

CMS Person-centered Planning Project

Guide for Supporting Caregivers Resources for Assessing Caregiver Stress

Purpose: To bring awareness to the unique role family caregivers have in the lives of people with developmental disabilities, individuals with mental illness, and persons with co-occurring or dual diagnoses.

How to Use This Resource: This guide is intended to serve as an additional, optional resource to existing service planning tools that are required by either the Division of Developmental Disabilities or the Division of Comprehensive Psychiatric Services. Service providers may use this information to help support and sustain family caregivers. Information from this may be shared with family caregivers when deemed appropriate and necessary. It is important for professionals to do their best to develop effective working relationships with family caregivers before sharing any of this information or to suggest that they complete a stress self-assessment.

“You will never change your life until you change something you do daily. The secret of your success is found in your daily routine.” – John C. Maxwell

Introduction

“All people need enduring, stable family and community relationships. All families need support at times in their lives to maintain these lasting relationships. Individual and family support must assist across the lifespan, supporting the child within the family and the individual reaching independence. This assistance builds on natural sources of support including extended families, friends, neighbors and community associations. The way support is provided is a reflection of what we believe about individuals and families, a way of thinking about individuals and a way of engaging with individuals and families” (Oklahoma Family Support Partnership Council, 2004).

Families are often the primary caregivers of children and adults with disabling conditions. Their role and participation in the development of a person-centered individual plan is critical. Family members are important sources of information and knowledge about their loved one including history, interests, needs and other essential details. At the same time, the physical and emotional support of family members serves a vital role in each person’s wellbeing and in achieving the goals of their individual plan.

“If one component of successful rehabilitation and recovery [from mental illness or addiction] is the individual’s increasing reliance on natural supports and decreasing dependence on professional services, the importance of family as a primary source of support cannot be underestimated” (Adams & Grieder, 2005, pg. 29).

Caregivers have unique support needs which need to be considered in the person-centered planning process. The following are some universal guidelines for plan facilitators, service coordinators, and case managers to consider:

Strategies to Support the Family Caregiver

“It is your duty to find yourself.” – John C. Maxwell

#1. Emphasize Self-Care

Only when people take care of themselves first can they effectively help others. Self-care is one of the most important – and one of the most often forgotten – things caregivers do. When a caregiver’s needs are taken care of, the person receiving care will benefit, too. Research has shown that caregivers have a risk of dying that is approximately 60% higher than that of people of the same age who are not caregivers. Regardless of age, sex, and race and ethnicity, caregivers report problems attending to their own health and well-being while managing caregiving responsibilities. They typically report:

- Sleep deprivation
- Poor eating habits
- Failure to exercise
- Failure to stay in bed when ill
- Postponement of or failure to make medical appointments (Family Caregiver Alliance website: www.caregiver.org)

Family caregivers are also at increased risk for excessive use of alcohol, tobacco and other drugs and for depression. Caregiving can be an emotional roller coaster. On one hand, caring for a family member demonstrates love and commitment and can be a very rewarding personal experience. On the other hand, exhaustion, worry, inadequate resources and continuous care demands are very stressful. Studies show that an estimated 46 to 59% of caregivers are clinically depressed (Family Caregiver Alliance website: www.caregiver.org).

Suggestions:

- Annual check-ups and immunizations (flu shots, tetanus boosters, etc...)
- Doctors need to know that a person is a caregiver – this will help them monitor signs and symptoms of stress
- Time each day, even for a few minutes, to do something for themselves
- Healthy eating habits and daily exercise
- Caregiver resources and support groups
- Reassurance that it’s OK to ask for help
- Recognize signs of stress and take action to reduce it and gain a sense of control

#2. Help Caregivers Set Goals

Setting realistic goals or deciding what needs to be accomplished during a set time period is an important self-care tool. Goals can sometimes be too big to work on all at once. It is more effective to break a goal into smaller action steps that can be easily accomplished. Creating an action plan can help a person decide how to proceed.

Suggestions:

Help caregivers identify realistic goals; for example “Take a break from caregiving” or “get more assistance with caregiving tasks”. Then assist with action steps to find resources to help them attain this goal.

#3. Seeking Solutions

Seeking solutions to difficult situations is one of the most important tools in caregiving. Once a problem has been identified, taking action to solve it can change the situation and also change negative attitudes to more positive ones, giving caregivers more confidence and helping their self-esteem.

Suggestions:

- Assist them in identifying problems and encourage an open mind when examining situations. The real problem might not be what first comes to mind. For example, they might think that the problem is that they are tired all the time, when the more basic difficulty is their belief that “no one can care for their loved one like they can.” The real problem is thinking that they have to do everything themselves.
- Help them make a list of possible solutions and to try different perspective from their current way of doing things or thinking about things. Select one solution from the list and then try it.
- Encourage them to keep trying and to not give up. The old adage of “taking one day at a time” holds true. Another adage “where there is a will, there is a way” is also very relevant.

#4. Effective Communication

This is one of the most important tools for professionals or for caregivers. Clear, assertive, and constructive communication will help everyone be heard and get needed help and support.

Suggestions that may be shared with caregivers when appropriate:

- Express feelings without blaming others or causing them to become defensive. Using “I” messages is more effective than “you” messages. For example, “I feel frustrated” rather than “You frustrate me.”
- Respect the rights and feelings of others. Acknowledge and realize that other people have the right to express their feelings.
- Speak directly to the person—be clear and specific. This will enhance the chances of reaching an understanding with others.
- Be a good listener!

***All You Can**
Do all the good you can,
By all the means you can,
In all the days you can,
In all the places you can,
At all the times you can,
To all the people you can,
As long as ever you can.
-John Wesley*

#5. Seeking out and Asking for Help

Many caregivers are reluctant to ask for assistance or do not know how to gracefully accept the goodwill of others. Some feel that this is a sign that they can't handle things themselves or feel guilty about it. Help can come from a variety of sources including natural supports like other family members, neighbors, and friends. It's important for caregivers NOT to wait until they are exhausted or until they develop health problems from the stress of caregiving. Reinforce the fact that asking for help is actually a sign of personal strength.

Suggestions:

- Help caregivers prepare a list of ways that others could help. Simple things can make a big difference. Examples could be: a neighbor picking up a few things for them at the grocery store, a friend or family member taking the person they care for on a 15 minute walk twice a week.
- After the list is made, break the jobs or requests down into simple steps or tasks. This will make it easier to ask others or for them to want to help. Let the helper choose what they would like to do.
- Try not to ask the same person over and over again. Spread requests out so no one gets "burned out."
- Try not to take it personally when requests are turned down. The person is turning down the request, not the caregiver. Ask again, the person who refused today may be happy to help at another time.

Summary

Remember to reassure caregivers that it is not selfish to focus on their own needs and desires. Emphasize that it is an important and necessary part of the job. Encourage them to do a "caregiver self-assessment" to gauge their level of stress. The focus should be on the following self-care practices:

- Learn and use stress-reduction techniques
- Attend to personal healthcare needs
- Get adequate rest and nutrition
- Exercise on a regular basis
- Take time off without feeling guilty
- Find pleasant and fun activities to do
- Seek and accept the support of others
- Seek counseling or support groups
- Identify and acknowledge feelings and emotions
- Try to change the negative ways that situations are viewed
- Set realistic goals

"Everybody can be great...
Because anybody can serve...
You don't have to have a college degree to serve.
You don't have to make your subject and verb agree to serve.
You only need a heart full of grace.
A soul generated by love." – Martin Luther King, Jr.

Web Resources for Assessing Caregiver Stress (Service providers may need to provide printed copies for families who do not have computer access)

Oklahoma Family Support Partnership Council, Center for Learning and Leadership/UCEDD – useful handbook on Principles to Practice Indicators that can be downloaded or ordered.

<http://www.ouhsc.edu/thecenter/products/oifsp2pi.html>

Caregiver Stress Self-Assessment (Dr. Steven Zarit, modified version)

www.mass.gov/Eelders/docs/caregiver_stress_self_assessment.rtf

American Medical Association – Caregiver Self-Assessment (English and Spanish Versions)

www.ama-assn.org/.../caregiver.../caregiver-self-assessment.shtml

Full Circle of Care Caregiver Website – includes Caregiver Burden Inventory

<http://www.fullcirclecare.org/caregiverissues/health/stress.html>

Caregiver Stress – The Impact of Caregiving Too Much – includes articles, questions to ask, helpful videos, and links to other resources

<http://www.squidoo.com/CaregiverStress>

References

Adams, N. & Grieder, D. (2005). Treatment Planning for Person-Centered Care: The Road to Mental Health and Addiction Recovery. San Diego, CA: Elsevier Academic Press.

Family Caregiver Alliance (www.caregiver.org)

Oklahoma Family Support Partnership Council (2004). Oklahoma Individual and Family Support Principles to Practice Indicators. Oklahoma City: Center for Learning and Leadership/UCEDD, College of Medicine, University of Oklahoma Health Sciences.

Maxwell, J. (2001). Success One Day At A Time. Nashville, TN: Thomas Nelson, Inc.