

REPORT TO SENATOR BAKER AND  
REPRESENTATIVE MIZUNO  
HAWAII STATE LEGISLATURE  
2019

PURSUANT TO PROPOSED HOUSE BILL 538 OF 2018 LEGISLATIVE SESSION  
REQUIRING THE HAWAII STATE COUNCIL ON DEVELOPMENTAL DISABILITIES  
TO SUBMIT A REPORT ON BEHALF OF THE WORKING GROUP TO REPORT ITS  
FINDINGS AND RECOMMENDATIONS RELATING TO THE INTAKE PROCESS  
AND SERVICE DELIVERY OF THE DEPARTMENT OF HEALTH DEVELOPMENTAL  
DISABILITIES DIVISION

PREPARED BY:  
STATE OF HAWAII  
DEVELOPMENTAL DISABILITIES COUNCIL

NOVEMBER 2018

## **EXECUTIVE SUMMARY**

### **Introduction:**

The Hawaii State Council on Developmental Disabilities (Developmental Disabilities Council or DD Council) continues to pave the way for change and innovation in our communities. We continue to serve as catalysts for systems change and work to support the desires of the community in the face of significant challenges such as employment, housing, transportation and delivery of health care and wellness for those with intellectual and developmental disabilities. Investing in the DD Council and nearly 23 thousand people with developmental disabilities in our state not only assists Hawaii in the effective use of resources, but it ensures that the noble values of the DD Act and Americans with Disabilities Act are fully achieved.

The proposed HB538 from 2018 Legislation requested a working group. The working group was created through a Permitted Interactive Groups (PIG), in accordance with Hawaii Sunshine law requirements, from among the working group members were to examine and evaluate the application process of the Hawaii Medicaid Section 1915(c) Home and Community-Based Services for people with Intellectual and Developmental Disabilities Waiver and existing services provided by the Developmental Disabilities Division.

### **Establishment of the Working Group**

The composition of the working group came from the established Public Awareness Education and Training committee of the Hawaii State Council on Developmental Disabilities. The following individuals or their designees were members of the working group:

1. Mary Brogan, Administrator, Department of Health - Developmental Disabilities Division.
2. Daintry Bartoldus, Executive Administrator, State Council on Developmental Disabilities.
3. Lou Eterchik, Executive Director, Hawaii Disability Rights Center.
4. Jacqueline Indreginal, RN, Med-QUEST Division, Quality, and Member Relations Section Administrator, Department of Human Services.
5. Melodee Haole, Keiki Education Living Independent Instruction (K.E.L.I.I.), Individuals who are parents or guardians of children with developmental disabilities.
6. Dezi McKenzie, Down's Syndrome Society.
7. Ashley Brown, representing military parents.
8. Michelle Muralt, representative from Hawaii Self-Advocacy Council.
9. State Representative - John Mizuno
10. Michelle Pestel-Maga, Chair of the State Council on Developmental Disabilities.
11. Barbara Ioli, Past Chair, State Council on Developmental Disabilities.
12. Lila Ota, RN, Staff, Children & Youth w/Special Health Needs Section (CYSHNS).
13. Abigail George, Outcomes and Compliance Branch Outcomes Section, Department of Health - Developmental Disabilities Division.

### **Permitted Interactive Group (PIG)**

Meetings of the permitted interactive working group were held once a month for three (3) consecutive months beginning on August 8, 2018 and ending on October 10, 2018. All meeting dates, times and agendas were publicly announced and posted on eHawaii.gov and filed with the Lieutenant Governor's office in accordance with Hawaii Sunshine law requirements.

## **PIG Group Findings and Recommendations**

### Findings

The sub-group found:

- Most states do not reassess annually for developmental disability services. Once a consumer becomes an adult, they remain eligible for developmental disability services for their lifetime.
- Every state annually reassesses the consumer for their continued need of Home and Community Based Medicaid Waiver services.
- In Hawaii, 98% of the people receiving DD services are in the Waiver program.
- Several state agencies use an online web-based application process to apply for developmental disability services.
- Intake workers in Hawaii call the consumer back in a timely fashion, following up on eligibility questions.
- Development Disabilities Division (DDD) does have real-time data on intakes.
- Intake workers in Hawaii have been known to discourage consumers from applying for services if the consumer sounded too “high functioning” or “probably not qualify for waiver services.”
- DDD developed an intake booklet explaining the process of applying for services through the Developmental Disabilities Division.
- DDD improved their website, with valuable links for consumers, families, and stakeholders;
  - <http://health.hawaii.gov/ddd/participants-families/apply/>
  - <http://health.hawaii.gov/ddd/participants-families/apply/apply-waiver-admission/>
  - <http://health.hawaii.gov/ddd/files/2018/01/DDD-Intake-Booklet.pdf>
- DD Council holds monthly meetings for parents
- The Community Engagement Branch/Community Children's Councils holds monthly meetings around the state and willing to add to their agenda topics to address parent concerns with services for their children.
- DDD is committed to addressing concerns from consumers, stakeholders, and communities.

### Recommendations

- Developmental Disabilities Division (DDD) will provide outreach to agencies in the community to encourage those agencies to educate families about DDD services.
- DDD will update intake booklet “Applying for Services DDD” as outlined in the minutes from the meetings. Updates to include such things as;
  - What are the standardized measures used in determining an Intellectual Disability (intelligence quotient) and Developmental Disability (functional limitations)?
  - Clarify the changed definition on page 11 and tie them to the seven areas on page 9. The seven areas are different for a 0-9-year-old.
  - On page 13, create a check off list and clarify what documents are “proof.”
  - Clarify what does “recent” mean.
  - Clarify what to do if a diagnosis was made after the age of 18 or 22, but a doctor can verify it occurred before the age of 18 or 22.
  - Will provide a checklist of what is needed to determine eligibility.

- DDD will review Hawaii's Statute to find out;
  - Why below age 18 for IQ and below age 22 for DD?
  - Why reassessed every year for DD Services?
- DDD will provide on-going training to their intake workers.
- DDD will provide support to the consumer or their designated representative when a denial letter is sent.
- DDD web page will include;
  - Consumer portal with email capability.
  - Include frequently asked questions and answers.
  - A call-in number people can call to ask questions as they try to navigate the web page.

### **Conclusion**

The Department of Health -Developmental Disabilities Division (DDD) is committed to improving the intake practice, family training, and accountability. DDD will review each of the recommendations provided by the sub-group and integrate the recommendations into their continuous quality improvement process. This report will be submitted to the DDD Quality Assurances and Improvement Program Steering Committee.

The Hawaii State Council on Developmental Disabilities will hold monthly meetings to address further concerns the workgroup had identified. The Council encourages interested parties to contact the Council at [INFO.DDC@doh.hawaii.gov](mailto:INFO.DDC@doh.hawaii.gov) to be placed on the distribution list for upcoming meetings.