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**Title: Transition into adult healthcare services in Scotland –findings from a study concerning service users at the Scottish Spina Bifida Association**

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## Abstract

**Background and Aims** Literature on interventions that enable young people with Spina Bifida and/or Hydrocephalus to have smooth transition, into adult healthcare services, stress the need for the process to start early and to include all family members. The study reported here was set to quantify and articulate the experiences of service users who are or due to be going through the transition process in Scotland today.

**Methods and Results** focus group sessions, in the North of Scotland and in the 'Central Belt', captured rich qualitative data. A survey, sent to eligible participants on the Spina Bifida National database, offered complimentary data source. Despite the fact that the number of returned questionnaires was low (n=20) data analysis identified a number of core recurring themes. These include issues concerning Communications, Respect, Choice and Control. Findings suggest that there is a significant chasm between the political rhetoric and the reality faced by young people with Spina Bifida moving to adult healthcare services.

**Conclusion** A possible way to facilitate successful transition of young people is using personal healthcare information as the locus for needed change. More research is needed to ascertain whether a 'Person Centred Record', which is set to empower young people on their transition pathway, is an appropriate transition tool.

### *Keywords*

Neurological conditions, Transition, Young People, Person Centred Record

## *Introduction*

Spina Bifida and/or Hydrocephalus is a condition with a myriad of clinical presentations and self-care challenges. Individuals may require help with bowel, bladder and shunt management, may experience kidney problems and some may face long term mobility difficulties. Patients may also present neurological symptoms, manifested as visual impairment, perceptual difficulties, learning difficulties and communication problems with varying degrees of severity. The Scottish Spina Bifida Association (SSBA) has over 3000 registered service users across Scotland, including children, adults and their carers and/or families.

The importance of access to specialist input for these patients is unquestionable and evidence of improved health outcomes, associated with a coordinated approach to service provision, is well documented (Sawyer and Macnee 2010) (Roebroek, Jahnsen et al. 2009), (Bent, Tennant et al. 2002) (Binks, Barden et al. 2007) (Cramm, Strating et al. 2014). Indeed, progress in treatments and care of children with Spina Bifida and Hydrocephalus, over the last 20 years, translates to increased life expectancy and babies born with the condition today are most likely to live into adulthood and go through a transition period from paediatric focused care onto adult health and care provision.

One of the many services offered by the SSBA is an adult health check clinic, where service users aged 16 and over, are given advice and guidance to help them to keep well and manage self-care. Those who use the service often tell nursing and family support staff that they face obstacles in an adult orientated support system, which has tremendous impact on their quality of life. As an active charitable organisation, the SSBA argues that such a reality

should be radically changed and a successful transition into adult healthcare system is core to needed transformational action.

The literature on interventions that enable young people, with a range of healthcare needs, to continue and receive optimal services during and following their move into adult healthcare services, offer a few models for consideration. Some were evaluated as more effective than others (Crowley, Wolfe et al. 2011) and include:

- Weekly one hour teleconference with a group of participants to cover an agreed 'transition curriculum' with topics such as Self-Management Skills, Diet & Fitness, Medication Safety, Social relationships, Continence, Money and Work and Education and Vocational activities.
- A weeklong 'Camp Training Programmes', where multi-disciplinary team of professionals offered specific interventions in support of set goals;
- A dedicated outreach transition service which targeted young adults as they negotiate the adult system
- A web based transition content including education and assessment tools for young people and their families
- A transition clinic with dedicated staff that can offer a 'one stop shop' for service users.

Prior to deciding on the most appropriate intervention, to support SSBA service users, we set to quantify and articulate the current experiences of those who are or due to be going

through the transition process. The study reported here, elicited views of both young people and their parents or carers and used a range of methods to engage participants. Prior to interacting with users we gained consent to conducting the study and ensured it had a perfect fit with the SSBA ethics protocol. We also shared results and benefited from the advice of a designated steering group, which included senior NHS staff, service users.

Pivotal to the success of the project was the guidance offered by the SSBA Honorary President – Professor Dan Young – who sadly passed away in late 2013.

This paper is dedicated to his memory.

### *Methods*

We used both focus groups and a survey, which was sent to young people (age between 12-25 years) on the SSBA National database. The first focus group session was conducted online, using Skype as the (voice) communication platform, to enable wider participation of those service users who live in the North of Scotland. Two families took the opportunity to share their views regarding the transition process, which they were embarking on. The discussion included all family members and offered rich insight to current needs and future aspirations from a successful transition process, for both parents and their children. The second focus group was set as a face to face session and included parents from the 'central belt' of Scotland. Attending the meeting were 12 parents whose children were in the early stages or in the midst of moving into adult healthcare services. A few were parents of young people who had already transferred onto adult care, and their contribution offered a reflection on the entire transition journey. This session gave parents an opportunity to share information, concerns, and 'stories', without their children being present.

To support a meaningful interaction, a semi structured framework was used with a few core or 'seed' questions given to parents prior to the discussion taking place. 'Ground rules' were set at the beginning of each session, to ensure all participants got an opportunity to hear their peers as well as be heard. All participants consented to the sessions being recorded, to aid analysis of the large volume of qualitative data. The transcript from each session was sent back to participants to seek amendments and comments. A succinct report from the two sessions was presented to the steering group, who guided the construction of a survey tool. Using this tool enabled further service user participation and offered access to data that complements results from the focus group sessions.

The survey, which had an online and printed versions, was distributed to service users between the ages of 12-25. The SSBA database identified a total population of 170 potential participants who were contacted to inform them of our study and its aims. Overall 71 emails were sent and 92 letters posted with a sub group of the 'North of Scotland' managed differently and excluded from analysis at this time. We received a small number of questionnaires back by post (n=12) and 8 responses on the electronic survey portal. Seven of the participants were young people themselves and the remaining 13 were parents or carers. The overall response rate was 12%.

### *Results*

Analysis of the qualitative data was focused on identifying key themes that served to clarify the meaning of transition, as described by participants. Interestingly, many parents described "moving 'up' to hospital care" in negative terms. One father referred to the transition process as: "... awful! One minute you would get loads and loads of support and

back up... and then all of a sudden it's nothing". Many questioned the reasons for limited specialist services for adults and suggested their children may have to wait "...until something goes wrong before 'something' is done about it". In contrast, paediatric care was perceived as attentive and described as "excellent" by the majority of participants.

Parents noted that paediatric staff, in specialist hospitals, address the holistic needs of their child or young person, by forging a "relationship" with the family as a unit. Staff in adult services are perceived as lacking specialist knowledge and showing little "respect" to the young person and their 'special needs'. Family doctors are often excluded from communication flows, regarding ongoing care, and an encounter with primary care providers often results in a frustration as the same key information is sought repeatedly.

Indeed, the core concepts of Communications, Respect, and Person Centred Care were interwoven into many aspects of the discussions. Choice and control were also noted when parents considered the implications of their children making the 'wrong decision'. It was argued that whilst transition is set to empower the child, the parent often feels powerless and the result is miscommunications and poor clinical outcome.

Some parents noted how exhausting and frustrating the 'constant fight' to seek more help is. Others resign to 'just getting on with it', stating that the transition phase is just one of the many challenges their children will face in managing their lives as they grow up. One parent offered an imagery of waves in the ocean, describing a process where "one wave comes crashing onto the shore and leaves a line of debris before going back to sea, just for the next wave to follow it". The same could be said about the constant transition of young disabled people who go through school, college, university and so on. The main fear parents



have is that the 'transition' will never end but at some stage they will no longer be there to help and support their child and that, they said, is a very difficult thing to come to terms with.

The results from the survey relate mainly to those in the 12 to 18 years category, with most noting that they have not yet started their transition journey. The service quality indicators that were explored in the survey, included perceptions of users regarding effective communications with them and between healthcare staff themselves. The results suggest that more needs to be done to reassure service users that all those who are involved in planning and delivering healthcare services, for young people with Spina Bifida, are doing so whilst being fully informed of all results. The survey also included questions to explore the 'level of control' and the degree of 'choice' users have, when charting the transition pathway - as an indicator of a provision that supports person centred care. As expected, many participants noted that these aspects of the transition process are not yet relevant to them. However, many of those who participate in 'negotiating the system' and those who are expected to make decisions - alongside professional healthcare staff - feel powerless. The free text comments reiterated this point and offered further insights, with two articulated 'stories' offered here in full:

"I was not happy with the change to adult (services) as I got an appointment every six months with childhood (paediatric care). I do not get my kidneys checked at all and my mum has to check with sticks she was given by the doctor. (Regarding) - my own GP, I do not get my hydrocephalus checked at all – I contact the doctor if I need them. Last year I had a bad time with my shunt and it took 3 months for me to get it checked. I ended up going blind in my two eyes because I could not go to my consultant in the (name of hospital). I got

referred to my local hospital and mum kept telling them it was my shunt but they would not listen. I was in my bed (with) constant headache and vomiting. I think the service could be a lot better!”

“Have not been offered the transition process but hope it works better than my transition from primary school to high school. Because I look capable and do not cause disruption in class I am passed by and forgotten about. I have been told on occasions that I am just a normal 14 years old teenager who sometimes forgets things. I do not chose to forget things – it is due to my condition and I wish people could see that ... Because I do not look disabled most people do not believe me and just think I am a bit slow, which is so frustrating!”

### *Discussion*

The results presented here describe the harsh reality that some service users face when preparing or engaging in a healthcare transition process in Scotland today. Considering the fact that the literature advocates an early start to a transition process (Viner 2008), it appears that most families with young people who participated in our study fail to benefit from a prompt launch of their transition pathway. This is a worrying observation as poorly planned transition is associated with increased risk of non-adherence to prescribed treatment and of lack of follow-up. This in turn is demonstrated to have measurable adverse consequences in terms of morbidity and mortality as well as social and educational outcomes (Department of Health 2006).

It may be argued, however, that those who chose to participate in the study found a platform to air their grievance whilst the great majority of families benefit from an uneventful transition. We believe this argument is unfounded as other UK studies of

patients with long term conditions identify similar results. It does, however, highlight the fact that many families chose not to participate in our study, a fact that may indicate a sense of hopelessness in attempting to change current reality.

Viner (2008), notes a few key elements to successful transition and argues that improving young people's self-management skills should be a central part of any transitional programme. He goes further and states that "young patients need to be trained and empowered to allow them to be an effective partner in their own transition" (p160). Our study also highlights core concepts that relate to empowerment including the desire for control, choice and effective communications.

One possible way to support efficient and safe transition, from paediatric services to adult healthcare provision, is through effective management of health and social care information (National Neurological Advisory Group 2013). Specifically, enabling young people to access their healthcare information and share it with those who provide them with the services they need. Such access, sharing and control of information may prompt young people to know more about their conditions and self-management options and encourage a greater degree of ownership and participation in life choices and planning for the future. It may assert their role as partners in decision making and eliminate inefficiencies where needed information is not available when and where the young person is seen within a traditional clinical setting. The move towards sharing a copy of the clinical management plan with the patient or providing a copy of the GP letter to the patient will go some considerable way to supporting this move towards a more person centred approach to healthcare.

However, there are risks and concerns that should be considered when such an approach is discussed. Healthcare information should remain confidential and secured and young people and their families should have the education, training and support to ensure they are able to understand the information and share it with people who are set to help them on the transition pathway. Healthcare professionals should also have the right training to ensure the information they share with the young people is appropriate to their level of understanding. They must also consider the implications of sharing inappropriate information and the impact it may have on their own practice and professional stand.

### *Conclusions*

In Scotland today there is a significant drive to build on patients' health assets and adopt co-production principles to planning care and delivering services that match the needs of service users (NHS Quality Improvement Scotland 2009). Yet, the results of the study presented here suggest that there is a significant chasm between the political rhetoric and the reality faced by young people with Spina Bifida moving to adult healthcare services. More must be done to ensure an effective process is executed, addressing the holistic needs of young people and their families as they move from a child centred to an adult orientated healthcare system. A possible way to facilitate successful transition is using personal healthcare information as the locus for needed change. More research is needed to ascertain whether a 'Person Centred Record', which is set to empower young people on their transition pathway, is an appropriate transition tool. The results of the study presented here reiterate that change is most needed to transform the reality faced by many on the transition pathway. They, too, should benefit from a person centred care offered by professionals in the modern healthcare system of Scotland.

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