

Presenter:
Leolinda Parlin

Launching into Adulthood

HIL PA'A
Family to Family Health Information Center

Training Objectives



HILOPA'A
Family to Family Health Information Center

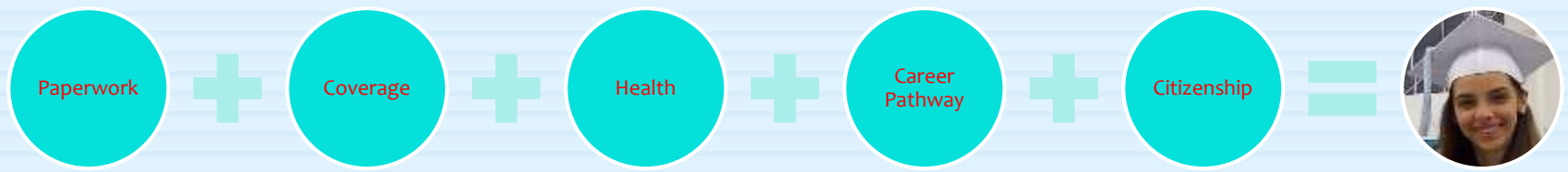
- Identify and address the challenges and issues related to transitioning youth to adulthood
- Identify opportunities to develop transition skills
- Identify traps in transition planning
- Review local resources and tools to assist with the facilitation of transition

What & Why?

A little perspective



What Is Transition?



Why Transition?

- 27% of young adults are uninsured
- 22% of young adults are living at the poverty level
- 37% of young parents are living at the poverty level
- 45% of young adults deferred medical treatment because of cost

U.S. Census Bureau 2010; Commonwealth Fund, “How the Affordable Care Act is Helping Young Adults Stay Covered” 5/2011



In Hawai'i

- 60% YSHCN have doctors who talked about changing needs
- 54% YSHCN have a plan for dealing with changing needs
- 36% YSHCN have doctors who discussed the shift to adult health care provider
- 29% YSHCN have received vocational or career training

Additional Hawai'i Data

YSHCN receive services necessary to make transitions to adult life, including adult health care, work, and independence

Hawai'i	Nationwide
37.3%	40%

Bottom Line

Kids are
living longer

Parents have
higher
expectations

Youth have
higher
expectations



Strategies

- 1 – Get in the Zone
- 2 – Get the Small Stuff Done
- 3 – Make the Big Decisions



Service Shift

- Family Centered to Person Centered
- Changing Focal Point
- Role as an Informer

Paper Work

- Valid Photo ID
- Wallet Emergency Card

<p>My Mother 12/29/25</p> <p>Drug Interactions</p> <p>Zestril - weakness Vioxx, Niacin - rash, swelling Aspirin irritation Erythromycin - nausea, vomiting</p> <p>Pain Management</p> <p>Fentanyl 50mcg/hr – 3 day rotation As Needed: Tylenol w/codeine 15mg</p> <p>Current Daily Medication</p> <p>AM: Diltiazem 250mg, Protonix 20mg 2 tabs PM: Ocuville 2 tabs, Xanax .125mg</p> <p>Vitamin/Supplements: Calcium 1000mg 50,000 IU alternating wks, Fiber 50g polycarbophyl, Senokot-S</p>	<p>My Mother 2/30/25</p> <p>In case of emergency, please contact:</p> <p>Leolinda Parlin – 282-6348</p> <p>Ana Gamble – 123-4568</p> <p>Marcus Welby –123-4569</p> <p>Or call 911</p>
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Paper Work

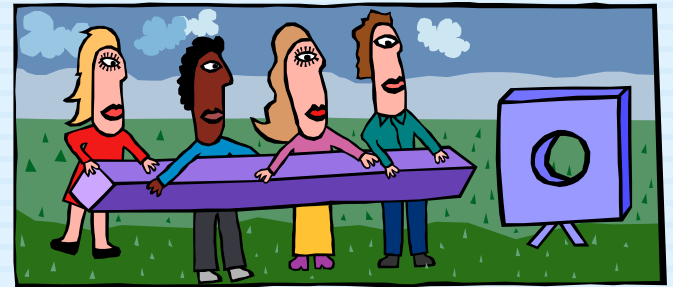
- Valid Photo ID
- Wallet Emergency Card
- Personal Health Record
- Power of Attorney
- Archive Diagnostic Documentation

Medical Coverage

- Dependent Adult Coverage
- Medicaid

Primary Care

- PCP
 - ▣ Parents' PCP
 - ▣ Specific Disease Management Experience
 - ▣ Med-Peds
 - ▣ Family Medicine
 - ▣ Geriatrics
- Reproductive Counseling



Career Pathways

- Volunteerism
- Diploma/Certificate
- Continuing Education
- Supported Employment



Volunteering

What

- Developing Skills
 - Stick-to-it-ness
 - Coping
 - Kuleana

How

- Reciprocal Outreach
- Find the Stuff That's Not Getting Done



Diploma/Certificate

Diploma

- Documentation of Proficiency within a Course of Study



Certificate

- Documentation of Completion of Special Education Requirements of an Individualized Program

Career Pathways Continued

Continuing Education

- No IEP in College
- Focus on ADA
- Campus Disability Coordinator

Employment

- Supported Employment
- Vocational Training

Citizenship

- Alternatives to Guardianship
- Special Needs Trusts
- Voter Registration
- Selective Service Registration
- Leisure Activities
- Social Programs
- Living Arrangements
- Transportation



Transition Philosophy



Starting Early

Community Response

- Support hope
- Celebrate the positive
- Talk about the future
- Provide respite
- Encourage families

Family Response

- View the child as a child, not by the condition
- Avoid “special treatment”
- Encourage learning new skills
- Have expectations and push the limits
- Support child’s/youth’s aspirations

Avoiding Traps

Don't get tripped up



Parent Traps

- Parent Traps
 - Diploma disappointment
 - Need to have all SPED type services carry over
 - Unaware of rights within the community colleges/employers


Provider Traps

- Waiting for the family to raise the issue
- Hoping “Somebody” will make connections to adult service programs
- Carrying over “old goals”
- Focusing on coverage/supervision of youth’s time


Resources for Families



www.hilopaa.org



Hilopa'a Family to Family Health Information Center
UNDER REVISION




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As a parent or a caregiver of someone with special health care needs, you are often the *ho'okele* or steersman navigating through the health care system. Often times, there's no map to help you figure out your next step. The Hilopa'a F2FHIC is here to help you. We are staffed by "veteran moms" who are prepared to give you the *kokua* you need to guide your family's canoe through the sometimes turbulent waters to good health.

HILOPA'A

Family to Family Health Information Center



We are just a phone call away and serve all islands:

O'ahu	 (808)791-3467 	Moloka'i	 (808)660-0063 
Hawai'i	 (808)333-3053 	Kaua'i	 (808)240-0485 
Maui & Lana'i	 (808)270-1536 	Fax - O'ahu	(808)531-3595

We are also the Obmudsman for the Hawai'i State Medicaid Programs.

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1319 Punahou St. Ste 739 Honolulu, HI 96826 email: info@hilopaa.org

Personal Health Record

Combined Pediatric & Adult Medicine Record

“Non-traditional” Information

- Guardianship
- Communication
- Behavior

Available online

<http://hilopaa.org/Documents/phr.doc>

Personal Health Record

www.hilopaa.org/med/phi/phi

Date form completed	By whom	Revised	Index
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Name:	Birth date:	Nickname:	<input type="checkbox"/> Adv. Directives <input type="checkbox"/> Self Guardian
Home Address:	Home/Work Phone:		
Parent/Guardian:	Emergency Contact Names & Relationship:		
Signature/Consent:			
HE:	WE:	Blood Type:	How I Communicate:
Primary Language:		Phone Number(s):	
Physicians:			
Primary care physician:		Emergency Phone:	
		Fax:	
Current Specialty physician:		Emergency Phone:	
Specialty:		Fax:	
Current Specialty physician:		Emergency Phone:	
Specialty:		Fax:	
Dentist:		Emergency Phone:	
Anticipated Primary ED:		Pharmacy:	
Anticipated Tertiary Care Center: <input type="checkbox"/> Queens <input type="checkbox"/> Kaiser <input type="checkbox"/> Tripler <input type="checkbox"/> Kapiolani <input type="checkbox"/> Straub <input type="checkbox"/> St. Francis			

Current or Active Conditions:	
1.	Baseline physical findings:
2.	
3.	Baseline vital signs:
4.	
Synopsis:	Baseline neurological status:

Transition Checklist

Recommendations based upon the broad categories


Paper Work

Medical Coverage

Career Pathways

Citizenship

Includes recommended timelines to begin discussions



HO'OPA'a

HAWAIIAN AUTISM SPECTRUM INITIATIVES GRANT

Transition Checklist

Hot Topics for Successful Transition to Adulthood

As you begin to consider the process of preparing our youth with ASD to adulthood, prepare to discuss these topics with your family and natural support system. Take care of the "easy stuff" first, so you have time to make good decisions.

Plan	Timeline	Do
Service Shift <input type="checkbox"/> Family Centered to Person Centered		Prepare yourself for the shift in service and legal systems and prepare youth for shift in increasing responsibility and expectations. Practice having youth answer questions before parents. Prepare youth with appropriate responses.
Paper Work <input type="checkbox"/> Valid Photo ID <input type="checkbox"/> Wallet Emergency Card <input type="checkbox"/> Personal Health Record <input type="checkbox"/> Power of Attorney <input type="checkbox"/> Archive Dx Documentation		
Medical Coverage <input type="checkbox"/> Dependent Adult Coverage <input type="checkbox"/> Medicaid		
Primary Care <input type="checkbox"/> PCP <input type="checkbox"/> Reproductive Counseling		
Career Pathways <input type="checkbox"/> Volunteering <input type="checkbox"/> Diploma/Certificate <input type="checkbox"/> Continuing Education <input type="checkbox"/> Supported Employment		
Citizenship <input type="checkbox"/> Alternatives to Guardianship <input type="checkbox"/> Special Needs Trusts <input type="checkbox"/> Voter Registration <input type="checkbox"/> Selective Service Registration <input type="checkbox"/> Leisure Activities <input type="checkbox"/> Social Programs <input type="checkbox"/> Living Arrangements <input type="checkbox"/> Transportation		Parents must initiate coverage through their employer prior to child's 19 th birthday – plan for 9 months lead-time. Medicaid is always an option, eligibility requirements change at age 18 - youth are considered household of "1". Begin early to find the right PCP. Consider parent's physician, MED-PEDs, and Family Medicine physicians. Insure youth have access to reproductive and genetic counseling. Job skills can be developed at any age. It is easier to get off the diploma track than it is to get on midway. All HI campuses have disability coordinators. There is NO JEP in higher education. Formal employment supports can be provided through Vocational Rehabilitation or the DD/MR Waiver – begin planning in fall prior to exit. Protect youth rights and insure the financial security of the family. Conduct research and discuss best approach. All men are required by law to register for the draft. It is only if the draft is called will the youth be determined fit to serve. Combine leisure and social activities to develop natural supports. Begin exploring social programs and potential living arrangements in fall prior to exit. Consider bus coaching or drivers ed during high school. Explore disability related passes and permits.

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Grant #HAWMRC20127 from the Health Resources and Services Administration (Maternal and Child Health Bureau), Hawaii Pediatric Association, Research and Education Foundation, © Hawaii's Department of Health's Children with Special Needs to Reach American Academy of Pediatrics Hawaii's Chapter, © Hawaii's Family to Family Health Initiative, © Family Issues in Hawaii's, www.hawaii.org/maai/Vol.asp

Transition Planning Workbook

Designed for Families

Talk Story Guide

- “What do I have to do?”
- “What do I have to decide?”
- “What skills does my child or child’s caregiver need?”
- Timeline for planning

Phone Support through
Hilopa‘a Family to Family
Health Information Center

Available online

<http://hilopaa.org/Documents/transitionplanningworkbook1.pdf>

Transition Planning
Workbook

Hilopa'a Style 1.1

Youth: _____

Team: _____

Grant #D70MCO4460 from the Health Resources and Services Administration:
Maternal and Child Health Bureau

Family Voices of Hawai'i, State of Hawai'i Department of Health Children with
Special Health Needs Branch
American Academy of Pediatrics—Hawai'i Chapter University of Hawai'i JABSON
Department of Pediatrics—Community Pediatrics Institute

Resources for Providers



Transition Planning PCP Checklist

Designed for Typical Youth and Youth with Special Health Care Needs

Single Page Covers the Hot Topics

Meant to Facilitate Discussions throughout the Transition Years

TRANSITION PLAN CHECKLIST

Transition Topic	All Youth	Youth with Special Health Care Needs
Insurance Coverage	<input type="checkbox"/> Eligible for Student Coverage? Parent Plan University Plans <input type="checkbox"/> Employer Based <input type="checkbox"/> Individual <input type="checkbox"/> Medicaid	<input type="checkbox"/> Dependent Adult Coverage <i>Parents must initiate coverage through their employer prior to child's 19th birthday</i> <input type="checkbox"/> Medicaid <i>Once the child is 18, the family's income and assets are no longer considered, only those of the individual applicant</i>
Finalize Prior to Transition	<input type="checkbox"/> Physicals <input type="checkbox"/> Vision <input type="checkbox"/> Dental Exam Reminder	<input type="checkbox"/> Hearing <input type="checkbox"/> Immunizations <input type="checkbox"/> GYN Referral
Medical Records	<input type="checkbox"/> Valid Photo ID <input type="checkbox"/> Personal Health Record	<input type="checkbox"/> Wallet Emergency Card (if needed) <input type="checkbox"/> Power of Attorney (if needed)
PCP Options	1. PCP caring for Parent/Family _____ 2. PCP w/specific disease mgmt _____ 3. PCP w/specialized background _____ a. MED/PEDS _____ b. Geriatrics _____	
Self Care Skills	<input type="checkbox"/> Uses a time management method <input type="checkbox"/> Schedules appointments <input type="checkbox"/> Identifies current medications <input type="checkbox"/> Explains purpose of medications <input type="checkbox"/> Refills prescriptions <input type="checkbox"/> Knows when to go to the doctor <input type="checkbox"/> Knows when to go to the emergency room	
Transportation	<input type="checkbox"/> The Bus <input type="checkbox"/> Driver's License <i>Requirements: Instruction Permit, Behind the Wheel Student Completion Certificate and Drivers Education Student Completion Certificate</i>	<input type="checkbox"/> Handi-van Pass <input type="checkbox"/> Accessible Parking Permit
Living Arrangements	<input type="checkbox"/> Home <input type="checkbox"/> Outside of Home	<input type="checkbox"/> Other residential settings <input type="checkbox"/> Natural supports
Additional Discussion Topics		
<input type="checkbox"/> Differences in Pediatric and Adult Care <input type="checkbox"/> Alternatives to Guardianship <input type="checkbox"/> Eligibility for new "Adult" Public Benefits <input type="checkbox"/> Redetermination for Public Benefits (SSI, etc.) <input type="checkbox"/> Other: _____		
<input type="checkbox"/> Graduation – Diploma vs. Certificate <input type="checkbox"/> Special Needs Trusts <input type="checkbox"/> Genetic/Reproductive Counseling <input type="checkbox"/> Selective Service Registration		

* Advice/assistance to get information from health plans on age and coverage dual requirements to qualify for student coverage

Indiana's Project - Grant #CPHNC00018 from the Health Resources and Services Administration, Maternal and Child Health Bureau
 Funds: Division of Health, State of Indiana Department of Health, Children with Special Health Needs Branch
 American Academy of Pediatrics—Indiana Chapter, University of Indiana, ARSOM Department of Pediatrics—Community Pediatrics Institute, University of Indiana

Transition Referral Form

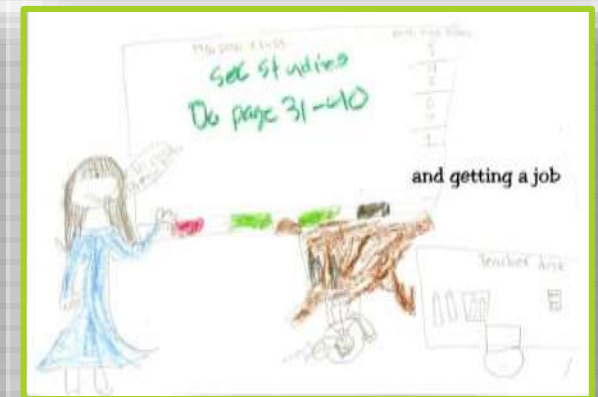
Identifies Minimum Dataset to Begin Discussion with Potential PCP

Referral Information	
To: Dr. P. P. Internist	F: _____ P: _____ E: _____
Fr: Dr. Kimo Pediatrician	F: _____ P: _____ E: _____
Patient Information	
Patient Name:	Date of birth: _____ Gender: M <input type="checkbox"/> F <input type="checkbox"/>
Guardian/Caregiver Name: (if other than ref)	Language Spoken at Home: (if other than English) _____
Insurance:	Translator or Interpreter Needed? <input type="checkbox"/> Yes <input type="checkbox"/> No
Current Living Situation:	<input type="checkbox"/> Independent <input type="checkbox"/> Family <input type="checkbox"/> Care Home <input type="checkbox"/> Other: _____
Treatment Summary	
The following ASD related concerns are currently being monitored by myself and/or others:	
Type	Description of Concern(s), Intervention/Monitoring Activities
<input type="checkbox"/> Behavior	
<input type="checkbox"/> Communication	
<input type="checkbox"/> Gastro	
<input type="checkbox"/> Genetic	
<input type="checkbox"/> Neuro	
<input type="checkbox"/> Psych	
<input type="checkbox"/> Other:	
Medications	
Other Medical Conditions	
Attachments	
<input type="checkbox"/> Consent to Release Information <input type="checkbox"/> Other: _____	

Follow up: _____

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 Hawaii Pediatric Association Research and Education Foundation © Hawaii Department of Health Children with Special Needs Branch
 American Academy of Pediatrics Hawaii Chapter © HHSU's Family Friendly Health Information Center © Family Values of Hawaii
www.hhsu.org/jrnl.asp

Where do we go from here?



Summary

- Transition doesn't happen over night
- Assist in building marathon skills
- Create opportunities to achieve little t's along the way
- Man had to walk on earth before he could walk on the moon

