

HILOPA'A

Level Up to Transition

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What We'll Talk About This Morning

What

Why

How



18



What Is Transition?

Transition is the deliberate, coordinated provision of developmentally appropriate and culturally competent services to prepare an individual for their next phase in life...



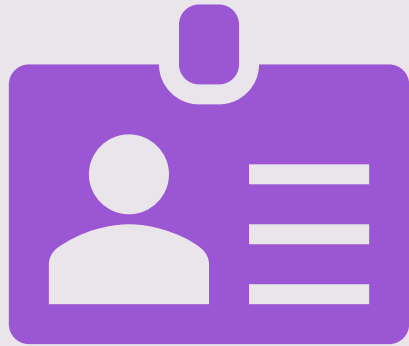
Victoria Murray

Talking about Transition

What Is Transition?



Health



Career



Citizenship



Inclusion



Why transition?

A little perspective

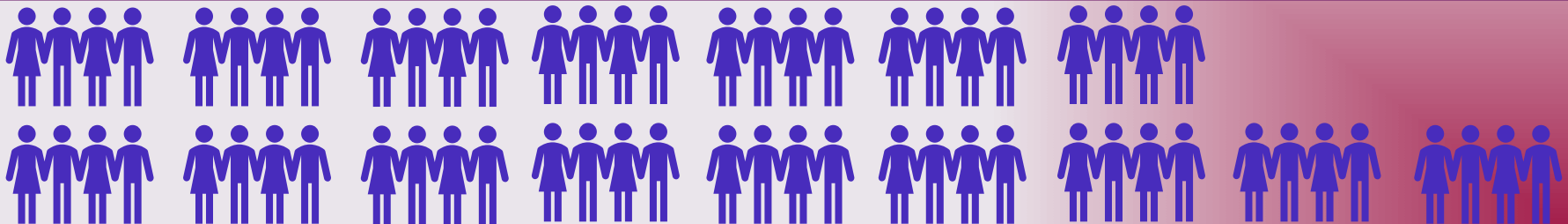
27% uninsured



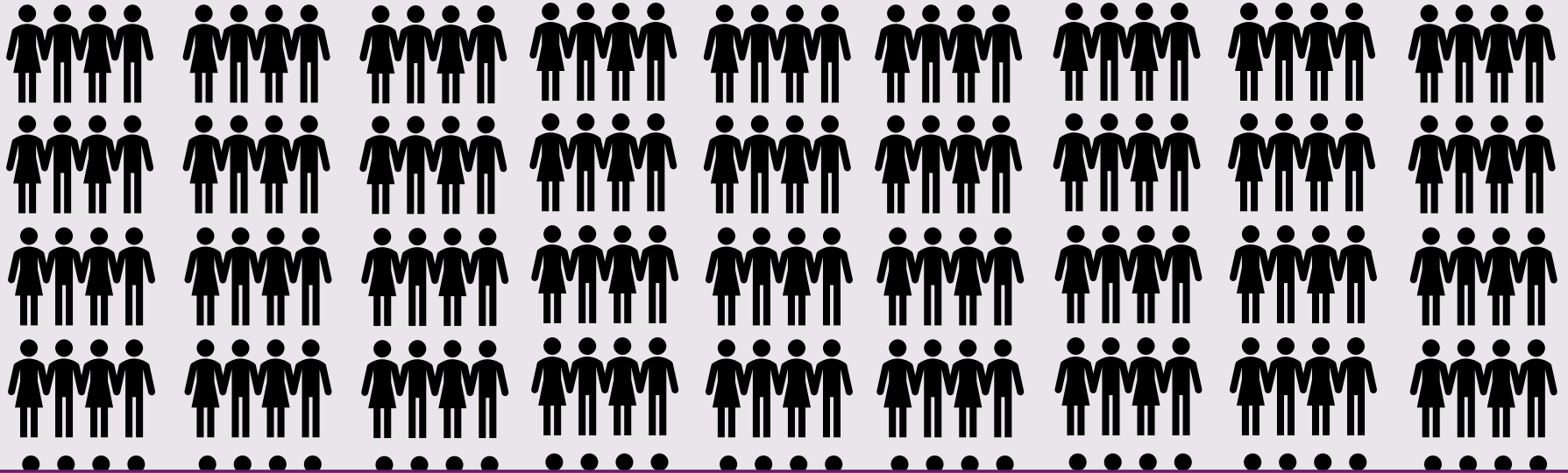
22% living below poverty



POVERTY LINE



37% young parents living below poverty



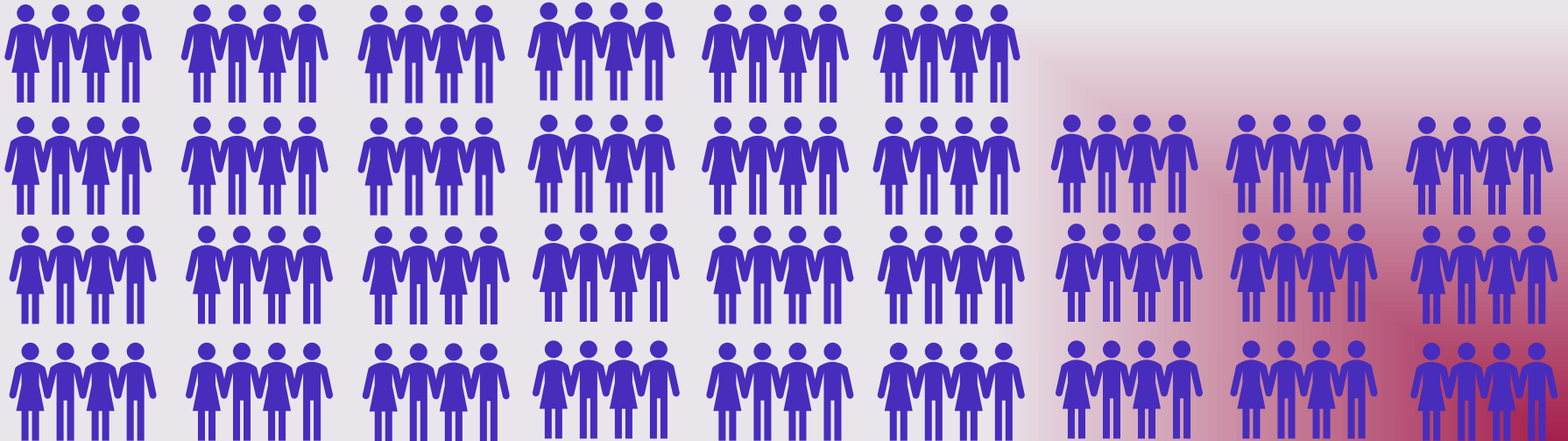
POVERTY LINE



45% defer medical treatment



NO MEDICAL CARE



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

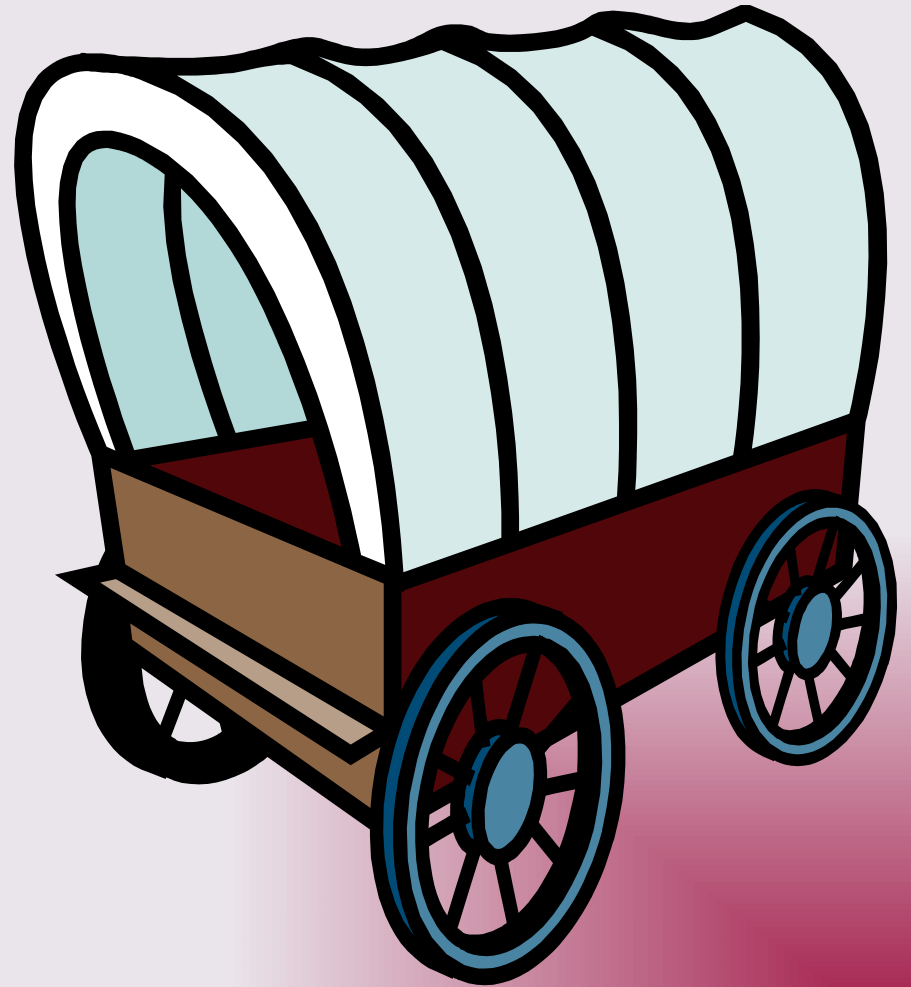
Additional Hawai'i Data

YSHCN who received services necessary to make transitions to adult health care

Hawai'i	Nationwide
23.3%	16.5%

What does that mean for YSHCN?

- 1973: the average age of survival for a child with CF=7 yrs
- 2005: half of all individuals with CF ≥ 21 yrs
- 1970s <33% with Spina Bifida reached 20 years of age
- 2000s >80% with Spina Bifida reach adulthood
- 90% of YSHCN reach their 21st birthday
- In Hawai'i, ~4,000 YSHCN between the ages of 15-17



Bottom Line

- **Kids are living longer**
- **Parents have higher expectations**
- **Youth have higher expectations**





Strategies

Getting Ready to Take The Steps...

Get in the zone and get with the paper work



Service Shift

**Family Centered to
Person Centered**

**Changing Focal
Point**

**Role as an
Informer**

Paper Work

- Valid Photo ID
- Wallet Emergency Card



Wallet Emergency Card

My Mother 12/29/25

Drug Interactions

Zestril - weakness Vioxx, /
Niacin - rash, swelling Aspirin
irritation
Erythromycin - nausea, vomiting

Pain Management

Fentanyl 50mcg/hr – 3 day rotation
As Needed: Tylenol w/codeine 15m

Current Daily Medication

AM: Diltiazem 250mg, Protonix 20
2 tabs

PM: Ocuville 2 tabs, Xanax .125mg

Vitamin/Supplements: Calcium 10
50,000 IU alternating wks, Fiber 50
polycarbophyl, Senokot-S

My Mother 12/29/25

In case of emergency, please contact:

Leolinda Parlin – 282-6348

Chad Domingo – 123-4568

Sam Aiona – 123-4569

Or call 911

Paper Work

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





Phases

Know what paths to
take

Health

- Reproductive Counseling
- Affordable Care Act
 - Dependent Adult Coverage
 - Medicaid – mybenefits.hawaii.gov
 - Exchange

Primary Care

- PCP
- Immunizations



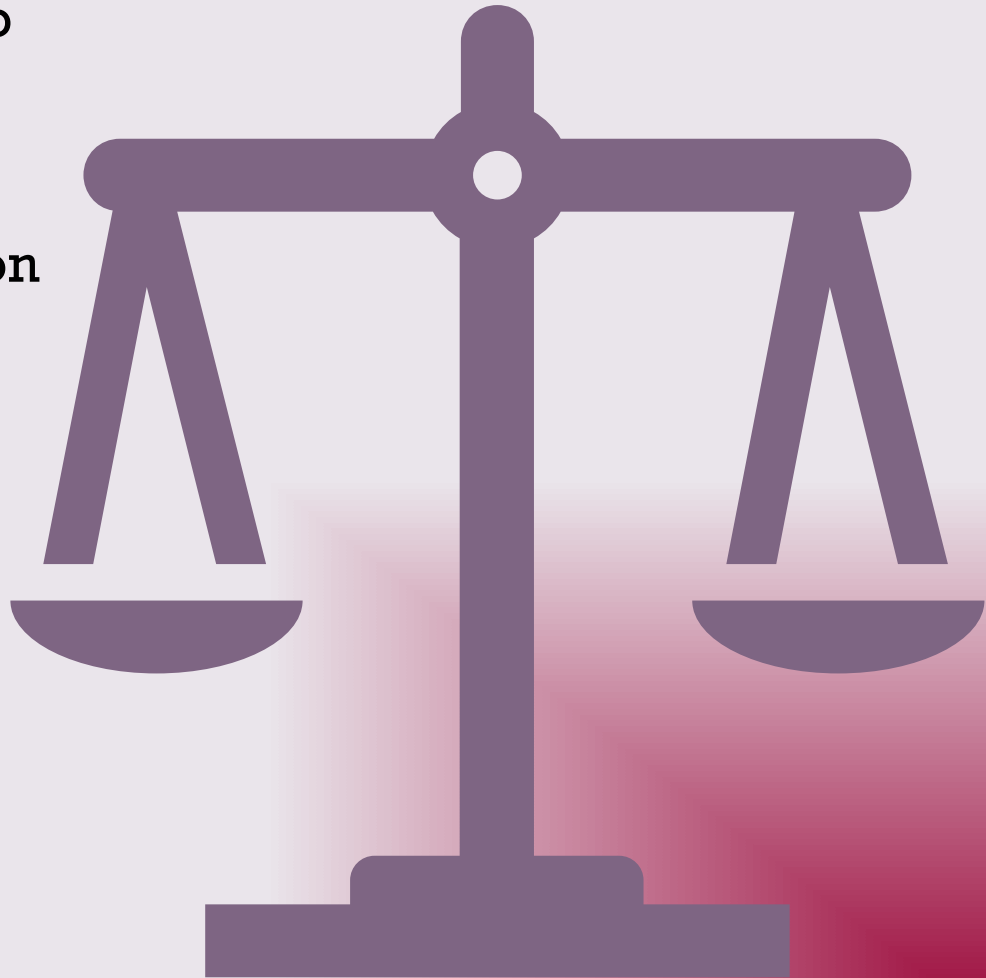
Career Pathways

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



Citizenship

- Alternatives to Guardianship
- Special Needs Trusts
- Voter Registration
- Selective Service Registration



Inclusion in Community Life

- Leisure Activities
- Social Programs
- Living Arrangements
- Transportation





Transition Philosophy |

Guiding Principles

You have to
get through
the little
“t”s to get
to the big T

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. Wolf 2005*

The Hawai'i State Team: 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 Pediatric Division



How Do We Make It
Work?

We're almost
there...

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

Avoid the 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 |



Where do we go from here?

Thank you!

Summary

- Transition doesn't happen over night
- Develop marathon skills
- Know you are where you are, when you are
- Be brave and take the first step to level up!

