Transition Seminar: TAND

Jamie K. Capal, MD
Professor of Pediatrics and Neurology
Director, TAND Clinic
Cincinnati Children's Hospital Medical Center

What is Transition?

- Movement of an individual from childhood to adulthood

- What changes?
  - Decision making
  - Daily routine
  - Living situation
  - Legal rights
  - Healthcare

What are the Differences? What are the Challenges?

Pediatric

- ✓ Family-centered
- ✓ Multi-disciplinary care
- ✓ School supports (IEP, therapies)

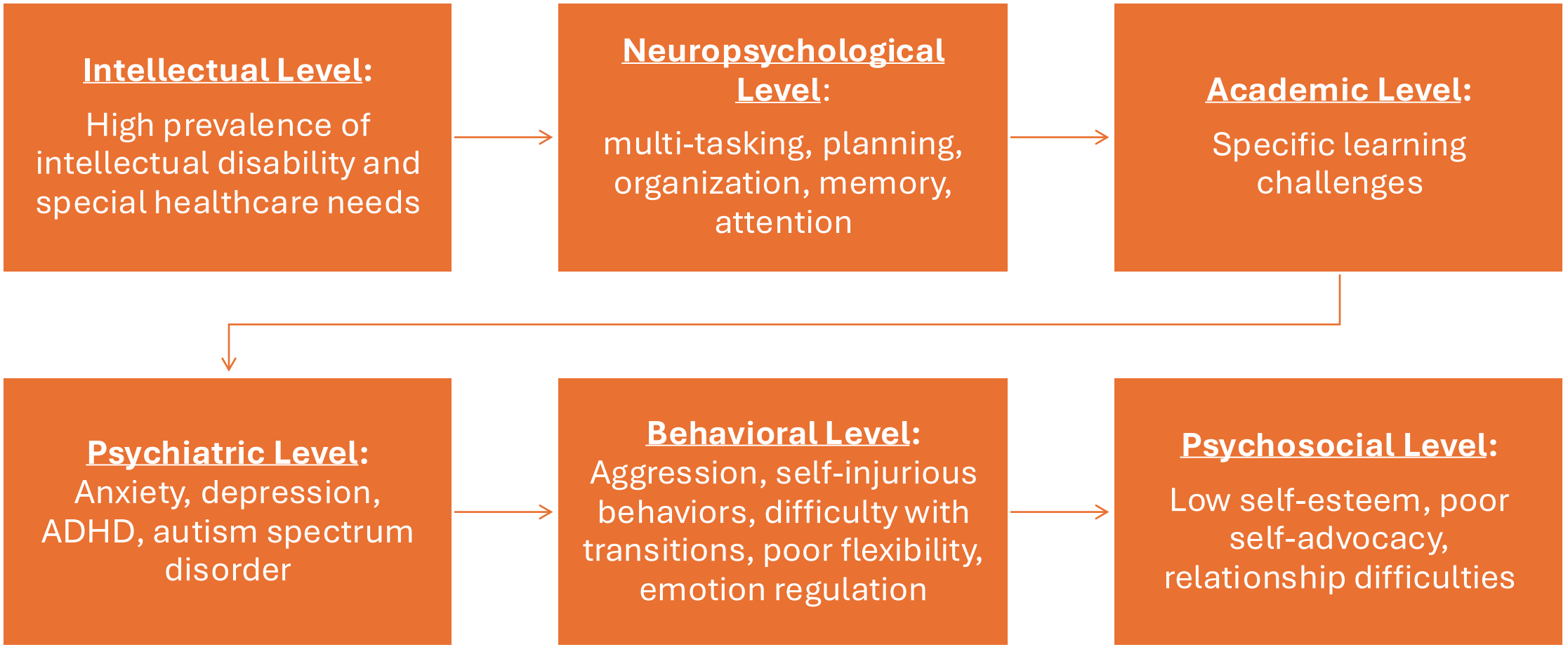
- Lack of transition discussion by providers
- Lack of a clear roadmap
- Inconsistent messaging and criteria
- Treatment bias (We are the only ones who can care for our patients)
- Disconnection from the adult system
- Unrealistic expectations

Adult

- ✓ Patient-specific
- ✓ Individualized care
- ✓ Responsibility is on the patient and/or caregiver

- Lack of training for adult providers
- Lack of behavioral supports (Child Life, Social Work)
- Gaps in mental/behavioral health services
- Poor communication and coordination across adult healthcare systems
- Need to accommodate special healthcare needs (sedated studies, support for lab draws, sensory friendly spaces)

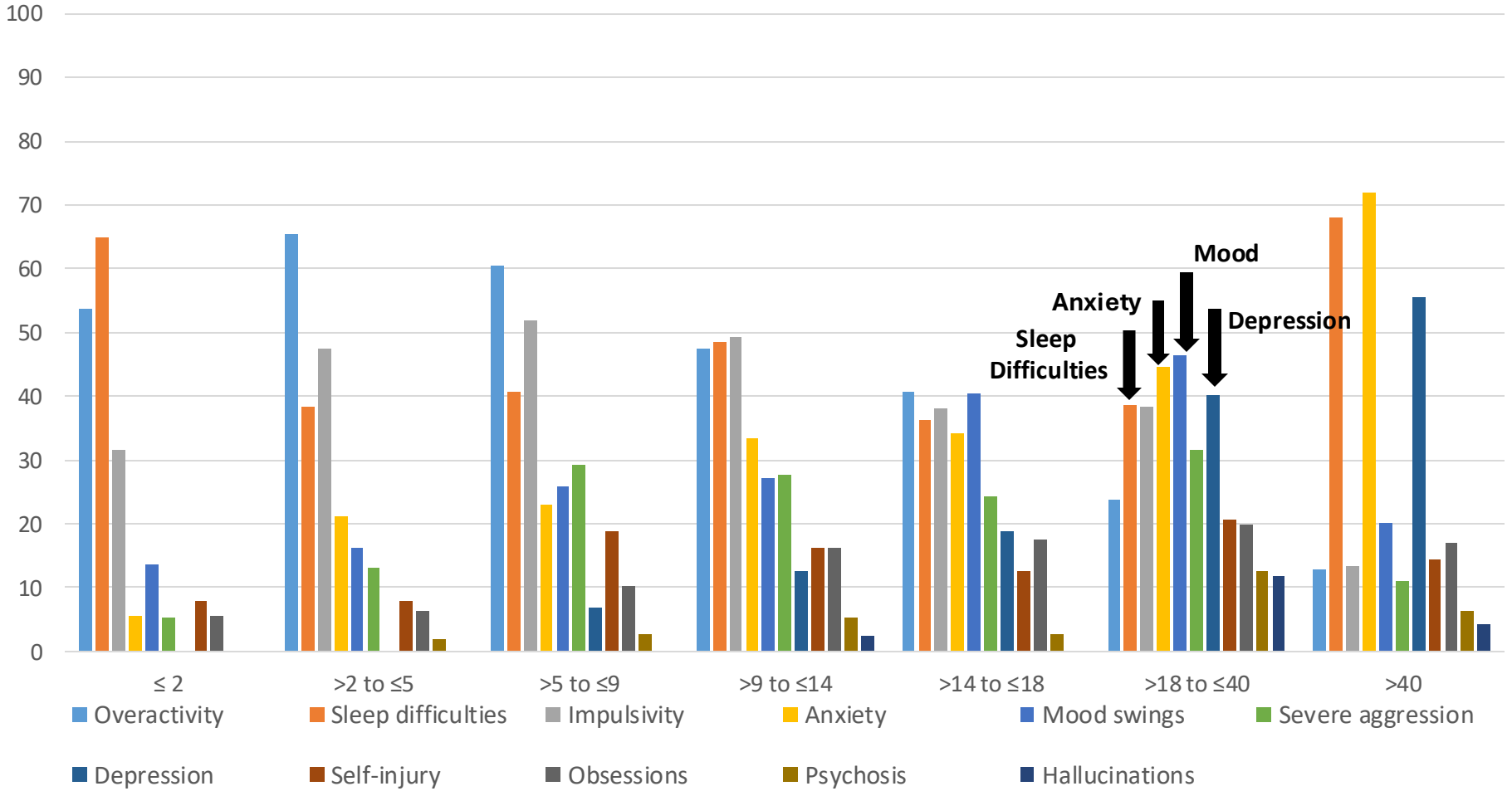
TAND-Specific Factors Impacting Transition to Adult Care



Intellectual and Academic Levels

- Intellectual disability or uneven skills
- Learning disabilities (reading, writing, math)
- Impacts ability to live, work, and function independently

Behavioral Level in TSC



- Anxiety, mood swings, and depression increased in prevalence with age
- Sleep difficulties (orange) were prevalent in all age groups

Behavioral Level in TSC

TAND-L Checklist, N = 488 children and 250 adults at CCHMC Over 3 Years

TAND Cluster	Behavioral Symptom	Overall (%)	Child (%)	Adult (%)
Behavioral Dysregulation	Rigid/Inflexible	43.4	40.7	48
	Difficulty with Peers	32.5	33	31.6
	Impulsivity	44.3	47.6	38.8
	Repetitive Behaviors	41.2	41.1	41.2
	Repeats Words	35.6	35.6	35.6
	Temper Tantrums	42.5	48.6	32.4
	Aggressive Outbursts	42.1	40.9	44
	Self Injury	25.1	26.3	23.2
Vegetative Symptoms	Sleep Difficulties	46.7	41.4	55.6
	Eating Difficulties	36.8	38	34.8
	Restlessness	46.1	48.1	42.8
	Overactive/Hyperactivity	34.9	40.2	26
Depressed Mood and Shyness	Extreme Shyness	21.6	19.6	24.8
	Depressed Mood	30.2	17	52.4
Mood Swings and Anxiety	Mood Swings	52.4	47.8	60
	Anxiety	52.5	43.3	68

90% reported at least one TAND symptom with an average of 12 symptoms reported at the first visit

- Can have difficulty finding an adult provider comfortable with complex behavioral profile
- Symptoms directly impact an individual's ability to:
  - Attend appointments
  - Comply with medications/therapies
  - Be eligible for specific day programs or employment

Samuel Alperin et al. Symptom rates and profile clustering in tuberous sclerosis complex-associated neuropsychiatric disorders (TAND). Journal of Neurodevelopmental Disorders. 2021

Psychiatric Level

- High rates of anxiety, depression, autism, ADHD→ OFTEN CO-OCCUR
- Higher rates of psychiatric conditions in individuals with intellectual disability and epilepsy
- Can also have associated medical conditions or organ-related problems (SEGA, AML, LAM) that complicate medical care
- Can result in difficulties with employment, relationships, finances, self-image, mental and physical health, substance abuse, suicide attempts

Neuropsychological Level

- Directing attention
- Regulating emotions
- Controlling impulses
- Keeping track of information to complete a task (working memory)
- Multi-tasking
- Planning
- Organization
- Self-monitoring
- Anticipating consequences

- ➢ Problems finding specialists and managing multiple appointments
- ➢ Problems filling medications
- ➢ Problems following through with recommendations
- ➢ Problems organizing medical information
- ➢ Problems recognizing when to see a doctor
- ➢ May not recognize how behavior impacts health

Psychosocial Level

- Self-esteem issues
- Self-advocacy issues
- Relationship difficulties
- Loss of social networks after school
- Challenges with health literacy
- Changes in support and resources

Transition Challenges

- Transitioning teens and young adults with TSC is difficult for the individual and for the caregivers regardless of level of independence
- TAND impacts all aspects of transition
- Difficult to find adult providers who are comfortable with TSC **and** TAND
- TAND symptoms directly and indirectly impact future planning and access to care

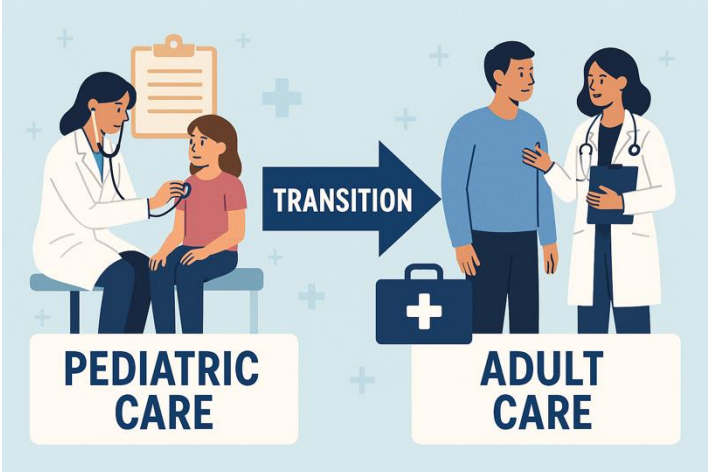
What Should Transition Look Like?

- Purposeful
- Planned
- Proactive
- Organized
- Address medical, psychosocial, educational, and/or employment needs
- Should be person-centered

Six Core Elements of Transition

- Expectation of Transition
- Yearly Self-Management Assessment
- Annual Discussion of Medical Condition and Age-Appropriate Concerns
- Evaluation of Legal Competency
- Child Neurology Team Responsibilities
- Identification of Adult Provider(s)
- Transfer Complete

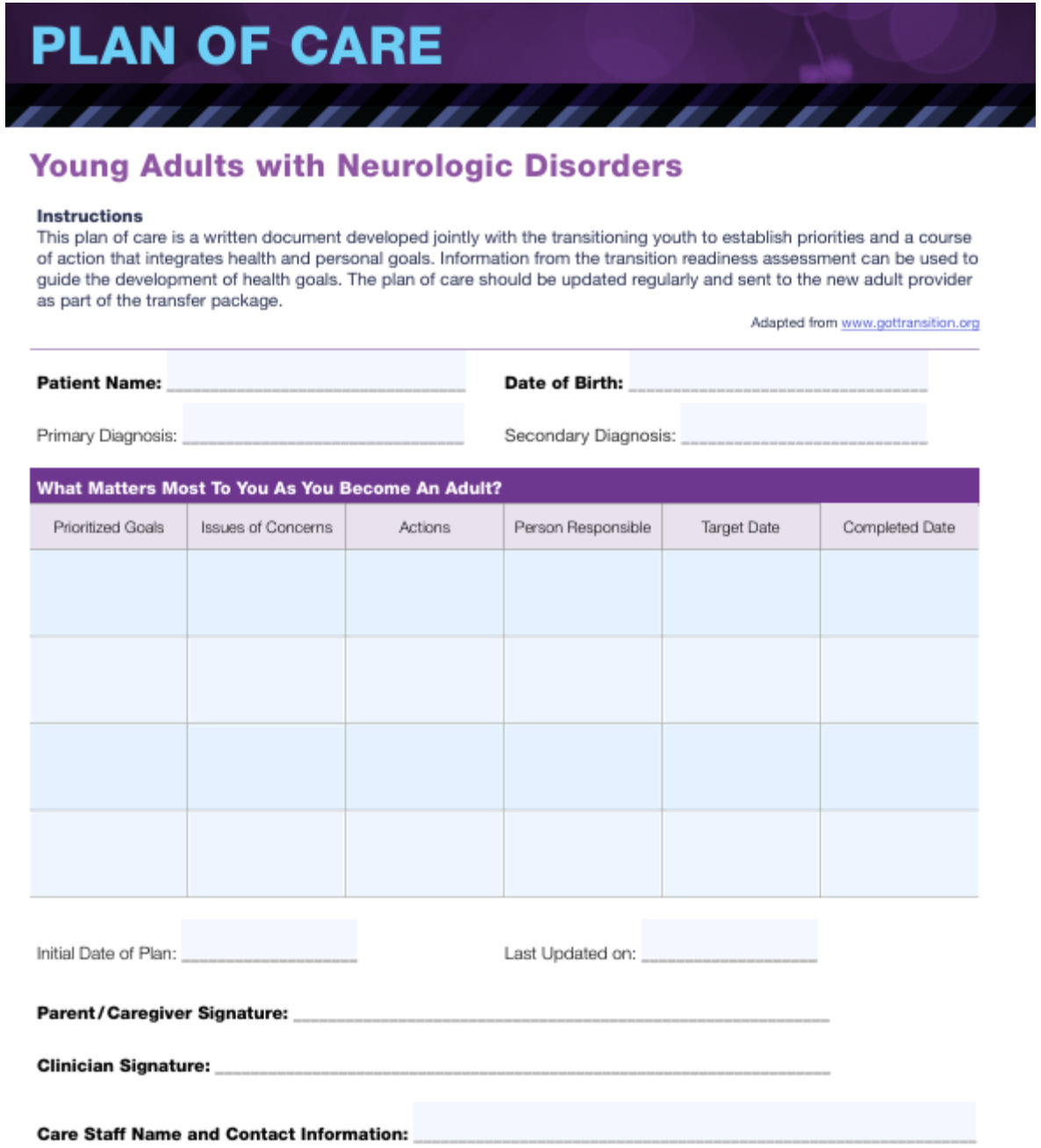
Transition Plan



- Start Early
  - 12-14 years
  - Transition readiness assessments
- Build a Transition Team
  - Healthcare providers, social work, teachers, community
- Implement future planning into IEP
- Address Emotional and Logistical Challenges
- Use Supported Decision-making Tools
- Keep a healthcare summary

Self-Advocacy

- Speaking up for yourself, asking what you need, negotiating for yourself
- Knowing your rights and responsibilities
- Using resources available to you
- Figuring out what is most important to you and/or your loved one (hopes, desires for the future)
- Knowing your TAND issues and how they affect you



PLAN OF CARE

Young Adults with Neurologic Disorders

Instructions
This plan of care is a written document developed jointly with the transitioning youth to establish priorities and a course of action that integrates health and personal goals. Information from the transition readiness assessment can be used to guide the development of health goals. The plan of care should be updated regularly and sent to the new adult provider as part of the transfer package.

Adapted from www.gottransition.org

Patient Name: _____ **Date of Birth:** _____

Primary Diagnosis: _____ Secondary Diagnosis: _____

What Matters Most To You As You Become An Adult?

Prioritized Goals	Issues of Concerns	Actions	Person Responsible	Target Date	Completed Date

Initial Date of Plan: _____ Last Updated on: _____

Parent/Caregiver Signature: _____

Clinician Signature: _____

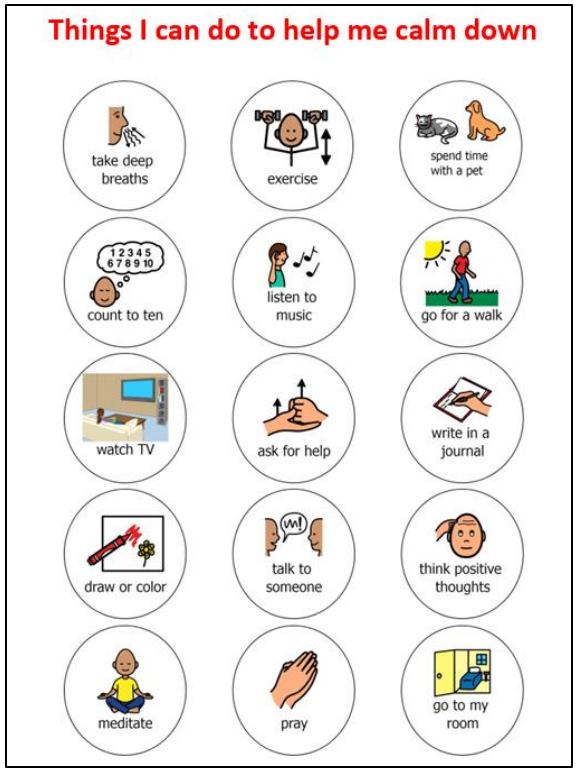
Care Staff Name and Contact Information: _____

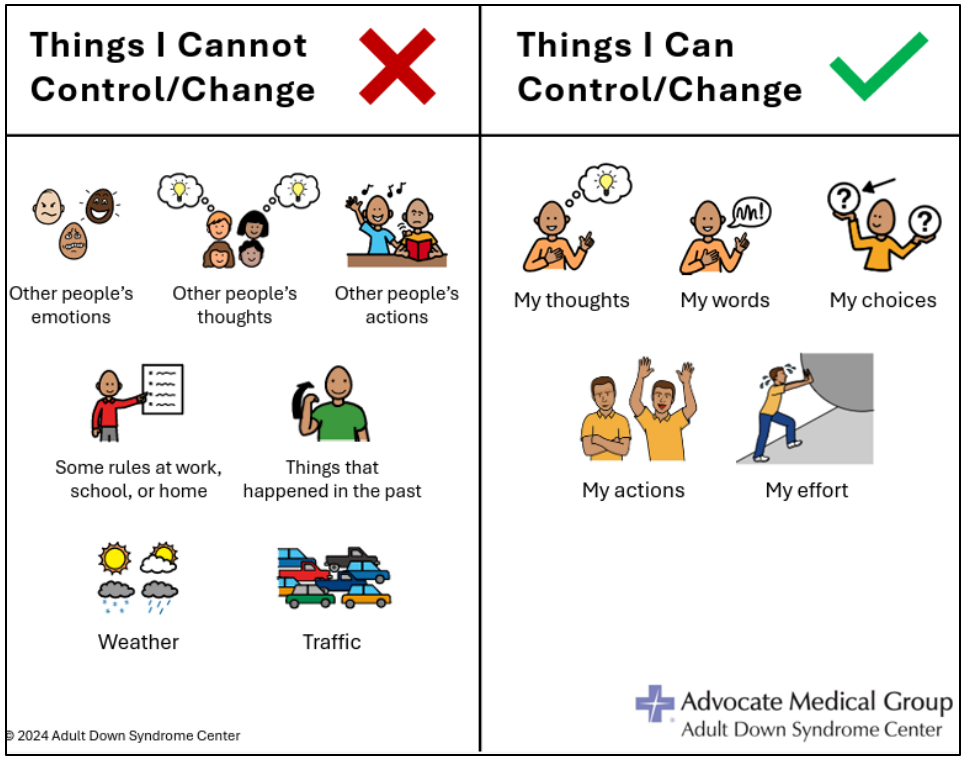
Building Independence

- **Strengthen Communication** to express preferences, desires, and feelings
- **Utilize Visual Schedules** to help with transitioning and decision making
- **Work on Self-Care Skills**
- **Teach how to request a break** to teach control and self regulation
- **Work on household chores** to teach responsibility and build skills
- **Practice money**
- **Teach community safety skills** including pedestrian safety and public transport, as well as identifying safe and unsafe people
- **Build leisure skills** to foster joy and community
- **Work on vocational skills**

Manage Mental Health and Wellness

- Take care of your body (eat healthy, get adequate sleep, exercise)
- Cultivate healthy relationships
- Develop positive coping skills
- Ask for help





Once you get there…

- Bring your healthcare summary
- Bring your loved one’s behavior plan
- Bring the TSC Alliance surveillance guidelines
- Bring your TAND-SQ Checklist
- Educate your adult clinicians
- Find someone who understands neurodivergent individuals and/or who listens to your concerns

Transition Readiness Assessments

Sample Transition Readiness Assessment for Youth

Please fill out this form to help us see what you already know about your health, how to use health care, and the areas you want to learn more about. If you need help with this form, please ask your parent/caregiver or doctor.

Preferred name | *Legal name* | *Date of birth* | *Today's date*

TRANSITION IMPORTANCE & CONFIDENCE *Please circle the number that best describes how you feel now.*

The transfer to adult health care usually takes place between the ages of 18 and 22.

How important is it to you to move to a doctor who cares for adults before age 22?

0 *not* | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 *very*

How confident do you feel about your ability to move to a doctor who cares for adults before age 22?

0 *not* | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 *very*

MY HEALTH & HEALTH CARE *Please check the answer that best applies now.*	NO	I WANT TO LEARN	YES
I can explain my health needs to others.	☐	☐	☐
I know how to ask questions when I do not understand what my doctor says.	☐	☐	☐
I know my allergies to medicines.	☐	☐	☐
I know my family medical history.	☐	☐	☐
I talk to the doctor instead of my parent/caregiver talking for me.	☐	☐	☐
I see the doctor on my own during an appointment.	☐	☐	☐
I know when and how to get emergency care.	☐	☐	☐
I know where to get medical care when the doctor's office is closed.	☐	☐	☐
I carry important health information with me every day (e.g., insurance card, emergency contact information).	☐	☐	☐
I know that when I turn 18, I have full privacy in my health care.	☐	☐	☐
I know at least one other person who will support me with my health needs.	☐	☐	☐
I know how to find my doctor's phone number.	☐	☐	☐
I know how to make and cancel my own doctor appointments.	☐	☐	☐
I have a way to get to my doctor's office.	☐	☐	☐
I know how to get a summary of my medical information (e.g., online portal).	☐	☐	☐
I know how to fill out medical forms.	☐	☐	☐
I know how to get a referral if I need it.	☐	☐	☐
I know what health insurance I have.	☐	☐	☐
I know what I need to do to keep my health insurance.	☐	☐	☐
I talk with my parent/caregiver about the health care transition process.	☐	☐	☐
MY MEDICINES *If you do not take any medicines, please skip this section.*			
I know my own medicines.	☐	☐	☐
I know when I need to take my medicines without someone telling me.	☐	☐	☐
I know how to refill my medicines if and when I need to.	☐	☐	☐

WHICH OF THE SKILLS LISTED ABOVE DO YOU MOST WANT TO WORK ON?

Transitioning Youth to an Adult Health Care Clinician
Six Core Elements of Health Care Transition® 3.0

got transition.

Sample Transition Readiness Assessment for Parents/Caregivers

Please fill out this form to help us see what your child already knows about their health and the areas you think they want to learn more about. After you complete the form, you can ask your child to share their answers from their completed form, and you can compare them. Your answers may be different. Your child's doctor will help you work on steps to increase your child's health care skills.

Youth name | *Parent/Caregiver name* | *Youth date of birth* | *Today's date*

TRANSITION IMPORTANCE & CONFIDENCE *Please circle the number that best describes how you feel now.*

The transfer to adult health care usually takes place between the ages of 18 and 22.

How important is it to your child to move to a doctor who cares for adults before age 22?

0 *not* | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 *very*

How confident do you feel about your child's ability to move to a doctor who cares for adults before age 22?

0 *not* | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 *very*

MY CHILD'S HEALTH & HEALTH CARE *Please check the answer that best applies now.*	NO	THEY WANT TO LEARN	YES
My child can explain their health needs to others.	☐	☐	☐
My child knows how to ask questions when they do not understand what their doctor says.	☐	☐	☐
My child knows their allergies to medicines.	☐	☐	☐
My child knows our family medical history.	☐	☐	☐
My child talks to the doctor instead of me talking for them.	☐	☐	☐
My child sees the doctor on their own during an appointment.	☐	☐	☐
My child knows when and how to get emergency care.	☐	☐	☐
My child knows where to get medical care when the doctor's office is closed.	☐	☐	☐
My child carries important health information with them every day (e.g., insurance card, emergency contact information).	☐	☐	☐
My child knows that when they turn 18, they have full privacy in their health care.	☐	☐	☐
My child knows at least one other person who will support them with their health needs.	☐	☐	☐
My child knows how to find their doctor's phone number.	☐	☐	☐
My child knows how to make and cancel their own doctor appointments.	☐	☐	☐
My child has a way to get to their doctor's office.	☐	☐	☐
My child knows how to get a summary of their medical information (e.g., online portal).	☐	☐	☐
My child knows how to fill out medical forms.	☐	☐	☐
My child knows how to get a referral if they need it.	☐	☐	☐
My child knows what health insurance they have.	☐	☐	☐
My child knows what they need to do to keep their health insurance.	☐	☐	☐
My child and I talk about the health care transition process.	☐	☐	☐
MY CHILD'S MEDICINES *If your child does not take any medicines, please skip this section.*			
My child knows their own medicines.	☐	☐	☐
My child knows when they need to take their medicines without someone telling them.	☐	☐	☐
My child knows how to refill their medicines if and when they need to.	☐	☐	☐

WHICH OF THE SKILLS LISTED ABOVE DOES YOUR CHILD MOST WANT TO WORK ON?

Transitioning Youth to an Adult Health Care Clinician
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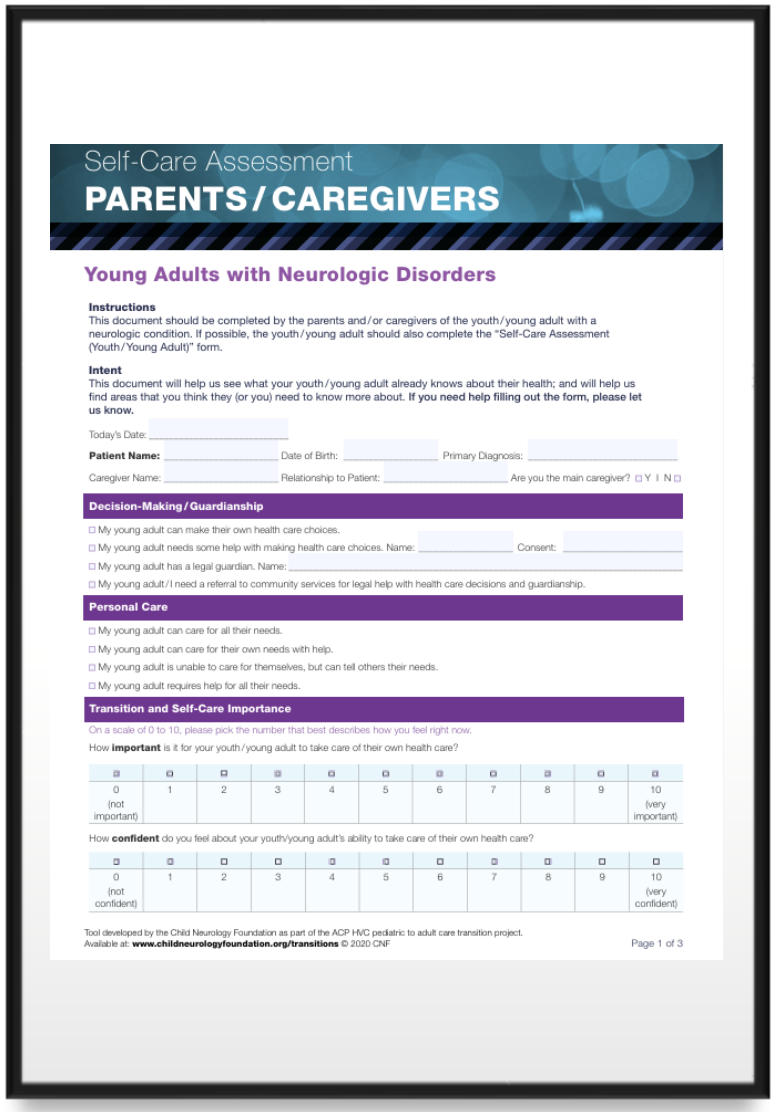
Transition Readiness Assessments



Self-Care Assessment

PARENTS / CAREGIVERS

Young Adults with Neurologic Disorders

Instructions
This document should be completed by the parents and/or caregivers of the youth/young adult with a neurologic condition. If possible, the youth/young adult should also complete the "Self-Care Assessment (Youth/Young Adult)" form.

Intent
This document will help us see what your youth/young adult already knows about their health; and will help us find areas that you think they (or you) need to know more about. **If you need help filling out the form, please let us know.**

Today's Date: _____

Patient Name: _____ Date of Birth: _____ Primary Diagnosis: _____

Caregiver Name: _____ Relationship to Patient: _____ Are you the main caregiver? ☐ Y I N ☐

Decision-Making / Guardianship

- ☐ My young adult can make their own health care choices.
- ☐ My young adult needs some help with making health care choices. Name: _____ Consent: _____
- ☐ My young adult has a legal guardian. Name: _____
- ☐ My young adult / I need a referral to community services for legal help with health care decisions and guardianship.

Personal Care

- ☐ My young adult can care for all their needs.
- ☐ My young adult can care for their own needs with help.
- ☐ My young adult is unable to care for themselves, but can tell others their needs.
- ☐ My young adult requires help for all their needs.

Transition and Self-Care Importance

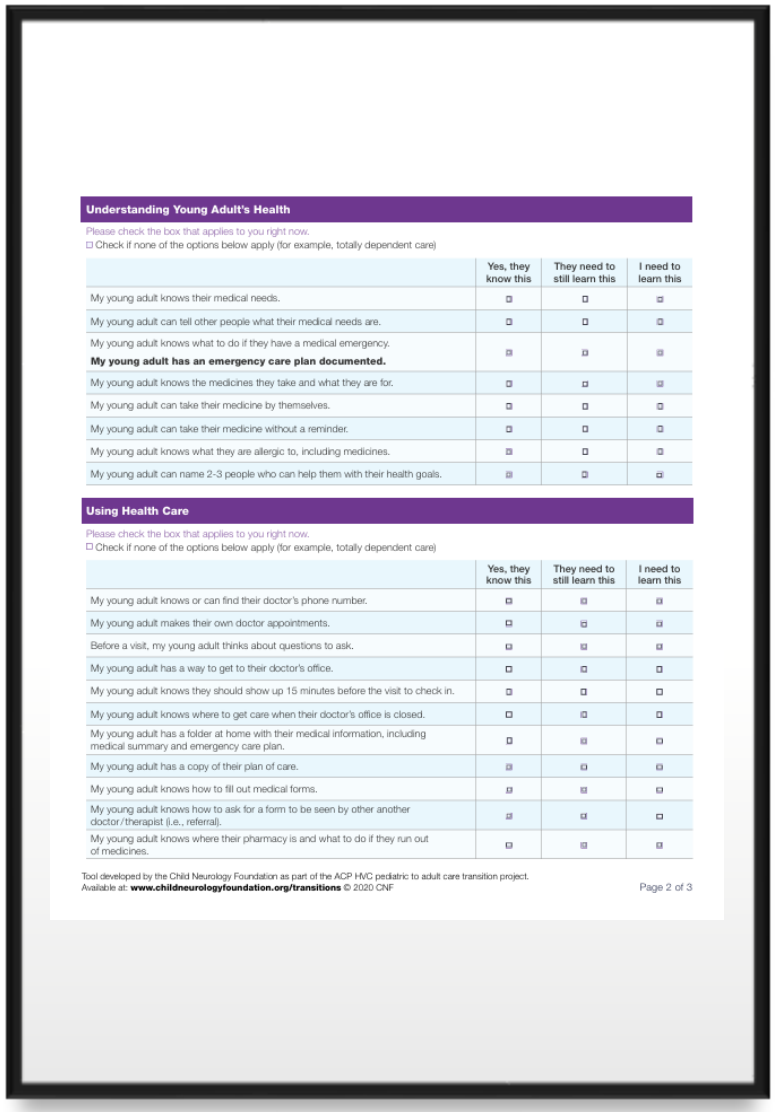
On a scale of 0 to 10, please pick the number that best describes how you feel right now.

How **important** is it for your youth/young adult to take care of their own health care?

☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
0 (not important)	1	2	3	4	5	6	7	8	9	10 (very important)

How **confident** do you feel about your youth/young adult's ability to take care of their own health care?

☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
0 (not confident)	1	2	3	4	5	6	7	8	9	10 (very confident)



Understanding Young Adult's Health

Please check the box that applies to you right now.
☐ Check if none of the options below apply (for example, totally dependent care)

	Yes, they know this	They need to still learn this	I need to learn this
My young adult knows their medical needs.	☐	☐	☐
My young adult can tell other people what their medical needs are.	☐	☐	☐
My young adult knows what to do if they have a medical emergency. **My young adult has an emergency care plan documented.**	☐	☐	☐
My young adult knows the medicines they take and what they are for.	☐	☐	☐
My young adult can take their medicine by themselves.	☐	☐	☐
My young adult can take their medicine without a reminder.	☐	☐	☐
My young adult knows what they are allergic to, including medicines.	☐	☐	☐
My young adult can name 2-3 people who can help them with their health goals.	☐	☐	☐

Using Health Care

Please check the box that applies to you right now.
☐ Check if none of the options below apply (for example, totally dependent care)

	Yes, they know this	They need to still learn this	I need to learn this
My young adult knows or can find their doctor's phone number.	☐	☐	☐
My young adult makes their own doctor appointments.	☐	☐	☐
Before a visit, my young adult thinks about questions to ask.	☐	☐	☐
My young adult has a way to get to their doctor's office.	☐	☐	☐
My young adult knows they should show up 15 minutes before the visit to check in.	☐	☐	☐
My young adult knows where to get care when their doctor's office is closed.	☐	☐	☐
My young adult has a folder at home with their medical information, including medical summary and emergency care plan.	☐	☐	☐
My young adult has a copy of their plan of care.	☐	☐	☐
My young adult knows how to fill out medical forms.	☐	☐	☐
My young adult knows how to ask for a form to be seen by other another doctor / therapist (i.e., referral).	☐	☐	☐
My young adult knows where their pharmacy is and what to do if they run out of medicines.	☐	☐	☐

Using Health Care (continued)

	Yes, they know this	They need to still learn this	I need to learn this
My young adult knows where to get a blood test or x-rays if the doctor orders them.	☐	☐	☐
My young adult carries health information with them every day (e.g., insurance card, allergies, medications, and emergency phone numbers).	☐	☐	☐
My young adult has a plan so they can keep their health insurance after 18 or older.	☐	☐	☐

Please include here any other concerns or thoughts you wish to share with your health care team regarding the health of your young adult:

Child Neurology Foundation Transition Toolkit

Healthy Living | Medication List

This Medication List Belongs To: _____ **Date:** _____

I Take This Medication:	How Much I Take:	Time of Day I Take This Medication:				Why I Take This Medication?	I Started Taking This Medication On:	I Stop Taking This Medication On:	I Was Told to Take This Medication By:
		Morning	Afternoon	Evening	Bedtime				
Ex: Aspirin	Ex: 81 mg	✓		✓		Ex: My Heart	Ex: February 4, 2023	Ex: March 24, 2024	Ex: Dr. Smith

Healthy Living | My Health Care Support Needs

My Name: ____________________ **Date:** __________

Supporter's Name (if needed): ____________________

MY HEALTH CARE SUPPORT NEEDS

Understand Medical Information

☐ I do not need help with understanding medical information.

I would like help to:

☐ Understand what my health care workers tell me or what they recommend.
☐ Learn about all my options or choices
☐ Understand the pros and cons of each option to help so I can make an informed decision.
☐ Other: ____________________
☐ Other: ____________________

How health care workers can best support me:

☐ Use photos or pictures to explain procedures or directions.
☐ Use simple language.
☐ Provide extra time.
☐ Other: ____________________
☐ Other: ____________________

Communicate with Health Care Workers

☐ I do not need help communicating with health care workers.

I would like help to:

☐ Share my current situation.
☐ Communicate my decisions or choices.
☐ Ask the health care worker questions.
☐ Respond to the health care worker's questions.
☐ Other: ____________________
☐ Other: ____________________

How health care workers can best support me:

☐ Repeat my answers back to me.
☐ Ask me to "teach back" instructions.
☐ Ask me questions.
☐ Other: ____________________
☐ Other: ____________________

Follow Through with Next Steps

☐ I do not need help following through with next steps.

I would like help to:

☐ Follow through with my medical decisions or choices.
☐ Set up my medications.
☐ Share a summary of my visit with: ____________________.

How health care workers can best support me:

☐ Write down instructions for next steps.
☐ Update and organize my information such as my medication list or health care visit summary.
☐ Give reminders of upcoming appointments.
☐ Check-in with me to see how it is going.
☐ Other: ____________________
☐ Other: ____________________

Healthy Living | My Health Care Support Team

My Name: ____________________ **Date:** __________

Supporter's Name (if needed): ____________________

MY HEALTH CARE SUPPORT TEAM

Personal Support

Name: ____________________ **Relationship:** ☐ **Family** ☐ **Friend** ☐ **Other:** __________
Role At Visit:
☐ Understand medical information
☐ Follow through with next steps
☐ Communicate with health care workers
☐ Other: ____________________

Name: ____________________ **Relationship:** ☐ **Family** ☐ **Friend** ☐ **Other:** __________
Role At Visit:
☐ Understand medical information
☐ Follow through with next steps
☐ Communicate with health care workers
☐ Other: ____________________

Name: ____________________ **Relationship:** ☐ **Family** ☐ **Friend** ☐ **Other:** __________
Role At Visit:
☐ Understand medical information
☐ Follow through with next steps
☐ Communicate with health care workers
☐ Other: ____________________

Formal Support

Name: ____________________
Relationship: ☐ Paid Staff (PCA, DSP) ☐ Residential/Provider Agency Staff ☐ Other: __________
Role At Visit:
☐ Understand medical information
☐ Follow through with next steps
☐ Communicate with health care workers
☐ Other (e.g., transportation, safety): ____________________

Name: ____________________
Relationship: ☐ Paid Staff (PCA, DSP) ☐ Residential/Provider Agency Staff ☐ Other: __________
Role At Visit:
☐ Understand medical information
☐ Follow through with next steps
☐ Communicate with health care workers
☐ Other (e.g., transportation, safety): ____________________

Name: ____________________
Relationship: ☐ Paid Staff (PCA, DSP) ☐ Residential/Provider Agency Staff ☐ Other: __________
Role At Visit:
☐ Understand medical information
☐ Follow through with next steps
☐ Communicate with health care workers
☐ Other (e.g., transportation, safety): ____________________

LEGAL DECISION-MAKING AUTHORITY

This document is for informational purposes only, not legal advice or use.

☐ **I have legal decision-making authority for my health care.**

☐ I use supported decision-making (SDM). This means I have people I trust that help me make choices for myself. They do not make decisions for me.

Supporter(s)
Name: ____________________ Name: ____________________
Name: ____________________ Name: ____________________

I have a Supported Decision-Making Agreement: (check one)
☐ Yes
☐ No

☐ I have a substitute decision-maker (select which one applies).

☐ **Power of Attorney (POA)**
Name: __________ Name: __________
Phone Number: __________ Phone Number: __________
Name: __________ Name: __________
Phone Number: __________ Phone Number: __________

☐ **Guardian**
Name: __________ Name: __________
Phone Number: __________ Phone Number: __________
☐ Limited ☐ Limited
☐ Full ☐ Full
☐ Other: __________ ☐ Other: __________

☐ **Conservator**
Name: __________ Name: __________
Phone Number: __________ Phone Number: __________
☐ Limited ☐ Limited
☐ Full ☐ Full
☐ Other: __________ ☐ Other: __________

Taking Charge of My Appointment

Date of my appointment: _____

Time of my appointment: _____

Doctor's name: _____

Who is going with me: _____

Why am I going to the doctor's office today? (Circle all that apply)

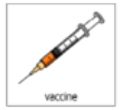
Physical

Follow up

Illness

Injury

Need medication change or refill



Vaccine

Need forms filled out

Do I have my…? (Check the boxes)

❑ ID

❑ Insurance card

❑ Medication list

❑ Forms for the doctor if needed

Adapted from Charting the LifeCourse Nexus; LifeCourseTools.com

Advocate Medical Group
Adult Down Syndrome Center

Questions to ask my doctor	Answers to my questions
I can fill this section out before my appointment. I can ask my parent or caregiver for help.	I can fill out this section during ***or*** after my appointment. I can ask my parent or caregiver for help.

Next Steps

I can fill out this section at my doctor's office *or* when I get home.

Lab Work

Do I need lab work? YES NO

Where will I have the lab work done? (Circle one)

Lab at or near my doctor's office **Lab near my house**

Tests

Do I need any tests? YES NO

What test(s)? (Circle all that apply)

X-ray **Ultrasound** **Sleep study** **EKG**

MRI or CT scan **Hearing test** **Vision test** **Other**

Medications

Was there a change in my medication(s)? YES NO

1. Medication & dose: _____
name and amount

When will I take it? _____
time(s) of day

2. Medication & dose _____
name and amount

When will I take it? _____
time(s) of day

Next Steps

I can fill out this section at my doctor's office *or* when I get home.

Next Appointment

Do I need to schedule another appointment with this doctor?

YES NO

Date of my next appointment: _____

Time of my next appointment: _____

Referrals

Do I need to see an additional doctor? YES NO

Who? _____

Resources

- County Board of Developmental Disabilities
- Got Transition (https://www.gottransition.org/)
- Autism Speaks Transition Toolkit (www.autismspeaks.org)
- Child Neurology Foundation (https://www.childneurologyfoundation.org/tools-resources/)
- https://movingtoadulthealthcare.org/toolkits/
- Talking About Complex Care Guide (https://www.chcs.org/media/Talking-About-Complex-Care-Guide_022322.pdf)
- Advocate Medical Group Adult Down Syndrome Center Resource Library (https://adscresources.advocatehealth.com/)