CF Ireland Annual Conference, March 29th, 2014

Transition from Child to Adult Healthcare Services:

Informing the Development of Healthcare Services

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What do we mean by transition?

“Transition is the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child centred to adult-oriented health care systems”
(Dovey-Pearce & Christie, 2013)

“Transition is the purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents and young adults as they grow up learning to live with their lifelong health condition”
(Dovey-Pearce & Christie., 2013)

Why is transition important?

- Increasing numbers of young people entering adulthood

- Experience a shift from family to individual-orientated consultations

- Transition associated with reduced attendance, loss to follow-up, & poorer health outcomes and behaviours – e.g. Crowley et al. (2011)

What influences successful transitions?

- Biological/physiological factors
- Patient psychosocial factors
  - Cognitive development & maturity
  - Attitudes, beliefs and emotions
  - Self-efficacy, self-management, & self-advocacy skills
- Family factors
  - Shift in responsibility
  - Collaborative vs. discordant/dependent relationships
- Service factors
  - Changes to range of and access to services
  - Decision-making & consent responsibilities of the young person
Emerging adulthood

Exploring risky behaviours

Developing self-care behaviours

Negotiation of autonomy
Aims of TRYCIS

➢ To obtain a comprehensive understanding of the experiences of young people and their families transitioning from child to adult healthcare services in Ireland

➢ To identify factors facilitators and barriers to smooth and successful transitions

➢ To help inform the development of healthcare services
Methodology

• Sampling
  – 3 diseases groups: cystic fibrosis, congenital heart defects, and type 1 diabetes
  – Young people (15-25 years), parents, and healthcare professionals (HCPs)
  – 9 services across 6 children's and adult hospitals

• Ethical approval

• Semi-structured interviews
  – 115 interviews with 47 young people, 36 parents, and 32 HCPs
  – Choice of setting

• Analysis
  – Thematic analysis
Transition experiences

Planning & preparation
Feelings about the move
Expectations of adult services
Adjustment to new environment
Health & health behaviour outcomes
Negotiation of responsibility
1. Planning and preparation
   - Variety of processes e.g. leaflets, information evenings, visits to adult services, joint transition clinics.
   - Most experienced very little communication
   - & discussion about transition - “it’s very ad hoc”
   - Dependent on willingness to discuss.

2. Feelings about the move
   - Wide range of feelings
   - Worries and fears
   - Conflicted about more responsibility and independence
   - Parents generally more apprehensive.

“'It was something I really wanted to do”
(YP, adult service)

“I’m absolutely devastated”
(Parent, child service)
3. **Expectations of adult services**
   - Cultural change - *“treated like an adult”* & exclusion of parents
   - Less hospitable environment: “more clinical”; “hostile”; “colder”
   - Reduced access & poorer service provision
   - Uncertainty or no expectation of differences

4. **Adjustment to the new environment**
   - *“Culture shock”* - intimidating and daunting
   - No man's land – adjusting to environment & building
   - trust in staff

“He was very blunt about my prognosis and I wasn’t prepared for that really so after my initial meeting with that consultant I then changed to a different hospital” *(YP, adult service)*

“They just tell you straight how it is, which is good but you know it’s just a lot to take” *(YP, adult service)***
5. Negotiation of responsibility and control

Child Services
- Shared illness ownership
- Parent typically leads healthcare management and consultations
- Great variety in young person’s involvement

Adult Services
- Renegotiation of roles: dynamic, interactive process
- Enhanced responsibility facilitates independence & privacy but, if unready, can have negative implications
- Parents difficulty trusting their children to assume full responsibility
- Staff have to balance the patient’s right to confidentiality with appropriate family involvement
“I had waited there from eleven that day and I have car parking fees and I have the whole lot and I was just dismissed out of the room without bye or leave, just excuse me … no hello, how are you, nothing” (Parent, adult service)

“I nearly have to do more psychological work on his mother than him because she’s impeding his ability to cope … parental over protection is a huge issue” (HCP, adult service)

“It’s easy to lie to them, like giving your blood sugars, you can just write down anything down in the book like and they believe you” (YP, adult service)
Facilitators & barriers

- Belonging & attachment
- Cognitions & emotions
- Parent/child responsibility
- Communication
- HCP skills & practices
- Adjusting to differences in environment
- Transition processes
- Service co-ordination
- Patient skills
Facilitators & barriers

1. Belonging and attachment
   - Sense of belonging and attachment to child services - “second home” or feeling out of place in adult services
   - Severing & building new relationships and trust

2. Patient skills
   - Interpersonal skills required for communicating with staff
   - Self-efficacy, self-care, and self-advocacy skills

3. Cognitions and emotions
   - Skills dependent on cognitive and emotional development
   - Influence adjustment to adult service environment
4. Differences in environment and service provision
   • Perceived & actual differences in, for example, the environment (e.g. more impersonal, exposure to more progressed disease) or access to services (e.g. less frequent visits)

5. Parent/child responsibility
   • Degree of shift in responsibility for healthcare management
   • Parent’s cognitions and emotions regarding relinquishing responsibility

6. Communication
   • Level of communication and discussion regarding transition and changes to service provision
Facilitators & barriers

7. HCP skills and practices
   - Facilitating development of young person’s skills and the changing role of parents, e.g. attendance alone in clinic
   - Interpersonal skills to communicate effectively with young people according to their stage of development and knowledge

8. Transition management processes and practices
   - Visits to adult services and meetings with staff
   - Transition/joint/adolescent/young adult clinics
   - Transition co-ordinators

9. Service co-ordination
   - Communication, information transfer, and mutual understanding between child and adult services
Conclusion

- Many young people and families are inadequately prepared and some had difficulty in adjusting to adult services, with negative health consequences.
- Numerous factors influence the success of transitions, many of which are modifiable.
- Strategies to facilitate smoother transitions should be incorporated into healthcare policies & practices.
- Service development required and evaluation of transitional care models needed.
- Development of SteppingUp.ie website aims to facilitate greater preparation for transition.
transition information for young people, with long-term illnesses, moving to adult health care services

Home  About Transition  Clinics and Personnel  Top Tips  Transition Stories  Q&A  Essential Reading  Links  Gallery

thinking about transition

"My first thought was why I have to move?"

Where to start?

planning your transition

"It's really important to familiarise yourself with what you are moving to."

Transition plans in action

making the transition

"Transition is a process...but I'm OK with that...cause now I am more confident!"

The Next Steps
Transition Stories

Six young people kindly share their transition stories and experiences with us. Young people can expect to experience different kinds of transitions, depending on their condition and the health services available. Listening to these stories will be useful when you are thinking about, planning for and making your transition.

Thoughts before transition.

Advice about transition

The first visit
Know about your medication and treatment

In preparation for your transition you should talk to your parent(s)/guardian(s) and health care team so that you can gather information on the following:

### Your Medication
- The name of the medication you take
- Why you take the medication
- The exact dosage that you need to take
- Specific rules or instructions for the medication (for example, any particular storage instructions)
- Any side effects from the medication
- The effects that could occur by mixing your medication with other medicine, drugs or alcohol
- Which chemist you use
- Which doctor/consultant prescribed the medication for you

### Your Tests or Treatments
- What medical tests have you had?
- What are the tests for?
- How often do you need to have the tests?
- Who carries out the tests?

### Your Medical History
- What surgeries/procedures, if any, have you had?
- When and where did the surgeries/procedures take place?
- Who carried out the surgeries/procedures?
- Have you had any allergic or adverse reaction to any medication/treatment?

If you need to ask advice about your medication and/or medical tests or treatments, speak to your parent(s)/guardian(s) and health care professionals who will be more than happy to give you the information you need.

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**TRANSACTION CHECKLIST**

Read the statements below and tick the relevant box for each. This will highlight the areas you need to get some advice about. This will help you as you prepare for your transition. You should discuss any concerns with your parent(s)/guardian(s) and health care team.

<table>
<thead>
<tr>
<th>KNOWLEDGE</th>
<th>Happy with this</th>
<th>Need some advice about this</th>
<th>NOTES</th>
</tr>
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<tbody>
<tr>
<td>I understand my medical condition</td>
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<td>I know about the tests that I need to have</td>
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<td>I know the names of my medications and what they do</td>
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<td>I know when and how to take my medication/treatments</td>
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<tr>
<td>I am aware of my medical history (e.g. hospital visits, procedures, tests)</td>
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<td>I know the main differences between child and adult health care services</td>
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<td>I am happy to talk to the chemist about my medication/treatment</td>
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<td>I know how to care for my medical equipment (if applicable)</td>
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<td>I know who to call in an emergency</td>
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**SPEAKING UP FOR YOURSELF**

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<th>Happy with this</th>
<th>Need some advice about this</th>
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<tr>
<td>I feel ready to prepare to be seen alone in the young person’s/adult clinic</td>
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<td>I feel confident to ask my own questions in clinic</td>
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<td>I understand that I will have to take more responsibility for my health care as I get older</td>
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www.steppingup.ie
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List of videos

- Ready for transition
- Thoughts before transition
- Advice about transition
- The first visit
- Becoming more independent
- Talking to the health care team
- Adult clinics are different
- Parents and transition
- Bad patches and getting support
- ‘Don’t hold back’
Acknowledgements

- All the young people, parents and healthcare professionals who participated
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Thank you!

For questions or queries, please contact:

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