

New Quasi-Institutions as Examples of Human Service Unconsciousness

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EDITOR'S NOTE: *This article raises important considerations in regard to the dynamics of institutionalization, the history of human services, and the SRV theme of unconsciousness.*

A RELATIVELY NEW DEVELOPMENT in the realm of residential services is the creation of large, congregate care settings or “big facilities” such as “large campuses or farmsteads” for people with autism and other developmental disabilities. These new residential services have champions (e.g., Lutz, 2015) who are very careful to separate their new settings from state institutions of the past saying that these new facilities “bear no resemblance to the institutions of the mid-20th century” (Lutz, 2015, p. 3) and quoting one executive director saying “there is nothing institutional about our homes” (Lutz, 2015, p. 6).

The thesis that these new large settings are apples compared to the oranges of old state institutions needs to be examined carefully. If “institutionalization” is a continuum rather than a dichotomy as their advocates propose by using terms like “nothing institutional” and “no resemblance,” then these “new” models become much more problematic and may simply be occupying a different place on the same continuum.

These new models include the following: Air-mountain Woods, NJ; The Arc Jacksonville Village, FL; Bittersweet Farms, OH; Lakeside, NJ; Safe Haven Farms, OH; Misericordia, IL; Sweetwater Spectrum, CA.

For this paper, descriptions of these new settings found in Lutz (2015) and Tortorello (2013) were compared with descriptions of historical institutions in the US found in Wolfensberger (1975) and Goode, Hill, Reiss and Bronston (2013). This comparison yielded thirteen similarities between new large scale congregate care settings and old large state institutions. These similarities are presented in the table. Similarities include the use of attractive names; presence of desirable campuses and grounds; large grounds; names that may reflect mindsets and models; presence of many on-site amenities; specialized architecture and design features; presence of on-site therapies; on-site activities and programs; desire for community involvement; attempts to reduce safety and risk concerns; refuge from an unwelcoming community; a concern to reduce costs; and a desire for model replication. (See the table at the end of the article, following the references.)

These similarities are, I believe, too close to be dismissed as irrelevant, insignificant or mere historical coincidences. The rhetoric that new large congregate care settings are not institutions and bear no resemblance to institutions is difficult to sustain given the similarities outlined above. Rather, these similarities point to the possibility that new large congregate care settings may be described as “quasi-institutions” in that they have aspects of old state institutions but with modern differences and influences.

It should be noted, however, that this review is a paper review only. No personal interviews or on-site visits were made to any of these settings. Readers are therefore cautioned about seeing this analysis as anything more than proposing an interesting observation and thesis for further review and research.

It should also be noted that there are many important differences between old state institutions and these new large scale settings. For example, these new settings, at least at present, do not experience overcrowding and understaffing, lack of freedom to come and go, sex segregation, dormitory sleeping arrangements and unethical research practices—all of which were prevalent in earlier settings (Goode et al., 2013). In addition, it is probable that any setting will have concerns for cost reduction and community involvement. However, I believe that there are enough similarities between these new settings and old state institutions to question whether we are comparing apples with oranges.

In addition, these similarities, along with strong denials of any comparison to large state institutions of the past, point to the possibility that the similarities may be largely unconscious. One way to think about this unconsciousness is the possibility of a meme for institutionalization that is continuing to influence our thinking about services for people with disabilities even to the present day.

Institutionalization as Cultural Meme

A MEME IS “an element of culture or system of behavior that may be considered to be passed from one individual to another by non-genetic means, especially imitation” (American OED). These cultural elements can be described metaphorically as “cultural recipes” or “packages of information” (Dennett, 2006, p. 350).

Three things are needed to qualify as a meme: replication, variation and competition (Dennett, 2006). Institutions as “cultural recipes” certainly

have these three characteristics, (a) institutions increased in number (replication) and size in the post World War II years (Wehmeyer, 2013) [Sweetwater Spectrum even refers to model replication as a goal], (b) the meme is manifested in a wide variety of forms such as large state institutions, intermediate care facilities, large group homes and now new large scale congregate care settings, (c) these settings have to compete for funds and clients not only between themselves but with other settings such as small group homes and supported living arrangements. Thus, the various forms of large scale settings that have been developed over the past 150 years may qualify as manifestations of a meme for institutionalization.

Interestingly, historians of institutions and critics of human services for people with intellectual and developmental disabilities use concepts that are remarkably consistent with the theory of memes. For example, Sarason (1969) held the assumption that “the beginning context is fateful for what comes later, i.e., the seeds for later success or failure are contained in the beginning context” (p. 348). Wolfensberger (1989) picks up on Sarason’s (1969) theme in the following manner, “One way to think of this is to say that settings, including organizations, have ghosts spooking within them. These ghosts may be good or evil spirits, and are the ways of thinking and doing things of the founder figures and era” (p. 25).

Wolfensberger (1989) goes on to use the concept of founding “contingencies,” such as the physical setting, social context and “atmosphere,” influencing future service forms and practices (p. 25). He gives the example of a service that was formed when the people served were seen as threats to society that was constructed with high walls, heavy locked doors and bars on the windows, and staff (called guards) carried weapons and many keys and clients wore prison-type uniforms and followed prison-type routines. Long afterwards, “even centuries later—the ‘spoor’ of this early ideology and these earlier practices may linger on, even if the people are not a menace at

all or are no longer perceived as such. Indeed, they may linger on when the building is used by an entirely different client group and staffed by people who have no idea of what the founding precepts were. For instance, a male staff supervisor might still be called ‘captain’” (p. 25).

Wolfensberger (2013) believes unconsciousness is prevalent in human services in general and believes that service planners and administrators can be “entrapped into unconsciousness” (p. 132), as for example, when image associations and role expectancies “are passed on for generations, such that even people who have never encountered a person who fits the stereotype may nevertheless not only carry but also transmit it” (p. 133). He believes that “any organization is deeply influenced, even controlled, by past contingencies of which its present members have zero awareness or understanding” (Wolfensberger, 1998, p. 25).

Goode et al. (2013) comes very close to describing a meme of institutionalization in the following passage regarding large state institutions: “Their presence, resilience to mortality, ability to mutate, and, again depending on definition, their widespread presence in society, is remarkable” (p. 307).

This language of “seeds” and “spoor” being passed unconsciously from generation to generation in various mutations is very consistent with the concept of cultural memes.

Conclusion

MANY LARGE SCALE SETTINGS, despite admirable beginnings, have been subject to degeneration. We know that the original institutional settings in the US lasted only 40 years before they began to experience forces of economization, overcrowding and isolation (Wolfensberger, 1975). It is not very much of a stretch to imagine that these new quasi-institutions, no matter how well intentioned, bear the seeds of a more fully-fledged “old” institution that may manifest themselves in the near future.

The overarching issue is not to label one setting an “institution” and another “not an institution,” but to maximize the humanity and dignity of the lives of people with disabilities. There are many ways to do this but one important way is to minimize institutionalization as much as possible. Decision makers need to determine exactly what these new models are offering that could not be rendered in settings that most people would see as typical, community-based and maximally non-institutional.

If there is a meme for institutionalization as I propose, then it is probably present in society at large and especially for workers in the field of intellectual and developmental disability. Therefore no one is likely to be exempt from its influence and the need to be constantly vigilant in recognizing its possible manifestations. Goode et al. (2013) recently warned that “one of the important lessons from Willowbrook is to look for *relatively* total institutions—institutions in changed forms, cloaked in different clothes, in a variety of sizes. It is important to be sensitive to new social conditions and places that may not be physically like total institutions but that accomplish similar purposes” (p. 305, emphasis added). We have learned a lot in the past 150 years about institutionalization and its role in the history of human services (e.g., Wehmeyer, 2013; Goode et al., 2013). In my view, a subtle and perhaps unwitting return to newer forms of institutionalization for people with disabilities would be highly problematic. ☺

For more information, see the following:

Airmount Woods, NJ (www.bergenunitedway.org/howwehelp/housing-works-2/build.php); The Arc Jacksonville Village, FL (www.arcjacksonville.org/thearcvillage/); Bittersweet Farms, OH (<http://bittersweetcsa.com/description>); Lakeside, NJ (www.bancroft.org); Safe Haven Farms, OH (www.safehavenfarms.org); Misericordia, IL (www.misericordia.com); Sweetwater Spectrum, CA (www.sweetwaterspectrum.org/autismspecific_design.aspx)

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THE CITATION FOR THIS ARTICLE IS

Elks, M. (2016). New quasi-institutions as examples of human service unconsciousness. *The SRV Journal*, 11(1), 30-40.

Table
Aspects of Similarity Between New Large Congregate Care Settings
and Old State Institutions

| Aspect of similarity | New large congregate care settings (Generated from the case examples described in Lutz, 2015 and Tortorello, 2013.) | Old state institutions |
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| 1. Use of Attractive Names | Lakeside Airmount Woods Sweetwater | Willowbrook |
| 2. Presence of a Desirable Campus and Grounds | "tranquil environment" (Lutz, 2015, p. 17) "collegiate, small-town community feeling" (Lutz, 2015, p. 13) | Willowbrook State School: "The grounds are beautiful. An entrance road winds between woods and wide lawns on which are spaced gracious, old willow trees. Pheasants and squirrels haunt the woods, all adding the first impression of a lovely park, a quiet retreat." (Goode, Hill, Reiss & Bronston, 2013, p. 131) Sonoma State Hospital had 1,600 acres and three streams: "The climate is perfect, the situation picturesque, the location central; and, altogether, the trustees are jubilant, and feel that the millennium is at hand." (Murdock, 1889, p. 316 cited in Wolfensberger, 1975, p. 60) |
| 3. Large Grounds | Bittersweet Farm has 80 acres Misericordia has 31 acres Airmount Woods has 8 units on 1.6 acres Sweetwater has 3 acres for 16 people | "It has been conceded for years that each institution should be provided with at least one acre per inmate" (Powell, 1897, p. 295; cited in Wolfensberger, 1975, p. 46) |

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| <p>4. Names That May Reflect Mindsets and Models</p> | <p><i>Safe Haven Farm</i></p> <p><i>Bittersweet Farm</i></p> <p><i>Misericordia</i></p> <p><i>The Arc Village</i></p> | <p><i>Custodial Asylum for Unteachable Idiots (Rome, NY 1893)</i></p> <p><i>"havens in which all shall live contentedly, because no longer misunderstood nor taxed with extractions beyond their mental or moral capacity" (Kerlin, 1885, p. 174 cited in Wolfensberger, 1975, p. 29)</i></p> <p><i>"Beginning in about 1880, so-called farm colonies had come into vogue." (Wolfensberger, 1975, p. 46)</i></p> <p><i>"Here and there, scattered over the country, may be 'villages of the simple' . . . 'cities of refuge' . . . 'havens'" (Kerlin, 1885, p. 174 cited in Wolfensberger, 1975, p. 29.)</i></p> |
| <p>5. Presence of Many On-Site Amenities</p> | <p><i>Art room; vocational building; communal kitchen, pool</i></p> <p><i>Greenhouse, gym, bowling alley, computer labs and pool where Special Olympics team practices, bakery, horticultural center, recycling program, commercial laundry, restaurant</i></p> <p><i>Exercise room, chicken coop, community kitchen, expansive greenhouse, social hall</i></p> <p><i>Library</i></p> | <p><i>"Others, in the vocational training center, were playing 'jacks.'" (Blatt & Kaplan, 1974, p. 47 emphasis in original)</i></p> <p><i>"Many people remember the Olympic-sized swimming pool that was a gift from veterans who stayed at Willowbrook when it was Halloran Hospital." (Goode et al., 2013, p. 136)</i></p> <p><i>"Apparently, running efficient laundries is one thing that institutions are good for." (Blatt et al., 1978, caption to slide 103 "Laundry Man")</i></p> <p><i>Randall's Island Asylum in 1914 is described as having "an industrial school, gymnasiums, and other buildings." (Goode et al., 2013 p. 33)</i></p> |

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| <p>6. <i>Specialized Architecture and Design Features</i></p> | <p><i>“therapeutically designed environment that would reduce sensory triggers such as light, noise, and vibration. The walls were built of tempered glass and heavyduty wallboard materials that could withstand violent meltdowns. Clear sightlines allowed staff to see almost the entire house from the kitchen.” (Lutz, 2015, p. 23)</i></p> <p><i>Layouts of all four dwellings is identical</i></p> <p><i>Oversize kitchen counter</i></p> <p><i>Open campus</i></p> <p><i>Extra-durable, high impact wall finishes and replaceable carpet tiles</i></p> <p><i>Floor drains in every bathroom</i></p> | <p><i>“Staff work behind isolating (protective?) partitions which keep out residents and perhaps even their sounds, but permit extensive or complete visual monitoring.” (Wolfensberger, 1975, p. 10)</i></p> <p><i>“thirty-seven cottages, comprising the main groups in the male and female divisions, are similar in exterior design and internal arrangement. . .” (Spratling, 1903, p. 265 cited in Wolfensberger, 1975, p. 80)</i></p> <p><i>“terrazzo has no equal. . . heavy battleship linoleum securely cemented to concrete underfloor may be used to advantage.” (Wolfensberger, 1975, p. 82)</i></p> <p><i>See photos showing floor drains in day rooms in Blatt (1974), pp. 24, 27</i></p> |
| <p>7. <i>Presence of On-Site Therapies</i></p> | <p><i>“extensive array of therapeutic services including occupational, physical and speech therapy” (Lutz, 2015, p. 12)</i></p> | <p><i>“Occupational therapy had just been introduced in 1914, and by the 1920s, Willard was a leader in offering arts and craft activities as primary therapy. They also offered the state’s first training on ‘activities of daily living,’ such as cooking, shopping, budgeting, and grooming, especially for those getting ready for leave or release.” (Goode et al., 2013, p. 181)</i></p> |

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| <p>8. On-site Activities and Programs</p> | <p><i>Dances once a month</i></p> <p><i>Care for animals, weave placemats and rugs to sell, and work in the fields and greenhouses, alpacas, chickens, dogs and miniature horses. Ceramics and jewelry, painting, Friday night is "activity night in the social hall." (Tortorello, 2013, p. 2)</i></p> | <p><i>At Randall's Island Asylum in 1914 "The residents are shown in a variety of classes learning academics, cooking, basketry and chair making, hammock and rug weaving, folk dancing, and gymnastics . . . The children are shown in uniforms playing baseball, and there is a band, also with uniforms and instruments." (Goode et al., 2013, p. 33)</i></p> <p><i>"Friday-night dances sponsored by the Benevolent Society" (Goode et al., 2013, p. 188)</i></p> <p><i>Belchertown's "cottage plan" included "a farm beauty parlor, a sewing facility for women, and a carpenter's shop for men." (Goode et al., 2013, p. 46)</i></p> <p><i>"Entertainment was considered therapeutic, so there were dances. Concerts. Lectures, amateur theater, and regular movies. Sports were common, with marching drills, calisthenics, basketball, baseball, and annual field days—they even had a bowling alley." (Goode et al., 2013, p. 181)</i></p> |
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| <p>9. Concern for Community Involvement</p> | <p><i>“Residents can work, play, and worship in Jacksonville, but come home and hang out with peers in a safe environment” (Lutz, 2015, p. 24)</i></p> <p><i>“residents are employed at local supermarkets, Loyola University, and US Cellular Field”</i></p> <p><i>Two groups perform all over Chicago: a dance troupe (“Heartbreakers”) and a sign/singing choir.</i></p> <p><i>Annual art exhibit at Art Institute of Chicago.</i></p> | <p><i>At Willowbrook, “Jimmy remembered that his family used to take him home for weekends, but he would also be able to go on trips for movies, shopping, and work.” (Goode et al., 2013, p. 178)</i></p> <p><i>“At Willowbrook there were actually some residents who worked ‘regular’ jobs in the community.” (Goode et al., 2013, p. 193)</i></p> <p><i>At Willowbrook “There was a choir, a band, and a girls’ touring fashion show each of which gave performances at Willowbrook, on Staten Island and even in other boroughs.” (Goode et al., 2013, p. 180) (NOTE: Goode, D. personal communication July 28, 2015. Goode et al., 2013, has a printing error on page 180 that omits this detail about a touring fashion show.)</i></p> <p><i>The Willowbrook Band would perform for the Benevolent Society luncheon in the spring “which was always held in one of the big New York hotels.” (Goode et al., 2013, p. 189).</i></p> |
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| <p>10. Reduction of Safety and Risk Concerns</p> | <p>Non toxic building materials</p> <p>Induction cooktops to limit the possibility of burns</p> | <p><i>"Some special constructional features should be incorporated, the more prominent of these being stairways broken by landings, to prevent patients from falling the entire length." (Sprattling, 1903, p. 266 cited in Wolfensberger, 1975, p. 80)</i></p> <p><i>"In every building in which the children live there should be placed on the hot water supply at a point beyond where the hot water is taken off for dish washing, a control or antiscalding valve . . ." (Wallace, 1924, p. 263-264 cited in Kugel & Wolfensberger, 1969, p. 159)</i></p> |
| <p>11. A Response to An Unwelcoming Community</p> | <p><i>"living in a small home can be especially isolating for a person with I/DD" (Lutz, 2015, p. 13)</i></p> <p><i>"Community integration is a myth" (Lutz, 2015, p. 14)</i></p> <p><i>[Emily] "didn't have one interaction with a neighbor during that time, good or bad." (Lutz, 2015, p. 16)</i></p> | <p><i>"The capacity of the individual is not at fault; but the world is not full of philanthropic people who are willing to take the individual from the asylum and surround him with the proper guardianship which his case demands." (Wilbur, 1888, p. 110 cited in Wolfensberger, 1975, p. 28)</i></p> <p><i>"On the other hand, some children did have experiences of the outside world, admittedly often negative in some important way, which is why they ended up at WSS [Willowbrook State School]" (Goode et al., 2013, p. 257)</i></p> |

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| <p>12. Concern to Reduce Costs</p> | <p><i>"Four-person homes cost too much to operate . . ." (Lutz, 2015, p. 8)</i></p> | <p><i>"If it cannot be done at a cheap rate, you can never get the money to do it." (Walk, 1890, p. 441 cited in Wolfensberger, 1975, p. 45)</i></p> <p><i>"The public, while liberal in all its charities, demands that the funds so appropriated should be wisely and economically expended, and that the cost should be kept as low as possible consistent with the best methods of carrying on the work" (Wilmarth, 1902, p. 152 cited in Wolfensberger, 1975, p. 44)</i></p> |
| <p>13. Concern for Model Replication</p> | <p><i>The goal of Sweetwater Spectrum is "to create and foster a model that can be replicated nationwide" (Tortorello 2013, p. 7)</i></p> | <p><i>Institutions greatly increased in number in post World War II (Wehmeyer, 2013).</i></p> |