

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

Leann Smith DaWalt, PhD



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



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 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





adison

Acknowledgements

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THANK YOU!!

Deep thanks to the many families who have partnered with us in this work. We have learned so much from your willingness to share your lives with us!





Center for Youth and Adults with Conditions of Childhood

**Bridging to
Adult Life**

Center for Youth & Adults with
Conditions of Childhood

Telephone : 317-948-0061

“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

CYACC – since 2006

- ▶ 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.

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?

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?

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?

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 questions 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 go?

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

Mary Ciccarelli, MD — Medical Director & CYACC Physician

Ike 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 Dhalliwal — Administrative Assistant



Youth with Autism –w/wo IDD

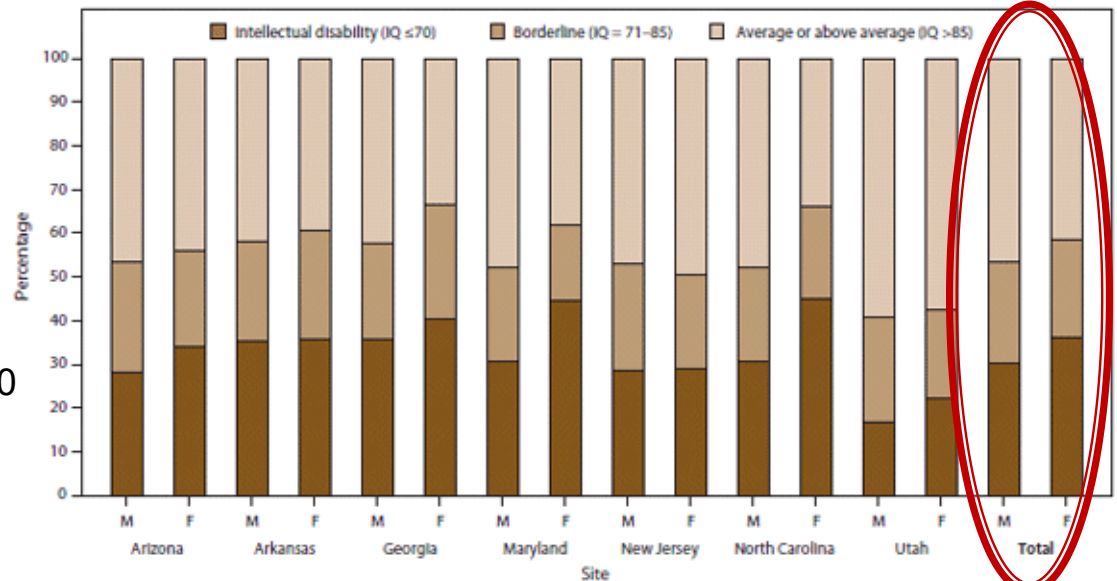
▶ 2019

- 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



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.
<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

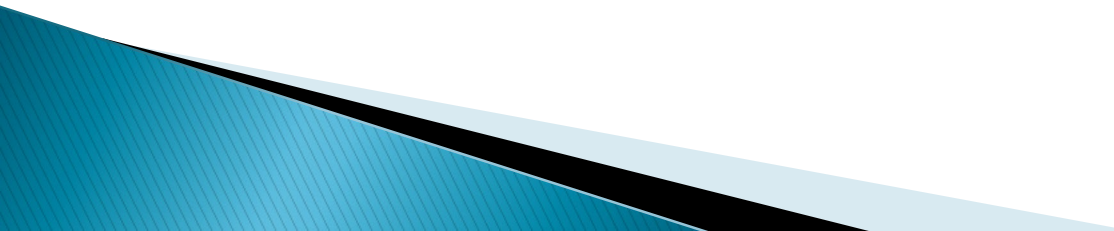
- Needs of equipment, environment and caregivers for independence
- Engaging services – paratransit/ adapted mobility issues, community supports for physical disability

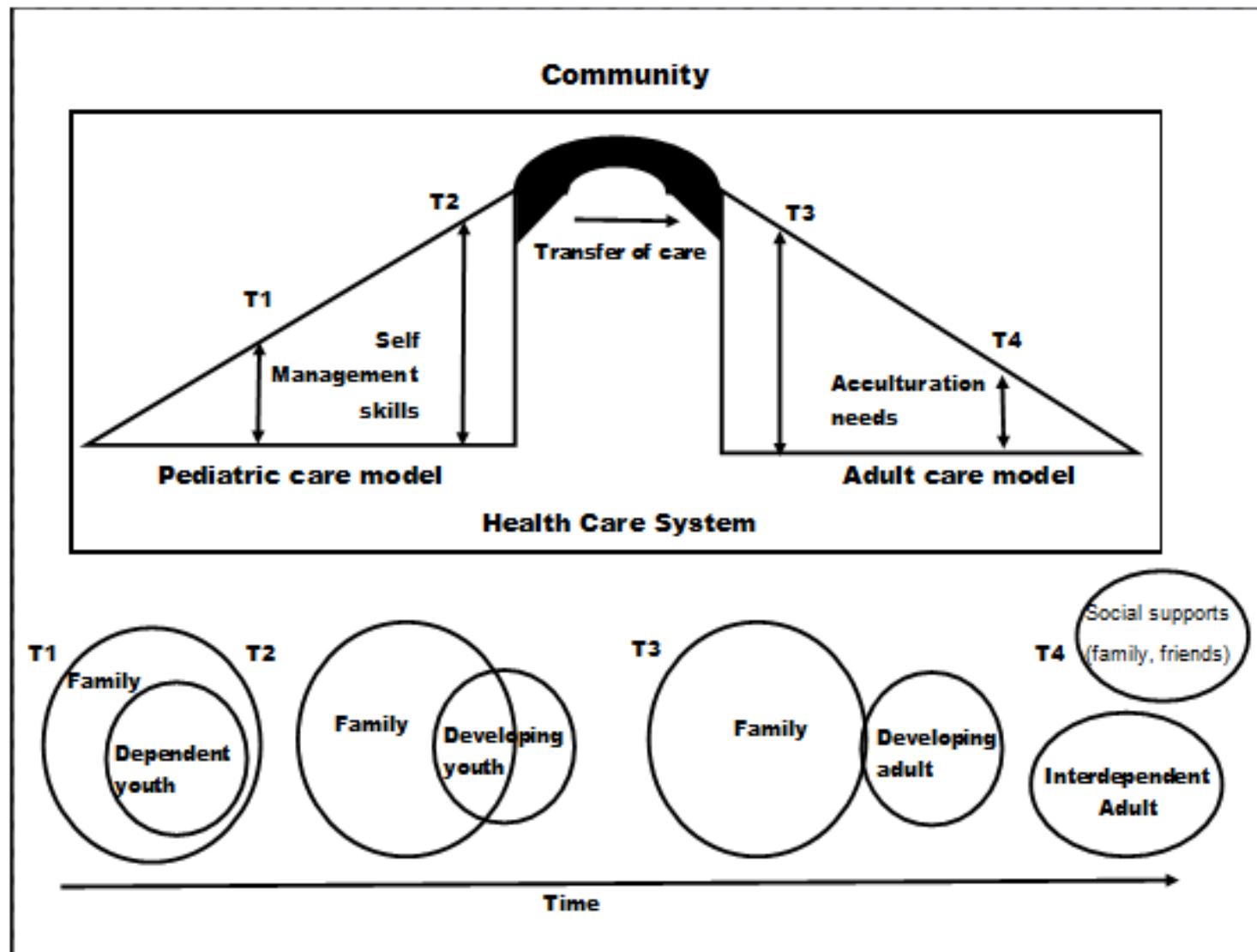
4– INTELLECTUAL DISABILITIES

- Adapted health habits, including sexual health
- Caregiver support adjusted to individual's ability
- Decision making supports
- Community supports for active life and community participation

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
 - www.gottransition.org

	No, I do not know how	No, but I want to learn	No, but I am learning to do this	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?					
2. Do you know what to do if you are having a bad reaction to your medications?					
3. 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?					
6. Do you follow-up on any referral for tests, check-ups or labs?					
7. Do you arrange for your ride to medical appointments?					
8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?					
9. 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 questions 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

- <http://hscj.ufl.edu/jaxhats/traq/>

When do I
need
support?

When can
I do it
myself?

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.



I can decide with
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 (<i>read ads, apply, use personal contacts</i>)?			
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? (<i>open bank account, make big purchases</i>)			
Do I make everyday purchases? (<i>food, personal items, recreation</i>)			
Do I pay my bills on time (<i>rent, cell, electric, internet</i>)			
Do I keep a budget so I know how much money I have to spend?			
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? (<i>check-ups, routine screening, working out, vitamins</i>)			
Can I make medical choices in serious situations? (<i>surgery, big injury</i>)			
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?			
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 (<i>substance abuse, overeating, high-risk sexual activities, etc.</i>)?			
Do I decide where, when, and what to eat?			
Do I understand the need for personal hygiene and dental care?			

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:

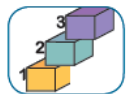


1.

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.

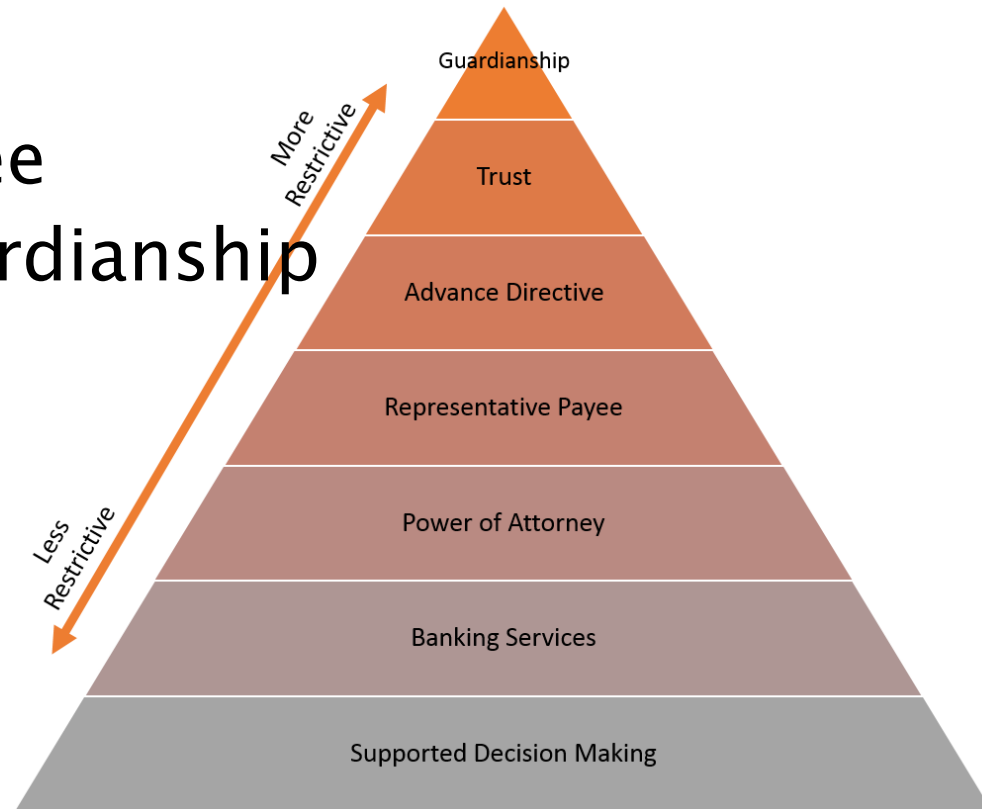
I will get support from:

- ☐ Friend
- ☐ Family
- ☐ Support Person

Name:

Opportunities for Decision Making Supports

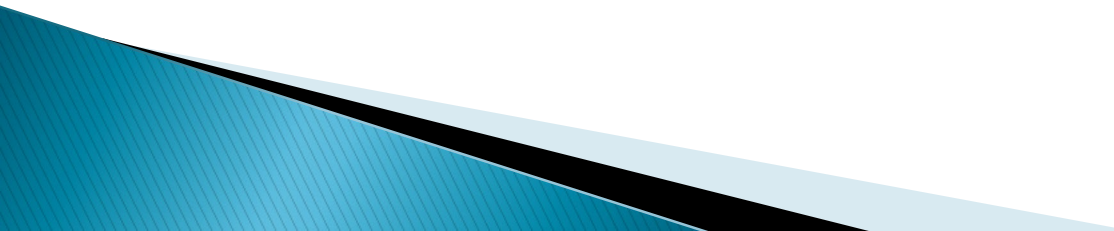
- ▶ Advocate
- ▶ Power of Attorney
- ▶ Representative payee
- ▶ Limited vs. Full Guardianship



Florida Developmental Disabilities Council

https://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?
- 

Daily Rules for Staying Healthy

NAME: _____

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: _____ for _____ minutes _____ times a week.

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: _____



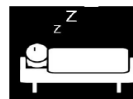
My lunch time: _____

My snack time: _____

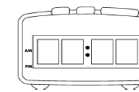


My dinner time: _____

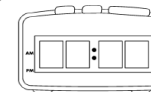
Sleep



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 _____,



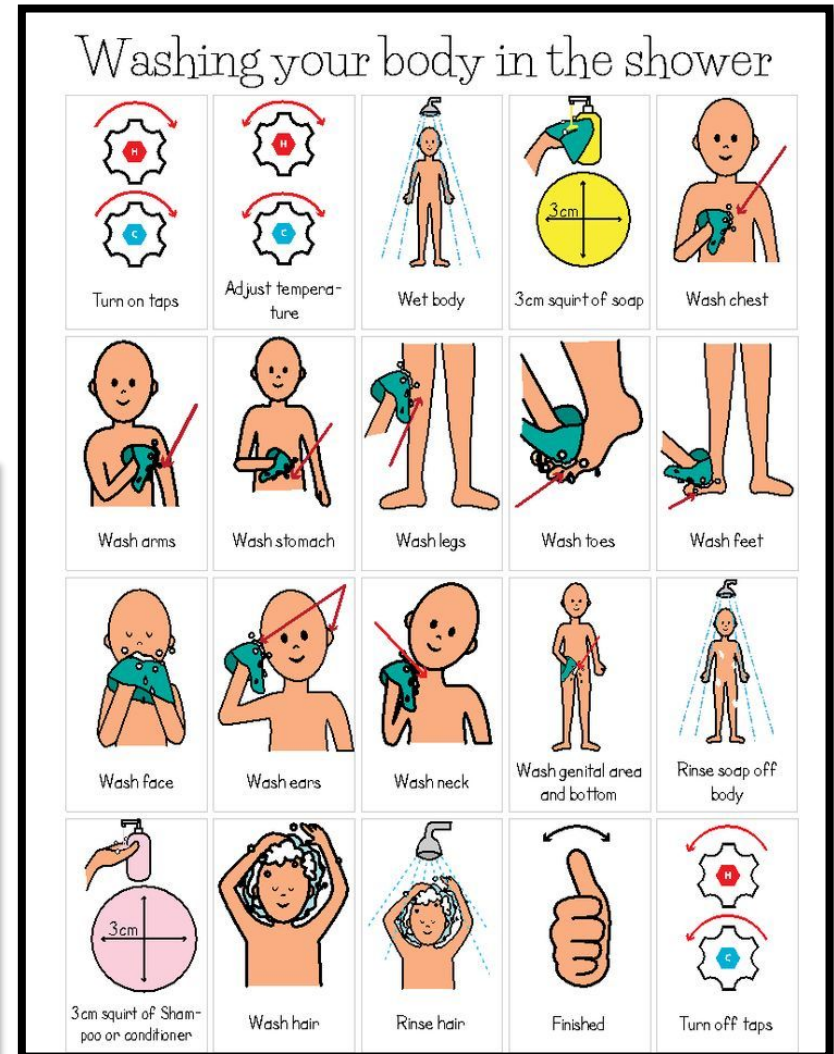
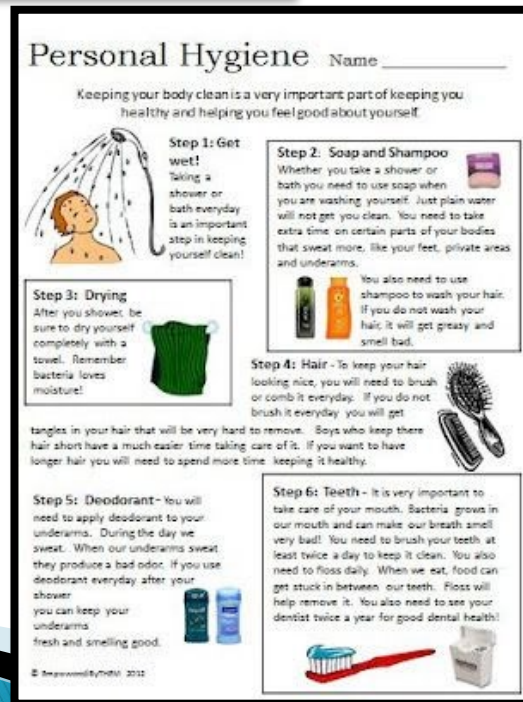
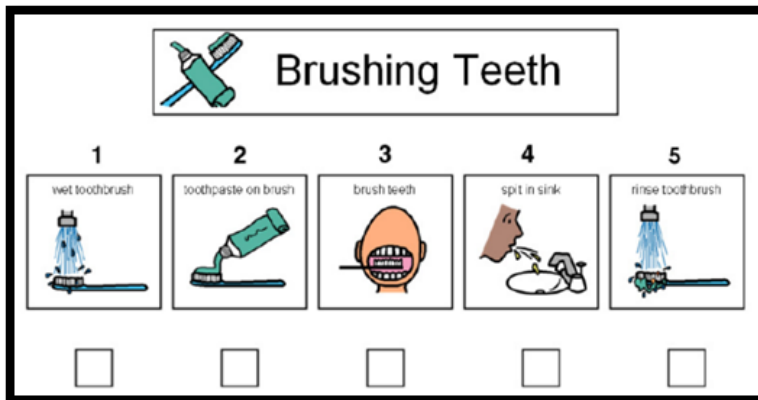
after dinner _____,



before bedtime _____.



Hygiene – phone apps, reminders



Vanderbilt Kennedy Center toolkits

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

VANDERBILT KENNEDY CENTER
VANDERBILT CONSORTIUM LEAD

Puberty, Sex, and Sexuality

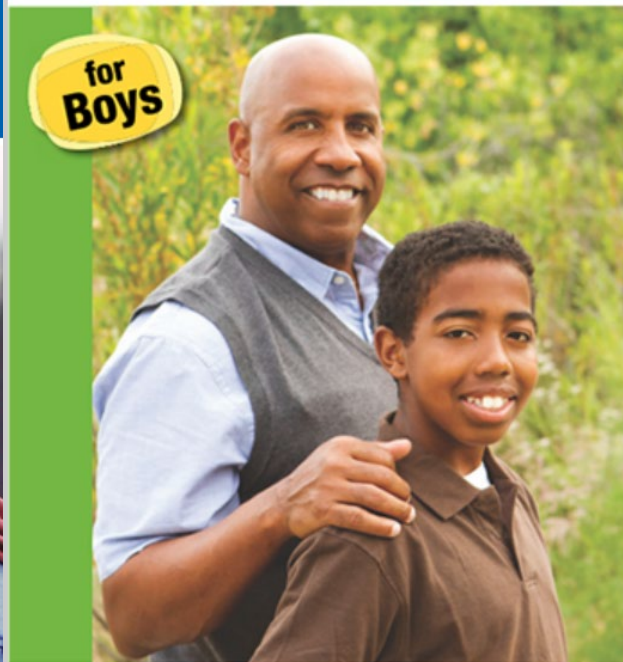


An Introduction for Autistic Teens and Adults

VANDERBILT KENNEDY CENTER
LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL DISABILITIES

Healthy Bodies

for
Boys



A Parent's Guide on Puberty for Boys with Disabilities

VANDERBILT KENNEDY CENTER
LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL DISABILITIES

Healthy Bodies

for
Girls



A Parent's Guide on Puberty for Girls with Disabilities

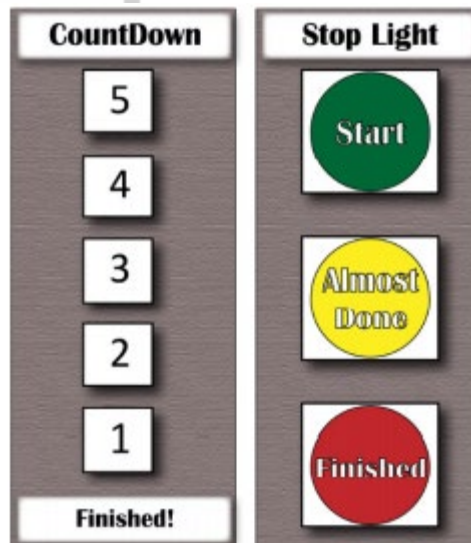
Health care accommodations

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



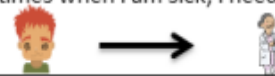
Hands In Autism

<https://handsinautism.iupui.edu/>



Going to Visit the Doctor

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



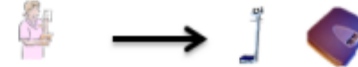
I will wait in the waiting room until my name is called.



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.



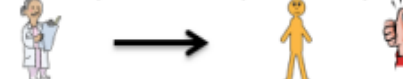
The nurse might take my temperature with a thermometer. This is OK, it does not hurt!



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.



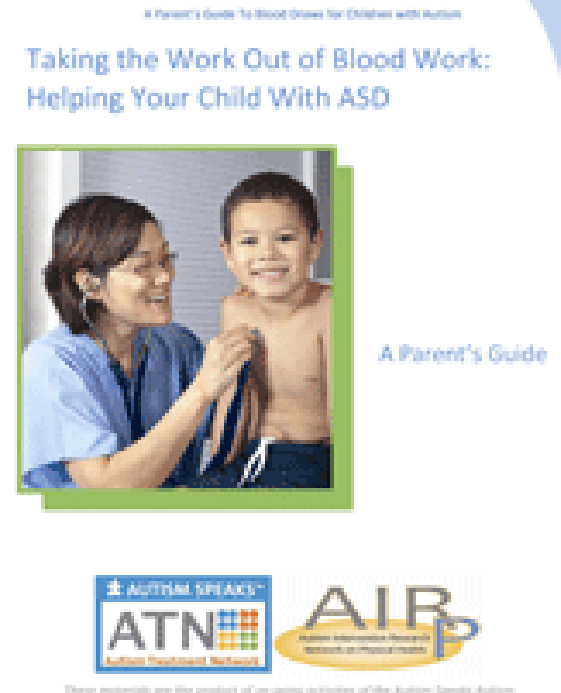
We may have to check out and pay before we leave. Then I am finished!



Medical Procedures

Think outside the box!

- ▶ Communication
- ▶ Blood pressure
 - <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

	Text	Image	Symbols	Gesture
Unaided (no device)				<ul style="list-style-type: none"> • American Sign Language • Body language
Low-tech	<ul style="list-style-type: none"> • Writing with pencil/paper • Letter board 	<ul style="list-style-type: none"> • Drawing with pencil/paper • Picture board • Photographs • Manipulation of physical objects/ models 	<ul style="list-style-type: none"> • Braille • Symbolic language like Bliss Symbolics or MinSpeak on a board 	
High-tech	<ul style="list-style-type: none"> • Text-to-speech device (example: DynaVox DynaWrite) • Text-to-speech software (example: Proloquo2Go for iPhone) 	<ul style="list-style-type: none"> • Picture-based device (example: DynaVox Maestro) • Picture-based software (example: AssistiveWare's LayoutKitchen) 	<ul style="list-style-type: none"> • 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. Oswald's Hospice, 2008
 - https://prc.coh.org/PainNOA/Dis%20DAT_Tool.pdf

Medication self-management smartphone apps



Pill Reminder
& Medicatio...



Medisafe Pill
& Med...



Pill Reminder
& Medicatio...



CareClinic:
Tracker...



Pills Time
Medication...



Pill Logger -
Meds Tracker



MedList Pro
(Medication..



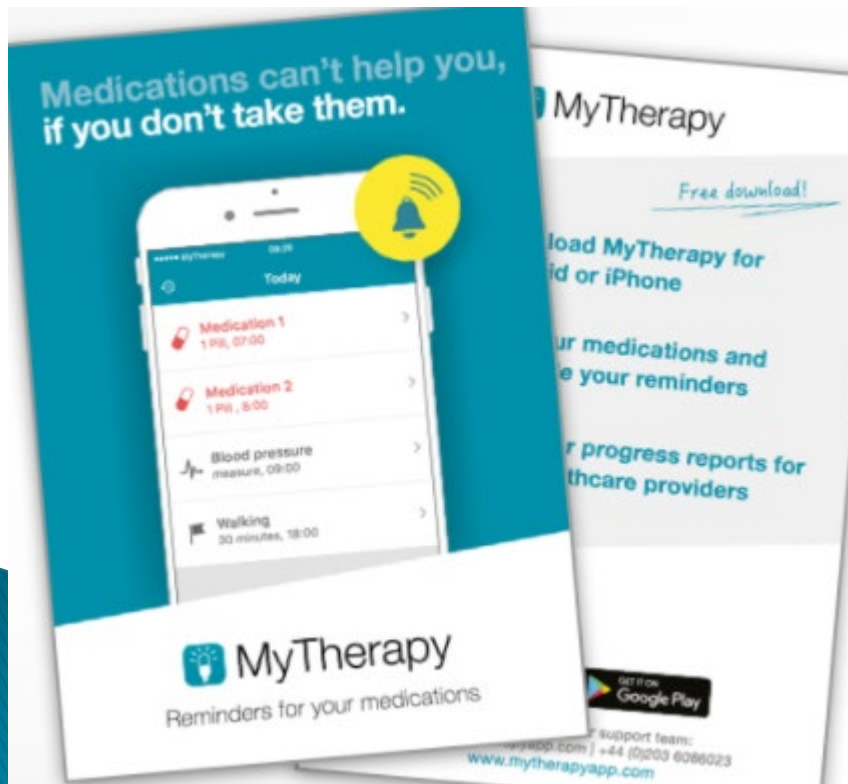
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Medication...



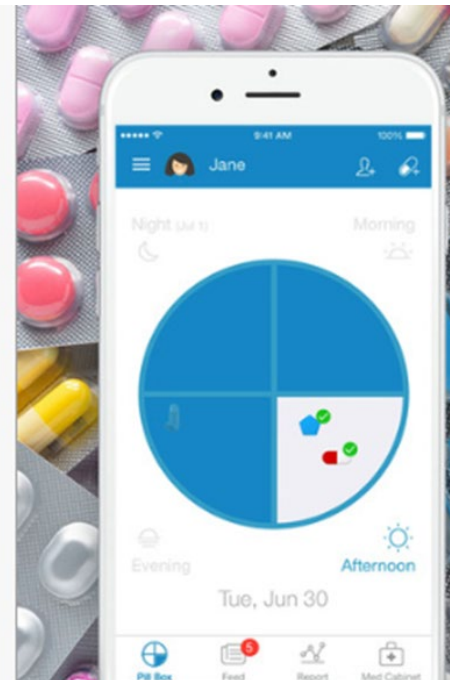
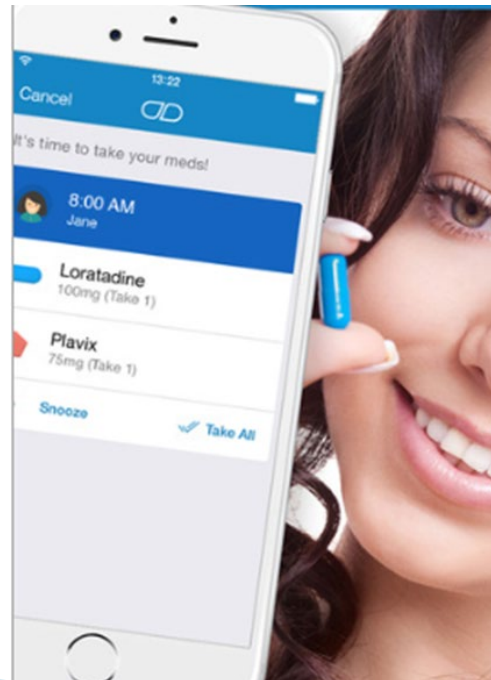
Medication
Reminder



Complete -
Medication...

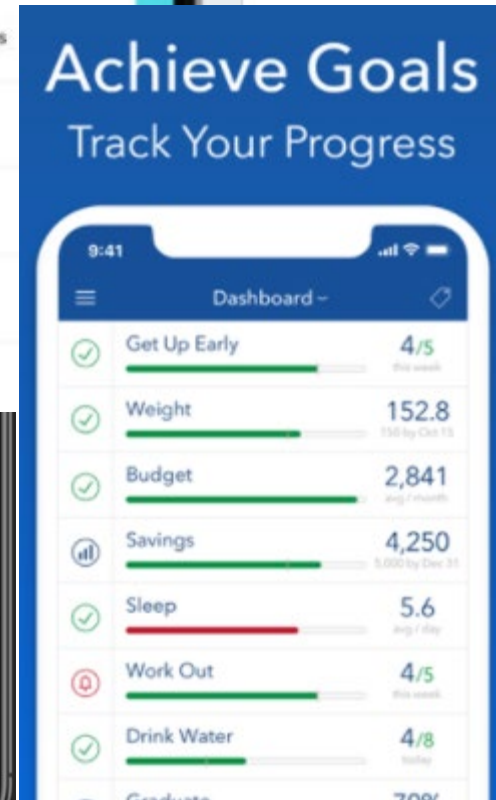
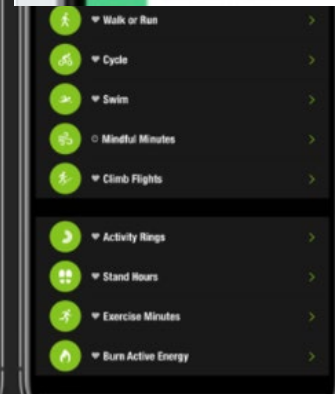
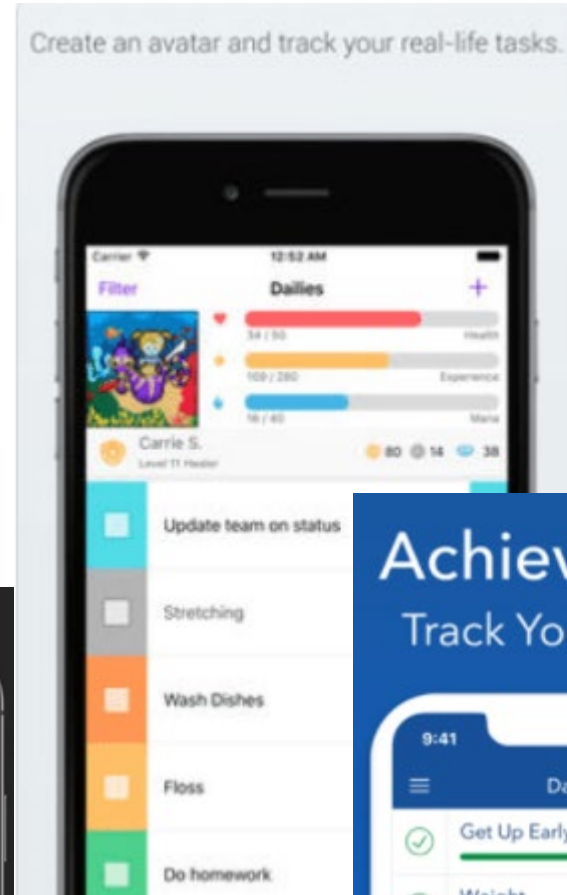
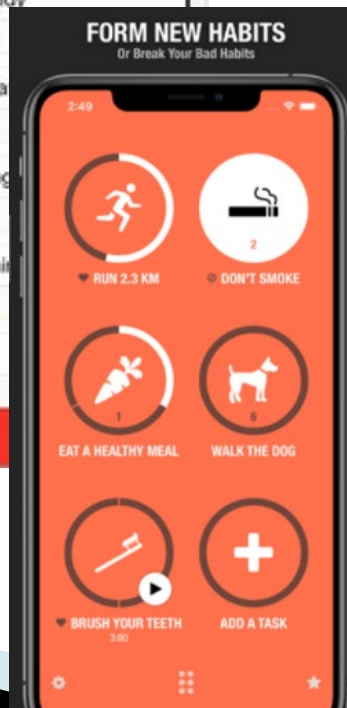
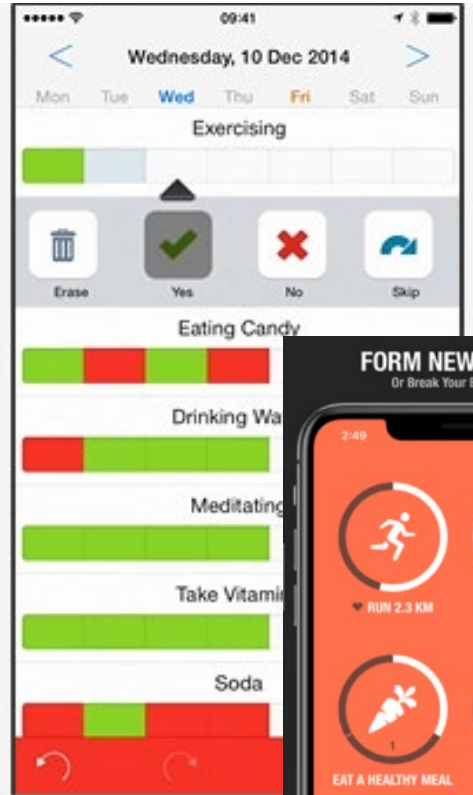
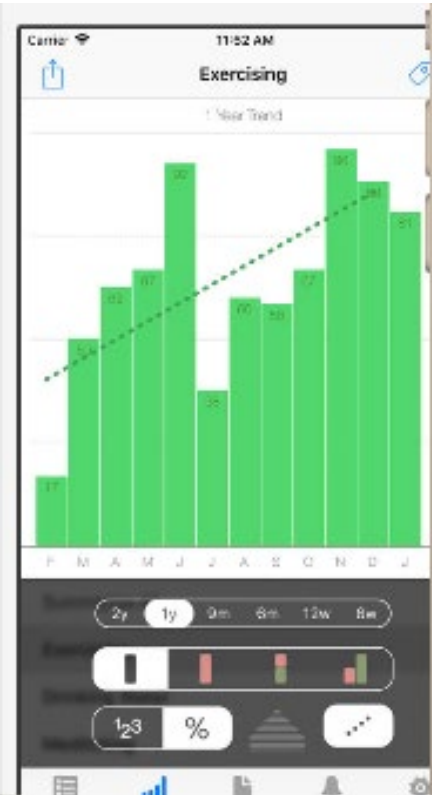


Medisafe

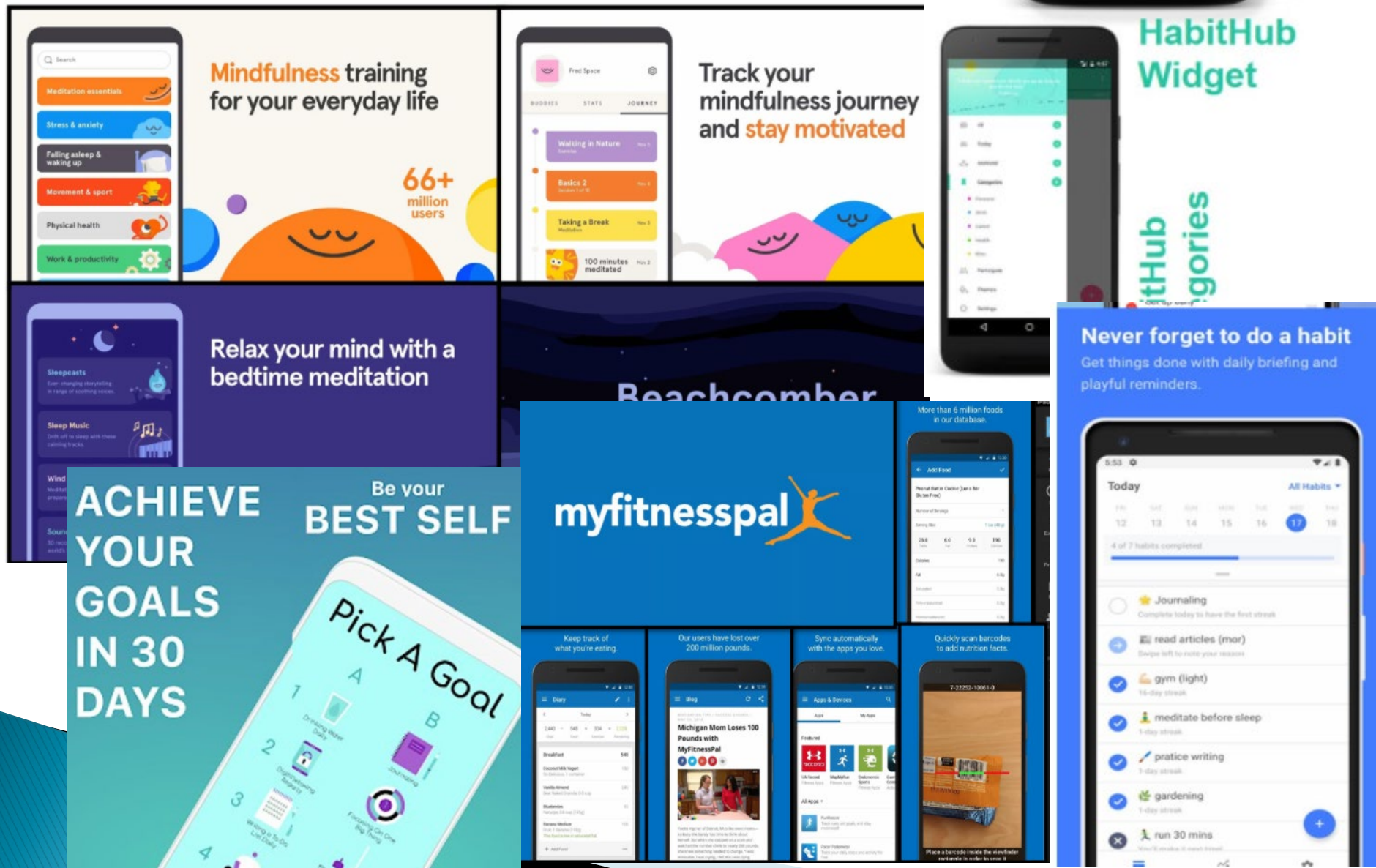


Health habit smartphone apps

Habitica, Stride, Streaks, Way of life



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



► Patient Education

ACTION PLAN

Name: _____

Date: _____

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 well.

Follow this plan every day:

_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

YELLOW LIGHT

Getting Worse:

These are signs of new problems:

- _____
- _____

You need to notice when your health is getting worse with the usual plan.

Add these to your daily routine:

_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

RED LIGHT

Medical Alert!

These are urgent problems to solve right now:

- _____
- _____

If your attempts to help the problem don't work, you need to act now and get help.

Do this immediately:

_____	_____
_____	_____
_____	_____
_____	_____

Call the Doctor's office NOW.
Tell them you have an urgent problem and you need help today!

Doctor: _____

Phone: _____

Reasons to get emergency medical help:

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
 - 404-785-8227