Guidelines for Service Providers

Supporting Youth & Families in Using the Skills for Growing Up Checklists



1. What are the Skills for Growing Up checklists?

- A series of three checklists: Getting Started, On My Way, Almost There
- Designed to help young people & families develop skills for growing up and get ready for the future

2. Why were the checklists developed?

- Acquiring life skills is not intuitive for young people with disabilities and their families (Kieckhefer & Trahms, 2000).
- Young people with disabilities are often deprived of everyday opportunities and life experiences as a result of institutional, social and environmental barriers (Bell & Quintal, 1985; Stewart et al., 2001; White 1997).
- As a result, young people with disabilities lag behind their peers in developing the skills required to successfully manage in the adult world (Bell & Quintal, 1985; Steele et al., 1996; Stevens et al, 1996). Adults with disabilities experience above average: unemployment, poverty, and psychosocial difficulties (McDonagh, 2006; Steele et al, 1996; Stewart et al, 2006).
- Preparations for adulthood should start early, be real and positive with shared expectations, and provide hope for the future (Kieckhefer, 2002; Reiss & Gibson, 2002).
- The checklists were developed as part of a framework for transition planning at Bloorview Kids Rehab. They help families begin preparations for adulthood at an early age by setting goals and making plans at all levels of development.

3. Who are the checklists for?

- The checklists are designed for all young people & their families.
- The intent is that young people & families will keep them.
- The checklists are not designed as standardized assessment tools.
- Professionals can play a key role in introducing the checklists to youth and families and supporting them in making action plans for the goals they identify.

Key principle: Universality

• Items in the checklists are designed to encourage conversation about growing up – making choices and participating actively in life.

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• Some items may not seem relevant to some young people & families. They may leave this item off their list. Or, parents may consider the item creatively (i.e., adjust the wording to suit their unique goal). Or, the item may simply serve as a reminder for parents to plan ahead for that aspect of growing up.

4. How do young people and families use the checklists?

- Young people and their families set goals together as a team they may ask service providers to assist them in working on specific goals.
- Young people and families choose items that they want to work on.
- When getting started, parents may take a leadership role in using the checklists. If developmentally appropriate, the young person should gradually take increasing responsibility for goal setting and planning.

5. How are the checklists formatted?

Front Cover	IntroductionOutlines what the checklists are, who they are for	
Inside page	Instructions	
	How to fill it out	
3 page fold out	Checklist All items can be viewed at once Five categories are used consistently across the three checklists: (1) Self Advocacy, (2) Social & Recreation, (3) Independent Living Skills, (4) School & Work, (5) Health & Wellness "My Own Stuff" – space to add additional issues/goals	

The items on the checklists cover a range of key skills. However, they do not represent an exhaustive list. The *My Own Stuff* section allows young people and families to write individual goals specific to their own needs.

Back Cover	Notes to Myself	
	Additional space for personalized use of the	
	checklist	

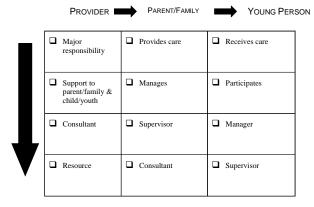
Key principle: Client/family-centred

Young people and families work on what is important to them.

Key principle: Shared Management Model

A Shared Management Model is a philosophical approach for transition planning and is the framework upon which the checklists were based.

- A therapeutic alliance between children, families and service providers is
 essential to allow young people with disabilities to develop into
 independent, healthy, functioning adults (C.M. Trahms, personal
 communication, March 5, 2004; Kieckhefer, 2002; Kieckhefer &
 Trahms, 2000).
- The roles of the players in the alliance change as the young person grows up leadership is gradually shifted (in a planned, systematic, and developmentally appropriate way) from the service provider and parents to the young person (Gall, Kingsnorth & Healy, 2006).



NOTE: The Y-axis is increasing age/time as you move down to the bottom of the grid.

Figure 1. The Shared Management Model. Reprinted with permission from G. M. Kieckhefer, 2002, Foundations for Successful Transitions: Shared Management as One Critical Component. Keynote presentation at the Hospital for Sick Children, Toronto, Canada.

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Key principle: Developmental approach

• The checklists include a developmental progression of skills.

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- The young person and family move from one checklist to another based on their level of preparation for adulthood. For example, one 10 year-old may be using the *Getting Started* checklist, another may be *On My Way*.
- More than one checklist can be used at a time.

6. Which checklist should the client & family use?

	Level 1 Getting Started	Level 2 On My Way	Level 3 Almost There
Colour	Green	Purple/blue	Yellow
Target group	 Just starting to think about growing up To be used as early as possible (e.g., as early as age 7) 	Have taken some steps in planning for future; focus on next steps	 nearly ready to transition to adult services OR nearing time for leaving pediatric facility
Sample item	"I ask at <u>least one</u> question during health care visits."	"I ask <u>many</u> questions during health care visits."	"I ask most questions during a health care visit."

7. What is my role as a service provider?

- Encourage clients and families to use the checklists to set goals and make plans for developing the skills needed for growing up.
- Ask what goals clients and families are currently working on.
- Assist families in making action plans to work on their identified goals. Suggest services, resources or strategies that may help them.
- Incorporate client/family's life skills goals into service plans.
- Raise developmentally appropriate life skills in goal discussions if young people and their families do not.
- Reflect on how you can incorporate the shared management model into your own practice to support young people in developing the skills needed for growing up.

8. How were the checklists developed?

- A best practice scan was conducted to gather evidence about effective transition practices and transition planning tools from literature reviews; conferences; presentations; site visits, etc.
- Forums with young people and families to get input on draft checklists changes made based on feedback
- Checklist drafts also reviewed by service providers, academics, other experts

9. Frequently Asked Questions

What if a family says that none of the items on the checklist are applicable to their son/daughter due to a cognitive or developmental disability?

The checklists are designed to encourage planning for the future. The wording of the items uses the first person (e.g., "I prepare meals...") but families should focus on the activity listed. They should consider if this is something that they think their child will do. If not, they still may wish to think about how this will be managed in the future.

Families can reword the items to match them to their situation and goals. For example: "I explore where I will live in the future" could be reworded as "We talk about where we see our child living in the future." Encourage families to be creative in thinking about how each of the items may apply to them.

Some items may be a reminder to parents to plan ahead for certain tasks/issues, for example, planning for the transfer from the pediatric service system to the adult system.

Some items still may not be relevant to some young people & families. Families then do not choose these as goal areas at that time.

Are there specific age ranges for these checklists?

Based on client and family feedback, no age ranges are listed on the checklist. Generally speaking, the checklists may be appropriate for the following age ranges:

Getting Started ages 7-12
 On My Way ages 13-16
 Almost There ages 17+

The rate at which clients move from one checklist to another is individual. When you review goals and progress with clients and families, discuss with them if they feel they are ready for the next checklist in the series (or ready for part of the next checklist). **However, certain key issues, particularly in the Health & Wellness section of the** *Almost There* **checklist, must be addressed prior to transition to adult services.**

Can more than one checklist be used at a time?

Yes. A client/family may be working on items in the Health & Wellness section of the *Almost There* checklist but be using the *On My Way* checklist for goal setting about Independent Living Skills.

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What are some day-to-day practices that promote the development of skills needed for growing up (and reflect the shared management model)?

- Speak directly to the young person whenever possible. When appropriate, suggest meeting for part of visit with young person alone.
- Direct your questions to the young person. Ask the young person if they have any questions.
- Discuss options with the young person and specifically get their input on decisions.
- Ask the young person to put their name on documents beside their parents.
- Provide the young person with choices in therapy sessions.
- Consider whether your standardized assessment tools promote participation from the young person.
- Periodically reflect (on your own or with client/family) about your level of involvement are you transitioning responsibility to the family & client or are you still playing a leadership role? Gradually move to asking questions to facilitate consideration of issues rather than providing suggestions.

10. What if I still have questions?

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From disability to possibility

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Selected References / Further Reading

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