

DSP and Doctor Partnership:

Preparing People with IDD for a Successful Doctor Visit

Jennifer M LeComte, DO, FAAP, FACP

Internal Medicine-Pediatrics

Associate Professor IM & Pediatrics

Medical Director RISN Center

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Disclosure

I have no relationships with any entity
producing, marketing, re-selling, or
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1. Discuss the role of DSP
2. List barriers to accessing healthcare
3. Introduce resources for improving the participation of people with IDD in their health
4. Understand relevant healthcare literature



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The DSP (Direct Support Professional)

Poem by Buck Hensley

Who? Who? Who shall hear my call?

To serve my people I see as great.

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Who will help them pave their own
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The poem was printed by the Direct Support Professional Association of Tennessee in their October 2008 newsletter.
[LV Chapter of the DCWA Blog: The Direct Support Professional Poem \(dcwlvaa.blogspot.com\)](http://dcwlvaa.blogspot.com)

What is a DSP?

Direct Support Professionals (DSP):

people who work directly with people with disabilities to help support them in activities of daily living. Staff in developmental sector agencies are typically called DSPs.

Intellectual and Developmental Disabilities (IDD):

conditions that are usually present at birth or at a young age and that affect the trajectory of the individual's physical, intellectual, and/or emotional development.



DSP Duties: “The calling often times seems difficult”

15 Competency areas:

- Participant Empowerment
- Communication
- Assessment
- Community and Service Networking
- Facilitation of Services
- Community Living Skills & Supports
- Education, Training & Self-Development
- Advocacy
- Vocational, Educational, & Career Support
- Crisis Prevention and Intervention
- Organizational Participation
- Documentation
- Building and Maintaining Friendships and Relationships
- Provide Person Centered Supports
- Supporting Health and Wellness

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Disparities

People with ID remain one of the most medically underserved groups in the world and still face significant health disparities, not directly caused by their disability.

- ID does not equal poor health
- Diagnostic overshadowing – health symptoms attributed to disability
- Die earlier – Women 16-20 years earlier, men 13 years earlier

<https://inclusivehealth.specialolympics.org/resources/background/health-disparities-for-people-with-id>



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The Bad News



People with disabilities have

Higher than average

- Rates of chronic conditions
- Difficulties in accessing care
- Rates of hospitalizations
- Rates of preventable medical problems

Lower than average

- Formal education
- Use of health care system for preventive care

Preventable mortality rate 4 times higher
than the general population

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Health Care Transition

Maximize lifelong functioning and potential through the provision of high quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood.

A Consensus Statement on Health Care Transitions for Young Adults With

Special Health Care Needs. *Pediatrics*. 2002 Dec;110: 1304-6



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Barriers to Health Care

- ☐ Architectural
- ☐ Medical equipment
- ☐ Communication
- ☐ Economic
- ☐ Social policy
- ☐ Attitudinal
- ☐ Inadequate provider knowledge



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Bridging the Gaps: DSP and Doctor



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Six Critical First Steps

- 1. Identify a primary care provider**
2. Educate care providers on transition skills
3. Create a portable medical summary
4. Transition plan by age 14
5. Age appropriate preventive care
6. Continuous health insurance coverage



Six Critical First Steps

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Know Your Diagnosis

FRAME

FACES REDEFINING THE ART OF MEDICAL EDUCATION

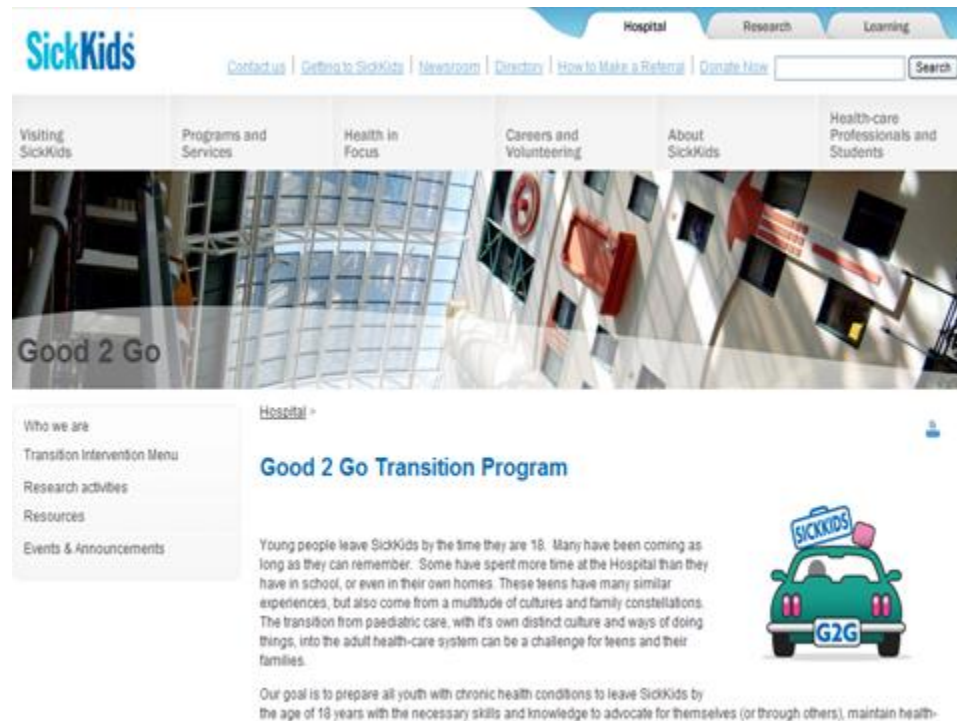
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My Health Passport

- Autism



<https://www.sickkids.on.ca/myhealthpassport/>



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[Visiting SickKids](#)[Programs and Services](#)[Health in Focus](#)[Careers and Volunteering](#)[About SickKids](#)[Health-care Professionals and Students](#)

Good 2 Go

[Who we are](#)[Transition Intervention Menu](#)[Research activities](#)[Resources](#)[Events & Announcements](#)[Hospital](#) >

Good 2 Go Transition Program

Young people leave SickKids by the time they are 18. Many have been coming as long as they can remember. Some have spent more time at the Hospital than they have in school, or even in their own homes. These teens have many similar experiences, but also come from a multitude of cultures and family constellations. The transition from paediatric care, with its own distinct culture and ways of doing things, into the adult health-care system can be a challenge for teens and their families.

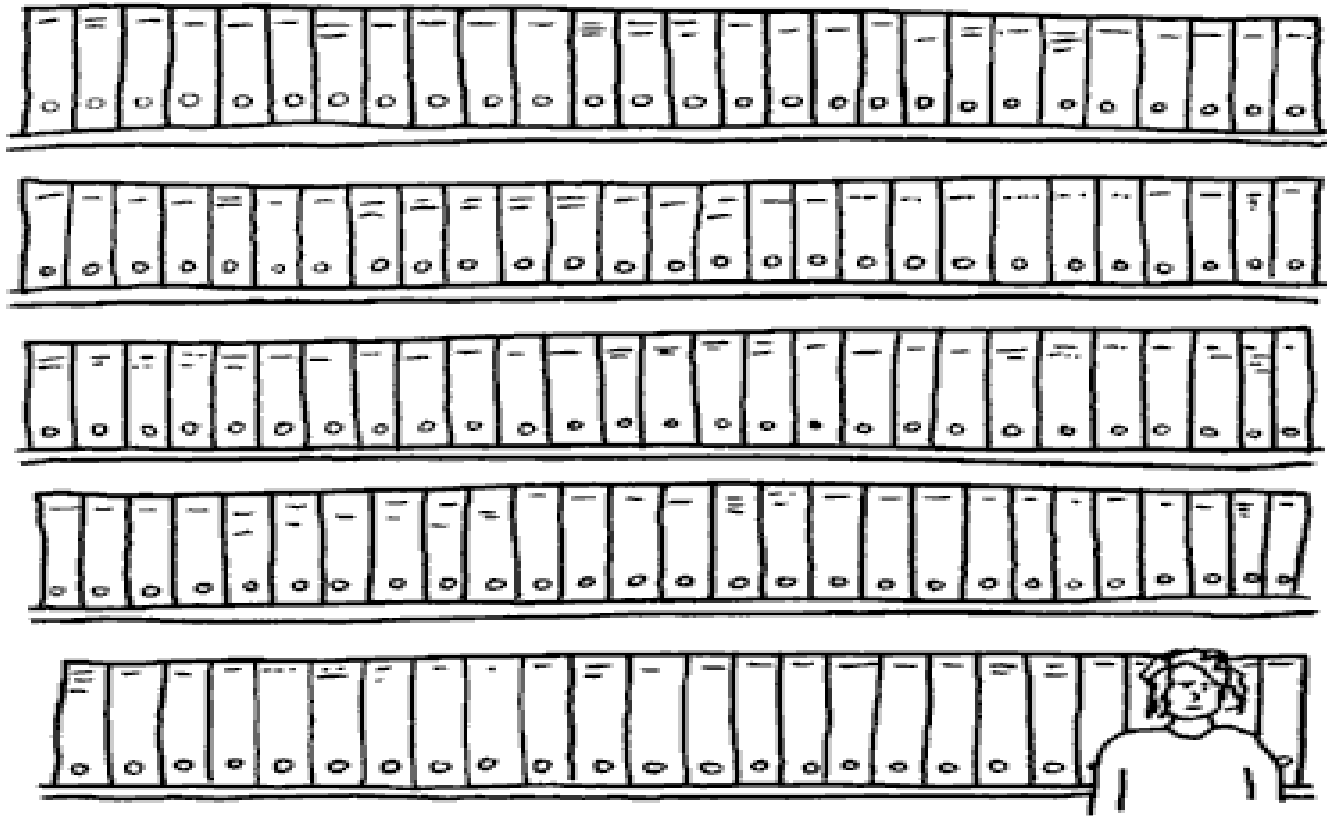
Our goal is to prepare all youth with chronic health conditions to leave SickKids by the age of 18 years with the necessary skills and knowledge to advocate for themselves (or through others), maintain health-



Six Critical First Steps

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THIS ONE THING I DESIRE: TO HAVE ALL
OF MY PERSONAL PAPERWORK SENSIBLY
ARRANGED IN LABELLED BOX FILES

Use the Portable Medical Summary as an Educational Tool

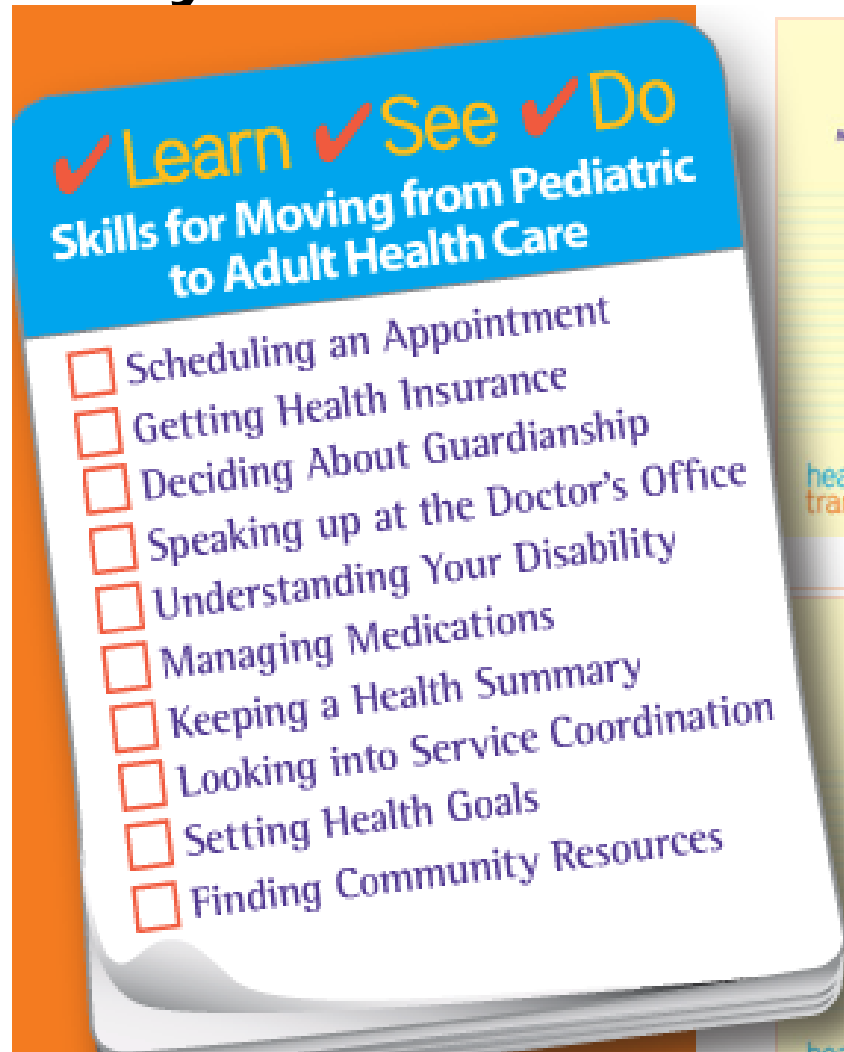
- Assists patient in understanding their medical history
- Helps patient take more active role in care planning
- Provides opportunity for primary providers to review new guidelines

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Healthy Transitions - NY



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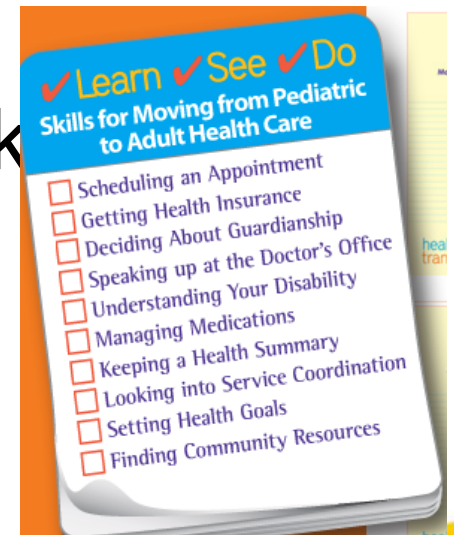


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Healthytransitionsny.org

See One, Do One, Teach One

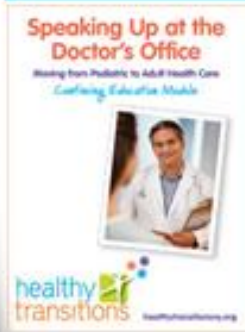
- **Learn** – Information about the skill
- **See** – Videos that demonstrate the skill
- **Do** – Tools for developing the skill



Healthytransitionsny.org

Speaking up at the Doctor's Office

Learn ✓ Information about this skill



See ✓ Videos that demonstrate this skill

AskMe3



Using a dynamic display device



Role of Aides at medical appointments



Acknowledge Circle of Support



Do ✓ Tools for developing this skill



Healthytransitionsny.org

✓ Learn ✓ See ✓ Do Skills for Moving from Pediatric to Adult Health Care

- ☐ Scheduling an Appointment
- ☐ Getting Health Insurance
- ☐ Deciding About Guardianship
- ☒ Speaking up at the Doctor's Office
- ☐ Understanding Your Disability
- ☐ Managing Medications
- ☐ Keeping a Health Summary
- ☐ Looking into Service Coordination
- ☐ Setting Health Goals
- ☐ Finding Community Resources

View All

Developmental Disabilities Primary Care Program



Tool and Tips for Health Care Visits

- About My Health
- My Health Care Visit
- Preparing for Future Emergencies: A Checklist
- Videos



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Why Encourage Self Management?

Patient-centered self-management with support improves health and physical functions outcomes as well as patient satisfaction regarding care

Self-management education of patients and families reduces the number of hospitalizations, emergency and unscheduled visits, and missed work and school days (*Gibson 2004*).

Patient education alone is not sufficient to promote health behavior (*Norris 2006, Haby 2004, Bartholomew 1991*)

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Supported Decision Making

- Allows a person with disabilities self-determination and self-direction over their own life
- Empowers individuals to make all their own choices with the advice and support of trusted individuals
- Reduces opportunities for abuse by
 - Empowering the individual to speak out and report abuse
 - Advisors providing checks and balances on each other



Supported Decision Making

People with greater self-determination are:

- Healthier
- More independent
- More well-adjusted
- Better able to recognize and resist abuse

(Khemka, Hickson, & Reynolds, 2005; O'Connor & Vallerand, 1994; Wehmeyer & Schwartz, 1998).

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The Future is Bright



“But the reward will be great at the end of it all”



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Thank You



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More Resources

- The National Alliance for Direct Support Professionals (NADSP) is a national non-profit whose mission is to elevate the status of direct support professionals by improving practice standards; promoting system reform; and advancing their knowledge, skills and values.
- [Journal Articles for Direct Support Professionals](#)





Rowan Integrated Special Needs (RISN) Center provides South Jersey with its first special needs primary care facility with embedded behavioral health focused on care-coordination of integral services for the special needs population.

To schedule an appointment:

855-932-7476 (RISN)

Email: risn@rowan.edu

Learn more about RISN Center at
<https://centers.rowanmedicine.com/risn>

We care about you
coordinate

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**Why do you wear a mask? Were you
burned by acid, or something like that?**



**Oh no. It's just they're
terribly comfortable. I think everyone
will be wearing them in the future**

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