



# For Families: Health and the Transition to Adulthood

## ***Building the Foundation for Success***

Developed by the Integrated Services Committee of the Illinois Chapter of the American Academy of Pediatrics and UIC Specialized Care for Children

Presented by:



# Why teach health skills in school?

- Everyone must deal with health problems and learn how to maintain good health
- Individuals with chronic health conditions have extra skills to master



# Why teach health skills in school?

It's the ideal environment for teaching health skills.

- Comfortable, structured learning environment
- Multiple supports
- Time to practice
- Fits with state learning requirements



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# How do we already do this?

- What skills in the IEP are similar to health care skills?
- Can your child use these skills for health care?



# Barriers to health goals in the IEP

- School staff and school nurses see the following barriers:
  - Their own lack of knowledge about health care transition (63.7%)
  - Lack of funding for such activities (62.7%)
  - Lack of time (47.5%)



# Potential resources from schools



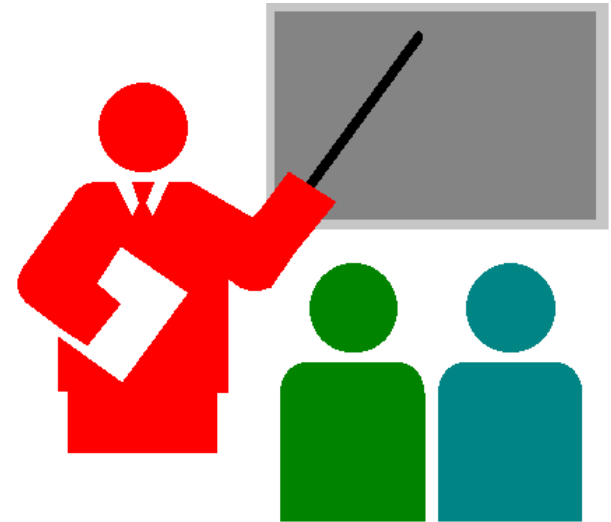
- Nearly one-third of schools connect students with community resources
- More than a quarter of schools believe that students and families find their own resources
- About one eighth of schools rely on the student's doctor to educate him or her



# Who teaches health skills?

## ■ Who should be responsible for teaching health skills?

- ❑ 95.1% - parents
- ❑ 69.3% - students
- ❑ 60.9% - student's doctor
- ❑ 47.9% - IEP team
- ❑ 32.5 % - UIC Specialized Care for Children
- ❑ 30.7% - teachers



# What Skills to Learn?

## ■ Daily health care needs

- ❑ Taking medications,
- ❑ Monitoring blood sugar level,
- ❑ Maintaining healthy diet

## ■ Using health care

- ❑ Making a doctor's appointment,
- ❑ Knowing & using insurance benefits

## ■ Health literacy and communication

- ❑ Asking questions during doctor visit,
- ❑ Explaining workstation accommodations to employer





# How to learn health skills

- Identify health skills, set goals and prioritize
- Include health goals in the IEP and transition plan
- Build and practice skills
- Review and monitor...



# The team

- Student
- Parent
- Teachers
- School nurse
- Care Coordinator
- Doctors? PT?  
Advocates?



# The team: students



- Identify strengths and limitations
- Develop and prioritize goals
- Identify supports
- Practice skills outside of school



# The team: parents

- ❑ Identify areas of strength and limitations
- ❑ Develop and prioritize goals
- ❑ Identify appropriate supports
- ❑ Coach your child in health care situations



# The team: school nurses

- ❑ Instruct students in specialized skills (injections, pressure sore checks)
- ❑ Coordinate referrals to community resources
- ❑ Coordinate with the physician and medical care team
- ❑ Write student-centered health goals



# The team: teachers

- Assess skill and ability level
- Identify priorities from educational perspective
- Align plans for education, employment, and independent living with health care needs
- Incorporate priorities into curriculum and instruction
- Assess student progress



# Assess, prioritize, set goals

- Use a checklist along with discussion
- Establish priority areas
  - Goals for education, career, independent living
  - Areas for improvement
  - Current and future medical needs



Early

Middle

Late

Name: \_\_\_\_\_ Birthdate: \_\_\_\_\_ Age: \_\_\_\_\_

Completed By: \_\_\_\_\_ Date: \_\_\_\_\_



## Transition Checklist for Teens

This *Transition Checklist for Teens* is about the skills you need to learn to take care of your health when you become an adult. Your teacher, guidance counselor, or school nurse will talk with you about the areas where you want help. Please complete this checklist by marking the box or boxes that describe you the best. If you do not understand a question, please ask for help.



ACCESSING HEALTH CARE-- Skills and Abilities:	YES, I do	NO, I will learn	Someone will need to do this for me	N/A, will not be needed	Need more info
<input type="checkbox"/> Do you wear or carry a medical alert (list of allergies, conditions)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you speak up for yourself in your doctor's office?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you help make health care decisions with your family or doctor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you see your doctor without your family/parents in the room?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you know your rights to keep your health information private?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you ever call your doctor(s) on your own if you have a problem?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you know how to schedule your own doctor appointments?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you have an updated portable medical summary and/or care plan?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you have an adult doctor (or a doctor for while you are at college)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MANAGING YOUR CONDITIONS AND TREATMENTS-- Skills and Abilities:					
<input type="checkbox"/> Do you know how to describe your own health conditions/disabilities and do you know how they affect your daily life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you know the names of your medicines and why you take them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you know what can happen if you skip your treatments or medicine?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you almost always take your medicines correctly on your own?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you know when and how to fill your own prescriptions (mail order, prescribing doctor, in time to keep from running out)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you use and take care of your own medical equipment and supplies?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Do you know when to call for routine checkups, urgent care, and when to go to the...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>





Name: \_\_\_\_\_ Birthdate: \_\_\_\_\_ Age: \_\_\_\_\_

Completed By: \_\_\_\_\_ Date: \_\_\_\_\_



## Transition Checklist for Parents/Caregivers

The purpose of this *Transition Checklist for Parents/Caregivers* is to identify issues and create a greater understanding of how your child is taking on some of the responsibilities of a young adult. This will be different for every child. Please complete this checklist to identify the skills and abilities that will help your child transition to adulthood. Mark the box or boxes that describe you the best. If you do not understand a question, please ask for help.

ACCESSING HEALTH CARE -- Skills and Abilities: □	My child can do this on his/her own □	I do this for my child □	I want to learn how to do this and need more information □	Someone else will need to help my child/family do this □	N/A □ will not be needed □
1. → Do most of the speaking for my child in the doctor's office □	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. → Schedule my child's doctor appointment(s) □	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. → Make health care decisions for my child with the doctor □	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. → Advocate for my child's rights (health information privacy, accessibility) □	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. → Keep my child's portable medical summary or care plan up-to-date □	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. → Find an adult doctor for my child □	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>MANAGING YOUR CONDITIONS AND TREATMENTS -- Skills and Abilities: □</b>					
7. → Describe my child's health conditions/disabilities and how they affect his/her daily life □	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. → Keep a list of my child's medicines and what each treats □	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. → Give my child his or her medicines/treatments □	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. → Fill my child's prescriptions or reorder supplies before they run out □	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. → Know when to call for routine checkups, urgent care, when to go to the emergency room and when to call 9-1-1 □	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. → Include health goals on my child's IEP or Transition Plan at school □	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>STAYING HEALTHY -- Skills and Abilities: □</b>					





## IEP transition plan

- Transition assessments
- Post-secondary outcomes
- Course of study
- Transition services
- Home-based support services



# Examples - Chantal



**Transition assessments:** Health care skills assessment showed that Chantal does not understand how health insurance works or what her options are for adult health insurance.

**Post-secondary outcomes:**  
Independent living- Chantal will maintain continuous health insurance and be able to use her benefits to cover her health care expenses.

**Course of study:**  
Year 2- Health

**Transition services:**  
Instruction- Chantal will participate in the insurance unit as part of her health class  
Related services- Chantal will meet with the school social worker to discuss insurance options  
Linkages to supports/services

# Examples - Rosa



**Present level:** This year, Rosa missed 10 school days due to pressure sores. She needs to learn ways to reduce the risk of pressure sores so she doesn't miss school or work.

**Goal:** Rosa will learn a routine of chair exercises in gym class that she will perform 3 times per day to reduce the risk of pressure sores. Rosa will complete her exercises 80% of the time.

**Supplementary services:** Rosa will receive PT services for 45 minutes per week during gym class. Rosa will schedule a 15 minute appointment with the school nurse once per semester to review methods of checking for early signs of pressure sores.

**Program modifications and support:** Rosa will report to the resource room during the first 10 minutes of study hall to perform her chair exercises.

Examples are fictional and do not represent actual persons.

Photo courtesy of the IL Medical Home Project and Colorado's health Care Program for Children with Special Needs.

# Examples - Jordan



**Present level:** Jordan can list his medications but does not remember to take them independently. He needs to establish a system to help him remember to take his medications on time. Jordan has difficulty completing his schoolwork when he does not take his medication on a regular schedule.

**Goal:** Jordan will use a programmed alarm on his cell phone 9 times out of 10 to ask to see the school nurse to take his meds.

**Accommodations:** Jordan will be allowed the use of a programmed cell phone as a medication reminder.

**Program modifications and support:** Jordan will be excused from class to visit the school nurse to take his meds.

# IEP and transition plan examples

## PRESENT LEVELS OF ACADEMIC ACHIEVEMENT AND FUNCTIONAL PERFORMANCE

Complete for initial IEPs and annual reviews.

When completing this page, include all areas from the following list that are impacted by the student's disability: academic performance, social/emotional status, independent functioning, vocational, motor skills, and speech and language/communication. This may include strengths/weaknesses identified in the most recent evaluation.

### Student's Strengths

Jenna is well-liked by her teachers and peers. She expressed that she is interested in the fields of business and medicine. She likes listening to music and playing on her computer. She does well in her computer and science classes. **Jenna can inform others of current medical diagnoses, including epilepsy/complex partial seizures, hydrocephalus, vision impairments, and tree nut allergies.**

### Parental Educational Concerns/Input

Jenna's mother is concerned that she does not always let others know when she needs print enlarged or needs to move closer to see materials and **would like Jenna to work on self-advocacy skills so that she is able to obtain the accommodations she needs in order to be successful.** Jenna's father would like Jenna to understand and educate others about how to respond if she has a seizure or allergic reaction.

### Student's Present Level of Academic Achievement (Include strengths and areas needing improvement)

Jenna is able to complete general education requirements with accommodations and maintains a B- GPA. She has the

# Sample health goals for IEPs

- Jessica will be able to explain how her condition affects her job choices and will be able to identify, from a list of job descriptions, which opportunities would be most suitable with 90% accuracy.
- George will apply for Medicaid by January 1 so that he can maintain insurance coverage while in college.
- Louisa will enroll in one athletic or physical fitness activity through the special recreation association to help maintain her energy and muscle tone and will attend 8 out of 10 sessions.
- Susanne will be able to explain the pros and cons of 2 different insurance plans and identify which plan would provide her with better coverage.



# Sample health goals for IEPs

- William will properly conduct a skin check for pressure sores 8 days out of 10
- Samantha will fill her own prescriptions before running out 9 times out of 10
- Christopher will be able to describe his condition with 90% accuracy
- Kayla will schedule her next doctor appointment on her own
- Alan will prepare and ask 2 questions at his next doctor appointment





# Teaching health care skills – at school

- ❑ Provide general instruction on health
- ❑ Teach health skills
- ❑ Adapt lessons/materials for individual students
- ❑ Set time with school nurse, special educator, resource teacher, social worker



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# Teaching health care skills – at home

- At doctor's appointments
- At the pharmacy
- When calling insurance company
- During treatments (nebulizer, dressings, trach care, g-tube, medications, orthotics)



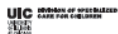
# Tools for Parents and Caregivers

## What Can You Do?

Use and make the most out of teachable moments to get you and your teen ready for the transition to adulthood.

Health Care	Living
<ul style="list-style-type: none"> <li>• Help your teen build skills to manage health care on his/her own</li> <li>• Put together a portable medical summary</li> <li>• Discuss a health care transition plan with your youth and doctors</li> <li>• Explore adult insurance options</li> <li>• Encourage your teen to ask questions of providers                             <ul style="list-style-type: none"> <li>• Promote healthy lifestyle choices to lower health risks</li> <li>• Ask your teen's doctor to help with health care transition and finding adult health care providers</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Give your teen more responsibilities for self-care (personal hygiene, taking care of medications)</li> <li>• Help your teen build skills in advocacy, communication and decision-making</li> <li>• Talk to other families and young adults with similar needs to help identify options</li> <li>• Identify your teen's need for accommodations</li> <li>• Teach your teen how to identify sources of support</li> <li>• Be creative and modify tasks to allow your teen to help out at home. Chores can lead to skills needed to get a job</li> </ul>
Education, Job or Training	Recreation
<ul style="list-style-type: none"> <li>• Recruit people to help you (IEP team, teachers, friends, doctors, nurses, co-workers and disability organizations)</li> <li>• Encourage your teen to take part in IEP meetings/transition planning meetings</li> <li>• Help your teen learn to advocate on his/her own</li> <li>• Be aware that all special education services will end at age 22 or when your teen graduates with a diploma (whichever happens first)</li> <li>• Have expectations that your teen can find a job after high school using his/her talents</li> <li>• Have your teen volunteer to explore jobs and build skills</li> </ul>	<ul style="list-style-type: none"> <li>• Create opportunities</li> <li>• Encourage your youth to "try out" different things to see what he/she enjoys</li> <li>• Make friendships a priority. Teens need other teens to talk to and share their life with</li> <li>• Help your teen find recreation and ways to reduce stress (relaxation, exercise, leisure)</li> </ul>

Materials supported through a grant from the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, D70Mc12845. Developed by the USC - Division of Specialized Care for Children and the Illinois Chapter, American Academy of Pediatrics.



For More Information Visit:  
<http://illinoisasp.org/projects/transition/>

05/11



## Transition Timeline

Use this timeline to keep track of transition activities. Some of these activities may not apply to everyone. Start by placing a check in the box next to each item that needs to be done. Then write down who will be in charge of that task. Use the space for notes to jot down information or questions. You may want to refer to the *Guide to Adult Benefits, Services, and Resources* to learn more about the agencies, benefits, and programs listed below. Use the key below to help you follow the steps to transition by stages.

Key: △ Activities for Early Transition    □ Activities for Middle Transition    ○ Activities for Late Transition

Health				
Action	✓ Do / ✗ Done	When to Begin	Person in Charge	Notes
△ Youth sees doctor independently for part of visit	<input type="checkbox"/>	Early Transition (Age 11 +)		
△ Youth takes more responsibility for medications and treatments	<input type="checkbox"/>	Early Transition (Age 12 +)		
△ Youth develops an understanding of health condition(s)	<input type="checkbox"/>	Early Transition (Age 12 +)		
□ Youth keeps and updates care plan, emergency plan, or medical summary	<input type="checkbox"/>	Middle Transition (Age 14 +)		
□ Youth makes own appointments	<input type="checkbox"/>	Middle Transition (Age 16 +)		
○ Youth manages insurance and payment for doctor visits	<input type="checkbox"/>	Late Transition (Age 17 +)		

## Transition to Adulthood for Parents and Caregivers

## Transition Timeline



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# Additional Resources

- ISBE Secondary Transition Website
  - <http://www.isbe.state.il.us/spec-ed/html/total.htm>
- Waisman Resource Center
  - <http://www.waisman.wisc.edu/wrc/cdrom.htm>
- Project MY VOICE
  - <http://cedu.niu.edu/tlrn/projectmyvoice/index.shtml>
- Got Transition
  - <http://www.gottransition.org/>



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# Wrap-up

- Thank you for your time and attention!



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# For Further Assistance

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# Acknowledgements

## Integrated Services Committee Members:

- **Sue Walter**, Illinois State Board of Education
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- **Linda Gibbons, RN, MSN**, Illinois Association of School Nurses and School Nurse Certification Program, National-Louis University
- **Donna Kunz**, Illinois Association of School Nurses and School Nurse, Huntley High School
- **Barb Marzillo**, North Suburban Special Education District
- **Sue McNamee**, North Suburban Special Education District
- **Karrie Potter**, Family Matters Parent Training and Information Center
- **Ingrid M. Thompson, RN, BSN, IL/NCSN**, North Suburban Special Education District
- **Susy Woods, MA**, Office of Disability Services, University of Illinois Springfield



# Acknowledgements

- **Tracy Aldridge, M.D.**, Division of Developmental Disabilities
- **Adjoa Denise Blalock, MSW**, Illinois Department of Human Services, Division of Mental Health
- **Marsie L. Frawley**, Health & Disability Advocates
- **Wilhelmina Gunther**, Illinois Assistive Technology Program
- **Pam Heavens**, Will-Grundy Center for Independent Living
- **Julie Ann Janssen, RDH, MA, CDHC**, Division of Oral Health, Illinois Department of Public Health
- **Carleda Johnson**, Access Living
- **Mike Kaminsky**, Illinois Lifespan Project
- **Susan Kaufman**, Clinical Services, Clearbrook
- **Margaret Kirkegaard, MD**, Automated Health Systems
- **Michelle Maher**, Illinois Department of Healthcare and Family Services, Bureau of Managed Care
- **Faye Manaster, MEd**, The Arc of Illinois Family to Family Health Information and Education Center
- **Ron Mulvaney**, Illinois Department of Human Services, Work Incentives Planning and Assistance
- **Purvi Patel**, Health & Disability Advocates
- **Sandy Ryan**, Illinois Council on Developmental Disabilities



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# Acknowledgements

- **Parag Shah, MD**, Lurie Children's Hospital
- **Stephanie Skipper**, AAP National Center for Medical Home Implementation
- **Barb Tobias**, Parent Representative
- **Marjorie Wilkey**, Parent Representative
- **Constance Y. Williams, PhD**, Illinois Department of Human Services, Division of Mental Health

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- Miriam Kalichman, MD, Children's Habilitation Clinic, UIC Specialized Care for Children
- Rita Klemm, MSW, UIC Specialized Care for Children
- Kathy Sanabria, MBA, PMP, IL Chapter, American Academy of Pediatrics
- Donna Scherer, RN, MPH, UIC Specialized Care for Children



# Acknowledgements

- This presentation includes content from the following sources:
  - Waisman Center/Wisconsin Children and Youth with Special Health Care Needs Program. *Embedding Health Outcomes in the IEP*.
  - Ingrid Thompson, Susan McNamee, Irene Dorfman, and Barb Marzillo. (2010). *Health Care Transition Services*.
  - Ceci Shapland. (2006). *What Does Health Have to Do with Transition?* NCSET/PACER Center Parent Brief.
  - Sue Walter, Darcy Contri, and Alicia Becker. (2005). *Transition Outreach Training for Adult Living Project, Module 9*.
- This project is made possible through funding from the Department of Health and Human Services (DHHS), Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB)

