THE UNIVERSITY OF ALABAMA AT BIRMINGHAM

STEP Program Update: Lessons in Building a Multidisciplinary Healthcare Transition Program

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Associate Professor, Internal Medicine and Pediatrics
UAB STEP Program, Medical Director

Objectives

- Discuss STEP Program Background & Growth
- Share Lessons Learned
- Growth for the Future

Where we started

The infamous UAB crosswalks

Children's of Alabama Needs Assessment

Patient Population

- Provide a list of all complex/chronic diseases that you care for that require transition to adult care.

# of patients

- For each disease, what is the estimated number of patients turning 19 years old each year?

Effectiveness

- On a scale of 1 (bad) to 10 (very effective), how would you rate the current process of transition for patients with each disease?

Qualitative Responses on Needs Assessment

"No formalized transition plan"

Average of 20-25 patients transitioning per year

"Essentially all of our patients have chronic disease that will need transition when they age out"

"We have not been very successful...."

- "It seems like COA is not interested in transition or having a hospital wide policy to address it"

"Patients regress after leaving pediatric management"

"We coddle patients which makes the actual transition more rough"

COA Needs Assessment of transition plans

Patients w/ a transition plan (scored >8)	Patients w/ NO transition plan (scored <2)
Cystic Fibrosis	Down syndrome (10)
Spina Bifida	Colorectal Disorders (20)
Hemophilia	IBD / patients with gastrostomy tubes (35)
Sickle Cell	Short bowel disorder (5)
Dialysis/transplant patients	Cerebral palsy (20)
Diabetes	Osteogenesis Imperfecta (5)
Epilepsy (program being developed)	Urinary reconstruction patients (prune belly, exstrophy, etc.) (2-3)
	Neuromuscular patients (25-35)
	Asthma / General Pulm (110)
	Home vent (10)
	Sleep disorders (100)
	Juvenile idiopathic arthritis
	Lupus
	Erythematosus, dermatomyositis, scleroderma

Timeline to STEP Development

Where we are now

STEP Clinic: our team

Betsy Hopson, MSHA
Director of STEP Program

Carlie Stein Somerville, MD
Assistant Professor, Internal Medicine and Pediatrics

Medical Director of STEP Program

Madeline Eckenrode, MD
Assistant Professor, Internal Medicine and Pediatrics

Marie Pfarr, MD
Assistant Professor, Medical Director COA Complex Care

Beth McGee, RN
STEP Program Nurse Coordinator

Social Work support

CRS + UAB Social Work
2021-2024

Care transitions 2.0
FTE 7/1/2024

STEP Clinic: a unique, multidisciplinary approach to care of adults with diseases of childhood

- One program to address transition for patients with complex diseases of childhood across specialties and systems
- Ownership + Concierge Care
- Access: Primary Care w/ Care Coordination
- Equity: Community engagement
- Effectiveness: Decreased ER visits, length of stay
- Education: Multidisciplinary learners
- Research: lifespan model of care development, patient outcomes

Innovative Multi-disciplinary Approach

- Physical Therapy, Ashley Parish, PT, DPT, CRT
- Rehabilitation Medicine, Dr. Danielle Powell, MD
- Epilepsy Management, Neurologist, Dr. Quynh Vo, MD
- Epilepsy Transition, Neurologist, Dr. Katy Lalor, MD
- Endocrine, Dr. Sajel Patel, MD
- Pulmonary, Dr. Joseph Barney, MD
- Neuromuscular, Dr. Rocio De Campo, MD
- Psychology, Dr. Melissa Greenfield, PhD
- Psychiatry, monthly rotating child and adolescent fellows and attending

Individualized, Diagnosis-specific approach

Patients with epilepsy and rehabilitation needs	• 3rd Wednesday every month • PCP, neurology,rehab medicine
Autism/ID	• 4th Wednesday- PCP, psychology, psychiatry, SW
Patients with neuromuscular conditions	• Quarterly clinic, patients seen by PCP, neurology pulmonary, PT, SW • Triages to one of her colleagues who specializes in each patient's specific condition
Technology Dependent	• PCP, Pulmonary, PT, SW
Endocrine	• PCP, Endocrine,SW

STEP patient demographics

Diagnosis Type	Patients	Percentages
CP	126	26.2%
Rare Genetics	58	12%
Autism	55	11.4%
Neurological	42	8.7%
Epilepsy	39	8.1%
Spina Bifida	32	6.7%
Endocrine	30	6.2%
Neuromuscular	29	6%
Renal	22	4.6%
Down syndrome	13	2.7%
Autoimmune	13	2.7%
Hem/Onc	10	2.1%
SCI	8	1.7%
Cardiology	7	1.5%
Other	9	1.9%

**Other: Incudes- congenital pulm, GI, fetal alcohol syndrome, narcolepsy*

- Clinic Inclusion criteria:
  - Intellectual disability or Autism Spectrum Disorder requiring caregiver assistance and/or
  - 2 or more organ systems with chronic issues and/or
  - 3 or more specialists following at COA and/or
  - Technology Dependence (Ventilator, BIPAP, Trach, GT/JT/ wheelchair, Shunt)

Communication	Patients	Percentages
Verbal	297	61.9%
Nonverbal	183	38.1%

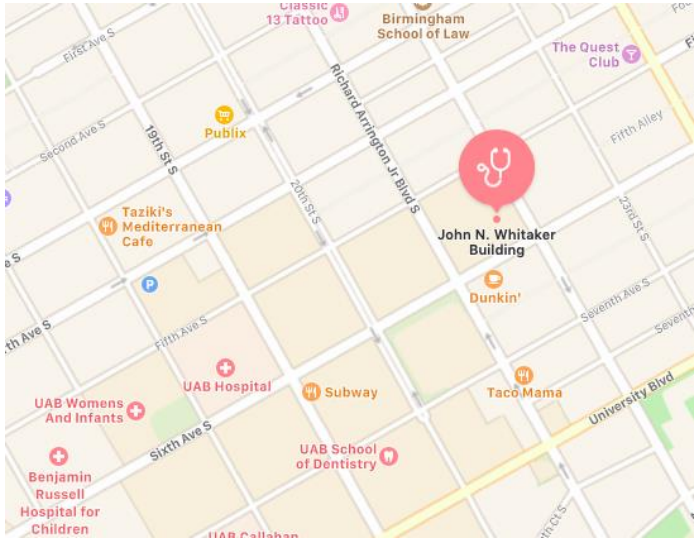
Transitioning out of STEP

- Clinic launched 9/2/20 - 664 patients
  - 546 still followed in STEP
  - 118 transitioned out of STEP

- Transitioning out of STEP criteria
  - Greater than 4.5 on the TRAQ
  - Identify and connect with all specialists
  - Connect with PCP (equal or better care)
  - Emergency care plan
  - No current acute issues

Where we see patients

- John N. Whitaker Building 2nd floor- Every Wednesday
- Pediatric Spina Bifida Clinic- 2nd and 4th Wednesday afternoons
- Coming soon- Down Syndrome Clinic at Sparks



Transition Readiness Assessment Questionnaire (TRAQ)

Directions to Youth and Young Adults: Please check the box that best describes ***your*** skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

Directions to Caregivers/Parents: If your youth or young adult is unable to complete the tasks below on their own, please check the box that best describes ***your*** skill level. **Check here** if you are a parent/caregiver completing this form. ☐

	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)?					

STEP Clinic Assessments

- Nonverbal Patients
  - Caregiver burden- Zarit Burden Index (ZBI)
- Verbal/Independent Track
  - Transition Readiness Assessment (TRAQ)
  - Depression Screening (PHQ-9)
  - Anxiety Screening (GAD-7)

Individualized Transition Plan (ITP)

GOAL 1- Referrals

Goal 2- Career/Education or Advanced Care Plan

Goal 3- Based on TRAQ or ZBI

Goal 4- Self/Parent Goal

Goal 5- Emergency Sick Plan

Hopson B, Eckenrode M, Rocque BG, Blount J, Hooker E, Rediker V, Cao E, Tofil N, Lau Y, Somerville CS. The development of a transition medical home utilizing the individualized transition plan (ITP) model for patients with complex diseases of childhood. Disabil Health J. 2022 Dec 13:101427. doi: 10.1016/j.dhjo.2022.101427. Epub ahead of print. PMID: 36621354.

Individual Transition Plan (ITP)

Instructions: This plan will be developed with your transition team and it will become part of your medical record.

Name:_____ Date of Birth:_____

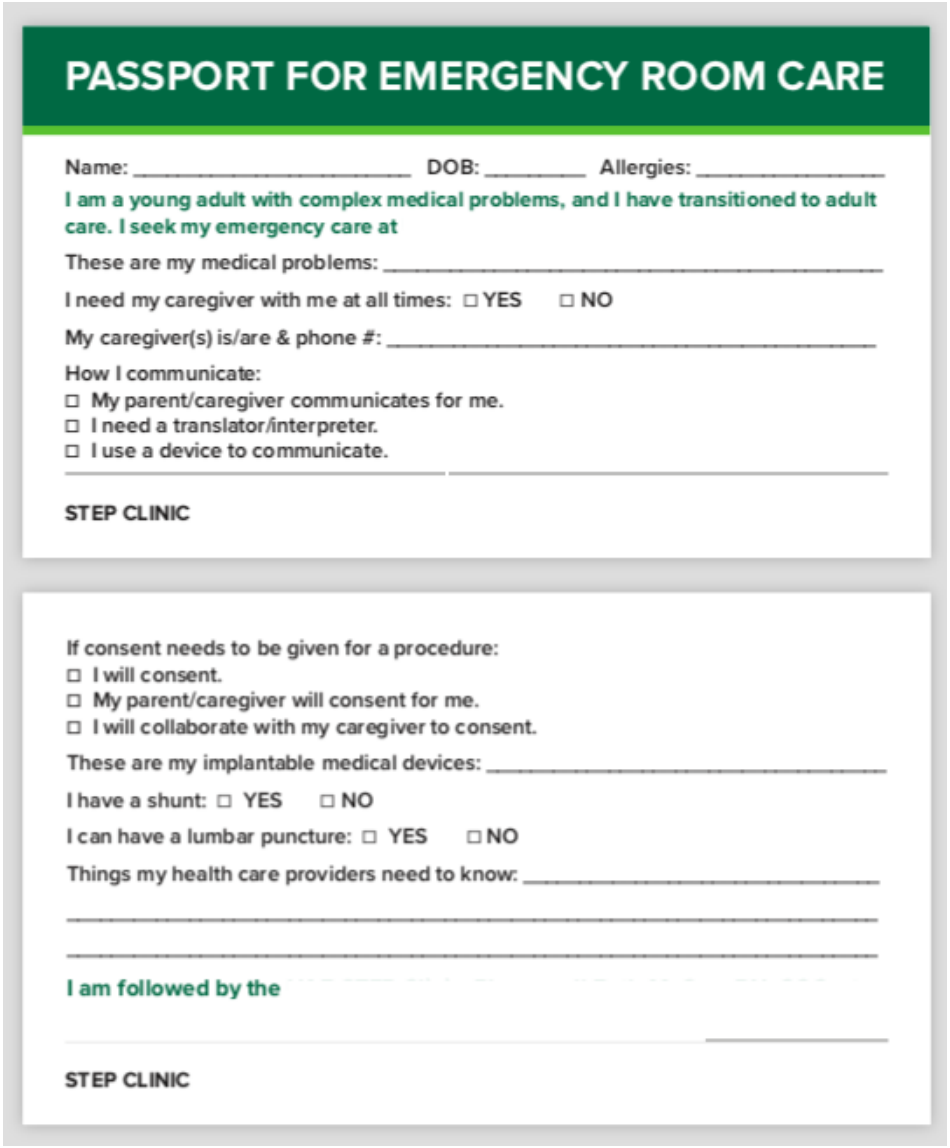
Primary Diagnosis: _____ Secondary Diagnosis:_____

Prioritized Goals	Issues or Concerns	Actions	Person Responsible	Target Date	Date Complete
1. Referrals	Goal 1 includes an assessment of predicted sub-specialist that will be needed in adulthood.	Transition team facilitates open communication between pediatric and adult specialist and promotes warm hand off.	Transition team communicates with various care teams to maintain continuity of care across all divisions.		
2. Career/Education Guardianship/Advanced care plan	Goal 2 focuses on long term education/employment goals. For patients who are most medically complex and/or non-verbal, goal 2 focuses on caregiver support and advanced planning.	Patients are referred to vocational rehabilitation and other community resources to aid in seeking employment. Families are provided with information regarding guardianship.	Information and support provided by transition team. Families/patients are given specific goals aimed at either a career plan, advanced care plan or both.		
3. TRAQ/ZBI	Goal 3 takes an area on the TRAQ or ZBI where patients score low and a goal is set to improve score.	Patient receives specific goal aimed at improved transition readiness or decreasing caregiver burden.	Measurable goal with target date given to patient.		
4. Self/Parent Goal	Goal 4: transition team partners with patient/caregiver on a self-goal.	Patient and/or caregiver share a personal goal with transition team. Resources provided.	Specific goal set and resources provided aimed at addressing most important goal from patient perspective.		
5. Emergency/Sick Plan	Goal 5: Development of sick plan.	Care team develops a sick plan for each patient that is specific to their location and needs.	Family verbalizes understanding with where to go for emergent/sick care.		

Emergency Planning

- At the first visit, we identify PCP, urgent illness plan and Emergency plan

***We do **not** recommend transitioning to adult ER/hospital for most patients until entire care team is in place and clear discussions with family



PASSPORT FOR EMERGENCY ROOM CARE

Name: _____ DOB: _____ Allergies: _____

I am a young adult with complex medical problems, and I have transitioned to adult care. I seek my emergency care at

These are my medical problems: _____

I need my caregiver with me at all times: ☐ YES ☐ NO

My caregiver(s) is/are & phone #: _____

How I communicate:
☐ My parent/caregiver communicates for me.
☐ I need a translator/interpreter.
☐ I use a device to communicate.

STEP CLINIC

If consent needs to be given for a procedure:
☐ I will consent.
☐ My parent/caregiver will consent for me.
☐ I will collaborate with my caregiver to consent.

These are my implantable medical devices: _____

I have a shunt: ☐ YES ☐ NO

I can have a lumbar puncture: ☐ YES ☐ NO

Things my health care providers need to know: _____

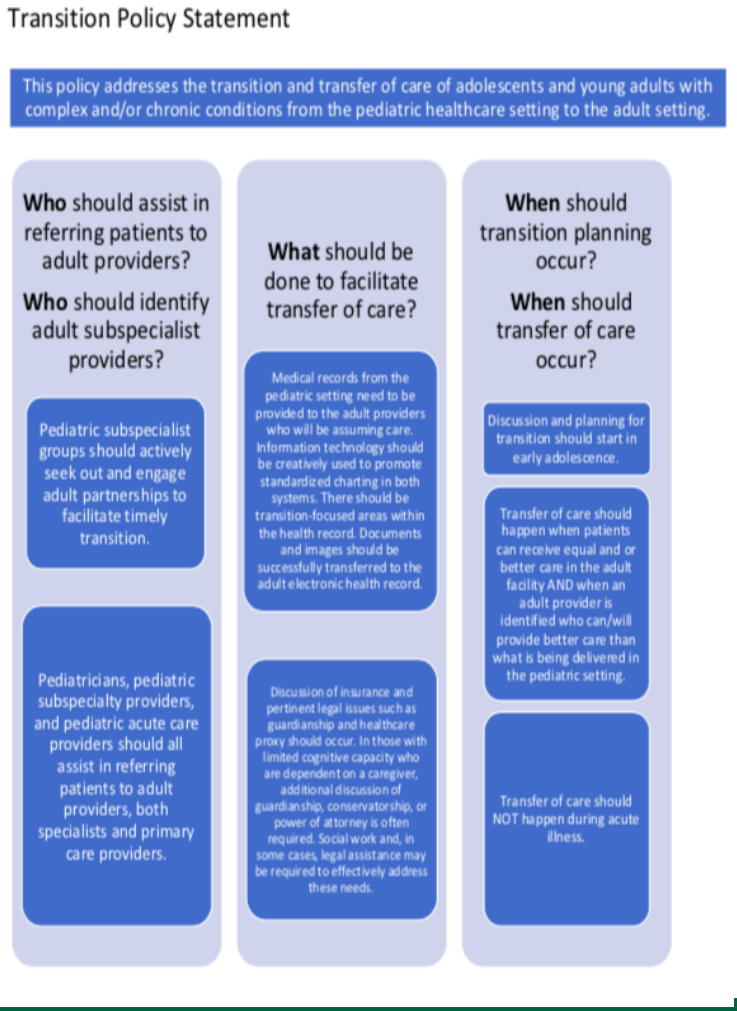
I am followed by the

STEP CLINIC

What our patients have taught us?

Lesson 1: Transition must be standardized across the system but individualized to the patient

- Review UAB and COA transition policy
- Role of all pediatricians in transition planning
- New COA policy exceptions
- Role of patient, parents and caregiver
- Anticipatory Guidance on timeline of effective transition



Needs have grown exponentially

"Last night we got a call from our ED about 23yo DiGeorge Syndrome, s/p truncus repair as infant, followed by adult congenital, hypocalcemia followed by peds endo, sz followed by adult neuro and scleroderma followed by adult rheum"

" 19yo UAB ED medically clear patient with Autism who has been in the ER for 4 days"

"24 yr with ASD, Level 3, Reactive airway disease, Multiple forms of seizures, Mitcohondrial Metabolism Disorder, Leigh's Syndrome, Chrousos Syndrome needs appt in STEP immediately"

"22 yr old is now suppose to be discharged from COA on TPN. Jejunostomy was removed. Could he get a UAB GI appointment and STEP appt immediately after discharge"

Sometimes patient's and STEP caught in the middle

Children's of Alabama administrative policies do not always mesh with our ground level experiences. When these patients are this old, this sick, and require this level of readmissions and inpatient care, we are often asked to provide care outside of our scope and comfort level. I don't know that this is what's best for the patient

I just don't have bandwidth to be point person for these patients. I already am up to my eyeballs in IBD patients

"As it stands, per new hospital policy, we have to request permission from the house supervisor to admit patients over the age of 22 each time they are brought to the ED. This places a significant burden on the admission team, which in this situation is Pediatric Pulmonary medicine. "

I probably have some of the most nutrition training of anyone on faculty, and I feel this is definitely out of scope of my practice. The nutrition societies have highly recommended guidelines on who should manage and appropriate infrastructure (pharmacist, weekly labs, etc). For me, I feel that this is practicing with risk should anything go wrong.

I would not recommend this patient transition to UAB providers until he is stable, out of the hospital and with stable follow-up and plans outpatient with his current team even if he is above 21. I also want to reiterate that in STEP, we do not recommend our patients coming to UAB for ER/hospital stays until they are safely transitioned to the entire adult team which for this patient includes multiple specialties.

Lesson 2: There are still major gaps

- Mental Heath support
- Transition readiness
- High Caregiver Burden
- Nutrition / GI support

Patient and Caregiver Screenings

Assessments	Scores	Number	Percent
PHQ-9	0-4	144	59%
	5-9	53	22%
	10-14	29	12%
	15-19	9	4%
	20-27	11	4.4%
	Not scored	259	
GAD-7	0-4	136	56%
	5-9	47	20%
	10-14	30	12%
	15+	28	12%
	Not scored	264	
TRAQ	Less than 4	156	65%
	Greater than 4	84	35%
	Not scored	259	
ZBI	Less than 17	71	41%
	18-35	60	34%
	36+	43	25%

42% of transitioning patients screened positive for depression, ranging from mild to severe. **20% of these patients report moderate to severe depression.**

43.5% of transition patients screened positive for anxiety. **24% of these patients report moderate - severe anxiety.**

Only 35% of patients are prepared for transition of care.

59% of caregivers of patients transitioning screened positive for high caregiver burden.

Embedded Psychiatry and Psychology

- Limited providers around state who will see adults with ASD
  - Almost none who also take Medicaid
- UAB psychiatry will not see adults with ASD or admit to inpatient unit
- One year wait now to see STEP providers
- Strategic Plan to UAB health system- in progress

Nutrition

- Gaps in expertise, experience, training
- Palliative Nutrition partnership for GT/JT feeds, malnutrition
- Strategic Plan to UAB health system- in progress

Lesson 3: Every “STEP” forward brings new challenges and opportunities

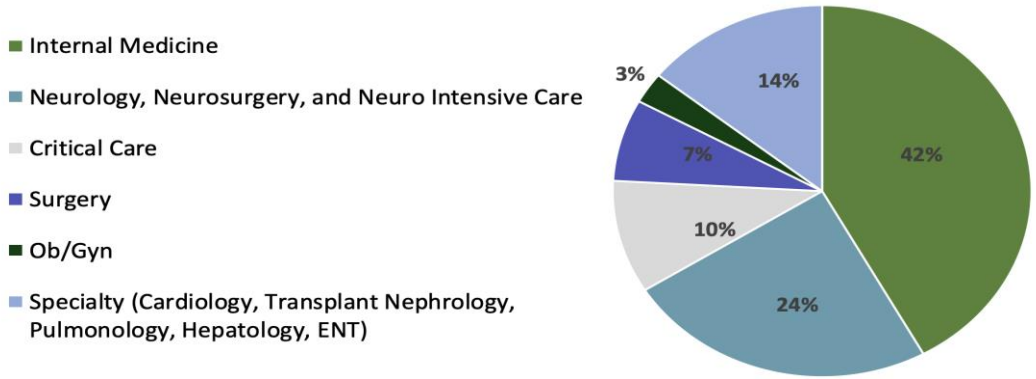
“Evidence based program building”

STEP team *reduces LOS and Improves Outpatient access*: STEP Hospitalization Data

	STEP Patients (n=56)
Gender	
Male	30 (53.6%)
Female	26 (46.4%)
Race	
White	29 (51.8%)
Black	19 (33.9%)
Asian	1 (1.8%)
Other	2 (3.6%)
Unknown	5 (8.9%)
Age (years)	24 (18 – 36)*
Mortality	7 (12.5%)

Table 3. Established STEP patients: Hospitalization Course Descriptors

	Hospitalizations (n=112)
Number of consult services in hospitalization	1.57 ± 2.05*
Length of hospitalization (days)	4 (1-97)**
Hospitalizations with 1 or more consults	71 (63.4%)
Hospitalizations with 1 or more MET calls***	6 (5.4%)
Hospitalizations with STEP clinic follow-up appointment attended after discharge	22 (19.6%)
Hospitalizations with STEP clinic contacted prior to admission	25 (22.3%)
Hospitalizations with readmission to UAB within 7 days of discharge	7 (6.3%)
Hospitalizations with readmission to UAB within 30 days of discharge	19 (17.0%)



- Over a recent 90-day study period, 111 STEP patients with CP and 163 non-STEP with CP patients were followed.
- 2% (2/111) of STEP vs. 7% (12/163) non-STEP were seen in ED- **70% reduction**
- 3% (3/111) of STEP vs. 11% of non-STEP (18/163) were admitted to hospital **72% reduction in hospital admission**
- Non-STEP patients are using these resources 3.5 times higher for both ED visits and inpatient needs.
- Hospital LOS was 1.67 ± 1.15d versus 6.05 ± 13.1d, p=0.19.

Challenges

Autism long stay pts

Supported Decision Making

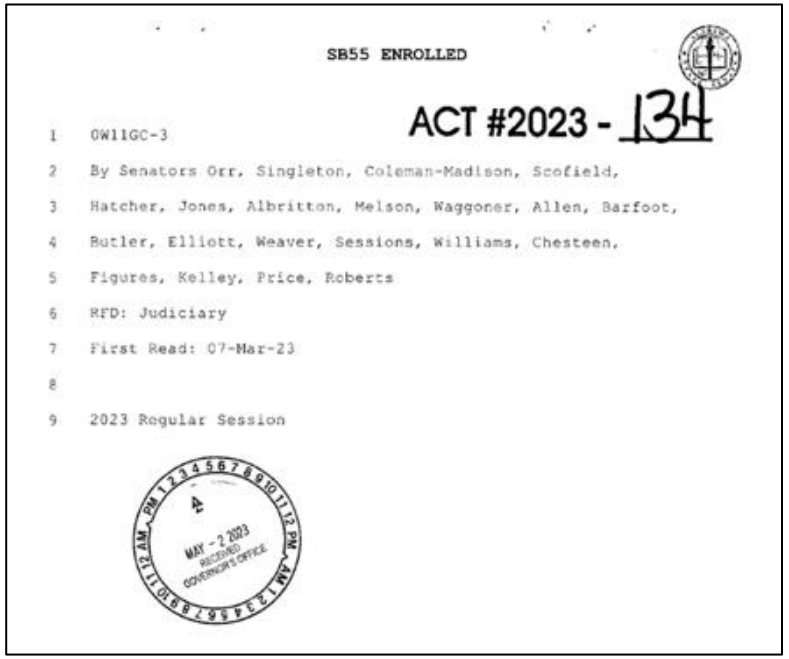
Sensory Pathway- need for child life resources

Adults with Autism

- Sensory Pathway
  - Kulture City training and equipment
- Education
- Neurodevelopmental Disorders Clinical Care team
  - Sensory Pathway: Education and tools for ER/inpatient stays
  - Inpatient Consult Service w/ psychiatry co-management + SW, child life, OT, psychology

Guardianship Reform: Supported Decision Making

- Vulnerable Patient Task Force
- Colby Act: SB 55



SB55 ENROLLED

ACT #2023 - 134

0W11GC-3

By Senators Orr, Singleton, Coleman-Madison, Scofield, Hatcher, Jones, Albritton, Melson, Waggoner, Allen, Barfoot, Butler, Elliott, Weaver, Sessions, Williams, Chesteen, Figures, Kelley, Price, Roberts

RFD: Judiciary

First Read: 07-Mar-23

2023 Regular Session

MAY - 2 2023
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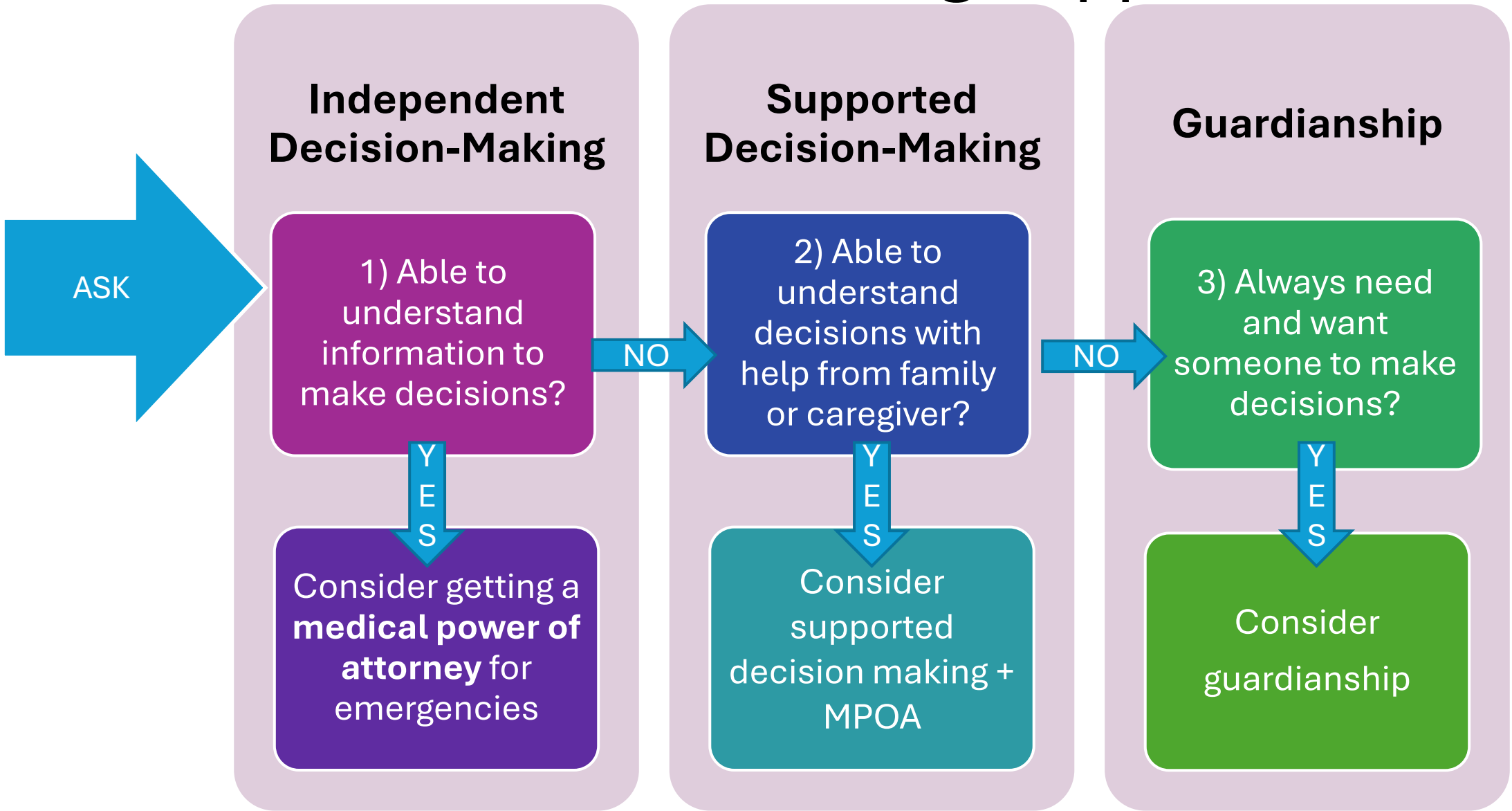
Follow Decision-Making Support Chart



Supported Decision Making in Practice

Support Preferences

Primary Supporter Name/Contact Info	Secondary Supporter Name/Contact Info	Additional Supporter Name/Contact Info

Pt Has Completed A Supported Decision Making Agreement	Copy Of Supported Decision Making Agreement	Healthcare Supporter Education Provided
○ Yes ○ No	○ Copy provided today ○ Already scanned into EMR ○ No, requested patient/family to bring copy	○ Recommended pt/supporter review and complete a Supported Decision Making Agreement

At UAB, a Healthcare Supporter may help pt with life decisions about:

Physical Health	○ Yes ○ No
Mental Health	○ Yes ○ No
Choosing and maintaining health-related needs (for example: equipment, in-home services, or community resources)	○ Yes ○ No

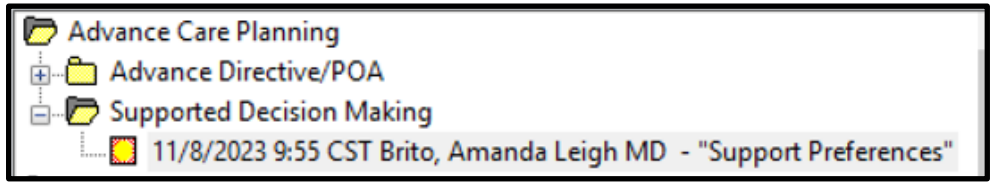
To help the pt make decisions, the Supporter may:

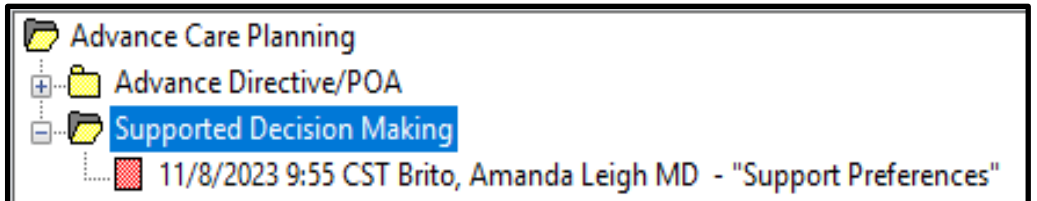
NOTE: A Supporter does not make decisions for the patient

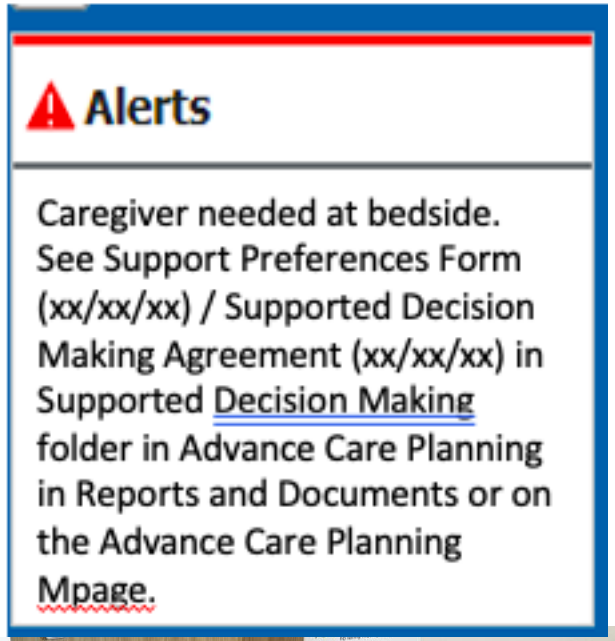
Help get information needed to make medical and/or psychological decisions	○ Yes ○ No
Help pt understand choices so pt can make the best decision	○ Yes ○ No
Help pt communicate decisions to the right people	○ Yes ○ No
Help pt understand and consider other social and support services that may be available	○ Yes ○ No
The Supporter may co-sign with the pt	○ Yes ○ No

In order for the Supporter to help the pt, the healthcare team:

May discuss the pt's private health information with the Supporter	○ Yes ○ No
Should allow the Supporter to remain at bedside to assist with making decisions	○ Yes ○ No







Lesson 4: We are in this together

- Outpatient
  - Adding STEP Provider to pediatric clinics to improve transition readiness
- COA inpatient consults
  - Marie Pfarr and Betsy Hopson inpatient consults for transition consultation
  - Examples:
  - Patient #1- Helping consult on adult related medical concerns (acute heart failure in adult patient), DVT recommendations.
  - Patient #2- Introducing transition and STEP clinic. Discussing community resources and outpatient follow up plan.
- Develop best strategies for referrals
  - Not during an acute crisis

Lesson 5: There is lots to celebrate

- Strategic plan with metrics to UAB health system leadership, prelim approval 9/2024
- Providers are contacting us to join STEP
  Neurology- epilepsy and neuromuscular
- Added additional Med/Peds provider 9/2024
- Hired Down syndrome nurse coordinator
- Transition “Champions” in nearly every division
- STEP recognized at national leader

Research and Publications

Disability and Health Journal 16 (2023) 101427

Contents lists available at ScienceDirect

Disability and Health Journal

journal homepage: www.disabilityandhealthjnl.com

Original Article

The development of a transition medical home utilizing the individualized transition plan (ITP) model for patients with complex diseases of childhood

Betsy Hopson, MSHA [a, b, c, *], Madeline Eckenrode, MD [a], Brandon G. Rocque, MD, MS [b, c], Jeffrey Blount, MD, MPH [b, c], Emily Hooker, BS [g], Virginia Rediker, MPH, LICSW [d], Emma Cao, BS [g], Nancy Tofil, MD [e], Yung Lau, MD [f], Carlie Stein Somerville, MD [a]

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Research and Publications

Health Care Transitions 1 (2023) 100005

Contents lists available at ScienceDirect

Health Care Transitions

journal homepage: www.sciencedirect.com/journal/health-care-transitions

Initial observations of medically complex young adults transitioning to adult care: Revealing data regarding mental health, nutrition, and transition preparedness

Emily Hooker[a,*,1], Madeline Eckenrode[b], Betsy Hopson[b,c,d], Carlie Stein Somerville[b,e]

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A STEP Towards Successful Transition- Conference

Where we are headed

What is next?

- Recruiting Med-Peds Faculty and dual trained specialists
- Accessible Clinic Space
- UME/GME educational initiatives
- Education across disciplines – Come Roll with Me HSF grant
- Expanded Model of Lifespan care: Autism, Down Syndrome
- Inpatient Consult Service at UAB to include Med-peds, Psychiatry, Psychology, Child Life, Social work
- Strategic Growth plan across UAB and COA

Our immediate ask to UAB

1. Med-Peds Physician
    a. Growth: 1.0 FTE to build consult service and support clinical volume
2. Psychiatrist 1.0 FTE
3. Advanced Practice Provider 1.0 FTE
4. Registered dietician with specialty in complex feeding 1.0 FTE
5. Behavioral Psychologist 1.0 FTE
6. Child life Specialist .5 FTE

Lifespan Down Syndrome Clinic

Down Syndrome: Lifetime Care Model

Initial consultation within 3 months of delivery in Civitan Sparks Clinic. Establish care and follow AAP Health Supervision Guidelines for Individuals with Down Syndrome.

Begins at age 14- All peds services plus ADD
-Transition Readiness Planning
-Career/education support

All adult services- plus ADD
- Dementia care
- Palliative
- Geriatrics

Consultation offered via telemedicine

Civitan-Sparks Clinics – Patients age 0-13
Pediatrician
-Audiology
-Sleep referral
-Nutrition
-Therapy (PT, OT Speech)
-Care Coordination
-Social work
-Identify community partner

Patient care moves to STEP Clinic at Whitaker (age 18)
-Adult Primary Care
-Physical Therapy
-Care Coordination
-Social work
-Identify adult community partners
-Vocational rehabilitation

Future opportunities at COA

- Discuss transition early- in ALL pediatric clinics
  - Medicaid Waiver and maximize support for families BEFORE transitioning
- Understand optimal timing of healthcare transition and how to guide families
- Screen for Mental Health disorders
- Join our advocacy efforts in building this program
- Consider supporting additional complex care NP to do more inpatient transition consultations at COA
- Child life collaboration

Conclusions

- Transition programs cannot be the landing zone for every transitioning patient so transition must be embedded across systems in pediatric and adult hospitals
- Value of Med-Peds trained physicians in all specialties
- Interplay of advocacy, QI, equity and innovation

So much progress and so many STEPs yet to take!!

Questions and Contact

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