Reach for the Stars: Maximizing Health and Ability for Adolescents and Young Adults with Chronic Childhood Conditions

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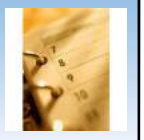
Disclosure

We declare that neither we, or our immediate family, have a financial interest or other relationship with any manufacturer/s of a commercial product/s or service/s which may be discussed at the conference.

Objectives

- Describe a model that you can use in your setting to improve transition from pediatric-centered to adult-centered health care
- Identify where to find validated tools to use for patients and/or their caregivers to assess their needs in transitioning
- Identify where to find resources for patients with chronic childhood conditions and their families



Healthcare Transition

- Definition: the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered care to the adult-oriented health care system.
- Goal: Help adolescents and young adults gain the skills and/or supports needed to successfully manage their health.

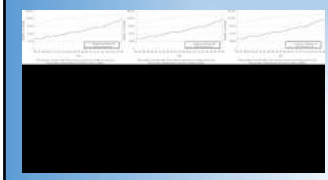
Transition ≠ Transfer

- Transition includes:
  - Directed preparation of adolescents to assume responsibility for their healthcare and maximize their livelihood as adults
  - Advanced planning for actual transfer event
    - Creating portable health summary
    - Arranging for insurance continuity, education/vocations services
    - Assessing legal needs
    - Assessing needs for income supports
- Transfer: Movement from pediatric providers to adult providers

Why is healthcare transition important?

- ALL ADOLESCENTS must transition from pediatric to adult-centered care even if they NEVER change providers
- There are an estimated 18 million adolescents, ages 18-21, about ¼ of whom have chronic conditions; many more millions if you count those 12-26.
- More than 90% of children born today with a chronic or disabling condition will live more than 20 years.

Why is healthcare transition important?



- 750,000 youth in the US with special health-care needs graduate to adulthood yearly
  - YSHCN account for 13% of all youth but 70% of medical expenditures

We need better healthcare transition

- Adolescent/young adult with chronic childhood illnesses/disabilities aren't prepared for the future:
  - High unemployment
  - High drop-out rate
  - Dependency on SSI/Medicaid
  - Limited day programs
- Recognized as a priority by the AAP, AAFP and the ACP.
  - The ACA stated that healthcare transition is an essential service
  - Healthy People 2020 incorporated transition planning as public health goal

Structured transition planning often leads to positive medical and social outcomes

- Improved adherence to care
- Increased patient-reported health and QOL
- Increased satisfaction with transfer
- Decreased gap between last pediatrician visit and first adult-provider visit
- Increased adult clinic attendance rates
- Decreased hospital readmission rates
- Increased condition-related knowledge

Gabriel P et al. "Outcome evidence for structure pediatric to adult healthcare transition interventions." J Peds. Sept 2017.

Barriers to Successful Transition

- Medical complexity
- Family involvement
- Psychosocial needs
- System issues
- Maturity/autonomy
- Transition coordination

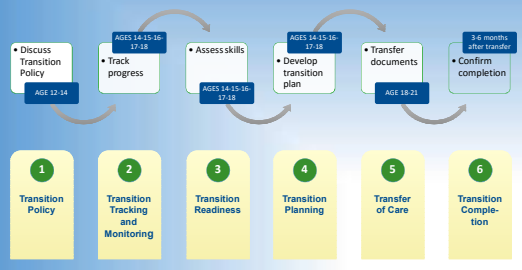
- Internist may feel uncomfortable with childhood conditions
- Family-centered care to Patient-centered care
- Social work
  - Insurance, guardianship, day programs, respite
- Pediatricians & families uncomfortable transitioning
- Few set transition plans/ guidelines

Peter, N. et al. Transition from Pediatric to Adult Care: Internists' Perspectives. Pediatrics 2009, 123 (2); 417-23.

Core Elements of Transition

1. Transition/Young adult care policy
   - Create and disseminate a policy amongst staff and patients
2. Transition/Young adult tracking and monitoring
   - Create a transition/young adult registry
3. Transition Readiness/Orientation to Adult practice
   - Conduct regular transition-readiness assessments
   - Establish a process to welcome young adults into practice
4. Transition Planning/Integration into adult approach to care
   - Update plan of care, portable medical summary, legal documents
   - Determine what supports may be needed
   - Ensure delivery or receipt of transition package
5. Transfer of Care
   - Confirm visit with new provider or clarify adult approach to care
6. Transfer completion/ongoing care
   - Communication between providers regarding transition process
   - Elicit feedback from young adult

Six Core Elements of Transition



Transition Timeline

There are many ways to approach healthcare transition

- Clinic dedicated solely to healthcare transition housed with a pediatric hospital
- A healthcare transition consult service
- A clinic dedicated to adults with developmental disabilities

A HCT Consult Service

AT THE FOREFRONT
UChicago Medicine

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Comer Children's

568 beds
47,000 annual ED visits

161 beds
31,000 annual ED visits

Average admissions of adolescents per year:
2,200
55% admitted to our adult hospital

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Med-Peds PATHways
Program for Adolescent and Adult Transition to Health

- Offers inpatient and outpatient consultation services
- Targets adolescents and young adults (primarily 14-25 years old)
- Consultations address key areas
  - Maintaining health insurance
  - Assessing health care skills and providing actionable ideas and resources for further autonomy
  - Assessing need for guardianship and providing referrals to legal services
  - Connecting families to educational, vocational, and independent living resources
  - Creating portable health summaries
  - Providing referrals to adult-centered primary and specialty care

Our Consultants

University of Chicago Med/Peds Residents

PATHways Referral Form

Date of referral: _____

Patient Name: _____ Patient DOB: _____ MRN: _____

Parent/Guardian: _____ Phone: _____

Referring Physician: _____

Phone: _____ Fax: _____ Email: _____

Please indicate follow up contact preference: :

MP PATHways provides transition support with a portable medical summary, youth-centered transition plan, and information about community resources and services.

Reason for referral:

_____

Please indicate specific youth and family interests or needs: We plan to focus on **top three** at the first visit, helping the youth and family with other topics at subsequent visits.

_____ Preparation for transfer to an adult provider (Specialty type _____ if applicable)

(Age at which you plan to transfer youth from your practice_____)

_____ Future health care financing issues

_____ Decision-making development and legal support recommendations

_____ Develop youth's health self-management skills

_____ Develop youth's activities of daily living skills

_____ Assist with parenting approach through transition process

_____ Recommendations for secondary school transition plan/IEP

_____ Post-secondary education/employment recommendations

_____ Clinical accommodations due to disability, i.e. hi-lo table, visual cuing, facilitated exams

_____ Assess and refer behavioral concerns to appropriate services

_____ Referral to community resources for adaptive services/supports

_____ Other: :

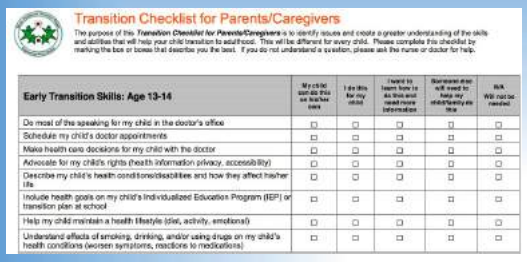
_____

(Please attach last office note, relevant past history, immunizations, etc. as available)

Please fax this form to 773-834-3950

Page for inpatient or outpatient consults X6788 (MPTT: Medi-Peds Transition Team) or if you have a question regarding the PATHways clinic.

Transition Evaluation

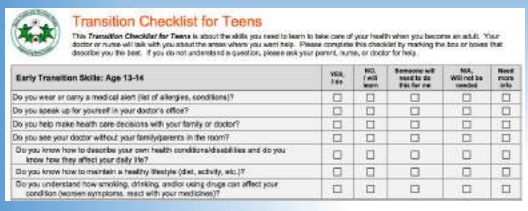


Transition Checklist for Parents/Caregivers

The purpose of this ***Transition Checklist for Parents/Caregivers*** is to identify issues and create a greater understanding of the skills and abilities that will help your child transition to adulthood. This will be different for every child. Please complete this checklist by marking the box or boxes that describe you the best. If you do not understand a question, please ask the nurse or doctor for help.

Early Transition Skills: Age 13-14	My child can do this on his/her own	I do this for my child	I want to learn how to do this and need more information	Someone else will need to help my child/family do this	N/A Will not be needed
Do most of the speaking for my child in the doctor's office	☐	☐	☐	☐	☐
Schedule my child's doctor appointments	☐	☐	☐	☐	☐
Make health care decisions for my child with the doctor	☐	☐	☐	☐	☐
Advocate for my child's rights (health information privacy, accessibility)	☐	☐	☐	☐	☐
Describe my child's health conditions/disabilities and how they affect his/her life	☐	☐	☐	☐	☐
Include health goals on my child's Individualized Education Program (IEP) or transition plan at school	☐	☐	☐	☐	☐
Help my child maintain a health lifestyle (diet, activity, emotional)	☐	☐	☐	☐	☐
Understand effects of smoking, drinking, and/or using drugs on my child's health conditions (worsen symptoms, reactions to medications)	☐	☐	☐	☐	☐

Transition Evaluation

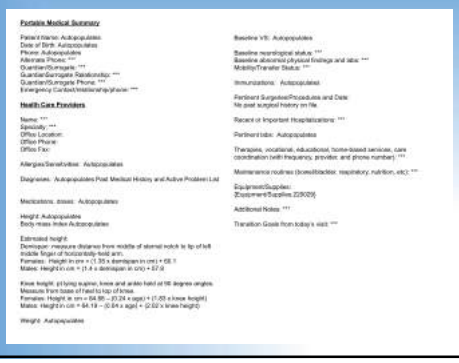


Transition Checklist for Teens

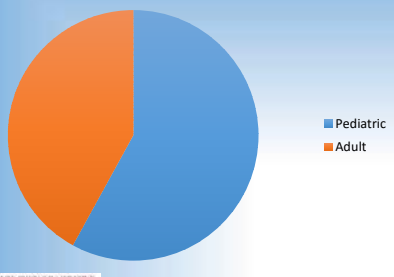
This ***Transition Checklist for Teens*** is about the skills you need to learn to take care of your health when you become an adult. Your doctor or nurse will talk with you about the areas where you want help. Please complete this checklist by marking the box or boxes that describe you the best. If you do not understand a question, please ask your parent, nurse, or doctor for help.

Early Transition Skills: Age 13-14	YES, I do	NO, I will learn	Someone will need to do this for me	NA, Will not be needed	Need more info
Do you wear or carry a medical alert (list of allergies, conditions)?	☐	☐	☐	☐	☐
Do you speak up for yourself in your doctor's office?	☐	☐	☐	☐	☐
Do you help make health care decisions with your family or doctor?	☐	☐	☐	☐	☐
Do you see your doctor without your family/parents in the room?	☐	☐	☐	☐	☐
Do you know how to describe your own health conditions/disabilities and do you know how they affect your daily life?	☐	☐	☐	☐	☐
Do you know how to maintain a healthy lifestyle (diet, activity, etc.)?	☐	☐	☐	☐	☐
Do you understand how smoking, drinking, and/or using drugs can affect your condition (worsen symptoms, react with your medicines)?	☐	☐	☐	☐	☐

Portable Health Summary Creation



Who is consulting us?



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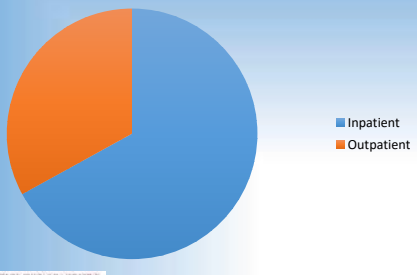
Consult Location



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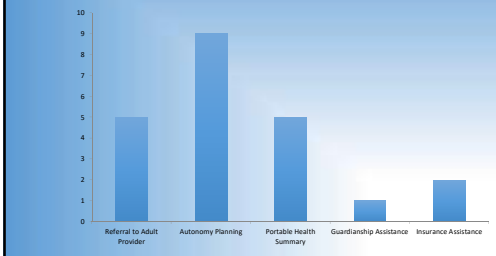
Reason for consultation



THE UNIVERSITY OF CHICAGO MEDICINE
Med-Peds PATHways
Program for Adolescent and Adult Transition to Health

Next Directions

- Introducing education to subspecialty ambulatory clinics
- Welcoming and engaging LEND scholars
- Expanding our consultation services within the pediatric and adult hospital

Adult Developmental Disabilities Clinic

Developmental Disabilities Population

- Severe, chronic conditions prior to age 22, mental or physical impairments, continue indefinitely
- Affect 3 or more areas of life activities, require life-long multi-disciplinary care:
  - Self-care
  - Receptive/expressive language
  - Learning
  - Independent Living
  - Mobility
  - Economic self-sufficiency
- Examples: Cerebral Palsy, Autism Spectrum Disorders, intellectual disability, cystic fibrosis, many others

Why is Medical Care for Adults with Developmental Disabilities Needed?

Increasing Prevalence due to increased live births and increased survival to adulthood

- Intellectual Disability: 1% of the general population
- More than 90% of individuals with severe disabilities reach adulthood.
- Each year in the U.S., ½ million children with special health care needs cross the threshold into adulthood.

Adults with Developmental Disabilities

Increasing Life Expectancy:
following similar trends in the general population

Intellectual Disability (ID): 1930s: 19 yrs, 1990s: 66 yrs

Down syndrome: 1920s: 9yrs, 56 yrs currently (Janicki, et. al)

Cerebral palsy: currently mid 50s.

Copus, et. al 2013

Adults with Developmental Disabilities(DD)

Challenges:

- No formal training
- Obtaining informed consent difficult
- Increased time for evaluation
- Access to healthcare: insurance
- Each provider has a small percentage of DD adults.

Adult Developmental Disabilities Clinic(ADDC)
Primary Care Group
University of Chicago

- Intellectual Disabilities(ID)
- Cerebral Palsy (with or without ID)
- Autism
- Epilepsy
- Spina Bifida
- Cystic Fibrosis
- Genetic Disorders:
  Down Syndrome, Williams Syndrome, Fragile X , Cornelia de Lange syndrome, Angelman syndrome

Adult Developmental Disabilities Clinic(ADDC)

Demographics

- 194 unique patients seen in the last 18 months
- 112 Male (57%)
- 82 Female (42%)

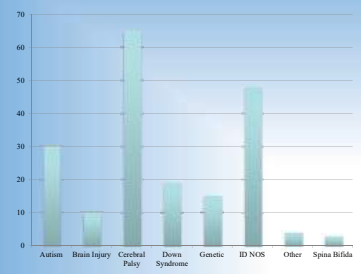
Race

- American Indian 1 (0.5%)
- Asian 1 (0.5%)
- Black/African American 153 (79%)
- White 35 (18%)
- Other 3 (1.6%)

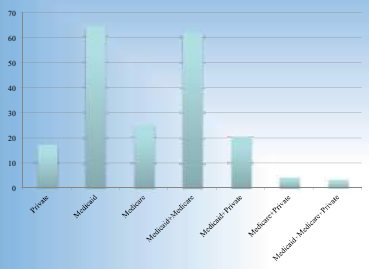
Ethinicity

- Hispanic/Latino 14 (7%)
- Not Hispanic/Latino 179 (93%)

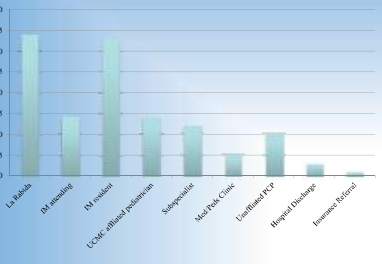
ADDC
Primary Diagnosis



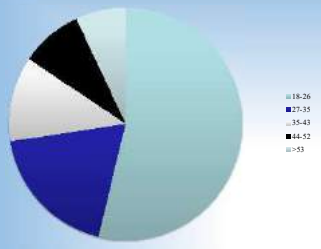
ADDC
Current Insurance



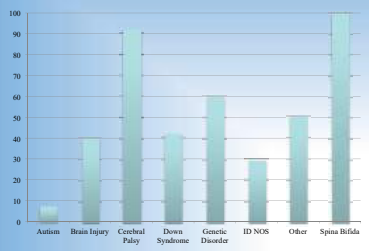
ADDC
Referral Source



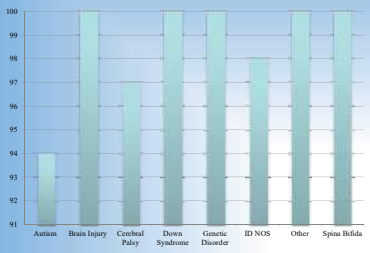
ADDC
Age at first visit



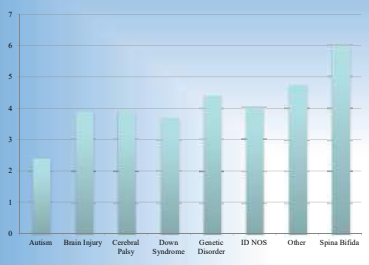
ADDC Percentage of patients with DME per condition



ADDC Percentage referred to subspecialists per condition



ADDC Average number of subspecialist seen per condition



Case: C.B.

Mr. C.B. is a 52 y.o. African American male with CP

- Using a wheelchair since early childhood, has hand contractures, neurogenic bladder, rare UTIs.
- Severe dysarthria, contractures of both hands, no decubiti
- He is obese (BMI 35), has hypertension, diabetes, and hypercholesterolemia
- He is accompanied by his brother for routine follow-up. His brother asks about colonoscopy.

A woman with Cerebral Palsy who died of inoperable cervical cancer after never having had a pap smear or pelvic exam despite annual physicals recorded by her assigned primary physician

Doostan & Wilkes 1999

Quality of Life and Disabilities (QOL)

Individuals with disabilities can accurately assess their QOL

Key to self report of QOL among people with disabilities:

Accurate modified instrumentation :

Self-Rated Quality of Life Scales for People with an Intellectual Disability: A review (R. Cummins, 1997)

Methodological Issues in Interviewing and Using Self-Report Questionnaires with People with Mental Retardation (Finlay & Lyons 2001)

Quality of Life and Disabilities

Public Opinion

"Non-disabled people believe that the QOL of people who live with disabilities is extremely low…When disabled people report about their own QOL, they rate it as only slightly lower than when non-disabled people self-report their own QOL" (Amundson 2010, pp374-375)

Professional Opinion

Healthcare professionals judge QOL of people with disabilities to be even lower (Albrecht & Devlieger 1999)

Screening Tests for Adults with Intellectual Disabilities

- Multitude of USPSTF recommendations for general population.
- Evidence-based screening recommendations are lacking in adults with intellectual disabilities.
- Wilkinson et al. reviewed literature and provided USPSTF grade recommendations

Adults with Developmental Disabilities

Health Disparities

Healthy People 2020 and Closing the Gap:

Goal is to eliminate health disparities among people with disabilities

Ethical considerations:

" equity in health is an ethical value, inherently normative, grounded in the ethical principle of distributive justice…"

Braveman & Gruskin 2003

In Hospital Comprehensive Program

OUR STRUCTURE

- 1 Medical Director, Physician
- 1 Transition Coordinator, Social Work
- Transition Steering Committee
  - Initially Representatives from divisions that received pilot grants
  - Opened to representatives from all divisions

MISSION

- Assist in all areas of transition
- CLINICAL
  - Direct Patient
  - Group Sessions
- RESEARCH
- ASSISTIVE PROGRAMS
- PROVIDER EDUCATION

Our vision:

We are guided by the belief that all youth with special health care needs should be prepared for adult life with maximum integration into school, work and community. These youth should also be prepared for the adult health care environment and have continued access to medical care as an adult. Our vision is inspired by the numerous children with special health care needs who are now surviving and thriving into adulthood.

Our mission:

Our mission is to prepare all teens with special health care needs for adult life and improve health care competency in order to ensure a successful transition to adult health care. In order to do so we focus on the following areas:

- Clinical
  - Build relationships with adult providers for primary and specialty care, and develop comprehensive, efficient, and satisfactory methods for transfers of care between pediatric and adult providers
  - Improve readiness of young adult patients with chronic illnesses to transfer care to adult providers
  - Prepare young adults to enter the adult world with regards to professional and social maturity
  - Ensure patients and families are aware of all public benefits and insurance opportunities that are available to them
  - Support specialty clinics to implement transition programming
- Research
  - Enhance knowledge of best practices in transition
  - Enhance the understanding of the current state of adolescent and transition related issues
- Education
  - Competency training for providers on transition
  - (one of the goals Chris and I were talking about was the confidentiality piece and having some education for providers-I think this is included in the above statement, confidentiality education as part of transition education)
  - Education for patients, families, and the community to prepare for transition to adult life and adult health care
  - Education for outside medical providers on the adult health care needs of patients with special health care needs

Lurie Transition Programs and Resources

- Quarterly Transition Steering Committee Meetings
  - Interdisciplinary team
- Transition Medical Visit
  - Referrals through EPIC
- Division Specific Transition Programs
  - MDA, Sickle Cell, Transplant, Spina bifida etc.
- SAILS: Supporting Adolescents with Independent Life Skills
  - Yearly group life skills program
- SAILS Work Force Development Program
  - Paid work experience in the hospital
- The POINT → Patient Education Materials → Transition
  - Transition Handouts for families
- Mini grant proposals in 2015
  - Concierge Service to 1st Appointment
  - Developing a Matrix of Specialists
  - Focus group of transitioned youth
  - Adult providers as part of Lurie clinic

51

PATIENT & FAMILY RESOURCES

- Lurie Children's Website
  - https://www.luriechildrens.org/en-us/care-services/specialties-services/transitioning-to-adult-care/Pages/index.aspx

Webinar: Transition 101: Introduction to Planning for Transition for Youth with Special Healthcare Needs

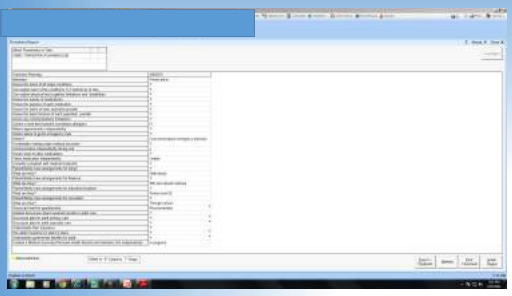
- Focus for parents with a young adult with developmental disability
- ParentWise Partnership
- https://www.luriechildrens.org/en-us/care-services/specialties-services/transitioning-to-adult-care/Pages/index.aspx

TRANSTION TEAM CLINIC VISIT

Outline/Structure

- NOT FUNCTIONING AS PMD
- Referral Based
  - Internal and external providers
  - Ideally for youth that don't have strong PMD
- MD and SW staff
  - Find adult PMD
  - Review Medical Summary
  - Checklist
  - Coordinate with specialists
  - Guardianship
  - Legal referrals
  - Federal and state programs
- 1 ½ hour long visits initial
- ½ day per week every other week
- 25 patients/year

Use A Checklist



ASSESSMENT

1. Health Care Knowledge and Skills

Mother describes conditions, medications, providers well.

2. Adult Care Plan:

Mother currently seeking adult provider that is comfortable with chronic illness. Option would be Dr. xxxxxxxx at NMH, to keep providers in one place. Transition team to contact Dr. xxxxxx.

Other options would be Med-Peds program in UIC, Rush, or Erie Family Health.

For specialty care:

Endocrine –Intention from Peds Endocrinologist was to have patient see adult endocrinology and then come back to Lurie for one more visit. Patient also recently had DEXA scan and will discuss with Dr. xxxxxx. Dr. xxxxxx has given number for mother to call for adult endocrine appointment at NMH.

Dentistry – Transition team to ask dentistry regarding how long they will continue to see patient.

Urology – Will need yearly follow up of epidydimal cyst for growth and/or surgery for removal if symptoms develop. Referral given by Lurie Endocrinology for urology at NMH.

Cardiology – Already seeing Pediatric/Adult Cardiologist. Patient to make appointment in 6/2016 for visit every 2 years with echo.

Neurology – Will need continued follow up for epilepsy care, and medications. Lurie Neurology may continue to see patient for forseable future.

In addition patient sees ophthalmology at a private clinic and orthopedics at xxxx. Mother to ask regarding continuing care at these sites.

ASSESSMENT

3. Education/Vocation:

Looking into last year in transition program at xxxx high school.

4. Living:

Currently living at home with mother and uncle.

5. Insurance/Benefits:

Is receiving adult SSI.

He is currently covered under adult Medicaid, received letter about placement into ICP managed care program. Discussed plans listed and discussed which plans accepted by Lurie and Northwestern. Will need to enroll in ICP plan soon.

6. Future Needs/Guardianship:

Guardianship established

RESOURCES:

Family given Clinical summary document

Follow up with transition team:

6 months

CLINIC DATA

Demographics	Average(SD)	SD or %
Age	20.0 (1.7)	1.7
Number of Conditions	6.5(3.6)	3.6
Number of Specialists	3.4(2.3)	2.3
Insurance as Adult		
Public	19	56
Private	11	32
Unknown	4	12
Transition to Adult Primary Care Providers		
Already Had	12	35
Family Chose	5	15
Transition Team Referred	7	21
Still Seeing Pediatric	4	12
Unknown	6	18

SAILS: Supporting Adolescents with Independent Life Skills

SAILS: Program and Partners

Community Partners

- Parent/Peer Wise Volunteers
- Lurie Children's Department of Child and Adolescent Psychiatry
- Walgreens Pharmacy (in hospital)
- Medical Legal Partnership- Legal Aid
- JVS Chicago Youth Work Program
- Center for Law & Social Work
- Local colleges (DePaul & Loyola University)

SAILS: Launching into Employment

SAILS: Launching into Employment

- Referrals from medical team
- Interview with HR Workforce/transition Team
- Corporate Health
- Triage to funding source
- Placement recommendations in collaboration with corporate health
- Group Orientation (Lurie and SAILS)
- On going workforce development sessions
  - Resume, interviews, communication, power points
- Feedback, evaluations, exit interviews
- Referral to ongoing support to JVS if eligible

Contact Information

- Rebecca Boudos, LCSW
  - rboudos@luriechildrens.org
- Parag Shah, MD
  - Pshah@luriechildrens.org

Transition Resources

Where to Start

www.gottransition.org

ICAAP Transition Handouts

http://illinoisaap.org/projects/medical-home/transition/

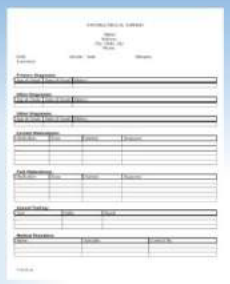
Resources and Tools for Families

File Name	Size	Link
TransitionAdulthoodTeen.pdf	571 KB	Transition to Adulthood Handout for Teens
HealthCareTransition.pdf	457KB	Health Care Transition Handout
ChecklistTeens.pdf	284 KB	Transition Checklist for Teens
ChecklistCaregiver.pdf	242 KB	Transition Checklist for Parents/Caregivers
HowWellKnowHCNeeds.pdf	239 KB	How Well Do You Know Your Health Care Needs?
TransitionAdulthoodParent.pdf	884 KB	Transition to Adulthood Handout for Parents and Caregivers
DifferencesInCare.pdf	559 KB	Differences in Care
TransitionTimeline.pdf	1,366 KB	Transition Timeline
TransitionIssuesSpecialNeeds.pdf	915 KB	Transition Issues for Adolescents with Special Needs Brochure
GuideToAdultBenefitsReadOrder.pdf	1,270 KB	Guide to Adult Benefits, Services, and Resources
GuideToAdultBenefitsPrintOrder.pdf	1,209 KB	Guide to Adult Benefits, Services, and Resources (for print orders)
Guardianship.pdf	761 KB	Guardianship and Alternatives
DoYouUnderstandInsurance.pdf	347 KB	Do You Understand Insurance?
FillingPrescription.pdf	456 KB	Filling a Prescription
MedicalEmergency.pdf	431 KB	What To Do In A Medical Emergency
TakeMedsAsDirected.pdf	337 KB	Take Medications As Directed
WorkingWithDoctor.pdf	477 KB	Working With Your Doctor
FindingAdultProviders.pdf	443 KB	Finding Adult Providers
PortableMedicalSummary.pdf	137 KB	Portable Medical Summary

My Med Schedule

www.mymedschedule.com

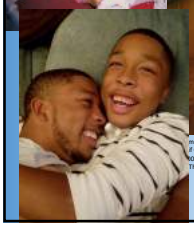
Portable Medical Record

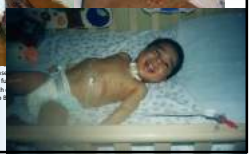


Health Care Transition
A Parent's Perspective

Gina M. Jones, BSN, RN

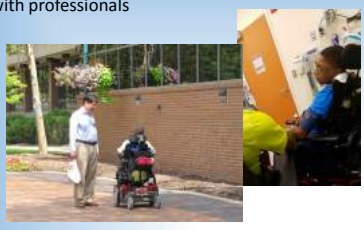
Our Story





Health Care Transition

- Partnering with professionals
- Tools
- Resources



Care Map

Gavin

Garrett


Thank You!