

# Transition Planning Workbook



## *Hilopa‘a Style 1.1*

Youth: \_\_\_\_\_

Team: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Grant #D70MC04468 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 JABSOM  
Department of Pediatrics—Community Pediatrics Institute

Greetings Family Navigators!

This workbook is meant to be a guide to help “talk story” and talk through the planning process of transitioning our youth to adult health.

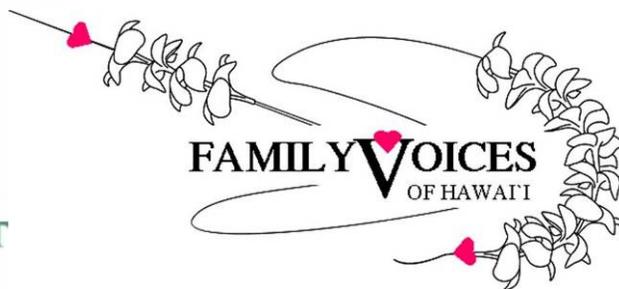
As our mentor Josie Woll has always taught us, life is a journey, not an event. Transitioning to adulthood does not happen overnight. Successful transition requires time, patience, and a sense of humor.

We hope you will find these materials helpful as you navigate through the complexities and the triumphs of Transition.

Aloha,

Leolinda Parlin  
Family Voices of Hawai‘i

Patricia Heu, MD  
Department of Health



American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™



Hawaii Chapter

# Identifying the Tasks



## Non-Negotiables:

Task	Activities
1. Find adult health coverage for youth	<ul style="list-style-type: none"><li>a. Contact “Personnel” to get requirements for “Adult Disabled Dependent” coverage</li><li>b. Review other commercial insurance plan coverage options</li><li>c. Apply for Medicaid for primary coverage or supplemental coverage if needed</li></ul>
2. Maximize existing benefits	<ul style="list-style-type: none"><li>a. Immunizations</li><li>b. Dental visits</li><li>c. Annual Physicals</li></ul>
3. Develop maintenance plan for DME	<ul style="list-style-type: none"><li>a. Wheelchair servicing</li><li>b. Wheelchair replacement</li><li>c. Warranty information on other equipment</li></ul>
4. Develop supply ordering schedule	<ul style="list-style-type: none"><li>a. Vendor information</li><li>b. Supply information</li><li>c. Frequency</li><li>d. Quantity</li><li>e. Delivery method</li></ul>
5. Track Personal Health Indicators	<ul style="list-style-type: none"><li>a. Identify health indicators</li><li>b. Determine how to monitor</li><li>c. Log in “wellness” calendar</li></ul>

## Identifying the Tasks

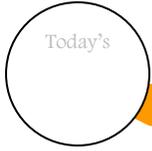


Task	Activities
6. Obtain Medical Power of Attorney	<ul style="list-style-type: none"> <li>a. Discuss with youth parent role in care</li> <li>b. Determine parameters</li> <li>c. Notarize document</li> </ul>
7. Complete Portable Medical Record Summary	<ul style="list-style-type: none"> <li>a. Obtain information</li> <li>b. Share responsibility for gathering information</li> </ul>
8. Create wallet emergency info and medication card	<ul style="list-style-type: none"> <li>a. Emergency contact info</li> <li>b. Allergies and drug interactions</li> <li>c. Medication list</li> <li>d. Pharmacy information</li> <li>e. Physician information</li> <li>f. Communication method</li> </ul>
9. Complete reproductive counseling	<ul style="list-style-type: none"> <li>a. Safe sex</li> <li>b. Family planning</li> <li>c. Genetics</li> </ul>
10. Transition to adult health care providers	<ul style="list-style-type: none"> <li>a. Primary care</li> <li>b. Specialty care (e.g, Gynecology, Cardiology, etc.)</li> </ul>
11. Access transportation system	<ul style="list-style-type: none"> <li>a. Handi-Van</li> <li>b. Bus pass/bus coaching</li> </ul>
12. Apply for SSI	
13. Obtain Hawai'i State ID	

# Identifying the Decisions



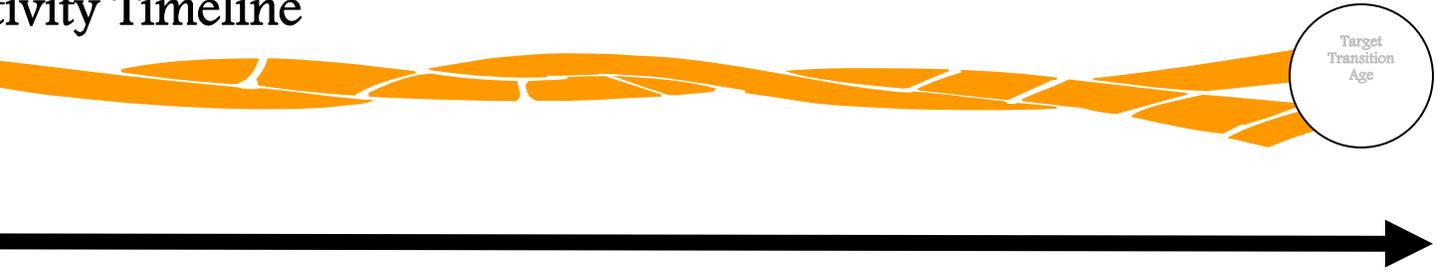
Decisions	Considerations
1. Alternatives to Guardianship	<ul style="list-style-type: none"><li>• Cost (time, money, hassle)</li><li>• Self Determination</li><li>• Conservatorship of property</li><li>• Guardianship</li><li>• Advanced directive for health care</li><li>• Power of attorney</li><li>• Trusts</li><li>• Representative Payee</li><li>• Joint accounts/money management</li><li>• Surrogate decision maker</li></ul>
2. Path to Employment	<ul style="list-style-type: none"><li>• Higher education</li><li>• Vocational training</li><li>• Supported employment</li></ul>
3. Natural Supports	<ul style="list-style-type: none"><li>• Compatibility</li><li>• Availability</li><li>• Location</li></ul>
4. Living Arrangements	<ul style="list-style-type: none"><li>• Location</li><li>• Independent living services</li><li>• Accessibility</li><li>• Safety</li></ul>



Map Out Things to Do:



# Activity Timeline



Target  
Transition  
Age

# Mapping the Resources



Health Insurance			
Now		Future	
Primary:		Primary:	
Primary Subscriber:		Primary Subscriber:	
Secondary:		Secondary:	
Secondary Subscriber:		Secondary Subscriber:	

Health Team			
Now		Future	
Primary CareProvider:		Primary CareProvider:	
Neuro:		Neuro:	
Cardio:		Cardio:	
Gastro:		Gastro:	
Pulmo:		Pulmo:	
Rheum:		Rheum:	
Allergy:		Allergy:	
Developmental Behavioral:		Developmental Behavioral:	
Psychiatry:		Psychiatry:	
Psychology:		Psychology:	
Pharmacy:		Pharmacy:	
Nutrition:		Nutrition:	
DME:		DME:	
Supplies:		Supplies:	
Other:	type:	Other:	type:
Other:	type:	Other:	type:
Other:	type:	Other:	type:

# Mapping the Resources



Related Services						
Now				Future		
Type	Frequency	Funding	Carry Over?	Type	Frequency	Funding
			<input type="checkbox"/>			
			<input type="checkbox"/>			
			<input type="checkbox"/>			
			<input type="checkbox"/>			
			<input type="checkbox"/>			
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			<input type="checkbox"/>			
			<input type="checkbox"/>			
			<input type="checkbox"/>			
			<input type="checkbox"/>			
			<input type="checkbox"/>			

Other Programs				
Now				Future
Program	Service	Funding	Carry Over?	Options
			<input type="checkbox"/>	

# Identifying the Skills



## Health:

Knows what health insurance is and how to use it	Understands diagnosis and impact on health
Understands the impact of aging on diagnosis	Able to tell someone about drug allergies and reactions
Able to identify medications and their purpose	Can identify pain on a scale of 1-10
Able to tell when something feels different	Knows who to contact in the event of emergency
Knows what to do when health is in danger	Able to tell the “danger signs” of the condition
Identifies personal health indicators and knows how to track them	Knows about the physical changes in becoming an adult
Understands the need to see doctors who care for adults, not just kids	Able to schedule own doctor’s appointment
Arranges transportation for appointments	Able to refill prescriptions and fill new ones
Knows what kind and when to take over the counter medicines	Has a method to remember when to take medications
Knows what vendors, pharmacies, or stores carry meds and supplies	Knows how to store supplies and care for equipment
Knows how to dispose of supplies	Knows specific situations to avoid for health reasons
Knows how often to see the dentist	Understands rights under the Americans with Disabilities Act
Practices monthly self examinations	Knows where to go in the event of an emergency
Prepares for first gynecological examination	Able to ask physicians questions

# Identifying the Skills



## Life Skills:

Able to use transportation to get around	Takes care of personal bathing needs
Takes care of personal toileting needs	Takes care of personal dressing needs
Prepares meals	Launders clothes
Has chores	Has hobbies or leisure activities
Has opportunities to volunteer	Budgets money
Maintains friendships	Has a communication system and uses it
Has reliable phone access	Identifies needs for work accommodations
Identifies needs for school accommodations	Aware of rights to community access under ADA
Participates in a community recreational activity	Understands SSI work incentives
Explores opportunities through Vocational Rehabilitation Division	Explores opportunities with Developmental Disabilities Division
Requests copies of reports, plans, and other documents	

# Bridging the Transitions of CYSHCN to Adult Life

## Guiding Principles of the Hawai'i State Team



Family-centered care is the acknowledged best practice model for families who have children/youth with special health care needs. It requires a commitment driven by a collaborative partnership between the family and professionals which enables children/youth to assume increasing ownership of the decision making process. Therefore:

- ☞ The transition process for children/youth with special health care needs and their family requires family-centered care which assures best practices, protocols and standards will achieve optimal outcomes including growth despite the difficulty inherent in any change.
- ☞ The transition of children/youth with special health care needs and their family requires a collaborative partnership between the family and the professionals involved.
- ☞ The transition activities for children/youth with special health care needs and their family begins with the initial referral and are on-going as needed or requested.
- ☞ The transition of children/youth with special health care needs and their family requires the exchange of information and the transfer of those skills individually determined as appropriate.
- ☞ The transition of children/youth with special health care needs and their family is one of shared responsibility between the family and professionals with varying degrees of accountability over time.
- ☞ The transitions of children/youth with special health care needs and their family should be successful and celebrated. *J. Woll 2005*