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# ASPN

## *Adult Services Practice Notes*

Produced under contract with the Adult Services Branch, Division of Social Services, NC Department of Health and Human Services

by

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*The aspen is perhaps the world's largest organism. Although some aspen forests cover acres and seem to be composed of individuals in all stages of life, they share a common root system.*

*ASPN: Adult Services Practice Notes is dedicated to providing information on excellent family-centered social work practice with adults and their families.*

## Growing Older with Developmental Disabilities

### Working with Clients and Their Families to Plan Their Later Years

Your first question may be, "What does this have to do with me? People who have developmental disabilities are supposed to go to the Area Mental Health Program for services." True, but did you know that the Department of Health and Human Services (2000) estimates that of the approximately 140,000 children and adults in North Carolina who have developmental disabilities (DD) only 37,000 are served through formal public services? Because the Area Programs are the single portal of entry for people with DD, as a DSS social worker, you may have limited responsibility for helping these adults locate services in the community. Nonetheless, you may have an important role modeling family-centered case management skills while you help your clients and their family members negotiate service systems.

For this issue, we looked at the literature and consulted a local expert. Colleen Kilsheimer knows both sides of the desk, when it comes to social work and advocating for services for people with developmental disabilities. A native of Shelby, NC, graduate of UNC-Chapel Hill and of the Richmond (Va.) School of Social Work, she and her family have lived across the country from California to Florida. When they returned to North Carolina, she worked full-time for seven years at Durham DSS in children's services, primarily with children with disabilities in foster care. At age 65, she scaled back her schedule to half time for a few years. She also raised five children and so gained a personal appreciation for the challenges that face families with children with disabilities, particularly as they age. Her second child, Stephen, now 42 years old, has Down syndrome. She and her husband Joe, and Stephen himself, are active participants in the ARC of Durham County, the local Association of Retarded Citizens and their parents. Colleen and her family have helped Stephen negotiate the transition from living with them to living in his own apartment. Some of her many insights appear here to illustrate what we learned from the current literature.

### The Boom is Coming

One effect of the boom in babies between 1946 and 1964 was a similar increase the number of people with developmental disabilities. Heller and Factor (2000) estimate that in the US there are currently 526,000 adults with DD who are 60 or older, and they predict that in the next 30 years, this number will almost double. The oldest boomers are 54 this year, while the youngest are 37. Their parents are likely to be in their 70s or 80s, although people with Down syndrome, who often are the children of older parents, may be living with siblings who are 20 or more years older than they are, after their parents' death. As you work with clients in their 70s and 80s, you may discover many of the "hidden" adults with DD who are the children or siblings of your clients. According to Heller and Factor (2000), "families continue to be the primary providers of care. An estimated 60 percent of individuals with mental retardation live at home. In 25 percent of these households, the family

## A Place in the Community for Stephen

*Colleen Kilsheimer told us about their efforts to help Stephen move into the community. "We first started looking for a place about six years ago. Because we are getting older, we felt we needed to help him separate from us. I didn't want him to end up in one room looking at one TV. At first he lived in a group home, but that wasn't the best place for him. Because there are usually two caregivers to four or five residents, often if one resident doesn't want to do something, none get to do it. Because Stephen is so very active, I didn't want him limited in that way."*

*Three years ago, they worked with other parents at the ARC of Durham County to develop Stephen's current living arrangement. "We moved a lot when he was little, and I didn't understand how hard it was for him. He has told me that Durham is his home and he doesn't want to move from here. He's sharing an apartment now with two other men with disabilities. One of his apartment mates has moderate autism and the other has cerebral palsy. Of the three, Stephen has the most intellectual impairment, but physically, he is the strongest. The three of them get along very well. All are capable of doing routine things. They don't need help with their personal care, and they can go to the store and fix a meal. Stephen is good at housekeeping. With three younger siblings, he had to learn how to do it. Stephen goes to work every day—he is a maintenance assistant. He's involved in many activities—swimming and Special Olympics—and we spend a lot of time getting him to those activities."*

caregiver was age 60 or older and the average age of the member with a disability was 38. . . . Older families become less able to provide care as parents and siblings deal with their own aging, careers, and other caregiving responsibilities."

## Supporting Older Caregivers

North Carolina serves people with DD through the Area Programs, state mental retardation centers, private providers, and community Intermediate Care Facilities for the Mentally Retarded (ICF-MR) homes. Additionally, people with DD who qualify for ICF-MR can be served through the CAP-MR/DD program (DHHS 2000), which provides services in the community. Because the Area Programs are the single portal of entry, Colleen told us that it is very important that families register with them for services, even though they might not have done so before. "Registering is the main way the state has to determine the need," she said. DHHS estimates that this fiscal year there are about as many "slots" available in the CAP-MR/DD program as there are people on the waiting list (about 6,500 for each), and that the wait for some kinds of services may be more than two years. Another strategy, however, may be to look into supports through the Home and Community Care Block Grant. Current rules permit some in-home services for people who are 60 or older to support them as caregivers, regardless of the age of the person for whom they are caring.

## Helping Plan for a Transition

Because so many people with DD live with older caregivers, one issue that pervades the literature on the subject is whether and to what extent older parents plan for the future of their adult children with DD. Alan Factor (2000) estimates that only one-third to one half of families do plan. Christine Bigby (2000) found that only five percent of her sample had made no plans, but she estimated that about a quarter of parents had made only "implicit" plans—that is, they had thought about what they would like to happen but they hadn't discussed the plans with the person they hoped would take over. She notes, though, that that person was often aware of their expectations. Only 15 percent of her sample had not only discussed the plan with the person they expected to take over care, but had made residential and financial arrangements.

Factor (2000) mentions several reasons why parents find it difficult to plan. First, it is "an overwhelming and emotionally laden process because older parents must confront their own mortality." Second, the shortage of residential services or the lack of fit between what is available and what the adult with DD needs can be discouraging. The Kilsheimers, for example, had to work out a unique arrangement for Stephen (see the sidebar). And finally, although parents often prefer that a sibling take over, many are reluctant to ask them to do so.

For social workers whose clients care for adults with DD, patient, but persistent, support for planning may be key. In a very practical review of this issue, Alan Factor (2000) proposes some guidelines that will sound familiar to social workers who are family-centered in their practice. To summarize them briefly, the first is starting "where the client is at," with the client and family's values. He points out that it is also important to recognize that these families may have been traumatized by their earlier contact with "the system," and that they have considerable strengths that have allowed them to keep their children at home. Other family members may be anxious or ambivalent about taking over from parents, and professionals should address these feelings. It may require small, manageable steps to begin planning, and it may take some families a long time to become ready for this task.

The Kilsheimers' involvement in the ARC of Durham County also could be an important model for other families with the same concerns. Beyond advocacy

### Some Points to Keep in Mind

1. Families differ widely by cultural background in their ideas about developmental disability, family responsibilities, and acceptability of services provided by outsiders, and these may be different from their attitudes about aging.
2. Although Bigby (2000) found in her study group that relatively few of the transitions were traumatic, it is important to remember that people with DD may need help understanding losses and the time and ways to grieve. They also may need help avoiding losses—extra support for communicating with friends at their workshop after they retire or ways to visit people in their old community if they move away.
3. Even successful transitions can be hard on parents. One study of mothers discovered that the rate of depression after the disabled adult had left the home was about 40 percent (about double the rate for age mates), even three years after the transition (Seltzer 2000). If you are working with a family that has made this transition, watch for the signs.
4. Plans don't last forever. As Bigby discovered, plans that families followed initially often were changed as time went on, sometimes because the person who took over from the parents could not continue or the availability of services changed, but sometimes because the adult with DD was quite successful at living more independently than the plan foresaw. What Colleen would like for Stephen is someone she could rely on to check on him and his apartment mates, not necessarily daily, but once or twice a week. She and the other parents now have an informal arrangement to check for one another when someone is away, but for the future, she would like to have a more formal arrangement in place.
5. Although providing for accommodation in the "least restrictive setting" has figured among the goals of human services providers for a long time, it takes special care for families and social workers to identify how any living arrangement will enable residents' growth or restrict it. Most people with developmental disabilities have interests, preferences, friends, and the ability to learn. When the Kilsheimers planned for Stephen's move to the community, they carefully took into account his activities and preferences and found a place to live that would accommodate them. When he told them that Durham was his home now, they listened.

and service programs, ARCs help parents by offering information and regular support groups. ARC of Durham also sponsors regular meetings and social activities for adults and children with disabilities. Membership may also result in better planning. Christine Bigby notes that "The voluntary parent associations, which established many of the disability day centres, and the staff of those centres . . . had raised planning for the future as an issue for parents by providing information and encouraging consideration of the future. . . . Some associations had also initiated building of hostels or group homes, thus ensuring that parents had concrete options for which to plan" (2000, 77–78). Just as the Kilsheimers have managed to create a situation that better suited Stephen's needs, other parents may find ways to work together to find solutions that aren't in the current array of services.

### Preparing Other Family Members to Be Case Managers

In her study, Bigby notes that most parents have a key person in mind to succeed them as caregiver. "The core element of key person succession plans was the transfer of responsibility for the person's overall wellbeing to one or

more people in their informal support network." Although the specific tasks were often left vague, they "were supervisory and managerial rather than the direct provision of care." She explains that these tasks "involve a myriad of unspecified, idiosyncratic tasks, such as monitoring the quality of services, negotiating with professionals, advocating on behalf of the adult with disability, taking major life decisions, managing finances, and providing affective support such as visits and assuring the celebration of key life events occurred" (2000, pp. 79, 179). In working with your older client, you have the opportunity to model excellent family-centered practice for the rest of the family members, while you demonstrate how to negotiate with the service systems to meet their own needs.

### Switching Systems?

Colleen has become aware of the challenges for people with less severe disabilities who are growing older. "Through my advocacy work, I've become aware of a number of people who have lived in DDA homes for a long time now—often since these homes were first developed 30 years ago—and who are getting near or have even passed age 65. Most continue to work all day in sheltered settings. The rules for DDA homes say they must be out of the home for eight hours a day. Unless something changes in the rules or they find somewhere else to spend those hours, they may have to leave their longtime homes if they need or wish to retire."

While the people she mentions are currently the clients of the Area Programs, when they turn 60, they are eligible for programs that serve older people generally. Some attend senior centers, although Colleen notes that centers may not fit their needs or interests. Some also may be eligible for adult day care programs. As the number of older people with DD grows, you may find more among your clients.

## Some Resources

- The ARC of North Carolina. There are 44 chapters across the state, 10 with websites. To find the nearest to you, see <http://www.arcnc.org/chapters.htm>.
- Bigby, Christine. 2000. *Moving on without parents*. Baltimore: Brookes.
- Factor, A. 2000. Family caregiving for older adults with developmental disabilities. <http://www.asaging.org/networks/nest/max-044.html>.
- Heller, T., and A. Factor. 2000. Older adults with mental retardation and their aging family caregivers. <http://www.uic.edu/orgs/rrtcamr/OlderAdults.html>.
- Seltzer, M. 2000. Aging parents of children with mental retardation (transcripts of a telecourse through the University of Wisconsin). <http://pro.la.wisc.edu/iidd/html/ageparen.html>.
- NC Department of Health and Human Services. 2000. *Serving Persons with Disabilities in Appropriate Settings*: <http://www.dhhs.state.nc.us/docs/draftolmsteadplan-toc.htm>.

## CARES Training Events in 2001–2002

- Adult Services Supervisors' Curriculum** (4 events: modules 1, 4, 5, and 6)
- Applications in Family-Centered Practice** (4 events)
- Effective Counseling in Adult Services** (4 events)
- Effective Social Work Practice in Adult Services** (3 events)
- Geriatric Mental Health** (2 events)
- An Introduction to Aging** (3 events)
- Working with Clients with Severe Mental Illness: The DSS Perspective** (2 events)

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### Next time:

## What the Census Tells Us about Older North Carolinians

### 2000–2001 Training Calendar

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