A Multi-family Group Psychoeducation Approach to Transition for Individuals on the Spectrum and their Families

Leann Smith DaWalt, PhD
Support for Families during the Transition to Adulthood

- Few supports for families during adolescence, despite it being a stressful period
- The Transitioning Together Program seeks to address this gap
- Based on results from the longitudinal research
Transitioning Together:
Program Goals

- Provide multi-family group psychoeducation for parents
- Provide therapeutic social group for adolescents to increase social interaction and prepare for adult life
- Emphasize problem-solving to decrease family stress and depression
Transitioning Together: Program Components

• 2 individual family “joining sessions”
• 8 weekly multi-family group sessions for parents
• 8 therapeutic social group sessions for teens
• Ongoing resources and referrals
Transitioning Together: Topics for Parent Sessions

- Autism in adulthood
- Transition planning
- Family topics
- Problem-solving
- Risks to adult independence
- Community involvement
- Legal issues
- Health and well-being
Transitioning Together: Topics for Teen Group Sessions

- Sharing interests
- Goal setting
- Problem-solving
- Social planning
Common Problems Parents Ask to Solve

- Perseveration
- Coping with stress
- Independent living skills
- Filling unstructured time
- Following through on tasks
- Homework
- Lying
- Social isolation
- Getting stuck on media
- Motivation
- Hygiene
- Sibling concerns
- Getting to sleep and waking up
Common Goals of Teens

- Graduate
- Better at time management
- Be more efficient
- Be more organized
- Make better choices
- Get in shape
- Have a more positive attitude
- Get good grade on test
- Meet new people
- Do something fun everyday
- Get into police academy
- Become a blackbelt
- Get a job at a pet store
- Keeping a clean locker
Program Outcomes

- 45 families of teens (aged 14-17 years; M=15.44; SD=1.03) with average/above average average IQ

- For families in the intervention group:
  - Improvements in adolescent social engagement
  - Improvements in parental attitudes about their children
  - Reductions in parental depressive symptoms

DaWalt et al., 2018, JADD
Extensions of Transitioning Together

- School-based version through the Center on Secondary Education for Students with ASD (CSESA)

- Cultural adaptation for Spanish speaking families (Kuhn et al., 2020, Family Process)

- Young adult version, *Working Together*

- Adaptations for virtual delivery
CSESA Resources: http://cresa.fpg.unc.edu/
Acknowledgements

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Center for Youth and Adults with Conditions of Childhood

“Steering Youth with Special Health Care Needs to Successful Adult Life”

Mary R Ciccarelli, MD mciccare@iu.edu
Indiana University School of Medicine
July 2021
Referral for transition support – cyacc@iu.edu
- YSHCN 11–22yo with transition needs beyond current team services
  - Clinical supports for adults w/ intellectual disabilities, older adults with possible dementia

Funding – MCH Title V, IUSM Dept of Peds, Eskenazi Health county system

Comprehensive assessment
- Review of records and current services
- Psychosocial, functional assessment
- Expanded review of systems – “Health Check”

Transdisciplinary team case conferencing – nursing, social work, medicine, family reps, etc.

Care coordination
https://www.rileychildrens.org/departments/center-for-youth-adults-with-conditions-of-childhood
Cross the bridge to your future—Focus Areas

With the help of CYACC, you will work on your future goals. Please prepare for your visit by thinking about the topics below.

We may not cover all these topics but this is a good way to think about your life as a whole.

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**Health Care Financing**
- What are your insurance options as an adult?
- Are you eligible for Medicaid Disability and Social Security?
- Would Medicaid waiver services benefit your family?

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**Community/Social Activity**
- Do you get out of the house?
- What clubs and activities do you do?
- Do your friends help you in good ways?
- Do you know how to keep yourself safe at home and in community?

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**Care Coordination Supports**
- What community resources may help you with specific personal or medical needs?
- Can you or your family navigate the health system?
- Do you get or need help coordinating care?

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**Behavior/Mental Health**
- How well do you deal with life stresses?
- How could counseling help you?

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**School & Work**
- What are your plans for your education?
- Do you have an IEP (Individual Education Plan) or 504 plan?
- What are your career interests? Do you need more training?
- How will you work and keep your benefits?

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**Family/Caregiver Support**
- What groups can provide your family or caregivers with support and advice?

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**Health Habits**
- Do you eat healthy? Are you active? Do you sleep well? Do you take care of your body?
- Do you have questions about puberty?

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**Self-Management**
- Do you manage your own health care?
- Do you understand and have skills to explain your own health needs?

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**Transportation**
- How do you get to the places you need to go?

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**Healthcare Team**
- Do you have a primary physician for your adult care?
- What types of adult specialists will you need (e.g., heart, lung, etc.)?
- When will your pediatric doctors want you to transition to adult doctors?

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**Independent Living**
- Where do you want to live in the future?
- Can you take care of your own home?
- How will you learn to be more independent and safe at home, work or school, and in the community or on social media?

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**Decision-Making/Legal**
- Are you practicing speaking for yourself?
- Who helps you decide how to handle your finances and health needs?
- Do you need information on special needs trusts, ABLE accounts, guardianship and other decision making options, or advance care plans?

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**Meet Our Team!**

Our youth and family centered team consists of doctors, nurses, social workers and support staff.

Mary Ciccarelli, MD — Medical Director & CYACC Physician
Ike Means, MD — CYACC Physician
Daniel Linesty, MD — CYACC Physician

Christina Rogers, BSW, MSW, LSW — Social Worker
Jane Taylor-Holmes, MSW, LSW — Social Worker

Jennifer Barber, RN, BSN — Nurse
Amy Logsdon, RN — Nurse
Sapreet Dhillon — Administrative Assistant
Youth with Autism -w/wo IDD

- **2019**
  - Youth w/ ASD N = 101 (~30% total CYACC#)
  - Avg 16 yo; range = 12–22

- **2018**
  - Youth w/ ASD N = 82 (~ 27% of total #)

Autism and DD Monitoring Network, 2010
- Most recent IQ as of age 8
Management of person with ASD

National Institute for Health and Care Excellence (NICE) UK

1. Access to health and social care services
2. Train health professionals in autism awareness and management.
3. Provide meaningful visual supports, adapt personal space, consider sensory sensitivities
4. Adapt processes of care
5. Assess family needs
6. Specific social–communication interventions
7. Systematic approach to challenging behavior
8. Manage co–existing mental health conditions
9. Life skills training
10. Address sleep

https://ep.bmj.com/content/edpract/100/1/20.full.pdf
Transition planning – by category 1 & 2

1– ALL YOUTH
- Sustainable health care financing
- Point of contact for primary care rather than utilization of urgent care
- Basic info re: health needs and history

2– WITH CHRONIC CONDITION
- Self-management of steady state, flare and emergencies
- Anticipation of adult care team and services in adult model and scope of care
By category 3 & 4

3 - PHYSICAL DISABILITIES
- Needs of equipment, environment and caregivers for independence
- Engaging services – paratransit/ adapted mobility issues, community supports for physical disability

4 - INTELLECTUAL DISABILITIES
- Adapted health habits, including sexual health
- Caregiver support adjusted to individual’s ability
- Decision making supports
- Community supports for active life and community participation
5– SERIOUS MENTAL ILLNESS

- Disease acceptance and de-stigmatization, diagnosis clarity
- Self-management within a support system with springing decision making supports and safety plan
- Service eligibility, care transfers and continuation – prescriber, counseling
Got Transitions

6 core elements of transition

1. Transition policy – consult, family & team support
2. Tracking and monitoring – social complexity scoring, hotspots
3. Readiness assessment – TRAQ
4. Planning – transition plan
5. Transfers of care – portable medical summary
6. Integration and completion of transfers
   ◦ www.gottransition.org
<table>
<thead>
<tr>
<th>Transition Readiness Assessment Questionnaire</th>
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</thead>
<tbody>
<tr>
<td>Wood, Sawicki, Reiss, Livingood &amp; Kraemer, 2014</td>
</tr>
<tr>
<td><a href="http://hscj.ufl.edu/jaxhats/traq/">http://hscj.ufl.edu/jaxhats/traq/</a></td>
</tr>
</tbody>
</table>
When do I need support?
When can I do it myself?

www.lifecoursetools.com
### Exploring needs for decision making supports

#### SOCIAL & SPIRITUALITY
- Do I choose where and when (and if) I want to practice my faith?
- Do I make choices about what to do and who to spend time with?
- Do I decide if I want to date, and choose who I want to date?
- Can I make decisions about marriage (if I want to marry, and who?)
- Can I make choices about sex, and do I understand consent and permission in regard to sexual relationships?

#### SAFETY & SECURITY
- Do I make choices that help me avoid common environmental dangers (traffic, sharp objects, hot stove, poisonous products, etc.)?
- Do I make plans in case of emergencies?
- Do I know and understand my rights?
- Do I recognize and get help if I am being treated badly (physically, emotionally or sexually abused, or neglected)
- Do I know who to contact if I feel like I’m in danger, being exploited, or being treated unfairly (police, attorney, trusted friend)?

#### COMMUNITY LIVING
- Do I decide where I live and who I live with?
- Do I make safe choices around my home (turning off stove, having fire alarms, locking doors)?
- Do I decide about how I keep my home or room clean and livable?
- Do I make choices about going places I travel to often (work, bank, stores, church, friends’ home)?
- Do I make choices about going places I don’t travel to often (doctor appointments, special events)?
- Do I decide how to get to the places I want or need to go? (walk, ask a friend for a ride, bus, cab, car service)
- Do I decide and direct what kinds of support I need or want and choose who provides those supports?

#### CITIZENSHIP & ADVOCACY
- Do I decide who I want to represent my interests and support me?
- Do I choose whether to vote and who I vote for?
- Do I understand consequences of making decisions that will result in me committing a crime?
- Do I tell people what I want and don’t want (verbally, by sign, device), and tell people how I make choices?
- Do I agree to and sign contracts and other formal agreements, such as powers of attorney?
- Do I decide who I want information shared with (family, friends etc.)?
Setting the Goal

**THINK**

Why do I want to make my own decisions?

Why does thinking first, before taking action help me?

A decision I want to make:

Is it good for my future? Why?

Taking the Next Steps

**PLAN**

Think – A decision I want to make:
1. 
2. 
3. 

Plan – Steps I will take:
1. 
2. 
3. 

Do – What I need to do to make it happen:
1. 
2. 
3.

Making It Happen

I will start my plan:

Date

Action steps:
1. 
2. 
3. 
4. 
5. 

I will get support from:

- [ ] Friend
- [ ] Family
- [ ] Support Person

Name: 

Opportunities for Decision Making Supports

- Advocate
- Power of Attorney
- Representative payee
- Limited vs. Full Guardianship

Florida Developmental Disabilities Council
Health & Communication

- How does the patient communicate?
  - Do receptive and expressive language skills differ?
- How does the patient manifest pain or illness?
- Does the patient manage own body cues?
  - Toileting, swallowing, thirst, sleepiness, hunger, etc.
- Does a support person support or observe activities of daily living and unusual days?
Daily Rules for Staying Healthy

Use daily rules to help you stay healthy, especially if you are not good at feeling or using your own body messages.

Physical activity

I do this exercise: __________ times a week.

for: __________ minutes __________

Food & Drink

I eat _____ servings of fruit every day.

I eat _____servings of vegetables.

I eat _____ servings of calcium foods.

I eat _____ servings of protein.

I fill my plate once a meal.

I pick one day a week (__________) for a treat.

I drink _____ glasses of water.

I drink _____ glasses of other drinks too.

My total number of glasses per day is

Times to Eat

My breakfast time: __________

My lunch time: __________

My snack time: __________

My dinner time: __________

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Sleep

My bedtime is:

My wake up time is:

Clean your body

I wash my hands before I eat, and after the bathroom.

I brush my teeth 2x, mornings and evenings.

I shower every _____ day(s).

I wash my hair every _____ day(s)

I put on clean clothes every day.

I cut my finger & toe nails every _____ week(s).

Bathroom — I go

when I get up __________

after breakfast __________

after lunch __________

after work/school __________

after dinner __________

before bedtime __________
Hygiene – phone apps, reminders

**Brushing Teeth**

1. Wet toothbrush
2. Place toothpaste on brush
3. Brush teeth
4. Spit in sink
5. Rinse toothbrush

**Washing your body in the shower**

- Turn on taps
- Adjust temperature
- Wet body
- 3cm square of soap
- Wash chest
- Wash arms
- Wash stomach
- Wash legs
- Wash hair
- Wash face
- Wash ears
- Wash neck
- Wash genital area and bottom
- Wash feet
- Wash groins
- Rinse soap off body
- 3cm square of shampoo or conditioner
- Wash hair
- Rinse hair
- Finished
- Turn off taps

**Personal Hygiene**

- **Step 1:** Get wet
- **Step 2:** Soap and Shampoo
- **Step 3:** Drying
- **Step 4:** Hair
- **Step 5:** Deodorant
- **Step 6:** Teeth

- Keeping your body clean is very important to keeping you healthy and helping you feel good about yourself.

- When you shower or bathe, you need to use soap when you are showering. Your skin won’t get clean.
- You need to take extra time to wash certain parts of your body, like your feet, private area, and underarms.
- Make sure your hair is wet and you need to use shampoo to wash your hair.
- If you do not wash your hair, it will get greasy and smell bad.
- When you shower or bathe, you need to brush or comb your hair. If you do not brush it every day, you will get tangles in your hair that will be very hard to remove.
- Boys who have longer hair should wash their hair every day.
- You should apply deodorant to your underarms.
- Keep your teeth clean by brushing your teeth at least twice a day to keep them clean. You also need to floss daily. When we eat, food can get stuck in between our teeth. Floss will help remove it. You also need to see your dentist twice a year for good dental health.
Vanderbilt Kennedy Center toolkits

https://vkc.vumc.org/healthybodies/
Health care accommodations

- Adapted interactions
  - Slow down, easy things first
  - Do prep work – i.e. blood draws
  - Limit restraints – premedication, conscious sedation
  - Clinical supports – adapt the environment
### Hands In Autism

[https://handsinautism.iupui.edu/](https://handsinautism.iupui.edu/)

#### Going to Visit the Doctor

- **Sometimes when I am sick, I need to see a doctor.**

- **I will wait in the waiting room until my name is called.**

- **When my name is called, I will follow the nurse to a new room.**

- **She will check how tall I am and how much I weigh.**

- **The nurse may put something around my arm to check my blood pressure. This might feel tight, but it lasts just for a short time.**

- **The nurse might take my temperature with a thermometer. This is OK, it does not hurt!**

- **The doctor might ask me to sit on the table or on the chair.**

- **The doctor may check lots of places on my body. This is OK!**

- **When the doctor is all done checking me and talking to _____, I can get dressed.**

- **We may have to check out and pay before we leave. Then I am finished!**
Medical Procedures

Think outside the box!

- Communication
- Blood pressure
  - https://www.youtube.com/watch?v=nbkHH1fOf58
- Exam modifications
- Medication administration
  - https://www.youtube.com/watch?v=pNDqeoE15-0
- Blood draws, etc.
  - https://www.youtube.com/watch?v=fnvC2bHM4To
# Augmentative Communication

## Table 2
Examples of alternative and augmentative communication (AAC) assistive technology

<table>
<thead>
<tr>
<th>Text</th>
<th>Image</th>
<th>Symbols</th>
<th>Gesture</th>
</tr>
</thead>
</table>
| **Unaided (no device)** | | | • American Sign Language  
| | | | • Body language |
| **Low-tech** | • Writing with pencil/paper  
| | • Letter board | • Drawing with pencil/paper  
| | | • Picture board  
| | | • Photographs  
| | | • Manipulation of physical objects/models | • Braille  
| | | | • Symbolic language like Bliss  
| | | | • Symbolics or MinSpeak on a board |
| **High-tech** | • Text-to-speech device (example: DynaVox, DynaWrite)  
| | • Text-to-speech software (example: Proloquo2Go for iPhone) | • Picture-based device (example: DynaVox Maestro)  
| | | • Picture-based software (example: AssistiveWare’s LayoutKitchen) | • Symbolic device (example: DynaVox with Bliss Symbolics package)  
| | | | • Symbolic software (example: WinBliss software) |
Disability Distress Assessment Tool – DisDAT

Instrument to compare content vs. stressed appearance and behaviors for individuals with severely limited communication

- Communication level
- Appearance – face, jaws, eyes, skin
- Vocal sounds, speech
- Habits/mannerisms
- Posture
- Body observations
  - St. Oswold's Hospice, 2008
  - [https://prc.coh.org/PainNOA/Dis%20DAT_Tool.pdf](https://prc.coh.org/PainNOA/Dis%20DAT_Tool.pdf)
Medication self-management smartphone apps
Health habit smartphone apps

Habitica, Stride, Streaks, Way of life
Others – Fabulous: Self Care, Habit Hub, Habitify, Headspace, My Fitness Pal
Patient Education

ACTION PLAN

Name: ____________________________ Date: ____________________________

**Doing Well:**
Here are the ways you can tell you are doing well:

1. ____________________________
2. ____________________________

These are things you need to do every day to stay well.
Follow this plan every day:

1. ____________________________
2. ____________________________
3. ____________________________

**Getting Worse:**
These are signs of new problems:

1. ____________________________
2. ____________________________
3. ____________________________

You need to notice when your health is getting worse with the usual plan.
Add these to your daily routine:

1. ____________________________
2. ____________________________
3. ____________________________

**Medical Alert!**
These are urgent problems to solve right now:

1. ____________________________
2. ____________________________

If your attempts to help the problem don’t work, you need to act now and get help.
Do this immediately:

1. ____________________________
2. ____________________________
3. ____________________________

Call the Doctor’s office NOW. Tell them you have and urgent problem and you need help today!
Doctor: ____________________________
Phone: ____________________________

Reasons to get emergency medical help:

1. ____________________________
2. ____________________________

Go to the hospital or call an ambulance (Call 911):

Who else do you need to tell? ____________________________
Supportive Services for Transition to Adult Care

Chris Booth, LMSW
Lead Care Coordinator
The Marcus Autism Center
Programs at Marcus that serve young adults

Clinics within our center that serve patients ages 15 – 21

• Severe Behavior Program
• Medical Program
  – Psychiatry
  – Pediatric Nurse Practitioners
• Research Programs and Studies
• Diagnostic and Evaluation Program
What is care coordination at Marcus?

“Our care coordination team offers individual and group services to help you navigate the healthcare system, connect with others, find additional services and advocate for your child.”
Timeline of Supports

• 2014-2019
  – Team members responded individually to clinicians (psychiatrists, psychologists, etc.) referring families to care coordination that needed help navigating the steps from pediatric care to adult care

• 2019
  – Care coordination team met with Marcus clinicians to identify and plan a more proactive approach to this transitional planning
Timeline of Supports

• January – February 2020
  – Goals:
    • Launch an in person workshop that reviewed core concepts such as:
      – Finding autism services such as psychiatry, PCP, psychology, etc. that serve adults with ASD
      – Planning for post secondary or adult education opportunities
      – Planning for vocational training
      – Adult Medicaid and waiver services
      – Planning for legal needs (wills, special needs trusts, conservatorships, etc.)

• March 2020
  – Mailing Project from home
  – Goal: mail all patient families (ages 18 – 21) a packet of resources listed above along with contact information from our team
Timeline of Supports

• April and May 2020:
  – Care coordination team conducting follow-up calls with each family from the mailing

• 2020 and 2021:
  – Partnering with Emory Medical Students
  – Focus Group
    • Community Partners
    • Marcus Parents

• 2021 and 2022:
  – Data from focus group
  – Embedding a care coordinator into each program
Future Plans

• Workshops to resume
• Parent events
• Partnerships to make adult referrals a more seamless process
• Learn from other centers
Networking

• My contact information:
  – [Chris.booth@choa.org](mailto:Chris.booth@choa.org)
  – 404-785-8227