

# **Moving Systems that Serve Individuals with Intellectual and Developmental Disabilities to the Next Level**

## **Redefining Leadership**

31<sup>st</sup> Pacific Rim International Conference  
on Disability & Diversity  
May 18, 2015

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- OR: Things that keep me up at night



- **HMW?**

- Develop the skills and mindsets we need to provide quality services and outcomes people want?
- Truly partner with individuals, families, stakeholders and the community?
- Be the kind of leaders that will take our collective vision forward?

**How Might We: Influence the Future?**

- Delivers **Superior Performance** relative to its mission
- Makes a **Distinctive Impact** on the communities it touches
- Achieves **Lasting Endurance** beyond any leader, idea or setback
- **HMW be a Great System?**

**Features of Great Systems\***

# HISTORY OF DD IN HAWAII

## 1920's

Waimano Home for the Feebleminded opens in 1921 as an "institutional incarceration facility"



## 1930's to 1940's

Campus expands and placed under the Department of Institutions with a focus on agriculture



## 1950's to 1980's

1. Institution transferred to Dept. of Health, renamed Waimano Training School & Hospital (WTSH)
2. DDD established by Legislature
3. HCBS Waiver starts
4. ACT 341-foundation of deinstitutionalization - becomes HRS §333F



## Early 1990's

1. ADA
2. Act 189 calls for closure of Waimano
3. "Hawaii at the Crossroads" report recommends:
  - *Vision for future*
  - *"Action bias" for*
    - *administration/ planning*
    - *services*
    - *financing*
    - *system infrastructure*
  - *Broad partnership for unified response*

# HISTORY OF DD IN HAWAII

## 1998-1999

1. Act 133: consumer-directed services
2. WTSH closes in 1999; transitions residents to community
3. Olmstead Decision
4. Makin lawsuit (to address waitlists)
5. "What Do We Do Now?" report issued by DD Council:  
Recommends:
  - Fix problems with waiver; align with Act 133
  - Implementation in line with current DD philosophies

## Early to mid 2000s

1. Development of community-based services
2. HDRC v. State of Hawaii (non-compliance-with Makin)
3. 2001-2005 Strategic Plan issued
4. 2006-Action Plans



## 2008-present

1. Fiscal crisis
2. Waiver standards/ compliance focus
3. Refinement of services/ infrastructure
4. Focus on employment, housing, and consumer-directed services
5. QAI program started
6. Reorg approved
7. Olmstead enforcement by DOJ

## 2014-future

1. Strategic planning identifies needs:
  - *Focus on outcomes, effectiveness, and philosophy of care*
  - *Consistency of implementation and oversight for quality*
  - *Strengthened leadership and accountability*
  - *Better organizational culture*
  - *Statewide focus*



- High reliance on integrated living options
  - 97% live in residences serving 1-6: 60% in supported living; 37% in foster care and group homes
- No waitlist for I/DD services
- Rank in the top 25% of states in supporting individuals in family homes
- Community-centered service philosophy

**A Few Things We Do Well**

- Low overall fiscal effort compared to other states
  - *Hawaii ranked 45th<sup>th</sup> in 2013; largest fiscal effort reduction among all states (15%); largest reduction in comm. services (15%)*
- Low percentage living in their own home or apartment
  - *Hawaii ranked 27th out of 30 reporting states*
- Low percentage enrolled in competitive/supported employment
  - *2% vs. national average of 18.4%*

## Where Hawaii Struggles

- Build a stronger focus on measuring outcomes, service effectiveness, and philosophy of care
- Have greater consistency of implementation and oversight for quality
- Strengthen leadership and accountability
- Cultivate a positive organizational culture
- Develop a statewide focus

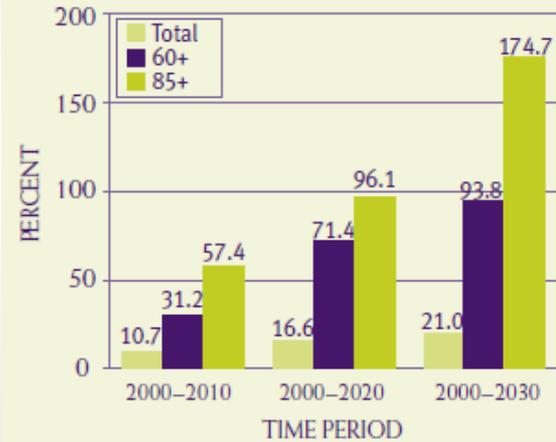
**What our Stakeholders Said**

- Focus on a greater connection and engagement with families
- Reduce risk in the system including for people with medical/health issues
- Assure adequate resources to address system infrastructure and support the work of CMs
- Build an employment first focus
- Be responsive to mandates and CMS requirements

**What our Stakeholders Said**

**Figure 2**

Projected Growth Rates of Total and Older Adult Populations, State of Hawai'i, 2000-2030



HMW: Better Understand the Future?

- Growth in aging population
  - Improvement in longevity during the 20th century was unprecedented.
  - Hawaii ranks 5<sup>th</sup> in the nation for population over 85
- Stress on federal budget:
  - Every day 10,000 Baby Boomers qualify for Social Security
  - % of people with I/DD living at home in Hawaii is among the nation's highest.
  - Family Caregivers are the Nation's LTC system
- It's clear that states can't afford to expand services requiring 24-hour care.

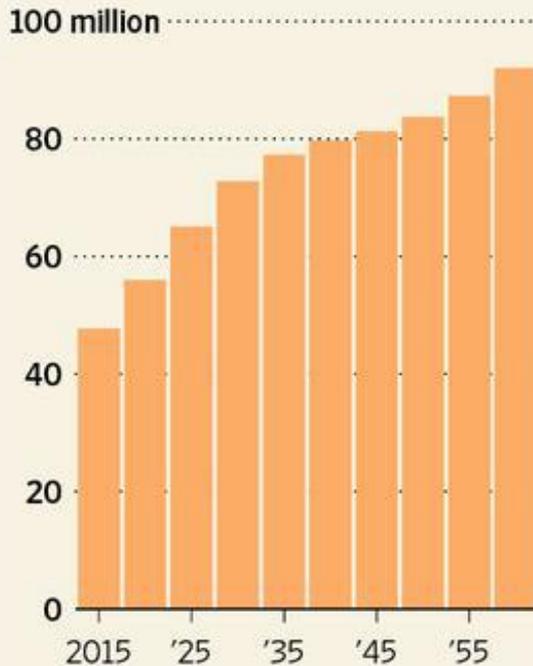
**Baby Boom**



## Caring for an Aging Population

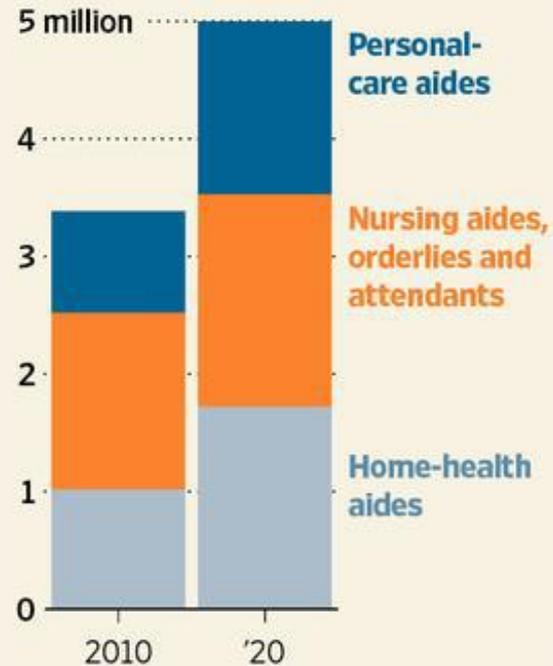
As Americans age...

Projected population, 65 and older



Sources: Census Bureau; Bureau of Labor Statistics; PHI

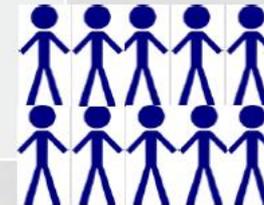
...the need for health-care aides is expected to soar.



The Wall Street Journal

# Need for skilled workforce

Type of Service	Cost per Person	20 yrs. Cost	30 yrs. Cost
Institution	\$238,500	\$4,770,000	\$7,155,000
HCBS 24 hr. staffed Residential	\$150,000	\$3,000,000	\$4,500,000
Shared Living Host Home Adult Foster Care	\$50,000	\$1,000,000	\$1,500,000
Support in Own or Family Home	\$25,000	\$500,000	\$750,000



Data Source: Lakin, K.C. MSIS and NCI data from 4 states (1,240 Individuals)

# Relative Costs for Settings



# OTHER BIG ROCKS

- CMS Community Integration Final Rule
- Waiver Renewal
- Infrastructure: EHR, Business Processes, Quality Management
- Quality of Care
- Strategic Plan Implementation
- Fair Labor Standards Act- Home Care Rule
- Adequate Resources, Service Rates



**Here's a few....**



# HMW: Redefine our Systems?

To ensure individuals with I/DD have the best possible lives in their communities

- *Access* to services and supports
- *Choice* including where individuals live and who provides services,
- *Outcomes* including having systems that support achieving outcomes people desire,
- *Integration* including service delivery that is integrated and coordinated to align programs and funding sources, and
- *Value* that is demonstrated to consumers as well as purchasers of services. This includes having comprehensive data collection and quality measurement.

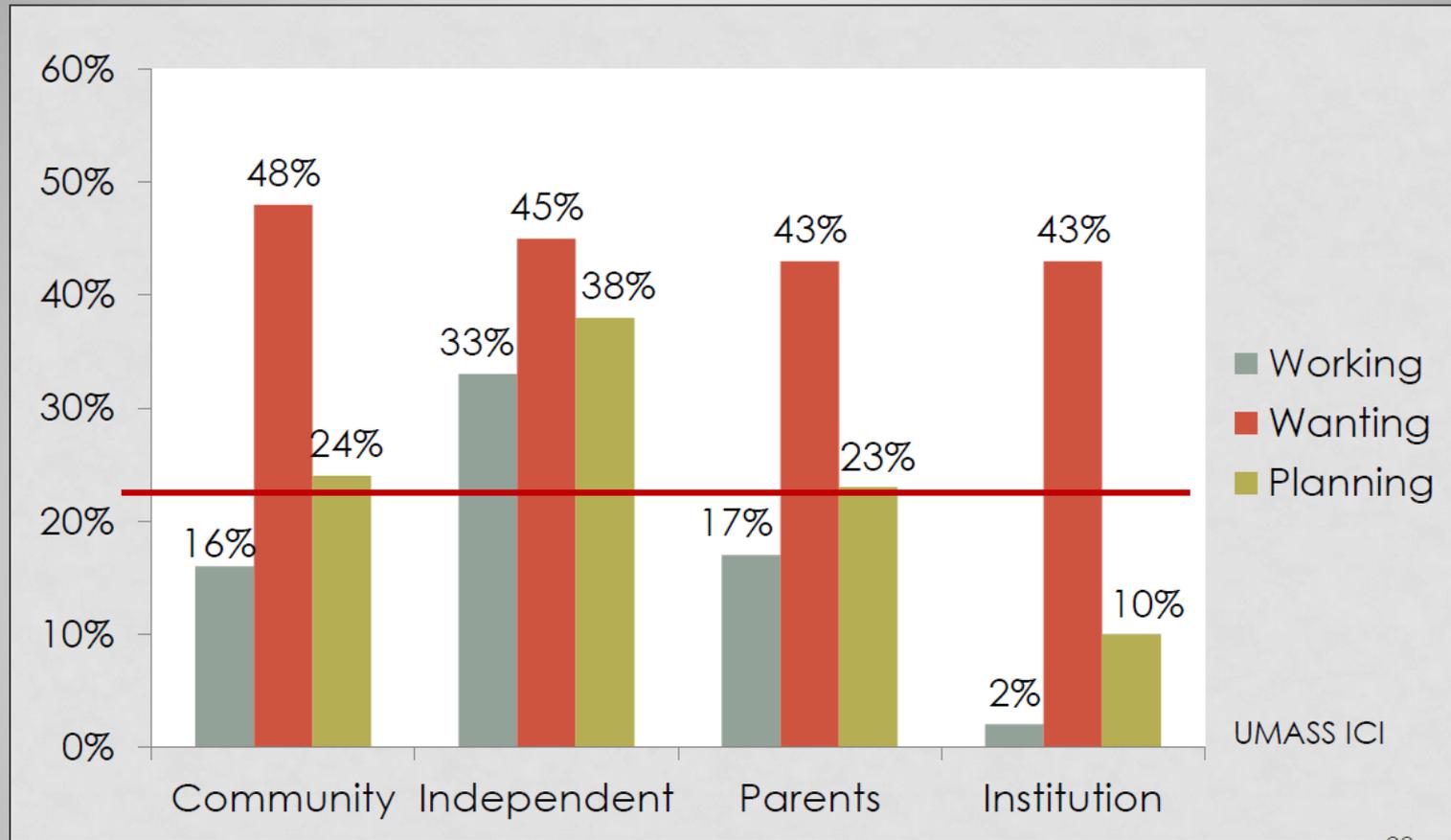
Structuring new service delivery models for individuals with I/DD

- Strengthened infrastructure and practices
- Skilled workforce- quality, quality, quality
- Shared living
- Supports match needs
- Family caregiving with expectations for outcomes, guidelines and agreements
- Transitions, transitions, transitions
- Employment

**These must be addressed**

- Independence and choices
- Social connections
- Contribute to community
- Individuals want to work

**Why employment?**



**People want to work**

Type of Service	1 yr. Cost	3 yr. Cost	10 yr. Cost
<b>Sheltered Work/Day Habilitation</b>	<b>\$20,000</b>	<b>\$60,000</b>	<b>\$200,000</b>
<b>Employment Services</b>	<b>\$20,000</b>	<b>\$50,000</b> <ul style="list-style-type: none"> <li>• \$20,000 yr. 1</li> <li>• \$20,000 yr. 2</li> <li>• \$10,000 yr. 3</li> </ul>	<b>\$120,000</b> <ul style="list-style-type: none"> <li>• \$50,000 - 3 yrs.</li> <li>• \$70,000 - 7 yrs. (\$10,000 per yr.)</li> </ul>

**And this.**

# Pushing Things Along...

“In the 1960’ s and earlier we were treated like plants. You fed us, clothed us, kept us warm, and wheeled us out to feel the sun.



In the 1970s and 80s you discovered we could be taught -- we could learn -- and we were treated like pets. You taught us all types of tricks and we stood by your side.

But now .... Here we are. We are not plants. We are not your pets.

We are people like you and we want to be treated as real people. We want the same opportunities as anybody.”

Dirk Wasano -- Hawaii Planning Council on Developmental Disabilities



# HMW: Better Support Families?

In ways that maximize their strengths and take a lifespan approach?

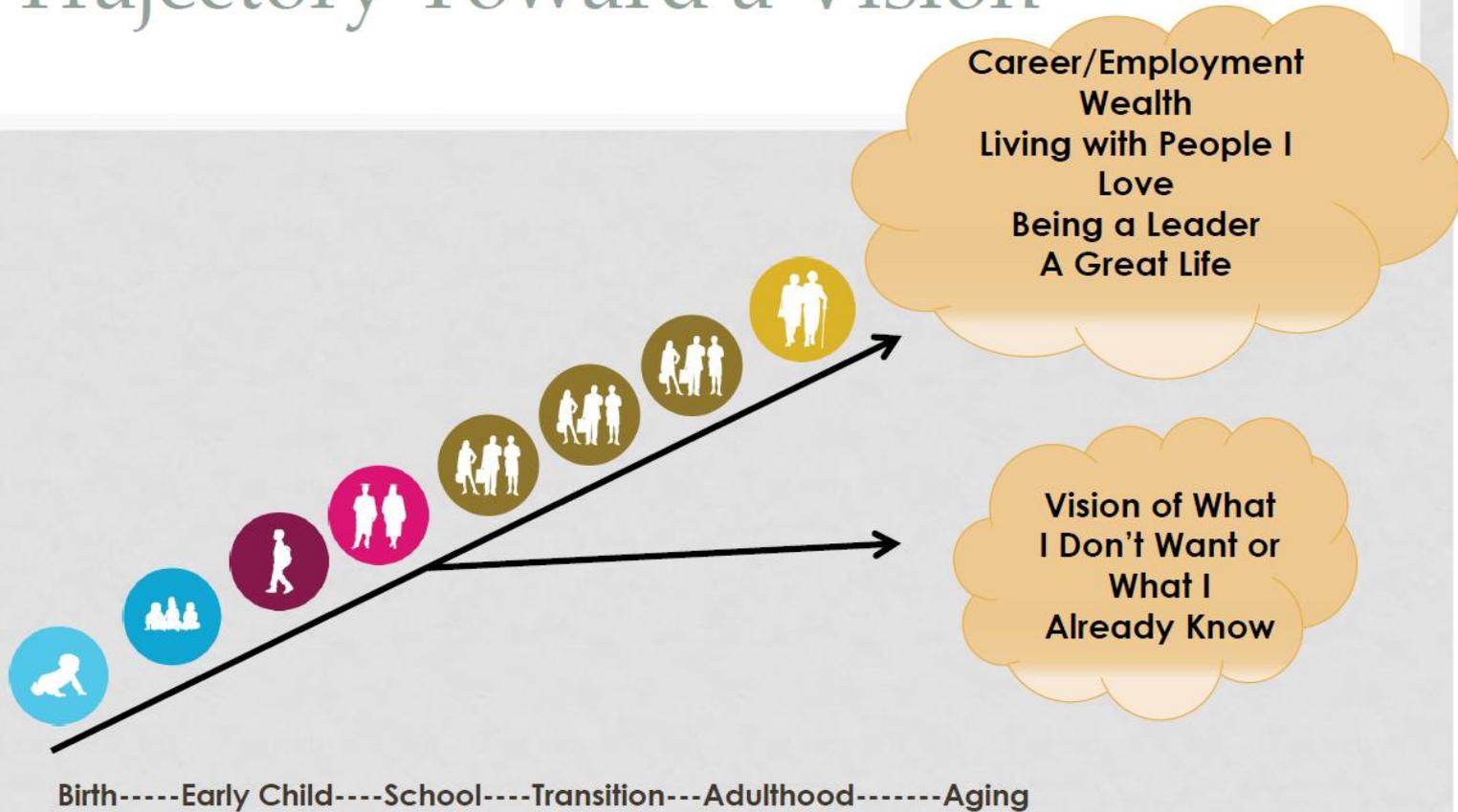


# SUPPORTING FAMILIES

of individuals with intellectual & developmental disabilities

THE NATIONAL COMMUNITY OF PRACTICE • FUNDED BY THE ADMINISTRATION ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES

## Trajectory Toward a Vision



### **Connecticut**

- Two FTE to focus on systems change to support families
- Changing eligibility process to be family friendly
- Cross department life span team
- Creating Sibling Network

### **District of Columbia**

- Waiver to support families
- Policy to add families and self-advocates to policy teams; stipends
- Legislation to create a family advisory council; supporting grants
- Regulation changes to allow families to be paid as direct support in all services
- Parent to Parent Network

### **Tennessee**

- Redesigning the process for the first point of contact
- Creating Parent to Parent Network

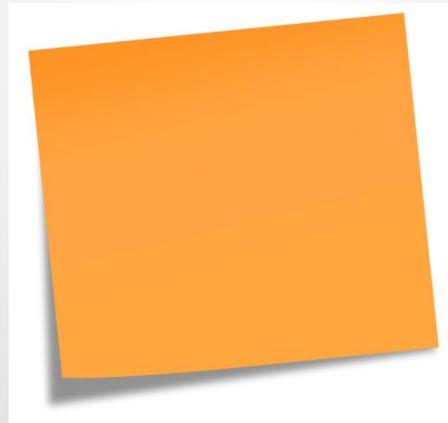
### **Washington**

- Redesigning the process for the first point of contact

### **Oklahoma**

- Retraining intake staff

**A few cutting edge efforts...**

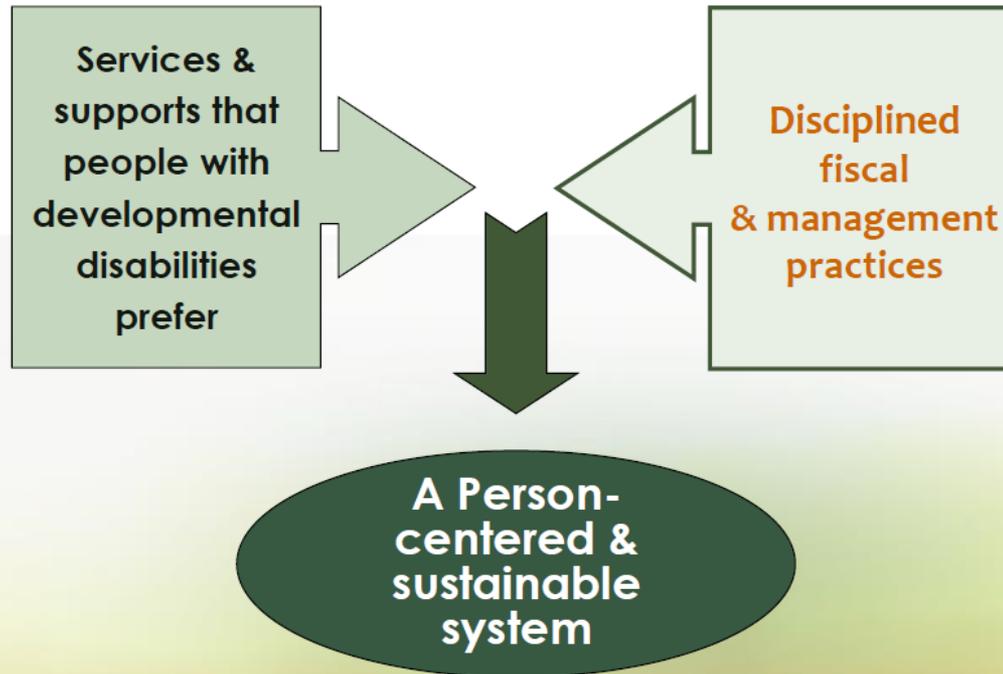


**HMW better support families?**



HMW Build Sustainable Systems?

## Blending Together Principles Related to Service Delivery & System Management

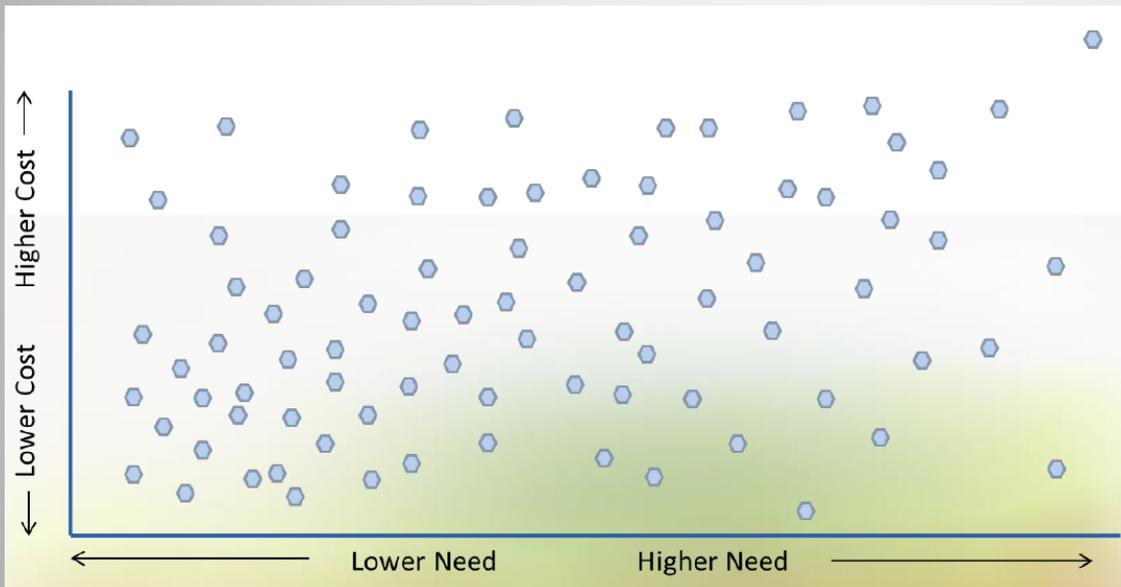


**Investment and Managing Resources**

- New HCBS Waiver
- ISP/Person-Centered Planning
- Supports Intensity Scale

**Equity and Fairness**

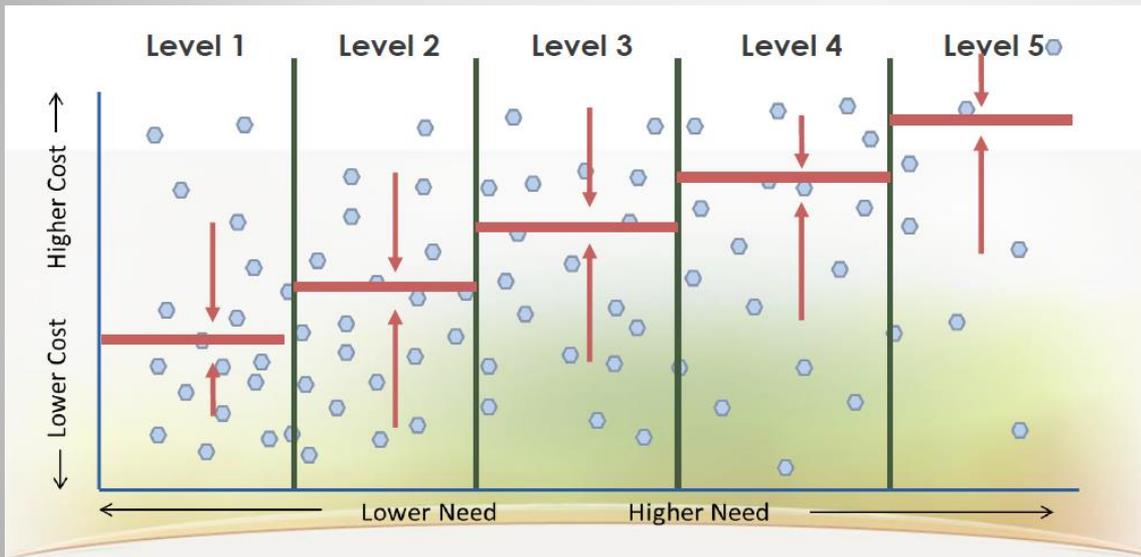
## Typical Data: Needs to Supports



Most often, there is only a modest relationship between needs and supports.

There is usually significant variability among individuals with similar needs.

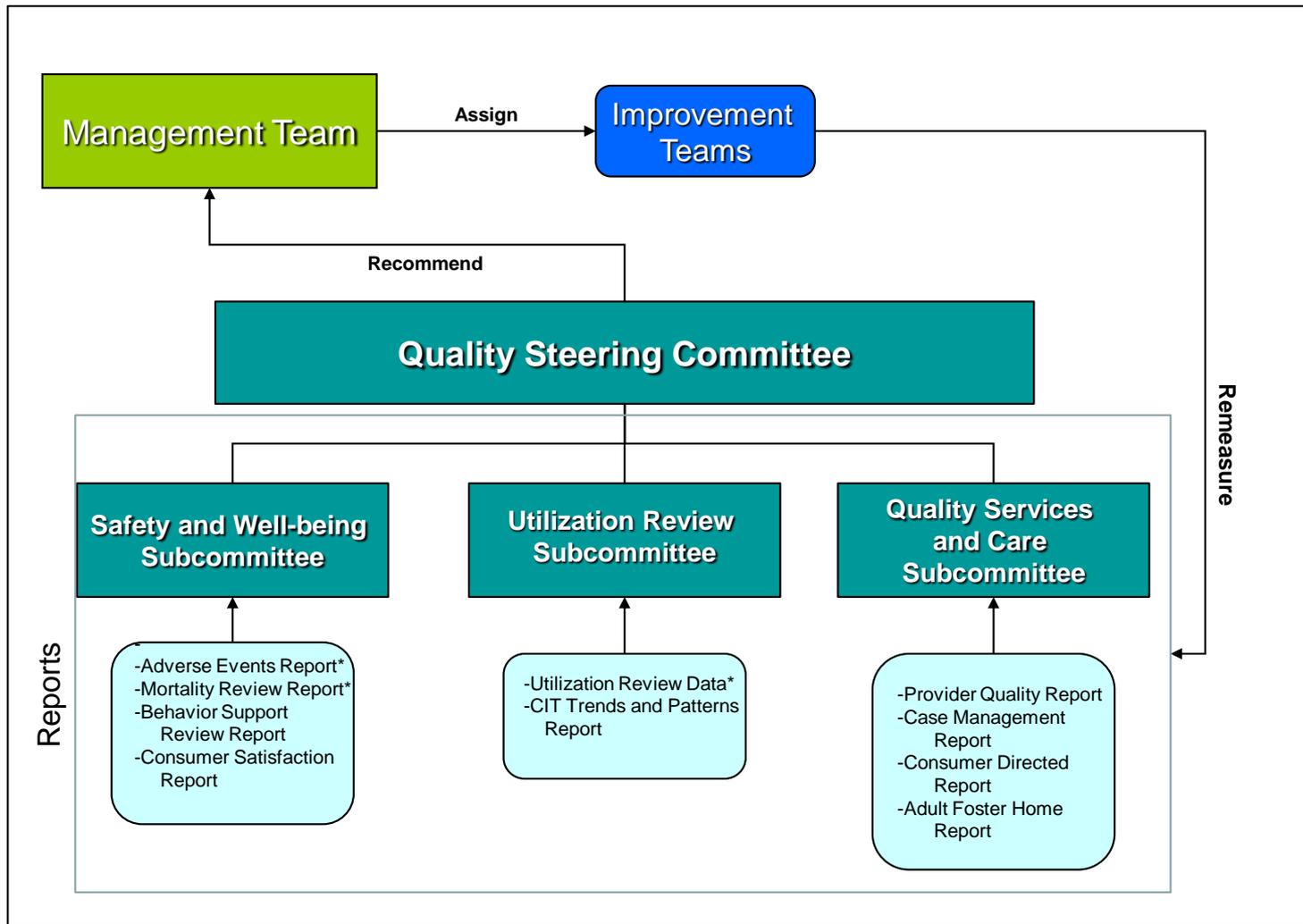
## Tying Supports to Needs



Those above budget for their Level are reduced and may be stepped down over time.

Those below may or may not be increased based on their decisions.

Exceptional support needs are accounted for.



**Quality counts!**

- Opportunity to refocus on what matters
  1. Voice and Choice
  2. Community Integration
  3. Employment First
  4. Outcomes and Effective Services
  5. Leadership and Accountability

## **DDD Hawaii's Strategic Plan**

- Listening to self-advocates and families
- Design Thinking- Stanford d.school
- Results Based Accountability
- Children's Mental Health/Family Advocacy
- Quality Management Practice (Deming, Health Plans, NCQA, etc.)
- Communities of Practice
- Resiliency and Protective Factors Research

**I have learned a lot from...**

*Individuals with intellectual and developmental disabilities have healthy, safe, meaningful and self-determined lives.*



HMW?

**Work together to engage our community with our vision?**

- Adult Consumer Survey 2013-14 Final Report. National Core Indicators. A Collaboration of the National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute. [http://www.nationalcoreindicators.org/upload/core-indicators/4\\_23\\_15\\_2013-14\\_ACS\\_508.pdf](http://www.nationalcoreindicators.org/upload/core-indicators/4_23_15_2013-14_ACS_508.pdf)
- Butterworth, J., Frank A. Smith, Allison Cohen Hall, Alberto Migliore, Jean Winsor, and Daria Domin. State Data: The National Report on Employment Services and Outcomes, 2013. Institute for Community Inclusion, University of Massachusetts Boston. [http://book.statedata.info/13/2013\\_web\\_F.pdf](http://book.statedata.info/13/2013_web_F.pdf)
- Communities of practice and social learning systems: the career of a concept, Etienne Wenger
- The Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities, <http://supportstofamilies.org/cop/>
- E. E., & Smith, R.S. (1982). Vulnerable but invincible: A longitudinal study of resilient children and youth. New York: McGraw Hill.
- Good to Great Diagnostic Tool developed by Jim Collins, Good to Great, The Project
- State of the States: Sustainable Models Nancy Thaler, National Association of State Directors of Developmental Disabilities Services
- Resilience And Recovery: Findings From The Kauai Longitudinal Study, Regional Research Institute for Human Services, Portland State University Werner,

## Resources

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**Contact**