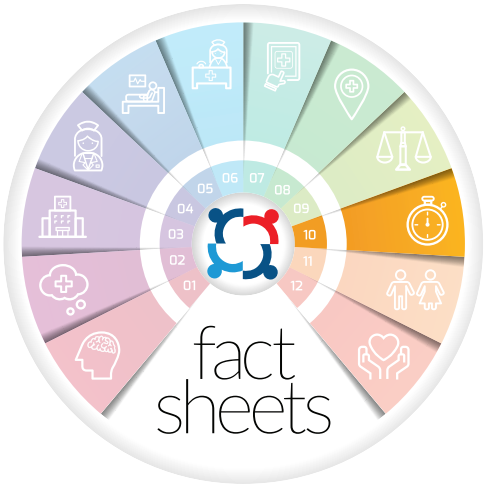
circle OF CARE



10: Planning for the Future

Introduction

Caring for someone with a mental health condition can be a lifelong journey. There is a growing population of older caregivers providing support to people with mental illness, most often parents who care for adult sons or daughters over extended periods. As these families age they face unique needs and challenges in planning for a future time when the primary caregiver passes away or can no longer continue providing care due to their own age-related needs.

If you are in this situation, you are not alone. About a quarter of caregivers in a national study of caregivers of adults with mental health conditions were 65 and older.[39] Among aging parents of adult children, most said their son or daughter was financially dependent on family and friends (64%). Less than a third (32%), however, reported having future plans in place. Only 35% said their care recipient could rely on other friends and family to help.

Uncertainty about the future is a constant source of stress for older caregivers, as well as the person with mental illness and other family members. Lack of planning can result in abrupt and traumatic transitions, sudden loss of critical support, and legal and financial difficulties. Planning cannot guarantee the future, but it can relieve stress and enhance the likelihood of positive outcomes for people with mental illness.

What Is Future Planning?

Future planning involves identifying hopes and concerns about the future of the care recipient and making arrangements to achieve the desired outcomes. It is best to think of it as an ongoing process:

- ***Planning should be person-centered.*** Plans should be primarily driven by the goals and desires of the person you care for, keeping in mind that people may outlive their parents by decades. Although transitions are challenging, this period of life can be a time of new opportunities and growth. It is a time to envision what the ideal future will look like and begin putting support in place.
- ***Planning should involve other family, friends, and circles of support*** In particular, it is important to include siblings in planning if possible. Studies

[39] National Alliance for Caregiving (February, 2016). *On Pins & Needles: Caregivers of Adults with Mental Illness.*

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have found that siblings are most likely to take over as primary caregivers when parents are no longer able to provide care.[40] Unfortunately, although many parents report that they hope this will happen, they seldom have conversations with siblings of the care recipient in advance to ensure they are willing, and prepared, to assume this role.

- ***Planning is not a one-time event.*** Planning is not easy, it cannot be completed overnight, and there is no cookie-cutter approach. Even the best plans need to be revisited on an ongoing basis as circumstances change, but it is important to take steps forward.

What Planning Is Needed?

Planning will vary based on the unique circumstances of each family. In general, major issues you should think about include:

1) Benefits and Financial Planning

Families frequently face the challenge of planning for the financial security of a person with mental illness. This typically involves researching publicly available benefits. There is a range of benefits that the care recipient may be eligible for but may not be receiving. Moreover, if their household composition or financial status changes in the future, they may become eligible for benefits — particularly benefits based on low-income and assets, referred to as 'means-tested benefits.' Many benefits exist outside of the mental health system — for example, Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Medicaid, Medicare and Medicare Savings Programs (that assist with Medicare cost-sharing and deductibles), Supplemental Nutrition Assistance Program (SNAP), and low-income housing assistance programs.

An older caregiver may also be eligible for benefits from the aging service system. In particular, a program called the National Family Caregiver Support Program, administered through local area agencies on aging, was recently amended to provide support for older caregivers (age 55 and older) caring for adult relatives with disabilities, including mental illness.

A common challenge that families of people with mental illness face is how to leave financial assets to their family without jeopardizing their eligibility for current or future means-tested government benefits — such as SSI and Medicaid. Fortunately, there are very specific legal and financial tools that can help you avoid jeopardizing the care recipient's eligibility for these programs while ensuring that money is available for their ongoing needs. Below are some common tools that families use. It is important to note, however, that most attorneys and financial planners are not experts in this area. It is critical to seek out knowledgeable professionals who understand disability benefits and have experience in using these tools to ensure they are set up correctly. Tools available include:

- ***Special needs trusts*** A special needs trust is a specific type of trust designed to support people with disabilities, including mental illness. There are certain limits on purchases that can be made with trust funds. In general, they can be used to cover a range of supplemental goods

[40] Hatfield, A.B. & Lefley, H. (2005). Future involvement of siblings in the lives of persons with mental illness. *Community Mental Health Journal, 41(3)*: pp. 327-338.

and services not covered by SSI and Medicaid. For example, special needs trust funds may cover supplemental therapies, assistive technology, transportation, recreational activities, and other support that enhance quality-of-life. Family members (or other third parties) can place money into a special needs trust via gifts, inheritance, or through the proceeds from life insurance. Since finances in the trust do not count as assets, individuals maintain their eligibility for means-tested government benefits.

- ***Pooled trusts***
  Pooled trusts operate in a similar manner to special needs trusts. The difference is that, instead of being established by individuals and families, they are established by non-profit organizations for the purposes of investment. Although the funds placed in a pooled trust are invested collectively, each beneficiary's account remains their own. Depending on the trust, beneficiaries might also receive other services and support from the non-profit agency.

- ***ABLE accounts***
  Achieving a Better Life Experience (ABLE) accounts are special savings accounts that allow people with disabilities to save for disability-related expenses. As with special needs trusts, individuals and family members can make contributions to the account within certain limits. Accounts also allow for a range of disability-related expenses without jeopardizing access to means-tested government benefits. ABLE accounts are modeled after Section 529 college savings plans. Therefore, one advantage over special needs trusts is that money in the ABLE account works as a savings vehicle and grows tax free. Not all people with mental illness, however, will qualify. Individuals must have a significant disability with an onset that occurred before the age of 26.

2) Residential Planning

Among parents of adults with mental illness, most lived within 20 minutes of their son or daughter (74%). Almost half of caregivers in a national study said that the person they cared for lived in their household (45%). More than half of the caregivers whose care recipient was financially dependent on family and friends, reported that the care recipient lived in their household (52%).

As a family caregiver, it is important to plan where the care recipient will live in the future. Depending on circumstances, you may face questions such as:

- Where does the care recipient desire to live in the future? If they move, will it impact services and support they may be receiving?
- If the care recipient lives in the family home, can that continue? What formal and informal support will need to be put in place to make this happen?
- Will the care recipient reside with another family member, such as a sibling? Have there been any conversations with that person? Is the care recipient willing and prepared for the transition ahead of time?
- Will the care recipient live independently in an apartment, home, or in a

supervised group setting? Has the care recipient or caregiver applied for, or been placed on, a waiting list for low-income housing support or residential support from the mental health system?

3) Support Networks

People with mental illness and family caregivers who have provided care for many years have often cobbled together networks of support, most often informal networks due to inadequacies in the service system. Planning can explore these circles of support and invite others to play key roles in the future to maintain and strengthen them.

Key areas of support that may need to be explored include:

- ***Care coordination***
  More than eight in ten caregivers say they actively manage the health care details of their care recipient, according to a national study of mental health caregivers. They act as default care coordinators – handling finances, paperwork, forms, bills, payments, health insurance, medication management, appointments, and crisis care. They often hold institutional memory about medication, treatment, and medical history — what has worked in the past and what has not. It is important to document this history, identify who will assume greater responsibility in the future, and pass this history on to ensure continuity of care.

- ***Decision-making supports***
  Depending on your personal circumstances, you may already have some form of decision-making supports in place, such as representative payee, powers of attorney, trusteeship, or guardianship. It is important to examine this support and identify individuals who will assume these roles in the future in the event that a caregiver can no longer continue. In addition, legal documents should be re-examined and modified to identify successors.

- ***Instrumental supports***
  Family caregivers frequently provide significant day-to-day support, such as grocery shopping, cooking, housekeeping, laundry, recreation, socialization, and transportation. It is important to identify all the roles you are playing and identify how to continue these roles through other formal and informal support networks.

Taking the First Step

Some families face significant barriers to planning.[41] Some of these include:

- ***Emotional barriers***
  It is difficult for most people to think about their own mortality, but for the caregivers who have spent much of their lives supporting someone with mental illness, it is incredibly emotional to think about a time when they will no longer be there. Who will provide their care? It is also deeply emotional for people with mental illness who may be providing day-to-day and social support to their parents as they age.

- ***Service system barriers***
  The service system is inadequate and sometimes makes planning difficult. In a study of mental health caregivers, respondents reported significant unmet service needs including needs for mental

[41] Hatfield, A.B., & Lefley, H.P. (2000). Helping elderly caregivers plan for the future care of a relative with mental illness. *Psychiatric Rehabilitation Journal, 24:* pp. 103-107.

health professionals, peer support, medical providers, case management, and day programs/treatment. Housing support is often limited and difficult to secure.

- ***Complexity of legal/financial planning*** Legal and financial planning can be extremely complex and can require the assistance of knowledgeable professionals. The financial cost involved in some planning options can also pose barriers. In the words of one parent, however: *"If I don't do it, no one else is going to."*

Connecting with other families in similar situations can be extremely helpful in overcoming some of these barriers.[42] Local chapters of the National Alliance on Mental Illness (NAMI) and other disability advocacy organizations occasionally hold workshops on future planning for families of people with mental illness. They may also be of assistance in local referrals to legal and financial planning experts.

Another step that has been helpful for some families is the development of what is called a 'Letter of Intent.' A letter of intent is not a legal document. It doesn't cost money or require going to legal and financial professionals. It is a person-centered planning tool intended to start a discussion. It helps families document their family history, begin discussions within the family and circles of support, envision dreams for the future, and begin identifying goals to ensure support is in place. The first step is the hardest: starting with a letter of intent can help some families begin the process.

Helpful Websites

BenefitsCheckUp
A free resource that can help individuals identify benefits they may be eligible for in their local community and nationally. Available at: www.benefitscheckup.org

Eldercare Locator
Find your local area agency on aging and supports and services available for older individuals, including family caregiver support: www.eldercare.gov

Legal and Financial Planning Resources
Special Needs Alliance: www.specialneedsalliance.org
National Academy of Elder Law Attorneys: www.naela.org
ABLE National Resource Center: www.ablenrc.org

National Alliance on Mental Illness (NAMI)
Find a local chapter: www.nami.org/local

The Arc's Center for Future Planning
A website designed to assist families of people with intellectual and developmental disabilities with future planning. However, it includes tools (including an interactive, online letter of intent tool) that may also be of assistance to families who care for someone with mental illness. Available at: futureplanning.thearc.org

[42] Heller, T. & Caldwell, J. (2006). Supporting adults with developmental disabilities and aging caregivers in future planning. *Intellectual and Developmental Disabilities, 44*: pp. 189-202.