Professor Imelda Coyne presented a powerpoint presentation to the audience on the topic of the transition from child to adult healthcare services in Ireland for people with long term illnesses. This presentation was based on research that was undertaken by Professor Coyne, with Dr Aisling Sheehan and Professor Alison White in Trinity College Dublin. The aim of the research was to inform the development and improvement of healthcare services and present a framework for best practice in transitioning people between child and adult healthcare services.

Interviews were conducted with children, adults and medical practitioners in the fields of Cystic Fibrosis, Diabetes and Congenital Heart Diseases. A range of transition experiences and influences were identified. The research states that the definition of healthcare provision for people with long term illnesses needs to be widened from the medical model to a process that addresses the psychosocial, educational, vocational and medical needs of people with CF.

One of the key outputs from the research is an informative website for young people entitled “Stepping Up”. Launched in December 2013, this website was developed in conjunction with young people with long term illnesses and is aimed at supporting young people to move from child centred to adult orientated healthcare provision. Several people with CF participated in the making of the website. Experiences are presented in a user friendly and age appropriate way and the website features a collection of helpful videos.

The notion of developing a similar resource for parents, tentatively titled “Stepping Aside” was introduced for discussion and feedback.

Key points in Dr Coyne’s presentation include:

- A standardised policy and process for the transition between paediatric and adult healthcare services does not exist nationally. Research outcomes point to the need to develop a standardised approach and significant behavioural change within the healthcare sector. Some hospitals have taken certain steps to facilitate young people to transition such as the appointment of a Transition Co-ordinator or the introduction of a 2 year transition programme but these are the exceptions rather than the rule.
- Research findings suggest that negative transition experiences can translate into reduced attendance at clinics and a distancing from healthcare provision. This leads to a loss within the system and poorer health consequences for the individual as a result.
- The shift from family centred to individual consultation takes significant adjustment and the negotiation of autonomy with the young adult can be a tricky relationship to work out. Maturity levels vary per child and many children prefer to have a parent present for consultations, especially initially. Some children do not have the confidence to ask questions
and they may not be aware of their full medical history. On the other hand, if children are not empowered or encouraged to take responsibility for their own welfare at the appropriate time, this can have later health repercussions. Participants were directed to the checklist on the ‘Stepping up’ website which highlights the key information that young people should be aware of.

- Respecting a young person’s right to individuality and confidentiality needs to be weighed up with their level of self-advocacy skills and what works best for the family involved. A change management process is needed for everyone.
- The transition between services must be done on a gradual basis as an abrupt transfer can lead to feelings of loss, bewilderment and fear. Some respondents thought of their health care team in terms such as “an extension of the family”.
- The fact that the young person may be facing multiple transitions and decisions at once can also add to the complexity of the issue. For example, a person may be moving from school to college; from home town to new city; from local hospital to a new hospital, in addition to a move between paediatric and adult clinics.
- An added challenge for people with CF is the multitude of Doctors and Consultants from different specialities (for example: respiratory, liver) that are involved in their care. Communication can be difficult, particularly in the absence of introductions and patients have recorded their annoyance in having to explain their story time and time again.
- Unforeseen communication difficulties may also exist. It is not always correct to assume that all patient files have been transferred between the services or that Consultants naturally communicate on all aspects with each other.

RECOMMENDATIONS FROM THE WORKSHOP

Recommendation 1

The merit of introducing a parental website on the issue was discussed. This website might contain similar categories of information to ‘Stepping up’, along with coping mechanisms and advice for parents going through this transition. Workshop participants felt that, while a website might be of some support, it would be more important and helpful to have a Transition Co-ordinator and process in place in each hospital to assist and guide young people with CF and their parents.

Recommendation 2

For people who have to choose what adult service they are transferring to, the development of a practical checklist would be a valuable tool. This guide would set out the characteristics that people should be considering such as:

- Distance
- Range of services offered
- Availability of beds and number of beds
- Ease of transfer /shared care arrangements