



PAL Quality of Life Initiative

***Moving from Awareness to Action:
A Five-Year Report***

December 2004

Funded by the Rhode Island Department of Mental Health, Retardation and Hospitals

Division of Developmental Disabilities

PAL Quality of Life Initiative, 96 Rolfe Street, Cranston, RI 02910, 401-785-2100, www.pal-ri.org

Introduction

Since 1991, PAL, a parent information and advocacy organization, has been contracted by the Rhode Island Division of Developmental Disabilities (DDD), within the Department of Mental Health, Retardation and Hospitals, to assess individual and statewide satisfaction with services offered to Rhode Islanders with developmental disabilities and their families. The PAL Quality of Life Initiative (QLI) is a face-to-face opportunity for people to voice their experiences about the supports they receive. The project is also part of a national effort for comparison with other states called the National Core Indicators (NCI) project, which is administered by the National Association of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI).

Process

A QLI Visitor meets for about one hour with people, asking questions about their lives at home and at work, their social opportunities, goals and dreams. The process offers point-in-time information about how the person reports their overall experience of the supports and services provided. Each participant answers a series of 100 questions. Approximately half are from the NCI project, available through HSRI for

state-to-state comparison.¹ At times, a staff person, family member, advocate or other person may have assisted the participant in answering the questions. The ability of participants to respond to our questions varies widely, from independently responding to all questions to participation through a helper/representative. Some NCI questions require that an answer be coded as "don't know, no response, unclear response" on the data sheet if someone other than the participant answers a question. We have opted to include these occasions in the percentiles of responses in order to ensure greatest consistency.² We continuously try to meet the ongoing challenge to get as close to a person's direct response as possible.

We recognize that sitting and answering questions for an hour can be difficult for the population of people we are interviewing. We have analyzed our previous year's data to assess the most important questions and highlight them on the interview tool. This year, if a visit must be abbreviated, we are able to quickly move to and focus

¹ A report of responses to NCI questions with state-to-state comparison is available at www.hsri.org.

² This report presents all responses, including percentages of "don't know, no response, unclear response". This report will vary from the report published by HSRI in that regard.

on the most important questions while we have optimal attention from the person we are visiting.

Project Scope

From September of 1999 to June of 2004, approximately 3600 people have been selected through the sampling process to participate in NCI/QLI interviews. Approximately 750 have declined, over 1000 are currently participating in the 2004-05 interview cycle. Over 1800 people with developmental disabilities have been interviewed in the NCI/QLI since 1999. The people interviewed are randomly chosen from a database of people who receive services through DDD. Each year after the initial year, we sampled a database of individuals from those who had not been visited in order to ensure everyone would eventually have an opportunity to participate. For various reasons, 7 of the 1829 people we visited over the past five years participated twice.

An effort has been made over the years of the project to proportionately distribute the participant interviews among the currently licensed private providers, the state's public provider and people who administer their own plans through a fiscal intermediary or are not supported through a provider agency. Participants reside in all counties of the state

of RI. Additional demographic details are provided in the first section of our report.

Report Details

Our *Moving from Awareness to Action: Five Year Report* includes the data we have collected over the past five years. It consists of seven sections, with items representative of the full questionnaire³: background information, employment/day support, home, health and safety, relationships, support, choice and human rights. The questions represent domains and sub-domains of the Core Indicators⁴ developed by NASDDDS and HSRI, and specific areas of interest identified by stakeholders in RI.

Unless otherwise noted, each item includes data for the over 1800 people we visited throughout the past 5 years. Some questions have been revised or updated over the years in an ongoing effort to collect ever-more-meaningful information. The RI Quality Consortium has helped the QLI to refine the questions from the perspective of various statewide

³ A copy of the full questionnaire and background information form is available upon request.

⁴ A complete list of NCI Core Indicators is also available upon request. The instruments used include both NCI standard questions, and those included by the QLI for clarification or expanded understanding.

quality efforts, dialogue and priority setting about the most important areas of focus. Over the past five years we have increased and expanded our capacity in data analysis and the provision of various reports using database applications. Year-to-year comparisons are provided where possible, based on continuity of the wording of items in the NCI/QLI questions. Some statistics are provided in conjunction with the National Core Indicators Project through the Human Services Research Institute (HSRI).

This report is intended as a source of information for assessing our collective progress in the developmental disabilities system and determining the need for increased focus. Some Concluding Thoughts are provided at the end of each section, with some final thoughts, Beyond Data and Concluding Reflections for the Future, closing our report.



It is a capital mistake to theorize before one has data. Insensibly one begins to twist facts to suit theories, instead of theories to suit facts.

Sir Arthur Conan Doyle
(1859 - 1930)

Statistics: The only science that enables different experts using the same figures to draw different conclusions.

Evan Esar (1899 - 1995)
Esar's Comic Dictionary



3842 people have been chosen to participate in the QLI since 1999.

And, since 1999, 1829 have accepted the opportunity and been visited through the QLI.

77.8% of the people we visited in the past three years had assistance with the visit

Over the past two years, when asked to rate how well assistants believe they know the person, the average rating was 4.58. (Scale 1-5; 5=very well)

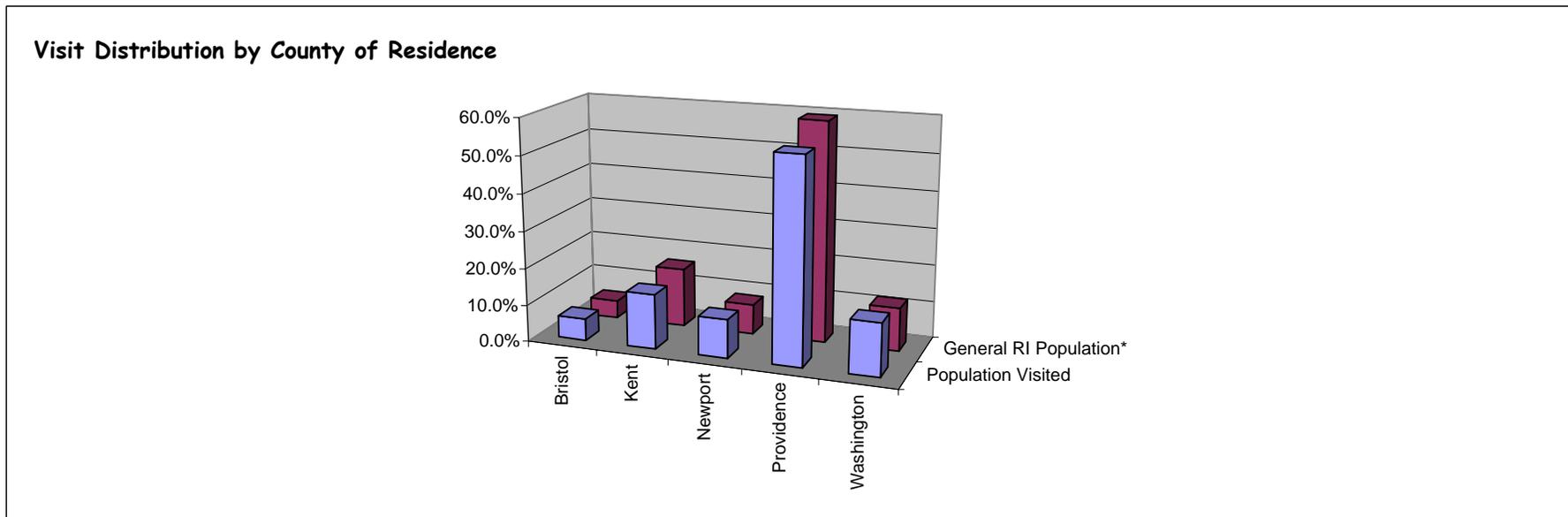
17.7% of the people invited to participate since 1999 declined the opportunity.

After a visit, PAL has followed up with almost 1000 people to assess progress with issues/requests noted during a QLI visit

We have distributed over 1800 resources from our Resource Library as a result of a need we noted at a visit since 1999.

The most popular include:

<i>Human Rights information</i>	<i>"What's on the Menu"</i>	<i>Employment</i>	<i>Dating/relationships</i>
<i>Self-Advocacy</i>	<i>"This is Your Life"</i>	<i>Voting</i>	



* Source: 2000 Census Data, United States Bureau of Census, from a table prepared by Mark G. Brown, RI Statewide Planning

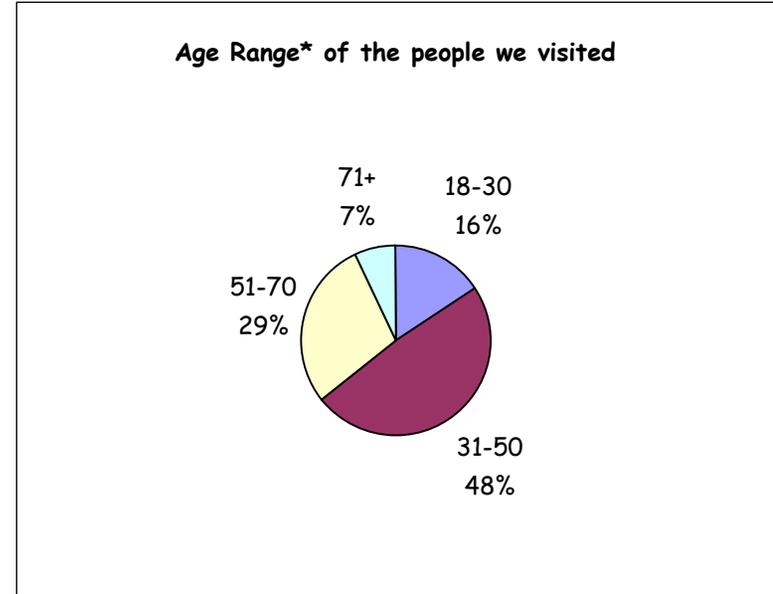
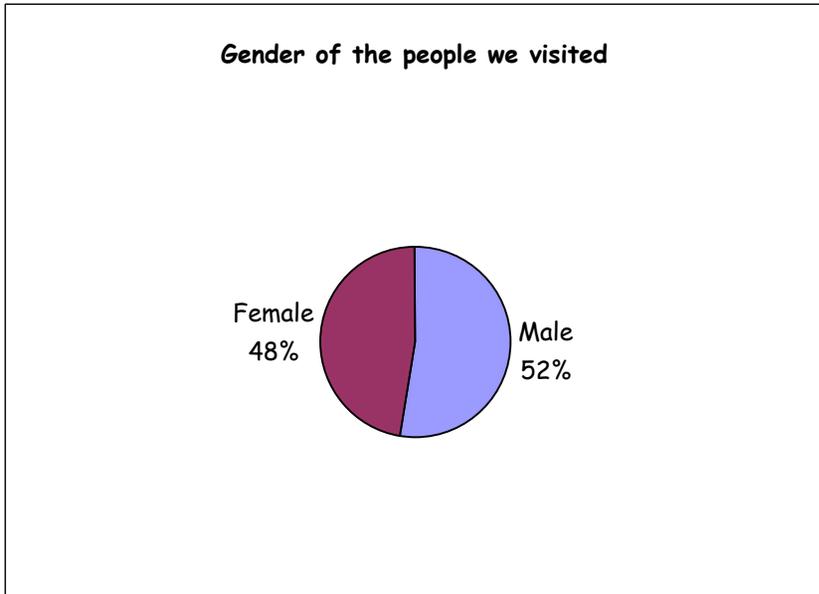
Visit and decline distribution by Support Provider

Please note: the first two columns should be approximately equal to indicate proper visit distribution/agency representation.

<i>% Visits</i>	<i>% of overall supports provided by agency**</i>	<i>% Declines</i>	
1.20%	7.92%	18.22%	No agency providing support; self-managed
7.22%	7.01%	11.40%	Arc of Northern Rhode Island
2.62%	1.43%	0.70%	Avatar
0.27%	0.09%	0.00%	Bev's Bees Nest
2.41%	1.71%	0.97%	Bridges
7.60%	7.76%	5.84%	Blackstone Valley Chapter RIArc
0.38%	0.65%	0.00%	Community Living of Rhode Island
0.38%	0.67%	0.56%	Corliss
1.97%	2.27%	0.70%	COVE Center
5.25%	5.43%	5.98%	Cranston Center
7.33%	5.85%	4.03%	The Fogarty Center
3.99%	3.48%	1.25%	Gateways to Change
0.16%	0.39%	0.14%	Justice Resource Institute
1.64%	2.49%	1.95%	LaPlante Center
2.62%	2.99%	2.50%	Life in Fulfilling Environments (LIFE)
4.87%	2.87%	1.11%	Looking Upwards
6.62%	6.79%	7.65%	Maher Center
0.05%	0.05%	0.00%	MENTOR
1.15%	2.42%	1.67%	Olean Center
1.37%	0.82%	0.42%	Opportunities Unlimited
2.84%	3.40%	0.56%	Ocean State Community Resources
8.37%	6.52%	8.21%	Perspectives
0.27%	0.34%	0.14%	Project Friends
0.00%	0.03%	0.00%	Rocky Knoll
3.94%	2.76%	2.92%	Re-Focus
9.02%	7.44%	0.70%	Rhode Island Community Living and Supports
1.42%	0.73%	0.14%	New England RMS
2.24%	1.33%	0.56%	Spurwink/RI
5.80%	7.88%	11.96%	Trudeau Center
0.98%	1.01%	0.83%	Training Thru Placement
1.69%	1.64%	2.50%	United Cerebral Palsy
4.16%	3.74%	5.84%	West Bay Residential
0.16%	0.80%	0.56%	Work Opportunities Unlimited

** % of services provided (not people supported); proportions provided from Department of MHRH database 09/04

83.3% of the visits over the past five years took place in the person's home. Almost 15% were conducted at a person's workplace And, 1.8% took place in an alternative location, such as at a parent's home or provider agency.



* Ages were calculated by the person's age as of 2004.

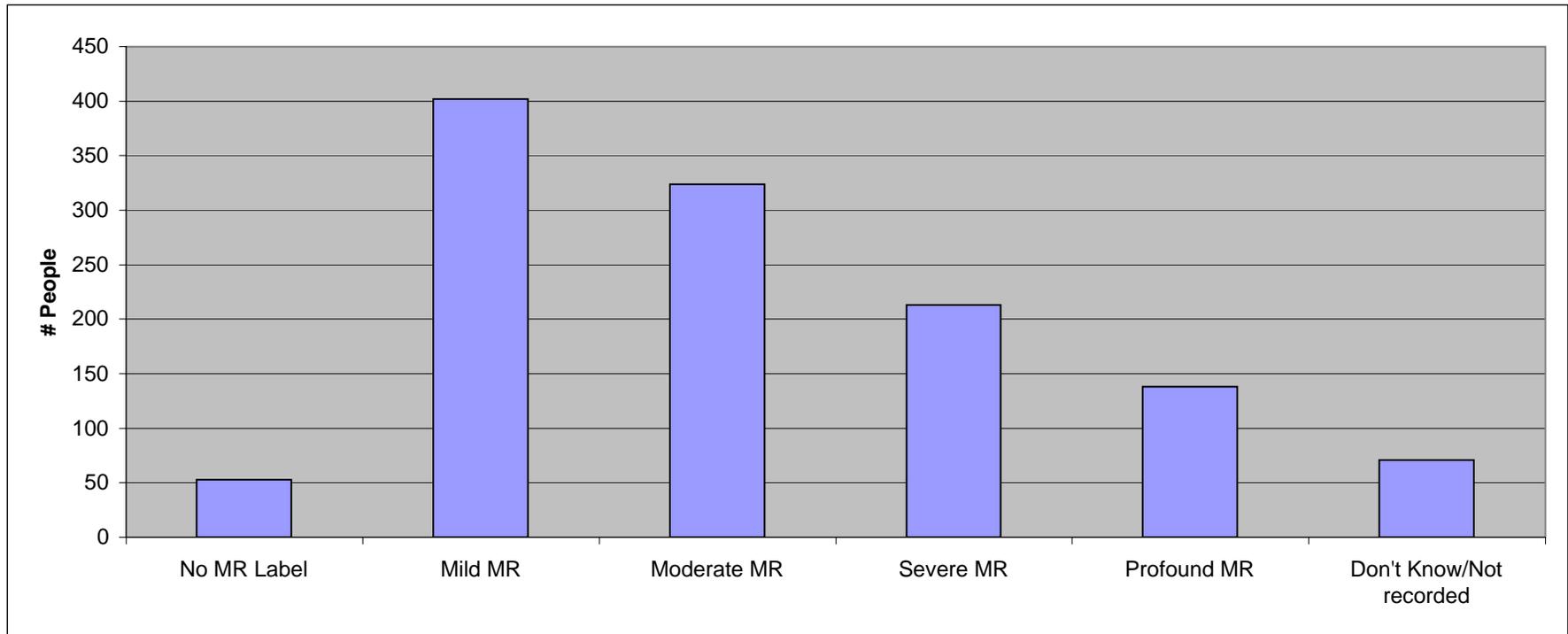
What is this person's primary means of expression?

	2000	2001	2002	2003	2004
Speaks English	83.2%	77.59%	75.3%	79.2%	84.0%
Uses gestures	11.2%	12.36%	13.0%	11.7%	8.3%
Uses communication device	1.0%	1.72%	1.8%	1.2%	1.8%
Speaks other primary language	0.7%	0.29%	1.3%	0.7%	1.0%
Uses sign language	0.3%	1.44%	1.3%	2.5%	0.8%
Other	3.6%	5.75%	7.5%	4.5%	4.3%

Does this person have a legal guardian or conservator appointed?

No, Person is independent of guardianship	76.47%
Yes, Person has a <u>private</u> guardian or conservator	21.95%
Yes, Person has a <u>public</u> guardian or conservator	0.32%
Don't know	1.27%

The people we visited experience various degrees of developmental disabilities.



6.7% of the people we visited experience vision problems that limit their activities; another 6.8% are considered legally blind.

People we visited with a developmental disability and...

a mental illness/psychiatric diagnosis	17.4%
a physical disability	10.2%
a vision or hearing impairment	12.4%

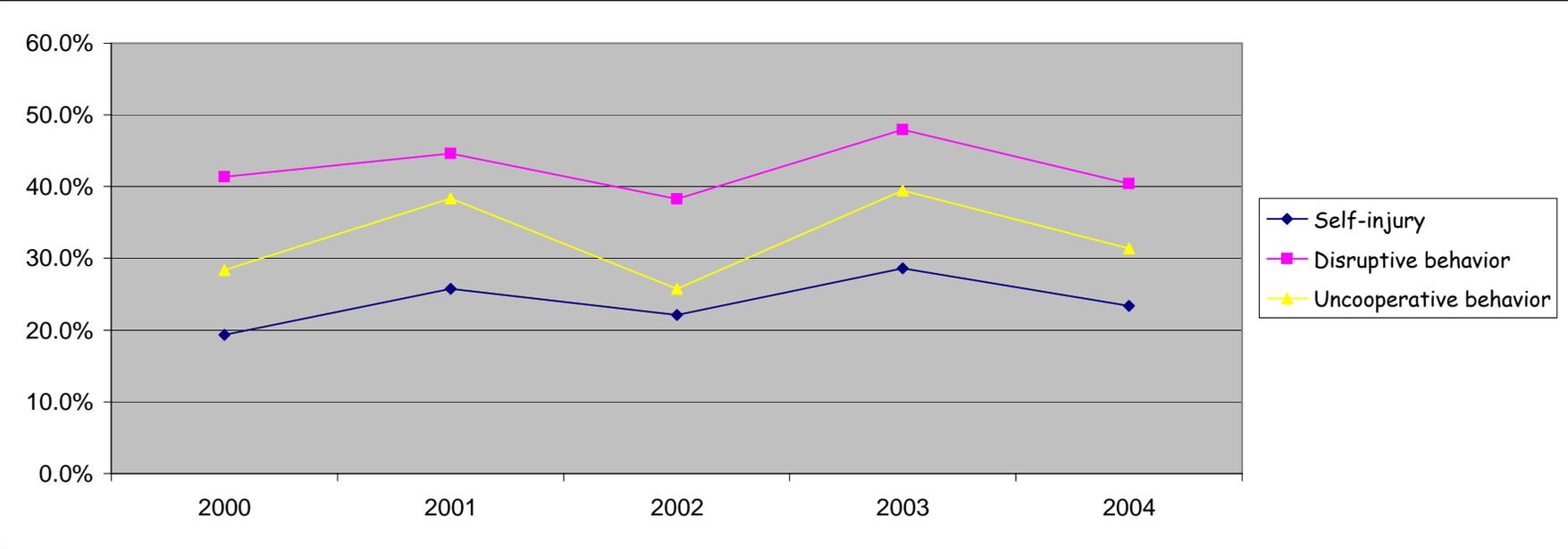


In comparison, based on the National Center for Health Statistics, 36% of all Rhode Islanders reported "poor mental health" (during the past 30 days). *Source: Behavioral Risk Factor Surveillance System data, 2001, unpublished data. National Center for Health Statistics, Center for Disease Control and Prevention, United States Department of Health and Human Services.*

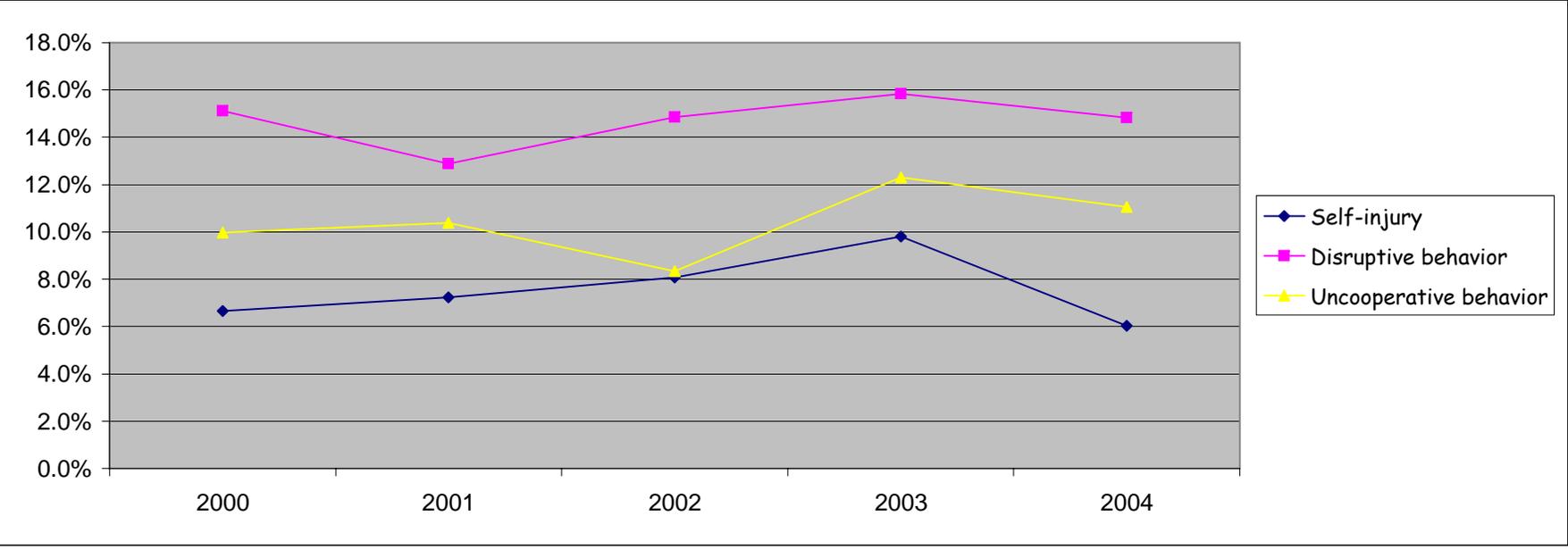
Also in comparison, the Human Services Research Institute's 2003 Consumer Outcomes Final Report indicated that overall 28% of respondents in 22 participating entities were reported to have a mental illness/psychiatric diagnosis.

Source: Consumer Outcomes Final Phase V Report 2002-03 Data, available at www.hsri.org

Percentage of people who exhibit self-injury, disruptive behavior or uncooperative behavior



Percentage of people who exhibit self-injury, disruptive behavior or uncooperative behavior at least weekly



Concluding Thoughts...*about our Background Information*

"The real voyage of discovery consists not in seeing new landscapes, but in having new eyes."

Marcel Proust



Notable findings...

RI appears to provide service to significantly fewer people with co-occurring mental illness and developmental disabilities, compared to other states participating in NCI.

The population of people we visited in the state has a significantly lower percentage of identified mental illness than that of all Rhode Islanders.

Positive Outcomes...

We learned about areas of need for resource development; we created pictorial learning materials about relationships and human rights.

We were able to provide over 1800 pieces of material from our Resource Library.

Further Exploration...

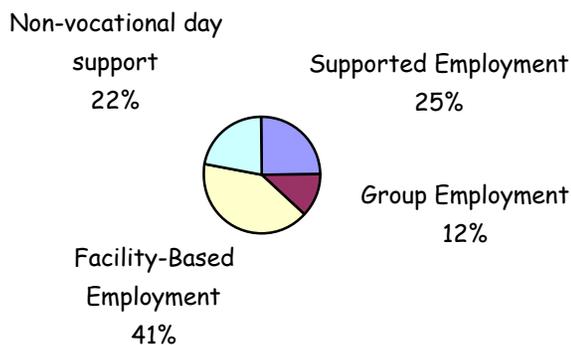
The structure of NCI requires that a lengthy background information form (BIF) be completed prior to an interview. Provider agencies have gathered this information. Our attempts to collect this information for people with no lead agency has been more challenging. They have no lead agency because they may administer their own plans, are eligible and pursuing support, or are currently receiving case management from a DDD caseworker. Therefore, people with a lead agency are better represented in our sampling than those without one.

Since we understand that the length of the BIF could be prohibitive for those folks who only receive case management services or who administer their plans, for the coming year we are going to make the process more accommodating and choose only a few key BIF questions that we will ask at a visit. We know that these folks will not be included in the NCI numbers because of this abbreviated format, but we feel that it is important to provide a way for these folks to be visited and to assess their satisfaction with their plan or whatever they are getting or doing. These numbers and responses will be reported in-state.

We have added more questions about positive behavior support plans for the 2005 project year, enabling us to provide trend information in the future.



Vocational Support In RI



Note: Some people receive more than one type of employment support.

The Human Services Research Institute's 2003 Consumer Outcomes Final Report indicated nationally: 19% of people receive supported employment, 9% are in group employment/enclave, 38% in a facility based service, 35% receiving non-vocational daytime support.

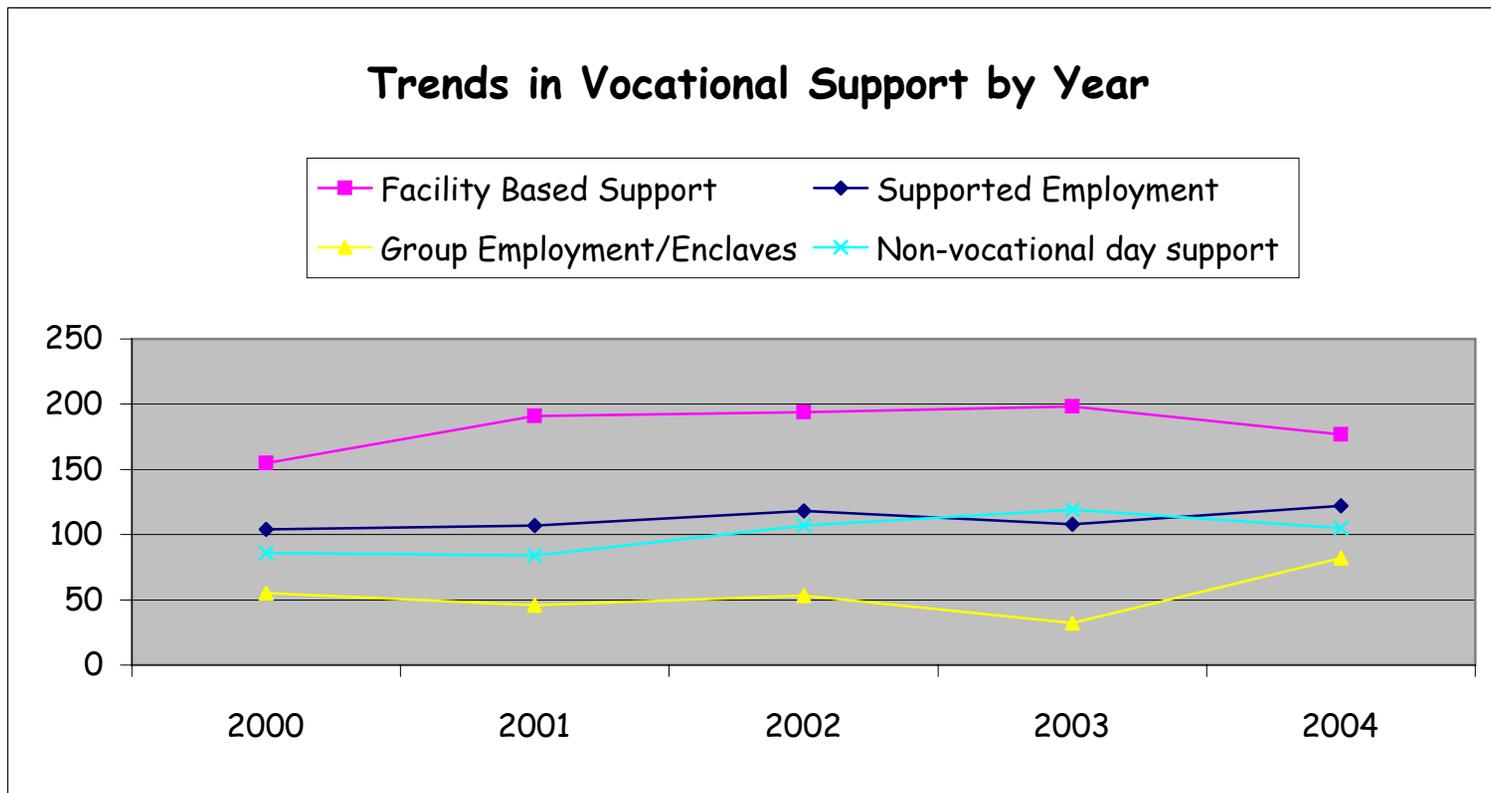
Source: Consumer Outcomes Final Phase V Report 2002-03 Data, published February 2004, available at www.hsri.org

In RI, of the people receiving each type of employment support, the following indicated that they like going/working there.

Group Employment	73.5%
Supported Employment	65.8%
Facility-Based Employment	64.2%
Non-vocational day support	45.5%

In 2004, people we visited in each type reported liking their work, but also wanting a different job/day activity.

Facility-Based Employment	38.3%
Group Employment	35.5%
Supported Employment	34.1%
Non-vocational day support	22.5%



Of 1028 responses, 7.9% of the people said that they are at least sometimes afraid or scared at work. In the 2004 project year, PAL began collecting data regarding why people are afraid or scared. Most people said "co-worker's behavior".

Also in the 2004 project year, PAL began referring people who were interested in finding a job to PAL's Employment Information Network, asking if someone from EIN had permission to call them. 100 people were referred. 67 were contacted. 47 are actively involved with the network. And, 11 have been matched with mentors. The Network connects people who are successfully employed with people in the process of choosing, seeking or keeping a job.

In the 2003 Project Year, we began asking for more detail regarding supported employment.

Of the people whose background information indicated that they receive supported employment*, how would you describe their work?



	2003	2004
Permanent**, full time	16.0%	4.2%
Permanent, part time	60.0%	73.1%
Occasional	11.0%	8.4%
Seasonal	2.0%	8.4%
Not answered	11.0%	5.9%
Average hours per week	16.7	12.4

**Please note that these percentages are of the 30.6% receiving supported employment support, as indicated above.*

*** Permanent work is defined as regularly scheduled weekly employment in the community.*

In September 2004, Rhode Island Department of Labor and Training Director Adelita S. Orefice announced that Rhode Island's seasonally adjusted unemployment rate for last August fell to 5.5%.* In 2004, only 23.1% of the people we visited were reported to have permanent work in the community.

**Source: RI Department of Labor and Training website, http://www.dlt.state.ri.us/News_Releases/NR_091704.htm*

Of the people in permanent work (full or part time), the following experience various degrees of developmental disability:

	2003	2004
No MR Label	5.3%	9.8%
Mild MR	47.4%	47.8%
Moderate MR	32.9%	32.6%
Severe MR	6.6%	4.3%
Profound MR	2.6%	2.2%
Don't Know	5.3%	3.3%

For the past 1200 people we visited, when asked if there are any changes people would want to make to their work/day activity...

39.9% said they would make no changes*

Of the people who said they would make changes, the top four changes were...

Find a different job

Work more hours

Make more money

Expand duty options in current job



**This does not mean that alternately 61.1% said they would make changes. If people indicate that they would make a change, they can offer more than one response regarding specific changes in their work. Therefore, we do not have clear numbers of people who said they would make a change. For this reason, we are only including people who specifically stated that they would make no changes in the data.*

Concluding Thoughts...*about Employment*

The celebrated Galen said that employment was nature's physician.

It is indeed so important to happiness that indolence is justly considered the parent of misery.

C. C. Colton

Notable findings...

RI appears to have a higher percentage of people receiving supported employment, but also a higher percentage of people in facility-based services, when compared to national percentages from the HSRI Consumer Outcomes Final Phase V Report 2002-03 Data.

Positive Outcomes...

PAL began making referrals to our Peer Support Network for people indicating that they want to make a job change.

Further Exploration...

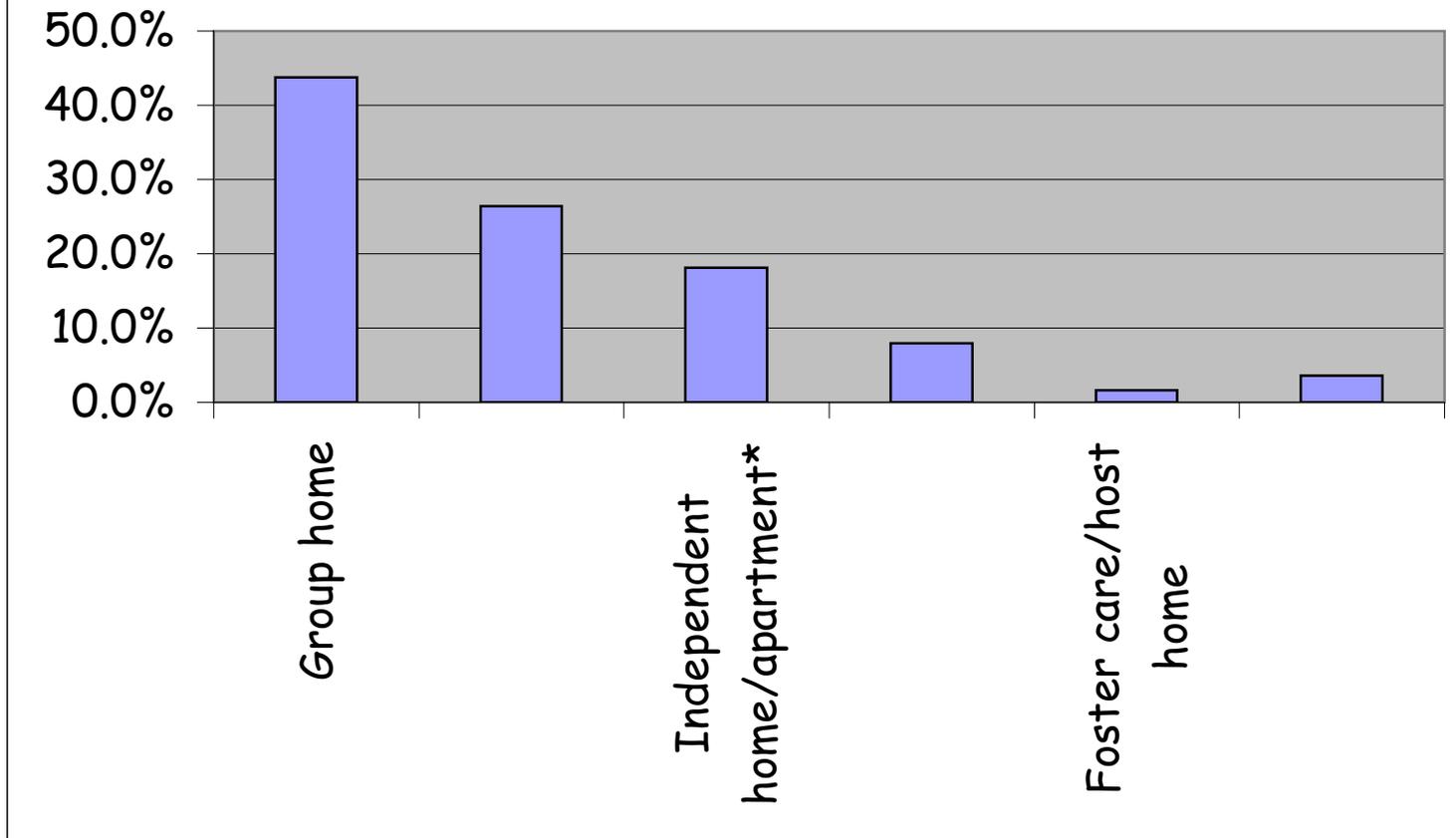
We have opted to make clearer the standardized work definitions from the National Core Indicators*. We intend to make future references to each type of employment more consistent.

The greatest percentage of people who report liking their work are involved in group employment, defined through NCI as "two or more individuals employed by a community provider agency and perform work as employees of the provider agency at sites in the community, e.g. "mobile crews". Group-supported employment also includes persons who are employed in an affirmative industry or as part of an enclave".

** A complete list of work definitions is available upon request.*



Overall 5-Year Percentages: Types of Residences



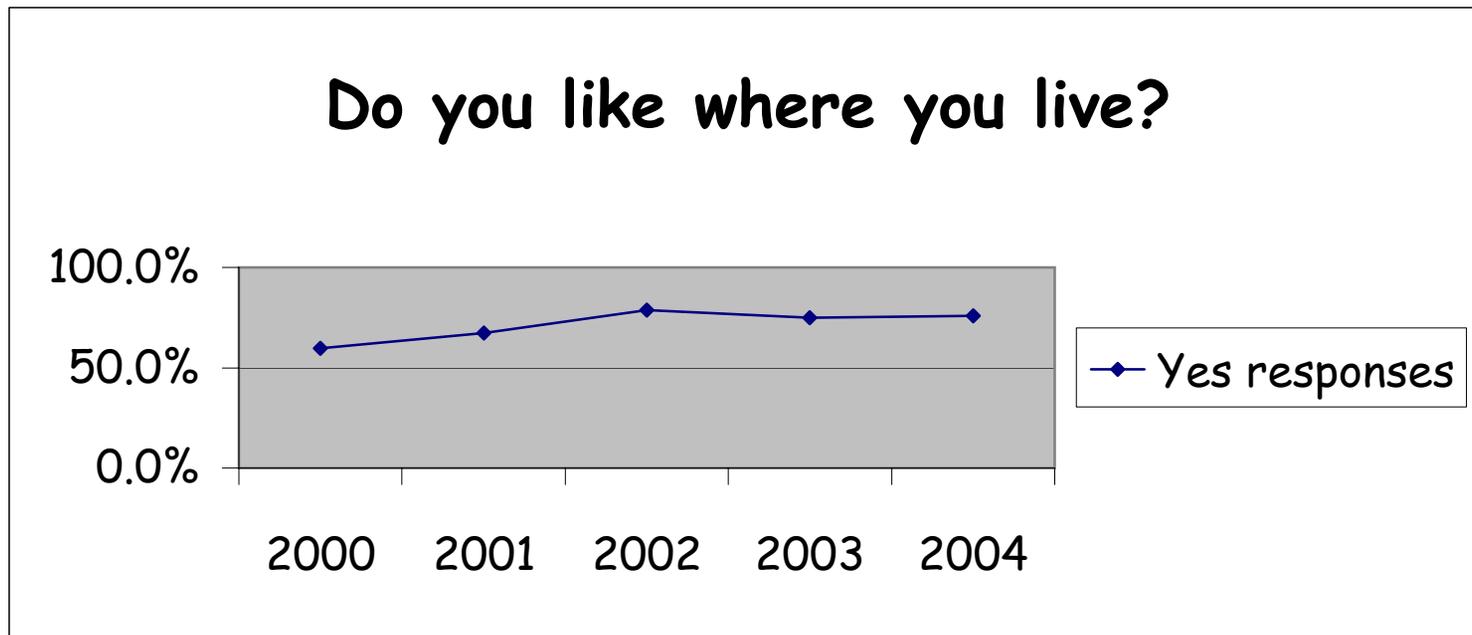
* NCI defines an independent home/apartment as a residence owned or leased by a person for themselves; in an apartment program the provider agency owns or leases the apartment.

The Human Services Research Institute's 2003 Consumer Outcomes Final Report indicated that nationally: 30% live in a parent/relative's home, 27% in a group home, 18% in an independent home/apartment, 7% in foster care/host home, 6% in an apartment program, and 13% in other, e.g. a specialized facility.

Source: Consumer Outcomes Final Phase V Report 2002-03 Data, published February 2004, available at www.hsri.org

How would you characterize the place this person lives? (year-to-year distribution)

	2000	2001	2002	2003	2004
Group home	37.2%	42.1%	39.1%	60.6%	38.4%
Parent/relative's home	26.3%	31.4%	31.5%	13.6%	30.4%
Independent home/apartment	17.2%	19.8%	15.1%	18.3%	20.4%
Apartment program	6.0%	10.1%	12.0%	4.8%	7.3%
Foster care/host home	2.4%	2.5%	2.6%	0.5%	0.3%
Other: Specialized/Nursing Facility, etc.	3.3%	3.5%	3.9%	3.5%	3.8%



The Human Services Research Institute's 2003 Consumer Outcomes Final Report indicated **nationally**: 94.6% of respondents from all participating states indicate they like where they live. *Source: Consumer Outcomes Final Phase V Report 2002-03 Data, published Feb. 2004, www.hsri.org*

Of the people living in each type of residence, the following indicated that they like their homes.

Apartment program	80.1%
Independent home/apartment	76.5%
Parent/relative's home	72.5%
Foster care/host home	72.4%
Group home	49.3%
Other: Specialized facility, nursing facility, etc.	56.1%



What amount of paid support does this person receive at home?

	2000	2001	2002	2003	2004
24-hr. on-site support (around-the-clock)	50.5%	55.3%	61.2%	74.1%	67.3%
Daily on-site support (not around-the-clock)	12.7%	13.2%	11.5%	13.8%	17.1%
Less frequent than daily support	8.8%	15.1%	8.1%	9.5%	7.3%
As needed visitation	19.9%	21.4%	17.4%	2.3%	6.8%
None of the above	N/A	N/A	3.9%	1.0%	1.3%
Don't know	N/A	5.0%	2.1%	0.5%	0.8%

61.5% of the responses we received indicated that people can be alone in their homes if they want to; they have privacy.

Are you ever afraid or scared...	Yes	Sometimes
in your home?	3.8%	7.5%
in your neighborhood?	5.7%	6.3%



In the 2004 project year, PAL began collecting data about why people are afraid or scared. At home, people reported feeling afraid of lightning or thunder, or a housemate's behavior. In their neighborhood's, most people told us, "strangers, busy streets and dogs".

Do people let you know before they come...	into your home?	2% said, "No".
	into your bedroom?	3% said, "No".

For the past 1200 people we visited, when asked are there are any changes people would want to make to their home... 41.0% said they would make no changes*

During our last project year, most people who said they would make changes told us they would choose a new location, make some home renovations or fix some things, or get some new equipment, such as air conditioners or television sets.

**This does not mean that alternately 59% said they would make changes. If people indicate that they would make a change, they can offer more than one response regarding specific changes to their home. Therefore, we do not have clear numbers of people who said they would make a change. For this reason, we are only including the data for people who specifically stated that they would make no changes in the data.*

Concluding Thoughts...*about Home*

A good home must be made, not bought.

Joyce Maynard, "Domestic Affairs"

Notable findings...

Nationally, most people live at home with parents or relatives. In RI, most people in our sampling live in group homes.

Positive Outcomes...

There seems to be a steady rise in overall satisfaction with the places people live.

A very small percentage of people indicated ever feeling afraid or scared in their homes/neighborhoods.

Further Exploration...

People reporting the greatest satisfaction with their homes live in apartments or independent homes, yet most people in RI live in group homes where the lowest level of satisfaction was noted.

* *NCI defines an independent home/apartment as a residence owned or leased by a person for themselves; in an apartment program the provider agency owns or leases the apartment.*



Health and Safety

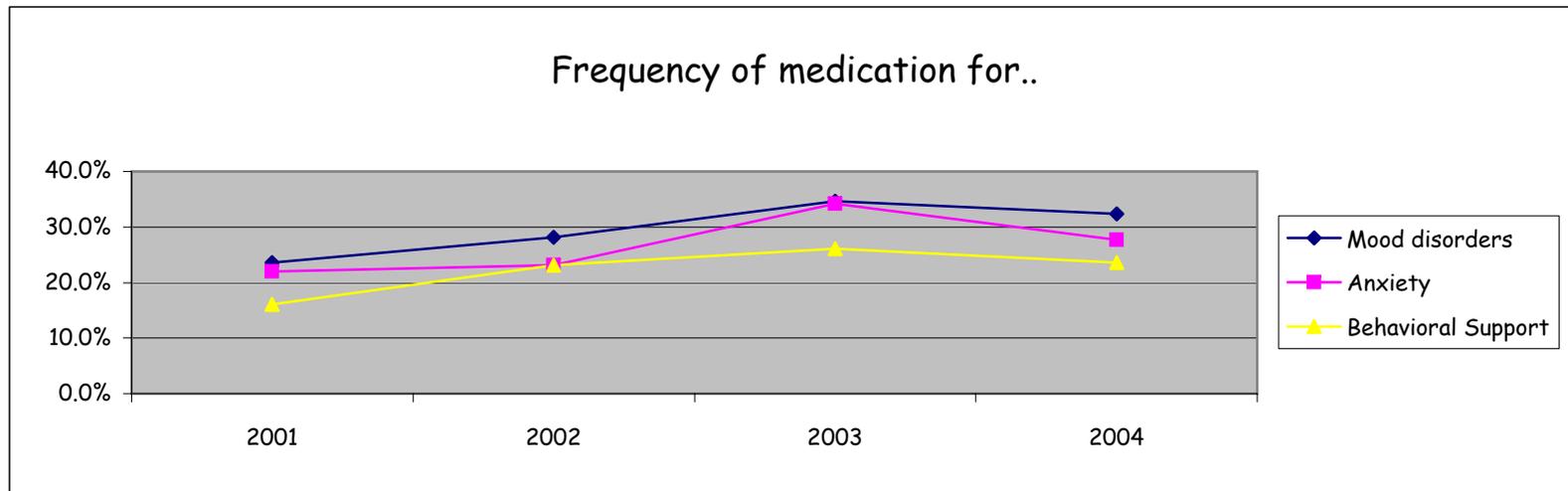
Person requires care by a nurse or physician...

Less than 1x/month	56.3%
At least 1x/month	20.1%
At least 1x/week or more	19.0%

Reported having a(n)...

89.2% Physical exam w/in the past year
64.5% OB/GYN exam w/in the past year (female)
67.2% Dental visit w/in the past six months

Note: We were unsuccessful at getting comparative statewide healthcare utilization data from the RI Department of Health's website and the Center for Disease Control and Prevention website.



The Human Services Research Institute's 2003 Consumer Outcomes Final Report indicated that nationally the average percentages among all participating states were: 31.5% of people taking medications for mood disorders, 19.2% for anxiety and 25.3% for behavioral support. RI's percentages for that same year were: 34.7% for mood, 33.7% for anxiety and 25.7% for behavioral support.

Source: Consumer Outcomes Final Phase V Report 2002-03 Data, published February 2004, available at www.hsri.org

Of 1200 responses when asked, "If there was a fire in your home, what would you do?":

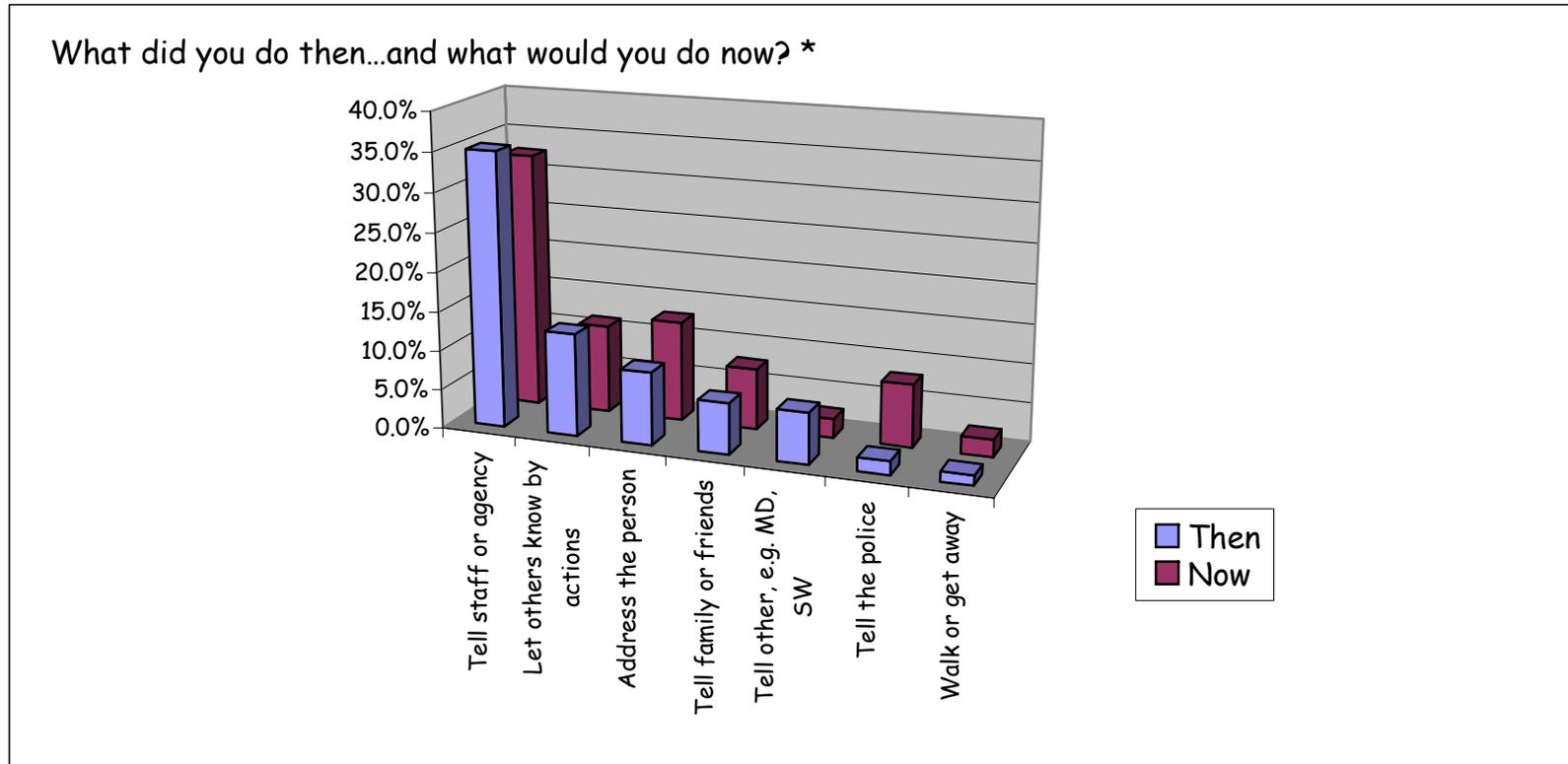
65.0% of the people responded to the question.

Of them, 61.1% gave a safe response; 38.9% gave an unsafe response.

6.5% (or 30 of the 1189 responses received) of the people who responded gave unsafe responses, and receive less than daily support or no in-home support.

Over the past 4 years we asked if people have a form of identification with their picture and current address on it. 25% did not have such a means of identification.

Since 2001, percentage of responses indicating that something happened in the past that made people feel uncomfortable, or that they did not like, e.g. yelling, an assault 33.3%



* May have given more than one response



Concluding Thoughts...*about Health and Safety*



Happiness is nothing more than good health and a bad memory.

Albert Schweitzer

Notable findings...

Incidence of people taking psychotropic medications seemed on the rise for the first three years, and somewhat leveled off this past year.

1/4 of the people we visited do not have a picture identification card.

Positive Outcomes...

Most people seem to have regular physical exams.

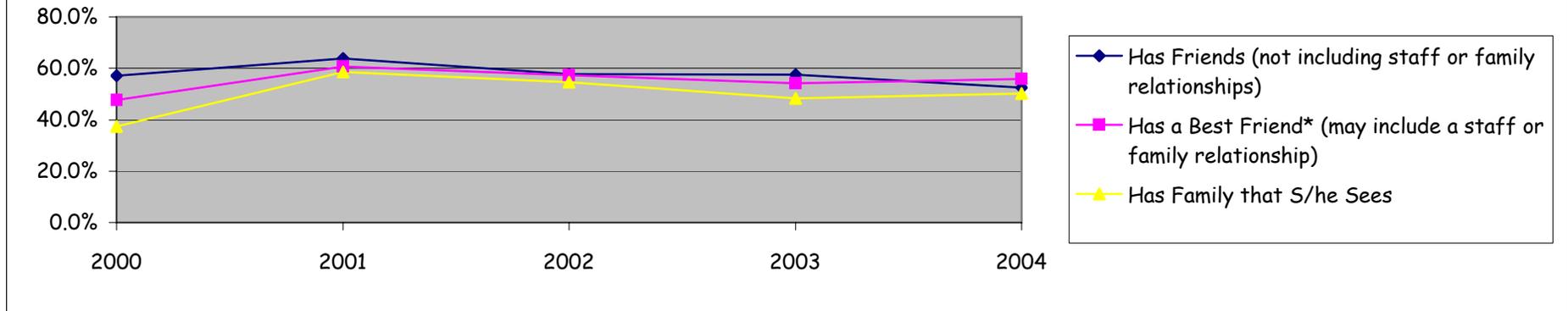
Further Exploration...

In 2003, RI appeared to provide service to significantly fewer people with co-occurring mental illness and developmental disability compared to other states participating in NCI, but has higher incidence of medication use for anxiety and about equal percentages for mood disorders and behavioral support. This year, we have added the capacity to our database to track frequency of medication use.

30 of 1189 people did not respond safely when asked what they would do in case of a fire, and they do not have 24-hour support. Through the PAL follow-up process, agencies were notified about these individuals and their possible need for further safety training.



Five Year Trends in Relationships



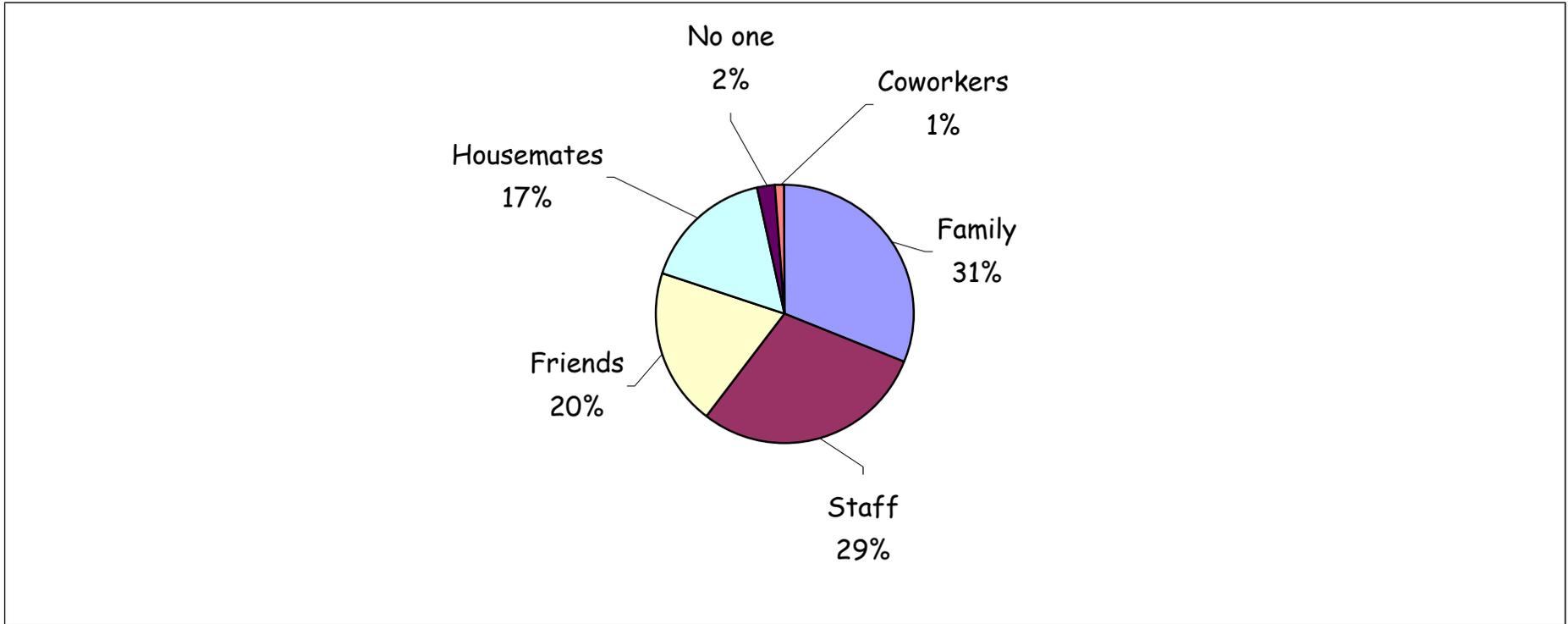
* NCI defines best friend as someone you are really close to; someone you can talk to about personal things.

In 2004 we began differentiating between those responses given by the person we visited and those of a helper. We thought it would be interesting to see how the percentages were impacted, if at all, by the separation. When asked if they have friends who are not staff or family relationships, the 56.2% of the people who responded for themselves said, "Yes". When the helpers responded on a person's behalf, only 9.6% told us that the person has friends.

Do you ever feel lonely, like you don't have anyone to talk to?	2000	2001	2002	2003	2004
Sometimes feels lonely	27.8%	29.9%	24.0%	31.2%	25.1%
Yes - Always or often feels lonely	7.6%	9.4%	10.4%	6.8%	8.3%
Total % of people who report sometimes or often feeling lonely	35.3%	39.3%	34.4%	37.9%	33.4%

5.5% of people who said they have friends, also reported feeling always or often lonely.

Who do you spend time with after work and on weekends? *



** Someone may have responded with more than one item.*



29.1% of the people visited in the 2004 project year reported having a spouse or boyfriend/girlfriend. Of those who reported not having a significant other, 27.1% said they would like to find one.

Concluding Thoughts...*about Family and Friends*

And in the sweetness of friendship let there be laughter and the sharing of pleasures.
For in the dew of little things, the heart finds its morning and is refreshed.

Kahlil Gibran



Notable findings...

When asked if they have friends who are not staff or family relationships, the 56.2% of the people who responded for themselves said, "Yes". When the helpers responded on a person's behalf, only 9.6% told us that the person has friends. However, when asked who they spend time with after work or on weekends, better than 60% indicated they spend their free time with support staff or family.

Of those who reported not having a significant other, only 27.1% said they would like to find one.

Positive Outcomes...

On average over five years, about 58% of the people we visited indicated that they have friends in their lives.
(in addition to staff and family relationships)

Further Exploration...

Though the data suggests that people have friends and relationships, our experience with visiting people causes us to question this finding. In order to test this hypothesis, we added a question for 2005, "Do you want more friends?"



*Friendship improves happiness and abates misery,
by doubling our joys and dividing our grief.*

Joseph Addison



Supports and Services

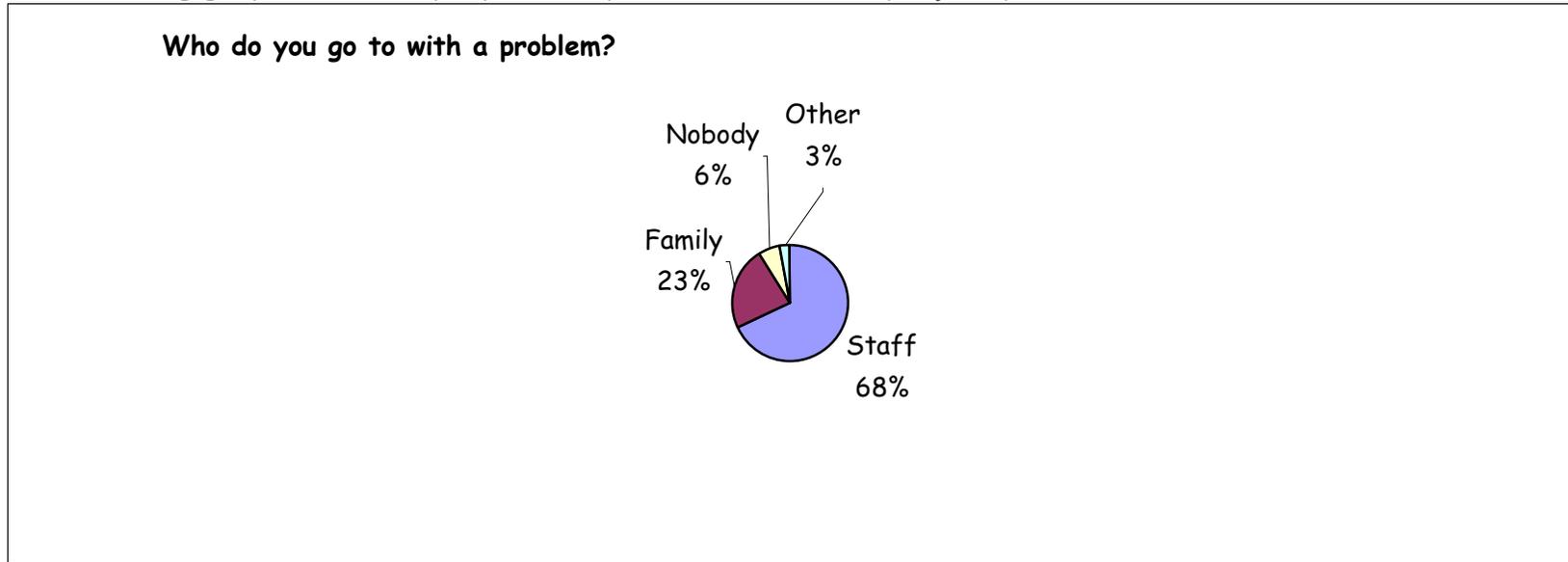
Are people aware of their right to voice a concern or file a grievance about their support?

We thought we'd ask.

Through the years, we got down to the basics...

and now simply ask, "Who do you go to with a problem?"

The following graph indicates people's responses in the 2004 project year.

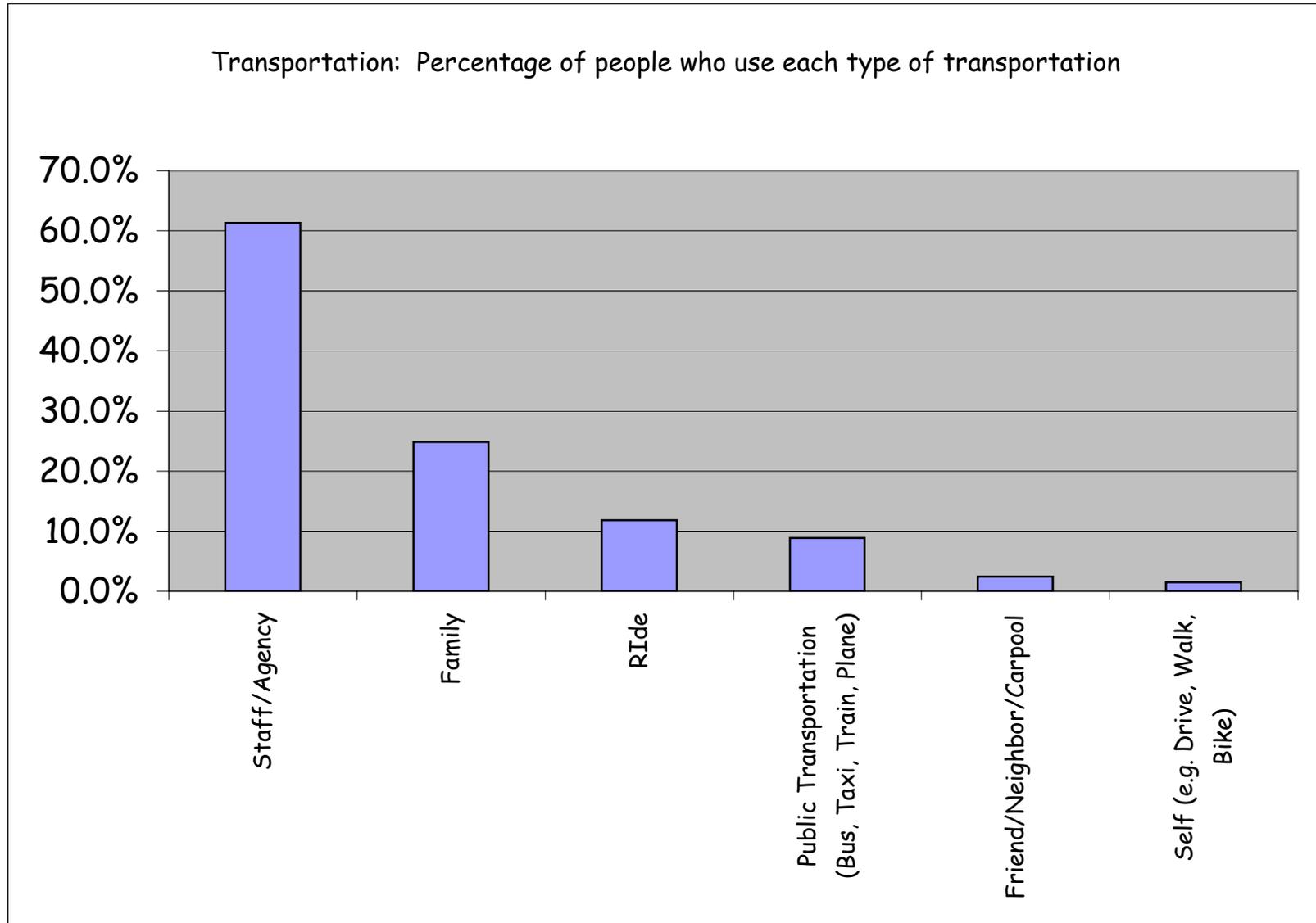
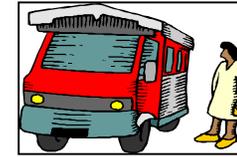


"Are these goals what you really want?"

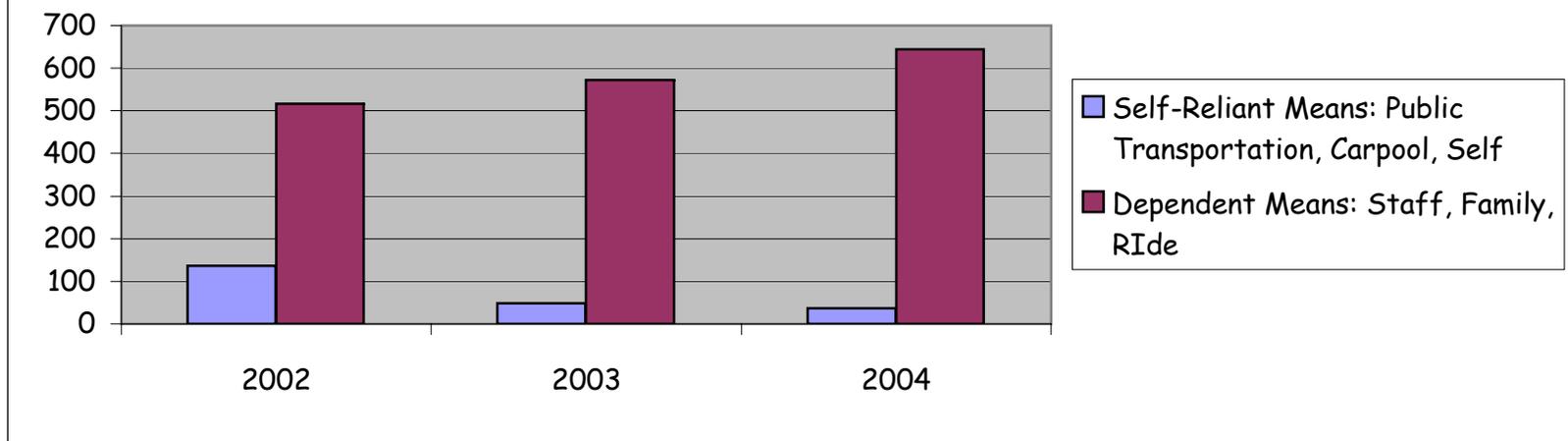
In 1999, we began the project by generally asking about the person's annual goals. Through the years of listening to people, we realized the value of giving people the opportunity of answering that question for each goal. *Data from the last 2 project years indicate...*

	2003	2004
Yes, I am working on my goals.	77.7%	72.8%
Yes, they are what I really want.	79.6%	70.9%

63.8% of the people we visited over the past five years reported that when they want to go somewhere, they always have a way to get there.



Year to Year Transportation Usage Trends



20.8% of the people we visited over the past three years told us that they need additional services

Beginning with the most often requested support, the top five responses given by people who reported needing additional support were...

1. *Tutorial, literacy or other education*
2. *Physical therapy/occupational therapy*
3. *Respite/family support*
4. *Transportation*
5. *Employment/job coaching*



Concluding Thoughts...*about Supports and Services*

Disability is a matter of perception. If you can do just one thing well, you're needed by someone.

Martina Navratilova

Notable findings...

Though most people's responses indicated that their goals are what they really want, when asked, "If you could have any three wishes come true, what would they be?" they seldom correlate with their annual plan goals. We prepare and distribute a "Three Wishes Report" for each provider agency annually, comparing people's plan goals with their wishes.

Positive Outcomes...

Most people's responses indicated that they are getting all the services they need.

Further Exploration...

Trends in transportation support indicate more dependent means are rising, and more self-reliant methods are declining.

People seem to feel most comfortable going to staff when they need to resolve a problem. However, that leaves the question, "Where do people go if they have an issue with their staff?"

People have consistently told us that their most unmet needed service is continued education, literacy, etc. How do we build more continuing education into people's lives?



Choice and Human Rights

In 1999, we began asking people if their human rights were explained to them

We later realized that it would be more effective to simply ask the person to give an example of their human rights.

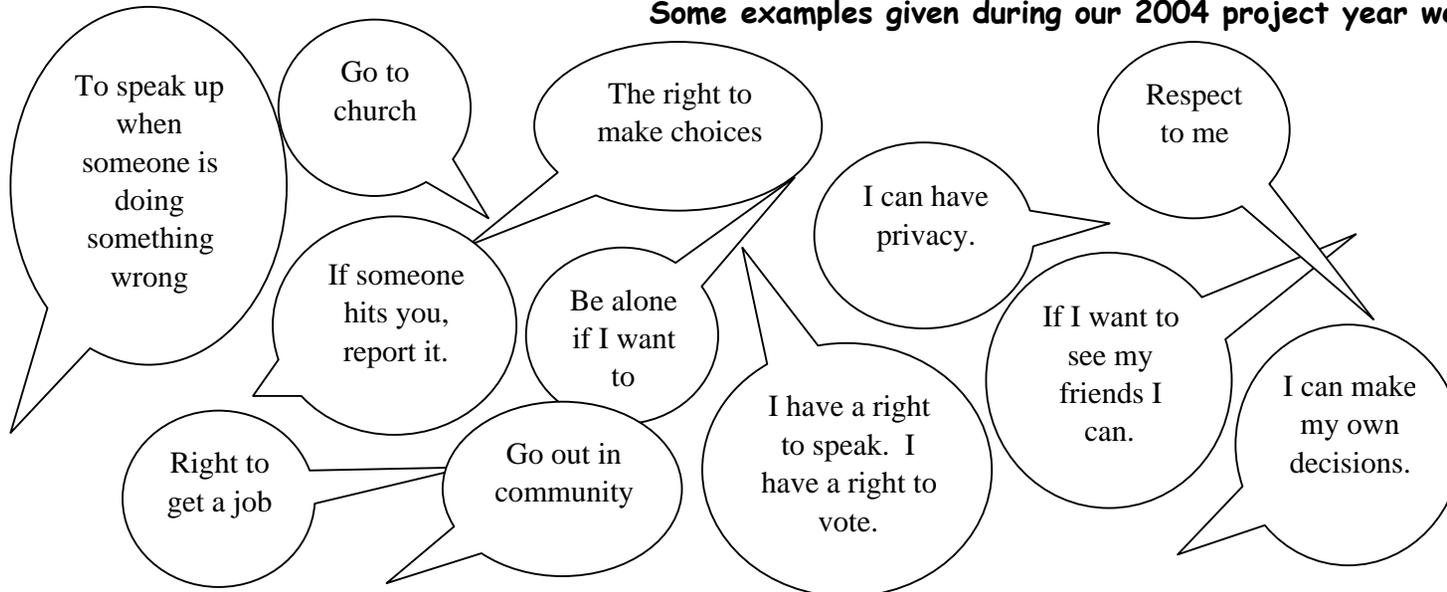
Over the past two years, we discovered the following...

Approximately 43% gave us an example of a human right.

About 23% appeared as though they should be able to give an example, but could not

Almost 34% did not appear able to respond on their own.

Some examples given during our 2004 project year were...

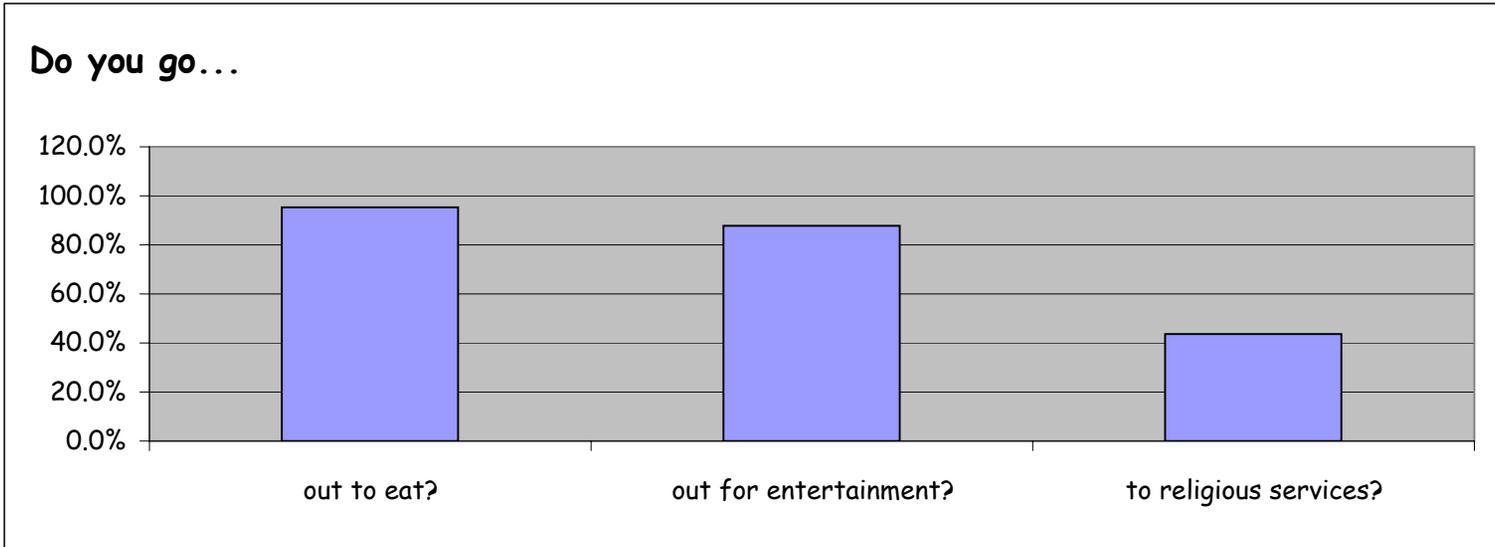


About a quarter of the population we visited exercise their right to vote.

This has remained consistent over the past three years.

In the election this past November, approximately 63.6% of Rhode Islanders voted.*

Source: Rhode Island Board of Elections, www.elections.ri.gov



Do you choose...

your daily schedule? 64.3%
 how you spend your free time? 70.6%
 what to buy with your spending money? 48.7%

...OR have at least some input about...

your daily schedule? 22.9%
 how you spend your free time? 20.5%
 what to buy with your spending money? 27.6%

84.1% of the people we visited over the past 3 years told us that they read their own mail, or others read it with their permission

**74.0% of the people we visited over the past 5 years told us that they can use a phone anytime, either independently or with assistance; and/or uses email
 (20% were not able to use the phone, even with assistance)**



Concluding Thoughts...*about Choice and Human Rights*

"There is no such thing as a little freedom. You are either free or you're not."

Walter Cronkite

Notable findings...

Almost a quarter of the population of the people we visited appeared as though they should be able to give an example of a human right, but could not.

Positive Outcomes...

The majority of people's responses indicate that they have at least some input into everyday aspects of their lives. The reality of relying on public assistance appears to leave little opportunity for choice about greater life aspects, such as which housing option will become available when you need it.

However, it appears that people are exercising their rights in the day-to-day parts of their lives.

As John O'Brien stated,

"When someone depends on services for housing, necessary personal assistance, and daily occupation over a long period, as many people with severe disabilities do *services become life defining.*" *

It is therefore all the more critical that people's service networks build in as many opportunities to exercise choice as one's structure can support.

Further Exploration...

This year we have included self-determination definitions** from the Core Indicators Project in order to begin reporting on progress toward greater empowerment of the people we visit

* *"What's Worth Working For? Leadership for Better Quality Human Services"* by John O'Brien

** *A complete list of self-determination definitions is also available upon request.*



Our impressions and observations through the data collection and interview processes lead us to reflect on what we are learning...

- Most people tell us, even if they like their sheltered work setting, that they want to work in the community. However, people who have tried community jobs have expressed that they do not have the support they need for various reasons. For example, employee turnover in the entry-level positions most people with disabilities hold hinders their reliance on natural supports. Also, Rhode Island job trends lie in small businesses, where there is less access to Human Resource functions. "Approximately ninety percent (28,689) of all Ocean State firms in the private sector were small businesses, defined as those with less than twenty employees."¹ It appears that we should re-think ways to provide increased support in community settings, e.g. small group employment opportunities within a business, entrepreneurships, customized employment. People want to be part of the community within the secure pockets of support they need.
- People seem to enjoy homes where there are fewer people and more privacy. Apartments, parents and relative's homes, foster care (also known as shared living) appear to be more satisfying than group living.
- Some people who do not have 24-hour or daily support need better fire and safety training. All people need some sort of photo identification to carry.
- When there is a problem, people need a network of people to turn to...not exclusively staff, family, etc.
- Most people answered that they have friendships, in addition to staff and family relationships. However, our experience in asking the question indicates to us that people may be reluctant to say that they do not have friends, are inexperienced with true reciprocal relationships, and rely primarily on staff or family members to develop and perpetuate friendships.

¹ Rhode Island Department of Labor and Training, *Quarterly Census of Employment and Wages, Private Covered Employers, Size Class by Industry, March 2004*



Concluding Reflections for the Future

In order to create or expand the capacity of communities to respond to their own members, it is clear that a fundamental activity of change is to welcome people with disabilities into ordinary, rich networks of relationship. To achieve such a welcome, disability and those who carry it must be seen as less threatening and burdensome, if not in fact as unusual gifts to the broader social structure.

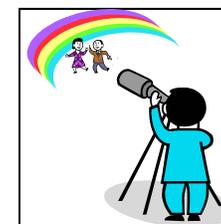
Judith Snow



In summary, the past five years has afforded many Visitors the opportunity to meet, talk to and appreciate the diverse talents, dreams and goals of folks with disabilities. Through this project, we have been able to offer specific information to provider agencies about how the folks they support really feel about the quality of their lives. We have attempted to assist those approximately 1000 individuals, who indicated there was an issue with their support, by building a follow-up process into the project in order to help strengthen their voices so that they could effect change in their lives.

The project has afforded us the ability to outreach to families whose sons/daughters are still living at home, and provide them with valuable information as well as offer opportunities to learn about best practices.

Rhode Island's participation in the NCI Project has contributed to the creation of the statewide Quality Consortium. The Consortium is made up of family members, individuals with disabilities, representatives of provider agencies, advocacy agencies and from various state departments. The Consortium has provided participants with rich dialogue, an opportunity to question, hypothesize and analyze what we are learning about how to measure quality and assure health and safety.



Because of the learning that has taken place with the Consortium, PAL made major additions to the NCI/QLI tool this past year in order for us to be able to gather information that the Consortium members said was important. Most of our follow-up work this past year reflected the three priority areas the Consortium identified: relationships, health and safety, and employment. Also, for the 2004-05 project year, we have included several questions from the Centers for Medicare & Medicaid Services (CMS) Participant Experience Survey tool.

To date, we have prepared a number of reports: our 2001 Trends Report, two annual "Three Wishes" Reports, annual data provision to the Department of Mental Health, Retardation and Hospitals, preliminary data reports for the Quality Consortium, and two agency-specific reports. None to date has been as comprehensive as *Moving from Awareness to Action: A Five Year Report*. The past five years have afforded many lessons. The most telling is...data is important to track progress. However, a higher

function is to catalyze change and move from awareness to action.

In "What's Worth Working For? Leadership for Better Quality Human Services", John O'Brien writes,

Human service organizations can't manufacture better lives. People weave better lives from the resources afforded by individual effort, personal relationships, available opportunities, and help from services.

Each year we realize new areas to explore and further details to uncover....getting ever closer to understanding the everyday lives, hopes and dreams of those we visit.



Report prepared by Christiane Petrin Lambert with project knowledge and inspiration from Barbara McCrae and steadfast dedication and vision from Doreen McConaghy