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“The Best Journey to Adult Life” For Youth with Disabilities

An Evidence-based Model and Best Practice Guidelines For The Transition To Adulthood For Youth With Disabilities



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Dedication

We dedicate this report to the memory of Dr. Beverly Antle, who was the co-principal investigator on this research project in its first phase. Her vision for a meaningful and satisfying life for all people has sustained us throughout this project.

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Executive Summary

This document represents five years of work by a research team and a network of youth, parents, community members and service providers in Ontario, Canada who were interested in identifying best practices for the transition to adulthood for youth with disabilities.

Our research team used an evidence-based approach to develop best practice guidelines and a model. The key forms of evidence that were used included:

1. critical reviews of the literature for the years 2000 - 2007;
2. an environmental scan conducted through focus groups across Ontario, and individual interviews with key policy and ministry persons.

A consensus exercise with an ‘expert panel’ of young adults with disabilities, service providers, parents, community members and researchers was held on two occasions to review all evidence and develop best practice guidelines and the “The Best Journey to Adult Life” (BJA Model). A graphic representation of this model was also developed at the consensus meetings in the form of a hot air balloon.

The “Best Journey to Adult Life” model represents the dynamic and ever-changing developmental process of a young person’s lifecourse, with the transition to adulthood depicted as an important ‘journey’. Best Practice Guidelines have been written using the words of the expert panel members. They are organized into six main themes that emerged from the consensus meetings.

1. Collaborative Initiatives And Policies Are Necessary Supports For The Transition.
2. Building Capacity Of People And Communities Will Enhance The Transition Process.
3. The Role Of A “Navigator” Within Communities Facilitates Capacity Building.
4. Information And Resources Are Accessible To All Involved In The Transition Process.
5. Education Is A Critical Component Of Any Transition Strategy.
6. Ongoing Research And Evaluation Provides The Evidence Needed For Success.

Within each theme, guidelines are provided for three key phases of the transition process: preparation, the journey itself and the landings in the adult world. Specific guidelines within each phase are written for the key stakeholders involved in the transition process.

The BJA Model and the Best Practice Guidelines for the transition to adulthood for youth with disabilities are based on current evidence from multiple sources. However, they have not been evaluated within the context of different communities, services or populations of youth. This would be the logical next step and our research team welcomes feedback and input about this document, and we welcome individuals and groups to use and evaluate the model and guidelines.

CHAPTER 1: THE RESEARCH PROJECT AND TRANSITION NETWORK

Background Information

This document represents five years of work by a research team and a network of youth, parents, community members and service providers in Ontario, Canada who have been interested in developing best practices for the transition to adulthood for youth with disabilities.

The research started as a response to a Request for Proposals from the Ontario Ministry of Health and Long Term Care (MOHLTC) and the Ontario Neurotrauma Foundation (ONF) for comprehensive systematic reviews for best practice models. This project had two overall research questions:

- a. What is the current evidence about best practice in transition to adulthood across the continuum of rehabilitation services?
- b. What is a best practice model in transition to adulthood across the continuum of rehabilitation services?

This first phase of our work resulted in the culmination of evidence from multiple sources:

1. a critical review of the literature;
2. an environmental scan conducted through focus groups across Ontario, and individual interviews with key policy and ministry persons; and
3. a consensus conference that included an ‘expert panel’ of young adults with disabilities, service providers, parents, community members and researchers.

The second phase of our work took place in 2007 – 2008, when we received funding from the Children’s Rehabilitation Research Network (CRRN) of the Ontario Rehabilitation Research Advisory Network to hold a second expert panel consensus conference. This conference was held in June 2007 with previous and new members of the expert panel. Groups of youth, parents, community members and service providers reviewed and expanded on the first recommendations, and reached consensus on a “Best Journey to Adult Life” (BJA) model and a hot air balloon graphic representation.

The Evidence

The goal of this research has been to develop Best Practice Guidelines that are evidence-based. The research team adopted an evidence-based approach that acknowledges multiple forms of evidence including the literature, current ‘clinical’ conditions and perspectives, and the experiences and perspectives of service recipients and the “public” (Haynes, Devereaux & Guyatt, 2002.)

The Evidence upon which the best practice guidelines are based includes:

- (1) **Literature**, both published and unpublished, about transition to adulthood for youth with disabilities. A review of the literature was conducted in two time periods. Appendix A summarizes the literature reviewed up until 2005 about transition to adulthood for youth with physical and developmental disabilities. The part of the project culminated in a publication of our critical appraisal of review articles (Stewart et al., 2007). Appendix B provides an extensive bibliography from a second literature review conducted in 2008. This second review expanded on the 2005 search to include youth with all types of disabilities.
- (2) An **environmental scan** provided experiential evidence to inform consensus-building best practice guidelines. A series of focus groups with youth, family members, service providers, community members and researchers in selected regions of Ontario were conducted. Locations for the focus groups were a) Hamilton; b) Ottawa; c) Kitchener-Waterloo/London; d) Toronto & e) Timmins.

Key informant interviews were held individually with senior policy staff in the Ontario Ministries of Children and Youth, Community and Social Services, Education, Health and Long term Care and Training, Colleges and Universities, following the focus group meetings. Five interviews were conducted.

Synthesis of Evidence for Best Practice Guidelines – A Consensus Process

A **consensus-building process** was used with an expert panel to synthesize all of the evidence gathered into a coherent set of Best Practice Guidelines. Members of the expert panel were drawn from a breadth of sectors including family members, health care providers, service providers, community members, and youth with disabilities. Evidence gathered from the literature search and environmental scan was sent to the expert panel, with specific questions for consideration.

The expert panel met the first time for one day in 2005. Recommendations for Best Practice Guidelines were developed through consensus. Following the consensus conference, a report and first set of Best Practice Guidelines were circulated to all participants for final review and comment. A summary report of this first version of the Guidelines has been posted on the *CanChild* website (www.canchild.ca).

At the second consensus conference in June 2007, the expert panel expanded upon the initial set of recommendations to write best practice guidelines for youth, parents, community members and service providers. Also at this conference, the expert panel agreed upon a model for these guidelines: The BJA (“Best Journey to Adult Life”) Model, in honour of Dr. Beverly J. Antle, who was a co-principal investigator of the first phase of this project.

The expert panel members have now formed the foundation for a “Transition Network” in Ontario, which is made up individuals (youth, parents, community members, service providers and government representatives) who are interested in ‘best practice’ for the transition to adulthood for youth with disabilities.

CHAPTER 2: “THE BEST JOURNEY TO ADULT LIFE” (BJA MODEL)

The Best Journey to Adult Life (the “BJA Model”) for youth with disabilities is represented graphically as a journey in a **hot air balloon**. Figure One shows the hot air balloon with the **six guideline themes** of collaboration, building capacity, navigation, information access, education and research. (The themes are explained in detail in Chapter 3).

Figure One: BJA Model – Hot Air Balloon (© Copyright 2009 McMaster University).



In the balloon basket, the main **people** involved in the journey include the youth, parents or guardians, and a navigator. A navigator is a person who provides support and guidance to the youth and family as they navigate along their transition journey. The navigator role is described in detail in Chapter 3 (Theme III). Note that in this basket, the youth is ‘in the driver’s seat’ but is being guided and supported by the navigator and parents. This situation represents the early stages of the transition journey. Later in the journey, the navigator may be less involved in guiding and supporting, and the youth will take more control in directing the balloon’s journey.

The **basket** represents the “**community**” of which the youth and family is part. The community is an integral part of the youth’s journey, and is inclusive and flexible in its support.

The **fuel tank** of the hot air balloon represents the **core foundational values** of all phases of the transition journey. Every model has underlying values and principles. These were articulated by the expert panel after reviewing all of the evidence.

The **values** that are the foundation of best practices should include:

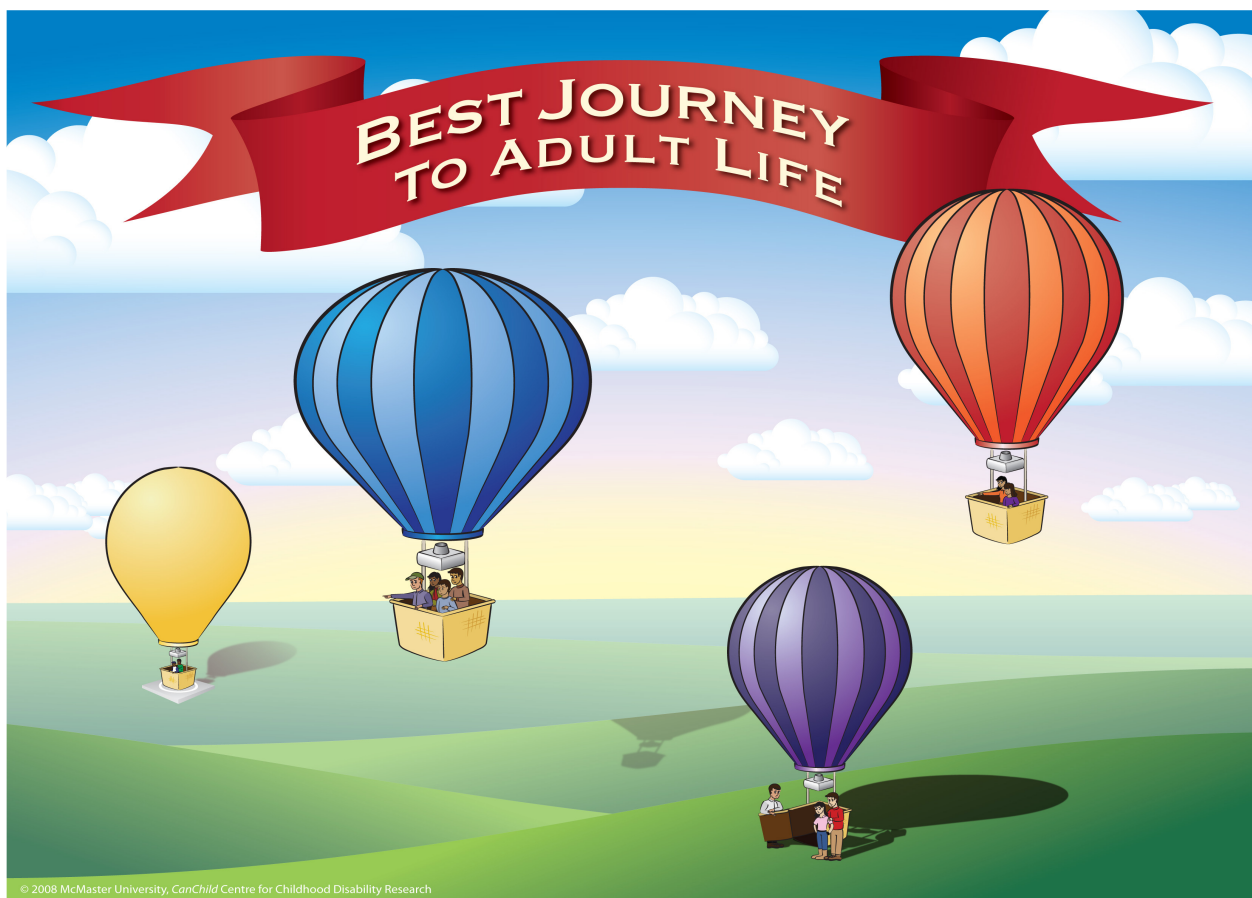
- person first
- family centred
- culturally sensitive
- strengths/needs based (vs. diagnosis)
- equitable
- flexible
- have a life course philosophy
- future orientation
- choices & options offered (individualized)
- include supportive environments
 - community capacity building
 - inclusive communities
- wellness promotion
- interdependence a focus (versus ‘independence’)
- outcomes of participation, contribution & belonging = citizenship

The **fuel** of the hot air balloon is the **evidence** that is the basis of the decisions made by the expert panel to develop the guidelines. It is our hope that any transition program, support, service or initiative uses evidence to fuel their planning and decision making.

A Journey within a Person's Lifecourse

The single hot air balloon graphic has been expanded to a landscape graphic to represent the transition to adulthood as a journey within an individual's lifecourse (Figure Two). Each individual has numerous journeys during their lifecourse, and these journeys take place at different developmental stages and transitions. The transition to adulthood is considered to be a critical journey within an individual's lifecourse, as there are significant changes taking place within the person and the environment.

Figure Two: BJA Model Landscape: Within a Person's Lifecourse (© Copyright 2009 McMaster University).



Although the core values, key components and guideline themes are the same for everyone, the landscape graphic depicts the balloons and the journeys as all different. Each youth and family is at different stages of the journey: some are still “on the ground” in preparation for the transition to adulthood; others are starting this journey, with the navigator guiding a great deal; others are nearing the end of the journey, when the youth has more control and self-determination; and there are others who have made one or more ‘landings’ in the adult world and are getting ready to take off again on another journey.

An individual is always on a journey at different stages of their lifecourse. A lifecourse approach to viewing the transition to adulthood, as well as other transitions during a person's life, acknowledges that there are many common issues and challenges along the way. An individual builds their capacity to participate in daily community life as they make their own journey. And a lifecourse approach also acknowledges that journeys are not done alone: we all benefit from supports along the way. A supportive environment can provide the tools and resources that an individual needs as they prepare for their transition 'journey' and also to make a smooth landing at their destination of choice.

CHAPTER 3: BEST PRACTICE GUIDELINES FOR THE TRANSITION TO ADULTHOOD FOR YOUTH WITH DISABILITIES

Six themes emerged from the consensus expert panel review of the evidence. Each theme includes the following information:

- (i) “What do we mean by this?”
- (ii) Guidelines for three key phases of transition.

In keeping with the hot air balloon model, we have organized the Guidelines into three phases of transition:

1. The **‘preparation’** phase which takes place during a youth’s late childhood and adolescence as they begin to look ahead and prepare for adult life;
2. The **‘journey’** during the transition itself, in which the young person is experiencing the changes and journeys from one developmental stage, environment or role to another; and
3. The **‘landings’** in the adult world, which recognize that there will be phases of reaching a destination, with outcomes and goals being met, and time taken to ‘refuel’ before starting on another journey in one’s lifecourse.

Guidelines for these three phases are provided for the different ‘stakeholders’ involved in the transition to adulthood: youth, parents/families, community members, service providers. Recommendations for government/policy makers are written for all transition phases, at the end of each theme.

It is acknowledged that relationships between all of these people and groups are interdependent throughout this journey.

THEME I: COLLABORATIVE INITIATIVES AND POLICIES ARE NECESSARY SUPPORTS FOR THE TRANSITION

“What do we mean by this”?

- Collaboration involves working together to create meaningful outcomes for all involved parties.
- Collaboration means seeing issues from all perspectives, compromising, and developing mutual, agreed upon, and meaningful dreams and goals for how to transition youth and families.
- Collaboration means that a seamless process/journey occurs at all levels from community to agency, from young persons to policy level, working toward the same outcomes.
- Collaboration must involve consistent and reliable follow-up by involved parties working together.
- Collaboration involves developing a shared vision at all levels with all people (youth, families, service providers, community, policy makers and ministry officials).
- Collaborative efforts may not always result in pleasant interactions; therefore, strategies are needed to deal with potential conflicts.

Guidelines for Best Practice

“PREPARATION” PHASE

YOUTH:

- Youth with disabilities need collaboration with others around them to get encouragement to:
 - Take on greater responsibility in the home or school, based on an individual’s maturity level (for example, chores).
 - Set collaborative and realistic goals that an individual can identify and agree with.
- Collaborative efforts will prevent “passing the buck” between family and service providers in making transition plans which could have youth caught in the middle. Everyone should work together with the youth on their goals and enable youth to gain responsibility and control for the direction of their own lives

PARENTS:

- Early preparation means that parents should have the opportunity to be prepared for all transitions throughout the life course, by working collaboratively with other families and service providers.
- Early preparation occurs collaboratively when someone ‘walks’ with a family through transition planning:
 - Focus should be on the individual and family rather than on the diagnosis alone.
- Increased community awareness of families allows any individual/family to expand their circle of friends/supports in natural ways.

COMMUNITY:

- Preparation involves finding the frontline “champions” that want to work collaboratively with youth and families from the start.
 - They want to address an individual’s assets and needs, not their disability.
 - They work collaboratively with youth and families to find the champions.
- Schools should work collaboratively with other community groups and service providers to begin transition planning early (i.e., in childhood).
 - Build this into the start of the IPRC process.
 - Create community co-op experiences and career planning opportunities within the community.
- Community programs/agencies must work together to develop common resources and processes, such as one common ‘intake’ package.

SERVICE PROVIDERS:

- Setting up a collaborative service system for the preparation process will help to ensure a balance of responsibilities, actions, etc., between school, services, community, family.
- For services such as Rehabilitation Centres: at intake of individual, teams should start preparing for transition and discharge and transfer into adult services.
- Services can work with communities, along with youth and families, to develop collaborative community capacity building opportunities. For example, create opportunities for youth to use and test skills in community settings such as businesses, community centers and extracurricular clubs or groups as part of preparation.

- Emphasize “shared management” with families within services, and take the focus off just the “expertise” among service providers.
- Peer support and word of mouth (for example, by a children’s agency to an adult program) can bring about collaboration and reduction of barriers between agencies in various sectors and communities.. Bring peers together to discuss collaborative initiatives.

“THE JOURNEY”

YOUTH:

- Youth can benefit from collaboration with a contact person such as a “navigator” or facilitator they can call on and fall back on as needed during their transition.
- Everyone around youth should work together to reduce the amount of assessments and people youth have to work with, in order to reach a goal. This requires collaboration on all levels.
- Everyone around the youth should also respect individual choices made by the youth with respect to their future, based on maturity level, and allow the youth to go on multiple journeys.
- Everyone around the youth should not expect every journey, no matter how carefully planned, to go smoothly and allow for the youth to make changes in direction as well as goals.
- Youth with disabilities may use collaborative opportunities to take leadership along with family members and service providers in the transition process.

PARENTS:

- Collaboration, in order to be effective, must acknowledge the necessity for input from parents, and other family members (a whole family approach), at each transitional stage, from one domain to the other (e.g. elementary to high school to postsecondary education; living in parents’ home to living in the community).
- Collaboration with a facilitator or navigator may assist parents in complicated situations (for example, when personal support workers vote to refuse work with young people with specific behavioural issues). This facilitator/navigator position should be developed through collaborative efforts with the community working with parents. A community facilitator has been successful in several communities in Ontario, such as Windsor, Hamilton and Timmins.

COMMUNITY:

- Collaborative efforts among community members and groups will reduce barriers by:
 - Developing “asset-based” and “needs-based” collaborative efforts throughout a person’s lifecourse.
 - Creating a “personal support network” through strong collaborative leadership with individualized supports (e.g., one person at a time)
- A focus on non-judgmental communication by everyone is necessary for solutions, working with what’s available and not solely relying on things to change.
- A community “navigator” will help individuals and family pull it all together, and promote collaboration of everyone in the community. This type of community ‘champion’ is needed to bring people together.
- Collaboration involves the community, not just one agency, to work on reducing barriers during the journey. Expect a goal of helping the individual first, not the agencies.

SERVICE PROVIDERS:

- A collaborative service system needs to have flexibility with ages of transition and discharge among different service systems. For example, create “staggered points of transfer” for each individual in a collaborative way among different services.
- Develop family and pediatrician collaboration early, and then the pediatrician takes on more of a consultative role as the process progresses and the young person gets older.
- Collaborate with youth to simplify ‘professional’ language used in services, and create guidelines together (e.g., addressing youth first and then parent if youth cannot continue).
- Develop a Youth Advisory Committee within services to collaborate actively with youth.
- To enable self-determination, collaboration can provide youth with a set of choices so that they can have a say in determining their own transition journey regardless of physical or cognitive ability.
- When dealing with youth with complex/multiple disabilities, such as behavioral issues, services must not be punitive (such as complete refusal to engage the youth) but rather based on evidence for sector wide practices.

“LANDINGS” in the adult world

YOUTH:

- Collaboration among and with young adults helps to address their desired outcomes, while always maintaining respect for their own choices and autonomy.
- Collaboration with young adults can help to reduce repetition in adult communities and service systems (for example, for applications and getting signatures).
- Collaboration with ongoing flexible support for young adults is necessary to be responsive to when they require support with another journey; for example, when they are ready to move out on their own later in their adult life.
- Collaboration for young adults includes friends/peers, family, and community members
 - Leading to vital and lifelong relationships for young individual, and becoming the basis of a personal support network
 - Type and amount of collaboration will vary partly depending on the ability of the young person to participate, and this must be considered.
- Collaboration should support notion of “interdependence” not independence. We need to work together to redefine the concept of independence to focus on individual control, growth and successful journeys. "Interdependence" acknowledges that everyone needs social supports and networks to succeed throughout life stages.
- The outcomes of transition planning should be identified collaboratively with the youth's goals and dreams at the center.

PARENTS:

- Collaboration for parents and families of individuals entering adulthood includes:
 - Respecting varied levels of parental participation (e.g., those with full time careers, other family demands, etc).
 - Addressing the individual's and their families' rights
 - Working together for political changes if 'landing' conditions are not right in any part of the adult world..

COMMUNITY:

- In the adult world, “landing” is an *ongoing* developmental process and not an outcome endpoint, so the community needs to be flexible in identifying who needs to collaborate with youth and families at different points in time.

- Community members should work together to evaluate whether individuals are aging/participating successfully as adults. They must recognize that different outcomes may occur at different developmental periods across the life course.
- Develop a collaborative evaluation process (within community programs) that focuses on person-centered outcomes not agency centered outcomes.
- Collaborate on how education can help engrain recognition of everyone's ability to contribute within a community. Education is a key activity that can bring people together whether through continuing education, postsecondary education or community workshops. The overall effectiveness of community education enhances positive outcomes.

SERVICE PROVIDERS:

- A priority must be to develop an adult service system that is capable of receiving transitioning youth through collaboration. The system should ensure that everyone works together to end the isolation of youth from adult providers.
- Outcomes of services should be set collaboratively with youth and family members.

POLICY/GOVERNMENT: FOR ALL PHASES

- Collaborative initiatives need to receive ongoing funding support from government with incentives for positive outcomes. Initiatives that have demonstrated collaboration and effectiveness need sustainable funding and advocacy from policy makers to make a difference over the long term.
- Funding from government should also be tied to programs and services sharing their successes and resources, so others do not have to 'reinvent the wheel'.
- Ministries of Education need to include transition planning for all students by instituting recommendations/mandates that increase overall accountability at all levels – school personnel, consultants, trustees, etc... Special Education in the school system should not be solely responsible for transition for youth with disabilities. Collaboration with other ministries and outside agencies will assist in planning.
- Joint collaborative meetings between ministries can sort out "needs based" not "disability based" responsibilities and funding.
- Mandatory collaboration among agencies, unions, and government programs can be promoted throughout any youth's journey by using funding as incentives.

- “Portable” funding can remove mobility issues among communities and provinces if a youth or family moves.
- Families with individualized funding need equal opportunity to connect with agencies and supports. Individualized funding as well as ministry-funded programs need to collaborate on transition to make a difference: for example, government providing individualized funding to purchase services and supports that youth and families need, and at the same time agencies provide ministry-funded resources such as medical passports or web-based information to youth and families.
- Funding is not the only method policymakers can use to reward program success. Recognition as well as credit for successful program collaboration and service delivery is a positive outcome for organizations, and also allows other jurisdictions to learn of the successes of others.
- Adequate sustainable funding for community-based navigators/facilitators is needed to assist families and to promote collaboration among communities and services.

THEME II BUILDING CAPACITY OF PEOPLE AND COMMUNITIES WILL ENHANCE THE TRANSITION PROCESS

“What do we mean by this”

- Building capacity means all of the individuals involved have a shared understanding of what transition means and a shared knowledge of where opportunities exist for capacity building, support groups and mentoring.
- Capacity building focuses on the strengths and assets that an individual brings to any situation rather than skills for specific outcomes such as employment.
- The goal of transition should not be focused on a series of outcomes such as employment, independent living and hobbies; but rather, active citizenship and involvement in meaningful occupations. The capacity for active citizenship needs to be built by all involved in transition.
- Individual capacity includes knowledge and skills, resources, strengths and experiences that all contribute to participation in daily life. It is much more than just traditional skills, such as motor or cognitive skills.
- In a community, capacity includes resources, partnerships, opportunities, (e.g. what’s available to meet needs and how the community uses resources and opportunities, aside from funding alone, to meet needs).

Guidelines for Best Practice

“PREPARATION” PHASE

YOUTH:

- Begin by building capacity early, so that youth with disabilities can be encouraged to “do it on my own with supports” and recognize the significance of interdependence for the rest of their lives.
- Create a base of knowledge (build knowledge capacity) about important transition issues in the early years, not as traditionally done by waiting until the teen years.
- Recognize that youth with disabilities are pushed forward by expectations of "independence" at an earlier age than able bodied peers. Capacity building should focus on building support and mentoring in *early* years as well as in the teen years, with the understanding that complete "independence" may not be realistic. Move toward the paradigm of "interdependence" which involves active collaboration between youth,

families and communities, and promotes healthier self-esteem and advocacy skills in youth.

PARENTS:

- Building the capacity of parents during all stages of the transition journey is critical, as parents are the stabilizing force, and have the best interests of their 'child' in mind. The capacity of parents to represent their child's interests in the best way at different stages of the journey is important. Often parent capacity can be built upon through participation in parent networks.
- Parents can build their capacity to naturalize experiences for children in their daily activities without a "finite capacity" mindset. A mindset of possibilities can build capacity.
- Parents can build their own capacity to challenge the traditional values of communities, to expand their youth's sense of belonging.
- Parents can also build their capacity to work with the community to develop support circles with intentional use of planned relationships. Financial support is needed to facilitate these circles of support and build capacity of parents.

COMMUNITY:

- Increase efforts in building the capacity of the *community* to support individuals in new ways, not only supporting the family & individual in isolation.
 - Recognize & celebrate gifts of all individuals and what they can offer.
 - Facilitate the capacity to dream and advocate for the individual to use their strengths to step forward toward their dreams.
 - Focus on preventative capacity - refer youth early to adult community programs.
- Community for some people can be their family or extended family alone. Recognize and respect each individual and family's sense of community.
- Family-centered, person-first supports need to start early where needs of the family come first (i.e. in childhood) within their community. Everyone can then build the capacity for full inclusion.
- "Circles of support" know/understand an individual's needs in the community and should be established at an early age.

- Capacity building workshops for agencies and programs can open the lines of communication through identifying common interests and goals, and demonstrating how change can occur if they collaboratively work together.
- Communities can plan proactively and begin slowly with resources and capacities that currently exist.
- Introduce a navigator/facilitator in the community to build capacity and collaborate with the individual and family.
- Recognize that persons with disabilities travel through life with the same ups and downs typical people do, but with the added dimension of developmental and/or health challenges which may be chronic or recurring.

SERVICE PROVIDERS:

- Building capacity for youth “clients” should begin early with a shared philosophy that has been discussed with youth and families. "Capacity" for youth needs to be defined and explained, as it is more than just ‘skill development’.
- Capacity building for services should include education at all service levels, and should address cultural shifts, and shifts in expectation of adult system service providers.
- Service providers may be involved in facilitating and building networks in the community, and mentoring the process, through a general practitioner or a community navigator for example.
- Emphasize service provider capacities to meet future expectations, such as, knowledge of child and family at an early age (for example, social appropriateness, learning the “language”, learning to present needs and history to providers they meet, such as, a teacher, doctor., babysitter). Youth should be included in this work.

“THE JOURNEY”

YOUTH:

- Youth capacities may change over time. New journeys may, therefore, require new capacity building efforts. For example, one journey to post-secondary education may require knowledge-building capacity; and another journey to living on their own may require building capacities of finding resources and making community connections.

- A life course approach addresses an individual's capacity building over time. Everyone can support children and youth to build their capacity towards self-determination, interdependence and "active citizenship" if they work together along the way.
- Youth need the benefit of working with a “coach” or ‘navigator’ to help them build capacity during their whole journey.

PARENTS:

- Parents should also be involved in capacity building efforts of their youth, and also themselves.
 - Parents need to develop the capacity to "let go" of their youth, while still providing support.
- There should be recognition that parents often supply the only continuity for their children’s support and also remain the main supports, financially and otherwise for most of their lives. Building and maintaining their capacity to be a main support is important.

COMMUNITY:

- Capacity building can occur when the community is brought together in a young person’s life, making all members aware of the individual’s needs, and expanding the breadth of relationships that will allow for the sharing and hearing of stories throughout the individual’s journey through life.
- Provide community information and contacts to youth and parents at various points along the journey in a collaborative setting to enhance knowledge and capacity building.
- Bring down silos within schools and other community programs, to build capacity of youth with all types of disabilities, including mental and behavioural issues. Programs and services should focus more on the needs of youth, and less on them having a ‘diagnosis’.
- There is a need for agencies in the community to be more flexible in ensuring the support of an individual to build capacity. Look at need versus disability. Many youth require similar needs but because of a different “diagnosis” they are not eligible for service or support.
- Schools and communities can work together to build youth capacity by offering non-credit courses in which a student attends a community program to develop skills for the future. This can be in addition to co-op experiences.

SERVICE PROVIDERS:

- Service providers must break down silos in all service systems to include a broad view of healthy living (i.e. Includes mental and behavioral health) in order to build the capacity of services to address all youth's journeys together.
- Service providers must work together to build capacity through inter-professional education in undergraduate professional education programs.

“LANDINGS” in the adult world

YOUTH:

- Youth view transition as an ongoing process because they never land in the adult world just once, and therefore they are always building capacity at each stage across the lifespan. An individualized approach with youth is best.
- In order to land successfully at different points along the journey, youth require care support (e.g. attendant care) as part of capacity building.
 - Care support should not be about the training that attendants/Personal support workers receive, but about their ability to build capacity to provide care at every stage of a young person's journey.
- “Resting places” should be created to celebrate the journey the young adult already has completed and to take time to build capacity for the next stage of the journey. Resting places can be in schools, communities or services.
- Outcomes for transition planning should focus on capacity building for future adult journeys and not just on specific component skills (e.g. cognitive or motor skills).

PARENTS:

- Parents can help build self-determination of their youth to make it through the many stops and legs of transition– but support is required from others to help parents build their own capacity to do this. Interdependence is key.

COMMUNITY:

- Build community capacity in the adult world by using a grassroots approach. For example, community members can join circles of support.

- Adult programs require evaluation and being held accountable for how they budget and spend their funding. First acknowledge the reality of current situation and then begin to build from there. Community programs can slowly build their capacity to include youth with disabilities. Taking small steps at first enables communities to build on the assets that currently exist in the community, and this may be the most successful approach.
- Outcomes should include families and communities in relation to capacity and participation. Always work to remain meaningful to the rights of young people and families within their community.

SERVICE PROVIDERS:

- Promote capacity building in the adult services sector to reduce the social isolation of adults with disabilities, which may contribute to secondary health issues. For example:
 - Provide opportunities to build capacity in adult service providers’ knowledge and understanding of chronic disability, and how this impacts on social participation;
 - Identify strengths and weaknesses of adult service supports and resources, and build capacities from the "grassroots" up. (e.g. start with service providers working directly with young adults).
- Create greater capacity within all service providers to listen and respond to “clients” (both youth and parents).
- Service outcomes should include capacity building at different stages of the transition journey. Outcomes of participation, belonging, self-determination broaden our view of the “end point” of a youth’s journey.
- Service providers must build capacity to be more client centered to enable young persons to build their capacity for autonomy. For example, attendant care should ideally be provided at the time an individual requests it, and not when it best fits their own schedules.

POLICY/GOVERNMENT: FOR ALL PHASES

- Political capacity equals citizenship. In cases where funding is not available, a process needs to be established to ensure that funding is available to families. Capacity can only be built if funding is sustainable over time.
- Funding for “navigation” is needed at points in time when young persons and parents need it (i.e. at different landings). Put this funding into communities to build collaborative, community-wide capacity to be inclusive.

- Youth may require funding supports (e.g. attendant care, worker, job coach etc.) to help them build capacity to participate in adult communities which may or may not reduce over time. Governments need to understand that chronic disabilities mean ongoing supports may be needed in adulthood, and that supports and funding need to have choices and options, as everyone’s situation is different.
- Ministries need to build their own capacity to work with the community and young people to develop funding criteria, etc.
 - Create capacity building as best practice / “critical service” along the way. Include youth, parents and community members in planning.
- Individualized funding is needed by families who want to direct and manage their own supports, and this funding needs to transfer with the individual when they transition to adult services and supports.
- Funding agencies should be required to be accountable for their projections based on community needs. Communities need to be “scanned” to first identify current capacity, and funding can then be focused on whatever is not available.
- Ministries of Education need to provide more than “guidelines” to school personnel about supporting the transition to adulthood. Transition guidelines are a first step, but specific strategies, such as how to write clear, useful and measurable IEP statements, are needed.
- There needs to be a process established in the system somehow that is user friendly, where a family and a youth who fit no mandate for service can access this system and a process be established to ensure that the youth and family can be supported.
- Options and flexibility are the two words that represent what is needed most for building capacity of youth, families, communities and services.
- Regulatory bodies are needed where consumers can go and have complaints and concerns about services heard independently.

THEME III THE ROLE OF A “NAVIGATOR” WITHIN COMMUNITIES FACILITATES CAPACITY BUILDING.

“What do we mean by this”

- A navigator is a person or possibly a group of people of various backgrounds, with knowledge and expertise of the transition process and of the adult world.
- Another term that represents this role is “champion”, or in some communities “broker” or “facilitator” is used.
- Any person can assume a navigator role with youth’s best interests at heart. The navigator can be a community member, a broker – “connector”, not constrained by service agencies.
- A navigator can act as a coordinator with all persons involved to allow the sharing and telling of transition stories. A navigator shares similar values as the individual, and can be a mentor, facilitator, planner, and provider of information.
- A navigator is independent of institutional and agency affiliation. Youth should choose their navigator(s) along their journey.
- This role fits a chronic versus acute care model allowing for a lifecourse approach that doesn’t create reliance on one person alone.
- A navigator can collaborate with case managers and services to promote a successful transition. The youth's relationship with the navigator is a time limited involvement in which the individual would build capacity.
- Navigator qualities include:
 - Having personal investment and dedication to families.
 - Understanding how asking for help is a difficult step for people and be able to nurture this in them.
 - Being a creative thinker and explorer.
 - Having an understanding of specific ethnocultural and socioeconomic considerations for specific populations.
 - Taking a whole family approach.
 - Assisting the person/family to develop a network of support and nurturing community inclusion.
 - Helping the person/family to ensue the continuity, integrity and evolution of a plan.
 - Monitoring the implementation of the plan, reviewing its effectiveness and ensuring the person/family’s choices are being honoured.

Guidelines for Best Practice

"PREPARATION" PHASE

YOUTH:

- A navigator should be chosen by the young person and their parents, based on skills, knowledge, and ability to be resourceful. The navigator needs to 'connect' with the young person, and should be a type of mentor chosen by the youth.
- In the preparation phase the youth and families learn about navigators and may begin to think about what they would want in a navigator. Then they can work on building the capacity to successfully work with a navigator.

PARENTS:

- In the preparation phase the navigator would support the parent at the parent's request to help them advocate on behalf of their son or daughter. A navigator could work with youth and parents on how youth can keep parents involved in aspects of their life/care even though parents may not physically be able to assist anymore.
- A navigator would work equally in intensity with parents as well as youth at this stage of the journey, while recognizing that there will be a "shift in roles" for parents over time (i.e. aging parents may require someone else to advocate on behalf of their child).

COMMUNITY:

- The navigator must be allowed to come into the schools and other community settings to develop a relationship early.
- A navigator should be part of any formal person-centered & unencumbered supports in the community.
- A community-based navigator can work directly for and with young people and families and can "walk" through the communities and find information, resources, supports, connections, etc. according to what a person and family wants. Part of their role should be making community connections.
- Create a resource centre in the community to support the work of the navigators. This could be a "virtual" centre (e.g. website) that is accessible to everyone. The resources should also include a cultural component, to ensure that navigators can be not only sensitive to disability issues, but also culturally sensitive.

SERVICE PROVIDERS:

- The next generation of service providers need to be informed of the role of the navigator and that any person could be a navigator if this suits the individual, to find information and develop solutions in the community.
- Services could also put in place a family facilitator for parents to access when they require help within services. The facilitator can then connect with the community navigator.
- A navigator must be able to advocate for youth to help reduce redundancy within the service systems. Service providers must therefore welcome the involvement of the navigator with youth and families.

“THE JOURNEY”

YOUTH:

- Part of the “journey” is having a navigator who has the capacity to refer a young person to knowledgeable supports, to enable an individual with a disability to take control over the "steering wheel".
- The navigator would identify and introduce possible support options, whether paid or unpaid, as well as alternate opportunities available in one’s community:
 - A navigator should advise and monitor the individual’s plan and create a relationship advocating self-management and resiliency where possible.
 - A navigator encourages the person to express his/her desired life direction and articulate areas they feel need support as well as how he/she would like to be supported.
 - A navigator must never complete tasks for youth.
- Navigator needs to keep the uniqueness of the person in mind and realize that resources and services required may not always be disability related.
- Navigators can also help youth set realistic goals and "outcomes" at different points in their journey.

PARENTS:

- A navigator needs to become a mentor and a connector to the community for the family as well as youth at different points in time. Focus on building a network of support and networking with other families experiencing some of the same challenges.

- Navigator needs to provide flexible support to match the level of family need.
- Families need to be able to connect with the navigator when they are ready, to gain knowledge about resources and also to connect among families.
- Navigator can support the family to work effectively with paid support providers.

COMMUNITY:

- The role of navigator should be clearly identified and explained to community members, with ongoing training for full understanding of all community members.
- A navigator needs to have capacities, resources to work well with everyone in the community, but also have supports to call upon. A resource "database" for a community should help with this.

SERVICE PROVIDERS:

- If a service has a "case manager" or a "transition coordinator" they should formally collaborate with the youth's navigator.
- Invite navigator to do inservice presentations to increase understanding of this role.

“LANDINGS” in the adult world

YOUTH:

- Having a navigator who has the capacity to refer to knowledgeable supports in the adult world should be part of every "landing" and "take off".
- Navigators will help the young adult develop self-determination and find a meaningful life in the adult world.
- An "on call" navigator could be available to support an individual/family in case of a crisis situation once the young person reaches adulthood. Some youth and their families will require much more assistance from navigators than others. The need for assistance should be articulated by the young adult.

PARENTS:

- Adult world expectations may have to be explained by the navigator to help parents and families support the different landings of their young adult.

- Family “outcomes” also need to be considered by navigators and others in the landings.
- Navigators can provide information to families when needed regarding available services and how to access, apply and evaluate them.

COMMUNITY:

- Navigators can help youth connect with the adult community and thus prevent them from not knowing how to access services in the community.
- Independent living centres may serve as a hub for navigators. Other possibilities are colleges or universities. It’s important for the navigators to be located in the ‘every day’ adult community.

SERVICE PROVIDERS:

- Navigators should connect with adult service providers regularly to learn what they have to offer young adults, and understand when and where referrals should be made at different landing points and in different domains of transition (education, employment, housing, etc.). Collaboration between navigators, case managers and transition coordinators is essential for success.
- Service providers should be willing to listen to navigators regarding gaps in service provision, based on their experience. The concept of reciprocal education and evidence-based practice should be welcome.
- Navigators could also participate in setting and evaluating service outcomes, to promote realistic and appropriate measures of success.

POLICY/GOVERNMENT: FOR ALL PHASES

- Funding for the hiring of community-based navigators should be allocated as a new initiative, as current funding is already committed for other transition needs. The funding must be *unencumbered* and not allocated to any service, but to families and communities. Governments need to work with communities to sort out who should pay navigators, and where they should be located.
- Funding for navigators should not preclude the need to fund a variety of options for supporting youth and families, as everyone’s needs are different. Options should include transition coordinators, case managers in services, and individualized funding for families who want to do their own hiring.

THEME IV: INFORMATION AND RESOURCES ARE ACCESSIBLE TO ALL INVOLVED IN THE TRANSITION PROCESS

“What do we mean by this”

- There are many different types of information and resources, such as:
 - Written and verbal information that is accurate and up-to-date.
 - Resources – people have information about funding, policies, media, technology etc.
 - Information about services – including ‘special’ services and ‘community’ services.
- Accessibility of information is not just about availability, but also means that information is easy to navigate, readable, & usable.
- “Accessible” information means user friendly language and simple technology that is universal and congruent between agencies and supports.
- Information exchange can be in two directions (e.g. youth to service provider and vice versa).
- Providing parents and youth with information during transition is key to "informed decision-making".

Guidelines for Best Practice

“PREPARATION” PHASE

YOUTH:

- Information must be available in a variety of formats.
 - These formats should include written, visual, auditory, large print etc.
 - The information should also be sensitive to different levels of reading.
 - The information should also be culturally sensitive.
- Accessibility of information relies on technology so that young people with all types of physical/sensory/cognitive disabilities can access information.
 - Increase access for youth regardless of their disabilities when they do not have the technology to work with the information (e.g. provide youth with a computer to go onto internet).

PARENTS:

- Information should be shared in the early years (childhood, early teen years) with parents through various diverse methods - (for example, videos of parents discussing disabilities; panels and groups attended by parents separately and together with their youth.)
- Help families recognize the long term needs for assistive technology – e.g. computer – early in a young person’s development.
- Establish meaningful information connections/networks between parents early on. Assist in providing families in learning how to articulate their information needs – this can be facilitated by navigator.
- Parents can benefit from using a “KIT”© (*CanChild*, 2004) to help them organize the information they receive

COMMUNITY:

- Create an accessible common information base in common areas (for example, a community library).
- A community needs to “own” access to information (i.e., share responsibility to provide accurate information) with policies that ensure accurate translation for different ethnic groups.
- Written community protocols are beneficial, to identify how the community will choose to collaborate on issues of transition with youths with disabilities, so that the community becomes willing to work at making their community a better place for all of their members including those with disabilities.
- Create a “single point” in a community to build informed decision making, where information can be easily accessed by youth, parents, and public (for example, schools, employers, etc.).
- Provide information with a life course focus for all disability populations. There are many common transition issues for youth with an event of disability, so information on these issues can be collaboratively developed and shared.

SERVICE PROVIDERS:

- Clear information should be available on service guidelines (e.g., checklists), and eligibility for services throughout a young person’s life course.

- Services need exposure to different opportunities to use different types of media: web based, communication networks, etc.
- Provide training to help all service providers effectively search for information and resources which may be in multi-media formats.
- Service providers can facilitate youth beginning to be responsible for keeping track of their own information by asking them some key questions about their health, their personal stories and other information that is important to them.

“THE JOURNEY”

YOUTH:

- Assist youth in learning how to share their own information positively (e.g., strengths/challenges).
- Useful and accessible information can help with periods of frustration where youth may question who they are “doing this for” and determining what may or may not be realistic for them – youth, parents, community, and service providers may differ on their perspectives of what’s realistic, so youth need to hear all perspectives to make informed decisions.
- Peer supports, mentors and navigators can help youth make sense of all the information they receive.
- Youth can benefit from tools (for example, a “Youth KIT”© (*CanChild*, 2008) to help them organize all of the information they get.

PARENTS:

- Regular networking/mentoring for families at different points along their journey can highlight challenges that may occur at different points in time. Support groups for parents are important in determining which information they can or do not have to share.
- Parents can encourage their adolescents to begin to take responsibility for getting and organizing their own information, and increase that responsibility as they get older (for example, keeping track of medical and school information).

COMMUNITY:

- Listing of agencies in community "red books/blue books" should include information about transition to adult programs and services for youth with all types of disabilities. This type of community information needs to be accessible in different formats – online, written, etc. – as people have different abilities and resources for accessing information.
- Create a public designated information point (for example, libraries, universities, city hall) with information that is up-to-date, maintained, and disseminated broadly. Navigators would have access to these points. A young person could always access the same information no matter what city/town they live in.

SERVICE PROVIDERS:

- Remove prescribed “readiness levels” for youth/families to access particular information or resources within a service. Let youth and families decide what information they need, and make it accessible to them along the life course continuum.

“LANDINGS” in the adult world**YOUTH:**

- Youth will need ongoing information throughout their adulthood. Information access should take a lifecourse perspective, and be accessible to all ages of persons with disabilities.

PARENTS:

- Information should be available on developing connections and growing circles of support with other parents throughout the journey into adult life.
 - Connect families with mentors with congruent values
 - Stories of successful and creative journeys into adult life can help other parents learn what works.

COMMUNITY:

- Include information and resources for people with disabilities of all ages including through adulthood in community settings and documents (for example, in a community “Red book”).

SERVICE PROVIDERS:

- Information on services must be up-dated regularly, be current, and culturally sensitive for all adults with all types of disabilities and ethnic backgrounds.
- The establishment of common practices in areas such as Independent living is needed, and then information about these practices must be made accessible to everyone.
- Service outcome should include accessibility, use and utility of information at different stages of transition.

POLICY/GOVERNMENT: FOR ALL PHASES

- Policymakers should work to remove prescribed readiness levels as part of eligibility criteria within specific services or funding models. Readiness is not determined by age, but rather a complex set of contextual factors, such as individual maturity, individual capacity, capacities of families, and community factors.
- Follow through on Accessibility for Ontarians with Disabilities Act mandate that all agencies provide information and changes to information to publicly accessible centres. Receive funding (e.g., interministerial) and create a provincial framework that will spread to all communities.
- Decrease information that misinforms and reduces the choices available to parents (for example, individualized funding does not mean that child cannot get a spot in a group home).
- Establish an ombudsperson to intercede on behalf of families and adults with disabilities when conflict exists between individuals and service providers.
- Work with service providers to standardize practices in areas such as Independent living (i.e. some service providers do not provide cleaning services, while others do).
- Acknowledge that living in rural areas poses unique challenges for adults with disabilities (i.e. transportation, the ability to participate actively and regularly in community activities), and provide more information and resources in these areas.

THEME V: EDUCATION IS A CRITICAL COMPONENT OF ANY TRANSITION STRATEGY

“What do we mean by this”

- Education means increasing awareness, understanding, capacity building of knowledge, and skill building of everyone involved in the transition process (youth, families, schools, communities, service providers, etc.).
- Education should be provided in various media (in person, over the web, written etc.) and follow accessibility standards for various disabilities.
- Education during the transition process allows the focus to be on inclusion, contribution, listening, sharing success stories and networking.
- Education occurs in a variety of contexts; to open people’s minds and encourage them to think outside of the “box” (e.g. prescribed set of “programs”). Education also takes place through opportunities and experiences, such as “situated learning”.
- Education is lifelong, and takes place at multiple levels and in multiple settings.
- Education is more than reading material, but also occurs through participation in a variety of different activities, and from learning from your own mistakes as well as the mistakes of others.

Guidelines for Best Practice

“PREPARATION” PHASE

YOUTH:

- Provide youth with realistic educational opportunities to help them gain insight into what their options are. The goal of early opportunities is to help youth develop realistic goals with respect to the future (i.e. independent living, employment, and higher education).
- Educational activities should keep what is “realistic” in mind for all age levels. Activities should be developmentally appropriate.
- Participation in educational opportunities should occur early so that youth are “growing up ready”. Everyone needs to work together to figure out the best way to engage youth in educational opportunities.

- Educating individuals should be based on values and attitudes related to inclusivity as well as learning how to be person-centred.

PARENTS:

- An inventory should be conducted to determine the most current parent-to-parent national and territorial resources available, and disseminated widely through communities and services.
- Workshops must be designed and offered by parents for parents early on to help them plan ahead (for example: “Future Directions” (Hamilton Family Network, 2000), and “PLAN Lifetime Circles” (Planned Lifetime Advocacy Network, 2004).
- Parents must be provided with educational vehicles to communicate with each other and receive information from peers in their own community as well as nationally.
- Parents need to be educated about ALL opportunities as their children travel through the life course. This will promote realistic goals & community opportunities being provided for their son/daughter.
- Parents need to be knowledgeable of Ministry funding and current policies that might be available.
- Parents need to have planning tools that can take them through the whole spectrum of transition planning. A navigator can assist parents in using planning tools.

COMMUNITY:

- Education within schools should offer increased flexibility with choices /options for different ages of children and youth as they develop:
 - Student could have credit courses (e.g., a course on attendant care) instead of sitting and watching gym. Also consider weighing out the benefits of the “experience” vs. “diploma” if they can’t get credits.
 - Create co-op credit courses keeping flexible hours, support needs, and school component in mind.
- Students can learn how to convey their needs and condition and how to provide this info between teachers/classes. A navigator or peer mentor can help with this.
- Individualized Education Plan (IEP) transition planning documentation needs to begin no later than grade 5, reviewed every 2 years at first, then every year in high school.

- Include education at school on disability, sensitivity, and awareness for all students.
 - Link with bullying programs.
- Community can offer co-op experiences as part of a student's education to build capacity – it is not only school's responsibility.
- Develop workshops, websites and provincial initiatives and systems for educating community members about youth with disabilities in transition. Multiple formats of delivery are most effective.
- Mandated education for school personnel (regular and special ed teachers).
 - Clearly written and defined information.
 - Focus on new and creative ways to include individuals of all abilities in all school activities.
- Educational Assistants need to know about a young person's accommodations, and how to encourage a young person to direct their own care.

SERVICE PROVIDERS:

- All professionals need to have a common base of knowledge about youth with disabilities and transition. This education should take place in their college/university training. This education could model the National HIV education program for clinicians in the United States (AETC National Training Center, 2009).
- Involve adult service providers early on in the education process, so that they can understand the transition to adult services is assisting youths to meet the goals established.
- Educated service providers are evidence based and focused on health promotion / prevention rather than "fixing".

"THE JOURNEY"

YOUTH:

- Provide youth with meaningful educational opportunities to build their own decision making capacity that includes a recognition of their maturity level (for example, paid or unpaid employment, with an educational component).
- Education opportunities should be inclusive throughout their school years. This needs to be a cultural expectation.

- Education opportunities for youth and families can focus on advocacy and self-determination throughout lifecourse.
 - Individuals require a variety of opportunities to learn these skills, and build capacity. An Individualized Education Plan (IEP) could address these opportunities.

PARENTS:

- Parents need to surround themselves with other parents that will keep their dreams alive and support them to move forward. This “informal” education is critical.
- Parents need education to help them “let go” of any strings that are holding their youth from full community participation as they get older.
- Parents can work as “community faculty” to educate developing professionals in all disciplines – focus on preparing the next generation of service providers about issues such as: one cannot follow a recipe
 - Parents can highlight experiential components in professional schools (for example, work with professional students to remember times when they felt vulnerable, isolated to increase their sensitivity and understanding when interacting with youth and their families.

COMMUNITY:

- Develop a curriculum/educational program for navigators in the community.
- Expand educational programs in the community at large to take place in different settings (e.g. libraries, community centers etc.) rather than in ‘special’ agencies.
- Establish community transition networks – representatives with a community focus from all support networks can share and compare resources and information.
- Provide peer tutoring as a credit course in schools.
- Develop inclusive peer mentoring opportunities in schools and communities to encourage commonality between students with disabilities and their nondisabled peers.

SERVICE PROVIDERS:

- Education of service providers must emphasize the importance of shared management and responsibility as well as the active involvement of youth and families in service planning and delivery.

- Use youth and parent facilitators, advisory groups, mentoring, youth and parent volunteers to provide education to clients and service providers within service settings.

“LANDINGS” in the adult world

YOUTH:

- Young adults should be provided with ongoing educational opportunities in order to make educated decisions reflective of age level throughout their lifecourse.
- Self-determination should be a focus of education throughout adult life and an outcome of choice.
- Foster and support young adults to speak about their own life experiences in public education forums (e.g. workplaces, recreation programs etc.) and in health/education professional preparation programs as “community faculty”.
- Self-determination, capacity building and person-centered services should frame educational program outcomes.

PARENTS:

- Certain ingredients are needed in educating parents and family members for successful landings and outcomes. This may be accomplished by:
 - Developing strategies to keep stories alive from present and past years (e.g., families may learn from highlights and how issues were resolved);
 - Training mentors to help individual/family build a better life;
 - Focusing education of parents not only about “transition”, but about life as an adult, and future expectations of the adult world.

COMMUNITY:

- Educational opportunities should allow for individuals with disabilities to audit university/college courses for social participation rather than proving knowledge and research.
 - This may require flexible admission criteria at the university/college level.
- Provide education for the adult world (e.g., employers) to consider change and flexibility
 - Cultural and attitude shift away from rule-bound institutions needs to happen.
 - Change attitudes with pilot projects within communities (e.g. businesses).
 - Support community “champions” to bring about change through peer education and support.

- Create opportunities for youth with disabilities to share their stories in order to educate others in academic and training environments.

SERVICE PROVIDERS:

- Offer Inservices and continuing education opportunities to adult service providers through their associations and regulatory bodies.
- Facilitate increased number of adult facilities to set up lifespan clinics that include education as a key component.
- Create opportunities for youth with disabilities and families to share their own stories with staff and allow for opportunities for direct involvement when developing new programs.
- Service outcomes can include knowledge uptake for youth at different ages and stages.

POLICY/GOVERNMENT: FOR ALL PHASES

- Greater collaboration must take place between federal and provincial ministries and municipal departments in order to create educational strategies to inform families of those with disabilities of available sources of funding for educational opportunities.
- The idea of social citizenship and inclusion should be at the center of all education, social and health policy planning.
- Policies should be developed that encourage education of communities through the sharing of experiences from the perspective of young adults with disabilities themselves or their families.
- The creation and funding of multiple platforms to support families and youth to share their success stories with others (i.e. websites, videos, etc.) can build capacity quickly.

THEME VI: ONGOING RESEARCH AND EVALUATION PROVIDES THE EVIDENCE NEEDED FOR SUCCESS

“What do we mean by this”

- Evidence is gathered through different types of research including Participatory Action Research, which is driven by youth and families.
- Research methods vary to embrace different purposes and messages.
 - Qualitative Research is useful to listen truly to the voices of those who need to be heard, represent individuals from many different backgrounds/disabilities.
 - Some methods are better to evaluate the natural milestones and lifecourse that are important to each person – one person does not only get one landing but may need support to take off again.
 - Longitudinal studies help us learn about the lifecourse of youth.
- Any research should include a dissemination plan focusing on how the results will be shared with key stakeholders as well as applied to practice.
- The term “research” should be broadened to include “evidence based practice” and “informed decision making” of everyone involved.

Guidelines for Best Practice

“PREPARATION” PHASE

YOUTH:

- It is important to include youth of all disability groups in research activities early on, so they develop their own “research” capacity.
- Help youth learn about systems and how to bring about change within a system (i.e., foster champions) through participation in research projects – this may also bring positive consequences for the youth that may relate back to the research question (i.e. individual may indirectly learn more about themselves).
- Use a group format (e.g. Focus groups) with younger children while allowing adolescents to begin learning through individual involvement in research.
- Engage youth in research by starting with “advisory groups” and building their capacity over time.

PARENTS:

- Involve parents in participatory projects so that they can identify important research questions such as: “how to know that my child is ready?”
- Ensure research stays true to participant’s perspectives and a family’s values statements.

COMMUNITY:

- Create a “single point of access” to organize and disseminate research for families and for communities (e.g. social, health, and education researchers working together).
- Include community members as advisers on research teams.

SERVICE PROVIDERS:

- Involve key stakeholders within services in participatory research with a goal of social change aided by useful and understandable findings.
- Work on evaluating programs from pilot projects to academic research with a variety of research methods and focusing on clinical utility (e.g., for front line workers).
- Evaluate transition programs/process and their impact on an ongoing basis and pool results from different services and identify commonalities.

“THE JOURNEY”**YOUTH:**

- Youth could explore transitions process in greater breadth and depth through involvement in qualitative and participatory research projects.
 - This research may help youth to look beyond their own situation.
- Study the journey of youth with longitudinal (life-long focus) studies.
- Youth should be paid as members of a research team.

PARENTS:

- Increase parents’ knowledge of the role, power, and use of research; for example, how developing partnerships in research increases advocacy (e.g., as in special interest groups).

- Increase flexibility of research to change direction and incorporate results as new knowledge is gained by parents on a research team.
- Parents should be paid as members of a research team.

COMMUNITY:

- Community members can participate in research with youth and their families as they provide an important perspective to the table. Their involvement can also help to build community capacity to include youth with disabilities in daily life.
- Researchers should find ways to meaningfully share knowledge that has already been gathered (through research) with different community groups.

SERVICE PROVIDERS:

- Create a central place where evidence is gathered and disseminated to service providers in all systems.
- Demonstration projects and program evaluations are needed to find out what works, and findings need to be shared to learn from each other, build knowledge and capacity.

“LANDINGS” in the adult world

YOUTH:

- Use research to identify what’s working right now. Focus on:
 - What are the different outcome measures people are using?
 - Measure satisfaction as well as whether a particular service meets needs.
- Provide evidence of success – but carefully identify what constitutes success for individual youth and populations. Youth must be involved in this process.
- Encourage young adults to explore researching roles themselves.
- Research how young adults define their own best outcome (for example, what worked and what didn’t work for them along their journey and different landings).

PARENTS:

- A lifecourse approach requires recognizing that family priorities to meet goals can shift and change. Research is needed about family experiences at different landing points.

COMMUNITY:

- Pilot projects are needed to research the experiences of young adults with disabilities and community members within different adult settings such as colleges, universities, housing, employment and other adult community settings.

SERVICE PROVIDERS:

- Adult and pediatric service providers can influence service provision through shared and reciprocal evaluation and sharing of research findings.
- Adult and pediatric service providers must develop a collaborative framework to share research results easily and effectively as needed (e.g. a Clearinghouse).
- Researchers need to evaluate all initiatives of best practice
 - Work on connecting research and results by sharing, disseminating research findings in meaningful ways to everyone.

POLICY/GOVERNMENT: FOR ALL PHASES

- Identify the types of evidence ministries require to make informed decisions & mandate agencies to provide this type of evidence.
- Continue to develop person-centered policies, and apply them when assessing the overall success of strategies and programs (for example, “having a job” is one measure of the success of employment supports, but the provision of benefits for individuals with disabilities maybe more important for an individual to maintain employment). Any program “evaluation” should include asking the participants what is important.
- Funding for research should be dependent on collaboration, knowledge and information dissemination, and transition outcomes such as participation and active citizenship.

NEXT STEPS

The BJA Model and Best Practice Guidelines for the transition to adulthood for youth with disabilities are generic. Many of the phrases used in the Guidelines are written verbatim from participants, and when the research team paraphrased or added examples, we worked very hard to remain true to the participants' thoughts and words.

This document represents the early stage of development of a model and best practice guidelines. The Best Practice Guidelines are just that – they are ideas and recommendations to guide people and groups to think about what they are currently doing (or not doing) and begin to plan for transition services and supports that will adopt a lifecourse approach that is positive, inclusive and collaborative. The BJA model and Best Practice Guidelines have not yet been “tested” with any specific population or community. We encourage different people, communities and services to apply these guidelines, evaluate their efforts and share the findings.



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APPENDIX A: Summary of 2005 Literature Review

This literature review included published and unpublished literature about transition to adulthood for youth with physical and developmental disabilities, from years 2000 – 2005.

Source of Literature	What is Happening/ what is needed	What Works	Recommendations
70 articles from Unpublished Literature were reviewed, including <ul style="list-style-type: none"> – Information Bulletins – Conference Proceedings – Self-help Manuals / Guidebooks / Workbooks Most were available on the web/internet	<ul style="list-style-type: none"> – volunteer and work placements built into the curriculum – housing for students with disabilities – parents are the key persons organizing transition, issue as parents age. – number of workbooks and guides are on the web – e.g. how to prepare for transition – young adults are remaining in the pediatric system up until age of 21y.o – community capacity building is taking place, mainly in smaller communities – transition planning process is in place in Ontario School Boards – support from other parents is being offered to parents at different stages of the transition process 	<ul style="list-style-type: none"> – early planning – collaboration – individualized funding for families 	<ul style="list-style-type: none"> – Start planning at age 14 y.o. for healthcare transition – career and post-secondary planning to start in gr. 7 – collaboration across employers, teachers and healthcare providers. – sustainable funding for new and existing services – services to meet the developmental needs of youth – providers of healthcare in the adult system to be familiar with disabilities acquired at birth or in childhood. – transportation that is accessible and flexible – individualized funding that is separate from services for families who want this option

<p>85 Articles of Published literature from 2000 – 2005 were reviewed</p> <p>(Summary of Critical appraisal of 5 review articles published in 2006)</p>	<ul style="list-style-type: none"> – Evidence about what helps and hinders transition process – Service elements that best support transition for youth with a variety of disabilities – Global health ratings moderate for youth and poor for adults – -Models of individualized funding are being tested – Students are better prepared to enter post-secondary education – Increased participation in volunteer and paid employment for some disability groups – Models of transition services being explored- e.g. Shared Management Model; flexible, multi-faceted approach with underlying philosophy of self-determination 	<p>Specific elements of service delivery can make a difference, such as:</p> <ul style="list-style-type: none"> – individualized approach – communication and collaboration – peer mentors – skill development, such as problem solving – environmental supports <p>Evidence for coordinated transitional care programs for JRA, diabetes and CF</p> <ul style="list-style-type: none"> – What works for youth: development of self-determination skills; support for psychosocial development; support with developmental tasks i.e. relationships; focus on strengths – What works for parents and carers: family centered approach; parental involvement in planning; support to parents for changed relationships 	<ul style="list-style-type: none"> – Develop service models that address the developmental issues & real world experiences – Research should focus on outcome of participation – Build models that combine success factors & evaluate them – Collaboration of researchers, service planners & providers, youth and parents needed to develop and evaluate new service approaches. – Transition needs to become the expected outcome in pediatric care – Community capacity building is an important approach to raise awareness about the assets of persons with disabilities and increase opportunities in the community – More knowledge needed on how to best meet the mental health needs of youth in transition – Increase accessibility to information and resources needed for everyone – Services must be based on person’s needs and strengths, not diagnosis – Options for funding are needed – Mentorship for youth, corporate and families. – Service coordinator and family facilitator roles to be evaluated
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APPENDIX B: Bibliography of 2008 Literature Review

This bibliography includes published and unpublished literature on the transition to adulthood for youth with all types of disabilities.

The published literature is for the years 2000 – 2007 and includes journal articles, published documents and books.

The unpublished literature comes mainly from the internet. Due to the large amount of unpublished resources now available on this topic, a representative sample is provided in this bibliography. The focus of our literature review was on Canadian sources, but some resources from other countries are also included.

Published Literature: 2000 - 2007

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