

Helping Hands American Samoa Early Intervention Services

A Guide to Family Rights and Responsibilities

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Introduction

The <u>Helping Hands Family Rights and Responsibilities Booklet</u> describes your family's rights, as defined by Part C of the Individuals with Disabilities Act (IDEA). IDEA is a federal law which includes provisions for early intervention services for eligible children starting at birth. To support the implementation of these federal requirements, American Samoa has developed policies and procedures which meet these federal Part C requirements.

This booklet is an official notice of your rights under federal law and regulations and some terms may be unfamiliar to you. For this reason, some words and processes are outlined in boxes throughout the text to summarize key points and terms for your better understanding.

The service coordinator working with your family will review this booklet with you and can provide additional materials to help you understand your rights.

For more information contact: Helping Hands Early Intervention Services P.O. Box 7477 Pago Pago, American Samoa 96799 (684) 633-8553

Key Points in Process from Referral to IFSP Development

Referral:

Your child can be referred to the Helping Hands program by you or another individual, such as a pediatrician, nurse, child-care provider or another parent, etc. *Referrals* may be made by telephone, fax, in writing or in person. The **45-day** timeline begins on the day the complete referral is received by Helping Hands.

Intake:

The *intake* meeting might be your first face-to-face contact with Helping Hands personnel. During this meeting, you will be asked about your child and his/her developmental and medical history as well as your priorities as a family. You may also be asked for your written consent for Helping Hands to request pertinent information about your child from his/her doctors and others involved in his/her life. Helping Hands may assess your child's current abilities by using a developmental screening tool (see below).

Parental Prior Notice:

Written prior notice must be given to parents/legal guardians at least **5-days** before Helping Hands proposes to change the identification, evaluation, placement of your child, or the provision of appropriate early intervention services to your child and family.

Parental Consent:

Consent means that you, as your child's parental/legal guardians, have been fully informed of all information about the activity for which you are asked to consent. Information must be provided to you in your native language or other mode of communication unless it is not feasible to do so. You will be asked to provide consent before each evaluation and assessment, as well as for the release or to obtain personal identifiable information.

Screening:

Screening involves the use of selected tools or procedures during the intake visit or other appropriate time to determine whether further evaluation and assessment activities are needed for your child. Screening may or may not be conducted for your child.

Evaluation & Assessment:

Evaluation means the use of tools and procedures by qualified professionals to determine your child's initial eligibility for Helping Hands and/or to provide important developmental information about your child to help guide service planning. Assessment means the ongoing use of tools and procedures by qualified professionals to identify your child's unique strengths, needs, as well as the resources, priorities and concerns of your

family and the supports and services necessary to enhance your family's capacity to meet the developmental needs of your infant or toddler with special needs.

Individualized Family Service Plan (IFSP) Development:

Helping Hands policies require that each child's individualized family service plan (IFSP) must be developed within 45-days of the receipt of the complete referral. When delays are requested or initiated by a family for any reason (illness, hospitalization, vacation, work schedules, etc.), it may delay the initiation of services for your child and family, and may result in the development of the IFSP beyond the 45 day period.

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1. The Right to Informed Parental Consent

Giving consent means that you have been fully informed of all information about the activity for which consent is sought, in your native language, or other mode of communication and you understand and agree in writing to the carrying out of the activity for which your consent is sought, and the consent describes that activity and lists the records (if any) that will be released and to whom. Your consent is voluntary and may be withdrawn at any time without risking future participation with Helping Hands. In addition, you have the right to determine whether you, your child, or other family members will accept or decline any early intervention service under Part C in accordance with the law.

Native language is the language or mode of communication normally used by the parent of an eligible child.

As a parent, you have the right to give or refuse your consent for the following actions:

- The initial evaluation and assessment of your child;
- The initial placement of your child in Helping Hands; and
- The sharing of certain information that would make it possible to identify your child to unauthorized persons

Initial evaluation and assessment are testing tools and procedures used to measure a child's strengths and needs in development. This is also the process used to determine if your child is eligible for special services.

If you do not give your consent for initial evaluation, Helping Hands may provide you with relevant literature or other materials; offer supportive services to help your understanding of the value of early intervention and to address your concerns about participation with Helping Hands; and periodically renew contact with you, on an established time schedule, to see if you changed your mind about participation in the Helping Hands program. If consent is not given for the initial evaluation, assessment or the initial provision of services, Helping Hands must make reasonable efforts to ensure you are fully aware of the nature of the evaluation and assessment or the services that will be available, and understands that your child will not be able to receive the evaluation and assessment or services unless consent is given. In addition, the Department of Health shall have policies and procedures that are used in the event that you refuse to provide consent for release of records, which may include procedures to explain the consequences of not providing consent.

In addition, you have the right to written notice of and written consent to the exchange of any **personally identifiable information** collected, used, or maintained under Helping Hands. (See section on Confidentiality of Information).

Personally identifiable information includes the name of your child, your name or the names of family members; the address of your child; a personal identifier, such as your child's or your social security number; a list of personal characteristics or other information that would make it possible to identify your child with reasonable certainty.

2. The Right to Prior Notice

Written prior notice is the right to receive a written announcement in a way that is clearly understood by you, the parent, in advance of <u>any changes in early intervention</u> services to your child.

You must be given a written announcement within a reasonable time in advance to any action requiring your consent (as described above). In addition, you must be provided with written notice **5-days** before any of the following actions take place:

- When Helping Hands proposes to initiate the screening, evaluation, or placement of your child or proposes to make any changes in the provision of early intervention services to your child;
- When Helping Hands refuses to initiate the assessment or early intervention placement of your child or refuses to make any change that you request in the provision of early intervention services to your child;
- When Helping Hands refuses to amend your child's records or proposes to destroy unneeded records in accordance with confidentiality requirements; and

The content of the **prior written notice** must be detailed enough to inform you about:

- The action that is being proposed or refused;
- The reason Helping Hands is taking the action;
- All procedural safeguards available to you; and
- Information about Helping Hands complaint procedures including a description of how to file a complaint and the time lines under these procedures.

The content of the **prior written notice** must also:

- Be written in a language understandable to the general public; or
- Be provided in your native language, unless it is clearly not feasible to do so;
- Be communicated orally when necessary if your native or mode of communication is not a written language;
- Be offered in Braille or sign language or another mode of needed communication so that you, the parent, understand the content of the notice; and
- Contain a written record, which notes that this translation was provided.

3. The Right to a Multidisciplinary Evaluation and an Assessment of your Child

You have the right to a multidisciplinary evaluation of your child to determine eligibility or the identification of child's current abilities within **45-days** of his/her referral to Helping Hands. All tests must be selected and administered without being racially or culturally discriminating. As the parent, you have the right to participate in this evaluation and all test results must be explained to you. This process of evaluation and assessment provides information for you and early intervention professionals to help in selecting appropriate services for your child with special needs.

Multidisciplinary evaluation is a way of assessing the developmental abilities of a child. These evaluations or tests can determine a child's eligibility for early intervention services. It involves two or more professionals from different areas of training. These specialists can come from many backgrounds, such as education, nursing, social work, and speech, physical, and occupational therapies.

4. The Right to Services in a Natural Environment

A **natural environment** is any place where children of all abilities live, learn, or play. The everyday activities that make up your families lifestyle, such as those occurring in your home, school, church, or the village, may be considered your child's "natural environment."

Your child has the right to early intervention services provided in settings that are natural or normal for his/her age peers who have no disabilities. Early intervention services should be offered in a natural environment, to the maximum extent appropriate, to meet the needs of your child.

5. The Right to Review Records

Your child's records are confidential and may only be reviewed by you, and other authorized persons, such as those who are directly involved in working with your child and implementing the family plan (IFSP). Other authorized persons may include lead and/or funding agencies that may request information or audit/review charts for completion and compliance with federal regulations. In addition, at your child's second birthday, Helping Hands is required to send basic contact information (child's name, phone number and village) to Part B (Special Education) to ensure a continuation of services for your child. Records cannot be reviewed by anyone else unless you give your consent or an exception under the Family Educational Rights and Privacy Act (FERPA) applies.

The following safeguards must be in place to ensure confidentiality of records:

- Helping Hands protects the confidentiality of personally identifiable information at collection, storage, disclosure, and destruction stages;
- Helping Hands staff members are responsible for insuring the confidentiality of any personally identifiable information;
- All persons collecting or using personally identifiable information receive training or instruction regarding compliance with confidentiality policies and practices.
- Helping hands will inform parents when personally identifiable information collected, maintained, or used is no longer needed to provide services to the child;
- And if the information is destroyed; at the request of the parents, permanent early
 intervention records of the child's name, address, phone number, and dates of
 early intervention services shall be maintained.

Remember:

You, the parent or guardian, have the right to see and examine all early intervention records related to your child in no case more than 45 days after a request is made. The right to inspect and review the early intervention records related to your child includes the right to a response from Helping Hands to reasonable requests for explanations and interpretations of the records, and the right to have someone inspect and review the records on your behalf.

You are allowed the opportunity to inspect and to review records without unnecessary delay and before any meeting regarding:

- Evaluations and assessments,
- Eligibility questions,
- The development and implementation of the Individualized Family Service Plan (IFSP),
- Individual administrative complaints filed on behalf of your child and the investigative report or a due process hearing,
- And any other area involving the records about your child and family.

You must be informed of the types and location of early intervention records collected, maintained, or used by Helping Hands. Helping Hands must keep a record of persons obtaining access to your child's records, including name, date, and their purpose for access.

You have the right to obtain copies of any materials pertaining to your child. These materials will be made available to you upon request at no charge.

You have the right to ask for that any records that you feel are inaccurate or misleading be removed or amended. You also have the right to request a hearing if your child's records are not adjusted as you have requested.

You may also ask that information be amended if it violates the privacy or other rights of your child.

Helping Hands may presume that the parent has authority to inspect and review records relating to his or her child unless Helping Hands has been advised that the parent does not have the authority under applicable American Samoa law governing such matters as guardianship, separation, and divorce.

If any early intervention record includes information on more than one child, the parents of those children have the right to inspect and review only the information relating to their child or to be informed of that specific information.

Helping Hands shall decide whether to amend the information in accordance with the request within a reasonable period of time of receipt of the request, and if Helping Hands decides to refuse to amend the information, Helping Hands shall inform you regarding the refusal and advise you of your right to a hearing.

If, as a result of the hearing, Helping Hands decides that the information is inaccurate, misleading or otherwise in violation of the privacy or other rights of the child, it shall amend the information accordingly and so inform the parent in writing. If, as a result of the hearing, Helping Hands decides that the information is not inaccurate, misleading or otherwise in violation of the privacy or other rights of the child, it shall inform the parent of the right to place in the records it maintains on the child a statement commenting on the information or setting forth any reasons for disagreeing with the decision of the agency. Any explanation placed in the records of the child under this section must be maintained by the agency as part of the records of the child as long as the record or contested portion is maintained by Helping Hands, and if the records of the child or the contested portion is disclosed by Helping Hands to any party, the explanation must also be disclosed to the party.

6. Surrogate Parents

The rights of children eligible under Helping Hands are protected even if:

- No parent can be identified;
- Helping Hands, after reasonable efforts, cannot determine the whereabouts of a parent; or
- Courts have placed a child in the ward of American Samoa.

An individual is assigned to act as a "surrogate" for the parent according to the procedures that follow. The procedures include a method for determining whether a child needs a surrogate parent and assigning a surrogate to the child. The following criteria are employed when selecting surrogates:

- Surrogate parents are selected in the manner authorized by American Samoa Code, as necessary; or
- Helping Hands can assign the appropriate surrogate parent at the time of intake
 and will provide training to ensure that surrogate parents fully understand their
 roles and responsibilities to represent the best interests of their child.
- A person selected as a surrogate parent:
 - a) Has no interest that conflicts with the interest of the child he or she represents;
 - b) Has knowledge and skills that ensure adequate representation of the child;
 - c) Is not an employee of any American Samoa governmental agency or an employee of a person providing early intervention services to the child. A person who otherwise qualifies to be a surrogate parent under this section is not an employee solely because he or she is paid by a public agency to serve as surrogate parent, and
 - d) Resides in the same general geographic area as the child, whenever possible.

A surrogate parent may represent the child in all matters relating to:

- The evaluation and assessment of the child;
- Development and implementation of the child's IFSP, including annual evaluations and periodic reviews;
- The ongoing provision of early intervention services to the child; and
- Any other rights established under Helping Hands.

7. Conflict Resolution

There are three levels of conflict resolution: Complaint, Mediation and an Administrative Hearing.

You have the right to disagree with services or with the way services are being provided. As a parent, you have the right to request changes and this is done through established procedures. These disagreements can frequently be settled through an open discussion between you, the service coordinator and the Helping Hands Program Director. If the disagreement is not resolved to your satisfaction through the informal process, the following options can be pursued. Your child must continue to receive services from Helping Hands that are currently being provided during the conflict resolution process(es) unless agreed otherwise. In addition, if the complaint involves an application for initial Part *C* early intervention services, your child must receive any services that are not in dispute.

The Complaint process involves filling out a complaint form or writing a letter of complaint and submitting it to the Helping Hands Program Director for review and resolution.

Mediation is a problem-solving process that allows you and the involved members of the Helping Hands team to talk about details of your disagreement with someone who is impartial and determined skilled in the area of conflict-resolution.

An Administrative Hearing is a formal process that allows you and Helping Hands to present all positions before an impartial administrative hearing officer. An Administrative Hearing is available to you at any time even if you have chosen one of the more informal methods first. All levels of complaint resolution are at no cost to

8. The Right to File a Complaint

You have the right to file a Complaint when you believe Helping Hands has violated federal regulation in the provision of services to your child.

As a parent, you have the right to file a complaint with the Helping Hands Program. As a parent, you can register a complaint when you believe that Helping Hands has failed to comply with regulations governing the provision of early intervention services (IDEA regulations). In addition, an organization or individual from another state may also file a complaint. This complaint should include a statement and the facts of which you have based your complaint and a statement that the American Samoa Early Intervention Program has violated a requirement of Part C of the Act or the regulations in this part.

The alleged violation must have occurred not more than one year before the date that the complaint is received by Helping Hands unless a longer period is reasonable because (1) the alleged violation continues for that child or other children; or (2) the complainant is requesting reimbursement or corrective action for a violation that occurred not more than three years before the date on which the complaint is received by Helping Hands.

Upon review, the Helping Hands Program Director will determine if the complaint appears to be a violation of IDEA regulation. If determined so, an investigation will follow. Upon receipt of the complaint, Helping Hands then has **60-days** to conduct the following actions, and extensions will only be allowed if exceptional circumstances exist with respect to a particular complaint.

The complaint procedures include the following:

- The Helping Hands Program Director will carry out an independent on-site investigation, if it is determined that such an investigation is necessary;
- All involved persons have the opportunity to submit additional information, either orally or in writing, about the allegations in the complaint;
- The Helping Hands Program Director will review all relevant information and make an independent determination as to whether Helping Hands has violated a requirement of the law;
- The Helping Hands Program Director will issue a written decision to you that addresses each allegation and contains the following:
 - A) Findings of fact and conclusions and
 - B) The reasons for the final decision.
- Helping Hands will forward the complaint, findings and conclusions to the Department of Health.
- Helping Hands, in partnership with the Department of Health, will provide
 procedures for effective implementation of the final decision, if needed, and
 technical assistance activities, negotiations, and the corrective actions to achieve

compliance, which may include remediation for any required service/s which has found to be denied. Remediation could include monetary reimbursement and the appropriate future provision of services for all infants and toddlers with disabilities and their families.

You also have the right to inspect and review Helping Hands records without unnecessary delay and before any meeting regarding an individualized family service plan (IFSP), or any due process hearing, and in no case more than 45 after the request is made.

If a written complaint is received that is also the subject of a due process hearing under Part *C*, or contains multiple issues, of which one or more are part of that hearing, the State must set aside any part of the complaint that is being addressed in the due process hearing until the conclusion of the hearing. However, any issue in the complaint that is not a part of the due process action must be resolved within the 60-calendar-day timeline using the complaint procedures described in paragraphs (a) and (b) of this section. If an issue is raised in a complaint filed under this section that has previously been decided in a due process hearing involving the same parties, the hearing decision is binding and Helping Hands must inform the complainant to that effect. A complaint alleging a public agency's or private service provider's failure to implement a due process decision must be resolved by Helping Hands.

9. The Right to Mediation

Mediation is an informal process for settling disagreements between parents and the Helping Hands Program. A mediator is an impartial person who is asked to settle a disagreement.

Family members can request **mediation** for resolution of disputes involving any matter, including matters arising prior to the filing of a complaint. Requests for mediation should be filed and submitted to the Helping Hands Program Director; if the findings and resolutions of the complaint procedure are not satisfactory to the family; and/or when a request for an administrative hearing is filed; and/or at any other time the party requests. Mediation is viewed as voluntary and needs to be freely agreed to by both parties. Parents/providers are not required to use it. If mediation is requested, it must be completed within **30-days** of the request. A complaint investigation, if applicable, will continue and be resolved within 60-days even if mediation is used as the resolution process.

- Mediation may be requested by the parents when a conflict arises regarding the early intervention services of a child that cannot be resolved without third party assistance.
- Mediation may not be used to delay a parent's right to a due process hearing.
- The mediation process is voluntary. Both the family and Helping Hands must agree to try mediation. At any time either party may decide that they want to stop the mediation process and proceed with a due process hearing.
- The mediation process is confidential. Information shared by either party with the mediator during the mediation will not be given to the other party or anyone else without your permission. Any material gathered or used for mediation cannot be used in a due process hearing.
- A person determined skilled in mediation will be appointed to the mediation session. Helping Hands shall maintain a list of individuals who are qualified mediators and knowledgeable in laws and regulations relating to the provision of special education and related services. The Helping Hands Program will provide an appropriate meeting place that is convenient to all parties and covers all administrative costs.
- Any agreement reached by mediation is included in your child's Individualized
 Family Service Plan (IFSP). If no agreement is reached, all information from this
 process is destroyed.

If a resolution is reached regarding the complaint through the mediation process, the parties shall execute an agreement setting forth the resolution that: (1) is legally binding; (2) states that all discussions that occurred during the mediation process shall be confidential and may not be used as evidence in any subsequent due process hearing or civil proceeding; (3) is signed by both the parent and a representative of the agency who has the authority to bind such agency; and (4) is enforceable in court.

10. The Right to Request an Administrative Hearing

An Administrative Hearing is a formal procedure designed to protect your rights.

As a parent, you may request an administrative hearing in writing to the Helping Hands Program Director. You must give a brief statement of facts supporting the allegation that Helping Hands has (or is about to) initiated or changed and you do not agree to:

- The identification of your child;
- The evaluation of your child;
- The placement of your child; and/or
- The provision of appropriate early intervention services to your child and family.

A Hearing Officer will be appointed by Helping Hands to conduct the hearing. This person may not be an employee of a public agency that is involved in early intervention services. The Hearing Officer may not be the care provider of your child or have personal or professional interest, which would conflict with his/her objectivity in the hearing. (Hearing Officers are not considered employees of the Helping Hands Program or the Department of Health solely because they are paid to serve in this capacity). The Hearing Office must have knowledge about the provisions of Part C and the needs of, and services available for, eligible infants and toddlers and their families.

The Hearing Officer will perform the following duties: listen to the presentation of relevant viewpoints about the complaint, examine all information relevant to the issues, seek to reach a timely resolution of the issues, and provide a record of the proceedings, including a written decision.

If you request a due process hearing, you have the following rights:

- To be accompanied and advised by counsel and by individuals with special knowledge or training with respect to the problems of infants and toddlers with special needs;
- To present evidence and confront, cross examine, and compel the attendance of witnesses:
- To prohibit the introduction of any evidence at the hearing that has not been disclosed to all others involved at least five days before the hearing;
- To obtain written or electric verbatim record of the hearing;
- To obtain written findings of facts and decisions;
- To open the hearing to the public.

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You have the right to receive a final decision no later than 30-days after Helping Hands receives your request for a hearing. A copy of the final decision will be provided to the participants of the hearing. The hearing must be conducted at a time and place convenient to you and your child. Any party <u>aggrieved</u> by the findings and decision regarding a hearing has the <u>right</u> to appeal the decision in court.

Contact Information

My Service Coordinator is:
His/Her phone number is:
<u>(684) 633-8553</u>
Other ways that I can contact him/her include:
Visit Helping Hands office:
Located in the Lumana'i Building, \mathbf{l}^{st} floor, in Fagatogo next to the Public Safety.
Phone: (684) 633-8553 (684) 633-6953
Mailing Address:
P.O. Box 7477 Pago Pago, American Samoa
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