



# BRIDGING TRANSITION

## Journey to Adulthood

Andrew McCormick MD

# OBJECTIVES

- Appreciate the importance of a holistic and longitudinal transition process
- Develop a framework for successful transition
- Build a tool kit for transition visits

# OUTLINE

- WHY – what is the purpose of transition?
- Looks at GAP
- Look at SOLUTIONS
- Building Your Transition Tool Kit

# MODEL OF VALUE



DISABILITY = DISEASE

Congenital Heart Disease

Duodenal Atresia

Developmental / Intellectual Disability

Behavioral Disorders

# MODEL OF VALUE



DISABILITY = ~~DISEASE~~

Congenital Heart Disease

Duodenal Atresia

Developmental / Intellectual Disability

Behavioral Disorders

# MODEL OF VALUE



DISABILITY = DIVERSITY

Employed

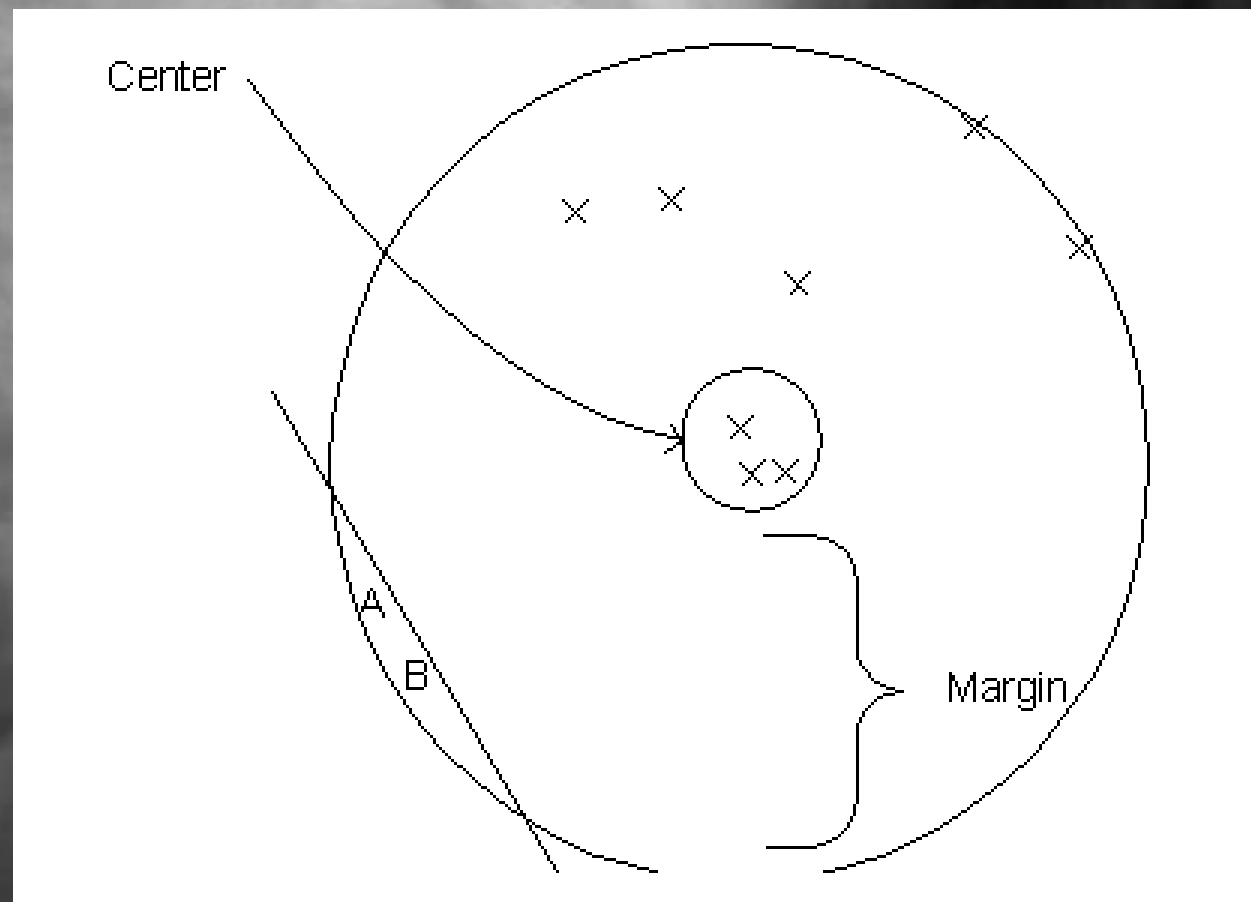
Healthy Relationships

Self Advocate

Living Interpedently / Interdependently









# MODEL OF VALUE



DISABILITY = DIVERSITY

Employed

Healthy Relationships

Self Advocate

Living Interpedently / Interdependently

# TRANSITION = INCLUSION

Inclusion:

Person belongs to the group and uniqueness is valued

	Valued	Devalued
Included	Inclusion	Assimilation
Excluded	Differentiation	Exclusion

# Transfer Leap



# GAPS IN TRANSITION








# BRIDGING TRANSITION





Discovering      Tracking      Preparing      Planning      Transferring      Completing

LONGITUDINAL TRANSITION



# SILOS OF CARE



# HOLISTIC TRANSITION



TRANSITION  
TUG-OF-WAR



## TEEN / YOUNG PERSPECTIVE

Teens/Young Perspective:

### **Worry about facing the unknown**

1. develop new trust relationship
2. uncertainty about maintaining self-care



# PARENT PERSPECTIVE

## Parent Perspective

- Desire greater involvement in process
- Felt undervalued in transition process



"I'm not looking forward to moving because I'm out of the picture then, you know what I mean, I'm gone ... I can't sit in with her, I can't ask questions..."

<b>Age/ Time</b>	<b>Provider</b>	<b>Parents</b>	<b>Youth</b>	<b>Adult Provider</b>
Early	Has major responsibility	Caretaker	Receives care	Aware
Middle	Provides support to parent/youth	Manager	Participates	Aware + set goal for transfer
Late	Consultant	Supervisor	Manages	↑ communication summary
Adult	Resource	Consultant	Supervisor/ CEO	Partnership in care

From: Good2Go and Bev Kosmach



**Discovering**

**Tracking**

**Preparing**

**Planning**

**Transferring**

**Completing**

# TRANSITION BRIDGE



# TRANSITION TOOLBOX

Transition Policy Statement

Individual Transition Plan

Assess Progress / Readiness

Create Goals

Portable Medical Summary





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# BUILD YOUR TEAM

- Develop a Transition Contract
- Define responsibilities
- Define who is on the Team
- Define our goal!!!

The Down Syndrome Center of Western Pennsylvania is committed to helping our patients make a smooth transition from pediatric to adult health care. This process involves working with youth, beginning at ages 12 to 14, and their families to prepare for the change from a "pediatric" model of care where parents make most decisions to an "adult" model of care where youth take on new responsibility for decision-making. This means that we will spend time during the visit to assess your teen's readiness from a developmental perspective to assume these roles. This will also mean we will meet with your teen without the parent present during part of your visit in order to assist them in setting health priorities and supporting them in becoming more independent with their own health care.

At age 18, youth legally become adults. We respect that many of our young adult patients choose to continue to involve their families in health care decisions. Only with the young adult's consent will we be able to discuss any personal health information with family members. If the youth has a condition that prevents him/her from making health care decisions, we encourage parents/caregivers to consider options for supported decision-making.

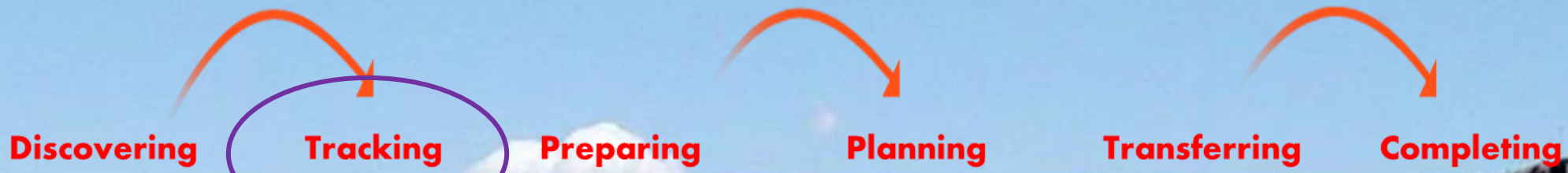
We will collaborate with youth and families regarding the age for transferring to an adult provider and recommend that this transfer occur before age 21. We will assist with this transfer process, including helping to identify an adult provider, sending medical records, and communicating with the adult provider about the unique needs of our patients.

As always, if you have any questions or concerns, please feel free to contact us.

Sincerely,

*Andrew McCormick MD*





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# Down Syndrome Center of Western PA

## Transition Policy

-Practice policy on transition discussed/shared with youth and parent caregiver \_\_\_\_\_  
Date

## Transition Readiness Assessment

-Conducted transition readiness assessment \_\_\_\_\_  
Date Date Date

-Included transition goals and prioritized actions in plan of care \_\_\_\_\_  
Date Date Date

## Medical Summary and Emergency Plan

-Updated medical summary and emergency plan \_\_\_\_\_  
Date Date Date

## Adult Model of Care

-Decision-making changes, privacy, and consent in adult care discussed with youth and parent/caregiver (if needed, discussed plans for supported decision-making) \_\_\_\_\_  
Date

-Timing of transfer discussed with youth and parent/caregiver \_\_\_\_\_  
Date

-Selected Adult Provider

Name	ClinicPhone	Fax	First Appointment	Completed
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## Transfer of Care

- Prepared transfer package including:
- Transfer letter, including effective of date of transfer of care to adult provider
  - Final transition readiness assessment
  - Plan of care, including goals and actions
  - Updated medical summary and emergency care plan
  - Legal documents, if needed
  - Condition fact sheet, if needed
  - Additional provider records, if needed

-Sent transfer package \_\_\_\_\_  
Date

-Communicated with adult provider about transfer \_\_\_\_\_  
Date



TRANSITION BRIDGE

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## Readiness Assessment

### Medication Management

	No, but I want know how	Yes, I to learn	Yes, I started doing	always do
Do you fill a prescription if you need to?	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Do you know what to do if you are having a bad reaction to your medications?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Do you take medications correctly and on your own?	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Do you reorder medications before they run out?	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Appointment Management

Do you call the doctor's office to make an appointment?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you follow up on any referral for tests or check-ups or labs?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you arrange for your ride to medical appointments?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you call the doctor about unusual changes in your health (eg, allergic reactions)?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you apply for health insurance if you lose your current coverage?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you know what your health insurance covers?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you manage your money and budget household expenses (eg, use checking/debit card)?	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

### Tracking Health Issues

Do you fill out the medical history form, including a list of your allergies?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you keep a calendar or list of medical and other appointments?	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	No, I do not know how	No, but I want to learn	Yes, I started doing	Yes, I always do
Do you make a list of questions before the doctor's visit?	<input type="checkbox"/>	<input type="checkbox"/>	x	<input type="checkbox"/>
Do you get financial help with school or work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	x

### Talking with Providers

Do you tell the doctor or nurse what you are feeling?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	x
Do you answer questions that are asked by the doctor, nurse or clinic staff?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	x

### Managing Daily Activities

Do you help plan or prepare meals/food?	<input type="checkbox"/>	<input type="checkbox"/>	x	<input type="checkbox"/>
Do you keep home/room clean or clean up after meals?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	x
Do you use neighborhood stores and services (eg, grocery stores and pharmacy stores)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	x





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Do you keep a calendar or list of medical and other appointments?	<input type="checkbox"/>	x	<input type="checkbox"/>	<input type="checkbox"/>



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Do you get financial help with school or work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	x

### Talking with Providers

Do you tell the doctor or nurse what you are feeling?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	x
Do you answer questions that are asked by the doctor, nurse or clinic staff?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	x

### Managing Daily Activities

Do you help plan or prepare meals/food?	<input type="checkbox"/>	<input type="checkbox"/>	x	<input type="checkbox"/>
Do you keep home/room clean or clean up after meals?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	x
Do you use neighborhood stores and services (eg, grocery stores and pharmacy stores)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	x

### GOALS:

1. Learn to do the Laundry
2. Learn to use a calendar to track your schedule / appointments
3. Learn to take medication independently
4. Learn to take a shower / bath by yourself

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## OPERATIONALIZE GOAL

Buy a Pill Tray

Start with learning to fill pill  
tray and take medication  
daily with supervision

Manage medication  
independently

# A Teen's Guide to Medical Transition





# How to Talk to Your Doctor

Here are the three most important things you might want to talk with your doctor about before your appointment is over. Remember, your doctor only has 5 minutes, so try to practice!

## Know your rights!

Once you turn 16 you can request for your parents to leave the room so you can talk to your doctor alone.

1. Tell your doctor if your health has changed or stayed the same since your last visit  
*For example, are you coughing more?  
Do you have a sore that has not been healing?  
Are you feeling more tired during the day?*
2. It's okay to ask questions if you don't understand something. If your doctor uses a new word you don't understand, you can ask them to explain what they mean. They are here for your care.
3. Don't be afraid to tell your doctor what is going on with your body, and be honest with them.

## Try saying...

"Since my last visit my health has been..."

"Can you explain what that word means?"

"I have a few concerns I want to ask about..."

# Prepare for an Appointment

*You can make the most of your routine appointments by preparing and gathering everything you will need the night before.*

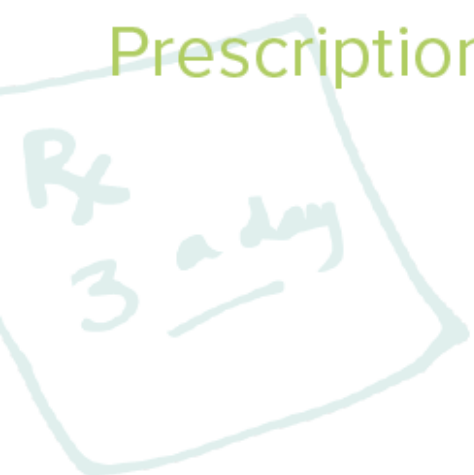
## Prepare

1. Know what you want to ask your doctor about. It helps to write a list of questions down.
2. Bring a list or the bottles of the current prescription medications you are taking.
3. Bring something that will help you relax in the waiting room, such as a book to read, a game to play, or music to listen to.

### What to Bring: Routine Appointment

- A list of health concerns and questions
- Insurance card
- A list of current medications or all your medication bottles
- Something to help you relax

# Prescriptions



Got a new prescription from your doctor, or changed the dose of the one you were taking?

Make sure you know what the medicine is before you agree to take it. Sometimes a medicine can cause problems with medicine you are already taking, or the medicine could give you side effects.

If you are concerned about a medicine's side effects, speak up and ask your doctor if there are other medication options.

Use these questions on the right to check what you know and to ask what you still need to know.

## Taking my Medicine

How and when will I know if it is working?

Do I need any accessible supports to take my medication? (Ex.: Talking prescription bottles, brailled prescriptions, medicine organizers?)

What is the name of the medication?

How many pills or how much liquid do I take?

When do I take the medicine?

When do I stop taking it?

## Side Effects of my Medicine

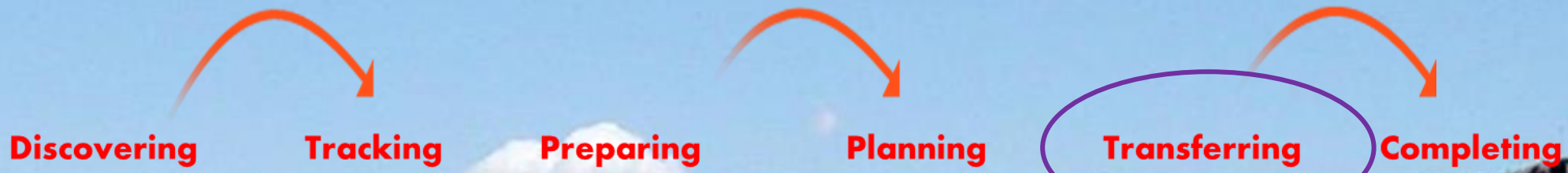
Will it be okay to take this with my current medicine?

Would smoking and drinking affect my medication?

What side effects could happen?

Do I need to store the medication in a special way?





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**LEGAL NAME**  
Address, City, State, Zip  
Phone, cell, email

<b>INSURANCE</b>	Certificate #	BC Plan / BS Plan	Rx BIN
	Group #	Phone / 800-	

<b>Legal Health POA *</b>	<b>Name</b>	<b>Relationship</b>	<b>Cell</b>	<b>Work</b>	<b>Home</b>

**DOB** \_\_\_\_\_ **HEIGHT/WEIGHT:** \_\_\_\_\_ **ADVANCE DIRECTIVES: YES\_NO** **DNR: YES NO**

**SS#** \_\_\_\_\_ **BLOOD TYPE:** \_\_\_\_\_

- Activities of Daily Living:
- Pain:
- Communication:
- Preferences:

**ALLERGY:**

System	Problem & Summary

<b>MEDICATIONS</b>		
Drug	Dose, Rout of Administration & Timing	Reason

<b>MEDICAL EQUIPMENT</b>	
Type	Name, Size & Settings

<b>IMMUNIZATIONS</b>					
Tetanus	TB	Pneumococcal vaccine	Flu		

<b>FAMILY HISTORY</b>		
Member	Age and Status	Health Problems
Father		
Mother		
Sibling		

<b>PHYSICIANS &amp; PROVIDERS</b>		
TYPE	NAME	Contact Information
PRIMARY CARE		
PHARMACY		



**LEGAL NAME**

Address, City, State, Zip  
Phone, cell, email

<b>INSURANCE</b>		Certificate #	BC Plan / BS Plan	Rx BIN
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<b>Legal Health POA *</b>	<b>Name</b>	<b>Relationship</b>	<b>Cell</b>	<b>Work</b>	<b>Home</b>

**DOB**

**HEIGHT/WEIGHT:**

**ADVANCE DIRECTIVES: YES NO**

**DNR: YES NO**

**SS#**

**BLOOD TYPE:**

- Activities of Daily Living:
- Pain:
- Communication:
- Preferences:

Activities of Daily Living: Dressing, Bathing, Toileting, Feeding and Hygiene

**LEGAL NAME**

Address, City, State, Zip  
Phone, cell, email

<b>INSURANCE</b>		Certificate #	BC Plan / BS Plan	Rx BIN
		Group #	Phone / 800-	

<b>Legal Health POA *</b>	<b>Name</b>	<b>Relationship</b>	<b>Cell</b>	<b>Work</b>	<b>Home</b>

**DOB**

**HEIGHT/WEIGHT:**

**ADVANCE DIRECTIVES: YES NO**

**DNR: YES NO**

**SS#**

**BLOOD TYPE:**

- Activities of Daily Living:
- Pain:
- Communication:
- Preferences:

Pain: how is pain expressed and managed

**LEGAL NAME**

Address, City, State, Zip  
Phone, cell, email

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<b>Legal Health POA *</b>	<b>Name</b>	<b>Relationship</b>	<b>Cell</b>	<b>Work</b>	<b>Home</b>

**DOB**

**HEIGHT/WEIGHT:**

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**SS#**

**BLOOD TYPE:**

- Activities of Daily Living:
- Pain:
- Communication:
- Preferences:

Communication: skill level and supports



**LEGAL NAME**

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**DOB**

**HEIGHT/WEIGHT:**

**ADVANCE DIRECTIVES: YES NO**

**DNR: YES NO**

**SS#**

**BLOOD TYPE:**

- Activities of Daily Living:
- Pain:
- Communication:
- Preferences:

Preferences: Conversation starters and important things to share

**ALLERGY:**

System	Problem & Summary

Endocrinology: Dx of IDDM since age 9 currently managed with Insulin (Lantus 40 units at bedtime and carb counting insulin sliding scale). Most recent Hgb A1c was 8.2 in Feb 2022. Normal thyroid studies (TSH 3.2) and negative Celiac Screen (TTG <10) in Feb 2022.

**MEDICATIONS**

Drug	Dose, Rout of Administration & Timing	Reason

**MEDICAL EQUIPMENT**

Type	Name, Size & Settings

**IMMUNIZATIONS**

Tetanus	TB	Pneumococcal vaccine	Flu		
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**FAMILY HISTORY**

Member	Age and Status	Health Problems
Father		
Mother		
Sibling		



PHYSICIANS & PROVIDERS		
TYPE	NAME	Contact Information
PRIMARY CARE		
PHARMACY		

- Should include:
1. PCP
  2. All subspecialist
  3. Pharmacy
  4. DME companies
  5. Community supports



**TRANSITION BRIDGE**

# TRANSITION TOOLBOX

Transition Policy Statement

Individual Transition Plan - REBOOT

Assess Progress / Readiness

Create Goals

Portable Medical Summary



# Down Syndrome Center of Western PA

## Transition Policy

-Practice policy on transition discussed/shared with youth and parent caregiver \_\_\_\_\_  
Date

## Transition Readiness Assessment

-Conducted transition readiness assessment \_\_\_\_\_  
Date Date Date

-Included transition goals and prioritized actions in plan of care \_\_\_\_\_  
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## Medical Summary and Emergency Plan

-Updated medical summary and emergency plan \_\_\_\_\_  
Date Date Date

## Adult Model of Care

-Decision-making changes, privacy, and consent in adult care discussed with youth and parent/caregiver (if needed, discussed plans for supported decision-making) \_\_\_\_\_  
Date

-Timing of transfer discussed with youth and parent/caregiver \_\_\_\_\_  
Date

-Selected Adult Provider

Name	ClinicPhone	Fax	First Appointment	Completed
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## Transfer of Care

- Prepared transfer package including:
- Transfer letter, including effective of date of transfer of care to adult provider
  - Final transition readiness assessment
  - Plan of care, including goals and actions
  - Updated medical summary and emergency care plan
  - Legal documents, if needed
  - Condition fact sheet, if needed
  - Additional provider records, if needed

-Sent transfer package \_\_\_\_\_  
Date

-Communicated with adult provider about transfer \_\_\_\_\_  
Date

## Transfer of Care


-Prepared transfer package including:

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LONGITUDINAL TRANSITION

# HOLISTIC TRANSITION





# QUESTIONS



Verizon 12:37 PM facebook.com

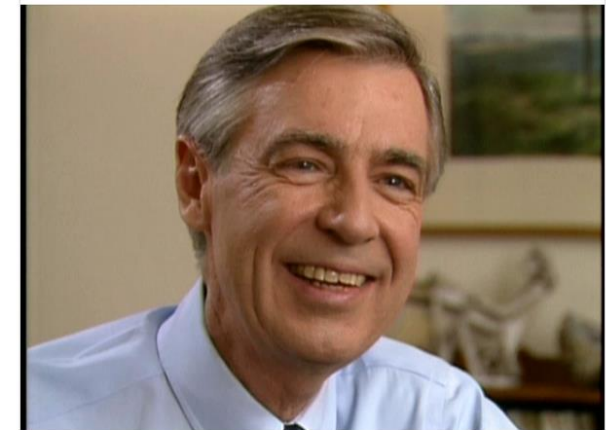
I just love Mr. Rogers.



**The Fred Rogers Company**

1 hr · 🌐

"Transitions are almost always signs of growth, but they can bring feelings of loss. To get somewhere new, we may have to leave somewhere else behind." - Fred Rogers



3 Likes

👍 Like

💬 Comment

➦ Share

# EDUCATION FOUNDATION

- Pieces of Transition Puzzle
  - **Employment**
  - Finance
  - Legal
  - Community
  - Healthcare





## EDUCATION TO EMPLOYMENT

80% children with intellectual  
disability graduate to  
unemployment





## EDUCATION TO EMPLOYMENT

- Develop a vision for future
- Build a team to support you
- Access resources
- Learn to be a self-advocate



# DEVELOP A VISION FOR YOUR FUTURE

- Volunteerism is a First Key Step
  - Try out career choices
  - Learn the soft skills of the work place
  - Build your resume



## BUILD YOUR TEAM

- Individual Education PLAN (IEP)
  - Transition Planning starts at 14 years of age
  - Designed to move a student from school to adult life: Based on the individual's needs and taking into account strengths and vision of that student
  - To include instruction in preparation for post-secondary education, employment assessment, development of employment, community experience, self-advocacy and daily living skills.



# BUILD YOUR TEAM

*Who's on the IEP Team?*

- The Student
- Parents/Guardians
- Teacher and Support Staff
  - Transition Coordinator
  - Special Education Director
  - Social Worker / Therapist
- Office of Vocational Rehabilitation Counselor / Supports Coordinator



# Planning for the Future Checklist









Use this checklist as a discussion guide in preparing for life after high school. Bring it to your meetings with your school and/or agency supporters to talk about your progress and how best to plan for your future. The checklist is meant to be individualized and not all of the items listed may pertain to you.

Name: \_\_\_\_\_

Date: \_\_\_\_\_







Every Year

1. Meet with your agency and school supporters.
2. Take time to talk about information learned from any assessments about your abilities and interests.
3. Ask about accommodations and technology you can use to meet your school, work, and other life goals.
4. Use your individualized education program (IEP) to create the right goals to help you get ready for life after high school (transition).
5. Build on what you started the year before.

	14-15 Year Olds	15-16 Year Olds
Education/Training After High School	<ul style="list-style-type: none"> <li><input type="checkbox"/> Talk with your school and/or agency supporters about your interests and what you want to study after high school.</li> <li><input type="checkbox"/> Study websites to learn about training, technical school, college programs and classes where you can explore an interest or hobby. Visit at least one of these educational programs.</li> <li><input type="checkbox"/> Meet with your school's transition coordinator to make sure you are taking the right classes for your goals.</li> <li><input type="checkbox"/> Understand your disability. Ask for your own accommodations and/or assistive technology.</li> </ul> 	<ul style="list-style-type: none"> <li><input type="checkbox"/> Learn how accommodations may be different at the educational program you've chosen for after high school, so you can start to prepare.</li> <li><input type="checkbox"/> If you've chosen college, sign-up for the PSAT test (given in fall of sophomore and junior years) and make an appointment with your guidance counselor to talk about colleges and your plan for applying.</li> <li><input type="checkbox"/> Visit technical schools or certificate programs you may be interested in.</li> </ul> 
Employment	<ul style="list-style-type: none"> <li><input type="checkbox"/> Sign up to volunteer and job shadow during school and/or summer months.</li> <li><input type="checkbox"/> Start keeping a list of the names, email addresses, and phone numbers of people who can be references for jobs.</li> <li><input type="checkbox"/> Learn about programs at your local career and technical education (CTE) centers. If you are interested, ask to visit. If you like it, learn how to apply.</li> </ul> 	<ul style="list-style-type: none"> <li><input type="checkbox"/> To get ready for a job, practice filling out job applications and answering questions an employer might ask you.</li> <li><input type="checkbox"/> Ask your school and/or agency supporters for help with on-the-job training, job exploration, and/or part-time employment in your areas of interest. Your school can help you get this experience during school and during the summer.</li> <li><input type="checkbox"/> Ask your parents/guardians to sign forms that will allow Office of Vocational Rehabilitation (OVR) and/or other adult agencies to come to your transition meetings.</li> </ul> 
Community Living	<ul style="list-style-type: none"> <li><input type="checkbox"/> Join an activity at your school, community, or place of worship.</li> <li><input type="checkbox"/> Practice asking for what you need during your IEP and other meetings.</li> <li><input type="checkbox"/> Ask about certified transportation training at your IEP meeting.</li> <li><input type="checkbox"/> Know the medications you take (names, dosage, why you're taking them). Talk with your doctor about sexuality and boundaries, and about how behaviors like smoking and drinking affect our bodies.</li> <li><input type="checkbox"/> If you have an intellectual disability and no one has contacted the County's Office of Intellectual Disabilities (OID), ask your parents/guardians to call the county to complete an intake to register for services.</li> <li><input type="checkbox"/> If needed, create an Individual Health Plan with your doctor and school nurse.</li> </ul> 	<ul style="list-style-type: none"> <li><input type="checkbox"/> Talk with your school and/or agency supporters about the possibility of funding through Medicaid Waivers.</li> <li><input type="checkbox"/> Keep a list of your medical conditions and physicians. Be able to describe your health needs.</li> <li><input type="checkbox"/> If you have questions about your emotional or mental health, talk to your parents/guardians, school or agency supporters, and your medical team. You can also call the county crisis line for help.</li> <li><input type="checkbox"/> Find out about adult agencies (like OVR) that can help you prepare for work, training, and independent living. The back of this checklist has a list of these agencies.</li> <li><input type="checkbox"/> Keep copies of your medical, education, and government papers in a file to have ready when you need them.</li> <li><input type="checkbox"/> Learn the differences between wants and needs, and the differences between earned and unearned income.</li> </ul> 





	16-17 Year Olds	18-21 Year Olds
Education/Training After High School	<ul style="list-style-type: none"> <li><input type="checkbox"/> If your goal is a trade or higher education, sign up for standardized tests in your junior year and ask for any testing accommodations you might need.</li> <li><input type="checkbox"/> Ask your counselor about financial aid to pay for tests and test-prep classes and books.</li> <li><input type="checkbox"/> Apply to these schools during the fall of your senior year. If needed, apply for financial aid during the winter.</li> </ul> 	<ul style="list-style-type: none"> <li><input type="checkbox"/> Know how to access current documentation of your disability before you leave high school.</li> <li><input type="checkbox"/> Contact the office for disability services and support at the school you'll be attending. Let them know the accommodations you need.</li> <li><input type="checkbox"/> Talk with your IEP team about how you can use your "Summary of Academic Achievement and Functional Performance" after high school.</li> <li><input type="checkbox"/> Make sure you have the assistive technology you need as you leave high school.</li> </ul> 
Employment	<ul style="list-style-type: none"> <li><input type="checkbox"/> Research 5 to 10 jobs that interest you and discuss what accommodations you may need.</li> <li><input type="checkbox"/> Apply for part time, summer, and/or weekend jobs. Ask for help finding good matches with your skills, interests, and location.</li> </ul> 	<ul style="list-style-type: none"> <li><input type="checkbox"/> Ask adult agencies to come to your IEP meetings at school to assist with job placement, training, and accommodations.</li> <li><input type="checkbox"/> Ask your school and agency supporters for help in arranging community-based, on-the-job training, and employment in your areas of interest. They can help you with this for work during school, nights and weekends, and during the summer.</li> </ul> 
Community Living	<ul style="list-style-type: none"> <li><input type="checkbox"/> Decide whether you want to live independently after graduation. Talk with your family, school and agency supporters about options for housing.</li> <li><input type="checkbox"/> Learn about community activities you can get involved in.</li> <li><input type="checkbox"/> Apply for a driver's license or state ID card.</li> <li><input type="checkbox"/> If needed, apply for Supplemental Security Income-Social Security (SSI) and Medical Assistance (health insurance). Ask for help to understand working and adult benefits.</li> <li><input type="checkbox"/> If possible, schedule and attend at least some of your medical appointments by yourself.</li> <li><input type="checkbox"/> Practice budgeting your money and develop savings goals.</li> <li><input type="checkbox"/> If you have autism, call the Bureau of Autism Services to request information about applying for their adult autism programs. A parent/guardian can also call on your behalf.</li> </ul> 	<ul style="list-style-type: none"> <li><input type="checkbox"/> If your goal is to live on your own or with a roommate, talk with your family, school and agency supporters.</li> <li><input type="checkbox"/> Contact the Special Needs Units (Medicaid plans) or Customer Service (private health plans) to choose a physician who treats adults. Ask your pediatrician to send a transfer summary of your records.</li> <li><input type="checkbox"/> Verify your healthcare insurance coverage and continuation of benefits past age 18.</li> <li><input type="checkbox"/> Apply for Personal Assistance Services, if needed.</li> <li><input type="checkbox"/> Register to vote (age 18). Young men need to register for the Selective Service after their 18th birthday.</li> <li><input type="checkbox"/> Practice getting around your community by taking public transportation or arranging medical transportation.</li> </ul> 

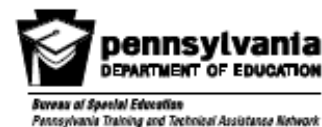
The "Planning for the Future Checklist" was developed and supported through a partnership between the United Way of Allegheny County's 21 and Able Initiative, the Pennsylvania Bureau of Special Education, and the Pennsylvania Training and Technical Assistance Network, with input from stakeholders across Pennsylvania.



### Adult Agencies

Bureau of Autism Services	866-539-7689
Bureau of Children's Behavioral Health Services	717-705-8289
CareerLink	717-787-3354
Department of Human Services	800-692-7462
Office of Developmental Programs	888-565-9435
Office of Vocational Rehabilitation	800-442-6371
Pennsylvania Statewide Independent Living Council	717-364-1732
Pennsylvania Elks Home Service Program	800-986-4550
Social Security Administration	800-772-1213
Pennsylvania Office of Long Term Living	866-286-3636

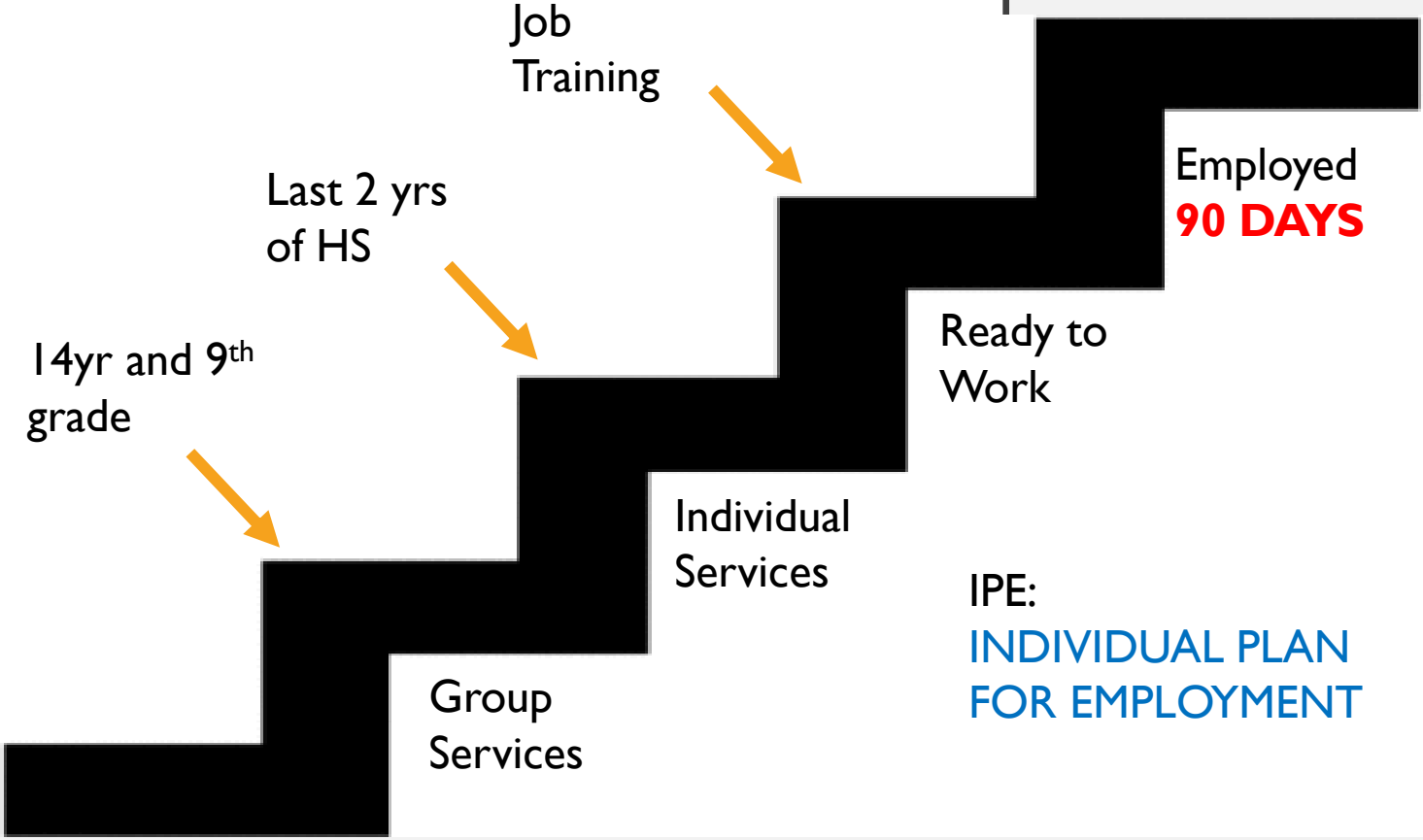
For information and resources on secondary transition in Pennsylvania, go to the Pennsylvania Secondary Transition Guide at: [www.secondarytransition.org](http://www.secondarytransition.org).



- Office of Vocational Rehabilitation
- Post-Secondary Program

# ACCESS RESOURCES

[www.thinkcollege.net](http://www.thinkcollege.net)



# SELF-ADVOCACY

- CHANGE
  - Children's Hospital's Advisory Network for Guidance and Empowerment
- PA Youth Leadership Network





# EDUCATION FOUNDATION

- Pieces of Transition Puzzle
  - Employment
  - **Finance**
  - Legal
  - Community
  - Healthcare



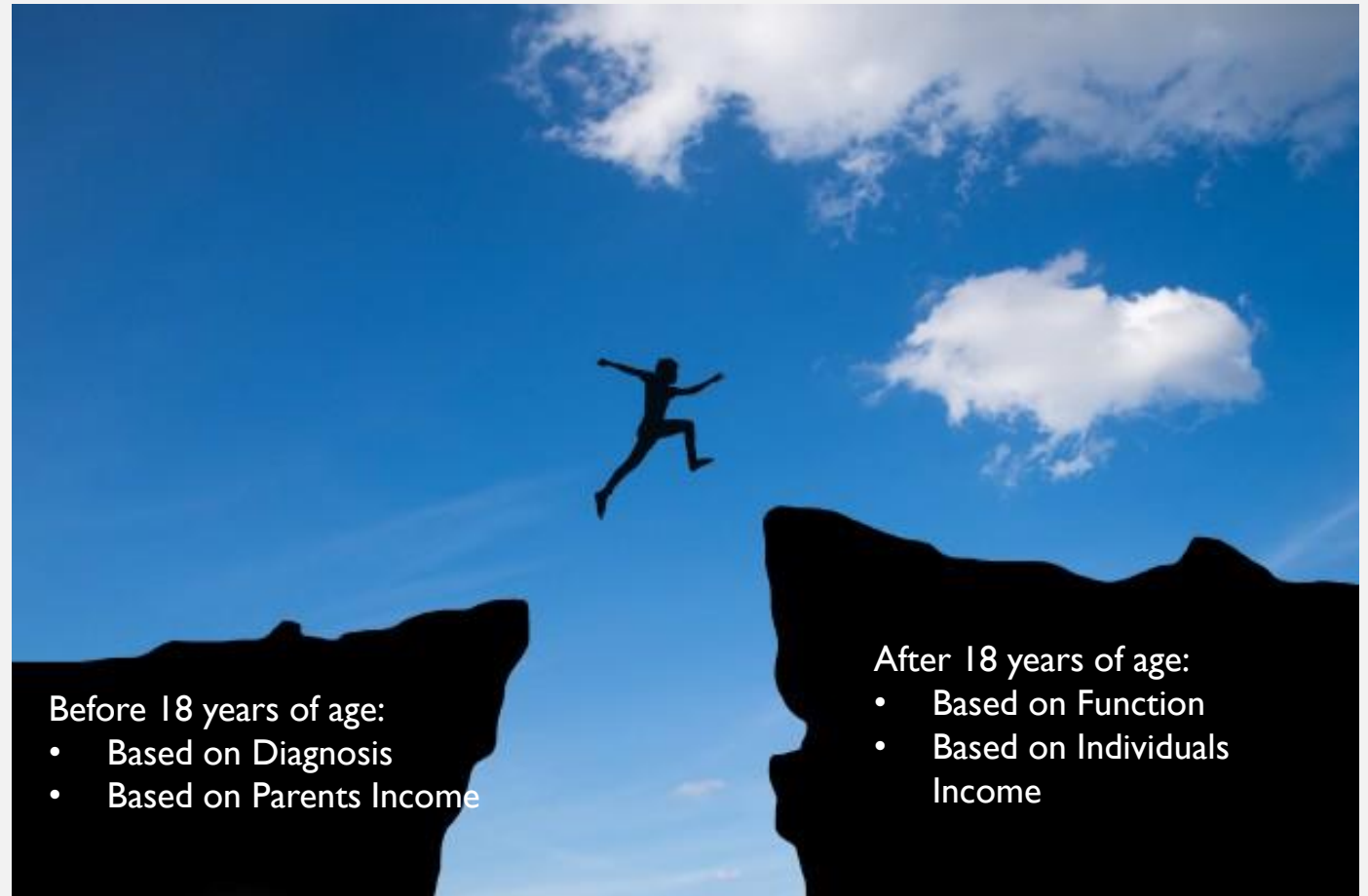


# BRIDGING THE FINANCIAL GAP

- Supplemental Security Income
- Social Security Disability Income
- Special Needs Trusts / ABLE Act
- Waivers



# SUPPLEMENTAL SECURITY INCOME



Before 18 years of age:

- Based on Diagnosis
- Based on Parents Income

After 18 years of age:

- Based on Function
- Based on Individuals Income

# SUPPLEMENTAL SECURITY INCOME

1

YOU MUST REAPPLY, DOES NOT ROLLOVER

2

Make sure you are considering **FUNCTION**

- People with intellectual disability will need IQ testing

3

Based on individual's income

- Resource Limit of \$2000
- Excluded in resource count are home, car, and trusts



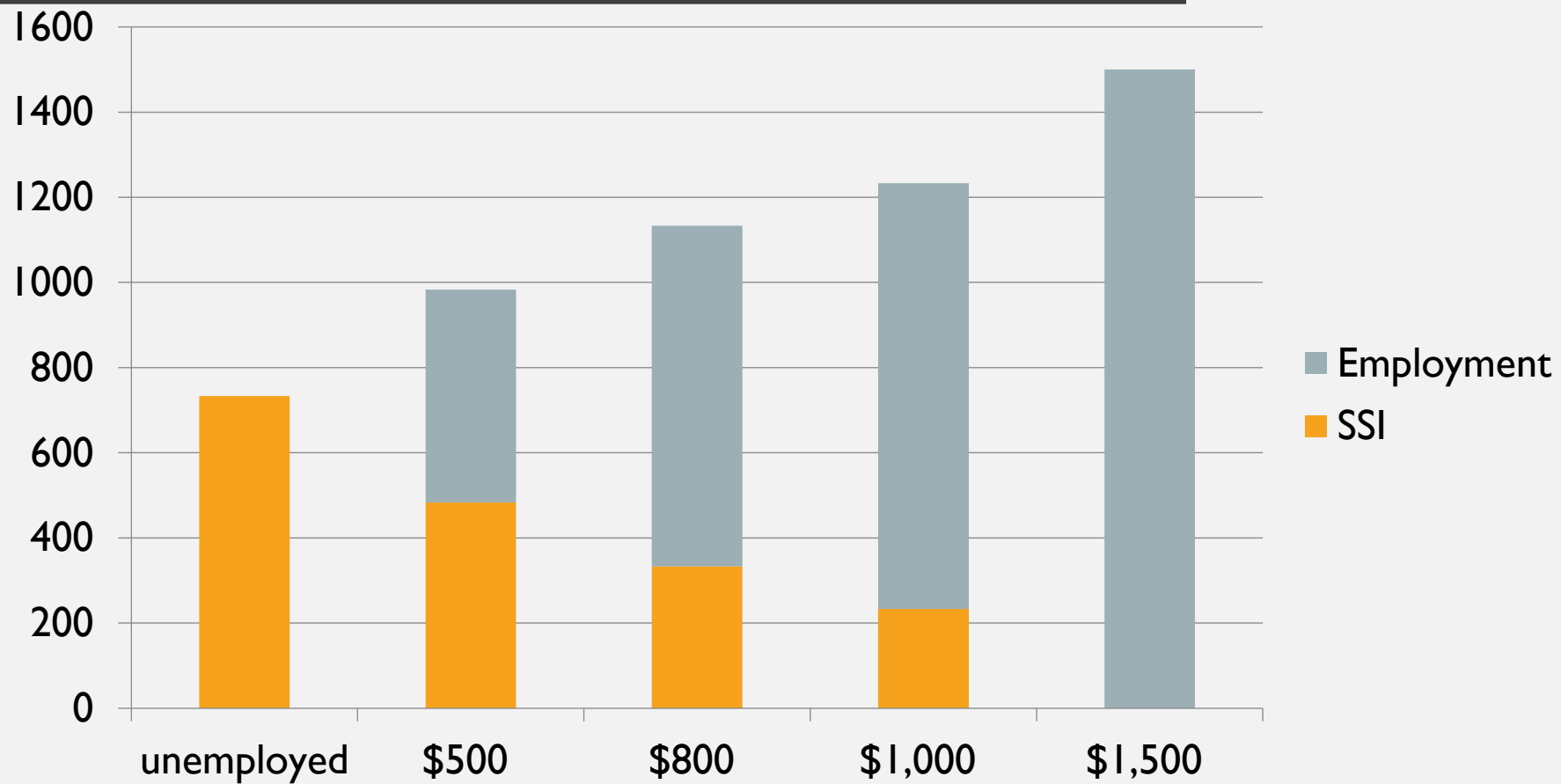
## SUPPLEMENTAL SECURITY INCOME

### BENEFITS

- Cap \$750/month benefit for individuals
- Linked to Medicaid Benefit
- Eligible for Waivers



# FINANCIAL BENEFIT OF WORKING



# SOCIAL SECURITY DISABILITY INCOME

- Eligibility:
  - Adequate work history (40 quarters) and chronic/permanent disability
  - Parent with adequate work history who
    - Becomes Disabled
    - Dies
    - Retires

# SOCIAL SECURITY DISABILITY INCOME

- Based on wage earner's contributions and number of dependents drawing from work history
- Linked to Medicare





## POOLED TRUST

- Administered by non-profit organization
- At death, money stays in trust

## PAYBACK TRUST

- Administered privately
- At death, payback Medicaid benefits but then disperse remainder to designated beneficiaries

## THIRD PARTY

- Administered by third party and not individual
- At death, distributed to family





# ABLE ACCOUNTS

*state-offered program that gives individuals with qualifying disabilities a tax-advantaged way to save or invest without impacting their government benefits*

- No initiation fee, maintenance fee \$45/yr
- Annual max contribution \$15,000.00
- Save up to \$100,000.00 before counting as a resource toward SSI benefits
- No taxation on money paid towards qualifying expenses

[PAABLE.gov](https://PAABLE.gov)



Federal government “waives” Medical Assistance/Medicaid rules for funds that pay for care services in the community that allow an individual to avoid institutionalization.

# CONSOLIDATED WAIVER

designed to help individuals with an intellectual disability, autism or developmental disability to live more independently in their homes and communities and to provide a variety of services that promote community living, including self-directed service models and traditional, agency-based service models.

# CONSOLIDATED WAIVER

- Family/Caregiver Training and Support
- Home Accessibility Adaptations
- Homemaker/Chore
- Housing Transition and Tenancy Sustaining Services
- In-Home and Community Support
- (Licensed and Unlicensed) Life Sharing
- Music, Art and Equine Assisted Therapy
- (Licensed and Unlicensed) Residential Habilitation
- Respite
- Community Participation Support
- Companion
- Consultative Nutritional Services
- Education Support
- Shift Nursing
- Small Group Employment
- Specialized Supplies
- Supported Employment
- Supported Living
- Supports Broker
- Supports Coordination
- Therapy
- Transportation
- Vehicle Accessibility Adaptations
- Advanced Supported Employment
- Assistive Technology
- Behavioral Support
- Benefits Counseling
- Communication Specialist



# EDUCATION FOUNDATION

- Pieces of Transition Puzzle
  - Employment
  - Finance
  - **Legal**
  - Community
  - Healthcare



## LEGAL TRANSITIONS

# Power of Attorney vs. Guardianship

*Decision Making Capacity*



# DECISION MAKING CAPACITY

CAPACITY:

An adult's ability to receive and evaluate information effectively and communicate decision

DEPENDENCY



INDEPENDENCE



INTERDEPENDENCE

# POWER OF ATTORNEY

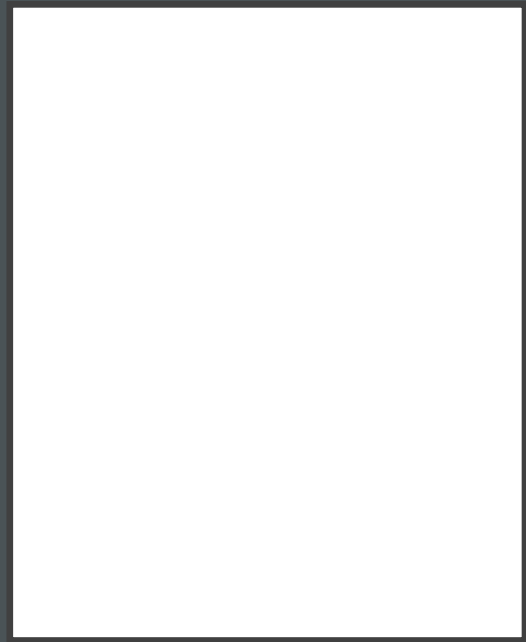
Shared Decision Making Capacity

Health Care Power of Attorney:

Allows an individual to name an agent who can act on his or her behalf to make medical decisions for the individual in the event the individual cannot.

- Authorize Treatment
- Withdrawing Treatment
- Implementing a DNR
- Hiring medical professional/Support Staff
- Admit or Discharge from the hospital
- Admit or Discharge from a nursing home
- Access to Medical Record
- Participate in Appointments





Healthcare Power of Attorney

Financial Power of Attorney

Durable Power of Attorney

# GUARDIANSHIP

- ~~An individual is determined to be incapacitated~~
  - Medical Evaluation / Court Review
- Court appoints a agent to be decision maker for the individual
  - Costly
  - Invasive
  - Time consuming

Limited vs Plenary Guardianship

# EDUCATION FOUNDATION

- Pieces of Transition Puzzle
  - Employment
  - Finance
  - Legal
  - **Community**
  - Healthcare



# COMMUNITY BUILDING

Inclusion:

Person belongs to the group and uniqueness is valued

	Valued	Devalued
Included	Inclusion	Assimilation
Excluded	Differentiation	Exclusion



# SEXUALITY AND RELATIONSHIPS

- Body Boundaries
- Privacy

