

Family Support

a check for quality



A family that has a son or daughter with mental retardation or other disabilities may have needs above and beyond those of other families. These needs can often be met by family support programs and services provided by state, local, not-for-profit or for-profit agencies. Family supports vary in type and quality from state-to-state and even between and within local communities.

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 with a disability from having to live outside his or her natural home. Some examples of family supports are:

- ✓ Respite and child care
- ✓ Changes to the family's home or car
- ✓ Support services (counseling for families, parent-to-parent support, self-help groups, sibling groups, etc.)
- ✓ In-home assistance (to help with the personal needs of the individual with a disability, to assist with household chores, etc.)
- ✓ Personal futures planning for the whole family
- ✓ Financial or other types of assistance to meet needs that may arise when a family member has a disability
- ✓ Education and training for families to help them develop skills to meet the needs of the family member with a disability. This may include providing the family with disability information and/or advocacy training
- ✓ Information for families about all available resources
- ✓ Service coordination/case management
- ✓ Recreation
- ✓ Assistance with programs that provide services
- ✓ Crisis intervention

- ✓ Special clothing
- ✓ Transportation to and from services
- ✓ Medical and dental services
- ✓ Testing
- ✓ Behavior intervention
- ✓ Any other support needed by the family

The goals of good 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 caregiving ability of families and to improve their ability to meet the many needs of the family member 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.

**The
Arc**

*a national
organization on
mental retardation*

Family Support Quality Checklist

Having many different family support services and programs is important. But it's also important to have good quality family supports. For this reason, The Arc, as part of a project through the Minnesota Governor's Planning Council on Developmental Disabilities, brought together parents, professionals and other experts on family support to discuss and develop the questions below to help families know if they are receiving good quality family supports.

How will this checklist help your family? Look at the questions below and think about the family supports your family receives. Then check if your family supports **Always**, **Sometimes** or **Never** meet these signs of good quality. Checking **Always** to each question shows a high quality of services and programs. However, a lot of **Never** checks means that your family supports need improvement. And even family supports that **Sometimes** meet these signs of quality may need to improve.

Join with The Arc and other disability groups to advocate for good quality family supports. Share this information with other families, local service providers and government officials in your community!

Information and Planning

	ALWAYS	SOMETIMES	NEVER
■ Do you feel information is easily available in order to seek support?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Is the paperwork to receive family support services simple to understand and fill out (e.g., easy to read, short application form, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Is the family urged to be part of the planning for support services?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Does the family support service offer many different services, supports and equipment to assist your family member?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Are you given a choice of service providers?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Is the information you receive from support service providers current and reliable?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ When a meeting of support providers is necessary, do you help decide who will attend the meeting and when it will be held?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Does the family support program advertise its services in different languages and formats (e.g., easy-to-read for people who cannot read, Braille for people who are blind, etc)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Service Availability

■ Can you get family supports when needed (e.g., can you make contact or receive supports 24 hours a day)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Can you get to where the supports are provided or can the support services come to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Are services accessible (i.e., are people with mental and physical disabilities able to get to and use the services)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Are good quality services available regardless of where you live?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Does the program obtain hard-to-find services for the family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Does the family support service encourage the use of natural supports (i.e., neighbors, friends, relatives, community volunteers, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Can you get services whether or not the family can pay for them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Do you qualify for services based on your family member's disability and not just on your income?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Can you get more services even if you are already receiving some family supports?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	ALWAYS	SOMETIMES	NEVER
■ If you are getting vouchers or cash payments for services, does the program allow you to buy the service from a provider of your choice?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Does the program give the services at no or very low cost and not require you to spend a lot of money to match or share the costs of services?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Is the family support service available without causing the loss of other necessary family resources (e.g., income assistance, health benefits, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Can you get supports that meet your family's unique needs which include cultural, language and ethnic background?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Does your family support program provide services during a crisis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Are you urged to contact and meet with other parents (parent-to-parent networking)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Is advocacy skills training given (or available) for the entire family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Staffing

■ Is there a single contact person to help you obtain services for your family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Are the supports provided by good staff who know about services and how to work with people with disabilities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Does your service coordinator or case manager:			
- accept and consider your ideas?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- act sincere and respectful toward you; and not judge you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- treat you like a partner instead of a "client"?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- pay full attention during appointments and meetings?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- show interest in what you think and say?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- respond to your concerns?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- stand up for your family and not the service system?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- arrange other services when necessary?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Do providers carefully and clearly explain their services?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ When the service providers come to your home, are they invited by you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Are providers sensitive to and respectful of:			
- your culture and lifestyle?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- your verbal skills?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
- your family's needs and preferences?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Do providers keep their promises about supports and services?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Program Values

■ Does the support provider share ideas and beliefs about families/family supports?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Does your support service build on your family's strengths and abilities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Does the family support service offer services that are not forced on your family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Does your support give you hope for the future and raise your expectations?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Do you feel helped by the supports, not hurt by them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
■ Does the support service make the public aware of the abilities of people with disabilities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Tips for Working with Family Supports

- ✓ *Be informed about your rights.*
- ✓ *Think through both what you need and what you want before meeting with potential service providers.*
- ✓ *Be persistent and firm about what you need and want.*
- ✓ *Bring along a friend when you meet with family support service providers. Another person can help provide the emotional support you may need. You can also enlist support from family members or your local chapter of The Arc.*
- ✓ *Advocate for family support providers. They may need consumers like you to push for funding, changes in regulations, etc.*
- ✓ *Let providers know when they've been helpful to you.*
- ✓ *Take notes during meetings to ensure there are no misunderstandings later.*
- ✓ *Keep records, duplicate copies of forms, etc. from your family support services.*

♦ ♦ ♦

For more information on family support, contact:

**Family Support Project
The Arc**

**National Headquarters
P.O. Box 1047
Arlington, Texas 76004**

Voice 1-800-433-5255

**TDD 1-800-855-1155 (ask operator to call
collect 817-277-0553)**

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Family Support Forum Participants

In August of 1992, The Arc convened a consensus forum to develop the information for this Family Support Quality Checklist. The group consisted of consumers, family members and professionals including:

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