

ON THE FRONTIER

by Thomas E. Pomeranz, Chief Clinical Officer

Positive Rituals: Steps Toward "Getting A Life"

"Get a life."

This catchy, cryptic, pronouncement has recently surfaced as a call to arms for professionals and significant others in the lives of persons with mental retardation. This declaration carries with it a broad range of contemporary connotations which are perceived in conflict with current professional practice.

Our all too familiar ICF/MR service system is structured to

provide schedules, programs, menus, training, habilitation, treatment and other strategies focused on "fixing" the person with mental retardation. The charge, "Get a life," implies that we must reassess these attempts to DO TO people (manage and control) through our commonly accepted practices of programming and habilitation.

Those of us who have grown to understand the charge, "Get a life," are realigning our efforts to more effectively support persons

with mental retardation in getting a life and having a life. In this regard we have made great strides.

We must continue to nurture opportunities for those we serve to develop meaningful relationships with others. Our sensitivities to the importance of choice and self determination in people's lives has moved toward center stage and is now accepted as the quintessential element needed in "getting a life."

For many of us, there are grand and glorious attainments and achievements to which we aspire. They may be a cruise through the

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Greek Isles, owning a new Lexus, financial stability to allow for early retirement or the joy of experiencing parenthood. As valued as these experiences are, we recognize that having a life cannot solely be realized through these attainments or accomplishments. Rather, we tend to gauge the value and quality of our life based upon the pleasure realized from seemingly trivial everyday rituals and routines that we hold precious.

Everyday Rituals

Critical questions we must assist those we support in answering are, "What do you wish to do with your life," and "How do you wish to carry out your rituals?"

Can you imagine what it might feel like if someone came into your life and without your permission prohibited you from engaging in your desired rituals? I have spent considerable time thinking how my life would be affected if someone denied me the opportunity to choose the rituals which have become my essence. For example, waking up in the morning to the sounds of my favorite classical music radio station, savoring a black cup of coffee before my shower, shaving in the shower (only after I shampoo my hair), brushing my teeth with a toothpaste I order from a specialty catalog from Maine.

Each of these events (rituals), as well as the many hundreds of

others which follow throughout the course of my day, are uniquely "me." I actively choose my rituals as they evolve and as they develop over time--the evolution in an ongoing process. These rituals provide me with a sense of security, predictability and continuity in my life. How unsettling and tragic it would be if all my quirky mealtime rituals, like salting everything whether it needs it or not, using a teaspoon to eat my cereal, etc., were prohibited.

Many persons with mental retardation who require the assistance and support of others in their daily routines are denied the joy of developing and engaging in positive rituals. The barriers to practicing positive rituals do not come from malicious or indifferent attitudes on the part of those who provide support. Though we who have accepted the challenge of providing support do so with the clear intent of helping people improve their quality of life, we too often allow our zeal to "habilitate," to obscure people's attempts to engage in the personal rituals that are meaningful to them.

Our drive to assist the person in gaining greater independence in bathing or eating results in part from a misapplication of task-analysis procedures. Conventional task-analysis procedures fail to account for the person's desire to wash their hair at the end of their shower rather than at the beginning or wishing to coat their peas and mashed potatoes with mustard rather than eating them in a more conventional way.

This interference with the person's positive rituals results more often than not from our failure to listen to what the person is communicating to us. We must apply both attention and tolerance if we are to assure that the persons we support are afforded every opportunity to engage in positive rituals of their choice.

When we support persons who have limited verbal skills we must listen with our eyes. Our observations of the individual's preferences of options offered should speak loudly. We must use these observations to structure opportunities for engaging in preferred positive rituals. It is, in part, the carrying out of these rituals by persons who require extensive support that proclaim that they are on the road to "getting a life."

How You Can Make A Difference

In serving people with mental retardation, it is important to remember that although it is our responsibility to teach people life's daily routines, it is also our responsibility to give people the freedom to accomplish these tasks in whatever manner they choose.

Because we often get so wrapped up in teaching people the correct way to do something, we may forget they want to develop their own routines. We must watch and listen for their preferences and help people to incorporate them in their lives. By remaining sensitive to the importance of choice, we can better help people with mental retardation carry out the rituals that represent a large part of their lives.