

Consumer Guide
Living Arrangements

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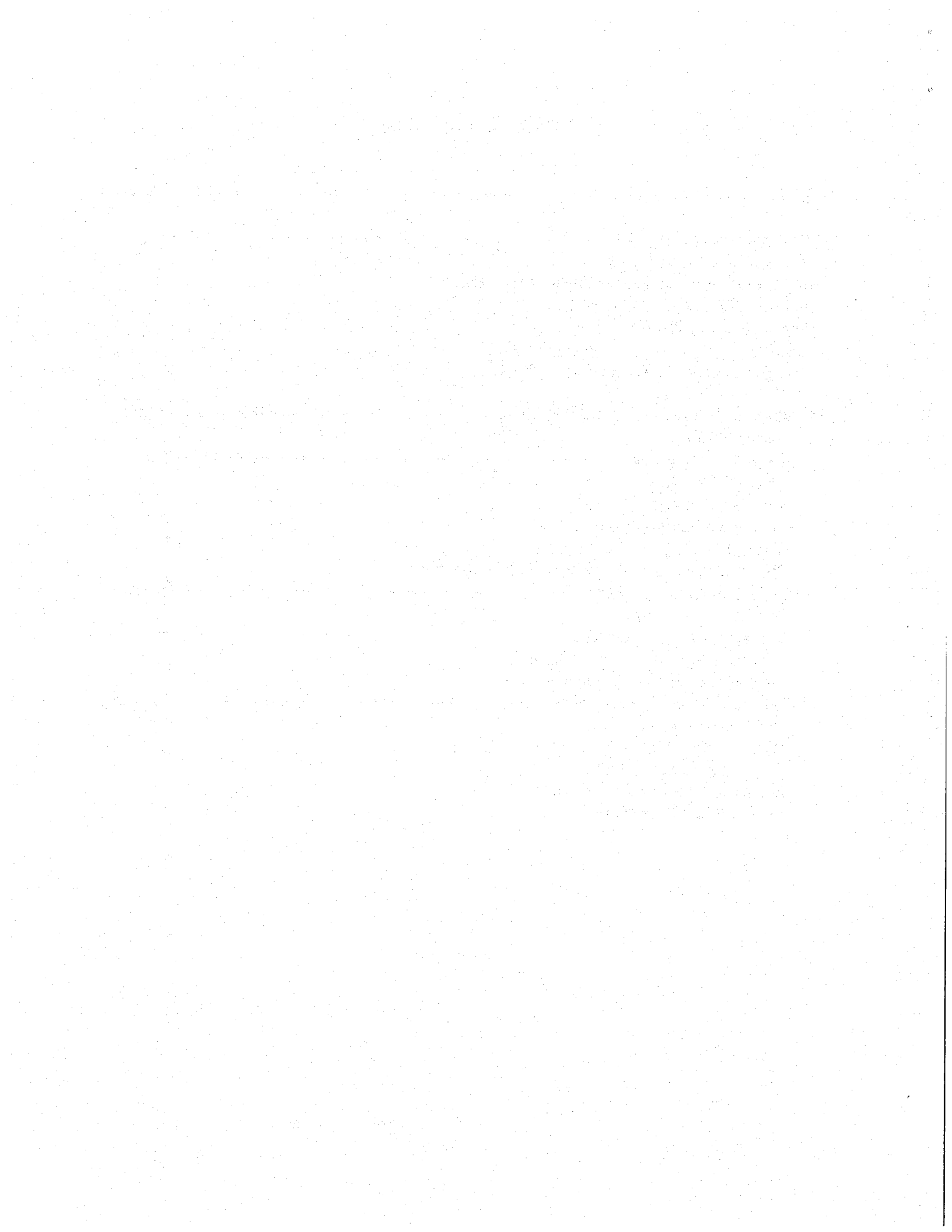
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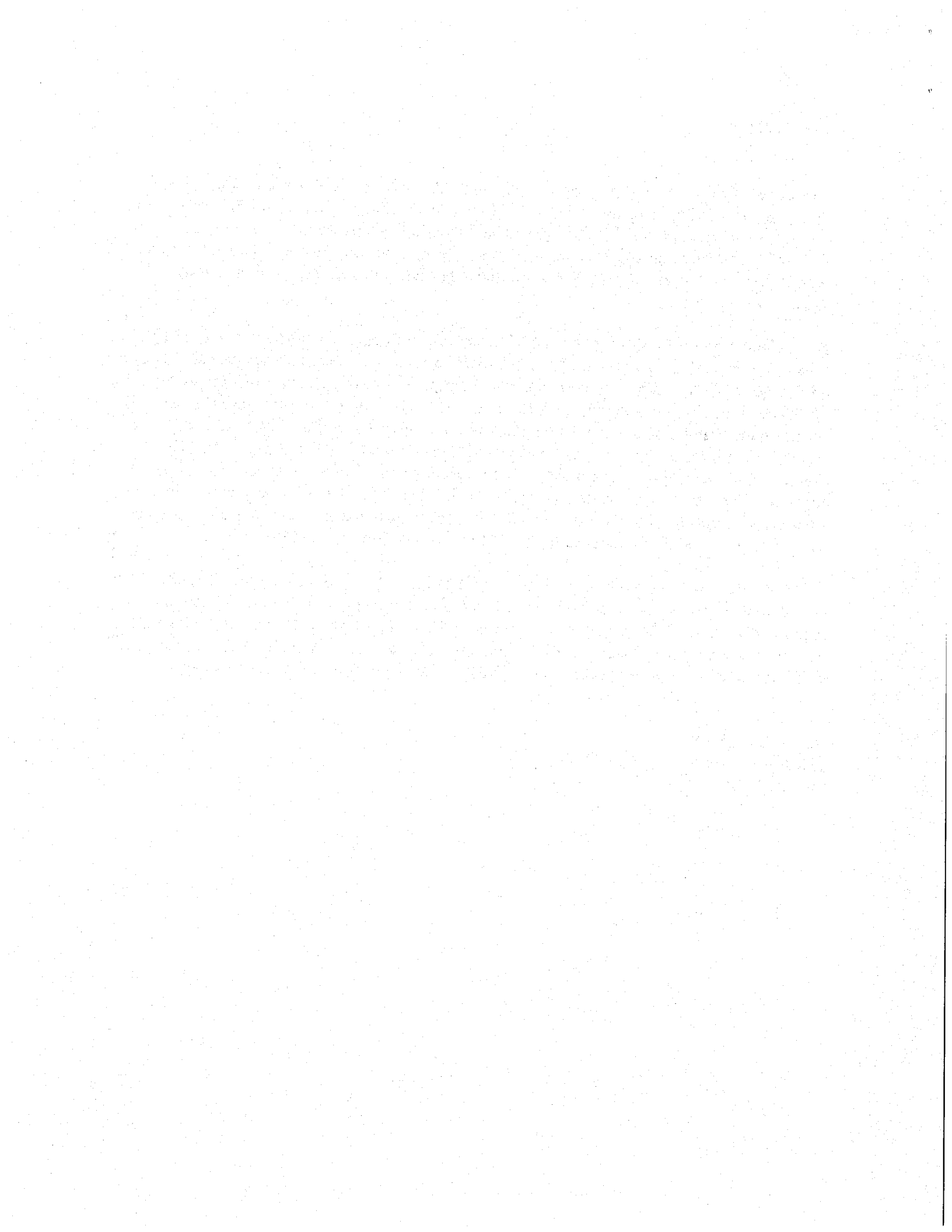
Forward

This Consumer Guide is one of a series of booklets about the kinds of services available in the community for children and adults with developmental disabilities. Consumers and parents, like yourself, have asked for this kind of information because they want to know their options. They also want to better understand the regional center decision-making process. That is why every booklet contains important background material beginning with a statement of the agency's philosophy.

The regional center Board approved its Philosophy and Working Principles after much public debate. Along with the Lanterman Act, the Principles encourage us to consider the supports and services most likely to promote normal lifestyles for persons with developmental disabilities. The list of consumer rights in the Guide, contained in the Lanterman Act, offers a similar reminder--persons with disabilities have the same rights as every other citizen. These rights should act as a beacon as we listen to the hopes and dreams of individuals and families. Supporting these ambitions is a tremendous responsibility. The Department of Developmental Services (with the help of people with developmental disabilities, family members, service coordinators, advocates, other professionals and community members), has developed 26 individual life quality outcomes which further define that commitment. You'll find the outcomes listed in the guide.

Also presented in every booklet is a review of the Individual Program Plan (IPP) process. It tells who should attend a person-centered planning meeting, the purpose of assessment, and the importance of the IPP document. Next comes a summary of the kinds of activities the Lanterman Act considers important to meet the goals and objectives in an IPP. Finally, every booklet tells what consumers and parents need to keep in mind when they select a service provider.

Bernie Schaeffer
Director of Training and Information
December 18, 1995



TCADD Board Philosophy and Working Principles

Information

TCRC will work with the Area Board to provide consumers with good, useable and timely information about options. Consumers cannot make informed choices without current and complete information. This means making consumers aware of generic as well as vendored support services.

Advocacy

TCRC will work with the Area Board to advocate for other publicly-funded agencies to meet their legal obligations to serve consumers. Consumers must receive those options which are needed and are the responsibility of other publicly-funded agencies. This requires that TCRC employ due diligence to demand or provide needed services in a timely manner.

Options

TCRC will facilitate the creation of better options for consumers. Consumers cannot make good choices unless there are a sufficient number of quality options available. TCRC will work with the community to assure the monitoring and continuing improvement of options. Better options are those which enable persons with developmental disabilities to:

- Achieve a pattern of everyday living available to non-disabled persons of the same age with emphasis on community and school integration, natural supports, stable and healthy environments, meaningful involvement with people without disabilities.
- Avoid dislocation from the home or community.
- Be assured of protection of their constitutional and statutory rights.
- Experience more positive outcomes including creation of more independent, productive and normal lives.

These principles will guide TCRC's efforts in development and implementation of service plans with consumers.

Consumer Choice and Responsibility

TCRC will respect the choices of consumers and expect them to accept that responsibility. With useable information and a wide range of supports and services available, TCRC presumes that consumers know best. Except where consumer choices jeopardize health and safety, these choices will be respected. TCRC also respects and will be responsive to the cultural differences which are reflected in those choices.

Excellence

TCRC will promote excellence in support by the Board, staff, vendors and family members. TCRC will collaborate with community members to assure excellence through the provision of

support, technical assistance and training needs. The TCADD Board of Directors accepts its responsibility for adoption of policy which assures that TCRC is effectively and efficiently managed. Accordingly, the Board assures that services will be purchased within the framework of the law and service standards as set forth by the Board.

The Lanterman Act

Rights of Persons with Developmental Disabilities

- A right to treatment and habilitation services and supports in the least restrictive environment. Treatment and habilitation services and supports should foster the developmental potential of the person and be directed toward the achievement of the most independent, productive and normal life possible. Such services shall protect the personal liberty of the individual and shall be provided with the least restrictive conditions necessary to achieve the purposes of the treatment, services, or supports.
- A right to dignity, privacy, and humane care. To the maximum extent possible, treatment, services and supports shall be provided in natural community settings.
- A right to participate in an appropriate program of publicly supported education, regardless of degree of disability.
- A right to prompt medical care and treatment.
- A right to religious freedom and practice.
- A right to social interaction and participation in community activities.
- A right to physical exercise and recreational opportunities.
- A right to be free from harm, including unnecessary physical restraint, or isolation, excessive medication, abuse, or neglect.
- A right to be free from hazardous procedures.
- A right to make choices in their own lives, including, but not limited to, where and with whom they live, their relationships with people in the community, the way they spend their time, including education, employment, and leisure, the pursuit of their personal future, and program planning and implementation.

State of California

Department of Developmental Services

Individual Life Quality Outcomes

People with developmental disabilities will be provided with opportunities to participate in valued ways with their friends, neighbors and co-workers in all areas of community life, with supports being provided which enable them to have real choices in where they live, work and spend their leisure time. The Department of Developmental Disabilities has developed the following 26 individual life quality outcomes which further define that commitment.

Choice

1. Individuals identify their needs, wants, likes and dislikes.
2. Individuals make major life decisions.
3. Individuals make decisions about everyday matters.
4. Individuals have a major role in deciding what services and supports they need.
5. Individuals have a major role in choosing the providers of their services and supports.
6. Individuals' supports and services change as wants, needs and preferences change.
7. Individuals experience continuity in their services and supports.

Relationships

8. Individuals have friends and caring relationships.
9. Individuals build community supports which may include family, friends, service providers/professionals and other community members.

Lifestyle

10. Individuals are independent and productive.
11. Individuals are comfortable where they live.
12. Individuals' lifestyles reflect their cultural preferences.
13. Individuals are provided opportunities for participation in integrated home, work and leisure settings.
14. Children live in homes with families.

Health and Well-Being

15. Individuals are safe.
16. Individuals have the best possible health.
17. Individuals know what to do in the event of threats to health, safety and well-being.
18. Individuals have access to needed health care.

Rights

19. Individuals exercise rights and responsibilities.
20. Individuals are free from abuse, neglect and exploitation.

21. Individuals are treated with dignity and respect.
22. Individuals receive appropriate generic services and supports.
23. Individuals have advocates and/or access to advocacy services.

Satisfaction

24. Individuals achieve personal goals.
25. Individuals are satisfied with services and supports.
26. Individuals are satisfied with their lives.

The Individual Program Planning (IPP) or Person-Centered Planning Process

What is an IPP?

The outcome of the planning process is a written document called the IPP. The IPP is like a blueprint showing what needs to happen to support the individual or family.

Who should participate in the planning process?

Individual program plans are prepared together by one or more representatives of the regional center, including the service coordinator, the person with developmental disabilities and, where appropriate, the person's parents, legal guardian, or conservator. Often the person or family may choose other people to join them including friends, neighbors and co-workers. Service providers also regularly attend.

Why do assessments?

The purpose of collecting information is to learn about the abilities and positive qualities of the person with developmental disabilities. In the case of a child, the purpose is to review the needs, strengths and capabilities of the child and the family unit as a whole. Information about what is needed comes from a variety of people--including family members, friends and service providers. The wishes and desires of the person and family, however, should be given the highest priority. "Person-centered planning" is the commonly used term to describe such a planning approach.

What should the IPP contain?

The IPP is a list of goals and objectives based on what the person or family needs and wants. The goals and objectives often involve community participation, housing, work, school and leisure activities. For families, the goals and objectives may describe the help needed to allow a child to remain in the home.

Activities to Achieve Objectives in the Individual Program Plan

Services and Supports in the Natural Community

The Lanterman Act states that the planning team should first think about arranging services and supports in the natural community, home, work and recreational settings. This means considering supports and services which occur away from segregated programs serving only children or adults with developmental disabilities. Sometimes these natural supports and services--such as friends, neighbors and co-workers--may be unpaid.

The Use of Generic Resources

According to the Lanterman Act, regional center funds cannot be used when suitable generic service agencies already exist which have a legal responsibility to serve all members of the general public. Examples of such services are County Mental Health services, California Children's Services and the public schools. That is why the planning team has an obligation to advocate for services from these agencies when they have identified a need.

Purchase of Services

After other possibilities are talked over and ruled out, the regional center may purchase cost-effective services from vendors or contracted providers. A regional center may also issue a voucher to families for certain kinds of services.

Considerations When Purchasing Services

Regional Center Service Standards

The TCRC Board, following public input, has adopted service standards which regional center staff use as guidelines. These guidelines are required in the regional center's contract with the Department of Developmental Services. The guidelines help in making decisions about the kinds and amounts of supports and services which may be helpful in different situations. The guidelines do allow for exceptions. The Service Standards are also important because regional centers receive limited purchase of services budgets from the State of California. Regional center boards, therefore, are responsible for making certain that the money is spent fairly and responsibly.

A Provider's Ability

The planning team must consider the provider's ability to deliver quality services or supports which can accomplish all or part of the consumer's IPP.

A Provider's Success

The planning team must consider a provider's success in achieving the goals and objectives listed in the IPP.

A Provider's Cost-Effectiveness

The planning team must consider the cost of providing services or supports of comparable quality by different providers, if available.

Consumer Choice

The planning team must consider the consumer's or, where appropriate, the parents', legal guardian, or conservator's choice of providers.

Consumer and Regional Center Satisfaction

No service or support provided by any agency or individual shall be continued unless the consumer or, where appropriate, his or her parents, legal guardian, or conservator, is satisfied. The regional center and the planning team must also agree that all requested services and supports have actually been provided and reasonable progress has been made.

Introduction to Living Arrangements Section

Finding suitable housing for a child or adult with a developmental disability can be a difficult challenge. This section presents information about three different types of housing--licensed group home living, independent living services, and supported living. To help you better understand these choices, we have defined the most commonly used terms as well as what each of the programs does. However, there is no substitute for visiting housing sites, observing first-hand, and talking to both support staff and residents. Expectations are important. That is why the booklet contains the answers to commonly asked questions about each service, a sample of questions you may want to ask when doing your own research, and some typical examples of service outcomes. There are other ways to find out what you need to know. One of them is to talk to your service coordinator. And remember--planning for the future should always be a team effort.

Glossary of Terms

Adult Residential Facility (ARF)—Community Care Licensed (State of California, Department of Social Services) residential services for adults.

Family Home Agency (FHA)--means a private not-for-profit agency that is vendored to do all of the following: 1) recruit, approve, train, and monitor family home providers; 2) provide services and supports to family home providers; and 3) assist consumers in moving into or relocating from family homes.

Family Home --means a home that has been approved by an FHA and is owned, leased or rented by the family home provider and is the residence in which services and supports are provided to a maximum of two consumers regardless of their degree of disability, except for those consumers who require continuous skilled nursing care.

Functional skills--means those skills which enable an individual to communicate, interact with others and to perform tasks which have practical use and meaning at home, in the community or on the job

Independent Living Program (Services)--means a community-based program that provides to adult consumers the functional skills training necessary to secure a self-sustaining, independent living situation in the community and/or may provide the support necessary to maintain those skills.

Intermediate Care Facility/Developmentally Disabled (ICF-DD)—a licensed residential health facility (State of California, Department of Health Services), 16 beds or more, which provides care and support services to persons with developmental disabilities whose primary need is for developmental services and who have a recurring, but intermittent, need for skilled nursing services.

Intermediate Care Facility/Developmentally Disabled-Habilitative (ICF-DD-H)—a licensed residential health facility, 15 beds or less, which provides 24-hour personal care, developmental training, habilitative, and supportive health services in a facility to residents with developmental disabilities.

Intermediate Care Facility/Developmentally Disabled -Nursing (ICF-DD-N)—a licensed residential health facility, 4-15 beds, which provides 24 hour nursing supervision, personal care, and training in habilitative services to medically fragile developmentally disabled persons, or to persons who demonstrate a significant developmental delay that may lead to a developmental disability if not treated.

Mobility Training--means individually planned activities and instruction which enable adults with developmental disabilities to utilize the most normalizing independent transportation modes possible.

Natural Environment--means places and social contexts commonly used by individuals without developmental disabilities.

Natural Supports--means personal association and relationships typically developed in the community that enhance the quality and security of life for people, including, but not limited to: family relationships; friendships reflecting the diversity of the neighborhood and the community; associations with fellow students or employees in regular classrooms and workplaces; and associations developed through participation in clubs, organizations and other civic activities.

Residential Facility for Children (RFC)—Community Care Licensed residential services for children.

Residential Facility for the Elderly (RFE)—Community Care Licensed residential services for the elderly, 60 years and older.

Residential Services—the direct supervision and special services which staff provide to carry out the program design and achieve the objectives of the IPP for which the residential services provider is responsible.

Self-Advocacy--means the awareness, motivation and ability of an individual to represent and communicate his or her own interests, to exercise personal choice, to exert control over his or her personal environment, and to avoid exploitation and abuse.

Self-Care--means meeting one's physical and personal needs, such as dressing, grooming and hygiene without dependence on others, or having the ability to direct others to meet those needs.

Service Level—one of a series of four levels approved by a regional center. Service levels 2, 3 and 4 have specific direct supervision and special services requirements for facility residents. Each facility applying for service level approval submits a written program design to the regional center which is based on the principles of normalization as measured by a person's participation in a variety of integrated, age-appropriate activities which take place in natural environments, at home, at work, in the community and during leisure time.

Supported Living Arrangements--opportunities for adults to live in homes they own or lease themselves, with support available as often and for as long as needed, when that is the preferred objective in the IPP.

Licensed Group Homes What Do They Do?

Licensed group home staff provide the following supports and services for residents:

Direct supervision --which means assisting, prompting or training a person in areas relating to self-help, food preparation, household maintenance, handling money and making purchases, accessing community resources and participating in leisure time activities.

Special services--which means specialized training, treatment, and/or supervision required by the IPP and provided by the facility in addition to direct supervision.

Commonly Asked Questions About Living In Licensed Group Homes

What is the placement process?

It is the planning team which makes the decision to locate and evaluate alternative living arrangements. The service coordinator mails information about the person's needs and preferences to the facility administrators of appropriate group homes which have vacancies.

Can the person and family visit these homes?

Yes, the regional center recommends it. A facility administrator will schedule a pre-placement visit if it still appears that the group home is appropriate after reviewing the information packet.

How many people usually live in a group home?

The size varies. Regional center staff usually encourage community placement in more homelike settings with six or fewer residents.

Who makes the final decision?

It is your choice, if the planning team supports the decision and the facility administrator agrees.

Who pays for the residential services?

It depends on whether the group home or facility is licensed by the State Department of Social Services or the State Department of Health Services. Supplemental Security Income (SSI) covers

the partial cost of placement in Community Care licensed homes. Tri-Counties Regional Center pays the remainder of the total cost depending on the home's approved service level. In the case of a child under the age of 18, the law requires parents to contribute a share of the cost based on their income. Medi-Cal pays for group living in facilities licensed by the State Department of Health Services. No parental reimbursement is required. Residents also receive personal and incidental monies to cover special expenses. The amount differs depending on which department licenses the home.

Who monitors the quality of services provided?

The regional center, as well as the appropriate licensing agency, monitor the quality of services. The State Department of Social Services monitors Community Care Licensed homes. Intermediate Care facilities are monitored by the State Department of Health Services.

Important Questions to Ask Staff About Group Home Living Services

1. On the average, how many hours each week do individual residents spend in community activities outside of day programming or employment?
2. What are examples of the kinds of activities and organizations they participate in?
3. At what point is a person-centered plan developed with the resident?
4. If appropriate, how many persons have paying jobs in the community?
5. How does the agency insure prompt response to emergencies and generally promote the health and safety of residents?
6. Give examples of how skills are taught in places where there are people without developmental disabilities.
7. In what different ways are individuals encouraged to make responsible choices and decisions?

Also, you may use the list of Quality Life Outcomes, at the beginning of this booklet, as a guide to evaluate the living arrangement you are visiting.

Examples of Service Outcomes in Licensed Group Homes

The person will be able to:

1. Dress himself without assistance.
2. Ride a bus independently to and from downtown.
3. Make a pot of coffee.
4. Clean a small bathroom including tub, toilet, sink and floor.
5. Using a list, select, check-out and pay for at least 10 grocery items.
6. Independently drink liquid from a plastic cup.

The Lanterman Act

Rights of Persons with Developmental Disabilities in State Developmental Centers or Community Care Facilities

- To wear his or her own clothes, to keep and use his or her own personal possessions, including his or her toilet articles, and to keep and be allowed to spend a reasonable sum of his or her own money for canteen expenses and small purchases.
- To have access to individual storage space for his or her private use.
- To see visitors each day.
- To have reasonable access to telephones, both to make and receive confidential calls.
- To have ready access to letter writing materials, including stamps, and to mail and receive unopened correspondence.
- To refuse electroconvulsive therapy.
- To refuse behavior modification techniques which cause pain or trauma.
- To refuse psychosurgery.
- To make choices in areas including, but not limited to, his or her daily living routines, choice of companions, leisure and social activities, and program planning and implementation.

Listing of Group homes

See your service coordinator for a current listing of licensed group homes in the Tri-Counties.

Independent living Programs What Do They Do?

Independent living programs teach a variety of skills as well as provide the supports necessary for a person to maintain a self-sustaining, independent living situation in the community:

- Cooking
- Cleaning
- Shopping in natural environments
- Menu planning
- Meal preparation
- Money management, including check cashing and purchasing activities
- Use of public transportation in natural environments
- Personal health and hygiene
- Self-advocacy training
- Independent recreation and participation in natural environments
- Use of medical and dental services, as well as other community resources
- Community resource awareness such as police, fire, or emergency help
- Home and community safety

Commonly Asked Questions About Independent Living Services

Who provides independent living services?

Providers vendored by the regional center offer independent living services.

How are independent living services usually provided?

Persons receiving these services usually participate in an apartment-based program in close proximity with other residents receiving the same services.

What kinds of skills are taught?

Shopping, cooking, budgeting and use of leisure time are among the skills emphasized.

Who pays for the services?

The regional center pays for the services. The person's Supplemental Security Income (SSI) helps pay the rent, although usually more than one person lives in an apartment to cover the full cost.

Are independent living arrangements licensed?

No, they are not.

After completion of the program, is there any follow-up?

Yes, on an hourly basis depending on the need determined by the planning team. The goal is to maintain the skills which have been learned.

Who monitors independent living services?

The regional center monitors the independent living services through periodic visits and telephone contacts.

Important Questions to Ask Staff About Independent Living Services

1. On the average, how many hours each week do individuals spend in community activities outside of day programming or employment?
2. What are examples of the kinds of activities and organizations they participate in?
3. At what point is a person-centered plan developed with the individual?
4. How many persons have paying jobs in the community?
5. How does the agency insure prompt response to emergencies and generally promote the health and safety of residents?
6. Give examples of how skills are taught in places where there are people without developmental disabilities.

7. In what different ways are individuals encouraged to make responsible choices and decisions?

Also, you may use the list of Quality Life Outcomes, at the beginning of this booklet, as a guide to evaluate the living arrangement you are visiting.

Examples of Service Outcomes in Independent Living Services

The person will be able to:

1. Ride a bus independently to and from downtown.
2. Purchase and heat microwave dishes and meals.
3. Pay all monthly bills correctly and on time.
4. Belong to a health club and attend three days a week.
5. Complete a summer volunteer experience as a zoo feeding assistant.
6. Do dishes.

Listing of Independent-Living Providers

See your service coordinator for a current list of service providers offering independent-living services in the Tri-Counties

The Lanterman Act Supported Living Arrangements

Consistent with state and federal law, the Legislature places high priority on providing opportunities for adults with developmental disabilities, regardless of degree of disability, to live in homes that they own or lease with support available as often and for as long as it is needed, when it is the preferred objective in the IPP. Therefore, the Department and regional center shall ensure that supported living arrangements adhere to the following principles:

- Consumers shall be supported in living arrangements which are typical of those in which persons without disabilities reside.
- The services or supports that a consumer receives shall change as his or her needs change

without the consumer having to move elsewhere.

- The consumer's preference shall guide decisions concerning where and with whom he or she lives.
- Consumers shall have control of the environment within their home.
- The purpose of furnishing supports to a consumer shall be to assist that individual to exercise choice in his or her life while building critical and durable relationships with other individuals.
- The services and supports shall be flexible and tailored to a consumer's needs and preferences.
- Services and supports are most effective when furnished where a person lives and within the context of his or her daily activities.
- Consumers shall not be excluded from supported living arrangements based solely on the nature and severity of their disabilities.

Supported Living Programs What Do They Do?

Supported Living Services consist of the following :

Personal Support Services-- which assist the individual with activities such as eating, bathing, dressing, meal preparation, routine household activities, and arranging for appropriate medical services.

Training and Habilitation Services-- which help the person learn the skills to complete such tasks as establishing an independent and safe home environment, meeting essential personal needs, managing personal affairs, and participating in community life.

24-Hour Emergency Assistance-- such as beepers, lifelines, med-alert bracelets and telephone adaptive devices.

Commonly Asked Questions About Supported Living

What is the difference between independent living and supported living services?

The goals are very much the same because both kinds of services teach people to live more independently. The regional center purchases supported living services for persons who in the past might not have been considered able to live on their own because of the severity of their disabilities. For that reason, certain kinds of support services may continue much longer, if not indefinitely.

Where do people receiving supported living services live?

They live in their own home or apartment. Supported living is not so much a program as it is a means for people to receive the supports they need to live where and with whom they choose--no matter what their challenges. The person is much more in control and may even hire and fire needed support staff.

What are examples of supports?

Support can come from close friends or neighbors. It can come from a live-in attendant, from living in a barrier-free home, or from having special adaptive aids to function more independently at home, in the community, or on the job.

Who monitors people receiving supported living services?

The regional center monitors the delivery of services and, sometimes, volunteers trained by the local Area Board also monitor supported living services.

Important Questions to Ask Staff About Supported Living

1. Can persons select their own roommate?
2. Are any individuals living in a home or condominium they own?
3. How many persons served live without a roommate?
4. On the average, how many hours each week do individual residents spend in community activities outside of day programming or employment?

5. At what point is a person-centered plan developed with the resident?
6. How many persons have paying jobs in the community?
7. To what extent are persons helped by unpaid circles of support including family, friends and neighbors?
8. How does the agency insure prompt response to emergencies and generally promote the health and safety of residents?

Also, you may use the list of Quality Life Outcomes, at the beginning of this booklet, as a guide to evaluate the living arrangement you are visiting.

Examples of Service Outcomes in Supported Living Services

A person will be able to:

1. Use a cellular telephone to reach a list of emergency telephone numbers.
2. Learn how to operate an electric wheelchair.
3. Call a friend once a week to plan and carry out a social outing in the community.
4. Save enough money for an overnight vacation trip.
5. Live within a budget.
6. Train a personal attendant to carry-out responsibilities.

Listing of Agencies Providing Supported Living Services

See your service coordinator for the current list of service providers in the Tri-Counties.