

## A Fairy Tale for Our Time

Mary E. Wambach, Corliss Institute, Inc.

There are many myths circulating in Rhode Island these days, including the one about how 'the disabled and poor are using up far too much of everyone else's tax dollars'. Some of us need to peer over the fence and recognize that like the rest of the US, Rhode Island is becoming a state of baby boomers, senior citizens and people with disabilities. Anyone who lives into their fifth decade or beyond can expect one or more disabling conditions that are part and parcel of aging.

Regardless of reality, we support leaders and officials who caution that '40% of our state budget is spent on human services!' Does anyone really think that hefty salaries, luxury housing developments and pension colas will address the needs of people whose Social Security and Medicare/Medicaid are being eviscerated? Are there resources for housing, medical services and public transportation that some of us just don't know about? If you listen to the myths long enough, you may convince yourself that you will never age or depend on public supports, even when you no longer have a salary or other income.

My own favorite fairy tale is the one being promulgated by EOHHS and BHDDH. It follows closely the format of 'The Emperor's New Clothes', in which a team of tailors dupe an Emperor and his staff into believing that they are sewing elegant clothing for the Emperor, using the finest quality cloth and threads. In reality, there is no cloth, no thread, and the 'clothing' is not visible or real. The Emperor and his team are so afraid that everyone else can see the material described by the tailors that they don't admit to themselves or each other that he is unclothed. The pretense continues until the Emperor marches in a formal parade to display his 'exquisite garments' to the townsfolk, who are stunned. There is a long silence until finally a child asks, "Why isn't the Emperor wearing any clothes?"

In the Rhode Island version, state agency leaders and staff proclaim (to clients/consumers, families, service providers and each other) over and over again that "each consumer will receive only what they need - no more and no less" and "although the service agencies will be paid less money, services will remain the same".

For readers who are not familiar with the function of BHDDH (Behavioral Health, Developmental Disabilities and Hospitals), this Agency oversees services to thousands with disabilities, medical conditions and other syndromes. Consumers of BHDDH require various services and supports; often in residential placements.

Until recently, consumers/clients of BHDDH with developmental disabilities who qualify for residential and/or Day Program services could receive a range of support options that included staffing, a home, and transport/accompaniment to a range of appointments and activities. Provider agencies had flexibility to provide consumers with a broad menu of services, staffing supports and program choices. In addition to educational/daily living training and social skills development, consumers had opportunities to do what the rest of us do when we have a chance: go out for lunch or coffee, walk on the Bike Path or attend a festival in the park.

The recent funding cuts approved by the RI Legislature and conversion to a Medicaid regulated system has caused devastation to the thoughtfully crafted 'Rhode Island model' of services to people with developmental disabilities. After two decades of hard work to eradicate institutions that fostered abuse and neglect of this population, our state is returning to the practice of custodial care. Consumers once again must be in specified locations for proscribed time blocks (and 15 minute 'head counts' on which staffing and funding are contingent) in order to receive Day Program services.

Consumers who formerly benefited from paid work with 'supported employment' services cannot access this in the new system without some serious tweaking. Day Program consumers who formerly depended on providers for transport to medical, dental and other appointments cannot count on this

now: such staff-to-consumer ratios are not in compliance with regulatory or funding mandates.

BHDDH broadcasts the fictions that 'services will be the same' and 'consumers will exercise choices and options among a menu of opportunities'. A related pretense is that there are no 'waiting lists' (Medicaid doesn't like them very much). What we have instead is *many* consumers and families in 'pending mode', which sounds much nicer. Consumers have been individually advised by BHDDH that 'if services are changed, and that if changes are evident, they can file an Appeal'.

I hope that a statewide Appeal *is* filed on behalf of all consumers and families who don't realize that they are being sold a bill of goods. I hope that the Appeal will name EOHHS, BHDDH, the State of Rhode Island and the General Assembly. Our elected leaders voted to separate a large number of people into the 'them' category, then voted themselves raises and hired and promoted fledgling staff at executive salaries. They grumble that 'maybe even more funds should have been cut from human service programs...'

Although leaders pretend that the critical debate is one of funding; the most compelling concerns are the human and civil rights violations that will occur from inadequate staff, disrupted services and limited options.

I generally believe that most people are good, and that they try to do the right thing. It's hard to reconcile these beliefs with the concerted actions and statements of state agency heads and staff that deliberately and repeatedly mislead those they serve.

Then I remembered why we tell fairy tales in the first place - it's to help us go to sleep.

Wake up Rhode Island! The Emperor is naked, the tailors run amok and the wolves have been inside for years.