

Chapter 7 - Barriers

Consumer Issues -

The consumer who has been a nursing home resident for a year or more may have a strong desire to move back to the community. At the same time, however, they may have developed the inability to take the steps required to get it done. It can be very difficult to measure whether a consumer will be independent once they leave the facility. Even the most eager to leave may become fearful and not trust their decisions once they are out of the “safe” nursing home setting. They may have become overly dependent on others and reluctant to accept responsibility, and while they want to work on their independent living skills and become independent, may in reality want others to do all the work for them. The Person-Centered Planning process can show the consumer a way to regain their self-confidence, their independence and to take control of their own life.

History and Family Issues -

The consumer who has made bad choices in the past can use the transition planning process to acquire new skills. A person can't make good decisions if they don't have the facts. Coach the consumer to first resolve issues they are aware of then ask hard questions to uncover any hidden issues and get them resolved as well. Suggest the consumer talk to people whose judgment and character they trust. Finding family members who are reluctant to be involved in the planning

process can indicate personal estrangement and/or burnout from past experience working with the consumer. Work to ensure family members that they are not alone in the process. *Reassure everyone involved that these barriers CAN be overcome, but it will take work and cooperation on everyone's part.*

Systemic Issues -

The following systemic barriers to transition may be encountered:

- A **bias toward nursing home care**. Systems tend to like to put people in nursing homes because it is easier.
- **State Medicaid Agency policies** that prevent people living in nursing homes from receiving assessments to determine eligibility for receiving services in the community.
- Limited **access to waiver slots**.
- Limited or no access to information about **community alternatives**.
- Minimal help in **establishing eligibility** for housing.
- Limited or no access to **affordable, accessible and integrated housing**.
- Limited **access to equipment**, wheelchairs, medical alert systems, prosthesis, etc.
- Limited or no access to **substance abuse treatment**.
- **Poor communication** between service providers.
- **Inaccuracies in government information** and documentation.

- Difficulties in working with **state agency personnel** and **inconsistencies** in application of program rules and regulations.
- Limited or no access to **accessible transportation** in the service area. Transportation affects the choices people make in every aspect of their lives beginning with where to live.
- Lack of **disability awareness** among doctors and social workers. Many have no concept of independent living.

Other Issues -

Other identifiable barriers might include:

- **Geographical barriers** such as rural settings
- Lack of **public transportation**
- Access to **affordable, available services**
- **Age-based vs. disability** services (MR/DD, Brain Injury, MI, etc.)
- **Confusing jargon** on various long, complicated applications
- Differing agency requirements for **eligibility criteria**
- Differing agency requirements for **documentation**
- **Lack of collaboration** or sharing among agencies
- **Resistance to change** by the consumer, family or agency – keeping up the momentum
- **Resistant attitudes** of some nursing home staff and/or family members
- **Timing** issues (i.e., coordinating the availability of housing, durable medical equipment, and personal assistance)

Sarah's Story

Sarah M. was very eager to leave the nursing home where she had lived for quite some time. Upon checking her records so that she could transition back into the community, staff found that Social Security records indicated that Sarah was “deceased”, while the nursing home where she lived was still being paid to provide service. The *very-much* ALIVE Sarah provided a copy of her birth certificate and marriage license along with statements of her well being from nursing home and family members. With the help of an Implementation Team member/peer supporter/SSA employee, SSA records were corrected and Sarah's Social Security checks were reinstated.

Remember: Institutionalization affects individuals differently. Be aware that fear, confusion about the many details involved in transition, conflicting family attitudes and many other factors can all be part of the picture when someone is returning to the community. Being there to smooth out the rough spots and help restore confidence is an integral part of the transition specialist's job.

In summary, be sure to:

- ✚ Develop strong allies.
- ✚ Be persistent.
- ✚ Be flexible, have a Plan B.
- ✚ Take on barriers one at time. They CAN be broken down.
- ✚ Respect the fact that consumers can change their minds.
- ✚ Advocate, advocate, advocate!



Photos courtesy of Patricia Bailey