B.2 Informed Consent and Guardianship

The Informed Consent form was developed through extensive stakeholder input. In consideration of the age and disabilities of the population to be served, many of whom use English as their second language, care was taken to create an Informed Consent form at the lowest possible reading level consistent with providing true informed consent. That form, which follows at the end of this section, has an overall reading level of grade 6.8.

a. Procedures to Obtain Informed Consent

Transition coordinators will be responsible for providing written information consisting of a brochure and frequently asked question to eligible participants and their families or legal representatives in hospitals, nursing facilities, and ICF/MR facilities. Copies of the brochure and the list of frequently-asked-questions are included in the Appendix B. Participants will be fully engaged in all discussions and decisions about the *Going Home Plus* project even when the individual has a legal representative. The project will provide training and develop a script for use by the transition coordinators to assure consistency and uniformity in meeting the MFP requirements for informed decision-making and obtaining informed consent from project participants

To prepare the candidate to make an informed decision about the *Going Home Plus* project, the transition coordinator will meet with the candidate, their family, and legal representative to explain the program. The process will be tailored to the individual needs of the participant. The transition coordinator will cover information about the eligibility criteria, available home and community based services and supports, enrollment process, process for transition planning, and the continued services and supports after the demonstration period. As part of this process, the transition coordinator will conduct the preference assessment.

The Informed Consent form must be signed before demonstration project transition activities can begin. The Informed Consent for *Going Home Plus* is a Participation Agreement with the participant, their family, or legal representative. This agreement will be read aloud by the transition coordinator. As each item is discussed, the transition coordinator will place a checkmark in the appropriate box on the form. The form will be used as the guideline to ensure all demonstration participants are aware of all aspects of the transition process, have full knowledge of the services and supports that will be provided both during the demonstration year and after the demonstration year and are informed of their rights and responsibilities as a participant of the demonstration. The following items will be covered during the meetings preparing the participant, their family, or legal representative for true informed consent.

- Housing possibilities
- Confidentiality or privacy protections
- Description of voluntary enrollment and withdrawal from the project.
- Statement that evaluation is a part of the demonstration project and that personal information about the participant will not be released as part of the evaluation
- Persons to contact with questions or concerns
- Complaint and appeal process
- Rights and Responsibilities

The participant and their family or legal representative will be provided a copy of the signed Informed Consent and the Participant and (Family) Caregiver Rights and Responsibilities which has an overall reading level of 9.8 years. A copy of this is attached at the end of this section and also included in Appendix D.

Accessibility to all print materials will be ensured through the availability of all materials in large-print, Braille, and audio formats. Access to interpreter services will be ensured through utilization of family, staff, or contracted translators, including Hawai`i Services for the Deaf to provide sign language interpreters whenever needed.

After the Informed Consent is signed, the consents for release of information will be secured and the transition coordinator will set up meetings with the participant or representative to develop the transition plan for the move. The transition coordinator will work with the participant and/or their representative(s) to identify other individuals like family members, friends and providers who have important information about the participant or will be providing assistance for the participant in the community. These individuals will be invited to participate in the transition planning meeting(s) with the participant and the transition coordinator as part of the participant’s transition team. Transition team members will be oriented about the Going Home Plus project and how the participant will receive *Going Home Plus* services in the community while enrolled in either a 1915(c) Home and Community-Based Services waiver program or via home and community based service providers under contract with the State’s Section 1115a Quest Expanded Access (QExA) waiver health plans. The transition coordinator will maintain regular contact with the participant’s transition team while coordinating needed activities and services required for the move. Not more than 30 days prior to discharge, the waiver or health plan case manager will meet with the participant, their representative and the transition coordinator to review the progress on the transition activities and write the service plan for community living.

A log will be kept by the transition coordinators documenting each step of the process. That log is shown in Appendix D-4.

Currently, the Department of Human Services/Social Service Division is responsible for investigating adverse event reports and consumer complaints regarding violation of waiver participant rights. Additional information about the adverse event reporting and consumer complaints is in Section B.7 Quality.
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Guardianship. *Going Home Plus* participants are assumed to be legally able to make their own decisions unless there is a legal representative identified in the candidate’s facility record. Hawai’i Revised Statutes, §560:5-102, define ‘legal representative" to include an attorney, a representative payee, a guardian or conservator acting for a respondent in this State or elsewhere, a trustee or custodian of a trust or custodianship of which the respondent is a beneficiary, and an agent designated under a power of attorney, whether for health care or property, in which the respondent is identified as the principal. When individuals who have a legal representative ask to participate in the demonstration, the transition coordinator must obtain the written consent of the representative.

Prior to meeting with individual candidates, the transition coordinator will determine whether there is a documented representative on file at the facility. The candidate's legal representative will be required to participate in the informational meetings about the *Going Home Plus*. In Hawai'i, it is not uncommon for residents to have legal representatives who live on the mainland. Telephone sessions will be conducted in these situations. In this situation, the *Going Home Plus* project will also make every effort to identify an individual(s) locally who has a known relationship with recent knowledge of the individual's' welfare and interacts with the individual on an ongoing basis. Similarly, the project will seek out individuals with a known relationship to the candidate where the representative has little or no involvement with the individual and the individual is a good transition candidate with interest to move to the community. The goal will be to create a working relationship between the transitioning individual, their legal representative and the identified personal representative to facilitate a transition to the community.

The transition coordinator will determine and document the level of representative involvement during the six month period prior to the application for *Going Home Plus* through facility records and conversations with hospital, nursing home, the ICF/MR staff, or the candidate and their legal representative.

The transition coordinator will explain to the legal representative that their active participation and cooperation with the transition process will be required for the success of the community transition. This participation must include a monthly personal meeting with the *Going Home Plus* participant during the demonstration period, if the legal representative does not live in the same household as the participant.

The participation will include making service decisions and signing required program documents such as the Informed Consent Participation Agreement, choice documents, and service plans. The legal representative will also be asked to participate in the three (3) Quality of Life surveys after *Going Home Plus* enrollment.

All pre and post transition contacts between the legal representative and the participant will be recorded in the participant's *Going Home Plus* record For legal representatives living on the mainland or another island, a schedule for phone contacts between the *Going Home Plus* participant and the legal representative, and either the transition coordinator or case manager will be developed as part of both the transition plan and the *Going Home Plus* demonstration service plan.

HAWAI‘I’S *GOING HOME PLUS* PROJECT

INFORMED CONSENT FOR PARTICIPATION

Name	Medicaid Number

This project is to help people who live in a facility to move to a home in the community.

- ❑ A transition coordinator will ask me if I want to move to a home in the community.
- ❑ If I do want to move to a home in the community:
  - ❑ It is ok for the transition coordinator to see my health record.
  - ❑ The transition coordinator can also talk with my doctor and others about my health needs.
  - ❑ The transition coordinator will help me find a home, apartment, or small-group home and move there.
- ❑ The transition coordinator explained all the services I can have when I live in the community.
- ❑ I know the project is for 365 days.
- ❑ If I have to go to the hospital or to a nursing home, those days do not count toward my 365 days.
- ❑ After the project I will continue to get services in the community (except for telehealth and the transition coordinator services) if I am Medicaid eligible.

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.**Privacy:**

- ❑ My personal information is private.
- ❑ My information will be kept safe.

Leaving the Project:

- ❑ If I do not like my new home, my transition coordinator will help me find a new home.
  - ❑ I may not be able to return to the nursing home, ICF-MR or hospital.
  - ❑ It may be very hard to find me a bed at a nursing home.
- ❑ Being in the *Going Home Plus* project is my choice.
- ❑ I can leave the project at any time. My transition coordinator, case manager, or the Project Director will give me a form to sign.

Quality of Life Survey

- ❑ Someone will visit to ask me questions about how I like living in the community.
- ❑ My name will not be printed on any reports.

Questions or Concerns:

- ❑ If I have any questions I can ask one of the following people:
  - ❑ My transition coordinator_____ at _____
  - ❑ Madi Silverman, Project Director, at: (808)692-8072

Complaints:

- ❑ I understand I have rights to file a grievance or appeal a decision as a Medicaid waiver participant.
- ❑ The transition coordinator has provided me information about my rights and how can file a grievance or appeal.

- ❑ **I want to be part of *Going Home Plus.***
  - ❑ My transition coordinator has explained to me my rights and responsibilities under the *Going Home Plus* project.
  - ❑ My transition coordinator will give me a signed copy of this consent form to keep.
  - ❑ I received answers to my questions.
  - ❑ By signing this form, I agree to participate in the *Going Home Plus* project.

Signature-*Participant*	Date Signed
Signature- *Legal Representative* (If Applicable)	Date Signed

If unable to provide written consent, verbal consent given by:_____

Signature- *Witness*	Relationship

TRANSITION COORDINATOR ACKNOWLEDGEMENT

- ❑ I have read the informed consent materials to the applicant, and I believe that he/she (or the legal representative, if signed) understands the information presented.
- ❑ After going over the materials, the person declined to participate.

Signature- *Transition Coordinator*	Date Signed

PARTICIPANT AND (FAMILY) CAREGIVER
BILL OF RIGHTS AND RESPONSIBILITIES

Rights

- To live as independently, actively, and fully as desired and possible;
- To compassionate, courteous, fair and respectful care and treatment in a healthy environment;
- To prompt and willing response to requests for help within available resources;
- To know that my records and private information is kept confidential;
- To service without regard to race, color, age, sex, national origin, sexual orientation, physical or mental disability, or religious or political beliefs;
- To know my health problems, content of the service plan, and any changes in the service plan;
- To choose service providers from available qualified providers with the right to refuse specific providers;
- To know the title and names of all people entering my home and their purpose;
- To refuse any portion of the service plan, treatment and/or medications after being fully informed and understand the consequences of such action;
- To be free from neglect, physical abuse, dietary or physical punishment, exploitation, humiliation, threats or physical or chemical restraints;
- To have a grievance procedure and be able to voice objections or recommend program changes without reprisal;
- To be given advance notice of transfer, reductions in service hours or discharge from the program, except in an emergency; and
- To appeal decisions to discharge from the program.
- ***Responsibilities***
- To work with my case manager(s) to develop and understand the service plan;
- To follow the service plan which has been established with my knowledge, consent and cooperation;
- To follow the rules for the program and services I get;
- To try very hard to adjust to my home and other people in the home;
- To provide accurate and complete information about my needs, expectations, and matters that affect my care and services;

- To notify the case manager about any changes in my Medicaid eligibility, health, functional, social or economic status; including problems with service providers or if I feel my rights are not respected;
- To ask questions until I understood fully;
- To know my back-up plan to make sure my services are not interrupted and to notify my case manager when I need to use my back-up plan;
- To treat my case manager(s) and service providers with respect; and
- To work with the people who provide the services in my service plan.