Ease on Down the ROAD

2019 SPIN Conference

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Hawai'i MCH LEND Program

What We'll Talk About This Morning

- What
- Why
- How

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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…

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What Is Transition?

Health

Career

Citizenship

Inclusion

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Why transition?

A little perspective

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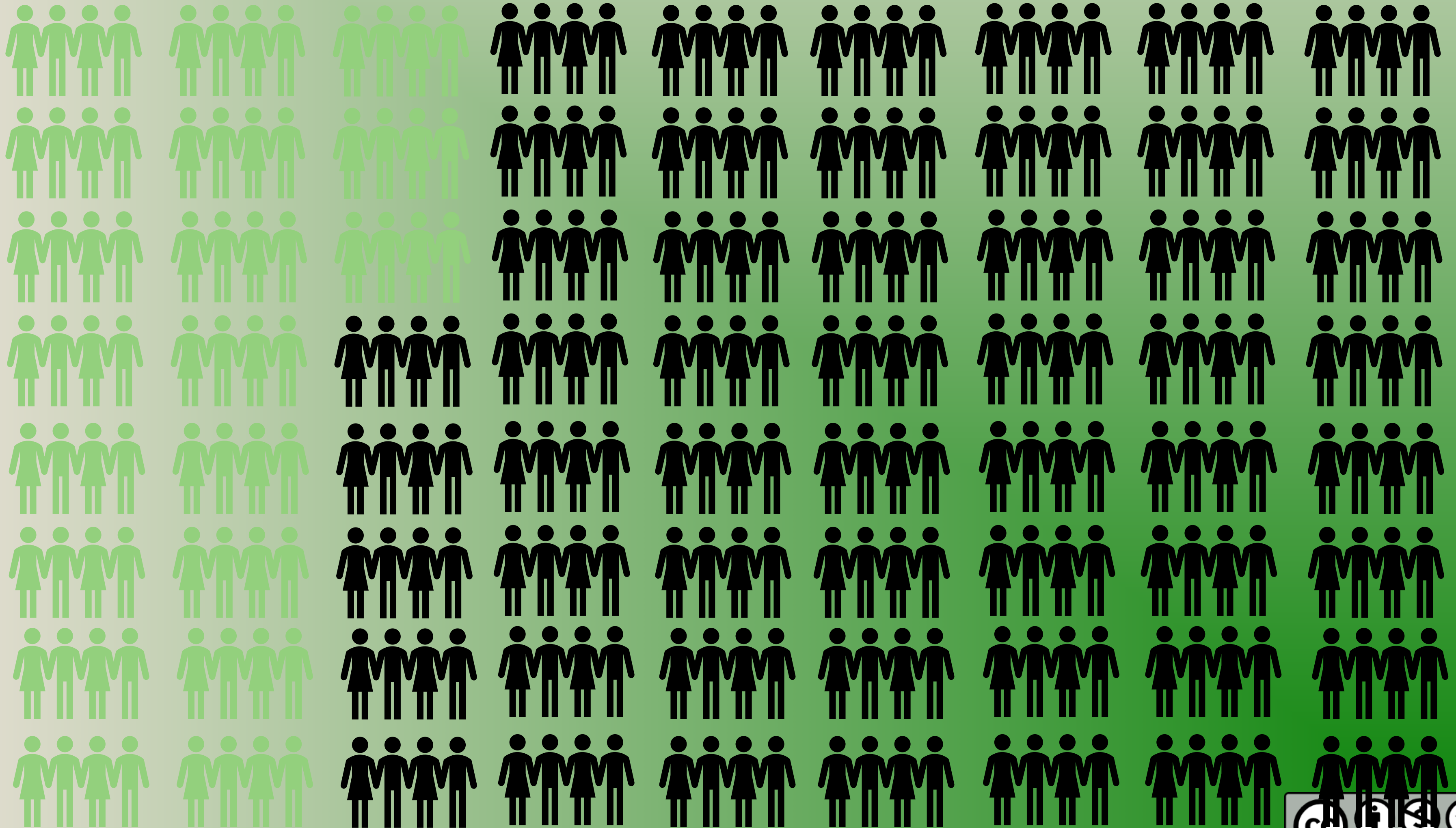
27% uninsured



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

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22% living below poverty

POVERTY LINE

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

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37% young parents living below poverty

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

45% defer medical treatment

NO MEDICAL CARE

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

Child and Adolescent Health Measurement Initiative. *2001 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health

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Additional Hawai'i Data

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

Hawai'i	Nationwide
23.3%	16.5%

Child and Adolescent Health Measurement Initiative. Data Resource Center for Child and Adolescent Health. 2016 National Survey of Children's Health (NSCH) data query. Retrieved [04/21/2018] from www.childhealthdata.org. CAHMI: www.cahmi.org.

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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

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Bottom Line

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

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Strategies

Getting Ready to Make a Move

Get in the zone and get with the paper work

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Service Shift

Family Centered to Person Centered

Changing Focal Point

Role as an Informer

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Paper Work

- Valid Photo ID
- Wallet Emergency Card

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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 15r

Current Daily Medicati

AM: Diltiazem 250mg, Protonix 20
2 tabs
PM: Ocuvite 2 tabs, Xanax .125mg
Vitamin/Supplements: Calcium 1
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

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Paper Work

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

Phases

Know what road to take

Health

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

Primary Care

- PCP
- Immunizations

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Career Pathways

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

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Citizenship

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

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Inclusion in Community Life

- Leisure Activities
- Social Programs
- Living Arrangements
- Transportation

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Transition Philosophy

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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. Woll 2005*

The Hawaii 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 JABSOM Department of Pediatrics—Community Pediatrics Division

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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

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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

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Resources for Families

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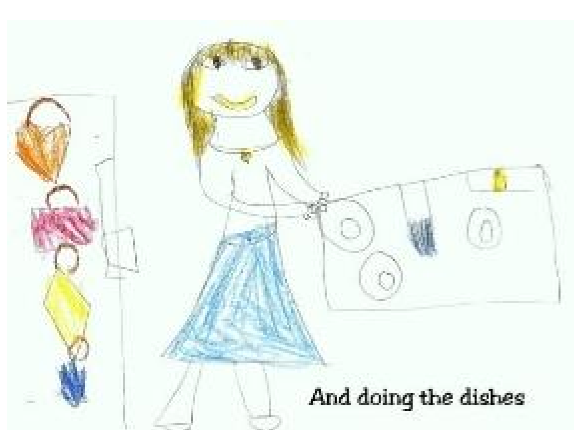

Where do we go from here?

Transition doesn't happen over night

Develop marathon skills

Know you are where you are, when you are

It takes courage to Ease on Down the Road!

CC BY NC SA

Mahalo!

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