

# *Who is Putting Whose Head in the Sand . . . . . . or in the Clouds?*

AN ALTERNATIVE VIEW OF NORMALIZATION

*In an era of divergent life-styles, it seems particularly ironic that we place such stress on normalization for the retarded. Somehow the gap between public policy and private preferences seems great at times.*

*The following excerpt has been taken from Who Is Putting Whose Head in the Sand or in the Clouds? by Elizabeth M. Boggs, one of the founders of the National Association for Retarded Citizens. Her paper originally appeared in Parents Speak Out: Views from the Other Side of the Two-Way Mirror, co-authored by Ann P. Turnbull and H. Rutherford Turnbull III, Copyright 1978. Charles E. Merrill Publishing Co., Columbus, Ohio.*

In an era of divergent life-styles, it seems particularly ironic that we place such stress on normalization for the retarded. Somehow the gap between public policy and private preferences seems great at times. Social reforms based on theoretical constructs are still pursued with the same missionary zeal as was the eugenics movement in times past . . .

There are some parents who like the idea of normalization because it is useful in glossing over the realities of difference. I sometimes think there are professionals who like it for the same reason. Rather

than trying to create a "normal" environment for my son, I try to think of how the world must look from his point of view, and what kind of environment would not only minimize his boredom and loneliness but enhance his sense of dominance. When I try to put myself in his skin, I realize that he, like me, has an immediate environment, a home; that is, the place where he sleeps, eats, and spends his leisure time with certain associates, and an immediate external environment which is called the community. His home environment could be improved from his point of view by reducing the noise level created by a really extraordinary architectural anomaly, reducing the size of and the number of people occupying the same daytime living space at the same time (i.e., subdividing the space appropriately), and reducing the total number of staff and residents with whom David has some interaction, provided this could be done in such a way as to retain in his "family" those people he would most like to have with him, while at the same time increasing autonomy and reducing the risk of burnout for the care-givers. (The particular residential facility in which he now resides still maintains an overly hierarchical as distinct from a colleague pattern of organization of the direct care staff.) All this could be done equally well in any residential unit whether on campus or in the community.

But what of the community environment? The "community" surrounding David's "home" is the campus of the state school. It is an ergonomic community; that is, one which has been planned to suit the inhabitants. Its swimming pool is designed so that any one can stand up in any part of it. There is a twenty-mile speed limit on all its roads. Its doctors make house calls. Its respite care arrangements are always available, that is, when the parent surrogate has an emergency, another one is available. There is a restaurant where no one stares at the sloppy eaters.

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Nobody there thinks that it is inappropriate for a thirty-two-year-old man to use a swing on the playground by choice; it is not considered dehumanizing to let a man act like a child if he wants to. David is not restricted by any such environmental taboos.

From his point of view this community is more facilitative and more enhancing than the town half a mile down the road. There were times in the past when I deliberately escorted David into my community. Because he does not like to be in the water where he cannot put his foot firmly on the bottom of the pool, the area of the community swimming pool actually available to him was very small. On the public beach he would trample the neighboring family's picnic because he wanted their banana. The nurses in the general hospital put him into an enclosed crib (normal for children) which was too short for him. Being integrated into the community means nothing to him. Perhaps we should consider ways of making the community more aware that people with his extreme problems exist and need special care and attention. But first, I think we have to persuade the armchair policy-making professionals of their very existence.

How can we describe their extraordinary need for an adaptive environment structured to their requirements, rather than ours? We need some new terminology, it seems. In a recent large meeting a well-known superintendent, who runs a facility in which there are residents like David, remarked that they had recently placed a number of profoundly retarded adults in the community, and that when these "profoundly" retarded adults were asked whether they would like to return to the institution, they all said, "No." I am sure that the adults to whom he referred were successfully placed, and I do not doubt their capacity and the voluntariness and lack of coercion in their expression of preference. If people who could make such a conceptual choice, who could understand the question, and express an answer are called profoundly retarded, then we need some new terms for those who cannot do any of these things.

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Jefferson, Wisconsin 53549

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