

Breaching the Last Frontier: Dignity and the Toileting Issue for Persons with Multiple and Severe Disabilities

Emma Pivato, PhD
Centre for Integrated Studies
Athabasca University

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 on normalization in the area of personal care, an important area of pro-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 Nirje, 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 became the catalyst for embedding the concept of normalization within the North American rehabilitation community.

In his classic 1969 paper, "The normalization principle and its human management implications," reprinted in *The International Social Role Valorization Journal*, 1994, Nirje 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. Nirje 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" (1994, p. 19). 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" (p. 19). 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...." (1994, p. 22).

Apart from the now politically incorrect language, one can see that this is generally 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 Nirje 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. Only a few articles turned up in a literature search on adaptive positioning toileting systems for individuals with high degrees of physical involvement and these were either exclusively focused on pediatric needs (Brotherson, 1996; Lee, Ryan, Polgar, & Leibel, 2002; Rigby, Ryan, & Kent, 2009; Ostensjo, Carlberg, & Vollestad, 2005), or referencing individuals with less severe disabilities (Clemson & Martin, 1996; Friedman, 1980; Shultz & Liptak, 1998; Sullivan-Bolyai (1986). None addressed the lifting, transfer and change table issues relevant to older children or adults with severe physical disabilities. The lack of attention in the literature to this obviously important issue can likely be explained as follows. 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. That is the belief that is being challenged in this paper.

Proposition

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

Participants: 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 (foster mother in one case), with two fathers participating. All were either guardians or co-guardians.

The target individuals for this study 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.

All ten had been diagnosed as spastic quadriplegic. Seven had seizure disorders ranging from moderate to severe. Three were blind or severely visually impaired and one was hearing impaired. Four had gastric tubes for receiving nutrition or fluids or both, and two 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.

Procedure

After preliminary information had been acquired by telephone, a two-part structured interview containing 21 questions was administered in person to each of the respondents. Part One provided further background information on 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, age of child when toilet training was first attempted, and duration of toileting attempts. Those results are presented in summary form. Part Two dealt with the management issues which were the specific focus of this project: lifting issues, transfers and adapted toileting facilities. Those results are presented in greater detail in a question and answer format.

Results

Part One: Background information

(a) *Pre-school Intervention:* All ten individuals received some form of pre-school intervention. Five participated in an in-home program with an assistant, organized and monitored by a specialized teacher and therapists. Two were provided with a program of therapy activities from a rehabilitation hospital, to be carried out by the parents at home. Two participated in a centre-based program and one received an informal, home-based program organized and funded by the parents. The ages of the individuals when their pre-school intervention programs began ranged from 18 months to 4 years.

(b) *School years intervention (ages 6-21):* Four of the 10 research individuals remained in a centre-based program throughout their school years, three attended inclusive public or separate school classes and three went to partially integrated public or separate school settings. All respondents indicated that the decision to initiate, continue or discontinue a toileting program at school was made in consultation with the family.

(c) *Adult Day Program: (21+)* Two remained in school settings at the time of the interviews since they were still of school age (18 or 19), four were in centre-based adult programs and four were in informal community-based programs through their home or group home settings.

Ages at which the individuals began receiving care outside the family home: Four remained in the family home and one remained in a foster home where he has been since age three. Five entered community-based group home settings at ages 11, 12 ½, 16, 18 and 22, respectively.

Family Structure and Function: Six grew up in nuclear families with 0-4 siblings and four grew up with single mothers or mothers as sole care providers following divorce.

Age at which children first indicated readiness for toileting In three cases parents reported never noticing any indicators. In one case there were signs of intention between six and 12 months. In four cases toileting

readiness was noted between 18 and 30 months and in two cases readiness signs were not evident until ages three and four, respectively.

Child's age when toilet training first commenced: In one case no attempt was ever made to train the individual. In two cases training began between age one to two years. In three cases it started between age two and three years and in two cases it started between age three and four years. In two cases training was initiated at school between ages six and seven.

How long was the toileting program maintained? In one case it was never implemented, either at home or at school, and in another case it lasted three months or less. In one case it lasted six to nine months and in another case it lasted two years. In two cases, a toileting program was maintained for ten years and then stopped. One parent explained, "The toileting program was implemented at age 2 ½ but slowed down about nine to 10 because she was not responding. It was causing her anxiety and physical stress." The other stated, "(He) moved into a group home – all was lost. Sometimes he's put on his commode but not enough for proper toileting."

In the remaining four cases the toileting program is still in place. Parents commented as follows: (1) "We never stopped. It was always a family priority." (2) "(She) went to school two days a week. (There was) no proper toilet seat there. She is in a home program now and toileting is done at home." (3) "We never stopped. He refuses to go at school because of the lack of an appropriate commode. Also, his sense of privacy." (4) "At (his day program) toileting facilities are available but the staffing model is two to five so it doesn't happen there."

Part Two – Specific Questions Related to Toilet Schedule Maintenance

Elaborated responses are entered below each question or question part. Some respondents chose simple yes or no answers, as the numbers indicate.

First, parents were asked which of a number of factors listed on the form had interfered with maintaining an effective toilet training regimen? Nine out of

10 reported difficulties in lifting and three elaborated as follows: (1) "I have chronic lower back problems from constant lifting and positioning of (name)." (2) "(We) tried with bladder training until age 16 but stopped then because care providers wouldn't do all that lifting." (3) "Lifting was always an issue."

When asked if the lack of an appropriate supportive seating arrangement for toileting had been a factor, six of the 10 responded positively. Here are their elaborated responses: (1) "I did not know they existed." (2) "We held her on a regular toilet when she was young ... no success." (3) "I battled with that for a long time. Molded ones are no longer available. It is a problem." (4) "She went to school two days a week. There was no proper toilet seat there."

In some cases, psychological barriers were present in addition to whatever physical ones were there. When asked, five of the 10 respondents reported not believing the child was capable. Two elaborated as follows: (1) "No. (According to the neurologist) she wasn't capable anyway and there were so many other things to do." (2) "No signs. No complaints when wet or dirty."

When asked about the impact of conflicting time demands, e.g., work or care of siblings, six of the 10 listed this as a problem and three elaborated as follows: (1) "I had no help. I was a single parent and I had to work." (2) "The younger siblings would not always want to wait for their brother's toileting routine when we were out having fun in the community (swimming, festivals, shopping, etc.)." (3) "I worked full-time and had other children."

Depression, fatigue and low morale were identified as factors in seven of the 10 cases and three offered further elaboration: (1) "I did suffer from post-partum depression. There is depression in the family." (2) "(I was too damn tired!" (3) "Yes, but toileting always a priority."

Ongoing medical problems and hospitalizations were identified as factors interfering with a toileting regimen in four of the 10 cases and all four offered explanations: (1) "Asthma-related ailments placed him in hospital many times when young." (2) "All the medical conditions ...

very fragile ... focused on keeping her alive." (3) "She was in and out of the hospital until age 5, up to two months at a time to stabilize seizure meds – had to have a shunt, now non-functional." (4) "He had major surgery on his hips – thigh muscles released. He spends a couple of weeks in hospital almost every year with aspiration pneumonia."

Limited or no assistance from father was identified as a factor in seven of the 10 cases: (1) "My husband was a workaholic when the children were young and had limited time available for them. He did believe his son was capable of being toilet trained and helped five or six times a week." (2) He didn't help but he didn't resist. Busy." (3) "His father had a drinking problem and was rarely home in the evenings. We have since divorced."

All ten families saw lack of access to appropriate toileting facilities in the community as a significant impediment to toileting maintenance. One mother stated, "We always manage but at a cost to our backs and putting ourselves and (our daughter) in embarrassing, unsafe and unhygienic conditions." She went on to say, "She would go to certain places more if it was easier to toilet her."

Two specific questions were then asked which addressed the lifting and transferring issue: First, parents were asked, "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?" and they answered as follows: (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) "I 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.”

Respondents were next asked, “If adult or large child-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?” They responded as follows: (1) “Huge!” (2) “If transferring (was 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!”.

A number of the parents mentioned that these factors also affected consistency of toileting attempts in the school.

Additional comments offered spontaneously by some respondents referred to the following factors which would have facilitated toileting success: (1) Proper equipment: easy-to-use lifts, change tables and adapted commodes both at home and at school; (2) “Early hands-on assistance in the home with implementing and maintaining a toileting Program;” (3) Appropriate toileting facilities in the community to make family outings easier; (4) Doctors and consultants who believed it was possible.

Discussion

The results suggest that a variety of logistical, medical, psychological and social factors appear to have coalesced to turn a physical barrier into a disability. According to parental reports, 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 likely interfered with this happening were the following: (1) lack of adapted commodes, easy-to-use lifts and height-adjustable change tables to facilitate toileting at home, at school and in the community, (2) lack of assistance and role modeling for families in the home during the early, critical years, (3) low expectations on the part of the medical professionals which, in turn, negatively influenced parental expectations, and (4) depression and resulting low energy in many of the care providers.

It needs to be mentioned that the data collected for this project were based on parental recall, often of events which happened many years previously. As such, there was some room for error. However, as all the individuals under discussion are still alive and the parents still actively involved in their lives, it seems safe to say that the core issues are valid and legitimate ones.

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 at least some degree of 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. Note, there do exist individuals who, due to the extent of their neurological impairment, are incapable of any degree of control over their eliminatory functions. They need to be treated with respect and compassion and their dignity guarded as much as possible. And they, too, could benefit from appropriately sized change tables in public washrooms.

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Author Note

The author can be contacted at emmap@athabascau.ca