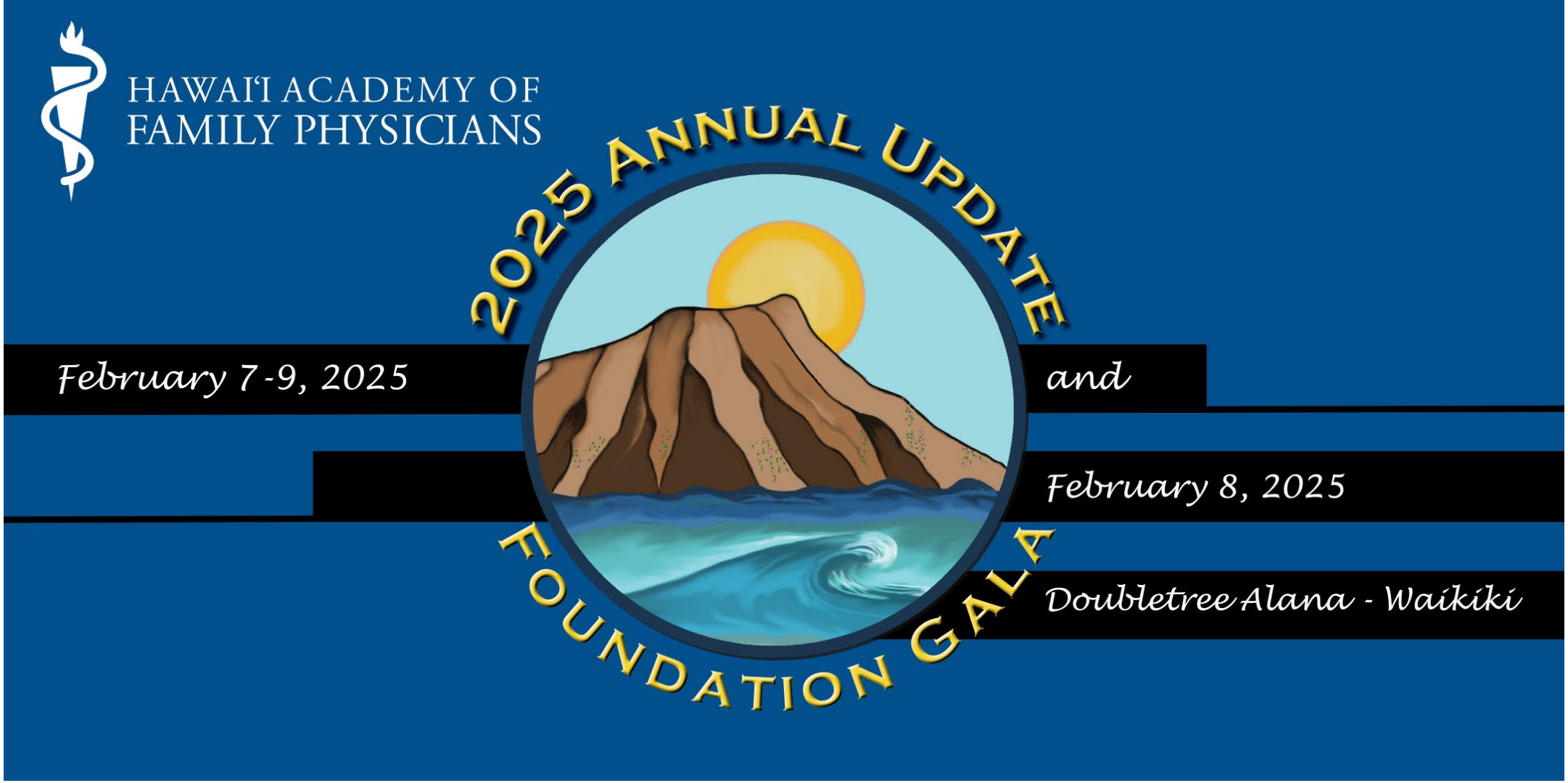


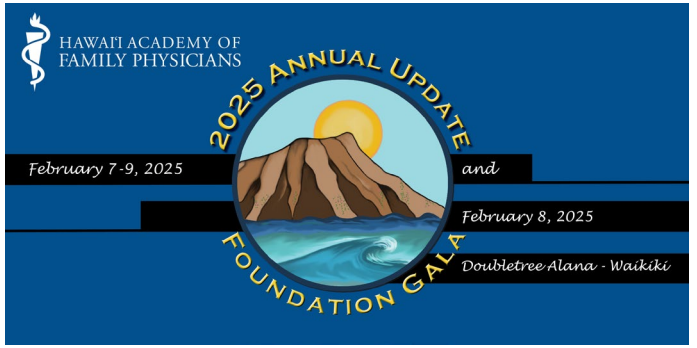
Not Institutionalized Anymore - The Care of Children and Adults with Autism and Other Developmental Disabilities by Family Physicians

Jeffrey Okamoto MD, FAAP

Developmental-Behavioral Pediatrician

John A. Burns School of Medicine, University of Hawaii at Manoa

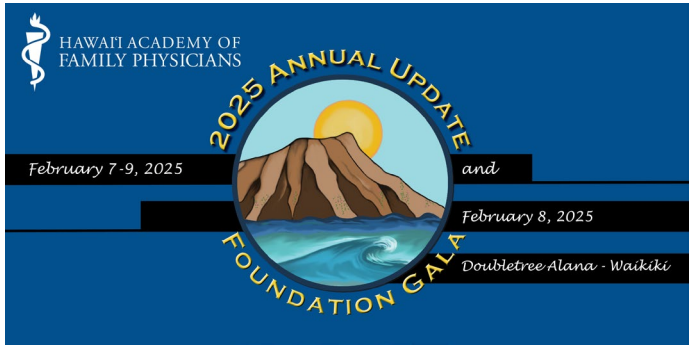
Disclosures



I have no relevant financial relationships with the manufacturers(s) of any commercial products(s) and/or provider of commercial services discussed in this CME activity

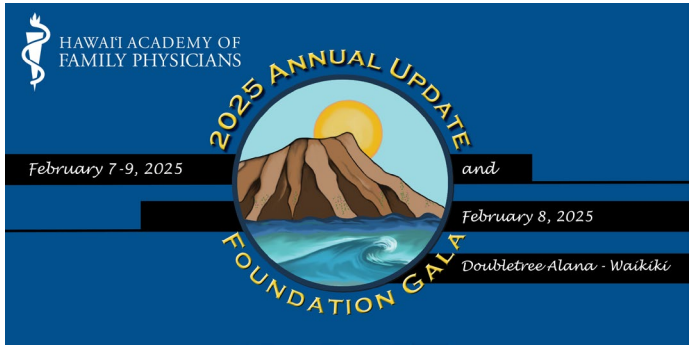
I do not intend to discuss an unapproved/investigative use of a commercial product/device in my presentation.

Objectives



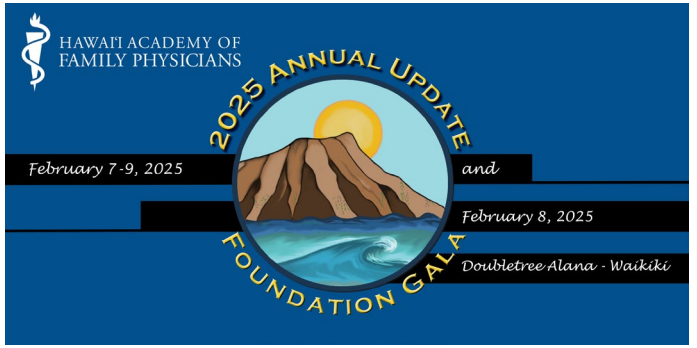
1. Understand the mistreatment that people with intellectual disabilities and other developmental disabilities (I/DD) had in the past and what care they need now
2. State the challenges that children with I/DD have as compared to the challenges that adults with I/DD have
3. Provide the care that both children and adults with I/DD need, and ease the transition from the pediatric years to the adult years for people with I/DD

Scenario A - Leonard



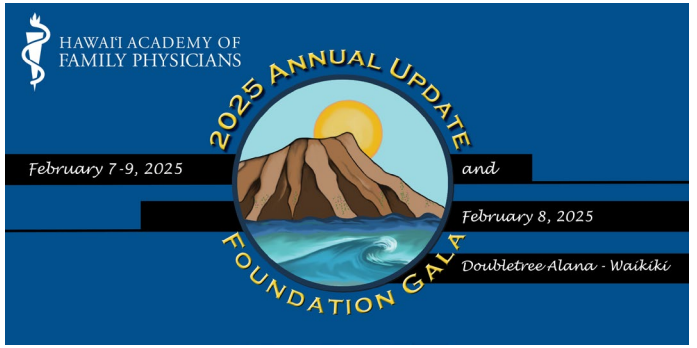
- A 19 year old named Leonard has significant autism. He cannot read but can converse (mostly about Star Trek). He can independently toilet, bathe, and eat with utensils. He can be taught how to do simple chores, such as cooking but needs supervision to do this safely.

Leonard



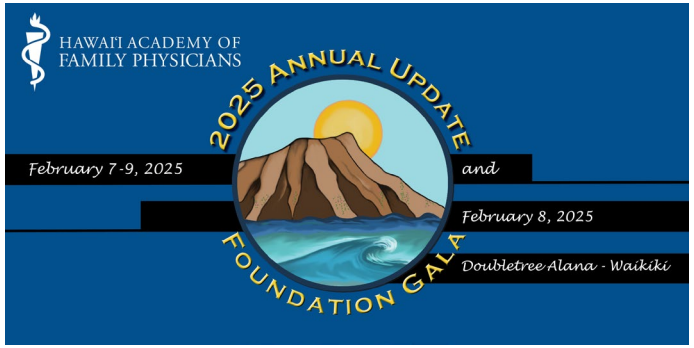
- He currently lives with his parents and younger 12 year old sister who does not have any significant developmental or medical issues.
- What is the future for the next five years for Leonard? What would be Medicaid Waiver Services that would support him and his family?

Scenario B - Cynthia



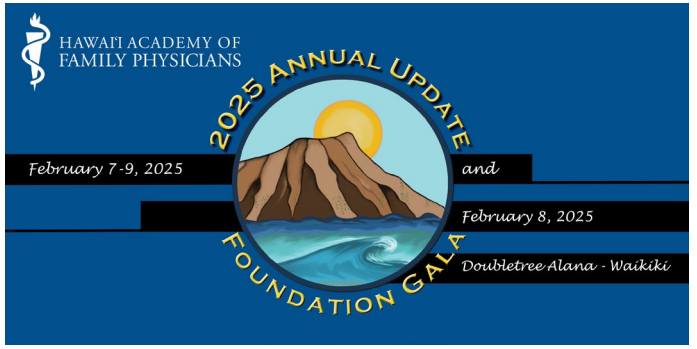
- Cynthia is a 55 year old woman with severe choreoathetoid cerebral palsy and deafness from kernicterus.
- She uses an augmentative communication device and is at a 12th grade equivalent reading and math level

Cynthia

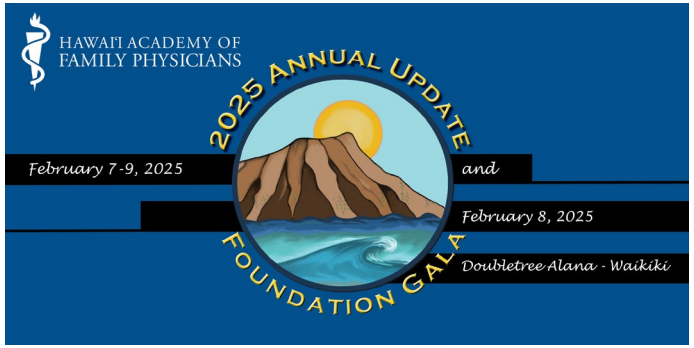


- She is in a electric wheelchair that she can steer
- She enjoys sports and watches games both live and on TV.

Cynthia

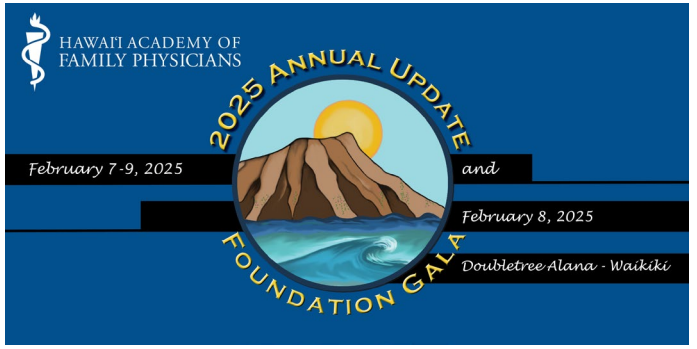


- She can make her desires known and also uses a computer to order things over the internet - she has a huge balance on her charge card
- Her parents are both elderly and wonder what will happen with Cynthia when they die, as all of their relatives are on the mainland with their own families.
- What is the future for the next five years for Cynthia? What would be Medicaid Waiver Services that would support her and her family?



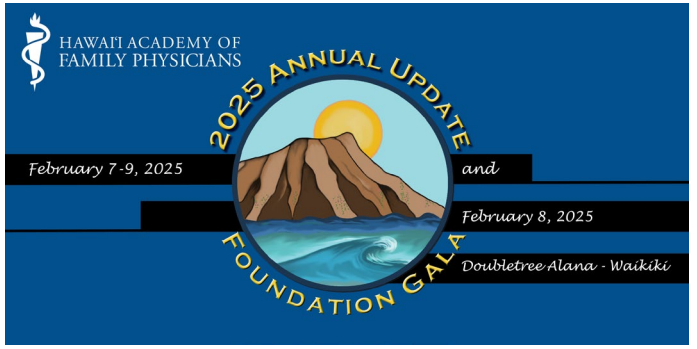
History of the Care of People with I/DD

A brief historical retrospective – Treatment and perceptions of people with disabilities



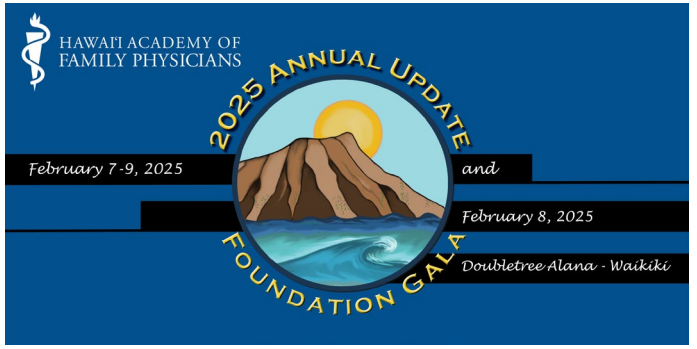
- Ambivalent throughout history – pity/ridicule (e.g. infanticide by Spartans/court jesters).
- Rise of state institutions began in the 19th Century.
- Overcrowding of facilities as the *Great Depression* prompted more families towards choosing institutionalization – segregation/eugenics movements prompted public opinion to regard individuals as a menace to society.

More History



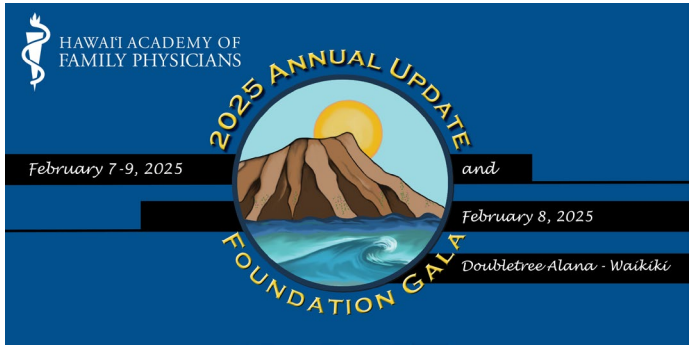
- During the first half of the 20th century there were 47,000 sterilizations of people with intellectual disabilities in 30 states.
- Residents of facilities were used for dangerous experiments such as ingesting radioactive foods (Fernald State School) and Hepatitis B transmission (Willowbrooke) –> Belmont Report 1974 – This caused establishment of Institutional Review Boards with Ethical Research Conduct.

“Developmental Disabilities” – This is NOT determined medically



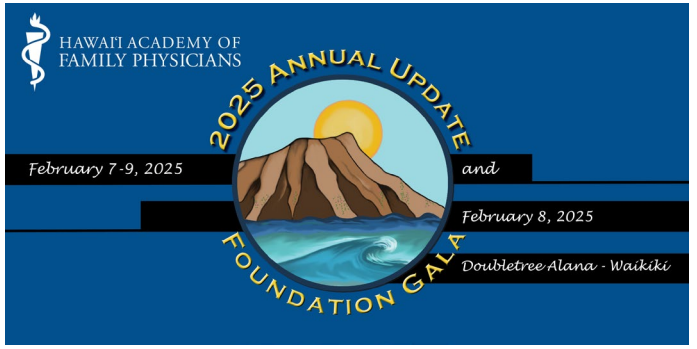
- This is a policy term
- President John F. Kennedy had a sister with intellectual disability (at that time called mental retardation)
- There was a call to action to support people with intellectual and related disabilities

Major Legislative Turning Points

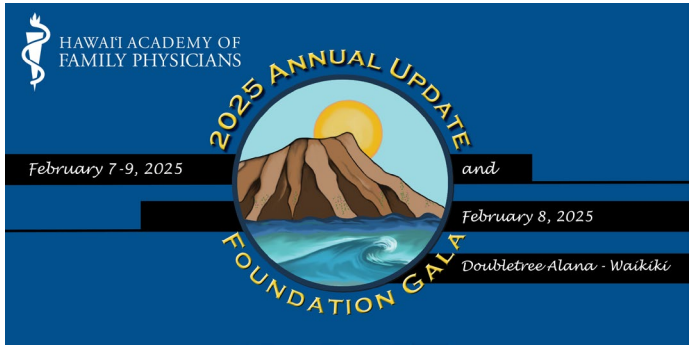


- 1962 - President Kennedy's Panel on Mental Retardation.
- 1963 - Maternal and Child Health and Mental Retardation Planning Amendments - comprehensive plans to improve residential, community, and preventive services.
- 1970 – Developmental Disabilities Act first passed (most recent reauthorization was in 2000)

Major Legislative Turning Points



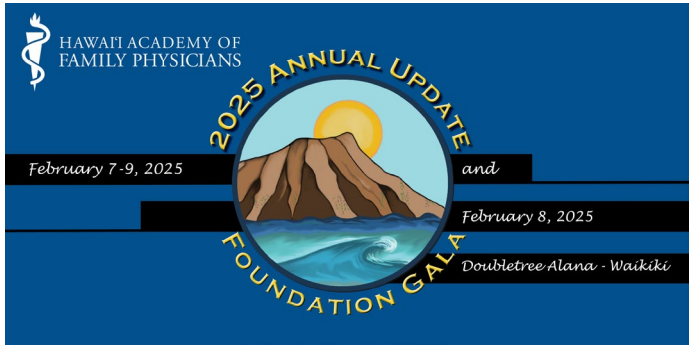
- 1975 - Education of All Handicapped Children (now referred as the Individuals with Disabilities Education Act).
- 1981 - Medicaid Home and Community Based Services Waiver, and 1985 Katie Beckett Waiver
- 1990 - Americans with Disabilities Act
- 1999 - Olmstead decision



Question 1

In the first half of the 20th Century (the 1900s) people with intellectual disability in the United States

1. Were mainly supported in their community and homes, and not in institutions
2. Were not sterilized (made infertile)
3. Were thought to be an asset to society
4. Were diagnosed with another term – mental retardation



Question 1

In the first half of the 20th Century (the 1900s) people with intellectual disability in the United States

1. Were mainly supported in their community and homes, and not in institutions
2. Were not sterilized (made infertile)
3. Were thought to be an asset to society
4. **Were diagnosed with another term – mental retardation**

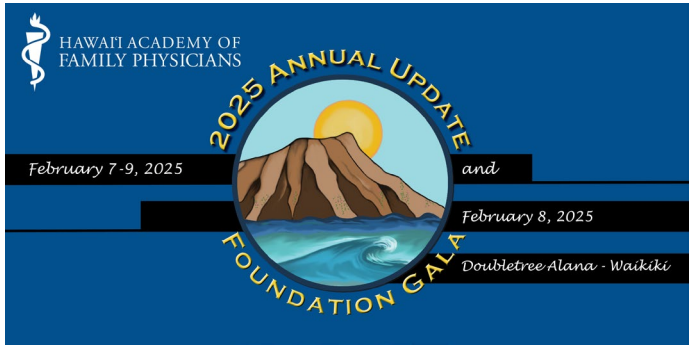
Developmental Disabilities - Federal GUIDANCE

Severe, chronic disabilities attributable to mental and/or physical impairment, which manifest before age 22 and are likely to continue indefinitely.

They result in substantial limitations in ≥ 3 areas:

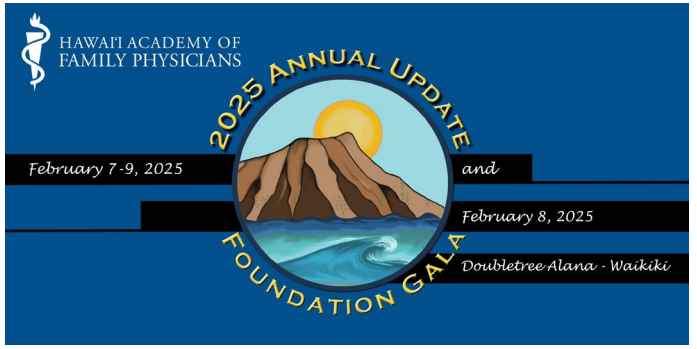
- receptive and expressive language
- learning
- mobility
- self-direction
- capacity for independent living
- economic self-sufficiency
- self-care
- continuous need for individually planned and coordinated services

Developmental Disabilities – Hawaii Definition



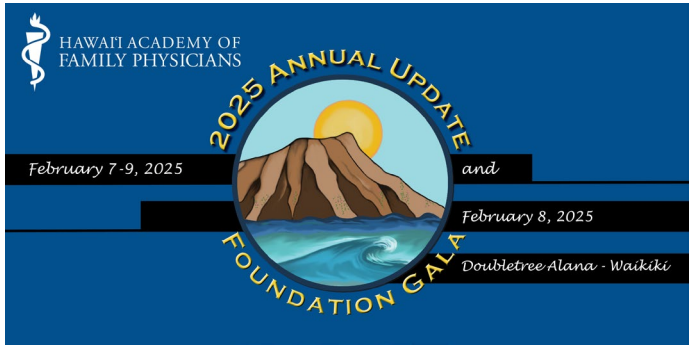
- Developmental disability, as defined in §11-88.1-5 means:
- a disorder or syndrome that is attributable to intellectual disability, epilepsy, cerebral palsy, autism spectrum disorder or
- evidence of an eligible condition or disorder due to a neurological condition, or central nervous system disorder, or chromosomal disorder that results in both substantial impairment of general intellectual functioning and adaptive behavior skill deficits similar to those of a person with intellectual disability

Developmental Disabilities – Hawaii Definition (continued)

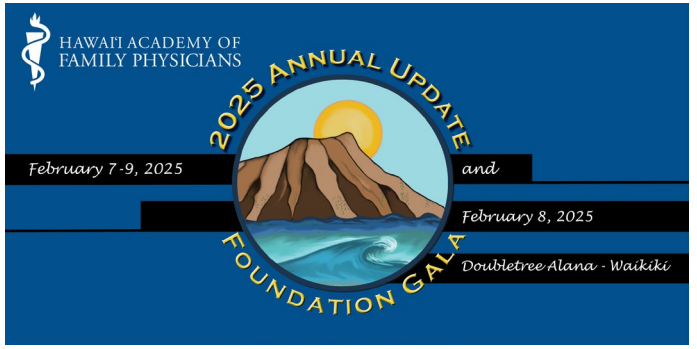


- The mental or physical impairment or combination of mental and physical impairments cannot be primarily from dementia, mental illness, emotional disorders, substance abuse, sensory impairment, learning disabilities, attention deficit hyperactivity disorder, spinal cord injuries, or neuromuscular disorders.
- manifests before the age of 18; and constitutes a substantial disability that can reasonably be expected to continue indefinitely.
- requires concurrent substantial deficits in at least three (3) adaptive functioning areas at least three (3) standard deviations below the mean as assessed on standardized measures of adaptive behavior.

Developmental Disabilities – Florida Definition



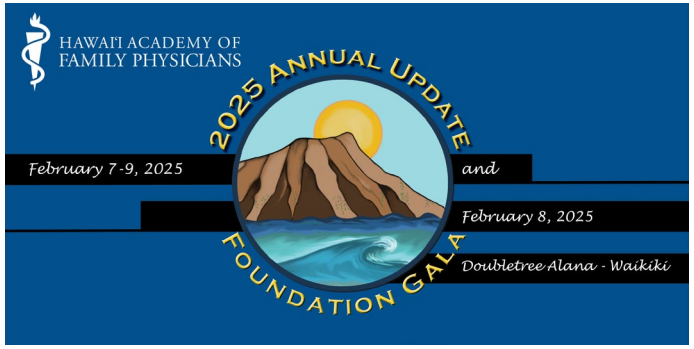
- Developmental disability, as defined in § 393.063(9), means:
- a disorder or syndrome that is attributable to mental retardation, cerebral palsy, autism, spina bifida, Down syndrome, or Prader-Willi syndrome;
- manifests before the age of 18; and
- constitutes a substantial handicap that can reasonably be expected to continue indefinitely.



Question 2

Which of these is usually not considered a developmental disability?

a. Seizure disorder
b. Cerebral palsy
c. Autism Spectrum Disorder
d. Anxiety disorder
e. Intellectual disability

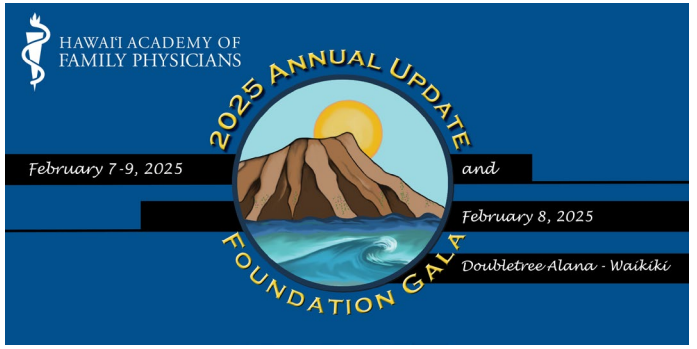


Question 2

Which of these is usually not considered a developmental disability?

a. Seizure disorder
b. Cerebral palsy
c. Autism Spectrum Disorder
d. Anxiety disorder
e. Intellectual disability

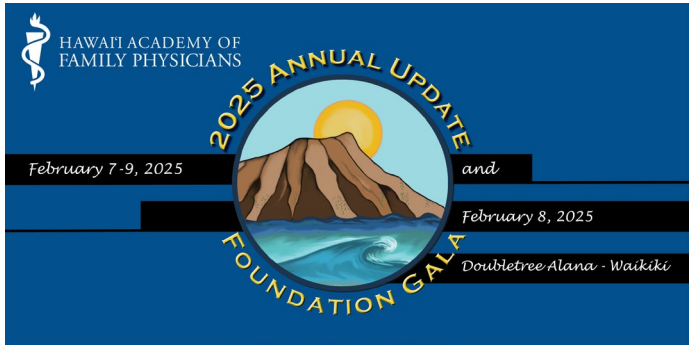
Question 3



The term “Developmental disabilities” is terminology that is

1. Medical
2. From federal policy
3. Developed from efforts by President Abraham Lincoln
4. Not derived from state definitions

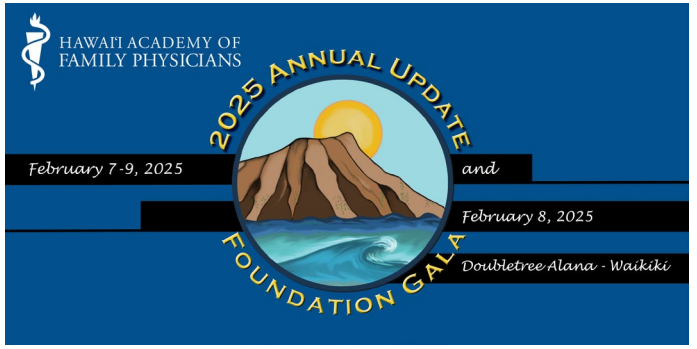
Question 3



The term “Developmental disabilities” is terminology that is

1. Medical
2. **From federal policy**
3. Developed from efforts by President Abraham Lincoln
4. Not derived from state definitions

History of DD Division Services in Hawaii



- Waimano Training School and Hospital: 1924-1998
- Community Based Waiver Services began in 1982
- 1990s: limited admissions and lengthy waitlists
- Legal catalysts: Olmstead/ Makin
- 2000s: Family Support Model

In years past,

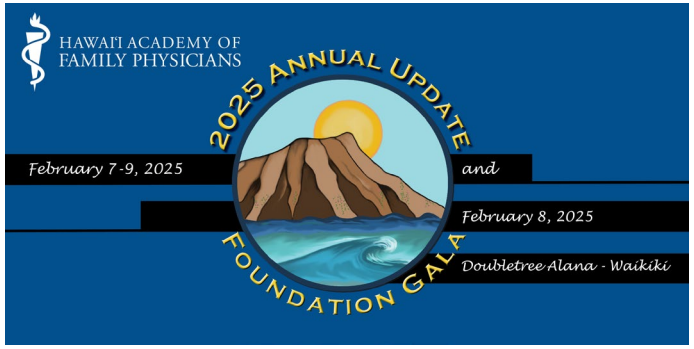
Individuals with DD/ID were served primarily by Hawaii's "institution for the mentally retarded" - Waimano Training School and Hospital

DEINSTITUTIONALIZATION

In 1999, Hawaii closed Waimano Training School & Hospital

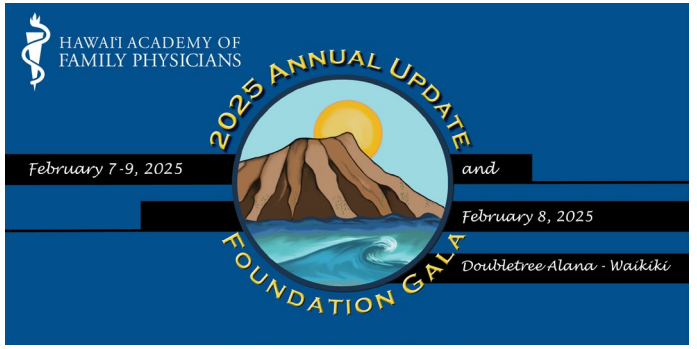
– One of the first ten states in the nation to eliminate all large state institutions

What is the DD Waiver?

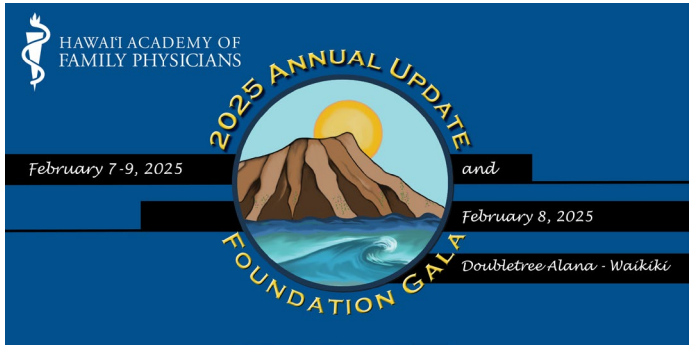


- Origin: The Katie Beckett "Waiver" in 1982 by President Reagan
- Community Support Services
- Not Medicaid State Plan Services i.e. medical services, medicines
- Not an entitlement program; but an option to State Medicaid agencies
- Services vary by State

What is the DD Waiver in Hawaii?

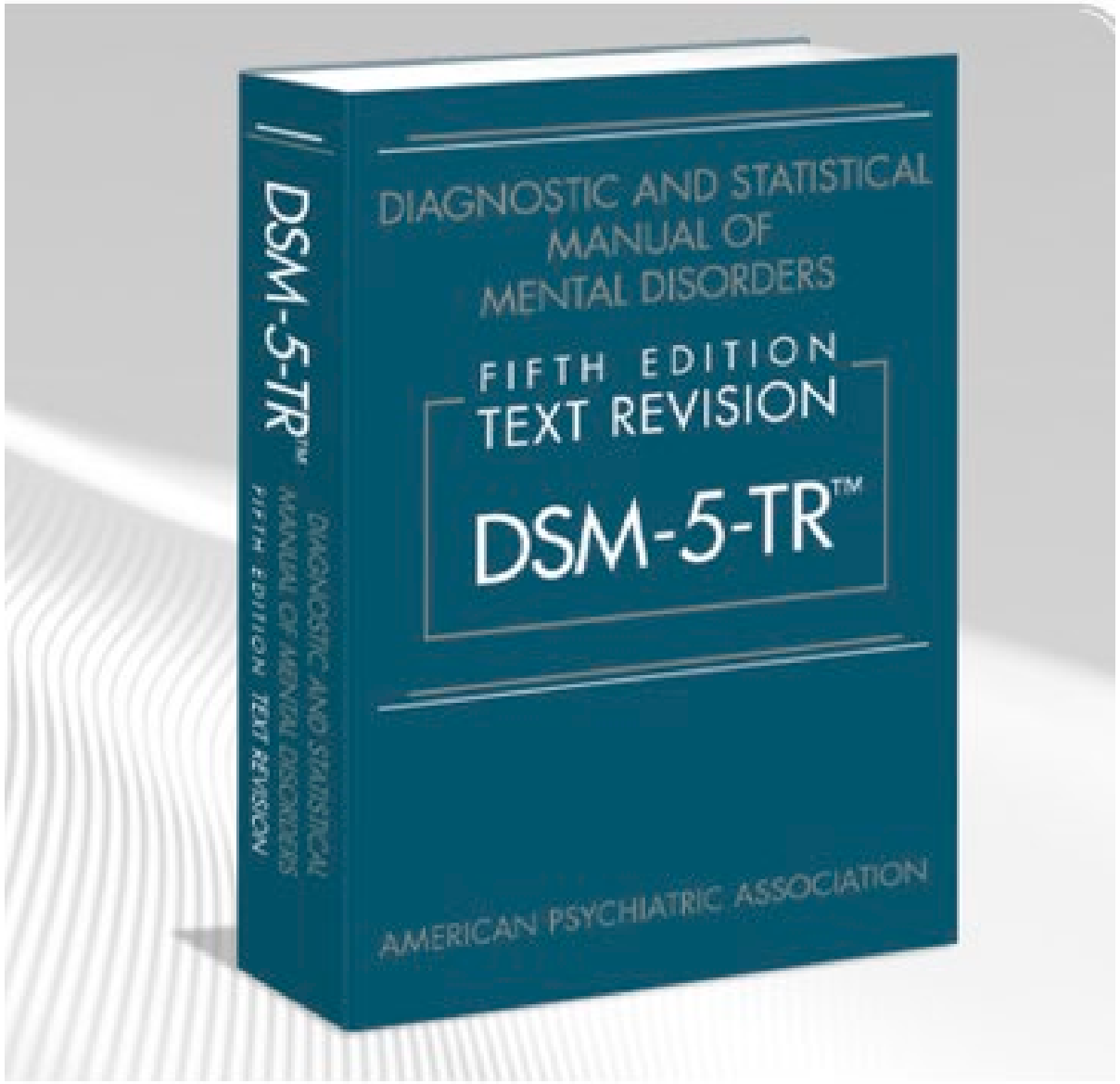


- Personal assistance, habilitation, behavioral assessment & planning, case management, emergency plan, environmental modifications, respite, pre-vocational services, specialized equipment
- Individualized Support Plan (ISP)
- Person Centered Principles



Common Developmental Disabilities

- Prevalence of population with developmental disabilities ≈ 15%
  - –Intellectual disability
  - –Autism spectrum disorders
  - –Cerebral palsy



HAWAII ACADEMY OF FAMILY PHYSICIANS

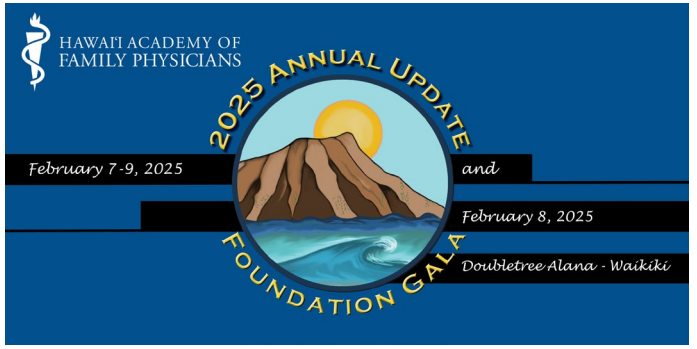
2025 ANNUAL UPDATE

February 7-9, 2025 and February 8, 2025

Doubletree Alana - Waikiki

FOUNDATION GALA

What Exactly is an Intellectual Disability?

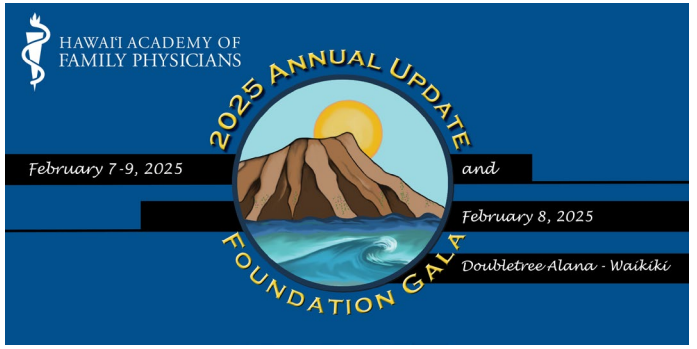


DSM-5 emphasizes the need to use both clinical assessment and standardized testing of intelligence when diagnosing intellectual disability, with the severity of impairment based on adaptive functioning rather than IQ test scores alone.

IQ or similar standardized test scores should be included in an individual's assessment.

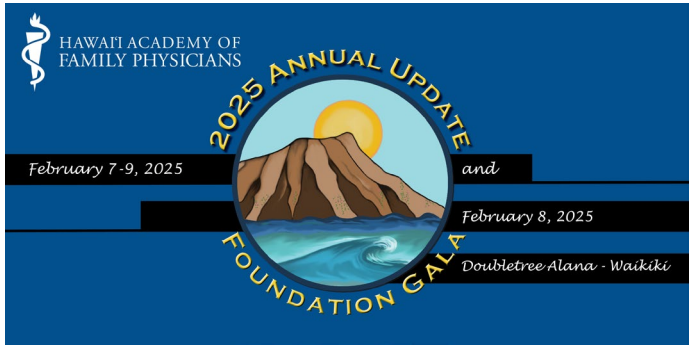
In DSM-5, intellectual disability is considered to be approximately two standard deviations or more below the population, which equals an IQ score of about 70 or below.

Intellectual Disability



- Intellectual disability involves impairments of general mental abilities that impact ADAPTIVE FUNCTIONING in three domains, or areas. These domains determine how well an individual copes with everyday tasks:
- The conceptual domain includes skills in language, reading, writing, math, reasoning, knowledge, and memory.
- The social domain refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities.
- The practical domain centers on self-management in areas such as personal care, job responsibilities, money management, recreation, and organizing school and work tasks.

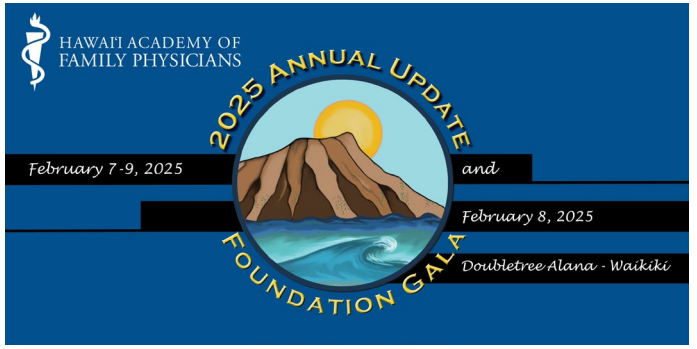
Risk of Poor Health Outcomes



CDC - White Paper 2009 "US Surveillance on Health of People with Intellectual Disabilities". Highlighted disturbing disparities. **Persons with ID** are a particularly vulnerable population. More likely to.....

- Live with complex health conditions
- Have limited access to quality healthcare/health prevention programs
- Miss cancer screenings
- Have poorly managed chronic conditions, e.g. epilepsy
- Be obese
- Have undetected poor vision
- Have mental health problems

Diagnosis of Autism Spectrum Disorder: DSM-5 Criteria



Persistent deficits in social communication/ interaction

All of the following symptoms must be met across contexts (and not accounted for by ID or global developmental delay):

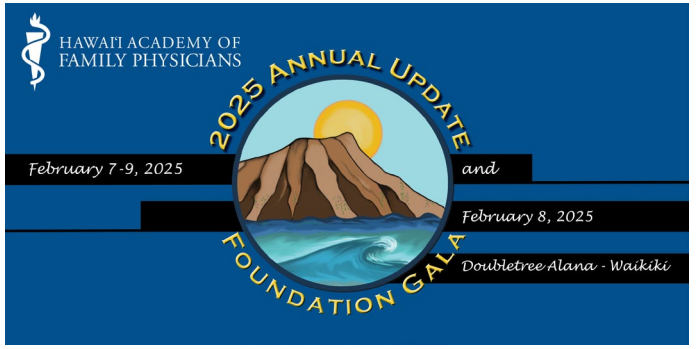
- Problems reciprocating social or emotional interaction, including difficulty establishing or maintaining back-&-forth conversations & interactions, inability to initiate or respond to an interaction, & problems with sharing of emotions & interests with others
- Nonverbal communication problems such as abnormal eye contact, posture, facial expressions, tone of voice & gestures, as well as an inability to understand these
- Severe problems maintaining relationships — ranges from lack of interest in others to difficulties in pretend play & engaging in age-appropriate social activities, to problems adjusting to different social expectations

Restricted & repetitive behavior (RRB)

Two of the four following symptoms need to be present:

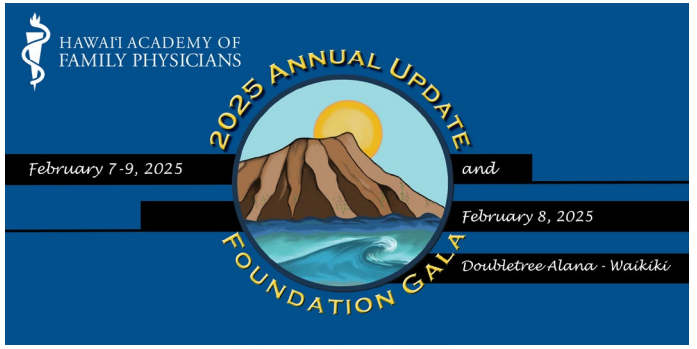
- Stereotyped or repetitive speech, motor movements, or use of objects
- Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change
- Highly restricted interests that are abnormal in intensity or focus
- Hyper or hypo reactivity to sensory input or unusual interest in sensory aspects of the environment

Diagnosis of Autsim: DSM-5 Criteria (Continued)



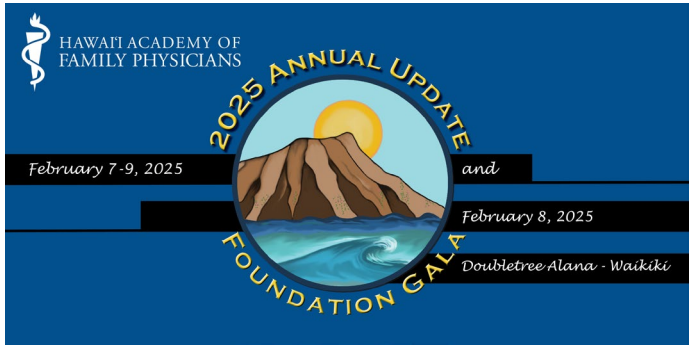
- Symptoms must be present in early childhood but may not become fully manifest until social demands exceed capacities. Symptoms need to be *functionally impairing* and not better described by another DSM-5 diagnosis
- In addition to the diagnosis, each person is also described in terms of:
  - level of language and intellectual disability
  - any known genetic cause (e.g. fragile X syndrome, Rett syndrome),
  - presence of medical conditions (e.g., seizures, anxiety, depression, GI problems)

Definitive Autism Diagnosis



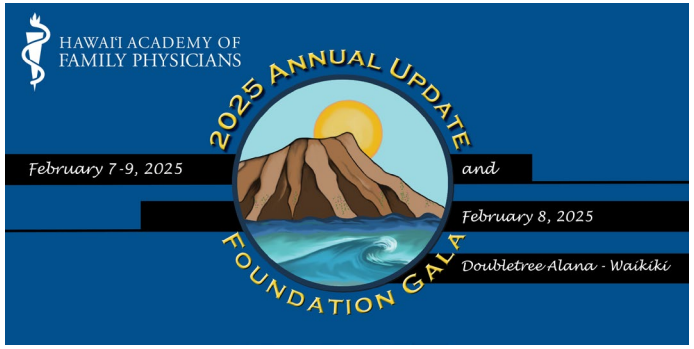
- This takes experience and training
- DSM-5 is the criteria
- The Autism Diagnostic Observation Schedule (ADOS) is the "gold standard" for the research world – many clinicians in Hawaii use this, especially in unclear situations
  - Need to have certification to do this
- Some clinicians uses standardized tools to interview family members
  - An example is the Childhood Autism Rating Scales (CARS)

Cerebral Palsy = Static Encephalopathy



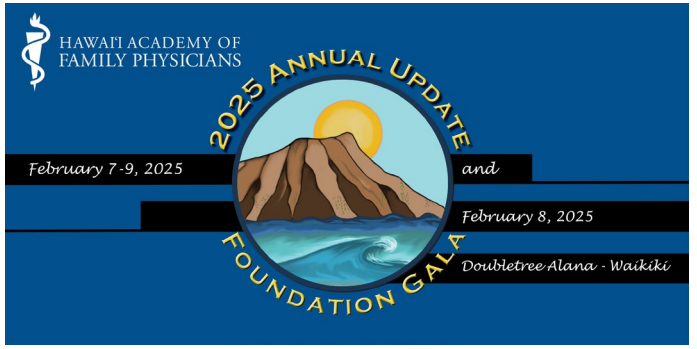
- It is a brain defect or lesion that affects motor and coordination function.
- If the condition affects the spinal cord (for instance, injury in a motor vehicle accident to the vertebra and spinal cord) then it is not CP
- If the condition affects the nerves to a portion of the body (for instance a brachial plexus injury) then it is not CP

Intellectual Disability in CP?



- Frequently the brain condition causing cerebral palsy also causes intellectual disability, behavioral conditions, or other brain based problems
- Sometimes it doesn't cause intellectual disability. A common example is the choreoathetoid type of cerebral palsy caused by kernicterus from severe jaundice (affects the basal ganglia and auditory system)

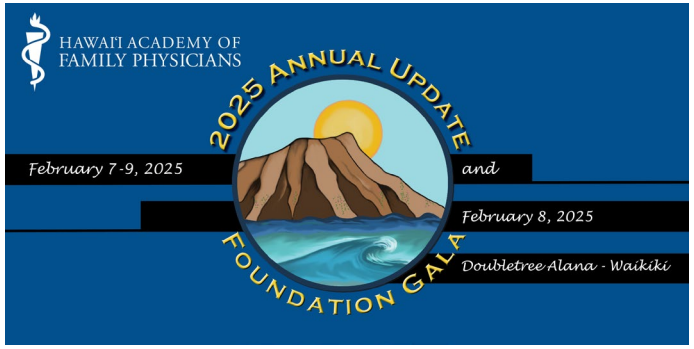
Cognitive Profile in CP



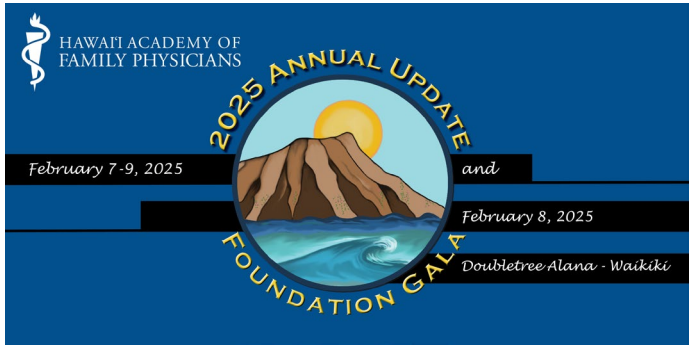
- But intellectual disability is frequent and correlated with the degree of motor impairment and early epilepsy
- Speech and language problems are prevalent in all forms of CP
- Most children with CP have deficits affecting visuospatial functions, attention, and/or executive functions.

Fluss J, Lidzba K, Cognitive and academic profiles in children with cerebral palsy: a narrative review, Annals of Physical and Rehabilitation Medicine (2020)

Challenges for Children with I/DD

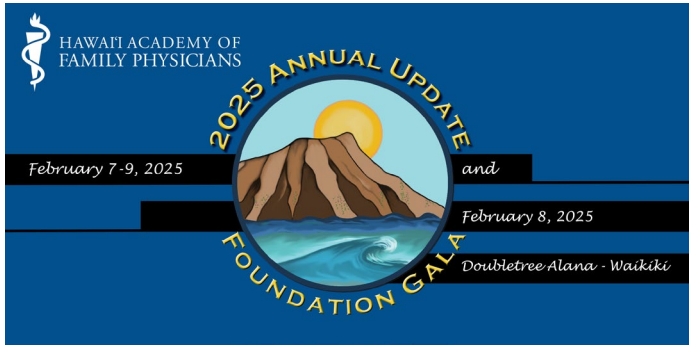


- School
- Home
- Getting Routine Care
- Getting Subspecialty Care
- Behavioral issues - This is affected by the level of functioning and learning the person has



Transition Health Care Checklist: Preparing for Life as an Adult go to http://www.waisman.wisc.edu/cedd/pdfs/products/health/THCL.pdf

Challenges for Adults with I/DD



- Residential
- What to do during the day?
- Supervision
- Getting medical care
- Sexuality

Transition Issues

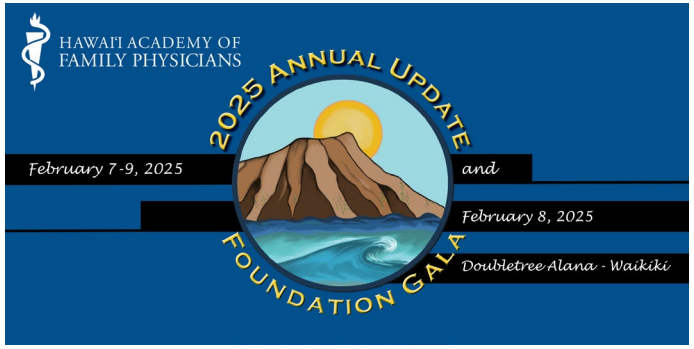


TABLE 1 Youth, Young Adult, and Family Transition[41,42,49,73,77-103]

Fear of a new health care system and/or hospital
Not wanting to leave their pediatric clinician and pediatric institution
Anxiety about how to relinquish control around managing their youth condition
Anxiety of not knowing the adult clinicians, adult health care system, and logistical issues (ie, finding parking, making appointments, finding a physician who is taking new patients, inadequate transferring patient records, and insurance issues)
Changing and/or different therapies recommended in adult health care
Families' fear that adult clinicians will not listen to and value their expertise
Negative beliefs about adult health care
Inadequate planning
Inadequate preparation and support from clinicians on the transition process and adult model of care
Not having seen clinician alone
Youth and young adults less interested in health compared with broader life circumstances
Adolescents' age, sex, and race and/or ethnicity and their parents' socioeconomic status can affect transition preparation
System difficulties
Lack of communication and coordination and transfer of medical records between adult and pediatric clinician or system
Limited availability of adult primary and specialty clinicians
Difficulty in locating adult clinicians who have specialized knowledge about and community resources for youth with pediatric-onset chronic diseases Loss of insurance coverage among young adults and cost of care barriers

White PH, Cooley WC; Transitions Clinical Report Authoring Group; American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians. Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. *Pediatrics*. 2018;142(5):e20182587

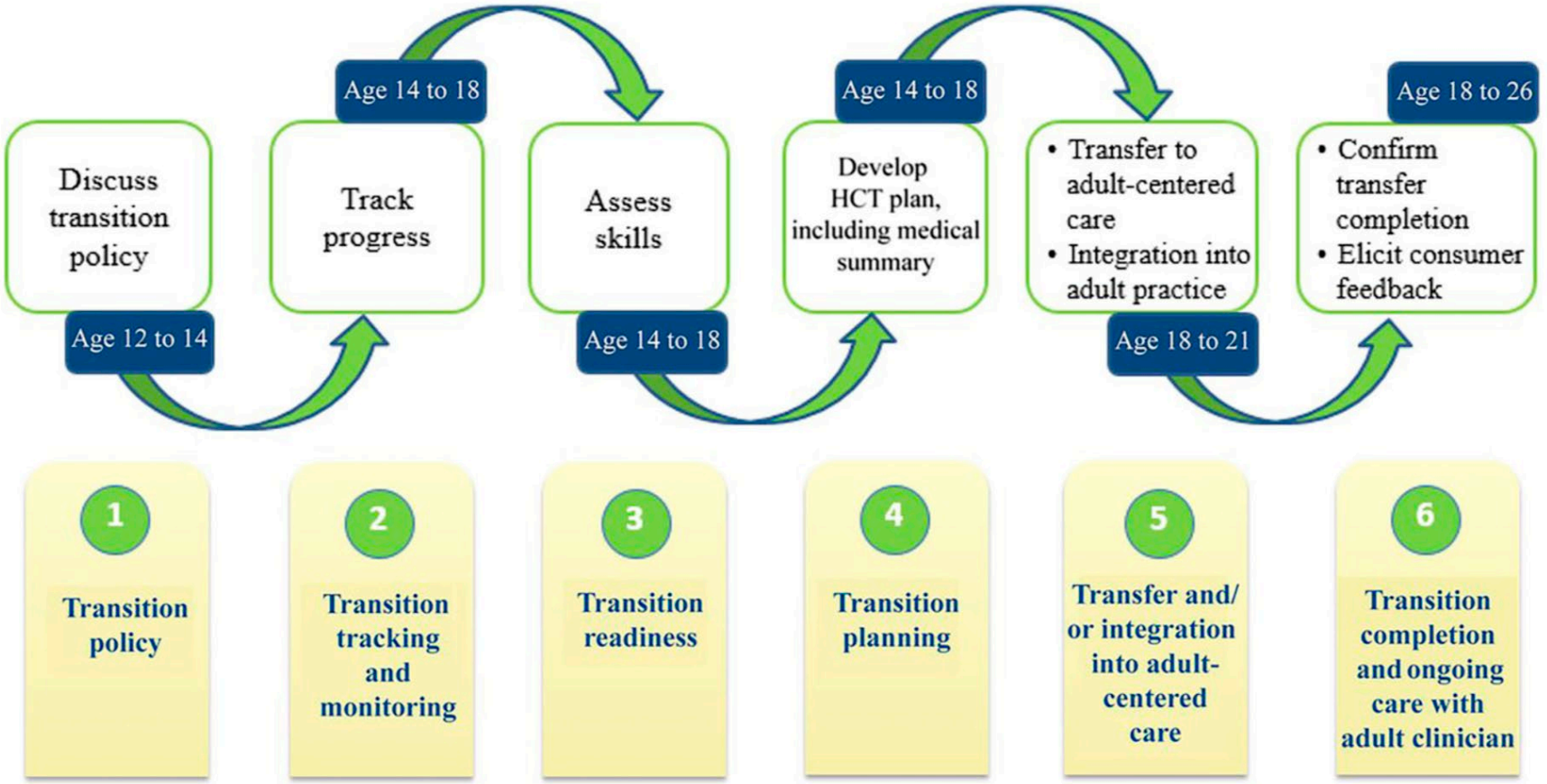
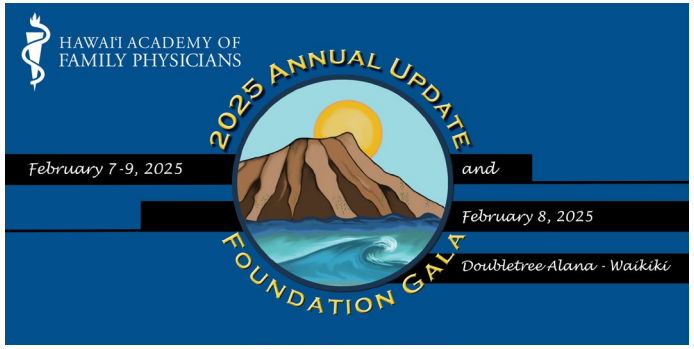


FIGURE 1
Timeline for introducing the Six Core Elements into pediatric practices.



Center for
Transition to Adult Health Care
for Youth with Disabilities

About Us Resources Data

Screenshot

About Us

The Center for Transition to Adult Health Care for Youth with Disabilities is a national health care transition (HCT) resource center. The goal of the center is to empower youth and young adults with intellectual and developmental disabilities (ID/DD) ages 12-26 to direct their own transition from pediatric to adult care with no reduction in quality of care of gaps in service.

Family Voices leads this project, in partnership with Got Transition, SPAN NJ, University of Missouri Kansas City, and the Waisman Center, as part of a five-year contract from The Department of Health and Human Services, Administration for Community Living.

Pediatric to Adult Health Care Transition Tool

Health Care Transition Readiness Assessment *for Students*

This health care transition readiness assessment is intended for students and their family/caregivers to compete as part of IEP transition planning meetings. If a student is unable to fill out this form, the student can complete it with the help of their family/caregiver.

Directions: Please check the box next to the answer that best applies to you right now. This helps us see what you already know about your health and using health care and areas that you need to learn more about.

Student Name: Student Date of Birth:

Completed By: Date Completed:

Personal Care *(related to dressing, eating, bathing, and moving)*	**Use of Communication Supports**
☐ I am able to care for all my needs	☐ Text-to-speech technology
☐ I need a little bit of help to care for my needs	☐ Assistive Listening Systems
☐ I need a lot of help to care for my needs	☐ ASL/Interpretation technology
☐ I need help to care for all my needs	☐ Other technology:
	☐ I do not use communication supports

Transition Importance & Confidence *On a scale of 0 to 10, please circle the number that best describes how you feel right now.*
**The transition to a doctor who cares for adults usually occurs between ages 18-22.*

How important is it to you to move to a doctor who cares for adults by age 22*?

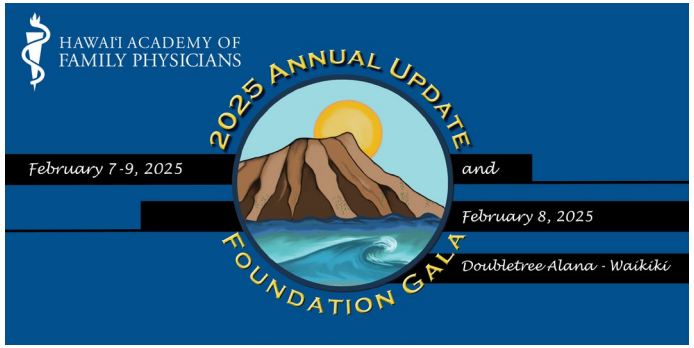
0 (not)	1	2	3	4	5 (neutral)	6	7	8	9	10 (very)

How confident do you feel about your ability move to a doctor who cares for adults by age 22*?

0 (not)	1	2	3	4	5 (neutral)	6	7	8	9	10 (very)

My Health *Please check the box that applies to you right now.*	Yes	I want to learn	No
I can name my learning differences, disability, medical, or mental health diagnosis (e.g. diabetes, depression).	☐	☐	☐
I can name 2-3 people who can help me with my learning differences, disability, medical, or mental health needs in an emergency.	☐	☐	☐
Before a doctor's visit, I prepare questions to ask.	☐	☐	☐
I know to ask the doctor's office for accommodations, if needed.	☐	☐	☐
I have a way to get to my doctor's office.	☐	☐	☐
I know the name(s) of my doctor(s).	☐	☐	☐
I know or I can find my doctor's phone number.	☐	☐	☐
I know how to make my doctor's appointments.	☐	☐	☐
I carry my health information with me every day (e.g. insurance card, emergency phone numbers).	☐	☐	☐
I know my food allergies.	☐	☐	☐

My Medicines *Please check the box that applies to you right now.*	Yes	I want to learn	No
I know the name of the medicines I take.	☐	☐	☐
I know the amount of the medicines I take.	☐	☐	☐
I know when I need to take my medicines.	☐	☐	☐
I know how to read and follow the direction labels on my medicines.	☐	☐	☐
I know what to do when I run out of my medicines.	☐	☐	☐
I know my medicine allergies.	☐	☐	☐



Sample Plan of Care

This sample plan of care is created jointly with youth and their parent/caregiver to set goals and outline a plan of action that combines health and personal goals. Information from the transition readiness assessment can be used to develop goals. The plan of care should be updated often and sent to the new adult clinician as part of the transfer package.

Preferred name | *Legal name* | *Date of birth*

Primary diagnosis | *Secondary diagnosis*

WHAT MATTERS MOST TO YOU AS YOU BECOME AN ADULT? HOW CAN LEARNING MORE ABOUT YOUR HEALTH NEEDS AND LEARNING HOW TO USE HEALTH CARE SUPPORT YOUR GOALS?

Youth's Prioritized Goals	Transition Issues or Concerns	Actions	Person Responsible	Target Date	Date Completed

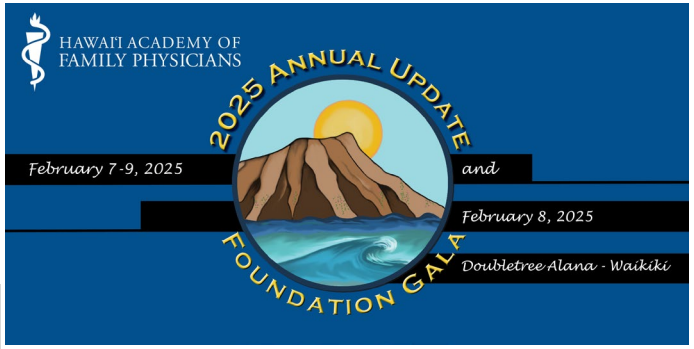
Clinician/Care staff name | *Date plan created/Updated*

Clinician/Care staff contact information | *Clinician/Care staff signature*

Youth signature | *Parent/Caregiver signature*

got transition

Canadian Family Physician



CLINICAL REVIEW

Improving transition to adulthood for adolescents with intellectual and developmental disabilities

Proactive developmental and systems perspective

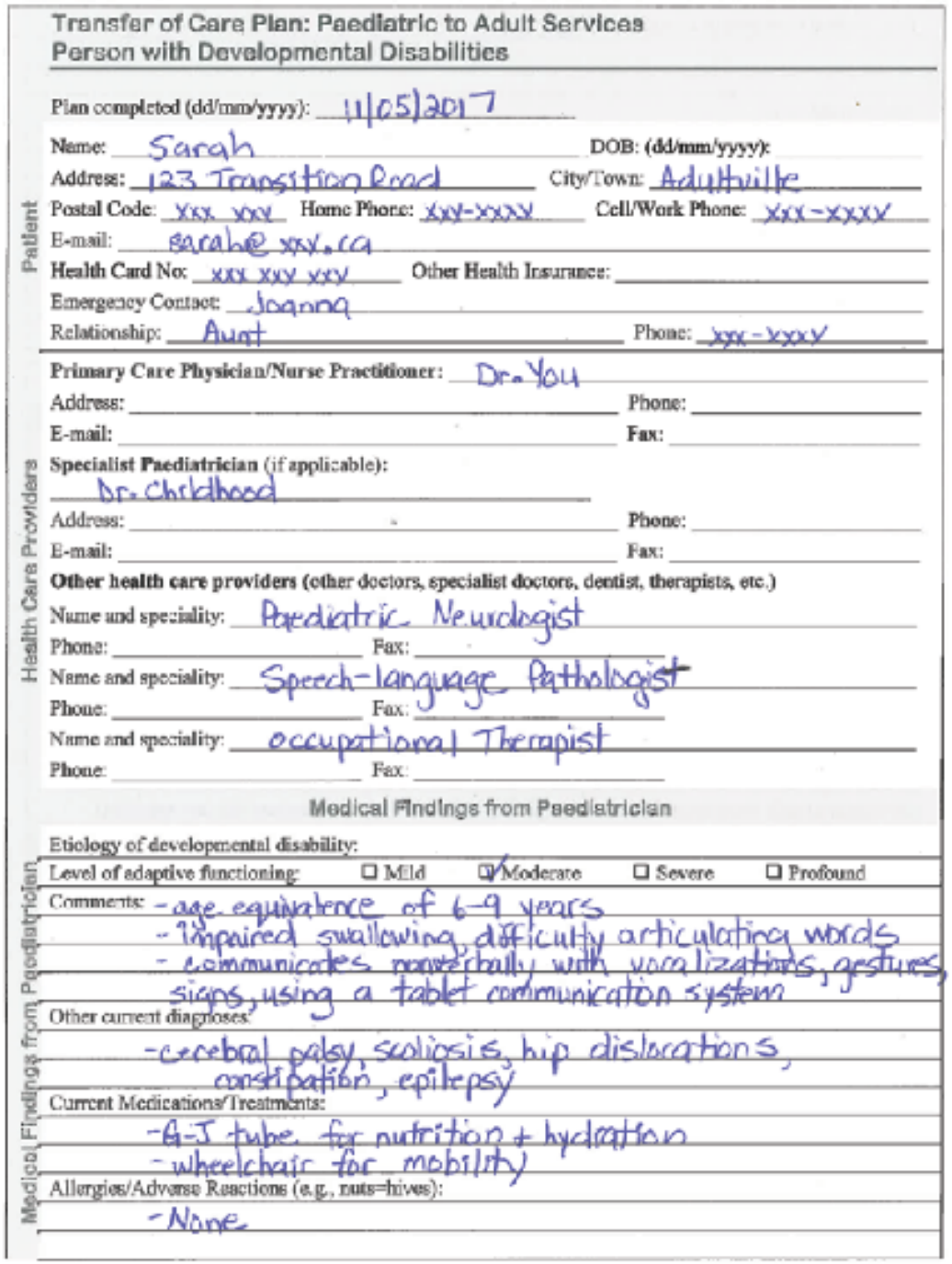
Shara Ally RN MN Kerry Boyd MD FRCPC Dara Abells MD CCFP MScCH Khush Amaria PhD CPsych
Yani Hamdani PhD OT Reg (Ont) Alvin Loh MD FRCPC Ullanda Niel MD CCFP Samantha Sacks MD CM CCFP
Sarah Shea MD FRCPC William F. Sullivan MD CCFP(COE) FCFP PhD Brian Hennen MD MA FCFP FRCGP

Abstract

Objective To demonstrate how family physicians can contribute to a piece of the journey of improving quality-of-life outcomes for people with intellectual and developmental disabilities (IDD) when they undergo the transition from adolescence to adulthood.

Sources of information The "Primary care of adults with intellectual and developmental disabilities. 2018 Canadian consensus guidelines" literature review and interdisciplinary input.

Main message Family physicians should be proactive in anticipating and supporting the transition of people with IDD from adolescence to adulthood. Interventions should be guided by a developmental perspective regarding the person with IDD and a life-cycle approach to supporting families. Family physicians also have a role in helping people with IDD and their families to navigate successfully through changing community-based support systems in their province,



Transfer of Care Plan: Paediatric to Adult Services
Person with Developmental Disabilities

Plan completed (dd/mm/yyyy): 11/05/2017

Patient

Name: Sarah DOB: (dd/mm/yyyy):
Address: 123 Transition Road City/Town: Adulthville
Postal Code: xxx xxx Home Phone: xxx-xxxx Cell/Work Phone: xxx-xxxx
E-mail: sarah@xxx.ca
Health Card No: xxx xxx xxx Other Health Insurance:
Emergency Contact: Joanna
Relationship: Aunt Phone: xxx-xxxx

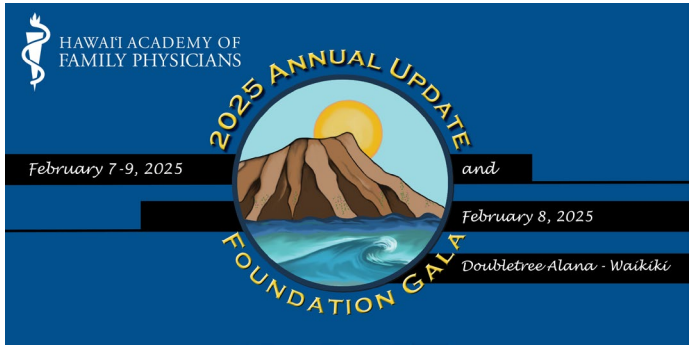
Health Care Providers

Primary Care Physician/Nurse Practitioner: Dr. You
Address: Phone:
E-mail: Fax:
Specialist Paediatrician (if applicable):
Dr. Childhood
Address: Phone:
E-mail: Fax:
Other health care providers (other doctors, specialist doctors, dentist, therapists, etc.)
Name and speciality: Paediatric Neurologist
Phone: Fax:
Name and speciality: Speech-language Pathologist
Phone: Fax:
Name and speciality: occupational Therapist
Phone: Fax:

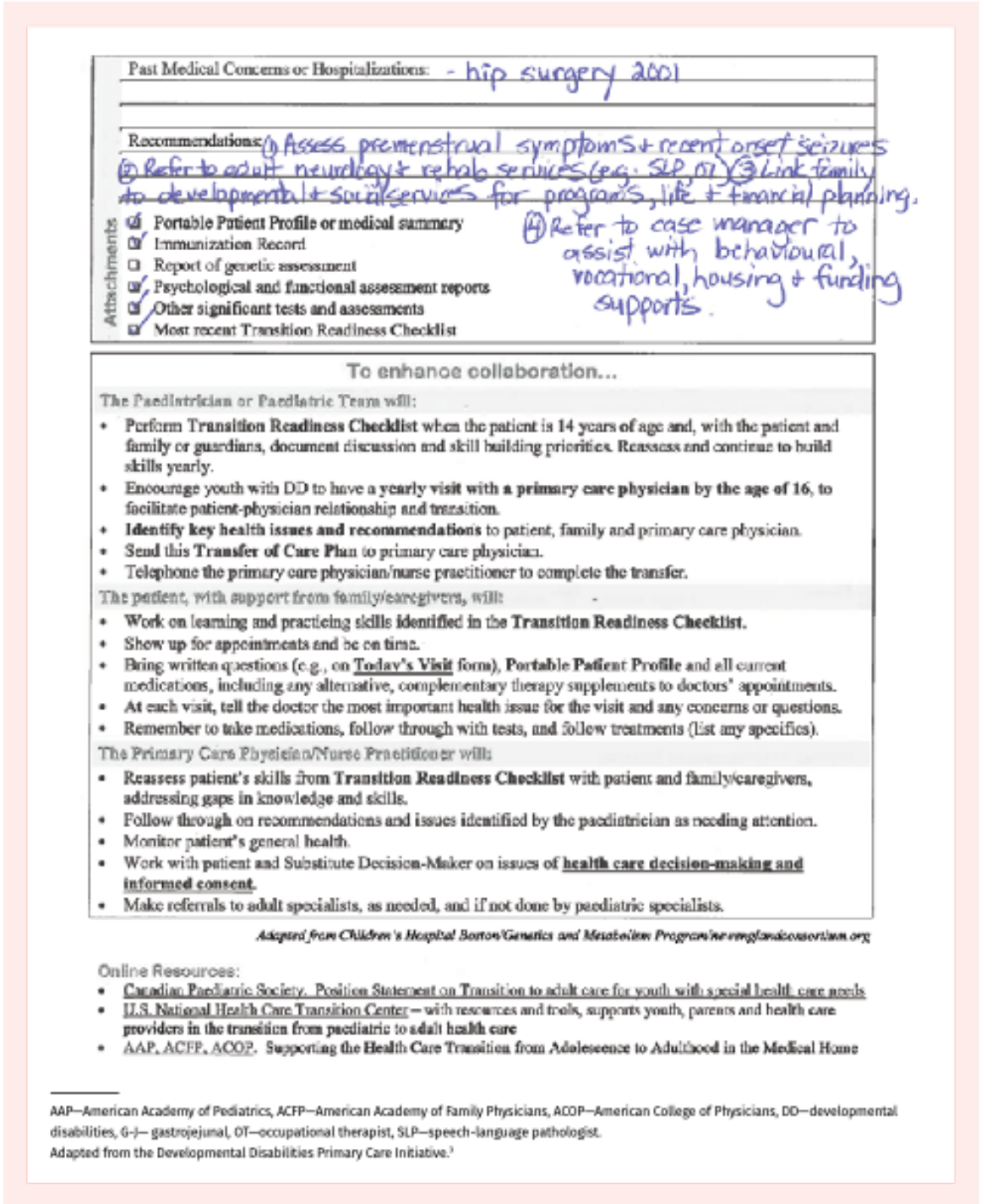
Medical Findings from Paediatrician

Medical Findings from Paediatrician

Etiology of developmental disability:
Level of adaptive functioning: ☐ Mild ☑ Moderate ☐ Severe ☐ Profound
Comments: - age equivalence of 6-9 years
- impaired swallowing, difficulty articulating words
- communicates receptively with vocalizations, gestures, signs, using a tablet communication system
Other current diagnoses:
- cerebral palsy, scoliosis, hip dislocations, constipation, epilepsy
Current Medications/Treatments:
- G-J tube for nutrition + hydration
- wheelchair for mobility
Allergies/Adverse Reactions (e.g., nuts=hives):
- None



Ally S, Boyd K, Abells D, Amaria K, Hamdani Y, Loh A, Niel U, Sacks S, Shea S, Sullivan WF, Hennen B. Improving transition to adulthood for adolescents with intellectual and developmental disabilities: Proactive developmental and systems perspective. Can Fam Physician. 2018 Apr;64(Suppl 2):S37-S43. PMID: 29650743; PMCID: PMC5906781.



Past Medical Concerns or Hospitalizations: - hip surgery 2001

Recommendations: (1) Assess premenstrual symptoms + recent onset seizures (2) Refer to adult neurology + rehab services (eg. SLP, OT) (3) Link family to developmental + social services for programs, life + financial planning. (4) Refer to case manager to assist with behavioural, vocational, housing + funding supports.

Attachments
- ☑ Portable Patient Profile or medical summary
- ☐ Immunization Record
- ☐ Report of genetic assessment
- ☑ Psychological and functional assessment reports
- ☑ Other significant tests and assessments
- ☑ Most recent Transition Readiness Checklist

To enhance collaboration...

The Paediatrician or Paediatric Team will:

- Perform **Transition Readiness Checklist** when the patient is 14 years of age and, with the patient and family or guardians, document discussion and skill building priorities. Reassess and continue to build skills yearly.
- Encourage youth with DD to have a **yearly visit with a primary care physician** by **the age of 16**, to facilitate patient-physician relationship and transition.
- **Identify key health issues and recommendations** to patient, family and primary care physician.
- Send this **Transfer of Care Plan** to primary care physician.
- Telephone the primary care physician/nurse practitioner to complete the transfer.

The patient, with support from family/caregivers, will:

- Work on learning and practicing skills identified in the **Transition Readiness Checklist.**
- Show up for appointments and be on time.
- Bring written questions (e.g., on Today's Visit form), **Portable Patient Profile** and all current medications, including any alternative, complementary therapy supplements to doctors' appointments.
- At each visit, tell the doctor the most important health issue for the visit and any concerns or questions.
- Remember to take medications, follow through with tests, and follow treatments (list any specifics).

The Primary Care Physician/Nurse Practitioner will:

- Reassess patient's skills from **Transition Readiness Checklist** with patient and family/caregivers, addressing gaps in knowledge and skills.
- Follow through on recommendations and issues identified by the paediatrician as needing attention.
- Monitor patient's general health.
- Work with patient and Substitute Decision-Maker on issues of **health care decision-making and informed consent.**
- Make referrals to adult specialists, as needed, and if not done by paediatric specialists.

Adapted from Children's Hospital Boston/Genetics and Metabolism Program/ne.emglandcoastism.org

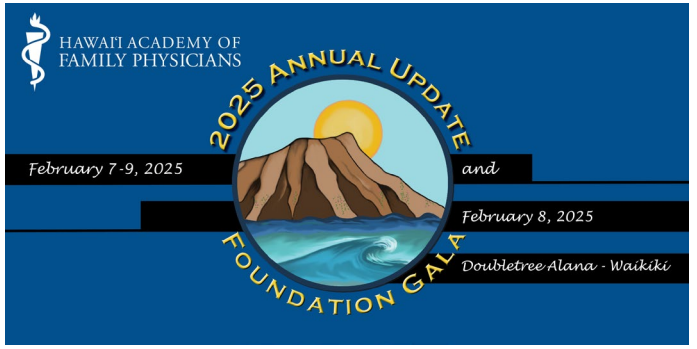
Online Resources:

- Canadian Paediatric Society. Position Statement on Transition to adult care for youth with special health care needs
- U.S. National Health Care Transition Center – with resources and tools, supports youth, parents and health care providers in the transition from paediatric to adult health care
- AAP, ACFP, ACOP. Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home

AAP—American Academy of Pediatrics, ACFP—American Academy of Family Physicians, ACOP—American College of Physicians, DD—developmental disabilities, G-J— gastrojejunal, OT—occupational therapist, SLP—speech-language pathologist.
Adapted from the Developmental Disabilities Primary Care Initiative.[3]

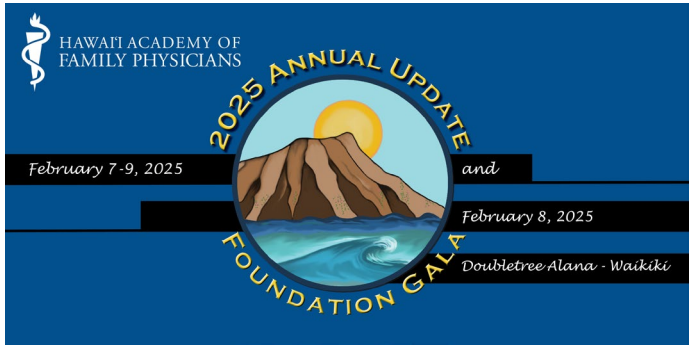
Ally S, Boyd K, Abells D, Amaria K, Hamdani Y, Loh A, Niel U, Sacks S, Shea S, Sullivan WF, Hennen B. Improving transition to adulthood for adolescents with intellectual and developmental disabilities: Proactive developmental and systems perspective. Can Fam Physician. 2018 Apr;64(Suppl 2):S37-S43. PMID: 29650743; PMCID: PMC5906781.

Transition from Pediatrics to Internal Medicine?



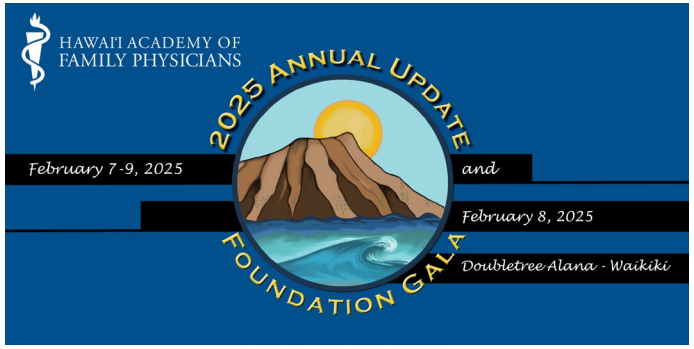
- Adult physician providers not comfortable with traditionally Pediatric entities
  - Spina bifida
  - Autism
  - Many genetic disorders
    - Prader-Willi Syndrome
    - Williams Syndrome
    - Neuronal migration Disorders
    - Mitochondrial disorders
    - Metabolic Disorders
    - Fragile X

Why Are Family Medicine Docs So Perfect to Care for People with DD?



- Family medicine physicians take care of both children and adults
- There are training programs for family medicine physicians

Training of Family Medicine Physicians for People with DD



Baylor College of Medicine

Department of Medicine

Meet Our Team | Sections | Education | Research | Healthcare | News

Baylor College of Medicine > Departments > Medicine > Sections > Transition Medicine > Education > Developmental Medicine Fellowship

Section of Transition Medicine

- Chief's Message
- Faculty
- Education

Developmental Medicine Fellowship

Training of Family Medicine Physicians for People with DD

UC CINCINNATI

COLLEGE DIRECTORY

College of Medicine

Departments / Family and Community Medicine / Fellowships / Developmental Fellowship

Department of **Family & Community Medicine**

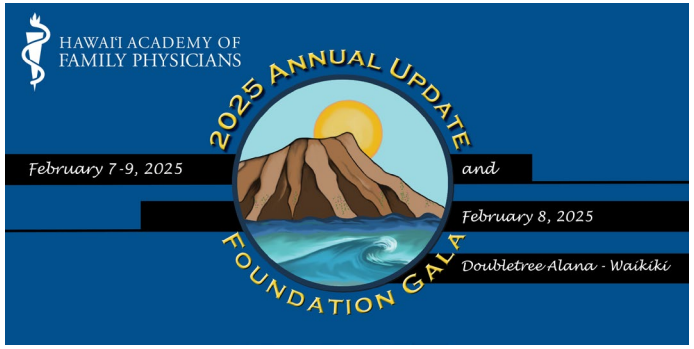
- Home
- About Us
- Leadership
- Directory
- Divisions

Developmental Fellowship

The University of Cincinnati College of Medicine Department of Family & Community Medicine (UCDFCM) is proud to offer a Developmental Fellowship for physicians interested in becoming leaders in the field of developmental medicine and caring individuals with intellectual and developmental disabilities. The fellowship program is one year in length, fellows will become certified in developmental medicine through the American Academy of Developmental Medicine, and graduate from the University of Cincinnati LEND program. Graduating fellows will be prepared to serve as leaders in developmental medicine in academic or community settings.

This is a non-ACME-accredited fellowship in which the Fellow is appointed as an entry-level faculty member in the University of Cincinnati Department of Family & Community Medicine.

Training of Family Medicine Physicians for People with DD



MICHIGAN MEDICINE
UNIVERSITY OF MICHIGAN

FAMILY MEDICINE

About Us + | Clinical Services + | Education + | Research + | Programs + | People

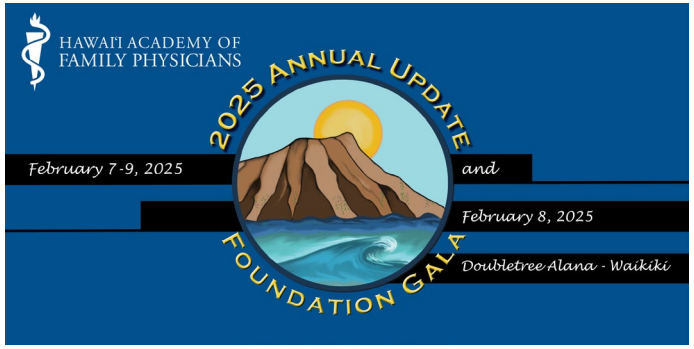
Disability Health Fellowship

The goal of the U-M Disability Health Fellowship at the University of Michigan is to create clinical leaders, educators, and advocates to improve the health and healthcare of individuals with disabilities.

The Disability Health Fellowship is a 12-month clinical fellowship that provides fellows the

Screenshot

Training of Family Medicine Physicians for People with DD



30 Osteopathic Family Physician (2019) 30 - 33 Osteopathic Family Physician | Volume 11, No. 3 | May/June, 2019

BRIEF REPORT

Curriculum on Developmental Disabilities in Family Medicine Residency

Bernadette Riley, DO, FACOFP, FILM

NYIT College of Osteopathic Medicine, Old Westbury, NY

KEYWORDS:

Developmental Disabilities

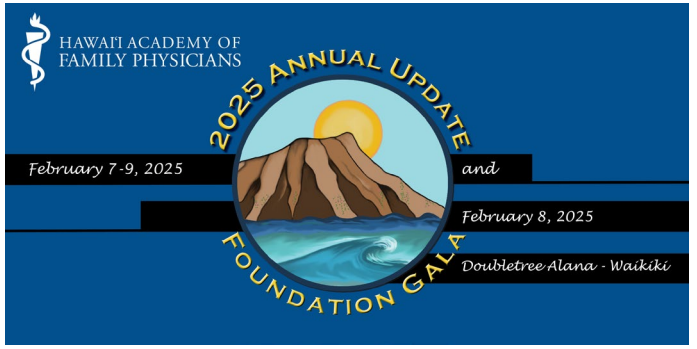
Family Medicine Residencies

Medical Education

Single GME Accreditation System

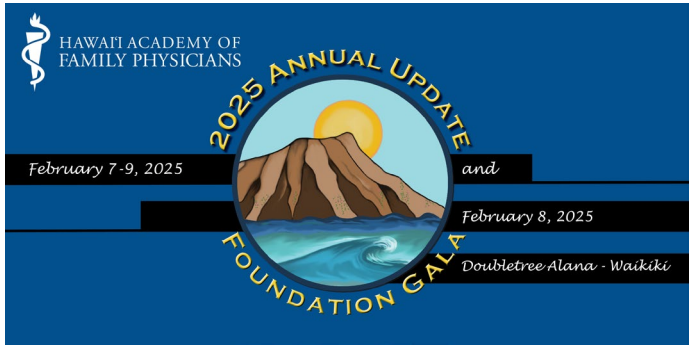
ABSTRACT: Some Family Medicine residency training programs are going through changes since the Single Graduate Medical Education (GME) Accreditation System was implemented. In this time of exponential growth this is the time for incorporating curriculum on patients with developmental disabilities (DD) during family medicine residency. During the 2017 American Medical Association House of Delegates (AMA HOD) a resolution was passed calling for GME to begin a curriculum on treating children and adults with DD. During the 2018 AOA House of Delegates a resolution was approved as amended on implementing curriculum regarding the care of people with DD. This resolution along with new topics

Scenario A - Leonard



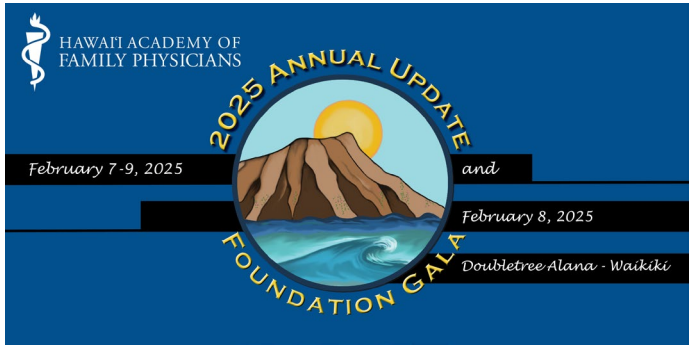
- A 19 year old named Leonard has significant autism. He cannot read but can converse (mostly about Star Trek). He can independently toilet, bathe, and eat with utensils. He can be taught how to do simple chores, such as cooking but needs supervision to do this safely.

Leonard



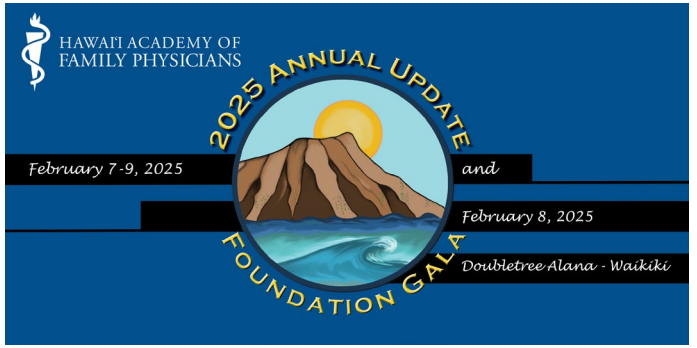
- He currently lives with his parents and younger 12 year old sister who does not have any significant developmental or medical issues.
- What is the future for the next five years for Leonard? What would be Medicaid Waiver Services that would support him and his family?

Transition from School to Work



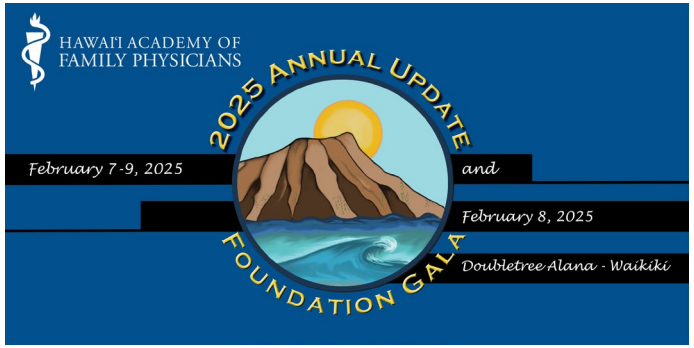
- Individualized Education Plans (IEPs) should have transition planning from age 14 for adult life
  - College?
  - Vocational training
  - Independent and semi-independent living

Scenario B - Cynthia



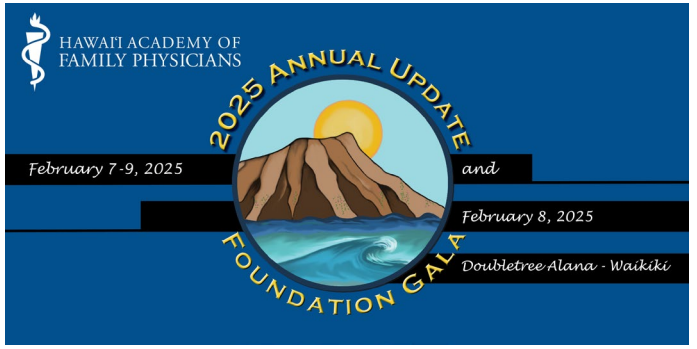
- Cynthia is a 55 year old woman with severe choreoathetoid cerebral palsy and deafness from kernicterus.
- She uses an augmentative communication device and is at a 12th grade equivalent reading and math level

Cynthia

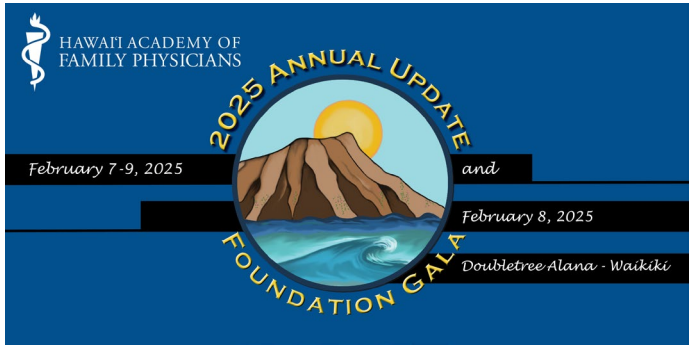


- She is in a electric wheelchair that she can steer
- She enjoys sports and watches games both live and on TV.

Cynthia



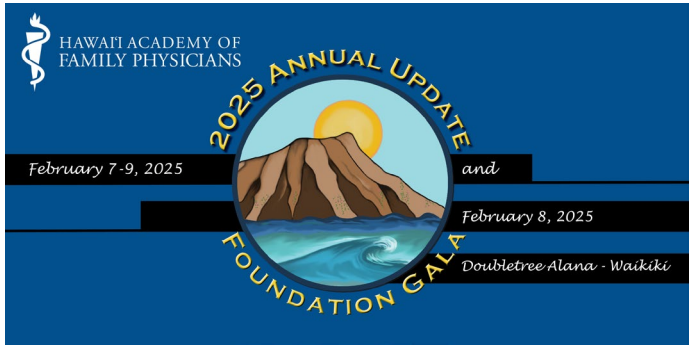
- She can make her desires known and also uses a computer to order things over the internet - she has a huge balance on her charge card
- Her parents are both elderly and wonder what will happen with Cynthia when they die, as all of their relatives are on the mainland with their own families.
- What is the future for the next five years for Cynthia? What would be Medicaid Waiver Services that would support her and her family?



Question 4

What was the most important change in the United States system that allowed people with severe intellectual and developmental disabilities to move from being in institutions to home and community settings?

a. The Individuals with Disabilities Education Act (IDEA law)
b. Licensing of group homes
c. The Medicaid Waiver for people with I/DD
d. Social Security Disability Insurance
e. Tax rebates to parents

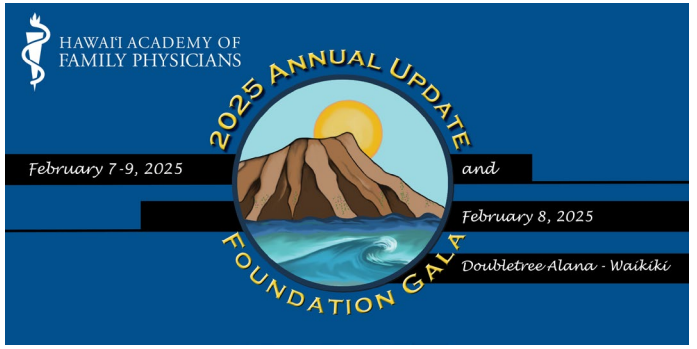


Question 4

What was the most important change in the United States system that allowed people with severe intellectual and developmental disabilities to move from being in institutions to home and community settings?

a. The Individuals with Disabilities Education Act (IDEA law)
b. Licensing of group homes
c. The Medicaid Waiver for people with I/DD
d. Social Security Disability Insurance
e. Tax rebates to parents

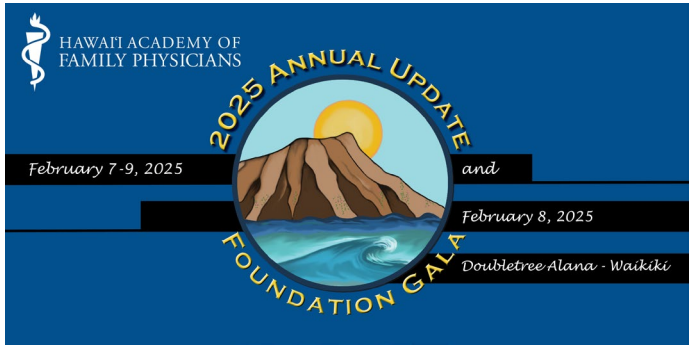
Last Question



Which should NOT be a part of the team for the transition from pediatric to adult life for a person with an intellectual / developmental disability?

a. Early Intervention Program
b. School
c. Parents
d. Physician who cares for kids
e. Physician who cares for adults

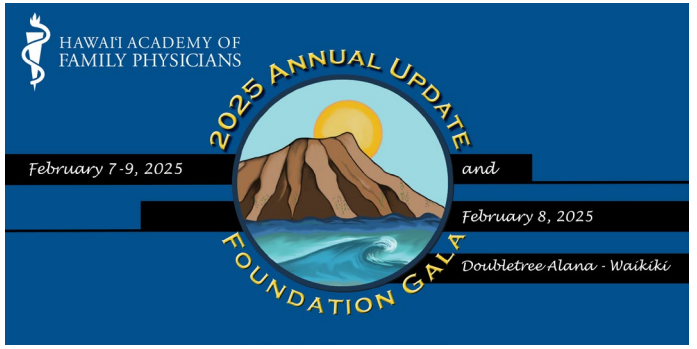
Last Question



Which should NOT be a part of the team for the transition from pediatric to adult life for a person with an intellectual / developmental disability?

a. Early Intervention Program
b. School
c. Parents
d. Physician who cares for kids
e. Physician who cares for adults

Summary



- People with developmental disabilities lead more fulfilling and less institutionalized lives
- Different states have different definitions for what a developmental disability is
- Family medicine physicians are perfectly poised to care for people with developmental disabilities and use the Medicaid Waiver