

Breaching the Last Frontier: Dignity and the toileting issue for persons with multiple and severe disabilities

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Abstract:

Although much has been written about the normalization and social inclusion of persons with developmental disabilities over the past 50 years, a small subset of this population has remained largely overlooked – individuals who are quadriplegic, non-verbal and who also have additional disabilities including cognitive impairment. The present project was designed to address one of the most glaring aspects of this neglect – personal control over personal hygiene and its connection to human dignity and sense of self-efficacy. Ten parents with adult children with severe and multiple disabilities were asked a series of questions to explore the following thesis: Are unnecessary physical barriers negatively impacting normalization in the area of personal care, an important area of social behavior?

Background:

The concept of ‘normalization’ was first formalized in 1959 through an Act passed in the Danish parliament decreeing that those responsible ensure that Danish subjects with “mental retardation” live a life as much as possible like the rest of the Danish population. In Sweden this idea was picked up by Bengt Nirge, Ombudsman of the ‘Swedish Association for Retarded Children’. He disseminated the idea of normalization through talks at home and abroad and through personal communication with colleagues in America. Two of his papers were included in an edited work by Robert Kugel and Wolf Wolfensberger (1969) and this work was the catalyst for embedding the concept of normalization within the North American rehabilitation community.

Bengt described eight features of the normalization principle which he identified as necessary to bring about parity with the rest of society for persons with developmental disabilities. These included normalizing of economic circumstances, living conditions and rhythm of life. In his classic 1969 paper, Nirge described these individuals as “...a group which is characterized by wide variations in age, degree of handicap, complicating physical and emotional disorders, social backgrounds, and educational and personality profiles.” And he went on to say that “This (normalization) principle should be applied to all the retarded, regardless whether mildly or profoundly retarded, or whether living in the homes of their parents or in group homes with other retarded.” Later in the same paper he commented that “Development of various abilities always has bearings on the development of the whole person.” and “The self-image of the retarded must be built on letting him experience his personal abilities....”

Apart from the now politically incorrect language, one can see that this is exactly the direction we have headed in North America with regard to the care and treatment of individuals with developmental disabilities. This is reflected throughout the age spectrum as evidenced by the strong emphasis on full inclusion in conjunction with individualized education plans for the school aged population and community living with access to appropriate work, volunteer and inclusive social activities for the adult population. Those with multiple and severe disabilities have also been accommodated as well as possible but the specialized training required to deal with some of their disabilities has limited the capacity of various school boards and staff in community homes to cope. Thus, the vision of Bengt Nirge to apply the precepts of normalization theory to the entire spectrum of individuals with disabilities has not been fully realized.

One area where innovation, accommodation and the very will to work towards as great a degree of normalization as possible for this population has been particularly lacking is self care in terms of meeting bathroom needs. Professionals and parents alike often believe that non-ambulatory individuals* considered to have severe cognitive deficits are incapable of any degree of self control over their bodily functions. This is the belief that is being challenged in this paper.

Hypothesis:

Many but not all non-ambulatory persons with indicators of severe cognitive deficit, e.g. lack of a formal communication system, do have the potential to partially or fully control bladder and/or bowel elimination but are prevented from doing so by both physical and psychological barriers which only the larger society can overcome. That is to say, their disability is often only a handicap that, like other handicaps, e.g. lack of sidewalk access or appropriate transportation facilities, can be overcome if beliefs can be changed and sufficient will and imagination applied to remedying the situation.

Method:

Between May and October, 2008, the care providers of 10 persons with multiple and severe disabilities were interviewed to explore access and management issues around bathroom needs. None of these individuals had a formal communication system which would have made discussion without an intermediary possible. The interviewees were mothers (or the foster mother in one case) with two fathers participating. All were either guardians or co-guardians.

The structured interview contained 21 questions surveying the history of the individual with the disability from infancy until the present time. The topics addressed included family structure and function, the nature and course of the individual's disability, education and other forms of rehabilitation which had been provided, care provision assistance and arrangements through the years, and access and management issues with reference to meeting the toileting needs of the individual.

The individuals with disabilities ranged in age from 18-31 with an Average age of 25.7. Five were male and five were female. All of them had multiple disabilities and only one was able to do some brief weight bearing with support. All ten had been diagnosed with spastic quadriplegia, meaning they had no functional use of their arms or legs. None of them had a formal communication system although two of them could speak a few isolated words on occasion, but not in a consistently communicative way.

Results:

Pre-school Intervention

5 of the 10 received an in-home program with an assistant, organized and monitored by a specialized teacher and therapists

2 received a program of therapy activities from a rehabilitation hospital, to be carried out by the parents at home.

2 began their intervention through a centre-based program.

1 received an informal, home-based program organized and funded by the parents.

The ages when active intervention programs were undertaken varied from 18 months to 4 years.

School years intervention: (ages 6-21)

4 remained in a centre-based program throughout their school years

3 went to inclusive public or separate school settings

3 went to partially integrated public or separate school settings

Adult: (21+)

2 remained in school settings since they were still of school age (18 or 19)

6 were in centre-based adult programs

4 were in informal community-based programs through their home or group home settings

Ages at which they began receiving care outside the family home:

4 remained in the family home and one remained in a foster home where he has been since age 3.

5 entered community-based group home settings at ages 11, 12, 16, 18 and 22, respectively.

Family Structure and Function:

6 grew up in nuclear families with 0-4 siblings

4 grew up with single mothers or mothers as sole care providers following divorce

Nature and Course of the Disability:

All ten had been diagnosed as spastic quadriplegic.
7 had seizure disorders ranging from moderate to severe
3 were blind or severely visually impaired
1 was hearing impaired
4 had gastric tubes for receiving nutrition or fluids or both
2 had scoliosis severe enough to compromise lung functioning
All ten were non-verbal and diagnosed as having severe cognitive impairment
Prognosis is guarded with respect to life expectancy in all ten cases

Age at which children first indicated readiness for toileting

3 - no indicators were noticed
1 - 6-12 months
3 - 18-24 months
2 - 3 years
1 - 4 years

Toilet Training:

For 1 of them no toilet training regimen was ever attempted.
For the remaining 9 the age of first attempt ranged from age 1 to 7 with an Average age of 3.
In 5 of these 9 cases toileting attempts ranged from “a few weeks” to 10 years and were then discontinued. 3 were discontinued at home and 2 in school.
In 4 cases toileting is ongoing with partial success in 3 cases and full success in 1 case.
In the partial success cases there is inconsistency in or lack of program maintenance in either the home or the center-based setting or both.

Issues related to Toilet Schedule Maintenance by parents and school staff

Difficulties in lifting: 9/10 *
Lack of appropriate supportive seating arrangement: 6/10*
Not believing the child was capable: 5/10*
Conflicting time demands (work or care of siblings): 6/10
Depression, fatigue, low morale: 7/10
Ongoing medical problems/hospitalizations: 4/10*
Limited or no assistance from father: 7/10
Lack of access to appropriate facilities in community: 10/10*

*these factors also affected consistency of toileting attempts in the school

Factors which would have facilitated toilet schedule maintenance:

1. Proper equipment: easy to use lifts, change tables and adapted commodes both at home and at school
2. Early hands-on assistance with implementing and maintaining a toileting program
3. Appropriate facilities in community to make family outings easier
4. Doctors and consultants who believed it was possible

Two specific questions related to lifting and changing were asked:

1. "If lifting could have been smoothly facilitated to minimize the time, energy and effort on your part what difference do you think this would have made to your child's toileting success? Exact answers are recorded below:

1. "It would be wonderful."
2. "A world of difference."
3. "No difference. (He) was always very small."
4. "It would have made a difference with pressure sores, I suspect."
5. "Doubt if it would work with Retts."
6. "No difference – no energy. Besides, she could walk when she was young. It didn't happen then so why would it happen later?"
7. "A lot! However, I still wouldn't have had the energy to do it every couple of hours."
8. "It would have made an enormous difference as it would have expedited the toileting process and been less painful to the primary caregivers (backs, arms)."
9. "It would have made a big difference. If I was able to do it I would have done it – habit training."
10. "It would have helped but at home we can cope – space in public washrooms not large enough."

2. If adult-sized change tables were available in 'handicap' washroom stalls when your child was growing up what differences do you think this would have made to his or her community access and overall quality of life?

1. "Huge!"
2. "If transferring (also) available it would have been way easier to feel like going out."
3. "A big difference."
4. "It would have a positive effect on our lives on outings days and we (may) have had more and longer outings."
5. "That would have been and would be an excellent help. We could stay out longer."
6. "She could stay out longer and be comfortable. Could even be out all day!"
7. "She could be out longer and would be more comfortable. And you could access more outings and avoid socially embarrassing situations."
8. "We would have had more family outings. He would not have stayed home with a caregiver as frequently as he did and he would have been included more in our family experiences and travels."

9. "There were times when he was little we spent time at the zoo or mall or park. A change table would have made all the difference. We could have stayed out longer."
10. "Much better!"

Discussion:

The results suggest that a variety of logistical, medical, psychological and social factors have coalesced to turn a physical barrier into a disability. Indications are that most of the individuals in the study were at least capable of habit training (scheduled bathroom training) if consistency and the appropriate equipment had been in place. Whether or not any or all of them could have learned to clearly communicate bathroom needs in advance had an optimized communication training program been in place we cannot now know.

Factors which interfered with this happening were the following:

1. lack of adapted commodes, easy to use lifts and height adjustable change tables
2. lack of similar facilities in public venues and schools resulting in inconsistency and eventual failure.
3. lack of assistance and role modeling in the home during the early, critical years
4. low expectations on the part of the medical professionals which likely influenced parents' expectations
5. depression and resulting low energy in many of the care providers

Conclusion:

This paper explores the thesis that many individuals facing multiple challenges are capable of attaining a degree of self-sufficiency in the area of bathroom control not previously assumed to be possible. Various physical and psychological barriers that have contributed to preventing this outcome are described. The impact of these barriers on ten families charged with caring for such individuals is examined. Based on the information acquired from these families it appears that if most or all of the obstacles described in this paper could be eliminated many more individuals with multiple and severe disabilities would be able to exercise control over their own bodily functions and many more families would be willing to do the necessary early training to make this possible. The benefits for all concerned of such an outcome are obvious.

List of Works Cited

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