Moving On: Preparing for transition to adult life.

Margie Rae
Department of Paediatric Rehabilitation
Royal Children’s Hospital
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Outline

- Themes
- Best practice
Types of Transition

- Service/institutional transition
- Lifecourse/developmental transitions

- Need to be integrated-service transitions in alignment with life course transitions
Domains of transition

- Health care—“purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems”
- Education/employment
- Independent living
- Recreation/socialization
Factors affecting transition

- Personal
- Environmental
- Double jeopardy risk factors - ethnicity, obesity, substance abuse
Environmental barriers

- Lack of understanding
- Service barriers
- Family barriers
- Attitudes !!!
Environmental facilitators

- Service supports
- Information
- Systems
- resources
Transition Themes

- Transfer process
- Growing Up Ready
- Shared management
- Professional Education
Transfer process

Best Practice: Organizations should adopt a formal transfer approach and process

Recommendations:

• Identify key champions to facilitate discussion

• Set explicit policies for planned and coordinated transfer

• Measurable outcomes and objectives
Transfer Process

Ideas and Examples:

• Consumers as partners - teens and family facilitators
• Educate everyone - professionals, families, agencies, admin staff.
• MOU’s between paediatric and adult services
• Include statements about transition in strategic plan
• Incorporate transition indicators into organizational performance evaluations
• Advertise that your agency has a policy of preparing young people to transition to adult service - posters
At SickKids we prepare our patients to graduate to adult care.

Don’t wait until you are 18 to start planning to leave. Talk with your health-care provider.
Best practice: Establish a clear procedure for transferring teens

- Gradual transfer
- Non age specific transfer
- Work with teen and family on a transition plan - contract, clinical pathway and curriculum
- Plan should span service systems eg health, education
- Need someone to co-ordinate transfer - eg transition coordinator, nurse, GP
- Resources and supports - web resources
Transfer process

**Best practice: Establish methods for communication and information sharing between paediatric and adult providers**

- Methods to transfer health and transition information - health care passport, health summary; binder
- Avoid ‘baton pass’ - joint adult/paediatric clinic, paediatric service provider participates in adult clinic or vise versa.
- Use terminology and language common to both sectors
Spina Bifida

This is where you put in your health information. Much of it you will know and the rest is available to the health care provider you are completing this with. If something doesn’t apply to you, skip to the next section. There is no need to enter “none” or n/a, unless you want the section to print on the final version. An example of this would be if you want your card to say “Drug Allergies: None”. At the end, there is a place you can put in anything that you would want an adult health care provider to know about you.
Transfer process

Best practice: Establish methods for communication and information sharing—between providers and consumers

- Clear expectations for moving on to adult services
- Educate about adult services
- Provide opportunity to teens and families to experience adult service environment—do tour of adult facility,
- Have resource person who is knowledgeable about transition—to help direct teens and families.
- Teen library/corner/message board—information on careers, independent living, recreation, relationships/sexuality
- Employ teen and family facilitators
Transition Clinic

Objectives of LifeSpan Clinic (Bloorview-Toronto Rehab):

Improve/Increase:

- Skills (particularly communication)
- Knowledge (their own health care needs, adult services)
- Confidence (skills and knowledge training, YOUTH FACILITATOR)
- Transfer process (transfer discharge summary, joint visit to adult service, liaison with adult service, co-hired clinic staff)
The LIFEspan Service Model

Growing Up Ready  Transfer Services  Adult Services

Maxwell, J., Zee, J. & Healy, H
Theme 2: Growing up ready

Best Practice: Develop skills and knowledge of teens and families for engaging in adult services.

- Service providers and families need to set expectations for teens to participate in and advocate for their health care needs from early age
- Teens and families must set expectations for health care providers to prepare them for the future
- Explicit message about planning for future
- Reliable information
- Educate teens
- Teach self advocacy and self management
Self-Management
Be your Own Boss

- Similar to adult self management programmes for chronic illness (Stanford)- geared for youth
- Information is good but youth need more
- Confidence and self efficacy
What does it take to be a good self manager

- Knowledge – information
- Consistency in behaviour-teens at risk
- Self efficacy
Self Management skills

- Goal setting
- Problem solving
- Accessing resources
- Communication skills
- Getting support
- Stress management
Growing up ready

Best practice: Provide support for youth and parents in preparation for transition

• Provide methods/tools for systems navigation eg transition coordinator, resource database, checklist and folder for teens and families; websites and information via the newsletter.

• Opportunities for peer mentorship and support -(identify young adults with disability who may be able to provide this)

• Involve teens and families in development of programs and resources

• Support family networks-families want to hear from other families!
Growing Up Ready Framework
(Gall, Kingsnorth and Healy, 2006)

Guiding Principles

- Family is the expert in raising their child
- Each child and family is unique
- Preparations for the future must start early
- Shared responsibility for promoting skills needed for adult life
Timetable for Growing Up

- Starts early
- Outlines a progression of skills targeted at age appropriate times
- Voice of text shifts
- Poster and pamphlet versions
<table>
<thead>
<tr>
<th>12 to 16</th>
<th>17 to 21</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Advocate for yourself.</td>
<td>• Begin guardianship process before age 18.</td>
</tr>
<tr>
<td>• Talk about sexuality.</td>
<td>• Apply for Income Support before age 18. (Ontario Disability Support Program (ODSP) in Ontario)</td>
</tr>
<tr>
<td>• Look for older role models.</td>
<td>• Become a mentor for younger children.</td>
</tr>
<tr>
<td>• Use your parents as a resource.</td>
<td></td>
</tr>
<tr>
<td>• Join teams and clubs at school.</td>
<td>• Find out about community programs for adults that match your leisure or athletic interests.</td>
</tr>
<tr>
<td>• Get involved in activities outside of school.</td>
<td>• Keep in touch with friends from high school or camp by phone or e-mail and make plans.</td>
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<tr>
<td>• Hang out with friends.</td>
<td></td>
</tr>
<tr>
<td>• Direct your own personal routines.</td>
<td>• Learn independent living skills.</td>
</tr>
<tr>
<td>• Cook together.</td>
<td>• Plan and prepare meals.</td>
</tr>
<tr>
<td>• Start to find your way around the community.</td>
<td>• Practice budgeting and banking skills.</td>
</tr>
<tr>
<td>• Talk with your parents about where you will live as an adult.</td>
<td>• Look at housing choices including attendant services and supported living options.</td>
</tr>
<tr>
<td>• Take part in meetings about your education and keep a record.</td>
<td>• Going to college or university? Contact the Office for Students with Disabilities on campus.</td>
</tr>
<tr>
<td>• Talk about career interests.</td>
<td>• Looking for Work? Contact Employment Support Programs for help with job search and training. (Ontario Disability Support Program (ODSP) in Ontario)</td>
</tr>
<tr>
<td>• Find volunteer work or a part-time job.</td>
<td>• Contact local Community Living</td>
</tr>
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Developing the Skills for Growing Up

Getting Started 1 2 3

Developing the Skills for Growing Up

On My Way 1 2 3

Developing the Skills for Growing Up

Almost There 1 2 3

Young people and their families will go through many changes as they grow up. To get ready for the future, young people and their families need to learn about new resources. Young people may also need to develop new skills and take on new responsibilities.

Developing the Skills for Growing Up is a series of three checklists. It will help you look at how ready you are for the future, think about what you need to work on and plan how you will do it. Almost There is the final level of the series.

Who is this checklist for?
### Developing the Skills for Growing Up: Almost There

<table>
<thead>
<tr>
<th>Self Advocacy</th>
<th>Something I want to work on?</th>
<th>What do I need to do?</th>
<th>Done</th>
</tr>
</thead>
<tbody>
<tr>
<td>I know how my role in my family will change as I become an adult.</td>
<td>y</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know where to find support and information related to my disability.</td>
<td>n</td>
<td></td>
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</tbody>
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<table>
<thead>
<tr>
<th>Social &amp; Recreation</th>
<th></th>
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<tbody>
<tr>
<td>I make plans to spend time with my friends.</td>
<td>y</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know about safe sex and healthy relationships.</td>
<td>n</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I participate in youth or adult social and recreation activities.</td>
<td>y</td>
<td></td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Independent Living Skills</th>
<th></th>
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<tbody>
<tr>
<td>I prepare meals or direct someone to do so.</td>
<td>y</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I do my laundry or direct someone to do so.</td>
<td>n</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I manage my personal care needs.</td>
<td>y</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I receive disability pension.</td>
<td>n</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I manage my budget.</td>
<td>y</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I buy the things that I need.</td>
<td>n</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I take public transportation on my own.</td>
<td>y</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I go out in my community on my own.</td>
<td>n</td>
<td></td>
<td></td>
</tr>
</tbody>
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TIPS

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- Staying Healthy
- A Place to Live
- Emotional and Transition Support
- Speaking Up
- Care and Support
- Getting Around
- Equipment
- Money Matters
- School & Work

Having Fun

Please send us your tips, ideas and comments for things you do to have fun.

Send them to: dlunan at bloorview dot ca
SINCE YOU'RE NOT A KID ANYMORE

IT'S TIME TO BE MORE IN CHARGE OF YOUR HEALTH
Transition Timeline

12 to 18 Years Old

By ages 12-18, or according to your child's developmental ability:

- Continue to allow your teen to help with family chores.
- Continue teaching your teen normal self-help skills as well as skills related to his or her special health care need.
- Continue to encourage hobbies and leisure activities.
- Assess your teen's perception and basic knowledge of his or her special health care need, and fill in gaps in his or her understanding.
- Begin helping your teen keep a record of his/her medical history, including conditions, operations, treatments (dates, doctors, recommendations) and Individualized Education Program (IEP) if on an IEP.
- If on an IEP, encourage teen to participate in IEP meeting.
- Begin helping your teen take responsibility for making and keeping his or her own medical appointments and ordering supplies.
- Begin exploring health care financing for your soon-to-be young adult.
- Discuss sexuality with your teen.
- Help your teen identify and build on his or her strengths.
- If your teen is interested, explore support groups.
- Begin to talk about and explore career interests with your teen.
- Help your teen find work and volunteer activities.
- Help your teen identify and be involved with adult or older teen role models.
- With your teen, encourage age-appropriate care from his/her family practitioner or pediatrician.
- With your teen, begin to identify with whom they will eventually be receiving their health care as an adult.
Theme 3: Shared Management

Philosophy of shared management  
(Kieckhefer and Trahms, 2000)

- Collaborative partnership
- Person centered
- Sharing power and responsibility for managing health care needs
Shared Management

Best practice: Prepare and support teens, families and organisations for a shared management approach in transition planning.

At an organisational level:

- Educate staff on all levels of the organisation to adopt concepts of shared management; for administrators to set expectations for the organisation. **Include in orientation programme**
- Organisation needs to challenge themselves to conceptualise shared management within a variety of situations—eg severity of condition, culture and religion
- Review terminology – shared management, consultation, consumer.
Promoting shared management in practice

- Involve teens in school meetings and medical appointments
- Provide quality information
- Service providers and parents – learn to accept choices made by teens
- Explain shared management to teens and parents - make it an expectation
- Individual approach - some may want more direction
- Protocols - need to consider teens who will require ongoing help to manage care - support circle.
- Develop creative tools to engage teens
Shared Management

Best practice: Support parents and service providers in respecting the role of teens as they take on more responsibility.

- Encourage teens and families to work together
- Respect the way teen approach life matters—relate what is important to them back to health
- Teens need to experience success and failure.
- Teens may need team of support people but they should be in ‘driver’s seat’
- Review and evaluate transition goals regularly
Theme 4: Professional Education

Best Practice: Transfer knowledge about best practices for transition to professionals.

Recommendations for Essential Knowledge and skills:

- Acquire knowledge about differences between adult and paediatric services
- Acquire holistic understanding of transition issues for adults with child onset conditions
- Understand approaches of facilitating transition and change
- Expect professionals will facilitate transition and shared management
- Develop methods of achieving closure
- Encourage professional reflection
Theme 4: Professional Education

Recommendations for Knowledge Transfer

- Create curriculum that includes experiential component
- Develop continuing education opportunities
- Develop plan for educating and creating culture change
Theme 4: Professional Education

- Adolescent health a speciality - create a curriculum
- Gain funding for research
- Establish open discussions and forums between paediatric and adult services
- Provide opportunities for paediatric providers to evaluate impact of early choices on later life
- Identify champions to promote cultural change
- Develop strategies to address challenges
In Summary

- Teens, families and service providers require education about transition
- Teens and families highly value learning and support from peer networks
- Teens and families need access to quality information
- Teens and families need support to navigate systems during transfer
- Skills in advocacy and self-management are essential
In Summary

- Should be shift in knowledge and responsibility from service provider to the parent to the teen (or circle of support)
- Consumers should be paid experts
- Parents and service providers should expect teen to think about and prepare for adult life
- Need to have explicit processes for transfer
- Clear lines of communication and information sharing
- Measurable outcomes and evidence
Thank-you