

# Positive Rituals and Quality of Life

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## **Rituals ease us through our day**

Every morning when you arrive at work, you head for that first cup of coffee. Only after the cup is in your hand and you have chatted about the prior evening's event with your co-workers do you feel that you are really at work and ready to start. If there is an urgent phone call before you have that first cup of coffee in your hand, you grumble to yourself because you are not really "in the office" until you have your coffee. When you arrive home from work, you do not feel like you are home until you have changed out of your "work clothes". Both of these are examples of the daily rituals that we employ to help us cope with transitions.

We give our daily rituals and habits scant conscious attention as they ease us through our days. Perhaps it is the absence of conscious attention that has led us to neglect the role of ritual in the quality of life of people with disabilities. However, rituals are as much a part of quality of life for people with disabilities as they are for everyone else. Families know this. They have looked for substitutes for the acquisition of the driver's license, realizing that this is the American secular rite of passage to adult life. They worked to make confirmation, bar mitzvah, and graduation ceremonies accessible to their sons and daughters. It is time for those of us who support people with disabilities to consciously consider the role of ritual and to insure the presence of positive rituals.

## **Daily Rituals**

Rituals begin every day with our morning routines. Each of us has developed a pattern of waking up and getting ready to face the day. These daily rituals are comforting. An example is bathing. Each of us has a pattern in how we wash our bodies. Is your face washed first or last? For those people who need assistance in bathing and cannot speak for themselves, the pattern of bathing may change with every change in staff. Yet when one mother in Ontario, Canada requested that her daughter's face be washed last, this was seen as an example of her being overly involved and too controlling.

“John” (who was learning how to do “essential lifestyle planning”) was sharing the person centered plan done on himself. He noted that he gets up slowly in the morning and does not want bright lights, loud music, or perky people around him until he has had his first cup of coffee. He described his fiancé as one of those perky morning people who bounce out of bed ready to go at full speed. Their accommodation is that she leaves the bedroom and is perky elsewhere. Because they respect and love each other, their incompatible morning rituals are accomplished without intruding on each other. Supporting the daily coping rituals of people with disabilities begins with paying attention to the personalities of those we support. Many direct care staff can tell you how they already do this, but the absence of sanction from professionals means that rituals that are supported today may be seen as non-compliant behavior tomorrow.

### **Maintaining and building rituals**

In Rituals for our Times, Imber-Black and Roberts describe the importance and nature of rituals for all of us. They note that: “Daily rituals define the boundary between the family and the outside world”. They include all of the important minutia of our lives at home. Common rituals around food include: the times at which we eat; what food is served on special occasions; where does each person sit at the table; and if we watch TV while we eat. These reflect our current preferences and our histories. Every time new people come into a home we need to remember that they bring their preferences and history with them. In houses owned or rented by the service provider, the rituals are often those of the staff and change as staff-turn over. Where people have spent decades in institutions, they may not have any rituals that work in small settings. People with disabilities and staff who come from families rich in positive rituals can help to create new rituals in the homes in which they live. However, systematic efforts to discover, build, and sustain these rituals are required.

Our efforts need to begin with these daily rituals. We have found that some of the people referred to us because of “non-compliant” or aggressive behavior simply have daily rituals that were not recognized. Our obsessions with implementing program plans and continuous training have resulted in our ignoring, suppressing, and trying to replace rituals

that are positive, individual adaptations to the rhythms of daily life. Once the issues are seen in this context, staff were able to accommodate the positive ritual of the individual within program schedule requirements and offer training as it made sense.

Beyond the daily rituals there are others that also deserve our attention. The topography that Imber-Black and Roberts uses divides rituals into those that express “relating, changing, healing, believing, and celebrating” (p. 56). To consider the significance of these we need only look to the importance of Sundays in our own pattern of rituals. For some of us, Sunday’s are days of spiritual renewal and relating to those who share out faith. For others Sunday is the day when you not only sleep late, but once you are awake you pad around in the sleeping garb well into the afternoon. During football season, Sundays are the day when family and friends get together to yell at the television set. The Sunday rituals of each home should be the rituals of the people who live there and not subject to the vagaries of changing staff.

### **Rituals of comfort**

We also need to remember that some rituals are rituals of comfort. We have sets of behaviors that we use to help us feel better when the “slings and arrows of outrageous fortune” strike us. After a bad day at work, we will say to our partner: “I do not want to do the chores planned for this evening. I had a really bad day at work. Let’s go out for dinner or the movies instead.” We say this even when it was our behavior that resulted in the bad day at work. If you are someone with a disability who goes to a day program it is not unknown to have your day program counselor call your residential counselor and say: “He was really bad at this day program, do not let him have any privileges at home tonight.” We need to ask ourselves why there is a saying among self-advocates that goes: “Never tell them what you like because they will make you earn it. Never tell them what you dislike because they will do it to you when you are bad.”

### **Rituals and relationship**

As we look at supporting people in their communities, we need to remember that much of the richness of “community” comes from the relationships that we have and the rituals that celebrate and build those

relationships. Despite of its central function, the role of ritual is rarely discussed. In our rapidly changing, mobile, and fragmented society, positive rituals deserve attention for all of us regardless of the presence of disabilities. For people who need substantial assistance to get through life, developing positive rituals must be a priority. For many people with disabilities, these rituals will need to be developed with the assistance of the staff and then supported by the staff. Once established, however, they should change at a pace dictated by the individual, not by the rate at which new staff arrive. The rituals must be rooted in who each individual is as well as each person's current circumstances. Properly used, ritual will help people through major life changes as well as each person's current circumstances. Properly used, rituals will help people though major life changes as well as daily existence. In the support plans of the future, more space should be spent on how to support people in their positive rituals and less on how to program every waking moment of their lives.

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Imber-Black, E. & Roberts, J. (1992). Rituals for our times: celebrating, healing, and changing our lives and our relationships. New York: Harper Collins.