

CONSENSUS ON BEST PRACTICES FOR TRANSITION TO ADULT SERVICES:

**Summary of Pre-Conference Workshop
Transitions Conference 3: Growing Up Ready**

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The “*Consensus on Best Practices for Transition to Adult Services*” pre-conference workshop capitalized on the attendance of international experts & presenters participating in Transition Conference 3: Growing Up Ready (May 12-13, 2006). This invitation-only meeting included 32 participants, in attendance were youth & parent consumers, service providers in paediatric & adult health, administrators, researchers, & policy makers. International representation included delegates from Australia, Canada, England, Ireland, Sweden, & the United States. Financial support was provided by The Royal Bank of Canada, SickKids Foundation, & Bloorview Kids Rehab.

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OBJECTIVES: The goals of the workshop were to share expert practice & research related to transition to adult services for youth with disabilities &/or special health care needs from an international perspective & to generate recommendations for best practices.

The workshop content focused specifically on the preparation of youth & families for transition to adult health/medical services & on the actual transfer process from child-oriented to adult-oriented health/medical services.

Participants worked in a series of small groups to discuss best practices based on **four themes** identified from the transition & transfer literature (see References):

1. **The Transfer Process**
2. **Growing Up Ready**
3. **Shared Management**
4. **Professional Education**

In this document, **BEST PRACTICES**, **RECOMMENDATIONS** for implementation, & **IDEAS & EXAMPLES** will be listed for each theme. The information will be most useful to service providers, administrators, & policy makers.



THEME #1: TRANSFER PROCESS

Participants shared perspectives on ‘best’ models, systems, & protocols of transfer, as well as suggestions for health care team membership & effective tools for information transfer.

BEST PRACTICE: *Organizations should adopt a formal transfer approach & process.*

RECOMMENDATIONS:

- Identify key champions to facilitate discussion about approach & process of transfer.
- Set explicit policies for planned & coordinated transfer.
- Continue to build on best practices & evidence for best practices to support transfer processes.
- Identify & develop measurable outcomes & objectives that will support research & program evaluation of transfer practices & service delivery models.

IDEAS & EXAMPLES:

- Have consumers as partners to ensure transfer services meet their needs (e.g. youth & family facilitators on transfer teams).
- Develop a ‘PowerPoint’ road show to educate professionals about the issue of transition to adult services & to recruit champions.
- Create a ‘memo of understanding’ between paediatric & adult service organizations to clarify roles, responsibilities, & expectations.
- Involve administrators & policy makers in creating a written transfer policy.
- Ensure organizational accountability by including statements about transition & transfer in strategic plans.
- Incorporate transition indicators into organizational performance evaluations (e.g. number of completed transition plans).
- Examine other models & populations for adoptable & adaptable concepts & approaches (e.g. Change Management Theory; Geriatric Medicine).

BEST PRACTICE: *Establish a clear procedure for transferring youth.*

RECOMMENDATIONS

- Recognize that transfer of services should be gradual & occur over a period of time rather than one full transfer at a single point in time. Change Management Theory supports the need to make one change at a time.
- Allow for non-age specific transfers. Take into account a youth’s stage of development & preparedness in determining transfer readiness.
- Work with youth to develop a clear plan for the process of transferring (e.g. a contract, clinical pathway, & curriculum).
- Create a clearly articulated & realistic written transition plan that is based on the youth’s & family’s hopes & expectations. It should span service systems, not just health & medical services. The health care team needs to be accountable to the plan.
- Identify a person to coordinate the transfer. In large urban centres, this may be a Transition Coordinator &/or Transition Clinic. In rural and under-resourced communities, physicians in general practice & nurse practitioners may take on this role.
- Identify transition plan supports such as a Systems Navigator &/or web resources.
- Acknowledge & celebrate the transfer as a significant milestone. Have a ‘graduation ceremony’ similar to high school – this will also raise awareness within an organization.

BEST PRACTICE: *Establish methods for communication & information sharing.*

RECOMMENDATIONS FOR COMMUNICATION SHARING BETWEEN PEADIATRIC & ADULT PROVIDERS

- Develop methods to transfer medical information (e.g. medical discharge summaries, health passports, memory sticks).
- Avoid a ‘baton pass’ model of service delivery: Conduct joint clinics or graduation clinics with adult & paediatric service providers.
- Create & adopt language & terminology common to both sectors (e.g. ‘transition’ may not have meaning for adult service providers but ‘engaging young adults’, ‘emerging adulthood’ or ‘patient orientation’ may be better understood).

IDEAS & EXAMPLES

- Have a service provider cross-appointed to paediatrics & adult services.
- Have a paediatric service provider participate in an adult clinic or vice versa.
- Have a team that specializes in adolescent health care to bridge between childhood & adulthood services.

RECOMMENDATIONS FOR COMMUNICATION SHARING BETWEEN PROVIDERS & CONSUMERS

- Have clear expectations for moving on to adult services; provide education & resources about these expectations.
- Educate about differences between the paediatric & adult service systems. It is unlikely that the adult system will replicate the culture & structure of the paediatric system – service providers need to prepare youth for the adult services that exist.
- Provide access to information about transition preparation programs & services.

IDEAS & EXAMPLES

- Provide opportunities for experiences in an adult service environment as part of an orientation or education about adult services (e.g. tours of the adult facility, structured observational visits with an adult service provider that include feedback to the youth about their performance & participation).
- Have key contacts or resource people who are knowledgeable about transition & can direct youth & families to services. Have a web-based resource for information about services related to transition & to adult services.

RECOMMENDATIONS FOR COMMUNICATION SHARING AMONG YOUTH & FAMILIES

- Develop opportunities for youth-to-youth & family-to-family networking & mentoring. Peer mentoring may also benefit the mentor by reducing the isolation many youth with disabilities experience once they graduate from high school.
- Hire Youth & Family Facilitators as part of the transfer.



THEME 2: GROWING UP READY

Participants shared evidence regarding interventions focused on future oriented & developmentally appropriate skill building including life skill programs, tools, checklists, & auditable approaches to achieving milestones.

BEST PRACTICE: *Develop skills & knowledge of youth & families for engaging in adult services.*

RECOMMENDATIONS

- Families & service providers should set expectations for the youth to participate in & advocate for their health care needs from an early age.
- Youth & families must set expectations for health care providers to prepare them for the future.
- Be explicit about adult information & ensure messages about planning for the future & preparing for transition are consistent across the lifespan & across service systems.
- Provide reliable & accessible information about community resources (e.g. booklets, websites – www.door2adulthood.org, diagrams of services & community information centres). The ideal situation would be a key contact person who the youth & family can call to help them navigate.
- Educate youth about the need for regular check-ups with specialists across the lifespan that are focused on disability or special health care needs.
- Educate & teach youth & families the skills necessary to access adult services. Self-advocacy & self-management will be critical for obtaining services during the process of transferring.

IDEAS & EXAMPLES

- Target self-management & self-advocacy skills early & continually within health care interactions.
- Develop specific programs to target self-advocacy & self-management.
- Direct funding to education & development of advocacy skills for youth.
- Encourage youth to get involved in leadership & advocacy groups & organizations (e.g. K.A.S.A. & National Youth Leadership Network in the United States).

RECOMMENDATIONS

- Provide methods/tools for systems navigation (e.g. a professional, parent, or youth as transition coordinator).
- Provide opportunities for peer mentorship & support for psychosocial & inspirational support & education.
- Enable youth & families to be advocates for services that will support them in planning & preparing for transfer. Adult service providers need to understand that young adults may bring support people to health care appointments.

IDEAS & EXAMPLES

- Provide peer programs for youth & for parents (e.g. mentorship programs, advisory councils, social events, etc).
- Develop safety nets (e.g. circle of support) to support youth as they develop skills & knowledge to prepare for adult life & to help them understand who can support them during transition.
- Invest a portion of core funding in an organization's budget to fund youth & family experts.
- Involve youth & families in program & resource development.
- Support family networks – this increases the capacity of youth & parents to advocate for their health care needs as individuals & as a community. Families want to hear from other families!



THEME 3: SHARED MANAGEMENT

Participants shared evidence & information about roles youth & families can play as participants in the process of transition to adult services & in the development of paediatric, transition & adult services.

A PHILOSOPHY OF SHARED MANAGEMENT (Kieckhefer & Trahms, 2000)

- It is a collaborative partnership based on trust, mutual respect, & sharing of knowledge;
- It is person-centered. Youth are encouraged to take control of their lives & plan for the future within the partnership;
- It involves sharing power & responsibility for managing health care needs. There is a knowledge & power shift compared to traditional consultative consumer-professional relationships.

RECOMMENDATIONS FOR ADOPTING SHARED MANAGEMENT IN AN ORGANIZATION

- Educate staff on all levels of the organization about models of shared management. It is important for professionals & clinics to incorporate the concepts of shared management into their interactions with youth & families & for administrators to set expectations for the organization. Ideally, the philosophy of sharing management & responsibility would be introduced to service providers in professional training programs, prior to entering the workforce.
- Organizations should challenge themselves to conceptualize shared management within a variety of situations (e.g. severity of disability, culture, & religion, life long conditions vs. acquired conditions).
- Review terminology to ensure terms are clearly defined & easily understood (i.e. shared management, consultation, & consumer).

IDEAS & EXAMPLES

- Youth & parents should have paid positions as expert resources/colleagues. Youth & parents provide expertise in what they need to know about transition to adulthood & to adult services & how they want to receive this information.

RECOMMENDATIONS FOR PROMOTING SHARED MANAGEMENT IN PRACTICE

- Involve youth in school meetings & medical appointments from an early age, with expectations that their participation in meetings will increase over time (e.g. children begin participating in medical consultations at 8-10 years of age at SickKids Hospital in Toronto, ON).
- Promote reciprocal information sharing & knowledge about health care needs, shared management, & transition issues. Providing access to quality information about health & transition services means youth &

families have the knowledge they need to take charge of their health care.

- Engage in annual discussions with youth & parents about what youth want & need in relation to planning for the transition. Service providers & parents must learn to accept choices made by youth (e.g. use of the Shared Management grid by the Healthy & Ready to Work Resource Centre in Washington, DC.).
- Provide explicit explanations about shared management to youth & families. 'Knowledge equals power' -- youth are more likely to take responsibility for managing their health care if there is an expectation to do so. Individualized guidelines or scenarios should be developed about what shared management may mean to a youth & his or her family. These guidelines should include explanations of key shared management concepts.
- Recognize that youth & families may have different needs or expectations. Some consumers may want shared or collaborative management, others may want to be told what to do. Service providers & families need to determine how they will work together & still prepare youth for the transfer to adult services.
- Share the philosophy through youth-to-youth or parent-to-parent education.
- Create a written protocol for shared & collaborative decision making demonstrating the shift in responsibility &/or participation in decision making from service provider to parent to young person over time. The protocol or model may need to be adapted to address situations where it is not realistic for the youth to be totally independent in managing his or her health care. Some examples may be youth with significant mental health, communication or intellectual disabilities. One way to address these situations is to identify someone in the youth's support circle or community who is responsible for managing health care & determining how decisions will be made on the youth's behalf.

IDEAS & EXAMPLES

- Develop creative tools to involve youth in shared management (e.g. colour-code information on a Shared Management grid).
- Provide youth with an opportunity to co-sign treatment plans at an early age, thus setting expectations for responsibility.

BEST PRACTICE: Support parents & service providers in respecting the role of youth as they take on more responsibility.

RECOMMENDATIONS

- Encourage youth & families to manage health care together & to share responsibility. Youth learn from parents as role models (e.g. asking questions, keeping medical health records, etc.).
- Respect the need for youth to be independent from their parents. Recognize the expertise of youth themselves & their knowledge & skills but accept that they may be more interested in issues other than health care such as social activities or independent living. Most issues can still be related back to health & wellness.
- Allow youth to experience success & failure. Youth should be in the driver's seat but may have a large group of people who support them. While youth may need assistance to navigate service systems, they can still control who is involved & in what way.
- Review & evaluate transition related goals regularly.



THEME #4: PROFESSIONAL EDUCATION

Participants shared evidence about the education & training of professionals in preparing youth & families for transition, transfer & shared management.

BEST PRACTICE: Transfer knowledge about best practices for transition to professionals.

RECOMMENDATIONS FOR ESSENTIAL KNOWLEDGE & SKILLS

- Acquire a thorough understanding of the differences between adult & paediatric approaches to health care.
- Develop an understanding of the developmental continuum of maturing with a disability.
- Acquire a well-rounded & holistic understanding of transitions experienced by individuals with disabilities across the life span. Be aware that although developmentally appropriate healthcare guidelines may be in place for youth in general, they may not be appropriate or applicable to young adults with paediatric-onset disabilities & conditions.
- Understand approaches & methods of facilitating transition & change.
- Make expectations for future orientation & shared management approaches an explicit responsibility of professionals.

- Develop methods of achieving closure with families transitioning from paediatrics.
- Develop approaches to orienting new clients to adult services.
- Encourage professional reflection (e.g. consider impact of paediatric interventions & approaches on adult life).

RECOMMENDATIONS FOR KNOWLEDGE TRANSFER

- Create a curriculum for professionals-in-training that includes an experiential component. Target groups to pilot the new curriculum (e.g. occupational therapy or medical programs at the university level).
- Develop continuing education opportunities for professionals.
- Develop a plan for educating & creating culture change in organizations.

IDEAS & EXAMPLES

- Adolescent health should be considered a specialty. Create a working group to create & test a curriculum. Review & build consensus on content. Evaluate (then redesign & further develop) curriculum through an iterative process & spiral out to a variety of audiences for pilot testing.
- Establish funding for a research associate who is responsible for pulling together & synthesizing the existing materials & with developing the curriculum.
- Establish open discussions & forums on existing transition-focused websites or mediated round table discussions between paediatric & adult service providers.
- Include opportunities for experiential learning through inter-professional education (e.g. mentorship between paediatric & adult specialists; fellowships to general practitioners; professional partnerships within & between paediatric & adult clinics such as participation in clinics that serve both paediatric & adult clients or specialty adult clinics with a paediatric culture of care).
- Provide opportunities for paediatric providers to evaluate impact of early choices on later life & ways of changing practice (e.g. occupational therapy program at the University of Toronto).
- Provide in-service training of staff.
- Identify champions to promote cultural change about transition & transfer practices. Clearly outline the nature of the culture change & the steps required in its implementation. For example, the adoption of successful paediatric approaches to care (e.g. power of the team) at the adult level may require the creation of a dialogical process for clients for separate specialties to maintain open chains of communication & move issues forward.
- Develop strategies to address internal challenges an organization may experience (e.g. identify predetermined responses to address the concerns of 'resisters' immediately).
- Provide financial incentives at the adult service level to change the current state of acceptance regarding patients with paediatric-onset disabilities & diseases.

RECURRING RECOMMENDATIONS ON BEST PRACTICES FOR TRANSITION TO ADULT SERVICES

1. Youth, families, service providers, & organizations require education about transition & transfer models, & shared management.
2. Youth & families highly value learning & support from peer networks & mentorship.
3. Youth & families need access to quality information about transition & adult services. Knowledge is empowering.
4. Youth & families need support to navigate systems during the transfer to adult services.
5. Skills in advocacy & self- management are essential for youth & families. The transition process should demonstrate a shift in knowledge & responsibility from the service provider to the parent to the youth (or to a circle of support).
6. Consumers should be paid experts to plan & provide services alongside professionals.
7. Parents & service providers need to set expectations for youth to think about & prepare for adult life.
8. Organizations need to set explicit expectations & processes for transfer to adult services.
9. Clear lines of communication & information sharing are needed between youth/families & service providers, & between paediatric & adult service providers.
10. Measurable outcomes & evidence for transition & transfer practices need to be developed.

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