TCRC

Consumer Guide
Family Support

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.

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Director of Training and Information
December 18, 1995

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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 Family Support Services

The Lanterman Act gives high priority to supports and services to strengthen families. Family support is often defined as "whatever it takes" to increase the family's ability to care for their child, improve the quality of the family's life and prevent a son or daughter from having to live outside his or her natural home. The ARC Family Support project recently stated what the goals of good family support should be, along with the outcomes to look for. They are worth repeating here and keeping in mind as you study this Guide.

The goals of family support should be:

- To keep families together (by providing whatever it takes until the person with a disability desires to or is able to live independently).
- To improve the care giving ability of families and to improve their ability to meet the many needs of a family with a disability.
- To respect cultural, economic, social and spiritual differences.
- To help families find and use available supports.

And, you know you are receiving good family supports when:

- You have time to work if you wish, spend time with other family members or take part in leisure activities.
- It is easier caring for your family member with a disability at home.
- Your family's emotional and physical well-being increases.
- Your family is able to use its money as other people do.
- Your family has better access to community services such as doctors, dentists and recreation and you are more visible in your community.

What should all of these considerations lead to? The Lanterman Act is clear about that as well It requires, for every child with a developmental disability, a special section of the IPP with goals, objectives and activities targeting family support.

To help you judge your satisfaction with family support services, this Guide includes a copy of the ARC Family Support Quality Checklist. In the Glossary of Terms which follows, the definition of Supports and Services is taken directly from the Lanterman Act. It is comprehensive, yet not fully inclusive. For this Guide, we have selected three family support services to present in greater detail: infant development programs, respite, and behavior intervention services. We hope you find the information useful.

The ARC Family Support Quality Checklist

The ARC, as part of a project through the Minnesota Governor's Planning Council on Developmental Services , brought together parents, professionals and other experts on family support to discuss and develop questions to help families know if they are receiving good quality family supports. With their permission, we are printing a selection of those questions, adapting them as appropriate. We believe they are valuable as an evaluation tool, whatever the family support service being considered.

Information and Planning

- Does the regional center offer many different services, supports and equipment to assist your family member?
- Are you given a choice of service providers?
- Is the information you receive about support service providers current and reliable?

Service Availability

- Can you get family supports when needed (e.g., can you make contact or receive supports 24 hours a day)?
- Are good quality services available regardless of where you live?
- Does the family support service encourage the use of natural supports (i.e., neighbors, friends, relatives, community volunteers, etc.)?
- Can you get supports that meet your family's unique needs which include cultural, language and ethnic background?
- Does your family support program provide services during a crisis?
- Are you urged to contact and meet with other parents (parent-to-parent networking)?

Staffing

- Do providers carefully and clearly explain their services?
- Are providers sensitive to and respectful of:
  --your culture and lifestyle?
  --your verbal skills?
  --your family's needs and preferences?
- Do providers keep their promises about supports and services?

Program Values

- Does the support provider share ideas and beliefs about families/family supports?
- Does your support service build on your family's strengths and abilities?
- Does the family support service offer services that are not forced on your family?
- Does your support give you hope for the future and raise your expectations?

- Do you feel helped by the supports, not hurt by them?
- Does the support service make the public aware of the abilities of people with disabilities?

Glossary of Terms

Circle of Support--means a committed group of community members, which may include family members, meeting regularly with an individual with developmental disabilities in order to share experiences, promote autonomy and community involvement, and assist the individual in establishing and maintaining natural supports.

Family Support Services--means services and supports that are provided to a child with developmental disabilities or his or her family and that contributes to the ability of the family to reside together.

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 community; associations with fellow students or employees in regular classrooms or workplaces; and associations developed through participation in clubs, organizations and other civic activities.

Services and Supports--may include but are not limited to diagnosis, evaluation, treatment, personal care, day care, domiciliary care, special living arrangements, physical, occupational, and speech therapy, training, education, supported and sheltered employment, mental health services, recreation, counseling of the individual with a developmental disability and his or her family, protective and other social services and sociolegal services, information and referral services, follow-along services, adaptive equipment and supplies, advocacy assistance, including self-advocacy training, facilitation and peer advocates, assessment; assistance in locating a home; child care; behavior training and behavior modification programs; camping; community integration services; community support; habilitation; homemaker services; infant stimulation; paid roommates; paid neighbors; respite; short term assistance; travel training; training for parents with developmental disablitities; vouchers; and transportation services necessary to ensure delivery of services to persons with developmental disabilities.

Voucher--means any authorized alternative form of service delivery in which the consumer or family members are provided with a payment, coupon, chit, or other form of authorization which enables the consumer or family members to choose his or her own service providers.

Infant Development Programs
What Do They do?

Infant development programs, often referred to as Early Start, serve children under age three. Program staff review assessment information and then, depending on an individual child's needs, provide early intervention activities to encourage growth in:

- Physical development (which includes vision, hearing , and health status).
- Cognitive development.
- Communication development (which includes language and speech).
- Social or emotional development.
- Adaptive development.

An equally important feature of infant development programs is the opportunity for parents and other care givers to learn valuable skills including the ability to better understand and respond to their child's needs. Through day-to-day activities such as bathing, dressing and feeding, the parent-child relationship is strengthened. Parents also learn how to use appropriate educational equipment, materials and play to encourage their child's development. Last but not least, parents help and support each other by sharing their ideas and experiences.

What is an Individualized family Service Plan (IFSP)?

Public Law 102-119 requires that an Individualized Family Service Plan (an IFSP) be established for each infant from birth to age 3 and for the infant's family. One reason for considering the family as a unit is to provide services and supports which take into account the child's environment including the persons who interact with the child on a daily basis. That is why the IFSP must include a statement of the family's concerns, priorities, and resources. The purpose is strengthen the family's ability to nurture and encourage a child with a disability as well as to successfully cope with family stresses.

Commonly Asked Questions
About Infant Development Programs

How often do I attend an Infant Development Program with my child?

Infant Development Programs typically tailor their services to meet the needs of families, therefore schedules may vary. Some therapies or specialist services occur right in the family home. Other times, they are provided at a central location.

What kind of information should I expect from program staff and specialists?

You should expect a great deal including information about your child's condition or disability or about how to handle your child's behavior or about how children grow and develop.

How might an Infant Development Program handle my family's need for support?

One way would be to discuss who you might feel comfortable talking to about your concerns, people such as a family member or a friend or another parent of a disabled child. These are sometimes referred to as natural supports. Other sources of help include your child's teacher or therapist, a professional counselor or clergyman, a regional center service coordinatior or other representative.

What other kinds of help can I expect from the Infant Development Center?

You can expect help in how to explain your child's condition to people such as other children in your family, your parents, your friends and neighbors, even strangers who stop you and ask questions. Another kind of help deals with ways families can support each other better during difficult times by discussing problems without getting angry or deciding who will do household chores, child care, or other family tasks without overburdening one person too much.

Important Questions to Ask Staff at Infant Development Programs

1. What kinds of assessment can I expect for my child, how is that decided, and who will do it?

2. Are there any early intervention services that might help my child or family which haven't been discussed with me?

3. When will my planning team discuss transition of my child to a public school educational program and other possible supports and services?

4 What do I do if I want to make a change in our IFSP or I have a complaint abut the supports and services I am receiving?

5. What kinds of informative written or audio-visual materials do you have which I can take home to share with other family members?

6. How will I really know my child is making progress?

7. Do you have a lending library of educational toys I can take home to use with my child?

Examples of Service Outcomes at Infant Development Programs

1. Katie will crawl using a hand/knee pattern for a distance of three feet when placed in the correct position and when a toy is put in front of her.
2. James will be able to make friends with other children in the neighborhood.
3. Family members will be able to know what Jose wants when he cries or makes noises.
4. Joy will go on family outings with her family once a week for three months.
5. Larry will communicate his needs and wants during meals by looking at a picture of "drink" or "food" to indicate what he wants.
6. Katie will play during free time with a minimum of three toys for a 10 minute period.

What Are Family Resource Centers?

Family Resource Centers provide information, education and support for parents of children three years and under. There are three Family Resource Centers in the Tri-Counties:

Parents Helping Parents
1160 Marsh Street, #202
San Luis Obispo, CA 93401
Tel. 549-8148

Family First Resource Center
P.O. Box 91859
Santa Barbara, CA 93190
Tel. 683-2145

Rainbow Family Resource Center
500 Esplanade, Suite 500
Oxnard, CA 93030
Tel. 485-9643.

What Are Respite Services?

Respite is typically defined as either in-home or out-of home:

In-Home Respite services--means temporary non-medical care and supervision provided by a service agency in the consumer's own home to do all of the following:

- Help family members in maintaining the person at home.
- Provide appropriate care and supervision to protect the person's safety in the absence of family members.
- Relieve family members from the constantly demanding responsibility of caring for a person with a developmental disability.
- Attend to the person's basic self-help needs and other activities of daily living, including socialization, and continuation of usual daily routines which would ordinarily be performed by the family member.

In-home Respite Services/Family Member--means that a family member selects, assigns, and monitors an individual who possess the skill, training or education necessary to provide non-medical in-home respite services for the person with a developmental disability

Out-of Home Respite Services --means temporary medical or non-medical care in a regional center vendored residential facility licensed by either the Department of Social Services or the Department of Health Services and which:

- Are designed to relieve families of the constant responsibility of caring for a member of that family who has a developmental disability.
- Meet planned emergency needs.
- Are used to allow parents or the individual an opportunity for vacations and other necessities or activities of family life.
- Are provided to individuals away from their residence.

Commonly Asked Questions About Respite Services

How much training do in-home respite service agencies give their respite workers?

This is a good question to ask the agency. All workers have received training which includes Cardiopulmonary Resuscitation (CPR). However, what is provided varies so it is a good idea for families to give a thorough orientation of their own which focuses on the needs and preferences of the person with a disability. Leaving a list of your son or daughter's likes and dislikes as well as usual routines is also advisable.

Do I have a choice of who the respite worker is who is sent to my home?

Agencies try to offer this choice but it may not always be possible because the worker is unavailable at the time needed.

Is it possible to receive in-home overnight respite services?

Yes, this is possible.

If I decide to choose my own respite worker, such as a neighbor, who pays that person?

You are responsible for paying the person, however the regional center will reimburse you up to an approved hourly rate, upon receipt of a time sheet. The regional center will give you a fact sheet with further details about other responsibilities you have when you employ your own respite workers.

How difficult is it to find an out-of-home respite living arrangement for my son or daughter?

Usually, it's quite difficult because first, an appropriate licensed home must be found as close to where you live as possible, and second, the home must have a vacancy. Some licensed homes are strictly for respite, or set aside several beds for this purpose, however the majority do not specialize in respite care.

What is the advantage of in-home respite services?

The advantage is that the person with a disability can remain in familiar surroundings and continue his or her usual daily routines.

What Are Behavior Management Services?

Behavior management services uses specialized approaches to teach consumers positive social and adaptive skills when unacceptable behaviors threaten the person's ability to get along successfully at home, at work, at school, or in the community. The service begins with a thorough behavioral assessment. While a specialist may interact directly with the individual to improve problem behavior, another important goal is to train parents or other caregivers how to appropriately manage the behavior on a daily basis using skills they have learned.

Commonly Asked Questions About Behavior Management Services?

Who is qualified to provide behavior management services?

These programs are provided or supervised by a professional (i.e. psychologist, Licensed Clinical Social Worker etc.) whose California licensure permits the design and/or implementation of behavior intervention services.

How long does behavior intervention usually last?

Typically, interventions are short-term and time-limited to meet specific and clearly measurable behavior objectives.

Will a regional center funded behavior interventionist work with my child in the classroom.

No. The regional center considers this to be the responsibility of the public schools and would encourage the need to be discussed at your child's IEP meeting.

What if longer-term behavior intervention is needed?

This should be considered by the planning team. In some situations, longer-term intervention may be needed and will be provided when a parent or other primary care giver is actively involved.

What is behavior intervention parent training?

This type of training teaches how to replace negative self-defeating behavior with more positive, socially acceptable conduct. The training may take place individually or in small groups of parents sharing similar concerns about their children's behavior.

What if more help is needed later on?

The planning team may approve additional hours of service to provide further support, consultation and guidance for parents and other primary care givers.

Examples of Service Outcomes with Behavior Management Services

1. Paul will learn how to appropriately talk to strangers on public busses.

2. Julie will follow her mother's requests at bed time without hitting other family members.
3. Eddie will listen to others without flapping his arms and hands.
4. Mary will learn to thoroughly brush her teeth in five minutes without getting distracted by other activities in the bathroom.
5. Robert will be able to remain living at home because he will no longer destroy property in the house.
6. Ted will ask for help from the manager or clerks in the supermarket instead of losing his temper.