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PARTNERING FOR A BETTER QUALITY OF LIFE, HEALTH, AND WELLNESS

Without question, quality of life is important to people. When health issues arise, service providers seek to deliver care that not only treats the disease or injury, but also addresses the resulting quality-of-life issues.

Many factors can hinder achieving optimal health and diminish a person's quality of life. To improve outcomes of services, providers need to partner with the persons served. These partnerships are especially beneficial for individuals who live with disabilities or age with gradual changes that affect their ability to function.

Together, persons served and service providers can make decisions and take actions to limit the negative impacts of health conditions and thereby improve their quality of life.

STEPPING UP TO MEET THE CHALLENGE

One might think that quality of life would automatically decline in the presence of a significant health problem or disability, although research shows that this is often not the case. Nevertheless, obstacles confront providers in their role of promoting health and wellness for individuals who have acute

onset or chronic disabilities. Teaching persons served new techniques or adaptive behaviors might be complicated by one or more of these challenges:

- Clinical settings are not optimal learning environments. Time is limited, and distractions are numerous and frequent.
- A person's preoccupation with serious health issues can hinder learning new or changing existing behaviors.
- Many health issues might interact at the same time. Where should the focus be?
- Service providers might give too much information for people to grasp or remember.
- How human behaviors change and how to influence those changes are not well understood in medicine.

Different tools and a combination of paper and electronic media can meet people's needs to record and maintain their health information.

Responding to these challenges, CARF introduced what has become known as the portable profile standard a few years ago in the *Medical Rehabilitation Standards Manual*. The standard provides for programs to help persons know and maintain their own important health information and take it with them to their healthcare appointments. The standard is one among many crafted to enhance the lives of persons served by CARF-accredited providers.

A portable profile includes basic health information, such as advance directives, allergies, functional status, emergency contacts, medical conditions, and medications.

The utility of portable profiles figured prominently in developing standards for home and community services, which CARF introduced in 2010. The home and community services standards may be applied in all CARF accreditation areas, including aging services, behavioral health, CARF-CCAC, child and youth services, employment and community services, and medical rehabilitation.

A portable profile can add value to the healthcare experience. Michael E. Porter, Ph.D., writes that value in healthcare can improve outcomes for patients (“What is Value in Health Care?” *New England Journal of Medicine*, vol. 363, December 23, 2010, 2477–2481). Healthcare value, he says, is established over an episode of care—or longer.

The absence of a health information organizing system makes it difficult for persons served to participate effectively in their own care. It also makes it difficult for service providers to respond appropriately to a person’s total health picture.

PUTTING THE PORTABLE PROFILE CONCEPT INTO PRACTICE

Service providers need to take five steps to advance the portable profile process:

1. DETERMINE WHO ORGANIZES A PERSON’S HEALTH INFORMATION AND HOW TO DO IT



Establish how individuals manage their own health information. Often, service providers haven’t considered how persons served can do this or if they do it at all. Many people fail to organize their health information, because it has never been suggested to them that it is beneficial or important. If a person has cognitive difficulties or a serious illness, it becomes

essential to identify the caregiver or other responsible adult who can help manage the person’s health information.

WHAT THE CARF STANDARDS SAY

The intent statement in several CARF standards manuals for home and community services clarifies, “The portable profile is a tool to help the persons served and their families/ support systems ensure that they receive ongoing quality healthcare.

“The portable profile will empower persons served to be responsible for an important step in their care, will lessen the fragmentation of care among healthcare settings, and will likely decrease the risk of medical errors.”

The intent statement in the *Medical Rehabilitation Standards Manual* adds, “The profile should be portable for persons served so that they have the appropriate information at each health encounter and healthcare providers can be efficiently informed by more complete and accurate information than might otherwise be available.”

The portable profile also may be called a medical passport, patient care notebook, shared care plan, smartcard, or healthcare folder.

CARF standards manuals are available in electronic and print formats at www.carf.org/catalog.

2. FORM THE PROFILE PROCESS ON WHAT'S FAMILIAR

Build on any system for managing information that people already use. If they do not have a system, offer a method that might work for them: paper forms on which they can update information, binders that compile the most recent information in one place, or documents on their computers (including flash drives and CDs, which are portable) that they can easily update. A CARF standards manual advises, "The format should facilitate ease of access and ready availability in case of an emergency." Different tools and a combination of paper and electronic media can meet people's needs to record and maintain their health information.

3. SIMPLIFY, SIMPLIFY, SIMPLIFY

The amount of information confronting everyone today, including people with multiple health issues and busy clinicians, can be overwhelming. In *The Paradox of Choice: Why More Is Less* (New York: HarperCollins, 2004), Barry Schwartz describes how the human mind can't make good decisions when it grapples with too much information. When swamped with complicated information from multiple physicians and other service providers, people might make a rash decision or no decision at all.

Added to today's information overload are problems with medical communication. Medical complexity and health literacy issues are common barriers in the health and human service field. Michael Wolf, Ph.D., M.P.H., and colleagues at Northwestern University have found that people's literacy level is correlated with their ability to perform cognitive tasks.

4. GIVE OR TEACH WHAT PEOPLE NEED TO KNOW

Health literacy expert Gloria G. Mayer, Ed.D., RN, FAAN, teaches service providers to give persons served what they *need to know*, not what's *nice to know*. Background information might be interesting, yet can clutter what is needed to ensure success in day-to-day care.

The process needs to include a simple way for people to add or delete information from their profile.

5. DEVELOP PROFILES THAT WORK OVER THE CONTINUUM

Ideally, a portable profile tool and process can be designed to work for individuals over time. The process needs to include a simple way for people to add or delete information from their profile. A single piece of completed information at one point in time is a good initial "snapshot" or summary. However, people's healthcare services change over time. Empowering persons to manage their health information helps them beyond the short-term contact with specific clinicians.

CARF-accredited providers have already distinguished themselves in going far beyond basic service delivery requirements. They will no doubt be among the first in the health and human service field to work out the processes and tools necessary to teach and support people in organizing and managing their own health information over extended periods of time and in different care settings.

With assistance from dedicated service providers in developing the profiles, the persons served will learn a skill that helps them achieve better health, wellness, and an optimal quality of life.

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