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

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waisman center, university of wisconsin - madison

Support for Families during the Transition to Adulthood

- Few supports for families during adolescence, despite it being a stressful period
- The Transitioning Together Program for adolescents seeks to address this gap

 Based on results from the longitudinal research



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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

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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

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Transitioning Together: Topics for Parent Sessions

- Autism in
 Comadulthood
 invol
- Transition planning
- Family topics
- Problem-solving
- Risks to adult independence

- Community involvement
- Legal issues
- Health and wellbeing



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Transitioning Together: Topics for Teen Group Sessions

Sharing interests

- Goal setting
- Problem-solving

Social planning









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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

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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

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Program Outcomes

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

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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

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CSESA Resources: http://csesa.fpg.unc.edu/

autism at-a-glance

Feb 2014

Autism at-a-Glance is a publication of the Center on Secondary Education for Students with ASD (CSESA)



Supporting Communication in High School

This issue of Autism This issue of Autism at-a-Glance focuses on understanding and improvir the communication skills of adolescents on the autism epectrum. The content specifically targets the needs of students who are able to communicate conversationally. Examples are provided in the context of academic courses and teacher and pee relationships.

If you serve students with more significant on needs pleas see our Autism at-a-Glance titled Supporting Functio Communication in High School

Aution at-a-Alanca is designed for high school staff members supporting students on the autism spectrum, as well as family members of adolescents Autism at-a-Glance provider a current summary of topics relevant to high school students on the autism spectrum as well as practical ips and resources for schoo and community personnel and family membera.



Potential Areas of Difficulty Related to Comprehension

- Speed of processing language. Students may process comments, questions, and directions more slowly than would be expected for their academic or cognitive abilities or age.
- Non-literal language. Students may struggle to understand sarcasm, hyperbole, figures of speech, or other forms of non-literal language
- Inferences. Students may have difficulty reading between the lines or making assumptions about information that is not directly presented. Vocabulary. Students may have difficulty generalizing vocabulary words outside of
- the st Point own. What Thi Mr. Va forwa paper A pee respo The s birthd

waism

chara



Emotions and Mood Increased moodiness which may include increased;

anger, irritability, sadness, tearfulness In the past two weeks Terri has been crving for her m and dad to come pick her up from school every day after kinch

- Feelings of worthlessness or fixation on mistakes Alex is noticing that he is different from his peers and this awareness is causing great concern. He offe makes comments that he is "not normal" and "will never be normal."
- · Need for excessive reassurance Joel is increasingly fearful of black holes and requires nce that he will not disappe
- · Loss of interest or pleasure in previously favorite

Rolando always enloyed swimming at the YMCA but ontly is resisting the pool and out his swimsuit on.

Behaviors and Skills · Accression

- Caleb is not typic cally aggressive but in the past m has hit his younger sister several times and pushed his mom when he became frustrated.
- Indecisiveness The choices in the c steria suddenly seen overwhelming for Taneisha and she has been getting uck* in line.
- Noticeable decrease in self-care Adam has started to move very slowly during his morning routine and is often leaving for school without brushing his teeth, washing his face, or combing his hair. Regression of previously learned skill
 - Charity, who usually navigates to the cafeteria and back without assistance, lately is found wandering the halls telling everyone she is lost Changes in autistic symptoms which may include
 - increased stereotypic behavior or decreased interest in restricted interests
 - Kevin used to flap his hands and rock on the floor when he was young. Since he started high school, he
- is rocking again every day after school. Thoughts or expressions of suicide or self-destructive
 - behavior

Promoting Social Competence and Peer Relationships for Adolescents with FPG Snapshot **Autism Spectrum Disorders**

#75

March 2014 The interactions and relationships students experience with their peers during secondary school can contribute to successes both during and after high school, influencing academic, vocational, and self-determination skills, as well as personal well-being. The social world during adolescence is multi-faceted. Peer relationships grow in importance and

complexity as adult support and presence fades. In addition, students encounter more peers and teachers throughout the day in secondary schools, and the expectations for social interactions are often nuanced across different environments.

While much attention has focused on addressing social competence of young children on the autism spectrum, less is known about promoting the social competence of adolescents with autism. Yet, the social-related challenges associated with autism spectrum disorder (ASD) become even more pronounced as the gap between

existing social skills and social Numerous avenues espectations widens. offer promise for strengthening Adolescents the social on the Autism competence and

Spectrum peer relationships Adolescents with ASD can face of students on the social competence and peer



Health and Wellness

Hyperactivity
 Abe usually enjoys reviewing meteorology reports

- in detail each evening. Lately, however, he has not en able to settle and concentrate in the evenings and has given up this favorite activity all together Agitation or restlessness (e.g., handwringing, pacing, inability to sit still
- vous during class periods, and has been tapping her feet continually and getting up to walk around during class time.
- · Fatigue or loss of energy Xavier keeps failing asleep in class, even when the class is watching You Tube videos about space, his favorite topic in science.
- Sleeping too much or too little Ell, who is usually the first one up in the morning is having great difficulty getting out of bed in th
- · Changes in appetite leading to weight loss or gain lackson has stopped eating some of his faw foods and is coming home with the food in his lunchbox half eaten Complaints of unexplained body aches and head
- aches, increased visits to the school nurse Sophie has asked more than once this week to go to the school nurse saying that her arm hurts but the nurse keeps sending her back saving there is nothing wrong with her

Challenges for



Look for changes in behavior. Since individuals with ASD often have characteristics that can mimic or mask depression, it is important to look for changes in behavior. For parents, it might mean paying attention to eating and sleep habits, and looking for changes in mood and behavior around the home and community. For teachers, it might be looking for changes in mood or behaviors d ass, or paying particular attention during other times such as transitions, lunch, or clubs.

3 Con licate regularly with team members Given that behaviors changes may be subtle or may manifest differently across environments, it is important that families and school staff are staying in touch with each other. Parents and school staff should be in regular communication about any changes in behavior in home, school, and nmunity environments

Seek out professional help. If you are concerned about possible depression in a teen with ASD, talk to a professional. Parents can talk to a healt care professional (who should be knowledgeable of ASD), and then determine if a referral to a mental health professional is needed. For school staff, schools or school districts typically have counselors and psychologists who are train in recognizing depression, and may be able to support the student.

If you will be meeting with a health professional, make a

- Any major stresses or recent life changes Anything different observed lately, even if it does not seem related to depression
- Information from discussions with other people in the teen's life such as school personne
- dison





particular challenges developing Suppositions for School Staff and Parents Check in with the teen with ASD. Although

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Bridging to Adult Life

Center for Youth & Adults with Conditions of Childhood

Telephone : 317-948-0061

Center for Youth and Adults with Conditions of Childhood

"Steering Youth with Special Health Care Needs to Successful Adult Life"

Mary R Ciccarelli, MD <u>mciccare@iu.edu</u> Indiana University School of Medicine July 2021

CYACC – since 2006

- Referral for transition support <u>cyacc@iu.edu</u>
 - 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-youthadults-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.

Health Care Financing

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

Community/Social Activity

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

Care Coordination Supports

- ٠ What community resources may help you with specific personal or medical needs?
- Can you or your family navigate the health ٠ system?
- . Do you get or need help coordinating care?

Behavior/Mental Health

- How well do you deal with life stresses? .
- How could counseling help you?

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?

Family/Caregiver Support

What groups can provide your family or caregivers with support and advice?

Health Habits

- Do you eat healthy? Are you active? Do you sleep well? Do you take care of your body?
- Do you have guestions about puberty?

Self-Management

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

Transportation

How do you get to the places you need to ao?

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 transfer to adult doctors?

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?

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?



Meet Our Team!

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

Mary Ciccarelli, MD -- Medical Director & CYACC Physician

ke Means, MD --- CYACC Physician Daniel Linfesty, 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

Satpreet Dhaliwal-Administrative Assistant





Youth with Autism -w/wo IDD

2019

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

<u>2018</u>

• Youth w/ ASD N = 82 (~ 27% of total #)



Abbreviations: ASD = autism spectrum disorder; F = female; IQ = intelligence quotient; M = male. * includes sites that had intellectual ability data available for >70% of children who met the ASD case definition.

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

Crowe BH, Salt AT. Autism: the management and support of children and young people on the autism spectrum (NICE Clinical Guideline 170). Arch Dis Child Educ Pract Edit 2014.

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 ca
- •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

By category 5

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
 - <u>www.gottransition.org</u>

	No, I do not know how	No, but I want to learn	Yes, I have started doing this	Yes, I always do this when I need to	
Managing Medications					
1. Do you fill a prescription if you need to?					
Do you know what to do if you are having a bad reaction to your medications?					
Do you take medications correctly and on your own?					
4. Do you reorder medications before they run out?					
Appointment Keeping					•
5. Do you call the doctor's office to make an appointment?					
Do you follow-up on any referred for tests, check-ups or labs?					
7. Do you arrange for your ride to medical appointments?					
 Do you call the doctor about unusual changes in your health (For example: Allergic reactions)? 					
Do you apply for health insurance if you lose your current coverage?					
10. Do you know what your health insurance covers?					
11. Do you manage your money & budget household expenses (For example: use checking/debit card)?					
Tracking Health Issues					
12. Do you fill out the medical history form, including a list of your allergies?					
13. Do you keep a calendar or list of medical and other appointments?					
14. Do you make a list of guestions before the doctor's visit?					•
15. Do you get financial help with school or work?					
Talking with Providers					
16. Do you tell the doctor or nurse what you are feeling?					
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?					
Managing Daily Activities					
18. Do you help plan or prepare meals/food?					
19. Do you keep home/room clean or clean-up after meals?					
20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?					

 Transition Readiness Assessment Questionnaire

> Wood, Sawicki, Reiss, Livingood & Kraemer, 2014 <u>http://hscj.ufl.edu/jaxhats/</u> traq/

For each question below, mark the level of support you need when making and communicating decisions and choices in the Charting the LifeCourse life domains.





no extra support

I need support with my decision I need someone to decide for me

DAILY LIFE & EMPLOYMENT

	Can I decide if or where I want to work?					
	Can I look for and find a job (read ads, apply, use personal contacts)?					
	Do I plan what my day will look like?					
	Do I decide if I want to learn something new and how to best go about that?					
	Can I make big decisions about money? (open bank account, make big purchases)					
	Do I make everyday purchases? (food, personal items, recreation)					
	Do I pay my bills on time (rent, cell, electric, internet)					
	Do I keep a budget so I know how much money I have to spend?					
ľ	Am I able to manage the eligibility benefits I receive?					
	Do I make sure no one is taking my money or using it for themselves?					
	HEALTHY LIVING					
	Do I choose when to go to the doctor or dentist?					
	Do I decide/direct what doctors, medical/health clinics, hospitals, specialists or other health care providers I use?					
	Can I make health/medical choices for my day-to-day well-being? (check-ups, routine screening, working out, vitamins)					
	Can I make medical choices in serious situations? (surgery, big injury)					
	Can I make medical choices in an emergency?					
	Can I take medications as directed or follow a prescribed diet?					
	Do I know the reasons why I take my medication?					
com	Do I understand the consequences if I refuse medical treatment?					
	Can I alert others and seek medical help for serious health problems?					
	Do I make choices about birth control or pregnancy?					
	Do I make choices about drugs or alcohol?					
	Do I understand health consequences associated with choosing high					
	risk behaviors (substance abuse, overeating, high-risk sexual activities, etc.)?					
	Do I decide where, when, and what to eat?					
	Do I understand the need for personal hygiene and dental care?					

When do I need support?

When can I do it myself?

www.lifecoursetools.com

Exploring needs for decision making supports

	COMMUNITY LIVING
<pre>60 SOCIAL & SPIRITUALITY</pre>	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 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 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 decide if I want to date, and choose who I want to date? Can I make decisions about marriage (<i>If I want to marry, and who</i>)? Can I make choices about sex, and do I understand consent and	Do I make choices about going places I don't travel to often (<i>doctor</i> <i>appointments, special events</i>)? Do I decide how to get to the places I want or need to go? (<i>walk, ask</i>
permission in regard to sexual relationships? SAFETY & SECURITY	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?
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 (<i>physically</i> ,	 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?
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)?	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





Why do I want to make my own decisions?



Why does thinking first, before taking action help me?







Is it good for my future? Why?



3. _____ Plan – Steps I will take:

Taking the Next Steps

2.



Think – A decision I want to make:

1.

Do – What I need to do to make it



 1.______

 2.______

 3.______



I will get support from:



Making It Happen

I will start my plan:

Date Date

Action steps:



1.	
2.	
4.	
5.	



https://www.dds.ca.gov/consumers/resources/consumer-friendly-publications/

Opportunities for Decision Making Supports

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



Florida Developmental Disabilities Council

nttps://www.fddc.org/sites/default/files/LTW_FamilyManual2017%20-%201.pdf

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?





Hygiene – phone apps, reminders

Wash chest

Wash feet

Rinse sodp off

body

Turn off taps



Vanderbilt Kennedy Center toolkits

VANDERBILT KENNEDY CENTER

https://vkc.vumc.org/healthybodies/



Puberty, Sex, and Sexuality





A Parent's Guide on Puberty for Boys with Disabilities

Healthy Bodies



An Introduction for Autistic Teens and Adults

A Parent's Guide on Puberty for Girls with Disabilities

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/



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
 - <u>https://www.youtube.com/watch?v=nbkHH1f</u>
 <u>Of58</u>
- Exam modifications

Medication administration

- <u>https://www.youtube.com/watch?v=pNDqeoE</u>
 <u>15-0</u>
- Blood draws, etc.
 - <u>https://www.youtube.com/watch?v=fnvC2</u>
 <u>bHM4To</u>

A Parent's Guide 'to Blood Draws for Children with Autom

Taking the Work Out of Blood Work: Helping Your Child With ASD



A Parent's Guide



Augmentative Communication

Table 2

Examples of alternative and augmentative communication (AAC) assistive technology

	Text	lmage	Symbols	Gesture
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: Prolo- quo2Go for iPhone) 	 Picture-based device (example: DynaVox Maestro) Picture-based software (example: Assis- tiveWare's LayoutKitchen) 	 Symbolic device (example: Dyna- Vox with Bliss Symbolics package) Symbolic soft- ware (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
 - <u>https://prc.coh.org/PainNOA/Dis%20DAT_Tool.pdf</u>
Medication self-management smartphone apps



& Medicatio...



& Med...





Pill Reminder & Medicatio... CareClinic:

Pills Time Tracker.... Medication...

Pill Logger -

MedList Pro Meds Tracker (Medication..







Reminder

Complete -

Medication..

Medisafe Medications can't help you, if you don't take them. MyTherapy OD Free download! t's time to take your meds! ≡ 👩 Jane 6 load MyTherapy for 8:00 AM id or iPhone Today Jane Medication 1 1 Pill, 07:00 Loratadine ur medications and 100mg (Take 1) e your reminders Medication 2 Plavix 1 PH. 5-00 75mg (Take 1) progress reports for Blood pressure A manure, 09:00 thcare providers Snooze Tako All . 0 Walking 😗 MyTherapy Afternoon Reminders for your medications Æ + www.wop.com | +44 (0)203 6066023 upport feam www.mytherapyapp.com

Medication...

Health habit smartphone apps



Habitica, Stride, Streaks, Way of life



Others - Fabulous: Self Care, Habit Hub, Habitify, Headspace, My Fitness Pal



Patient Education

	ACT	ON PLAN	
Name		Da	ate:
GREEN LIGHT	Doing Well: Here are the ways you can tell you are doing well:	These are things you need to do every day to stay Follow this plan every day:	v well.
YELLOW LIGHT	Getting Worse: These are signs of new problems:	You need to notice when your health is getting wo Add these to your daily routine:	orse with the usual plan.
RED LIGHT	Medical Alert! These are urgent problems to solve right now:	If your attempts to help the problem don't work, y Do this immediately:	rou need to act now and get help. Call the Doctor's office NOW. Tell them you have and urgent problem and you need help today! Doctor: Phone:

Who else do you need to tell?



NIH Autism Center of Excellence

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



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