeting</td>
<td>Actions not followed through</td>
<td>Person centred meetings</td>
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<td></td>
<td>Visual plans</td>
<td>Meetings without you present</td>
<td>Something written or drawn to take away</td>
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<tr>
<td></td>
<td>People act to make things happen</td>
<td>Decisions taken without your agreement</td>
<td>Someone to follow through and make sure things are happening</td>
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<td></td>
<td></td>
<td></td>
<td>Key people missing</td>
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<td></td>
<td>Written information plus the opportunity to visit places or have people visit from colleges or placements</td>
<td>No record of meetings</td>
<td>More accessible information</td>
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<td></td>
<td>Relevant information</td>
<td>Lack of options available</td>
<td>Better informed support</td>
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<td></td>
<td>Access to the Internet</td>
<td>Lack of support for form filling</td>
<td>Information about benefit entitlement</td>
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<td>Practical advice on interviews etc.</td>
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<td>Help for specific support for particular needs</td>
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<td><strong>Information</strong></td>
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<tr>
<td><strong>Question/Theme</strong></td>
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<tr>
<td><strong>Control of own planning</strong></td>
<td>Being confident and self-motivated</td>
<td>No understanding of roles</td>
<td>Learning how to make good choices</td>
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<td></td>
<td>Being prepared for meetings</td>
<td>Leaving schools without a plan</td>
<td>Getting support to make choices</td>
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<td></td>
<td>Being seen as a person not as a set of needs</td>
<td>Lack of experience in making choice</td>
<td>Being listened to</td>
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<td></td>
<td>Person centred planning</td>
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<td>Having your ideas made possible</td>
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<td>Support to stay as long as needed</td>
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<td>Knowing your rights</td>
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<td></td>
<td>Good information after a meeting</td>
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<td>Good communication</td>
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<td><strong>The right support</strong></td>
<td>People listening to you</td>
<td>Sudden loss of opportunities</td>
<td>Support to work out benefits</td>
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<td></td>
<td>Support staying as long as needed</td>
<td>Lack of opportunities</td>
<td>Learning about managing money</td>
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<td></td>
<td>People working together to offer support</td>
<td>Leaving planning too late</td>
<td>Support for health transition</td>
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<td>Not enough planning or support</td>
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<td>Adult social work services becoming involved earlier</td>
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<td>Support for writing letters or application forms</td>
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<td>Access to phone &amp; internet</td>
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This study offers further evidence in support of the recommendations that HM Inspectorate of Education (HMIe, 2008) offer for successful transition from school to post school including:

- discussing post-school options
- information about options
- gradual transition
- curriculum continuity
- information informs planning
- age-appropriate curriculum
- learning and teaching
- support linked to needs
- named staff member
- mutual awareness and communication

Benefits of the project approach

As an example of research into the views of young people with additional support needs this study demonstrates the challenge of hearing all young people’s voices and the creativity, flexibility and time that effective participation requires. As Lewis (2010) highlights, meaningful participation is a time consuming and painstaking process. This research went to great lengths to make sure the young people that were consulted were able to participate as fully as possible, that the challenges posed due to support need, or the young person’s status as ‘hard to reach’ were overcome.

A multi agency approach meant young people were consulted by adults who often already had their trust, also the consulters were familiar with the young person's communication preferences and through their professional experience had insight into how best to explore their stories. This supported the use of topics rather than questions as the professionals had the insight necessary to explore the young people's experiences in relation to the topic. Importantly the topics meant that although there was a diverse range of transition experiences, from the experience of a young person with significant physical and communication support needs to the experience of a young mother, the consultation process was able to adapt to fully explore each individual’s experiences. Offering young people the opportunity to contribute using a range of methods meant that the young people could choose a method that they were comfortable with and used their strengths to allow them to participate fully.

This approach fits many of the requirements. Lewis (2010) outlines for empowering young people in research through them setting the agenda, giving a choice of methods, strategies for not answering and for the young people to take the lead in deciding when to end an interview. Whilst at a practical level these features of the method enabled the young people to offer a rich picture of their transition journey, which gave policy makers in Highland the material they needed to develop policy and practice that will ensure the journeys of future school leavers are advised by these young people's experience and advice. Others may want to consider this approach when planning to support young people with additional support needs to be involved in policy and practice development and review.

Limitations

There were limitations with this approach, the research was conducted in one of the most rural authorities in Scotland. With a population that is dispersed across a large geographic area. The time consuming nature of the consultation meant that the researchers were forced, due to constraints on time, to focus the consultation on areas that were relatively accessible. This meant this study did not explore how rurality impacted on young people’s experience of transition, an issue that affects a significant proportion of the young people in the Highlands.
Furthermore, the style of consultation, with broad topics in which the young person contributed as they felt comfortable was important in empowering the young people, however this did mean some areas that were more sensitive, for example health issues, were not explored as fully as some professionals who were asked to comment on the final report would have liked. Finally, a significant limitation is that this approach only offers a snapshot into these young people’s experience of transition. A follow up study is planned to explore the participants changing experience of transition and there is ongoing review of the impact of the new transition process within Highland.

Conclusion

This paper highlights the need for, and the successful use of, the Mosaic Approach to consultation. It argues that meaningful consultation with young people with significant communication and learning support requires an adaptable style to enable as full participation as possible, but such an approach is time consuming, and its flexibility can mean some issues may be underexplored. It is hoped however that the research raises implications for consultation that future researchers will reflect on when considering research with young people with additional support needs. The project’s findings have had significant local impact on young people’s transition from school to post school services through informing the creation of an authority wide transition process. For a wider audience the findings offer suggestions for successful post school transition that could contribute to the review of existing practices and in the design of new transition planning processes.

References


**Appendix 1 Consultation topics**

1. **Questions about outcomes**
   - What the person does now: college, work, hobbies, holidays, socialising
   - Where & how the person lives: neighbourhood, independent living
   - Whether the person is well: health, hygiene, understanding of disabilities, relationships
   - What the person needs now, and whether these needs were identified in planning

2. **Questions about the young person’s understanding of transition planning**
   - The person’s experience of preparing for adulthood
   - Understanding of decision making and ability to make decisions
   - Knowledge and understanding of plans that were made

3. **Questions about meetings**
   - Whether meetings took place
   - The young person’s experience of attending meetings
   - Whether the right amount of people attended meetings (e.g. too few, too many)
   - Whether the right number of meetings took place (e.g. one large meeting, several meetings with one person)
   - What methods were used and whether these were appropriate (e.g. relationship-building methods, formal meetings in a school setting)

4. **Questions about information provided**
   - Whether information was provided
   - Whether information was in an appropriate format for the person
   - Whether information was interesting and useful for the person
5. Questions about ‘ownership’ of planning documents
- Extent of contribution to planning
- Physical ownership of documentation
- Whether the person could understand the content of documents
- Preferences for other possible forms of documentation

_Correspondence about this paper should be addressed to:_

Gillian Newman  
Children’s Consultation Worker  
Highland Children’s Forum  
gillian@highlandchildrensforum.org

Sam Collyer  
Trainee Educational Psychologist  
University of Dundee,  
sjcollyer@gmail.com

Marea Foulis  
Transition Coordinator  
Highland Council  
marea.foulis@highland.gov.uk

Simon Webster  
Project Co-ordinator  
FBS Advocacy, Coatbridge  
simon.fbs@btconnect.com