



It's All About

OPTIONS

**Living Alternatives For Adults
With Developmental Disabilities**



**HARBOR
REGIONAL
CENTER**

At Harbor Regional Center, we have a vision for the future.

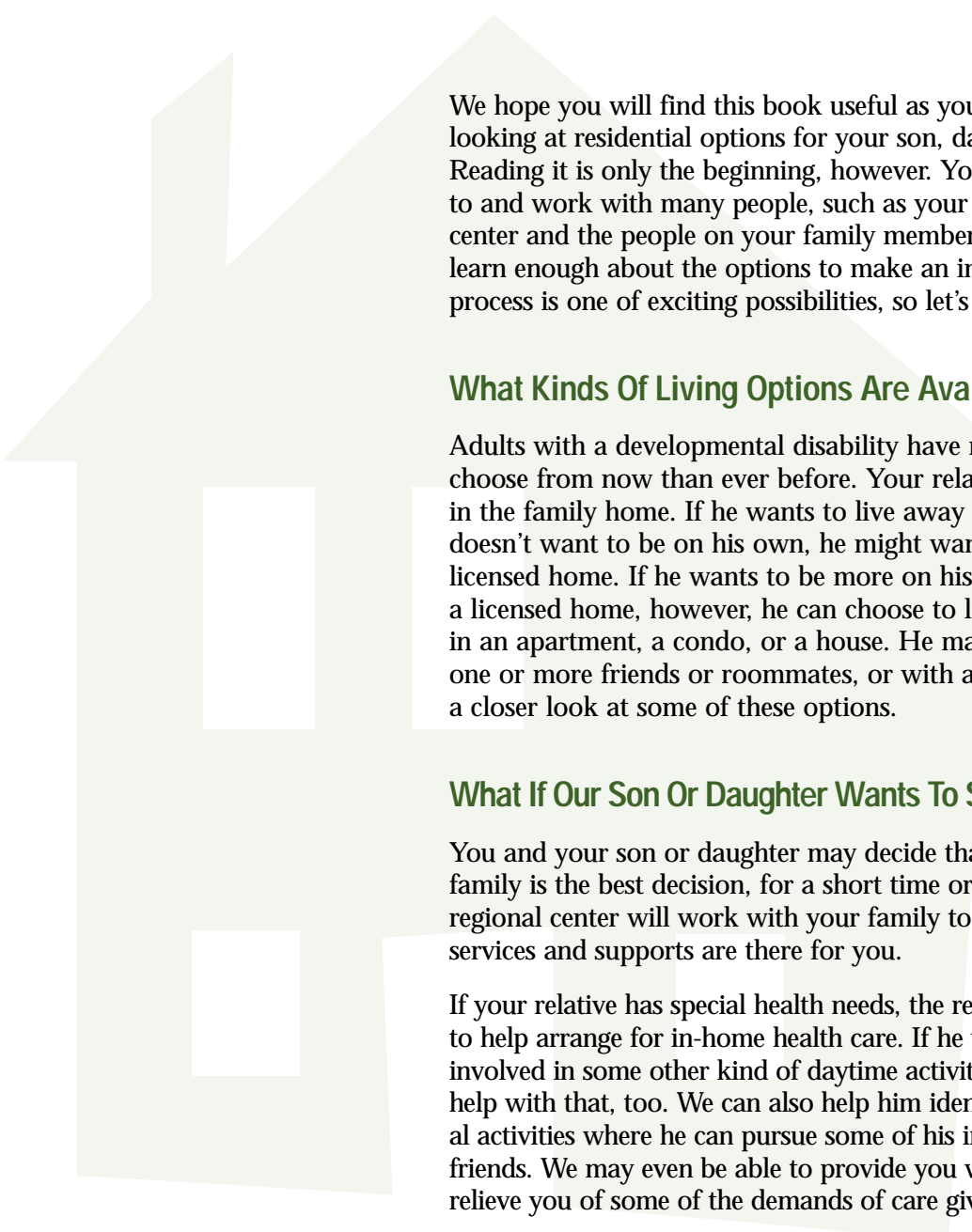
Adults with developmental disabilities live in the residence of their choice – with their families, with friends, or alone. They engage in activities of their choice – work, volunteering, education, or socializing. They have meaningful relationships with friends and co-workers. They are seen as valuable, contributing members of their communities.

As you can see, in our vision adults with developmental disabilities have living options just like all people. Fortunately, just about everyone with a developmental disability has a variety of good living options. The challenge for the person and his family is to evaluate those options to decide which one is right for him at that particular time in his life.

This booklet was written for families of adults with developmental disabilities, to answer the questions that families often ask about living arrangements. In it, we describe the different kinds of options that are out there and discuss how people are supported in different settings.

The booklet also includes a section on rights of people with developmental disabilities. The section covers the basic rights that everyone with a developmental disability has, as well as the additional rights of people living in licensed homes and people living on their own in supported living.





We hope you will find this book useful as you begin the process of looking at residential options for your son, daughter, or other relative. Reading it is only the beginning, however. You will also need to talk to and work with many people, such as your Counselor at the regional center and the people on your family member's planning team, to learn enough about the options to make an informed decision. The process is one of exciting possibilities, so let's begin.

What Kinds Of Living Options Are Available?

Adults with a developmental disability have more living options to choose from now than ever before. Your relative can continue living in the family home. If he wants to live away from the family but doesn't want to be on his own, he might want to try living in a licensed home. If he wants to be more on his own than is possible in a licensed home, however, he can choose to live with some supports in an apartment, a condo, or a house. He may live alone, or with one or more friends or roommates, or with a loved one. Let's take a closer look at some of these options.

What If Our Son Or Daughter Wants To Stay With The Family?

You and your son or daughter may decide that living at home with the family is the best decision, for a short time or a longer time. If so, the regional center will work with your family to make sure the necessary services and supports are there for you.

If your relative has special health needs, the regional center may be able to help arrange for in-home health care. If he wants to find a job or get involved in some other kind of daytime activity, the regional center can help with that, too. We can also help him identify social and recreational activities where he can pursue some of his interests or make new friends. We may even be able to provide you with respite assistance to relieve you of some of the demands of care giving.

Financial Assistance. Adults with developmental disabilities who live at home with their family are generally eligible to receive Supplemental Security Income (SSI) to help pay their living expenses. They are also usually eligible for Medi-Cal to pay their doctor, hospital, and other medical bills. If they have a job and receive a paycheck, they may use this money any way they choose. Depending on their income from their job, however, their SSI may be reduced.

If a person needs some type of special service (e.g., personal care assistance), financial support may be available through the In-Home Supportive Services (IHSS) program. The regional center may provide other services if they are not covered by sources such as private insurance, Medi-Cal, or IHSS.

If you would like more information about SSI or IHSS, ask your Counselor or visit the HRC Resource Center for copies of the “Making It Happen” booklets describing these programs.



What About Living In A Licensed Home?

A licensed home is a place where a group of people with developmental disabilities live together. Usually, between two and six people live in this kind of home. Clients either share a bedroom with one other person, or they have their own bedrooms.

Staff members in licensed homes offer 24-hour care and supervision and make sure clients get meals and take their medication. They provide support when residents need it and help residents learn skills they need to make them more independent. For example, if a client needs help with self-care such as bathing or dressing, the staff will provide that support. If he wants to learn a skill such as cooking or cleaning so he can become more independent, staff will help with that, too.

Staff in all licensed homes make every effort to ensure that the residents participate in the life of the neighborhood and surrounding community as much as possible. They also encourage families to remain fully involved with their sons or daughters living there.

If your family member lives in a licensed home, the staff there have a responsibility to help him do the things he wants to do. It's his home and he should be happy there. For example, he will be involved in things such as:

- decorating his own bedroom
- helping to decide what food will be served at the residence
- doing things he likes to do in the community
- seeing his friends and family when he wants to

All in all, he should have lots of opportunities to make decisions for himself about how he lives his life in his home and in the community.



Homes are licensed either by the California Department of Social Services' Community Care Licensing Division, or the California Department of Health Services. Community Care licensed homes generally provide basic care and supervision, but some are designed especially for people with specific needs. For example, some are set up for people with physical disabilities or medical needs, and some help people with behavior challenges.

If your relative has significant health or medical needs, he could be served in a home licensed by the state Department of Health Services. These homes are treatment-oriented. Residents receive ongoing supervision by a nurse, physician, or other health care professional, according to their individual needs. Residents may also receive services from clinical staff specializing in physical, occupational, or speech therapy.

Financial Assistance. If your adult son or daughter lives in a Community Care Home, he or she will probably be eligible to receive Supplemental

Security Income (SSI) and Medi-Cal. The SSI will go directly to the home to cover the cost of care, although it may not cover the full amount. The regional center receives money from the state to pay for what SSI does not cover. Medical care (doctors, hospitals, medications) is paid for by Medi-Cal.

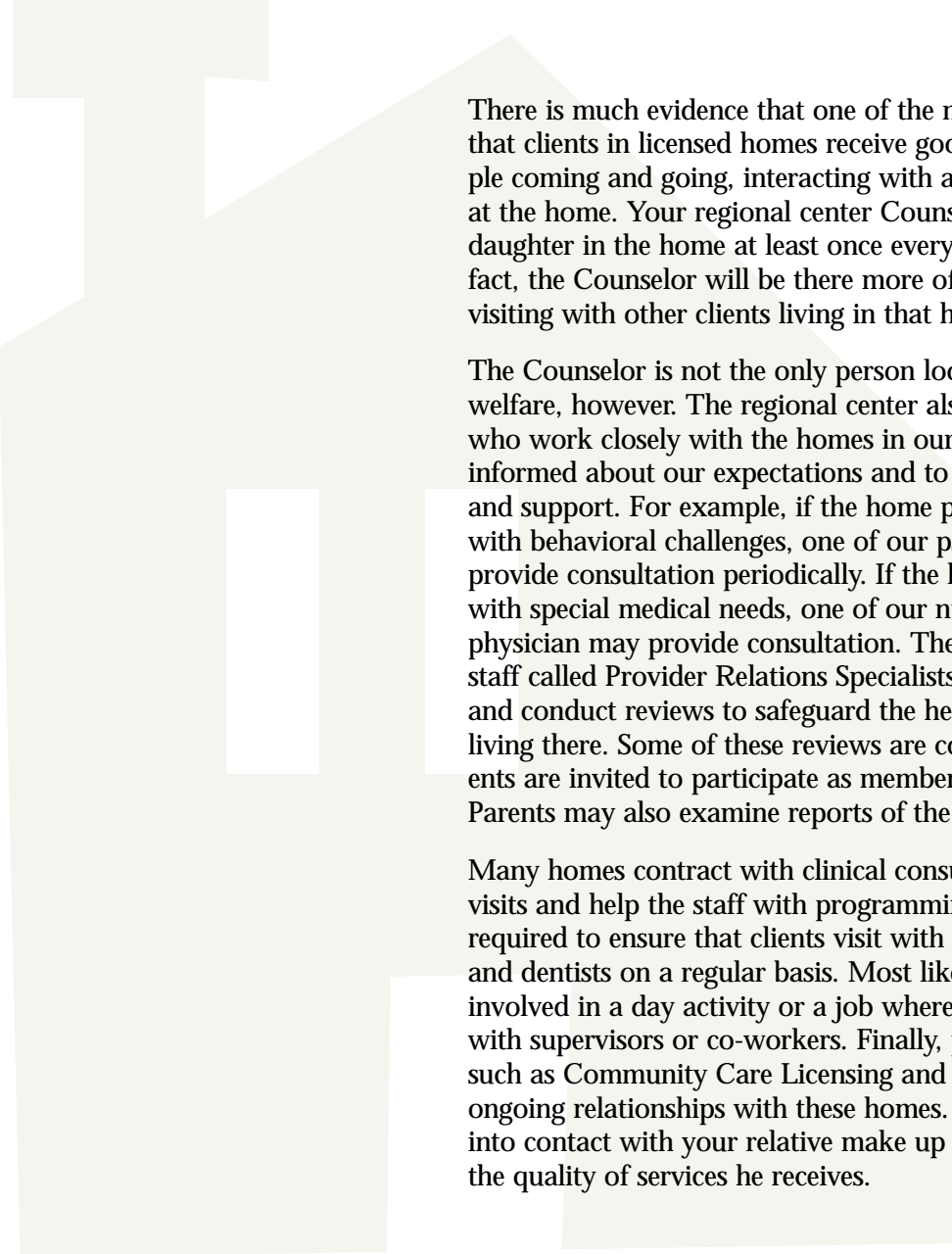
Costs of care in health-licensed homes are usually paid entirely by Medi-Cal. If a client is not eligible for Medi-Cal but has special health-care needs, then it is possible that the regional center would pay some or all of the cost of this type of home.

Personal and Incidental Funds. Residents of licensed homes receive a monthly sum to cover “personal and incidental” (P&I) expenses. P&I funds may be used for clothing, entertainment, or whatever else the person chooses.

How Do We Know Our Relative Will Receive Good Care In A Licensed Home?

Naturally, you wonder about the quality of care that your son or daughter would receive if he or she lives in a licensed home. At Harbor Regional Center, our primary concern is for the health and welfare of our clients. Because of this, we created a special program – called “Expectations and Aspirations for Group Homes” (located at the end of this booklet) – through which licensed home service providers are encouraged and assisted to continually raise the quality of their services above that required by law and regulation.

After consulting with many groups of people, including parents, adult clients, residential service providers, and regional center staff, we created a set of best practice guidelines that identify the kinds of things that people would expect to see in the best homes. We work with service providers to help them achieve the best practices, and we evaluate services on how well they have done. The results of these evaluations are available to families.



There is much evidence that one of the most effective ways to ensure that clients in licensed homes receive good care is to have lots of people coming and going, interacting with and talking to the residents at the home. Your regional center Counselor will visit your son or daughter in the home at least once every three months. Usually, in fact, the Counselor will be there more often, because she will be visiting with other clients living in that home.

The Counselor is not the only person looking out for your relative's welfare, however. The regional center also has a staff of specialists who work closely with the homes in our area to keep them well informed about our expectations and to provide ongoing training and support. For example, if the home provides care for individuals with behavioral challenges, one of our psychologists may visit and provide consultation periodically. If the home provides care for people with special medical needs, one of our nurses, a pharmacist, or our physician may provide consultation. The regional center also employs staff called Provider Relations Specialists who visit homes regularly and conduct reviews to safeguard the health and welfare of the people living there. Some of these reviews are conducted by teams, and parents are invited to participate as members of the review teams. Parents may also examine reports of the reviews.

Many homes contract with clinical consultants who make regular visits and help the staff with programming. Licensed homes are also required to ensure that clients visit with their primary care physicians and dentists on a regular basis. Most likely, your relative will be involved in a day activity or a job where he will interact regularly with supervisors or co-workers. Finally, professionals from agencies such as Community Care Licensing and Health Care Licensing have ongoing relationships with these homes. All these people who come into contact with your relative make up the system that monitors the quality of services he receives.

In addition to all of the people mentioned, you will be encouraged to maintain an active role in your relative's life when he is living away from your home. Your observations are most important and we will count on you to let us know if you see anything that would require us to increase our assistance to the home. In case you have a concern or see something that requires follow-up, we are only a phone call away. Our staff respond promptly to all calls alerting us to potential problems or a need for intervention.

What Is Supported Living?

In supported living, people with disabilities live in their own homes, apartments, or condos in the community. Most of the time they pay rent, but sometimes they may even buy the place where they live. People in supported living may live alone, with a loved one, with a friend, or with a roommate.

The purpose of supported living is to give people with disabilities the help they need to live as independently as possible in the community. Anyone, regardless of his level or type of disability, may live in the community, but almost everyone needs some kind of help to do this successfully. The regional center assists people to find the right help.

A person wanting to live on his own may need help learning to cook, to clean house, or to ride the bus. Most people, however, also need ongoing support. This may include, for example, assistance and support to make sure their bills are paid on time and to maintain their health.

Some of the support that people with developmental disabilities need in order to live on their own may be the kinds of things that friends or family members can do. This kind of support is called "natural support." For example, friends may take a person to church or synagogue. Parents, brothers, or sisters may help them get furniture for





their new place or help them learn to cook. For the things that families or friends cannot do, a supported living service provider helps the person learn how to do these things as independently as possible.

Financial Assistance. It is very important for people who choose supported living to understand that they need to have enough income each month to pay for their rent, utilities, food, and other regular expenses. People living on their own may receive SSI benefits, they may have income from a job, or they may have both. Whatever the source(s) of income, the funds must cover the person's monthly living costs.

The medical care of people in supported living is usually paid for by Medi-Cal or, if they have a job with benefits, by their private medical insurance. People with physical disabilities or other special needs who require someone to come into their home to give personal assistance can receive services through the In-Home Supportive Services (IHSS) program.

HOPE. Harbor Regional Center works very closely with a non-profit corporation that provides special residential opportunities for people who choose supported living. The organization is called Home Ownership for Personal Empowerment, or HOPE. HOPE buys residential properties – single-family homes, duplexes, and condominiums – fixes them up, and rents them at below market rates to clients of Harbor Regional Center. (The rents are usually not more than 30% of the renter's monthly income.) In the year 2002, more than 70 adults with developmental disabilities were living in HOPE properties in Torrance, Long Beach, Lakewood, and Bellflower. A special feature of these homes is that every client has his or her own bedroom. Because the homes are owned by a corporation set up solely for this purpose, HOPE offers greater stability than most other community-based options. If you would like to learn more about this program, ask your regional center Counselor to put you in touch with HRC's housing specialist.

How Do We Choose The Right Living Arrangement?

Choosing a living option for an adult is no different from making any other important life decision. You and your family member need to think about his immediate and longer term life goals, gather information about the options you are considering, and see which option is the best match in view of his preferred future.

As when taking other major steps, it's important to take some time so that you can make the best decisions. Many families begin the process of considering living options a number of times before their son or daughter actually makes a move to a licensed home or supported living. In addition, many service and support programs have waiting lists, so you need to start planning at least a year before your relative expects to make a change in living arrangements. Be sure to give yourself plenty of time.

If you want to investigate community living options for your son or daughter, it is especially important for you to talk to your regional center Counselor. She will probably suggest that you discuss the possibilities at the time of the annual Individual/Family Service Plan meeting. At that time, you may want to include the people who can play specific roles in your family member's life on his planning team to help ensure that his move to the community is successful.

Once you've talked with your Counselor and involved the planning team, you will have a better idea of what kind of living arrangement would work best – based on what your son or daughter wants, likes and needs, and what supports are available. There are as many possibilities as there are people.

If your decision is that a licensed home is the best for your relative, you should try to attend Harbor Regional Center's program called "Rainbow of Choices" to learn even more about options. Your Counselor can assist you in visiting a home or homes that may be appropriate for your relative.

If the decision is to try supported living, the client must choose a supported living service provider. This agency will work with the client and you to determine what supports he needs and how they will be provided. Your HRC Counselor will probably suggest a few service providers with whom you can meet before making a choice. It is a very good idea

for you to meet with them all. The supported living service provider will play a very big role in the life of your son or daughter. For more information on supported living and help in the planning process, see the regional center booklet, "Living On Your Own: A Guide To Supported Living Services."

It's available in the HRC Resource Center.



It is important for families to remember that planning a future is not a once-and-for-all kind of thing. A person's ideas about what he wants will probably change over time. Changes will occur as the person learns more about his hopes, talents, needs, and responsibilities. For example, a person may decide to live in a licensed home now, but decide to try supported living a couple of years from now.

How Do We In The Family Prepare Ourselves For The Move?

All families need to prepare emotionally for a change as significant as a son or daughter moving out of the home. When a son or daughter leaves home, families experience many emotions, including sadness and sometimes guilt. They wonder whether their child will be safe and well cared for, and whether he will still be eager to spend time with family and old friends. Parents who have devoted most of their time and attention to child rearing may, in addition, be at loose ends regarding what they want to do once that part of their work has been completed.

If you experience any of these emotions, you may find it helpful to talk to other regional center families who have dealt or are dealing with a relative leaving home. The best way to do this is to join a support group. For information on support groups, talk to your regional center Counselor or contact HRC's Resource Center.

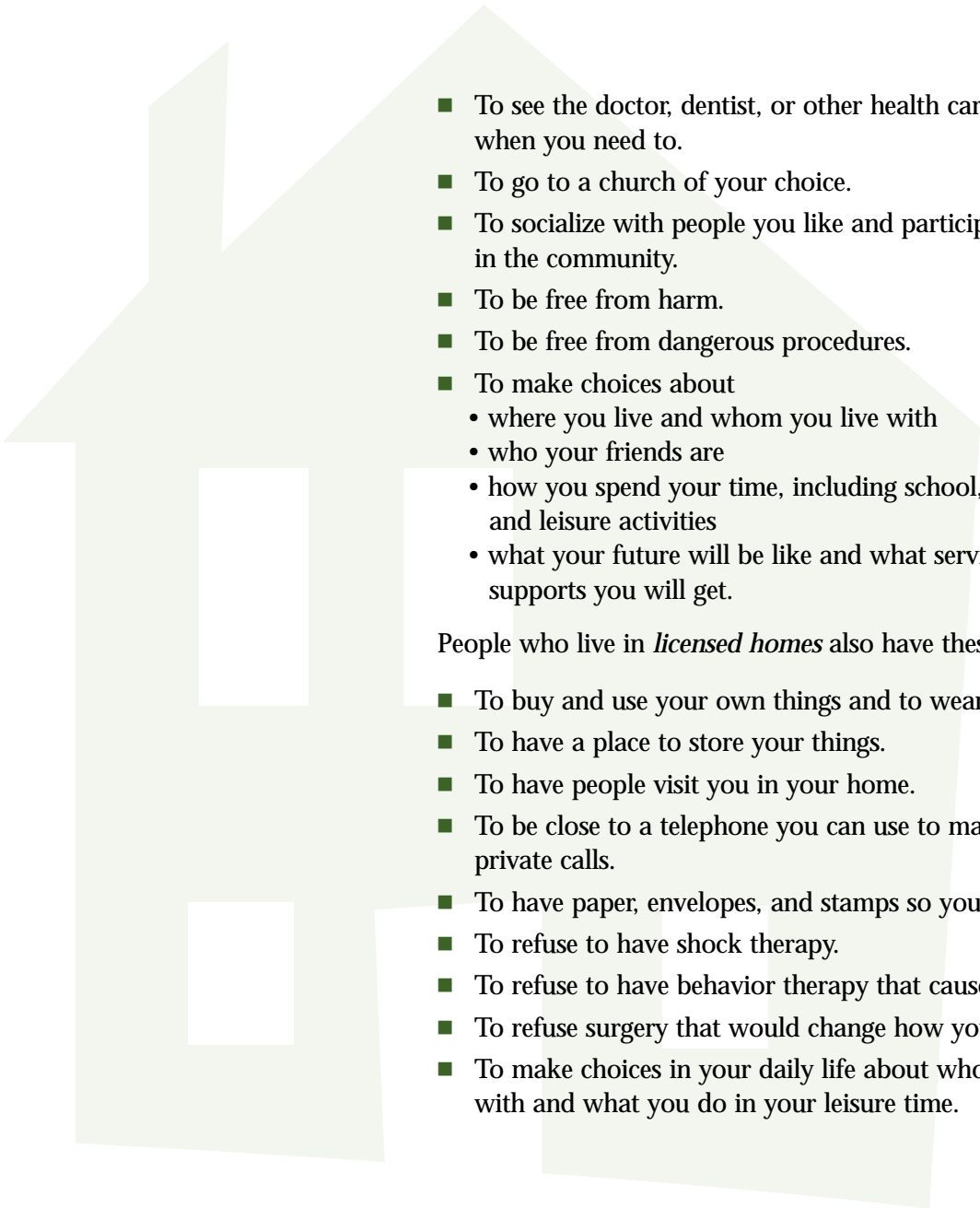
Whatever your family's decision about where your relative will live, it is most important that the decision be *informed*. Informed decisions require time and complete information. You should take enough time to investigate fully what the options are, and the advantages and disadvantages of each of them for your family member at that time in his life. Plan ahead, make many visits to different kinds of living arrangements, talk to service providers, talk to clients who are living in different settings, and talk to their family members. Careful planning will ensure that your family makes the best decision, both for you and for your loved one.

Rights of People with Developmental Disabilities

The law in California says that people with developmental disabilities have rights. Certain rights apply to everyone. Additional rights apply to you if you live in a licensed home or in a supported living setting.

Everyone with a developmental disability has the following rights:

- To receive services and supports that help you become as independent as possible. These services and supports should be provided in the least restrictive setting. This means you make your own rules about how you live as long as your decisions do not put you or someone else in danger, or interfere with the rights of other people.
- To have privacy and to receive help from people who are kind to you and respect you.
- To go to public school until you are 22 years old.

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- To see the doctor, dentist, or other health care professional when you need to.
 - To go to a church of your choice.
 - To socialize with people you like and participate in activities in the community.
 - To be free from harm.
 - To be free from dangerous procedures.
 - To make choices about
 - where you live and whom you live with
 - who your friends are
 - how you spend your time, including school, job, and leisure activities
 - what your future will be like and what services and supports you will get.

People who live in *licensed homes* also have these other rights:

- To buy and use your own things and to wear your own clothes.
- To have a place to store your things.
- To have people visit you in your home.
- To be close to a telephone you can use to make and receive private calls.
- To have paper, envelopes, and stamps so you can write letters.
- To refuse to have shock therapy.
- To refuse to have behavior therapy that causes pain or injures you.
- To refuse surgery that would change how your brain functions.
- To make choices in your daily life about whom you spend time with and what you do in your leisure time.

- To tell the regional center how satisfied you are with the services you receive and have this information taken into account when decisions are made.

People who live in *supported living* also have these rights:

- To decide where you live and whom you live with.
- To decide how your home looks, how it's decorated, and how it's arranged.
- To choose who provides your support services.
- To help develop your Individual/Family Service Plan so the services and supports you receive are what you want and what you need.
- To receive services that are right for your changing needs and wishes, without having to leave your home.
- To tell the regional center how satisfied you are with the services you receive and have this information taken into account when decisions are made.
- To end a service without having your decision make you lose other services you are getting from the regional center.
- To receive the information you need to make important life decisions.





Harbor Regional Center Expectations and Aspirations for Group Homes

Serving People with Developmental Disabilities

This document describes Harbor Regional Center's expectations and aspirations for group homes. It reflects what clients, family members, regional center staff, and service providers have told us a good group home should be like. We look forward to working in partnership with our homes in the coming years to help them move their services steadily closer to these expectations and aspirations.

Basic to these guidelines is the principle of client self-determination. This means that people with disabilities make their own reasonable choices about how they live their lives, and these choices are respected by people around them.

A goal of all group homes is to help clients become as independent as possible and achieve the objectives they choose for themselves. Client choice guides services as long as these choices do not pose a threat to the client's health or safety or infringe on the rights of others.

Mission

- The group home's mission statement promotes respect for people with disabilities and participation of people with disabilities in the community.
- Group home staff know the mission statement and can explain how the mission affects what they do with clients.

The Client's Support Network

- The client is helped to develop a reliable network of natural supports, including family, friends, and other people in the community.

- Clients and their families are encouraged to maintain contact with one another.
- A non-conserved adult gives his consent before staff communicate with his family about the client's life.
- Staff develop ways for the family to be involved in the client's life if that is what the client and family both want.
- Staff educate the community about people with developmental disabilities in order to increase community awareness and acceptance.
- Staff involve clients in activities that increase their interactions with people in the community.
- If a client is going through a major change at home, at work, or in the day program, staff work with the regional center Counselor and other people in the client's support system to help the client deal with the change.

Staff-Client Interactions

- Staff use positive approaches in all interactions.
- Staff treat the client with respect.
- Staff know the clients' likes and dislikes, goals and dreams.
- Staff know what outcomes each client is working to achieve in the home.
- A staff person attends the client's annual regional center planning meeting and the annual ISP (for clients attending day activities) or IEP (for clients in school).
- Staff know what medications clients are taking, what the medications are for, and their side effects.
- The client and staff members communicate using the client's preferred language and method of communication.

Training and Support

- Clients receive training and support to help them:
 - stay healthy,
 - stay safe from harm,
 - develop and maintain friendships and other social relationships,
 - make choices about how they live in the home and what they do in the community, and
 - get around in the community (including using public transportation).
- The group home gives clients access to computers.

Asking for Feedback

- Staff ask clients whether they are happy with the services they receive from the group home.
- Staff ask family members and other people important to clients how well they are helping clients.
- The group home makes changes in services as a result of what clients and others tell them.

Client Choice and Self-Determination

- A client's choices are reflected in his everyday life in at least the following ways:
 - individualized schedule and daily activities,
 - bedroom space that is individualized with personal items, pictures, and other decorations,
 - individualized and appropriate hair style, and
 - individualized and appropriate clothing.
- Clients have choices in meal and snack selection.
- Clients receive individualized training and support to help them express their opinions and advocate for themselves.

- The group home provides support for a client council that meets regularly.
- The client council makes decisions or takes actions that affect the lives of the people who live in the group home.

Home Environment

- The home is in a safe neighborhood.
- The home is designed for four or fewer clients.
- Each client has a private room.
- In homes where clients share bedrooms, they are free to change roommates if the new pairings are appropriate and compatible.



Staff Training and Support

- Staff are paid at least 150% of minimum wage.
- Staff receive medical and leave benefits.
- Staff members are paid for a minimum of 2 hours per month to participate in training.
- Staff receive initial training that includes:
 - basic methods of interaction and communication with clients,
 - the principle of dignity of risk,
 - assistive technology and how clients may benefit from the use of appropriate adaptive devices,
 - how to recognize signs of pain, other discomfort, or illness in residents.
- Staff are encouraged to attend outside training conducted by the regional center or other organizations.
- Staff are given access to computers.
- The group home management has instituted specific actions in an attempt to keep staff turnover low.



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