

How Self-Determined Are People With Mental Retardation? The National Consumer Survey

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Abstract: Although there is a growing acknowledgement that individuals with disabilities have the right to individual self-determination, people with mental retardation have been among the last for whom these issues have been addressed, despite calls to do so over the last 20 years. In this article, we examined the importance of self-determination for all people and reported the outcomes of a national survey that provides evidence regarding the self-determination of Americans with mental retardation.

There is a growing acknowledgement that people with disabilities have the right to individual self-determination (Ward, 1988; Williams, 1989). As a result, human service providers have begun to restructure services and supports to promote consumer and family empowerment and provide choice and flexibility in services (Bruininks, 1991; McFadden & Burke, 1991). Educators have also addressed these issues and have suggested that self-determination may be the most important outcome for successful transitions from school to adult life (Halloran & Henderson, 1990; Wehmeyer, 1992a).

Self-determination refers to the attitudes and abilities required to act as the primary causal agent in one's life and to make choices regarding one's quality of life free from undue external influence or interference (Wehmeyer, 1992b). Being self-determined involves having control over choices and decisions impacting one's life. This control is not absolute, and some authors have stressed that it is not control, per se, that defines self-determination, but instead the opportunity to be the causal agent in choice and decision-making (Deci, 1980; Deci & Ryan, 1985; Wehmeyer & Berkobien, 1991).

In order to assume control in one's life, one must have the opportunity to express preferences, indicate choices, and make decisions.

These opportunities need to have been preceded by experiences leading to a realistic self-awareness, self-confidence, positive self-concepts, and positive efficacy and outcome expectations. A self-determined person is autonomous, acting according to personal beliefs, values, interests, and abilities. *Self-determination* reflects *self-actualization*—the full development of one's unique talents and potentials—and self-regulation—self-controlled mediation of one's behavior (Wehmeyer & Berkobien, 1991). Ward (1988) argued that self-determination "refers to both the attitudes which lead people to define goals for themselves and to their ability to take the initiative to achieve them" (p. 2). In addition to self-actualization, he identified assertiveness, creativity, pride, and self-advocacy as traits reflecting self-determination. Other abilities typically included in self-determination are problem-solving, identifying consequences, and goal definition and attainment.

Perhaps least visible in this growing recognition have been people with mental retardation and other cognitive disabilities. In 1972, Nirje wrote:

One major facet of the normalization principle is to create conditions through which a handicapped person experiences the normal respect to which any human being is entitled. Thus the choices, wishes, desires and aspirations of a handicapped person have to be taken into consideration as much as possible in actions affecting him.

The road to self-determination is indeed both difficult and all-important for a person who is impaired. (p. 177)

Yet, despite the progress during the 2 decades since Nirje (1972) provided his overview, many people with mental retardation have had neither the experiences nor the opportunity to assume responsibility for basic choices and decisions that impact their daily lives. Relatively few studies document the extent to which people with mental retardation exhibit self-determination in their lives, but the few that exist suggest that adolescents and adults with mental retardation experience limited opportunities for expressing preferences and making choices and decisions (Houghton, Bronicki, & Guess, 1987; Jaskulski, Metzler, & Zierman, 1990; Kishi, Teelucksingh, Zollers, Park-Lee, & Meyer, 1988; Murtaugh & Zettin, 1990). In conjunction with the growing evidence that people with disabilities continue to experience social isolation, high unemployment, and low economic status (Chadsey-Rusch, Rusch, O'Reilly, 1991; Wagner et al., 1991) and anecdotal information provided by self-advocates and others with disabilities, one can presume that people with mental retardation have limited opportunities to be self-determining.

In the present study we have described the results from a nationwide survey of almost 5,000 people with mental retardation. Questions were selected in an effort to determine the extent to which respondents perceived themselves as being self-determining.

Method

In 1990, the National Association of Developmental Disabilities Councils (NADDC) reported the outcomes of a national survey of Americans with developmental disabilities (Jaskulski, Metzler, & Zierman, 1990). This document was prepared pursuant to the amendments of the 1987 Developmental Disabilities Assistance and Bill of Rights Act (P.L. 100-146) and was designed to answer three primary questions posed by Congress: (a) "Do people with developmental disabilities exert control and choice over their lives? (b) Do people with developmental disabilities engage in income-producing work or contribute to their households and communities? (c) Do people with developmental disabilities participate in our communities, become our friends and neighbors, and do the things that other people do?" (Jaskulski et al., 1990).

To address these questions, representatives of Developmental Disabilities Planning Councils from 46 states and 5 territories conducted interviews, resulting in a total of 13,072 completed surveys. Almost one third of the people surveyed were identified as having mental retardation. In the present analysis we have focused exclusively on those survey participants with mental retardation in hopes of providing a unique perspective on the extent to which people with mental retardation are self-determining.

Survey Design and Question Selection

The National Consumer Survey was developed by members of a design group comprised of disability advocates and research scientists from Temple University's University Affiliated Program. The instrument consisted of 79 questions in six sections: (a) Eligibility and Screening, (b) Demographics, (c) Services Satisfaction, (d) Independence, (e) Integration, and (f) Productivity. In an additional section (Supports, Services, and Assistance Needed), a series of rankings was used to determine what was the "best possible array of services the individual could receive." Greater detail concerning this process and the survey is available in the Final Report of the 1990 National Consumer Survey of People with Developmental Disabilities and their Families (National Association, 1990).

For the present analysis 7 demographic questions and 27 questions in the Services Satisfaction, Independence, Integration, and Productivity sections were selected as representative of the self-determination of individuals with mental retardation. Demographic information assessed included participant age, marital status, gender, years in educational setting, educational setting, racial status, and membership in advocacy organizations. The following are the questions we used:

1. Do you own your own home or hold the lease for your house or apartment?
2. Did you choose the place where you live?
3. Did you choose your attendant and/or residential staff?
4. Did you choose your roommate/housemate?
5. Did you choose your job or what you do during the weekday?
6. Do you usually choose what you do on weekends and evenings?
7. Do you give consent for medical care?
8. Do you determine what clothes you wear?
9. Do you usually choose your friends and acquaintances?

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10. Do you usually decide how your personal space is decorated?
 11. Do you go to the bank and deposit and withdraw money?
 12. Do you pay your own rent, gas/electric and phone bills?
 13. Do you usually decide what things you buy with your spending money?
 14. Do you determine which agencies and organizations provide services and support for you?
 15. Did you vote in the most recent general election?

How often do you:

16. Visit with friends, relatives or neighbors?
17. Go to the grocery store?
18. Go to a restaurant?
19. Go to church/synagogue?
20. Go to the mall/retail stores?
21. Go to a bar, tavern or nightclub?
22. Go to the bank?
23. Go to the movies?
24. Go to a live theater performance?
25. Go to a live popular music performance?
26. Go to a live sporting event?
27. Go to an athletic club?

Procedure

Interviews were conducted in each state or territory by members of the Council or organizations contracted by the Council. Representatives of each state were requested to conduct at least 300 interviews, with the exception of some low population states. These interviews were stratified by subgroups according to disability category, and all interviews were conducted face to face with the individual and/or a family member or surrogate when necessary. To protect consumer rights to privacy, interviewers explained the project to all respondents and gave them the opportunity to decline to take part. Participants were recruited through advocacy organizations that could identify people who met the functional definition of developmental disability. Interviewers were trained by project staff, who also provided ongoing technical support.

Participants

The present analysis concentrated on the survey results for 4,544 individuals with mental retardation identified as a primary diagnosis ($n = 3,365$) or as a secondary diagnosis ($n = 758$). The mean age of the sample as a whole was 35.2 years (standard deviation [SD] = 12.6, range = 21 to 89). The sample was 53% male (mean age = 34.7, range = 21 to 86, SD = 12.04), 47% female

(mean age = 35.8, range = 21 to 89, SD = 13.25). Eighty percent of respondents were Caucasian; 11%, African-American; 2.7%, Hispanic; 1.4%, Asian-American; 1.5%, Native-American; and 3.4%, other nationalities or not reported.

Limitations of the Survey

As was made clear in the Final Report from the National Consumer Survey (National Association, 1990), the limitations of the survey need to be recognized but should be considered within the context of the value of the information to be gained from the survey results, the source of this information (people with mental retardation), and the strengths of the survey. One important limitation is that due to functional limits placed on surveyors by the definition of developmental disabilities and the need to maintain individual rights to privacy, it is impossible to be certain that the results are representative of all people with developmental disabilities, and thus mental retardation.

The use of surrogate respondents poses a problem for data interpretation, and, although specific analyses were described to identify the extent to which this variable impacts the data, this limitation must be acknowledged. Finally, many of the responses reflect individual perceptions of a given outcome, such as independence, productivity, or integration. The data must be viewed as such, not as specific indicators of the actual integration, independence, or productivity status of individuals with mental retardation.

Analyses

Two types of analyses were performed. The first was conducted to allow us to assess the degree to which people with mental retardation were self-determining. These data are presented as percentage of responses to the various questions selected (see pp. 40-41). A second concern was the extent to which these data reliably represent the perceptions of individuals with mental retardation. Using this second analysis, we addressed two issues: (a) differences between responses for those individuals identified as having a primary diagnosis versus a secondary diagnosis of mental retardation ($ns = 3,365$ vs. 758) and (b) differences between respondents who answered for themselves versus those who relied upon a surrogate to respond either partially or entirely for them ($ns = 932$ vs. 3,191).

This second analysis consisted of a 2 (group: primary or secondary diagnosis) x 2 (respondent: self, other) x 5 severity (3,4, 5, 6, or 7 functional limitations) analysis of variance, with group, respondent, and severity as independent variables. Answers to six questions that provided Likert-scale responses were dependent variables. All analyses were performed using SPSS release 4.1 for IBM VM/CMS.

Results

Analyses of Variance

The six questions examined through analysis of variance asked respondents how independent, integrated, and productive they perceived themselves to be and how important each of these outcomes was to them. Interviewees rated each area on a Likert-type scale from 1 (*very independent, integrated, or productive*) to 5 (*not at all*) in each area. Following each question, respondents were asked how important that particular outcome was to them, again on a 5 - point scale from 1 (*very important*) to 5 (*not at all important*).

There were main effect differences between individuals with primary and secondary mental retardation on three of the six questions. There were no significant differences in the ratings of level of independence, integration, or productivity. Individuals with secondary mental retardation indicated that it was more important to be independent than did individuals with primary diagnoses (means = 2.94 and 2.10, respectively), $F(1, 6) = 16.869, p < .001$. The primary group rated integration as slightly less important than did those with secondary mental retardation (means = 2.06 and 2.05, respectively), $F(1, 6) = 8.38, p = .004$. Respondents with a primary diagnosis indicated that productivity was slightly more important than did respondents whose diagnosis was secondary (means 1.97 and 2.02, respectively), $F(1, 6) = 5.25, p .022$. There were no significant interactions for any of the main effects between group and respondent or severity of disability. In effect, there were no significant differences between respondents' perceptions of their integration, independence, or productivity based on whether their diagnosis was primary or secondary. Some minimal group differences occurred in the responses pertaining to importance of the outcome, but the only trend that emerged was that for two of the three areas (integration and inclusion); the group that rated themselves as less integrated or independent also rated the importance of that outcome as higher

Individuals responding for themselves rated themselves as more independent than if others rated for them (means = 2.7 and 3.5, respectively), $F(1, 6), p < .001$, and indicated that independence was more important than if others answered for them (means = 1.54 and 2.25, respectively), $F = 81.4, p < .001$. There were interaction effects for respondent and severity, $F(4, 9) = 3.316, p = .014$.

There were no significant differences in self and other ratings for how integrated individuals were, but there were minimal but significant differences between groups on the importance of integration. Self-respondents indicated that it was more important to be integrated than did those for whom others responded (means = 1.79 and = 2.14, respectively), $F(1, 6) = 4.337, p = .037$. There were significant interaction effects between respondent and severity, with ratings of importance of integration very similar if the individual had fewer functional limitations. In the case of importance of integration, self-responders with three identified limitations had a mean of 1.67 compared with an other responder mean of 1.69, whereas self-respondents with four identified limitations actually rated integration as less important than other-respondents (means = 1.87 and 1.84, respectively). For individuals with five or more functional limitations, self-responders rated integration as more important.

Again, there were no significant differences in ratings of productivity, but self-respondents indicated that this was more important than did other respondents (means = 1.45 and 2.13, respectively), $F(1, 6) = 68.84, p < .001$. There were significant interaction effects for Respondent x Severity, $F(4, 9) = 3.45, p = .008$, which stem from increases in the differences between means for self and other respondents at each level of functional limitation, culminating in a 1.07-point gap between self and other respondents at Level 7.

As would be expected, there were significant main effects for severity of disability for each question, with a direct relation between number of limitations and less positive indications of functioning or importance. These outcomes have implications for interpreting subsequent results. First, although there were differences in ratings of importance of the various outcomes, these appear to be minimal. There were differences in estimations of level

of independence and productivity for self and other respondents and differences in estimations of the importance thereof in each of the outcomes. This is at least partially explained by examining the level of severity, with surrogates answering for people with more severe disabilities less likely to place value on the importance of the given outcome. Differences in actual estimates of independence, integration, and productivity are, in and of themselves, not reflective of unreliable data but indicative of, at the least, different perceptions of these outcomes. In essence, the following results should be considered conservative estimates of self-determination because individuals responding primarily for themselves provided answers at least nominally more positive in both current status and importance of the outcome.

Outcomes Related to Self-Determination

Recently Kozleski and Sands (1992) reported the results of a survey of 133 adults (ages 18 to 70 years) concerning quality of life issues. These authors used a modified version of the Consumer Satisfaction Survey employed during the National Consumer Survey. The National Consumer Survey included a few questions from a previous survey, the International Center for the Disabled Survey of Disabled Americans (Taylor, Kagay, & Leichenko, 1986), which included a comparison sample of 1,000 Americans without disabilities. Findings from both the Kozleski and Sands study and the survey are

included when available to provide points of comparison between adults with and without mental retardation.

Results from questions designed to determine individual choice and control are presented in Table 1. In addition to the amount of choice and control an individual experiences, self-determination is reflected in the degree to which an individual is able to be autonomous, acting out of personal beliefs, interests, abilities and values, and, for this sample, engaging in activities and actions construed as synonymous with adult roles. One indication of autonomy for most people is the degree to which they are involved in daily activities and preferred leisure activities. Responses reflecting these outcomes are presented in Table 2.

One role frequently associated with adulthood is that of spouse. In the International Center for the Disabled sample of adults without disabilities, 58% were married or living together; 20%, divorced, widowed, or separated; and 22%, single. Participants in the Kozleski and Sands (1992) study included a high number of college students, and the marriage figures, therefore, were somewhat different. In that sample, 47% had never been married, 41% were married, and the remaining members of the sample were divorced, separated, or widowed. For adults with mental retardation, these figures are starkly different. Only 2.5% of the respondents were married, with an additional 2% divorced, widowed, or separated. Ninety-five percent of this group had never been married.

Table 1
Percentage of Responses by Level of Choice and Level of Control for National Consumer Survey (NCS) Participants and Adults Without Disabilities (ND)

Question	<u>Unassisted</u>		<u>With assistance</u>		<u>Others chose</u>		<u>Not applicable</u>	
	NCS	ND	NCS	ND	NCS	ND	NCS	ND
Level of choice								
Where you live?	6	46	27	42	66	10	1	2
Attendant/staff?	2	NA	10	NA	88	NA	0	NA
Your roommate?	9	59	13	6	77	13	1	0
Job/day activity?	11	77	33	10	56	0	0	12
Leisure activity	37	65	39	34	24	2	0	0
Your friends?	68	NA	18	NA	14	NA	0	NA
Level of control								
Select clothing?	56	NA	27	NA	17	NA	0	NA
Decorate room?	40	68	30	32	30	1	0	0
Control money	44	91	36	8	20	1	0	0
Do own banking?	12	96	30	3	58	0	0	1
Pay own bills?	7	69	19	17	74	13	0	2
Consent medical?	18	78	26	15	56	5	0	2

Note. Data for adults without disabilities from Kozleski and Sands (1992).

Table 2

Percentage of Participants in Community Activities and Leisure-Time Activities for National Consumer Survey (NCS) Respondents and Adults Without Disabilities (ND)

Question	More than twice weekly			1-4 per month			Monthly/less			Never		
	NCS	ND1 ^a	ND2 ^b	NCS	ND1	ND2	NCS	ND1	ND2	NCS	ND1	ND2
Community activities												
Visit others?	24	52	NA	32	35	NA	34	13	NA	10	0	NA
Shop at market?	19	21	29	42	75	67	18	5	1	21	0	2
Eat restaurant?	32	19	18	41	68	67	13	8	8	15	0	5
Go church/syn?	15	5	5	42	44	61	9	24	14	33	27	19
Shop at mall?	36	9	NA	40	65	NA	10	26	NA	14	0	NA
Go to bar?	6	4	NA	2	18	NA	1	43	NA	91	36	NA
Leisure-time activities ^c												
Go to movies?	-	-	-	25	32	26	33	63	53	42	5	22
Go to theater?	-	-	-	23	6	5	8	68	55	69	26	40
Go to concert?	-	-	-	26	7	4	12	43	48	62	49	47
Go to sports?	-	-	-	24	21	15	22	63	34	54	17	50

^aSubjects from Kozleski and Sands (1992). ^bSubjects from the International Center for Disability Survey. ^cHow many times in last year.

Finally, individual perceptions of independence, integration, and productivity were identified as reflective of the self-determination of people with mental retardation. As discussed previously, six questions were posed, asking respondents to indicate on a Likert-type scale from 1 (*totally*) to 5 (*not at all*) how independent, integrated, or productive they were. In addition to rating these outcomes, we asked individuals to identify, on the same scale of 1 (*very*) to 5 (*not at all*) how important each of the outcomes was. Figures 1, 2, and 3 provide these data.

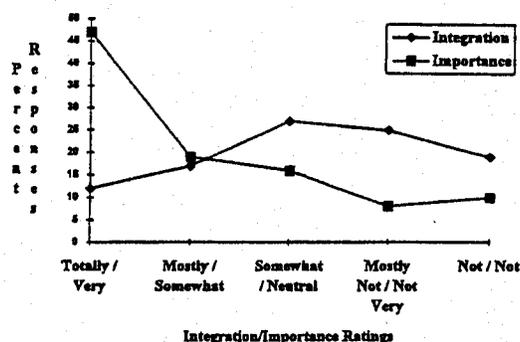


Figure 2. Percentage of National Consumer Survey responses by ratings of integration and according to how important integration was.

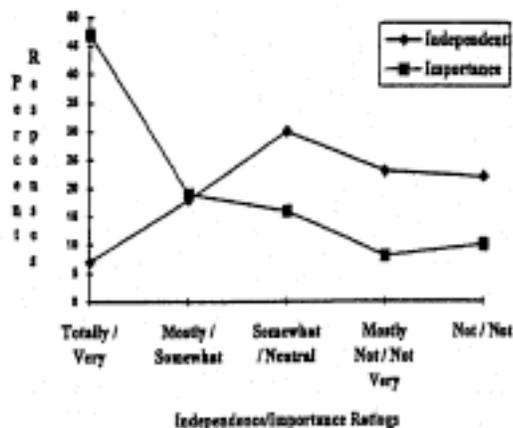


Figure 1. Percentage of National Consumer Survey responses by ratings of independence and according to how important independence was.

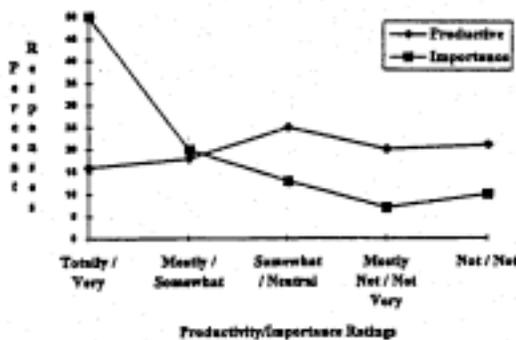


Figure 3. Percentage of National Consumer Survey responses by ratings of productivity and according to how important productivity was.

Discussion

These data suggest very strongly that people with mental retardation are not likely to be selfdetermining. Respondents perceived themselves as having fewer choices and less control than did respondents without disabilities. The dominant perception of the level of integration, independence, and productivity for individuals with mental retardation was one of neutrality, although the perceived importance of these outcomes was overwhelmingly affirmed. The reasons for this are undoubtedly numerous. Educational and home environments that are overly structured or overprotective and do not place emphasis on opportunities to make meaningful choices and decisions and to develop the skills necessary to make decisions and solve problems are contributors. Individual limitations inherent in the severity of a person's disability also play a role as do the expectations of families, educators, and service providers. People with mental retardation are not perceived as capable of assuming adult roles, such as spouse or home owner. The same was true several years ago about roles such as learner or employee, assumptions that have subsequently been shown to be erroneous.

Several trends that emerged from the data warrant discussion. The first is that the probability that people with mental retardation will be allowed to participate in choices and decisions that affect their lives appears to be related to the relative importance of these decisions. As such, these individuals are likely to have some voice in the selection of the clothing they wear or the leisure activity in which they engage, within certain parameters (see following discussion), but not likely to be involved in weightier decisions, such as choosing one's roommate or consenting to medical procedures. Again, the reasons for this are multiple and complex. There are difficult decisions resulting from conflicts between issues of protection and safety versus autonomy and risk. Nevertheless, to the extent that every human being deserves the right to participate in decisions that impact his or her life, there is much that can and should change. Although it may be prudent to request assistance in making decisions, such as consent to medication, there needs to be greater involvement of the individual in these decisions. Too large a proportion of National Consumer Survey respondents indicated that they had no say in selecting a roommate, choosing a house in which to live, or approving the hiring of staff members. Americans without cognitive disabilities would find

this situation largely intolerable, and we believe that it should be so for all Americans.

A second observation is that choices for adults with mental retardation are often "all or nothing." Although the modal level of participation for adults with disabilities in activities such as movie or theater attendance was moderate (i.e., a few times a year or month), the preponderance of responses from National Consumer Survey participants fell in the extremes, either never attending such activities or attending an inordinate number of times. One can only speculate as to the reason for this phenomenon, but we suggest that at least one contributing factor is that people with mental retardation have no real choice in whether they participate in certain functions or not. Instead, activities are selected by others, often people paid to supervise these activities, and the individual either goes on an outing with a group of peers-supervised of course--to a park or the mall, or--if the community is charitable--to movies, theaters, and sporting events with donated tickets. In other cases, because the supervising personnel do not, for financial, staffing pattern, or other reasons, initiate such activities, adults with mental retardation simply do not have those experiences.

Similarly, the choices that adults with mental retardation have appear to be limited in variety. Lord and Pedlar (1991) examined the choices available to residents of group homes and concluded that:

In a few situations, residents were exercising choice about such things as menu planning, leisure time activities and purchasing clothes. More often, however, they were at best invited and at worst cold to do something. Some staff members saw the residents as having choice in their lives because they could choose ways of filling unprogrammed free time in an evening. (p. 217)

Likewise, individuals can choose from a constrained number of social activities too frequently selected by others and reliant on variables that include the availability of staff, transportation, and money. Or, they can choose from two residential options: stay at the nursing home or institution or go to an 8-bed group home in an area away from family or friends; attend the movie with six others or stay at home; eat a hot meal at 5 o'clock or a cold one later (if that option is even available); work at the sheltered workshop or participate in daylong active treatment programs.

A final trend is that, due to economic, societal, and other variables, people with mental retardation are not assuming roles and engaging in activities that serve to define an individual as an adult. Adults with mental retardation do not appear to have the option of getting married, much less have children. Again, these are issues that professionals and family members struggle with and are concerned about, and there are no straightforward answers. The societal prohibition against individuals with mental retardation marrying is pervasive and springs from fears as old as the eugenics movement of the early part of this century. Mention the possibility of an individual with mental retardation marrying, and concerned others will raise questions about that person's understanding of love and marriage and the possibility that this union will result in children. The former is at best hypocritical in a society that leads the world in divorces, and the latter is based almost exclusively on fear, as empirical evidence regarding people with mental retardation as parents is virtually nonexistent.

Other roles are prohibited more by economic realities. People with mental retardation live too frequently on wages that are certainly poverty level and frequently absurd. This reality certainly prohibits outcomes such as home ownership, but how much do our own expectations for residential outcomes play a role in this? We do not perceive adults with mental retardation as home owners, and we typically do not consider that alternative.

Despite these unfortunate circumstances, there is hope that future outcomes will be more positive. Trends toward supported living and work provide increased opportunity for autonomy and choice. The increasing visibility of people with disabilities in the mainstream of American life through the auspices of the self-advocacy and self-help movements and through legislative actions such as the Americans with Disabilities Act will eventually break down attitudinal barriers and defuse stereotypes. Attitudinal and economic barriers will remain; however, individual self-determination really transcends either one of these realities. Sienkiewicz-Mercer described her life in an institution and then in the community, indicating that despite the fact that she and her husband lived at what can be described at best as a subsistence level economically, she would never return to previous times. Why? Simply put, she felt that she had the opportunity to be self-determining. "I go grocery

shopping for myself, and my personal care attendants ask me what I *want to do* and *when I want to do it* [italics added]" (Sienkiewicz-Mercer & Kaplan, 1989, p. 225).

Demaresse (1989), who like Sienkiewicz-Mercer lived in an institution for much of her early life, wrote eloquently about the erroneous dichotomy established too often in the human services between false hope and true hope. She wondered why we spend so much energy worrying about creating false hope when hope may be the only factor to sustain an individual and to give them a vision and a purpose:

In the end, I did move out of the institution and into the community; I am living with the kind of quiet, country setting I dreamed about; I do have the kind of assistance and help I had hoped for, and my time is spent writing the book I have always dreamed of, without the institution dictating where and when I could do all kinds of things I like best. I am glad that a group of us got together to share some "false hope." (p. 9)

There will always be excuses--some with face validity, others without—as to why people with mental retardation cannot be self-determining. It is clear that currently this is rarely an option. It is also clear that people with disabilities have the same right to self-determination as all human beings. We need to create some false hope and move forward to make this a reality.

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