

**Quality of Life of Marylanders with Developmental Disabilities  
Participating in the Robert Wood Johnson  
Self Determination Initiative**

**Final Report**

Prepared for the  
Maryland Developmental Disabilities Council

By  
Gordon Scott Bonham, Ph.D., President, Bonham Research  
Sarah Basehart, Director for Community Programs, The Arc of Maryland  
Cristine Boswell Marchand, Executive Director, The Arc of Maryland

September 16, 2000

## **Executive Summary**

The Arc of Maryland conducted interviews for 60 people participating in the Self Determination Initiative (SDI) in four Maryland counties around August 1998. Most (83%) responded for themselves to interviewers who also had developmental disabilities. Followup interviews were conducted an average of 19 months later for 54 people. The report analyzes the personal characteristics, services received and the quality of life of participants at the beginning of SDI and the changes that occurred during the SDI.

People participating in the SDI were more likely to be male than female and were adults of various ages. They were most likely to have mild retardation. Over half had behavioral or emotional challenges, and one-third had speech or communication problems. The majority lived in alternative living units (ALUs). Agencies reported one-third came from the waiting list, although only one-tenth had no support prior to the initiative. Planning started before 1998 for about one-half. The SDI participants differed on a few characteristics from people receiving services from ten agencies and interviewed as part of the FY1998 Ask Me! Year One— they were more likely than those in the Ask Me! Year One to have behavioral and emotional challenges, and live in ALUs, to be in day programs, and less likely to be medically fragile and live independently or with their families.

Three-fourths of the SDI participants at the baseline interview said they would like to change some of their services. Half felt they had a lot of choice in their service brokers, and half felt service brokers were always around when needed. County differences at the baseline were greatly reduced by followup. Although some people seemed confused at baseline about their service brokers, followup data confirmed the importance of baseline satisfaction with the broker.

The quality of life of reported by people at the start of the SDI was similar to that reported in the Ask Me! Year One, and the relationships among different life areas were also similar. Little net change occurred between baseline and followup in the way people answered the interview questions. However, the changes in Allegany and Garrett Counties tended to be positive, while those in Howard and Washington Counties tended to be negative, reducing the initial observed geographical differences. Changes in their quality of life for individuals between the baseline and followup confirmed the hypothesized causal relationships developed from both the SDI baseline data and the Ask Me! Year One data. Specifically, they demonstrate that:

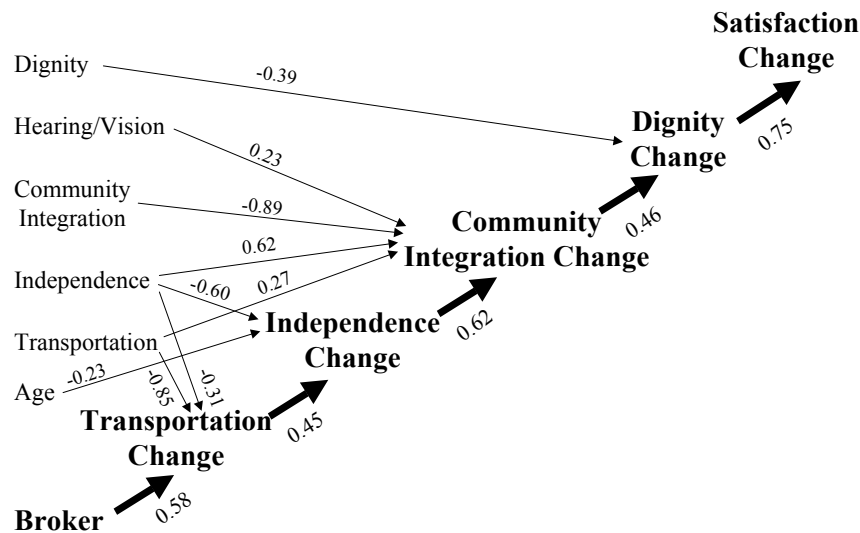
- General satisfaction with life is most affected by peoples' perceptions of dignity
- Perceptions of dignity are primarily affected by their integration into their communities
- Integration into the community is primarily affected by a person's level of independence
- Transportation is the service that consistently has impact upon people's quality of life
- Service brokers improved quality of life by improving the availability of transportation
- Quality of life of people can be increased independent of the baseline quality of life
- Most characteristics of people and the services they receive do not directly affect their quality of life, and those that do primarily affect people's levels of independence and community integration, not their sense of dignity and satisfaction with life in general.

## Key Findings and Recommendations

### 1. Service Coordination

Findings:

- The role of service coordination is central to the Self Determination Initiative. Baseline expressions of satisfaction with the service broker based on being chosen, knowledgeable, available, and open strongly related to people’s baseline quality of life measures.
- The changes in the quality of life of participants between baseline and followup interviews confirmed the importance of the service broker in improving the quality of life for people with developmental disabilities. Service brokers started a chain of events by improving the availability of transportation, which increased independence, which increased community integration, which increased dignity, which increased overall life



satisfaction.

- Satisfaction with the service broker was such a significant factor in increasing people’s quality of life that it overcame any characteristic related to the person’s disability, including their cognitive ability.
- The quality of life of all people can be improved, regardless of their baseline quality of life. The chain of cause and effect was independent of baseline availability of transportation, independence, community integration, dignity and life satisfaction. This chain was also independent of background characteristics of participants and their

services.

Recommendation:

- The Self Determination Initiative should focus attention on the role of the support broker/service coordinator by recognizing the significance of their impact on individuals with disabilities. The Initiative should consider what can be done to augment the effectiveness of service coordinators (such as training, support and authority roles) to enhance their impact on the lives of persons with disabilities.

## **2. Informed Choice and Decision-Making**

Finding:

- A majority of the individuals surveyed did not know they were part of a Self Determination Initiative. While two-thirds of the individuals at the time of the initial interview could identify services they wished to change, they were aware neither of the Initiative nor of new options available to them. Changes during the Initiative did not relate to desires for change at the beginning of the Initiative.

Recommendation:

- Individuals and their families need to know about the Initiative and all options so they can make meaningful, informed choices. The Initiative would benefit participants more by expanding outreach and information efforts to individuals and their families. Training and informational materials need to be specifically designed for individuals with developmental disabilities, self advocacy groups, and families to ensure outreach to those most impacted by the Initiative. Ongoing information is necessary to ensure that individuals with developmental disabilities and their families are fully informed of all efforts that can affect their lives.

## **3. Dignity**

Findings:

- Life satisfaction is most affected by people's perceptions of dignity afforded to them. This finding is consistent in both the pre and post surveys of the Self Determination Initiative, as well as, the three years of the Ask Me! surveys throughout the state.
- Many characteristics related to disability or the severity of disability had no impact on satisfaction with overall quality of life. Sex, age, complicating conditions (sight and hearing, speech, behavior, seizures, wheelchair use, and medical fragility) had no relation to any of the quality of life measures. Only IQ scores were related, and these related only to independence and integration into the community. IQ had no direct effect on quality

of work life, the dignity in which people felt treated, nor their overall satisfaction with life.

Recommendation:

- The finding regarding dignity should be shared with all stakeholders, providers and policy makers throughout the state to enhance all efforts and approaches aimed at increasing the dignity of persons with developmental disabilities. Dignity has other dimensions, such as individualized planning, how individuals' expressed wishes are addressed, and the manner in which individuals with disabilities are treated by family, friends and professionals. Training and information provided to families, providers, and individuals with developmental disabilities should highlight this important finding.

#### **4. Transportation**

Finding:

- Transportation is the one service that consistently affects people's independence and community integration and indirectly has impact upon all aspects of people's quality of life.

Recommendation:

- The perceived availability of transportation so strongly affects the quality of life of people with developmental disabilities that steps must be taken to improve transportation in order for them to realize the ultimate outcome of self-determined, integrated, and independent lives. It is recommended that this finding be widely distributed and emphasized with decision-makers at the state and local level, service providers, and service coordinators so they can combine their efforts to improve the availability of transportation. Transportation advocacy and improvement must not be left up to the individual with disabilities to figure out on their own.

#### **5. Employment**

Findings:

- Two areas directly contribute to overall satisfaction with life. The first is the dignity with which people feel they are treated by others. The second is the quality of their work lives.
- The individuals interviewed for the Self Determination Initiative primarily participated in supported employment and day programs.
- Only a few worked in competitive employment or were in vocational programs.

- Over 90% of the people remained in the same level of employment during the 18-month period.

Recommendation:

- Employment opportunities, earnings, and increased employment independence should be an important aspect of the Self Determination Initiative. It is recommended that the Initiative promote new opportunities, models and approaches to meaningful employment, including supported and competitive employment.

## **6. Residential Supports**

Finding:

- The evaluation analyzed changes in people's feelings of quality of life based on changes in their residential service and the funding level of that service. Those for whom a change in residential supports was realized but the service cost decreased expressed the greatest increase in their overall satisfaction with life, in their feelings of dignity, and their sense of integration into the community. People with other combinations of changes expressed declines in their quality of life. People with no change in living arrangements and no change in funding expressed no change in quality of life.

Recommendation:

- State funding authorities and agencies providing services should continue and encourage development of individualized residential supports that allow and support people with developmental disabilities to determine where they live and with whom, and what services are provided to support them in homes of their own choosing.

## **7. Longitudinal Study for Outcomes**

Findings:

- The Ask Me! Self Determination Initiative Evaluation was based on people's experiences over a 19-month period. Some changes in scale scores of independence and community integration occurred within this relatively short period. However, many changes in quality of life are expected to require a longer period of time before they become evident, and short-term changes may not endure or fully represent long term change.
- The Ask Me! SDI Evaluation demonstrated that individual outcome data can be linked to state funding of services. Such information can provide useful information to policymakers in determining the future direction of services and supports to persons with developmental disabilities.

Recommendation:

- It is recommended that the Council and DDA consider a longitudinal study regarding individual outcomes, including quality of life, of persons involved in Maryland's Self Determination Initiative to assist in providing information to guide the State in overall funding and policy decisions.