

**Independent Evaluation
of Tri-Alliance/Arc of North Carolina
Self-Determination Project**

Submitted to:
Tri-Alliance/The Arc of North Carolina
Attention: Lee Covington
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Submitted by:
Jeffrey X. Seiders, Marguerite Brown, Amanda Fullerton, and James Conroy
The Center for Outcome Analysis
1062 Lancaster Avenue, Suite 18C
Rosemont, Pennsylvania 19010
610-520-2007 and 610-520-5271 FAX
outcomeanalysis@aol.com

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Introduction

The Center for Outcome Analysis (COA) is conducting an intensive, longitudinal study of the impact of self-determination in North Carolina. COA's researchers have been committed to studying the principles and goals of self-determination since their participation with the Monadnock, New Hampshire project in 1993. COA has conducted individual interviews with more than 1,500 potential participants in the Robert Wood Johnson National Self-determination Project thus far. COA is also working with state and local authorities pursuing their own independent self-determination initiatives.

In today's climate of change, COA is uniquely qualified to assess the impacts of system changes on the lives of individuals. The essence of our work is the scientific, reliable measurement of individual outcomes. In order to fully comprehend the implications of major systems alterations such as deinstitutionalization, managed care, or self-determination, there is no substitute for measuring each person's qualities of life. Individual well being is the ultimate unit of accountability for service systems.

The evaluation of the Tri-Alliance self-determination project is an opportunity to examine the impact of the development, implementation and management of various strategies on the quality of life for the participants with disabilities and their families. COA is especially interested in studying this group, because they are all Thomas S. class members. We visited all of these people in past years, and collected the same kind of quality of life data that we are collecting for the Tri-Alliance self-determination evaluation. Thus we possess historical data the self-determination participants from interviews conducted in between 1993 and 1998 as part of the Thomas S. Longitudinal Study. This will provide enhanced

scientific power to explore long-term changes in the well-being of the participants in the self-determination work.

The primary research question for our evaluation of the Tri-Alliance self-determination initiative is to answer the question “Is this working?” In addition, we wish to ask “Under what conditions does it work best, how can we improve what we are doing, what are the ‘best practices’ in this realm, what individually-based accounting and accountability procedures can effectively replace the morass of red tape in which we all find ourselves at this point in history?”

Brief History of the Self-Determination Movement in the United States

The table below provides a condensed version of selected critical events in the unfolding of the self-determination movement.

- 1993 Original Proposal to Robert Wood Johnson Foundation (RWJF)
- 1994 Grants awarded to Monadnock Developmental Services, Keene, NH, and COA
- 1995 Preliminary 6-month evaluation outcomes at Monadnock show few significant changes
- 1996 18 month outcomes show large and diverse positive outcomes
- 1996 Statewide expansion in New Hampshire begins with additional RWJF grant
- 1996 RWJF Decision to go National
- 1997 Grants to 19 States
- 1998 10 More Planning Grants
- 1998 National Evaluation Begins via COA and HSRI
- 1998 10 More States Join With State Funds (including North Carolina)
- 1998 California is the first state to initiate self-determination via legislative action
- 1999 Michigan shows strong positive results in COA outcome database
- 2000 Three year cycles of RWJF grants are completed (several states extend)
- 2000 Center for Self-Determination is initiated by all five creators of the initial New Hampshire demonstration, housed in Wayne County Michigan

Obviously, self-determination has spread rapidly across the country. Even today, however, the movement must be viewed as a “demonstration effort.” The number of people across the country who are organizing their supports under the

principles of self-determination including individual budgets that they and their freely chosen allies truly control is between 2,000 and 5,000, depending on the details of the estimation method. Although the number of people is small, most analysts believe the efforts have the strong potential to effect massive, even revolutionary, systems change.

More detail on the unfolding of the national self-determination initiative is available from the RWJF National Program Office of the Self-Determination for Persons with Developmental Disabilities Initiative at www.self-determination.org.¹

¹ This website was closed recently without explanation. It will be necessary to contact the NPO by other means, such as telephone at 603-862-4810.

Methodology

The purpose of a Methods section in any scientific paper is to permit other scientists to duplicate our methods. This in turn permits science to advance via its most important criterion: replication. If many scientists, who may be working in different states, different situations, with different attitudes and different biases, obtain similar conclusions, then the conclusions are probably valid.

Methods: Instruments

The Center for Outcome Analysis (COA) package of measures of qualities of life is generally called the Personal Life Quality (PLQ) protocol. Many of the elements of this package evolved from the Pennhurst Longitudinal Study (Conroy & Bradley, 1985). Over the years, other groups have been added to the data base, such as all 600 people living in Community Living Arrangements in Philadelphia who were not members of the Pennhurst Class, more than 3,000 people receiving supports in Oklahoma, 2,400 people who moved from institution to community in California, and 2,500 people involved in self-determination efforts nationwide.

The battery of instruments was based on the notion that "quality of life" is inherently multidimensional (Conroy, 1986). It is essential to measure many kinds of individual outcomes to gain an understanding of what aspects of quality of life have changed over time (Conroy & Feinstein, 1990a). Modifications made to the battery of instruments over the years have been based on the concept of "valued outcomes" (Conroy & Feinstein, 1990b; Shea, 1992). Professionals may value some outcomes most highly, such as behavioral development; parents and other relatives may value permanence, safety, and comfort more highly; and people with mental retardation may value having freedom, money, and friends most highly. The goal in our research on deinstitutionalization, and later in self-determination, has been to learn how to measure aspects of all of these "valued outcomes" reliably.

Behavior

The behavioral measures were usually shortened forms of the original AAMR Adaptive Behavior Scale (Nihira, Foster, Shellhaas, & Leland, 1974). The first part contained 32 items on adaptive behavior, and the second, 15 items on the frequency of challenging behaviors. The measures were shortened on the basis of the mathematical criteria of factor structure and reliability. According to Arndt (1981), the best way to treat these type of data is as two simple additive scales, one reflecting adaptive behavior and the other challenging behavior. The adaptive behavior sum score has been found to be highly reliable (Devlin, 1989), with an interrater reliability of .95 and test-retest reliability of .96. For the maladaptive behavior section, interrater reliability was .96 and test-retest was .78.

Productivity

Productivity was reflected by earnings, by the amount of time engaged in daytime activities that were designed to be productive (adult day activities, vocational training, workshops, supported and competitive employment), and by the amount of time reported to be engaged in developmentally oriented activities in the home. Through the instrument package estimates were made of the amount of each of 17 services delivered in the preceding 4 weeks, such as dressing skills training, occupational therapy, and behavioral interventions.

Many versions of the PLQ also contain the “Orientation Toward Productive Activities” scale, composed of 12 simple items concerning being on time, showing enthusiasm about work, keeping a job, and getting promotions. This scale has not yet been subjected to reliability testing. It did, however, show significant increases during the first New Hampshire implementation of self-determination, and also

during deinstitutionalization in Indiana, so there is some reason to believe that it is sensitive to meaningful changes.

Choice Making

The scale of choice making is called the Decision Control Inventory. It is composed of 35 ratings of the extent to which minor and major life decisions are made by paid staff versus the focus person and/or unpaid friends and relatives. Each rating is given on a 10 point scale, where 0 means the choice is made entirely by paid staff/professionals, 10 means the choice is made entirely by the focus person (and/or unpaid trusted others), and 5 means the choice is shared equally. This is the same scale being used by COA to evaluate the Robert Wood Johnson Foundation's Self-Determination initiatives in 29 states. The interrater reliability of the Inventory was reported as .86 (Conroy, 1995.)

Integration

The scale used to assess integration was taken from the Harris poll of Americans with and without disabilities (Taylor, Kagay, & Leichenko, 1986). It measured how often people visit with friends, go shopping, go to a place of worship, engage in recreation, and so on, in the presence of non-disabled citizens. The scale tapped only half of the true meaning of integration; if integration is composed of both presence and participation, then the Harris scale reflects only the first part. Presence in the community is a necessary but not sufficient condition for participation in the community. The scale simply counts the number of "outings" to places where non-disabled citizens might be present. The scale is restricted to the preceding month. The interrater reliability of this scale was reported to be very low when the two interviews were separated by 8 weeks, but very high when the time interval was corrected for (.97).

Indicators of the Individual Planning Process

Most PLQ versions now include the “Elements of the Planning Process” scale, which is designed to reflect the degree to which planning is carried out in a “person-centered” manner. The Individual Planning section also captures aspects of how and how often planning events occurred. Another section captures the membership of the planning team, according to paid or unpaid, invited or not invited by the focus person, and family member or not. The section includes a snapshot of the plan’s content. This snapshot captures the nature of each goal, desire, or preference in the Plan, plus the degree to which each goal is being addressed by formal or informal supports, and the extent of progress seen thus far toward the goal. These new elements have not yet been subjected to reliability testing.

Personal Interview

One of the central problems in measuring quality of life among people with developmental disabilities has been that many people cannot communicate with interviewers, whether by traditional verbal, or by any non-traditional, means. Hence many researchers have permitted surrogates to “speak for” the person. We reserve the Personal Interview of the PLQ as the one section where no surrogates are permitted. This section is intended to capture the person’s thoughts. No surrogate or substitute respondents are permitted.

So much of the rest of the PLQ can be collected from third parties who know the person well, that it is fitting that there is one place where we who are “listening” to the data will know that this is directly from the focus person. The Personal Interview is left blank if we fail to find a way to communicate with the person. That may be unfortunate, yet it is mitigated by the fact that we still have

all the dozens of other quality of life measures that can be collected by third parties. And, in the final analysis, we must have one place that is set apart, and only the focus people themselves can put their thoughts and feelings into it.

The Personal Interview is primarily designed as five point scales, which can be asked as two Either-Or questions. (For example, “How is the food here? Good? OK, would you say Good, or Very Good?”) We know from the work of Sigelman et al. (1981) that Yes-No questions should be avoided when interviewing people with cognitive disabilities, because of the threats of acquiescence and nay-saying. The best overall question design for many purposes is Either-Or, because most people can answer it easily, and it is not threatened by the problems of the Yes-No format. There are also open-ended items throughout the Personal Interview, and answers to these are written down verbatim for qualitative analysis. (Example: “What things are most important for you to be happy?” and “If you had one wish, what would you wish for?”)

Methods: Procedures

The project recruited and trained local professionals, paraprofessionals, students, and advocates to perform a data collection visit with each person in the sample. These data collectors, called “Visitors,” functioned as Independent Contractors. They were paid a fixed rate for each completed interview. Here are excerpts from the written instructions from our Personal Life Quality Protocol that we provided to the visitors:

This package is composed of many measures, scales, instruments, and interview items. Practically all of the information collected in this package is related to quality of life. In order to complete the package, you must have access to:

1. The person (to attempt a direct interview of any length, usually 5 to 15 minutes)
2. Whoever knows the individual best on a day to day basis (about 30 to 60 minutes)

3. The person's records, including medical records (about 5 to 10 minutes)
4. Sometimes, a health care professional familiar with the person (about 5 to 10 minutes)

With access to these four sources of information, and after some practice sessions, you will probably be able to complete this package within the range of 45 to 95 minutes.

Training for the Visitors was conducted by COA staff and consultants. Most of the Visitors were already experienced in using the PLQ from their work on the Thomas S. project. Hence for this project the “training” was really a refresher session, designed to answer any confusions and questions that had arisen, as well as to go over in detail the differences between the self-determination form of the instrument and the form used for the Thomas S. study.

Results

1. Characteristics of the Participants

Table 1 shows the distribution of basic characteristics among the 34 participants, including sex, ethnicity, average age, and label for level of mental retardation.

Table 1
Demographic Characteristics of the Participants
Mean Age = 44 years

	Number	Percent
Gender		
Male	23	67.6%
Female	11	32.4%
Ethnicity		
Caucasian American	24	70.6%
African American	10	29.4%
Level of Mental Retardation		
None	1	2.9%
Mild	14	41.2%
Moderate	12	35.3%
Severe	3	8.8%
Profound	4	11.8%

The majority of the participants were male (67.6%), and Caucasian American (70.6%). The most common level of mental retardation label was “Mild” (41.2%).

Table 2 shows the distribution of “major” secondary disabilities among the participants. “Major” was defined by the participants and their representatives, not by the interviewers. Thus the definition of “major disability” was that of the perception of the respondents.

Table 2
Secondary Disabilities Reported as “Major Disability”

	Frequency	Percent
Ambulation	4	11.8%
Autism	2	5.9%
Aggressive Behavior	7	20.6%
Self-Abusive Behavior	4	11.8%
Brain Injury	4	11.8%
Cerebral Palsy	0	0.0%
Communication	5	14.7%
Dementia	1	2.9%
Health Problems	9	26.5%
Hearing	0	0.0%
Mental Illness	16	47.1%
Physical Disabilities	3	9.1%
Seizures	4	11.8%
Substance Abuse	2	5.9%
Vision	2	5.9%
Other	3	8.8%

The most common “major” disabilities were Mental Illness (47.1%), followed by Health Problems (26.5%), and Aggressive or Destructive Behaviors (20.6%). For Thomas S. class members, the Mental Illness finding was expected. These class members were identified by the courts as having characteristics or experiences related to dual diagnoses.

The participants’ current living situations are presented in Table 3.

Table 3
Current Living Situation for Participants

	Number	Percent
State MR Center	3	8.8%
Nursing Home or SNF	1	2.9%
DDA Group Home/Apt 24 Hr Supv	8	23.5%
Supv Living Home/Apt 11-23 Hr Supv	2	5.9%
Alternate Family Living Program	1	2.9%
Natural or Adoptive Family Home/Apt	7	20.6%
Independent Living	8	23.5%
Rest Home	4	11.8%

The highest percentages of participants lived either in DDA Group Homes or in Independent Living arrangements (23.5%), followed by those people living in the Natural or Adoptive Family Homes (20.6%).

2. Choice Making

As stated previously in this report, COA was involved with tracking the well being and progress of people who were class members in the Thomas S. suit. The instruments used for that study were slightly different than those used to evaluate self-determination. However, there were enough similarities to permit analysis of changes in several areas, including choicemaking and integration.

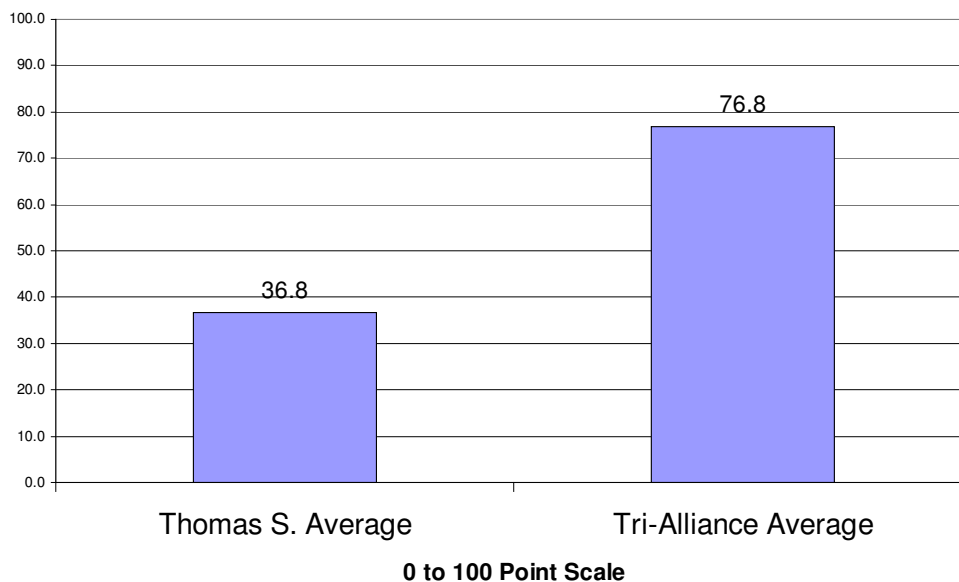
COA's first visits to these 34 Tri-Alliance people were conducted when they were involved in the Thomas S. case, sometime between 1993 and 1998. When we analyze changes in quality of life over many years, therefore, we cannot assume that the changes are the result of recent involvement in self-determination. It is actually more likely that any historical changes we detect will be the result of involvement in the Thomas S. case. (We already know that the changes for Thomas S. class members were very positive.) In the future, we will be able to

track *further* enhancements in qualities of life, and these future enhancements *can* be inferred to result from self-determination. The reason this is scientifically interesting is that we will be able to explore an issue never before studied: Are the quality of life improvements from deinstitutionalization similar to, larger than, or smaller than, those associated with self-determination?

The Decision Control Inventory measures who has power over 35 life areas such as clothes to wear, food to eat, places to go, and type of work or day program. The scale requires ratings from 0 to 10 on each dimension, with 0 meaning that paid staff hold all power, and 10 meaning that the focus person (and his/her freely chosen unpaid allies) hold all the power. A score of 5 or 6 means that power is shared about equally. The 35 “0-to-10” scores can be combined into a single scale which we compute so that it can range from 0 to 100, with higher scores meaning more individual control over life choices, and, conversely, less professional domination.

For this report, we took the average scores of all Thomas S. class members from our first visit with them. We compared those overall average scores to the average scores of the 34 current Tri-Alliance self-determination participants. This comparison is shown in the following graph.

Decision Control Inventory



Although we cannot assume that the large difference in choicemaking opportunities is “caused by” self-determination (and it probably is not), it is interesting and gratifying, in our view, to see how far these people have come in the past few years. The exciting research question for the future will be “How much farther can they go with self-determination.”

3. Integration

The scale used to measure integration was taken from the Harris poll of Americans with and without disabilities (Taylor, Kagay, & Leichenko, 1986). Respondents were asked to report how often people engaged in a variety of community events in a typical month. Events on the scale included activities such as: visit with friends, go shopping, go to a place of worship, engage in recreation, etc. A second qualifier for this scale was events that involved the presence of

people without disabilities. This tool simply counted the number of “outings” to places where there might be interaction with non-disabled citizens. It did not measure actual engagement or the degree of participation. During the 2000 Visit, the participants had opportunities for integrated activities an average of 46 times per month. This average was much larger than the Thomas S. baseline average of 9 times per month. Table 4 shows the average number of monthly outings by type for the baseline and the recent Tri-Alliance visit.

Table 4
Types of Integrative Activities

Type of Outing	First Visit Average # of Events Per Month	2000 Visit Average # of Events Per Month
Visit With Close Friends	1.4	9.9
Go To A Restaurant	1.2	6.7
Go To A Shopping Center	1.3	6.6
Other Kind Of Getting Out	0.2	6.6
Visit A Grocery Store	0.8	4.9
Go To A Health Or Exercise Club	0.1	2.6
Go To A Bank	0.1	2.5
Go To A Park Or Playground	1.4	2.4
Go To Church	1.1	2.1
Go To A Post Office	0.1	1.3
Go To A Library	0.4	1.2
Go To A Movie	0.4	0.6
Go To A Theater	0.1	0.6
Go To Bars	0.0	0.3
Go To A Sports Event	0.5	0.2
Use Public Transportation	0.0	0.2

The most frequent kind of integrated community activity reported by the participants, or by those who knew them best, was visits to friends, at an average of 9.9 visits per month. The next most frequent kind of outing was going to a

restaurant, (6.7 times per month), followed by going to a shopping center and “other” kinds of getting out (both 6.6 times per month). Examination of the table shows that the baseline integrative activities were not only less frequent than in our recent Tri-Alliance visits, but they also showed different patterns of activities.

4. Qualities of Life

The next analysis did not compare Thomas S. data to Tri-Alliance data. Instead, it explored peoples’ perceptions of their life qualities before self-determination and during self-determination.

The Quality of Life Changes scale addressed fourteen dimensions of quality of life, including health, friendships, safety, and comfort. The person, or whoever knew the person best, gave numeric ratings of the person’s qualities of life before becoming involved with self-determination (then) and during involvement with self-determination efforts (now). If the respondent did not have first hand knowledge of conditions prior to self-determination involvement, we accepted their perceptions based on what they had read, heard, and been told by the person and others close to the person. It is important to note that this scale measured perceptions only.

Table 5
Perceived Changes in Qualities of Life “Before SD” and “Now”

Quality of Life Area	Before SD	Now	Change	p
Running own life, making choices	3.1	4.1	1.0	0.000
Relationship with friends	3.3	4.1	0.8	0.001
Getting out/getting around	3.2	4.0	0.8	0.001
Comfort	3.3	4.1	0.8	0.001
Treatment by staff	3.6	4.4	0.8	0.000
Overall quality of life	3.5	4.3	0.8	0.000
What he/she does all day	3.3	4.0	0.7	0.002
Food	3.5	4.2	0.7	0.002
Happiness	3.5	4.2	0.7	0.002
Relationship with family	3.6	4.2	0.6	0.000
Safety	3.6	4.2	0.6	0.007
Privacy	3.6	4.2	0.6	0.004
Health care	3.5	4.0	0.5	0.002
Health	3.4	3.8	0.4	0.017

Table 5 shows statistically significant changes in all fourteen quality of life areas. The largest perceived change was in “Running own life, making choices.” Relationships with friends, Getting out/Getting around, Comfort, Treatment by staff, and Overall quality of life, were all tied. There could be little doubt that these participants believed their lives had improved over the recent past.

5. Living Arrangements

During the personal interview, the people were asked what they like about living where they live. Most of them responded with characteristics of their house or apartment, including the fact in the case of one respondent that they owned their home. Others responded that they liked the people living with or near them, or the people who worked with them. These responses are shown below.

Table 6
What do you like about living here?

- Go out eat, go to dance, eat
- On my own, food pretty good, get to do what I want
- Cleaning the house and floor
- Likes trees in yard, got new blinds, likes housemates
- Staff
- My neighbor
- Likes brothers and sisters, has his own rabbits, has his own room
- Take own shower, moved everything
- Cook out
- I like with my Mama and we get along good
- The people
- Apartment is nice
- It's mine, I like my apartment
- Living with my family
- No rent, own it

When asked what they did **not** like about living where they lived, the responses ranged from being nothing that they didn't like, to wanting to move to a specific place. Below are the verbatim responses to the question, "What do you not like about living here?"

Table 7
What do you not like about living here?

- A man living here is going to hit me
- Go bowling
- Likes everything
- Nothing
- Change
- Sometimes dislikes oldest sister, mows yard, paying rent here
- Nothing (3)
- Want to go to a project to be closer to places
- Want to move to Salisbury to be near my kids
- Kids here tease me
- Nothing like more privacy in the country

When asked where they would rather live, there were few responses overall, but most people responding to this question had a definite place in mind. These responses are shown below.

Table 8
Where would you rather live?

- Moving to another place, lease is up
- Live with brother
- Because of lease
- Oakdale
- Project
- Salisbury

6. Happiness

The question of what was important to the focus person's happiness was asked in both the caregiver portion of the questionnaire and in the personal interview portion. In the following two tables, the responses from both portions are given for comparison. Below are the responses from the caregiver portion of the questionnaire.

Table 9
Things Important to Happiness

Caregiver Response

Wife
Money (9)
Health (2)
To have stability
To engage in meaningful activities
To feel safe
Mail coming to him
Being left alone
Puzzles
His independence

Access to alcohol
Moving out on his own
Having a job (8)
Vacation
Carol for supports
Staff friendships
Drinks
Chocolate
People to talk to
Being connected (trust) (2)
Living where mother does at rest home
Family
School
Family be close
Positive stimulation
Going off campus
Being around people with the skills to redirect her
Independence from Mother
To be treated as an adult, not as a disabled child
Self-Advocacy (2)
Friends
Getting to choose
Eat favorite foods
Mom
Spaghetti
Rest
Depend on someone, support
Feel secure, accepted
Animals
Pocket things
Private rest time
Living independently
Friends
Getting a house
Continue to see Mom and brothers
Father
Own apartment
Shopping
Have a girlfriend/wife
Have a moped/means of mobility
Family
Church

Coffee
Sex
Staying active
Being cared about
Snuff
Feeling safe
His family
Talking about things from his past
Going to church and activities in Nursing Home
Going out
Someone to talk to
Having staff help him at home
Visiting with brother
Gayle girlfriend
Cynthia cousin
Food/going out to eat
Privacy
Make own decisions

On the following page are the responses from the personal interview portion of the questionnaire. The personal interview was conducted with persons who could communicate with the Visitors without assistance.

Table 10
Things Important to Happiness

Focus People's Response
Being with granddaughter
Being alive
Be with my wife
God (5)
People getting along
Happiness
People
My kids
Being alive
Taking care of children
My vacation
Not being treated differently because of disability
Speaking out on self-advocacy issues

Go places
 Friends
 Like to be with people
 Go places/Do things
 Having money
 Job (7)
 Daddy
 Cigarettes
 I want a moped and a driver's license
 Likes to tickle younger sister and make her laugh
 Lay down and go to sleep
 Take a shower
 Women
 Sex
 Working with Thomas
 Cleaning the house
 Brother
 Going to see brother
 Buy my brother cigar
 How your life is
 Get a haircut

Following are the caregiver responses to the question “what makes this person the most unhappy”? There was a broad range of responses but in general they reflect the fact that these caregivers have extensive knowledge about the people they support.

Table 11
What things make this person the most unhappy?

Caregiver Responses
 Not making decisions
 Not being healthy (8)
 Not working (3)
 Ask him not to do something
 Not able to get out
 No cigarettes and/or money (8)
 Unfamiliar people, settings
 Not able to complete his routine

Not getting his meds on time
Anxiety of going away from nursing home
Pat P. doesn't wk with him each day
Being without snuff
Being disappointed with herself
People taking advantage of her
Not having sex
People telling him what to do (7)
Nothing
When kids tease me
When things don't go right
If he didn't have staff support
Lack of privacy
Lack of transportation/mobility
Being brain damaged
Lack of family contact (5)
Moving back to a group home
Memories of Broughton
Having a bunch of meetings
Not getting her way
Others talking about her
Waiting to get a house
Talking about him when he is present
Not following up on promises made to him
Questions
Seizures
Helmet
No spaghetti
Pressure
No sleep
Bigots
Discrimination
Mother's controlling behavior
No sandwiches
Peers picking on her
Becoming overtired
People teasing her
Having dental exams/work
Friends
Food
Drinks
Taking meds (2)

Living in rest home
Living in rural area
No mail
Not having a puzzle to do

These are the responses from the personal interview section regarding what makes people unhappy.

Table 12
What things make you the most unhappy?

Focus People's Response

Wearing glasses
Guy next door
Going to work
Arthritis, can't walk
Get worried
Don't sleep good sometimes
Wishes he was married
Feels alone a lot; feels bored a lot
I want people to stop jumping on me all the time
Brother's death
Sometimes people do not understand
When no one to cheer me up
Dog bites me
Helmet
Being seen for disability only
Cruel people
Not having found a wife
People who aren't nice
Nothing

7. Wishes

The last question in the PLQ is “What would you wish for this person”? Although some responses refer to health or disability issues, in general the responses are positive in tone and communicate personal concern for the person.

Table 13
What would you wish for this person?

Caregiver Response

To work at a job in Community

Gayle could live with him

To quit smoking

More natural supports & get out and have fun

Be able to go out by himself

Move to his family home

Situation where she would be safe and in control

No mental illness or at least control over it (3)

Have more friends/relationships

Increased self-esteem/confidence (2)

That he would heal emotionally and he could live a normal life

For him to be generally happy

For her to see how very bright and capable she is

For John to continue to be independent and happy as he is today

Leave WCC with support of family and their help

Seizures to stop

For Mom to let him try new things

For him to be able to talk

For everyone to be kind to everyone

For her to laugh more

That she take care of herself

To get a job

Extensive dental work, another living arrangement in the future

Unlimited money

Family visits

Move out and live independently (2)

Overcome his alcohol addiction

Find a way to pay for dentures and hearing aid

Leave him alone

Below are the focus people's wishes for themselves.

Table 14

What would you wish for ”

Focus People's Response

- Nothing at all
- A housetrailer
- Brand new clothes
- Money
- Get funeral home paid for
- To live on my own
- Go home with my Daddy
- Don't know what to say
- A house, to call my mother
- That everybody love God
- Don't wish on nothing
- Everybody to be happy
- Happiness
- Be normal again, no disability etc.

Conclusion

The data from our visits with the 34 participants are still quite limited. We cannot say with certainty whether they are “better off” being involved in self-determination, although it is abundantly clear that they and the people close to them *believe* that they are better off. We also know that, in several major dimensions, these people are far better off than they were when they first became Thomas S. class members.

This initial report is the first of a series. We will continue to visit and track the progress of these 34 “pioneers” of self-determination in North Carolina. We will be looking for continued enhancements in their lives. The reliability and validity of our measurement instruments will insure that we can detect future enhancements in qualities of life.