

I'll Never Have a New Schwinn Bicycle

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(Author's note: This essay grew out of discussion with a parent whose daughter is in a state school for persons with mental retardation. Over a 12 month period the parent was very clear in his desire to have the state schools for persons with mental retardation kept open. He wants his daughter to be in a place where she is safe and protected. The author's response to this parent has been that in the 1960s, before S.B.230 in Texas and the subsequent P.L. 94-142 at the federal level, there was only one avenue of service: the residential placement for persons with mental retardation. Times have changed. The focus of court cases, legislation, and professional standards have moved to community-based services. It is the author's understanding that parents who followed the advice and placed their family member in a residential setting feel betrayed. They did what they were told and then someone said, "we have changed our minds...close the state schools." This not only angers the parents, but pulls whatever trust they have that services are predictable and permanent. Fueling their fears is the unspoken, "...okey, what will happen when the next change takes place?..." These fears are often held by parents who are aging and who are aware that their family member may outlive them. The approach to understanding the dynamics involved with parents who want state schools continued is that there is a cause for their concern, their feelings are justifiable, and the confusion understandable. However, times have changed. This essay was an attempt to express why the author feels the changes are permanent. The real issue, in the opinion of the author is that this is a mental health issue and needs to be studied in order to assist families whose trust has been challenged and whose feelings of betrayal come from specific causes).

The materials you sent have been received and read. As I told you, the contents will be kept confidential and not shared with others. It is important to me to be able to read your materials and react to them even if I do not talk about them to others or show them to any one else. That is the only way you and I can learn to trust each other and to build toward common goals that we hold. Likewise, if I were not honest with you in sharing my reaction to the materials, it would be false on my part. Trust is a two-way street. So I want you to know that I will not break your confidence by talking to others about what you have sent me, but I will reserve the right to talk to others about my reactions and my thoughts. In fact I will probably send a copy of this paper to select individuals we have spoken to in the recent past. It is a my way of keeping the group informed even though I do not talk about specifics.

This past week I was stunned to learn that the Schwinn bicycle company went out of business. When I was a young boy, owning a Schwinn was the ultimate goal of every kid. We all wanted Schwinns. They costs a whopping \$65 and that was about a week's wages for my dad and there were 7 children in the family. So, wanting a Schwinn and having a Schwinn were two different things. Now the Schwinn bicycle company has gone out of business. I will never own a Schwinn, or at least a new Schwinn. In fact, I have not even

thought about owning a Schwinn for maybe 60 years. Times change and I have changed. But I still remember longing to own a Schwinn.

The problems you present are complex. I wish I were brilliant and clever and could solve them quickly. But they are not that easy to address. First of all, in regard to the materials you sent me, I must be frank and tell you that this is new wine in old bottles. What you are asking simply continues what is, not aspires to what could be. They don't make Schwinn any more. But maybe I can disclose who I am and how I got to where I can read what you sent and review it at a certain level.

I am a professional in the field of mental retardation. That means that I went to college 9 full years to learn about mental retardation. I know who Itard was. I understand how Dr. Montessori "cured" certain forms of mental retardation. I have read the studies by Marie Skodak. I studied Berta Bobath, and E.H. Johnstone, and Goddard, and Doll, and even Newell C. Kephart. I listened to Edwina Youngblood and John Peck and Marguerite Thorsell and learned about mental retardation. I pre-date the times of Marc Gold, Wolf Wolfensberger and Bob Perske, but I can understand that they are building on the knowledge of the field in their contributions. There is a past, a history, and body of knowledge regarding mental retardation that does not even seem to be utilized in Texas. People who are hired to provide the leadership in serving persons with mental retardation are hired, in my professional opinion, to maintain the agency, not to bring the body of knowledge to bear on the problems presented by the nearly 2 million Texans with mental retardation. Instead of viewing change as a way to grow the system (and agency) the persons hired to provide leadership in mental retardation in Texas can only maintain...the system, the agency and the problems. They do not have the background to be able to view the process and emergence of services to persons with mental retardation. An example of this may be found in the use of the I-CAP in TDMHMR. This fiasco-in-the-making does not even seem to know about the Riles case in California, yet the department will use a single measure to determine eligibility for services. This approach has been out of the mainstream of the field for almost 20 years and yet Texas continues under the banner, "...you just don't understand, this is Texas and we have unique problems that others don't have..." My family has lived in Texas since 1847 so I am not an outsider. I can tell you, that dog don't hunt. Yet it keeps the problems brewing in Texas. You and I have shared our concerns over TDMHMR, mine from a professional standpoint, yours from a consumer perspective. The bottom line is that good hearts do not make good programs. It takes more. So, that is one problem area that needs to be addressed in order to move forward.

A second area is that of placement. The residential movement grew out of the Middle Ages with the concept of sanctuary as its base. That is, if you could make it to the steps of the cathedral you were "safe" from harm. You were protected and you were beyond the laws and customs of the community. Being safe in the "arms of charity" had its price to pay with loss of freedom, self, and individuality. In the United States that emerged under two concepts: the colony movement and the training school movement. The problem was that when a colony was established or a training school built, they were swamped with referrals and they became little more than warehouses holding people "away from the community."

It is not happenstance that state schools were located in small communities or out in the countryside away from the eyes of society and that the placement was a one way street. This system was maintained by the concept of predictive validity meaning that it was held that future performance could be predicted from samples of behavior observed in a structured setting. By predicting, self-fulfilling prophecies were set up. If you had an IQ of 70 (not 71, not 75) you were “mentally retarded” and could be educated to minimal academic skills. Such nonsense. The studies by Ziegler and those from the Sonoma State Hospital show that of the 2% of the general population with IQs under 70, only 2% are unable to live and work in the community with minimal support and protection. The other 2% can benefit from being allowed to “grow” over their life-span and become part of community activities through “job share,” “job coaching,” or “self-care.” Yes, I know that you are going to jump on that and say, “therefore, we need state schools for that 2% that do not live and work in the community.” To which I say, that is a self-fulfilling prophecy based upon prediction, not function. Marc Gold defined mental retardation as a condition for which society was unprepared to provide the necessary supports to achieve maximum potential. Murdina Desmond showed us that the most productive learning time in the life of persons with mental retardation may be in their 30s and 40s. They have a longer growing season than we thought. Predictive validity implies absolutes. The sheltered placement implies safety and protection. Both are up for questioning. Scobey reports that sexual abuse among persons with disabilities increases 7 fold over that of the general population, but we don’t talk about that. You see, when you are in the “arms of charity” you are supposed to become asexual. We want to believe in safety and protection. And we want the system to work. People at MH/MR talk about these issues in private but not in public.

Placement, to me as a professional, is not as important as content. By content I mean that the individual has opportunities for a life-time of learning. For me as a professional, content means that the individual is always moving forward with new interests and ideas. Helen Keller said “...life is an adventure or it is nothing...” If Helen Keller had lived in Texas in 2001, she would have been considered mentally retarded and would have had limited opportunity to explore those adventures. Content is not based on prediction. It is based upon offering opportunities. Any place that restricts or limits opportunities (or content) is an inappropriate placement to me as a professional in the field. Don’t misunderstand, I want every person to be safe and protected (that includes you and me) but I do not want any one to be cloistered (a word coming from the Middle Ages and signifying protection and safety), have limited opportunities just to participate in life, or denied the chance to explore the adventure of living. You will counter with your demand that your family member be allowed to have her own living space, to go to work, to walk down to the store, and to be safe on the street. That can be done in ANY placement. It is a matter of content, not where the person lives.

That gets down to what I think the REAL problem is. I have been telling you (and anyone else who would listen) that to me, as a professional in the field, the real issue in mental retardation services is a mental health issue that denies the stresses of trying to make the system work. This includes agency personnel, politicians, family members, parents, professionals, and persons with mental retardation. Because of these stresses, each of us

seeks refuge in groups or approaches that offer us feelings of less stress. These refuges are maintained by a false sense of prophecy or prediction that our way is right (or at least less stress producing). The result is that those most concerned with improving services to persons with mental retardation are the most fragmented and most isolated components in the delivery system. They can relate to a few who keep their anxieties down or validate their feelings, but they avoid sharing or getting past their anxiety and anger. The result is a cycle of struggle and dissension that feeds the anxieties and anger. The outcome is that the resources that could help persons with mental retardation are instead fragmented, isolated, and combative. This wastes whatever assets we have in solving the problem because we get to a point where you can't invite that person to talk to this person or that group to hear this group. There is no sharing or mutuality but growing resentment that the end product will be a feeling of loss or an actual defeat.

So, as we say in Texas, "if you are so smart, why ain't you rich?" I need to put my money where my mouth is, or whatever metaphor yields an image that things can get better and problems can be fixed. Or, at least as my old philosophy professor used to say "...you can resolve some problems, dissolve some problems, and absolve some problems..." How would I recommend us to go forward?

1. Let's change from a Predictive Validity approach to a functional behavior approach. This means getting away from the "deficit model" of identifying what a person cannot do and moving to an "abilities model" of defining what a person can do, seems to have some interest in doing, or demonstrates compensatory behaviors that does the same thing. This gets us away from setting up self-fulfilling prophecies and diminishing opportunities to opening up possibilities and fortuities. It moves us forward and away from being locked in the past. That knowledge exists. I can tell you exactly what your family member needs in the way of content today, now, here, and in the present. It is not based on IQ or placement or even motivation. I can do that without a Quija board or crystal ball (those, by the way predict, I want to describe). What I do is based upon training and others can be trained to do what I do and probably do it even better with individual clients that they know better than I will ever know that client. I can empower parents and family members to know exactly what services to request for their family member from an agency or professional. I can show you and other parents how to monitor progress in your family member over the entire life span. No magic. No predictive prophecies. No mumbo-jumbo with statistics.

2. Let's get away from letting the budget drive the system. It is not a question of "whether" money will be spent; it is a question of "how" the money is spent. There is lots of money in mental retardation services, but in my opinion it is used to maintain the system. The goal of intervention for persons with mental retardation must be to prepare that person to live and to work. Now living has been redefined along a continuum (not the way you define it, but the word is correct) that moves toward independence. Work has also been redefined (thank you, Lou Brown) from self-care (which Dr. Brown waggishly calls "self-employment" if you can teach a person to provide their own care they are self-employed since you do not have to hire someone else to do that for them) to competitive

employment with way stations along the route of effective time management, job sharing, enclaves, job coaching, and continual on-the-job training. I would suggest that we start with “zero-based budgeting” and act as if there were no funds and then ask what could be done to help that person with mental retardation find things of interest, opportunities, and quality of life based upon the choices the person has available. Of course I must share a war story...that is the way professionals get feedback that their efforts were worth the expense. I was working with a young girl (perhaps 8 years old) who was diagnosed by the formal system as being autistic, having mental retardation and being notorious for her aggressive behavior. My classroom was near the old cafeteria and we had flour, water, yeast, and an oven (rickety as it was). Not much else existed in the setting (a few tables and chairs and an old Easter basket). I found that the student liked to pull things apart. So we made yeast dough and she could spend long periods of time (probably too much, but I was young and inexperienced) kneading the yeast dough. She liked the smell of the dough, especially after I brought sugar and vanilla from home to add to it so she could also taste it. We started baking hot rolls and then started going around the school building giving hot rolls to secretaries, the principal, teachers, other students, bus drivers, anyone we could track down. She would carry the basket filled with hot rolls and with much prompting off a hot roll to another person. Eventually she would anticipate taking the hot rolls around the building and on some trips I would even see a smile from her as we walked the halls. She made eye contact as she offered a hot roll. Her head banging, biting, and scratching stopped even though I did nothing to intervene directly. So, she was moved back to her previous setting. The last I heard she was on Haldol and was in a stupor most of the time when she was not being aggressive. I’ll bet the Haldol costs more per dose than all the materials we used in baking. It was not a question of money. It was a question of being with the client and providing opportunities which could be built upon. I have seen such creative interventions in many settings and it has nothing to do with the budget. Too often budgets are seen as the source of power and those with power run the show. Pity that budgets are not seen as energy to improve services at the individual level (not aggregate or group level).

Finally, the solution to part of the problem(s) may be found in interventions that address affective domains. This, I mean, is addressing the feelings, thoughts, attitudes, confusions, frustrations, need for assurances, and lack of trust that is common among all of those who work and participate in this field of mental retardation. I presented a lecture at the Berry Brazelton, M.D. Lecture Series at Baylor University entitled Anticipatory Guidance for Parents of Persons with Disabilities. This paper reviews 30 years of research I have done with families of persons with disabilities. Basically, parents have taught me that they are going through a process of adjustment and that process is forever. The crisis times recur and the internal stresses can destroy a couple and a family. Parents have taught me that the condition (of mental retardation, for example) can take over the life and emotions of parents and family members. Families get to be dominated by the condition and become the mentally retarded family or the blind family, or the ...fill in the blanks. The system has responded to these family and parent needs in ways that are little more than PTA meetings where nose counts of how many came to the meeting are more important than whether the parents progressed and learned that their feelings are normal, found among many families, and that there are solutions. Let’s help parents become problem solvers, case managers (ah,

now there is a hot issue), or cultural transmitters for parents of newly diagnosed cases. Parents enter the “system” in mid-stream. They assume the system is in place. Yeah right! And parents lack any history of the condition, the system, or what goals are possible. I have told you of my desire to have “cultural grandparents” that utilize parents who have been there before and can help new families. One of the most successful programs in mental retardation services was a foster-grandparent program which was on the right track but needs to move further into cultural transmission and long term support. I hold that we don’t have time for arguing or putting each other down. There are precious little in the way of help, build upon the help that is there. That is about as close to a benediction as I will go. Let me know what you think. My goal is for us to talk, and talk, and talk, and talk and as we do this we will begin to see that we have more in common than we have in disagreement.