



TRANSITION TO ADULT HEALTH CARE

Michelle Maeda, MS, RD Children with
Special Health Needs Program

Kau`i Rezentes, Hilopa`a Family to Family,
Mama of Ava



GOALS FOR TODAY

- Understand why transition is needed
- Obtain an overview of what the adult healthcare system looks like
- Start a simple timeline of key items that should be done
- Start thinking of a game plan...Envision the first visit with an adult provider



WHAT IS HEALTH CARE TRANSITION?

"Health care transition, or HCT, is the process of moving from a child/family-centered model of health care to an adult/patient-centered model of health care, with or without transferring to a new clinician. It involves planning, transfer, and integration into adult-centered health care."

"What is Health Care Transition?"
Got Transition, The National Alliance to Advance Adolescent
Health. www.gottransition.org/six-core-elements/.

WHY DOES TRANSITION NEED TO HAPPEN?

- Once a child reaches age 18 (the age of majority) they are legally an adult, regardless of their capabilities
 - When applying for state/federal benefits, family income is no longer counted as the adult is considered a family of one
 - Legally, the individual will be looked upon to make their own life decisions
- As an adult, there are different medical issues that should be watched and screened for, in addition to any medical conditions that a person is born with



WHY IS THIS TRANSITION HARD?

ACTION

- Medical treatment for complex pediatric conditions dramatically improved lifespan for our keiki in the last few decades
- Society's views on disability have changed over the last few generations, going from institutionalizing individuals to encouraging community engagement and participation
- The prevalence of autism has dramatically increased in the last few decades

REACTION

- Adult medical providers may be unfamiliar with certain pediatric conditions and their treatments
- Adult medical providers may not be used to interacting with individuals with childhood disabilities and their families





3 AREAS OF CHANGE

INSURANCE

MEDICAL PROVIDERS

SYSTEM





Private Insurance

- **Hawaii PrePaid Healthcare Law-** Employers are required to offer health insurance to employees working at least $\frac{1}{2}$ time
- **Affordable Care Act-** children can stay on parents insurance until 26 years of age, regardless of employment/school status

State/Federal Insurance

- Children Quest/Medicaid coverage until 19th birthday, then need to apply for adult Quest/Medicaid
- Once individual reaches 18 years of age, income criteria is based on the individual's income alone, not family (this is also true for SSI)
- As of January 2023 adult Quest/Medicaid covers preventative dental



MEDICAL PROVIDERS

- Physicians-Some pediatricians and pediatric specialists see patients until age 18, some until 21
- Kapiolani Women and Children's Medical Center will not typically see males or females past the age of 21 or so.
- Shriner's Hospital see patients until 21 for the most part....please check if they have recommendations for wheelchair, ortho prosthetics follow up

PEDIATRICS

ADULTS

CARDIOLOGY

- Hypoplastic Left Heart Syndrome
- Tetralogy of Fallot
- Dextrocardia
- Double inlet L ventricle
- Coronary Artery Disease
- Heart Attacks
- Atrial fibrillation
- Congestive Heart Failure



SYSTEMS

Pediatrics

- Family Centered
- Longer length of appt
- Primary Care/Specialty Care affiliations
- Central pediatric center

Adult

- Patient Centered
- Shorter length of appt
- Primary care/Specialty Care affiliations possibly more distant
- Multiple adult hospitals



BARRIERS TO TRANSITION

ADULT SIDE

PEDIATRIC SIDE

- Lack of training in childhood onset conditions
- Doctor shortage
- Lack of insurance payment models for the level of care needed
- Lack of support staff and care coordination services
- Fragmentation of the adult health care system, poor integration with mental health and social services
- Communication gaps between Pediatric and Adult care
- Difficulty of pediatric provider to “let go”
- Lack of preparation for transition on both Pediatric and Adult side



RECOMMENDATIONS

- Preparing the future health workforce through education and training
 - Require medical students (MD, PA, NP) a minimum exposure to complex patients with childhood conditions
 - Establish fellowships focusing on YAMC
- Providing additional supports for the current primary care workforce
 - Create Regional Centers of Excellence for YAMC care to facilitate sharing of knowledge between pediatric and adult PCPs and specialist
- Supportive payment policy
 - Increase payment rates for PCP, add codes for complex YAMC care
 - Establish payment for care coordination
- Research on key needs and issues impacting on care of YAMC
- Coalition building for implementation and sustainability







BARRIERS TO TRANSITION

Providers

- **PCP, Specialists**
- **Adequate home nursing**
- **Specialty medicine provision**

SSA/Medicaid

- **Maintaining income eligibility**



- **Financial**
 - **ABLE accounts**
 - **Special Needs Trust**
- **Legal**
 - **Guardianship**
 - **Power of Attorney**
 - **Surrogate Decision Making-Health**

Declaration of Authority to Act as Surrogate For a Patient*

I, _____, under penalty of false swearing,
(Name of Surrogate)

provide the following statement of facts and circumstances establishing my authority to act as surrogate for _____
(Name of Patient)

who has been determined by the primary physician to lack capacity to make healthcare decisions and no agent or guardian has been appointed or the agent or guardian is not reasonably available.

(MARK APPLICABLE BOX)

A. Patient-Designated Surrogate

I have been provided information that the above named patient personally informed the supervising health care provider that I have been designated by the patient to make health-care decisions for the patient. This information was provided to me by the following means:

(e.g., orally by (name of supervising health-care provider--primary physician/designee, health care provider or designee); by letter dated _____ (copy attached); as recorded in patient's health-care record, etc.)

OR

B. Appointed ("Non-Designated") Surrogate

I have been selected by consensus of interested persons of the above named patient to act as the patient's surrogate

I. I am an interested person based on my relationship to the patient as:

(Mark or Circle One)

- | | |
|--|---|
| <input type="checkbox"/> Spouse (not legally separated or estranged) | <input type="checkbox"/> Reciprocal Beneficiary |
| <input type="checkbox"/> Adult Child | <input type="checkbox"/> Parent |
| <input type="checkbox"/> Adult Sibling | <input type="checkbox"/> Adult Grandchild |
| <input type="checkbox"/> Other Adult who has exhibited special care and concern for the patient and who is familiar with the patient's wishes. | |



SOME TIPS TO CONSIDER.....

- **Be Patient**
- **Ask around**
- **Complete legal paperwork**
 - **Legal guardianship- most restrictive**
Surrogate Decision Making for health care
Power of Attorney (requires capacity)
- **Schedule a well visit** (annual physical, etc)...do not wait until an illness for the 1st visit
- **Be prepared** Have a list of questions or concerns that you want addressed
- **Hospital systems**
- **Transition letter** from your current PCP/specialist





- One of the largest EMRs in the United States
- Allows individuals to view entire MD note from 2021 (not just the after visit summary)
- Most recent test results as well as previous results can be viewed, this also includes MRIs, CT scans and X rays
- Parents/caregivers can request Proxy access to manage family's healthcare
- If seeing a health care provider who does not have Epic, can utilize Share Everywhere that allows a one time access to your My Chart to anyone with internet access. That individual would also be able to chart a note

10:24 mychart.hawaiipacifichealth.org

MyChart by Hawai'i Pacific Health

Menu Michelle

Visits Messages Test Results Medicatio...

Welcome!

Appointment Scheduled

MyChart System
Feb 29

Appointment Information: Visit Type: Follow Up Visit...

[View message](#)

Appointment Scheduled

10:24 mychart.hawaiipacifichealth.org

Menu M

Last 3 Months

FEB 27 2024 Hospital Outpatient Visit
Women's Health - Kapi`olani Women's Center

[View After Visit Summary®](#)

FEB 20 2024 Telephone
Stephen D Arnold
Internal Medicine - Straub Clinic King St

[View notes](#)

[View After Visit Summary®](#)

FEB 15 2024 Office Visit
Stephen D Arnold
Internal Medicine - Straub Clinic King St

[View notes](#)

[View After Visit Summary®](#)

10:25 mychart.hawaiipacifichealth.org

Menu M

After Visit Summary® Notes

[Click here](#) to learn how to get the most out of your notes and to also learn about Information Sharing.

Progress Notes

Stephen D Arnold at 2/15/2024 6:30 AM

LCE 2/6/23*

This 58-year-old woman comes in today for her annual physical examination. She has some mild orthopedic complaints some discomfort in her right neck and shoulder which seem to be relieved by using a soft neck brace at night to sleep. She also has some occasional twinges in her knees. For the time being, exercise limited to elliptical and to outrigger paddling. She was diagnosed with DCIS upper outer quadrant left breast in May 2019 (E+//P+) -- she opted to be in a trial of Tamoxifen daily for 5 year (which will end October 2024) with opportunity to do a lumpectomy at any time. She is followed by Dr. Jamie Fukui and Dr. Laura Peterson. She opted not to do



10:26 mychart.hawaiiipacifichealth.org

Menu M

Settings and filters

- CBC PLT W/AUTO DIFF**
Feb 15, 2024
Stephen D Arnold
- COMP METABOLIC PANEL**
Feb 15, 2024
Stephen D Arnold
- HEMOGLOBIN A1C AND EAG**
Feb 15, 2024
Stephen D Arnold
- LIPID PANEL 2 W/RFX DLDL**
Feb 15, 2024
Stephen D Arnold

10:26 mychart.hawaiiipacifichealth.org

Menu M

Compare result trends

WBC
Normal range: 3.8 - 11.2 10(9)/L
6.5

RBC
Normal range: 3.9 - 5.2 10(12)/L
4.58

Hemoglobin
Normal range: 11.6 - 15.1 g/dL
14.8

Hematocrit
Normal range: 34.1 - 44.2 %

10:27 mychart.hawaiiipacifichealth.org

Menu M

Settings and filters

RBC
Normal range: 3.9 - 5.2 10(12)/L

Data table

Date	Value	Normal Range
Feb 15, 2024	4.58	3.9 - 5.2 10(12)/L



MyChart MyChart by Epic

Menu

Search the menu Close

Sharing


- Sharing Hub
- Share Everywhere
- Link My Accounts
- Lucy
- Request Access to a Minor's Record

Resources

- Search Medical Library
- Research Studies
- Education

Appointment Scheduled

here



Share Your Health Record

Grant one-time, limited access to the health information you can see in MyChart, including:

- Medications
- Allergies
- Health Issues
- Immunizations

The person accessing your record will also be able to write a clinical note to your care team.

If you request a share code it will expire after 60 minutes.

Who's accessing your record?

Request share code

[Back to the home page](#)

12:58 shareeverywhere.epic.com

Epic

- Medications
- Allergies
- Health Issues
- Immunizations

Share Code

Patient Date of Birth

[View Record](#)

Looking for more information [Privacy - Terms](#)



HAWAII HOSPITALS USING EPIC MY CHART

- HPH- Kapiolani, Straub Medical Center, Pali Momi Hospital, Wilcox Hospital
- Queen's Health System- Queen's Medical Center, Queen's West, (Wahiawa?)
- Hawaii Kaiser Permanente
- North Hawaii Medical Center
- Kona Community Hospital



THINGS THAT EPIC MY CHART MAY NOT HAVE

- Information on equipment and/or medical supplies (i.e. Medline, Pharmacare, Optioncare, Apria)
- Hospitalizations
- Assessments/information from the DOE system (including reports is individual was accessing services provided by CAMHD via DOE)
- Nursing information if nursing provided by Medicaid/DDD
- Shriners Hospital Hawaii does not use Epic



THINGS TO KEEP IN MIND

In Hawaii, minors have the right to see mental health and fertility professionals without parents consent at age 14, so parents access to information gets limited in their minor child's My Chart. Please discuss with your primary care provider prior to 14 birthday, or if you experience lock out. PCP needs to fill out a Diminished Capacity form for parents to maintain full access

At age 18, parents completely lose proxy access....but your 18 year old can log on and give you proxy access via the Share Hub....or please bring up with your PCP to ensure your continued access. At this point, you may have to show legal paperwork



RESOURCES

- Got Transition: <https://www.gottransition.org/>
- Footsteps to Transition: <https://footstepstotransition.weebly.com/>
 - Turning 18, Health and Money: [Surrogate Decision Maker](#) (healthcare)
[Uniform Healthcare Decision](#)
- Hilopa`a: Hawaii's family to family resource: <https://www.hilopaa.org/>
- Free template One Page Profiles: <https://oregonisp.org/lppa/>
- SPIN conference: <https://spinconference.org/>
 - Archived workshops 2016 Scott Suzuki, Esq: [“Rights of Passage”](#) (Guardianship and Alternatives)





QUESTIONS?

