

Human Rights, Life Choices, & Self Advocacy

At A Glance

Data From Background Information

-Choice of where a person lives: average of 4 years

31.20% of people live with their families 7.47% Chose without help 25.51% Had some input
22.21% Someone else chose 13.55% Don't know

-Number of places visited before moving to current home: average of 4 years

30.60% of people live with their families 10.97% More than 1 home 13.15% 1 place only
9.39% None 35.89% Don't know

Data From Visits

Human Rights:

-When asked for an example of Human Right:

27.73% of people over 4 years did not appear able to answer the question
28.68% of the people over 4 years appeared able but could not give a example of a Human Right

-Examples of Human Rights given (multiple answers possible by each person):

11.21%- Do what I want to do 10.48%-Speak up for yourself 8.3%- Privacy 4.95%- Right to vote

-Do people read your mail without your permission? 91.74% answered No.

-Are you allowed to use the phone when you want to?

17.78% either do not have or are unable to use a phone
77.07% can use the phone anytime
2.71% is not allowed to use the phone
2.45% don't know, no response or unclear response

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Data From Visits

Friendship

- 35.23% of people visited over this past 4 years either do not have friends or their friends do not visit them.
 - Of the 58.69 % of people (888 of 1513 visited) who have friends, 752 or 84.68% answered they can be alone with friends when they visit.

Voting

- 29.87% of the 1513 people visited said they vote.

Making Decisions

- 96.35% of people visited from 2005-07 who have a doctor & answered the question, said their doctor is nice to them.
 - 25% or 3 people did not have a doctor and needed one from 2005-2007, however 4 people in 2008 needed a MD.
 - In 2005-2007, of the people who have and need a dentist, 96.4% (991) said their dentist is nice to them
 - 3.75% or 45 people visited from 2005-2007, need but do not have a dentist.
 - 53.87% of the 1513 people visited say they decide their daily schedule and 33.38% have help deciding.
 - 34.9% of people decide what to buy with their spending money, while 50.63% have help choosing or has limits and someone else chooses for 11.43% of the people visited

Choice

- 81.89% can pick the time they go to bed.
- 59.02% pick on their own what they want to do during their free time and 33.18% have help deciding.

Choice of people you live with: average of 4 years

31.46% of people live with their families 17.71% Chose people or chose to live alone
28.88% Chose some or had some input 15.8% Someone else chose 6.15% Did not know, NR, UR

- Choice of staff and home and work: Data does not support all levels of participation, see comments

Choice of people who work or day program: average of 4 years

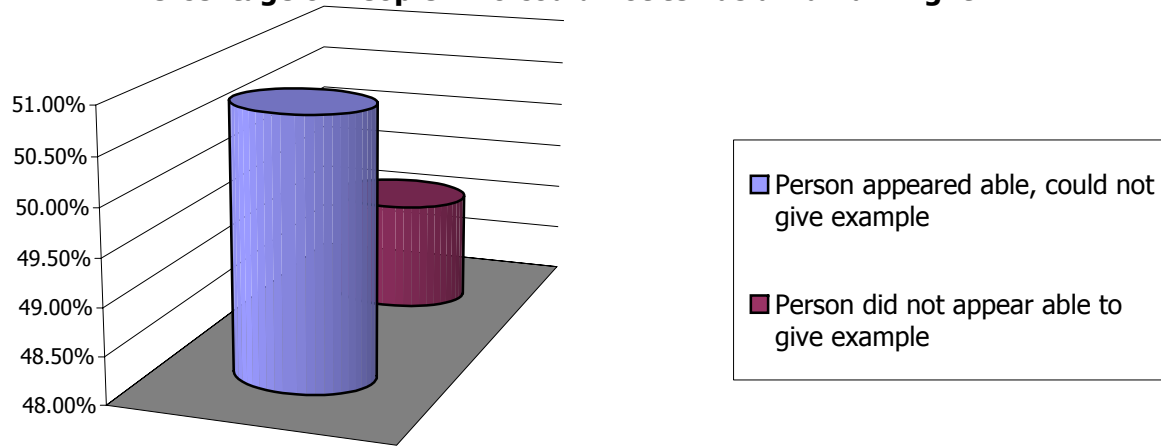
7.34% No work or day activity 16.33% Chose without help 49.44% Had input
17.45% Someone else chose 9.45% Don't know, no response, unclear response

Self Advocacy in past year

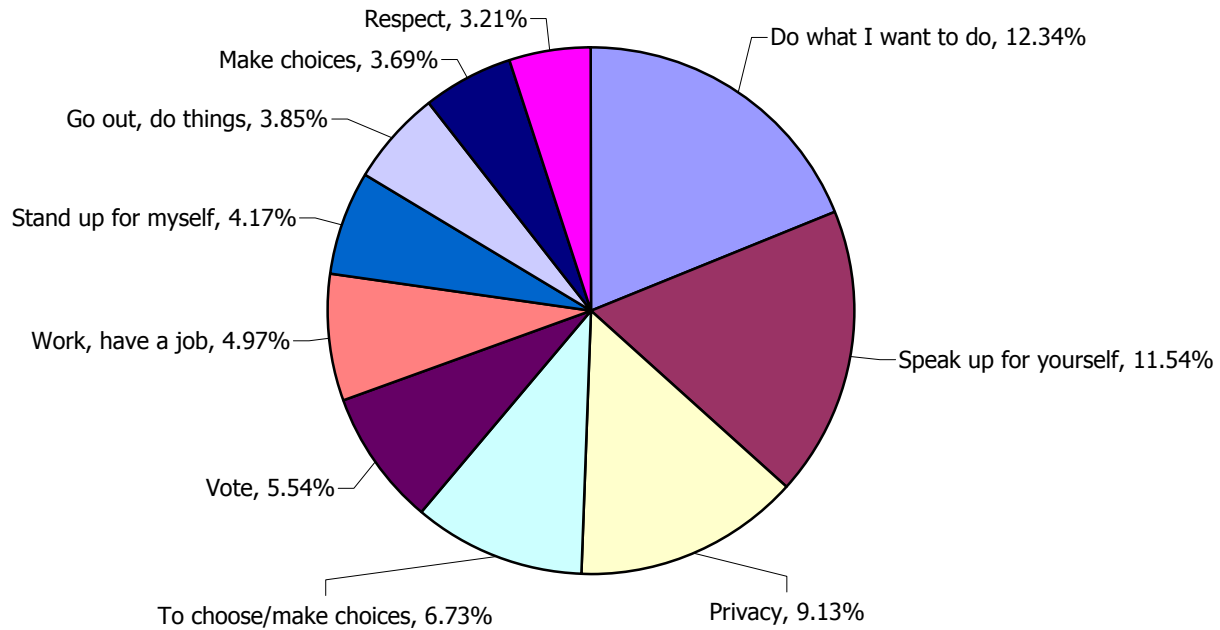
24.72% participated 3.83% Had opportunity, chose not to participate 63.71% Answered they did not participate

Human Rights

Percentage of People who could not tell us a Human Right.



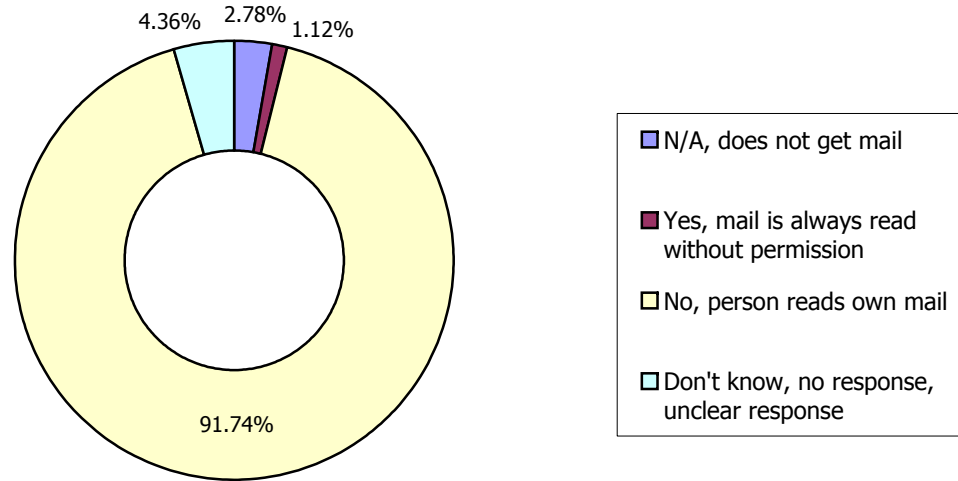
Can you tell me one of your Human Rights? (multiple answers possible) Top 10 answers*:



**Please see appendix for the full list of answers given*

Mail

Do people read your mail without asking you first?

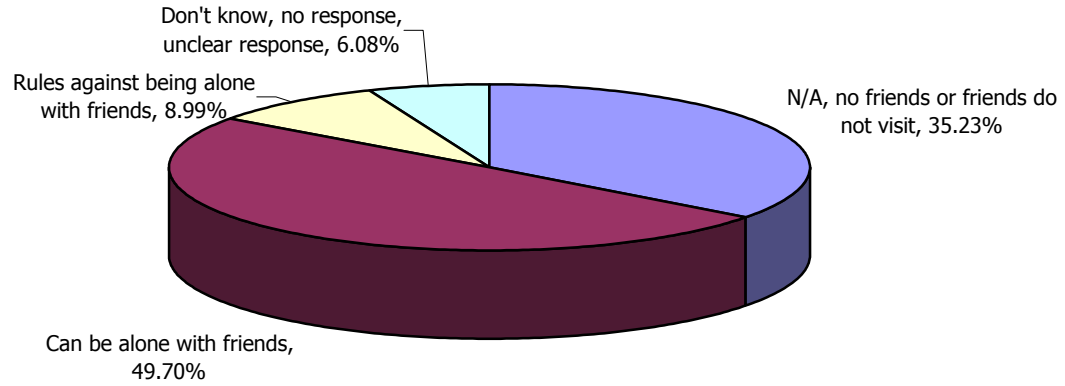


Are you allowed to use the phone when you want to?

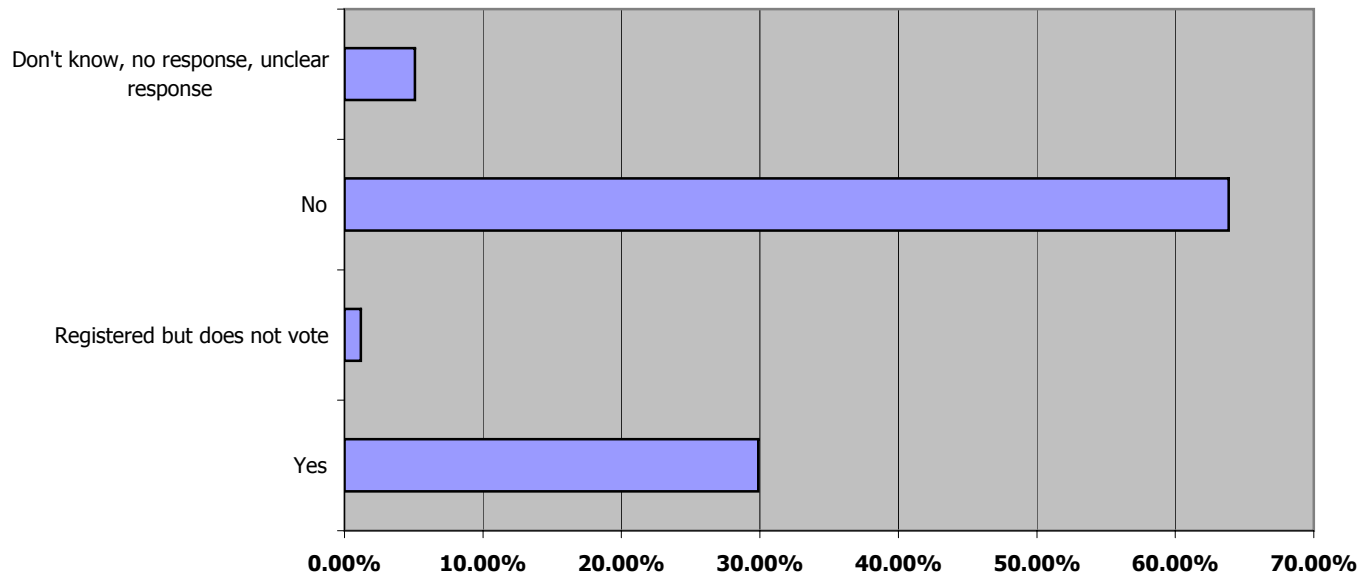


Friends

Do your friends ever come to visit?

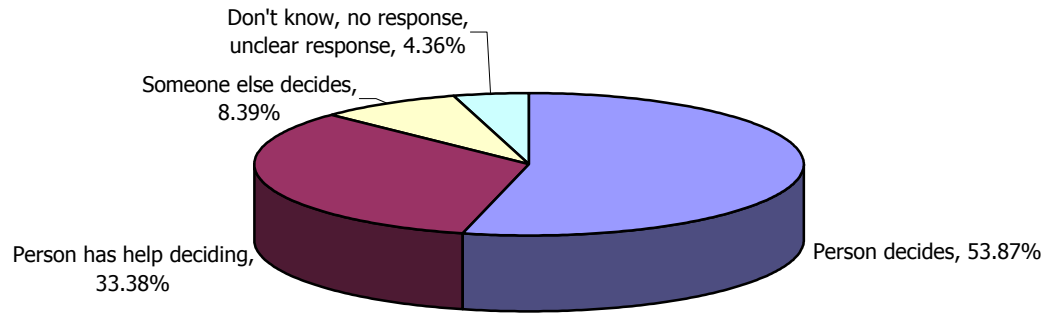


Do you vote?

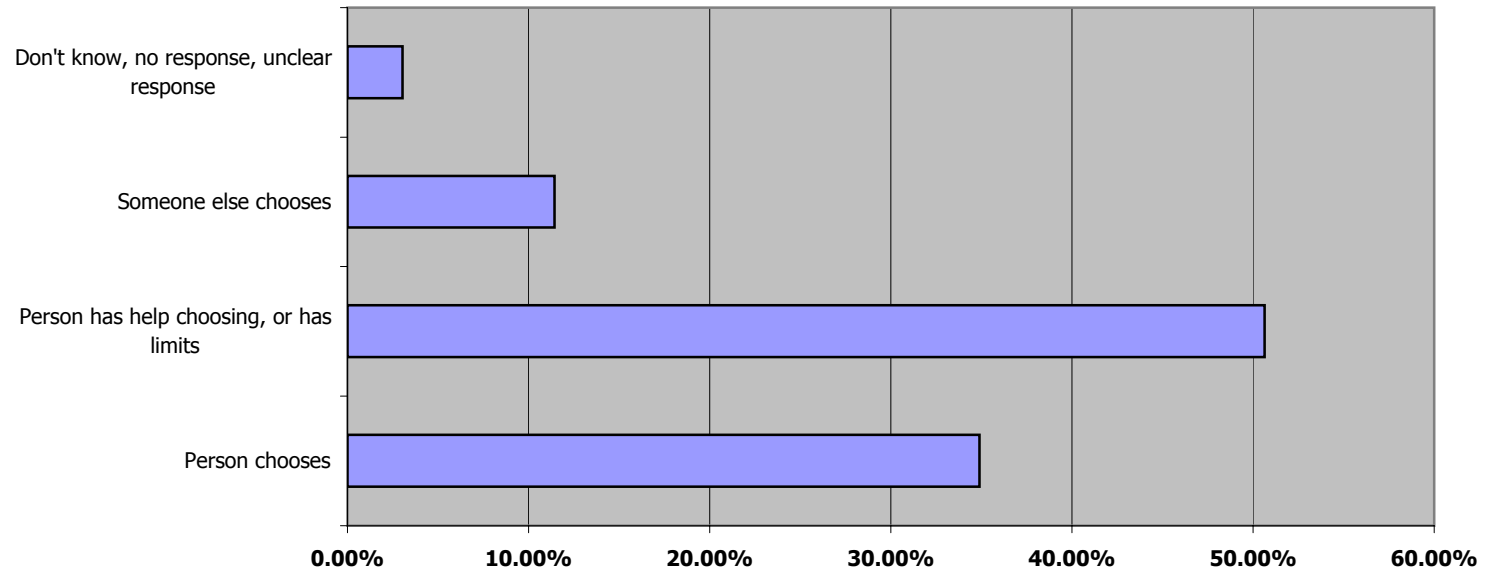


Daily Schedule

Who decides your daily schedule?

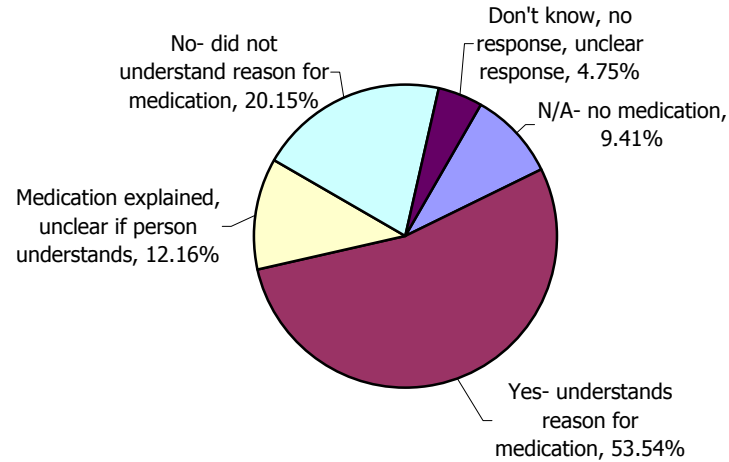


Do you choose what to buy with your spending money?

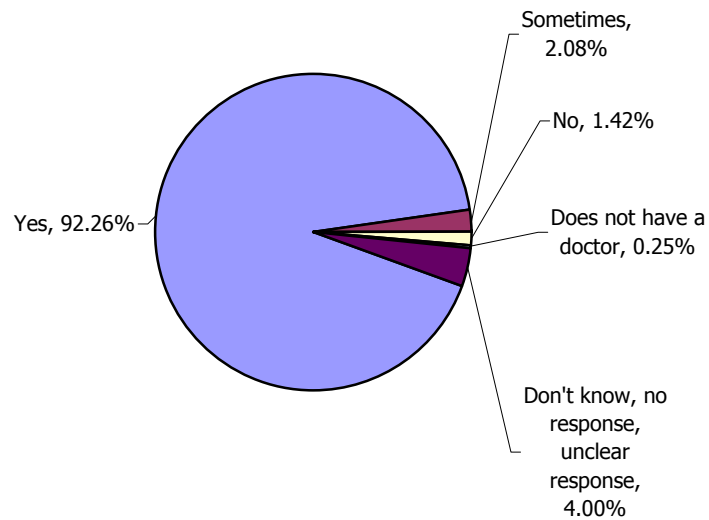


Medication

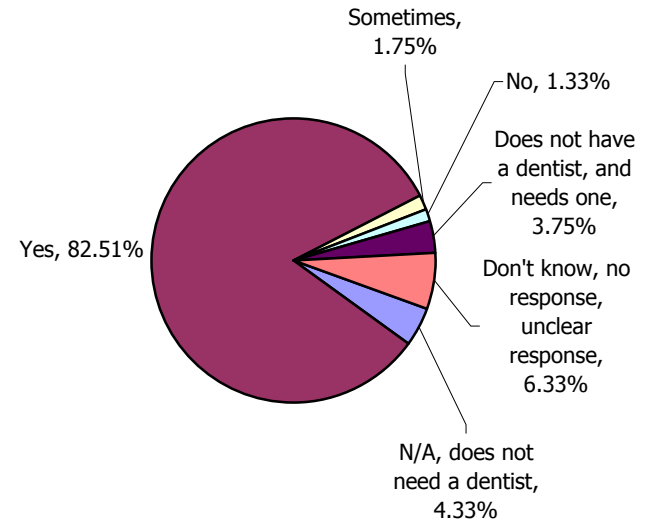
**Do you take medication (pills)? 2005-2007
If yes, why do you take them?**



Is your doctor nice to you? 2005-2007

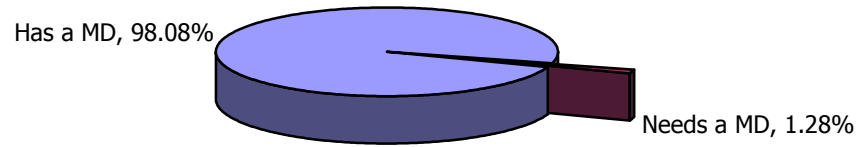


Is your dentist nice to you? 2005-2007

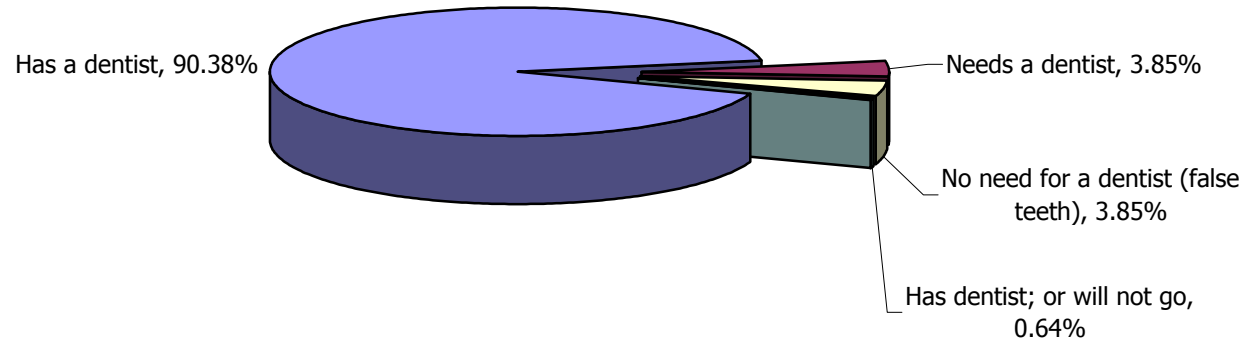


Doctor/Dentist

**Do you have a doctor?
2008 only**

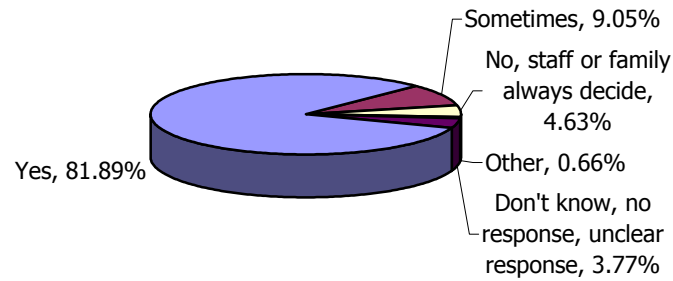


**Do you have a dentist?
2008 only**

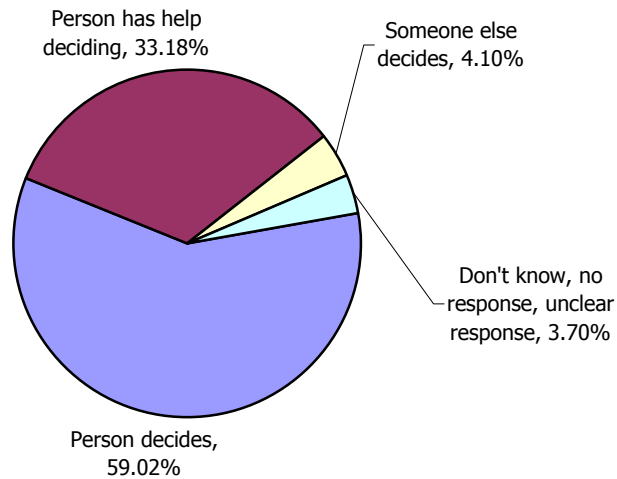


Bedtime, Free Time, Self-Advocacy

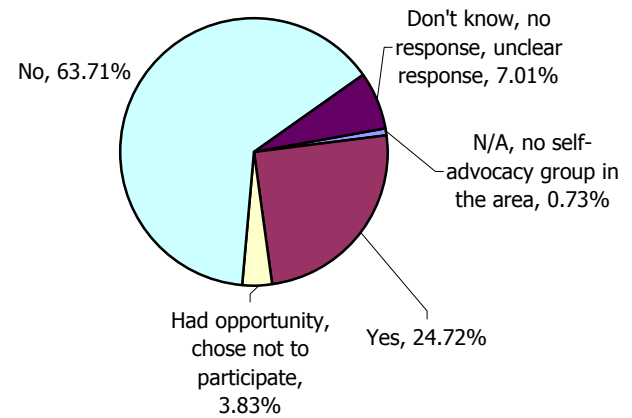
Can you go to bed when you want to?



Who decides how you spend your free time ?



Have you participated in a self-advocacy group meeting, conference, or event?



Human Rights, Life Choices and Self-Advocacy

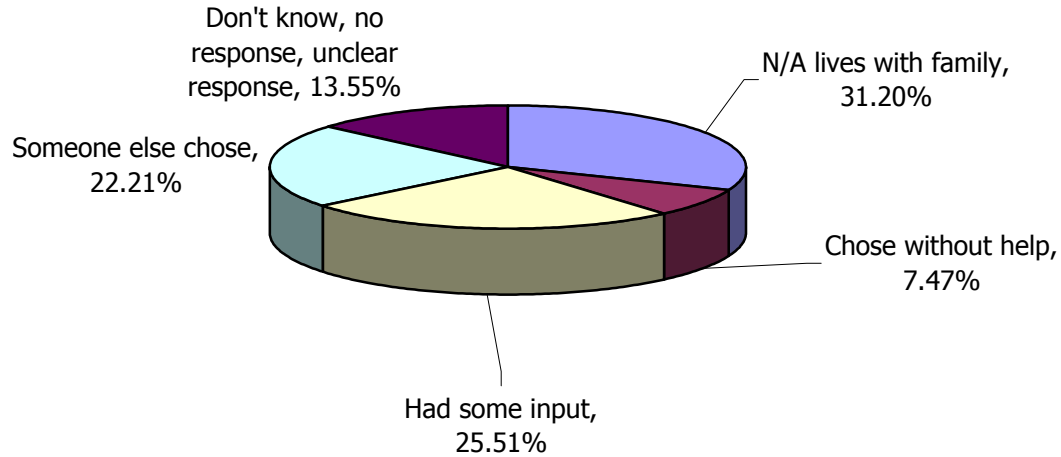
Comments:

- In 2003 & 2004, 43% of the people visited gave an example of their human rights and in 2005-2008- 43.59% gave examples.
- In 2003 & 2004, 23% of the people appeared able but could not to give an example of a human right as compared to 28.68% in 2005-2008.
- 91.74%, said no one reads their mail without their permission in the past 5 years compared to 84.1% from 2002-2004. This 7.6% increase is good, however we believe important mail about a person's services does not go directly to the person, but to family members or staff. Often people do not know how much their SS or SSI checks are for or how much is paid on their behalf for staffing. Often this information is not explained to a person in a manner they understand.
- 35.23% of people visited over this past 4 years either do not have friends or their friends do not visit them. This is a statistic is worthy of concern.
- There has been a huge push to increase voters this year, but in the past 4 years of 1513 people visited, only 29.87% answered they have voted. From 2002-2004 about 25% we visited said they vote.
- Regarding deciding their daily schedule: In our 1999-2004 report, 64.3% of people visited decided their own daily schedule compared to 53.87% over past 4 years. In our 1999-2004 report, 22.9% had input into their daily schedule compared to 33.38% over the past 4 years. 10% of the people visited over the past 4 years have less control over their daily schedules.
- Regarding choosing what to buy with their spending money: In our 1999-04 report, 48.7% chose on their own compared to 34.9% from 2005-08. Having help choosing what they buy or having limits has gone from 27.6% in 1999-04 report to 50.63% from 2005-2008. More people are involved in the process of choosing how to spend their money but there has been a 13.8% drop in people deciding on their own.
- People seem to have kind doctors and dentists, but a fair number of people have a difficult time finding a dentist. 57 people over the 4 years needed but could not find a dentist.
- A person making their own free time choices has gone down over the last 4 year from 68.49% in 2005 to 52.56% in 2008. As service hours tighten due to shrinking resources, people may have less choice, less opportunity to do what they want, a longer wait for their preferred activities, and increased compromise, by doing what the majority wants. Lack of money for transportation is also a negative impact on choices.
- There seems to be a huge self advocacy movement in RI, however 63.71% of 1513 people visited answered they did not participate in a self advocacy event or meeting the year prior to their visit.

Place Where You Live

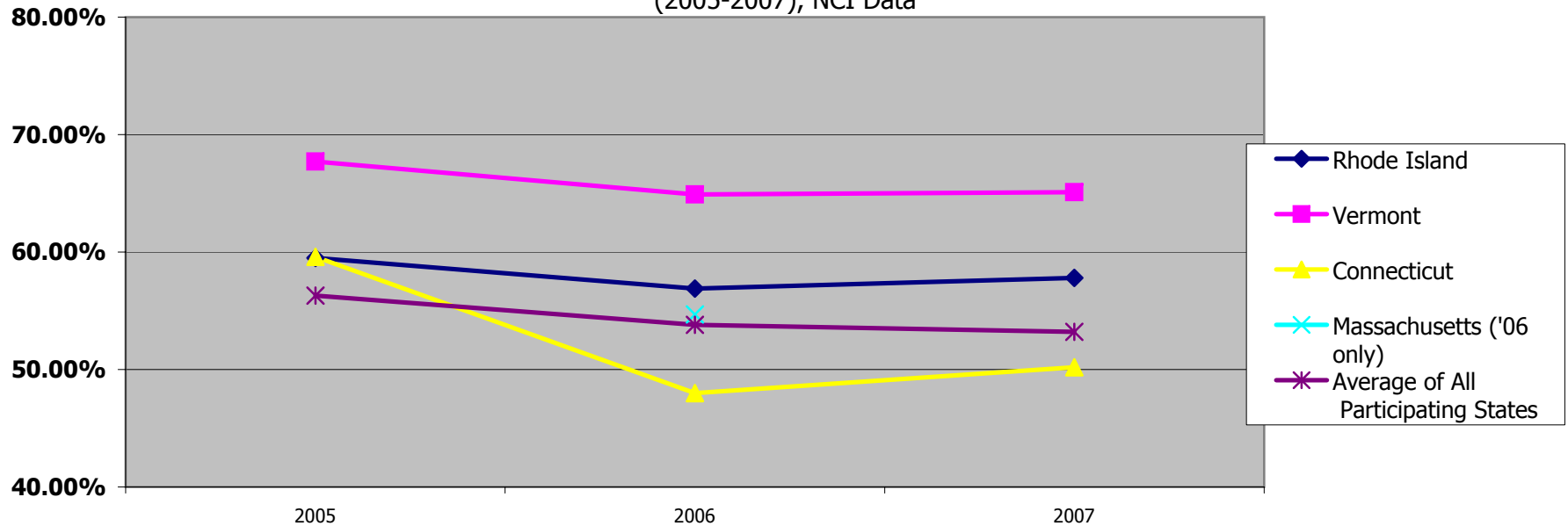
Who chose the place where you live?

Question answered on Background Information Form



Percent of People Who Chose the Place Where They Live

(2005-2007), NCI Data

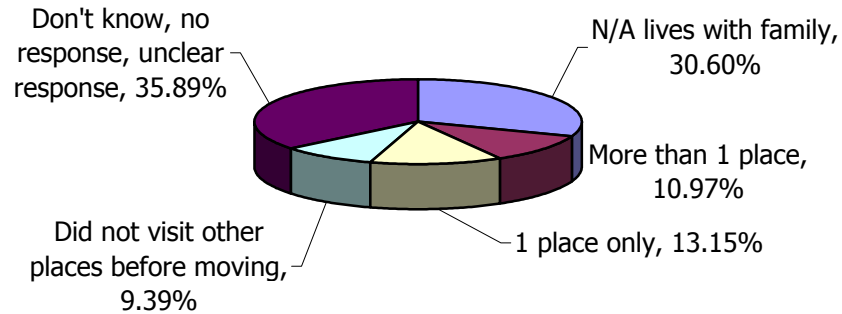


Rhode Island ranked 6th out of 17.34 participating states
(3 year average, variable number of states per year, per question)

How Many Places Did You Visit

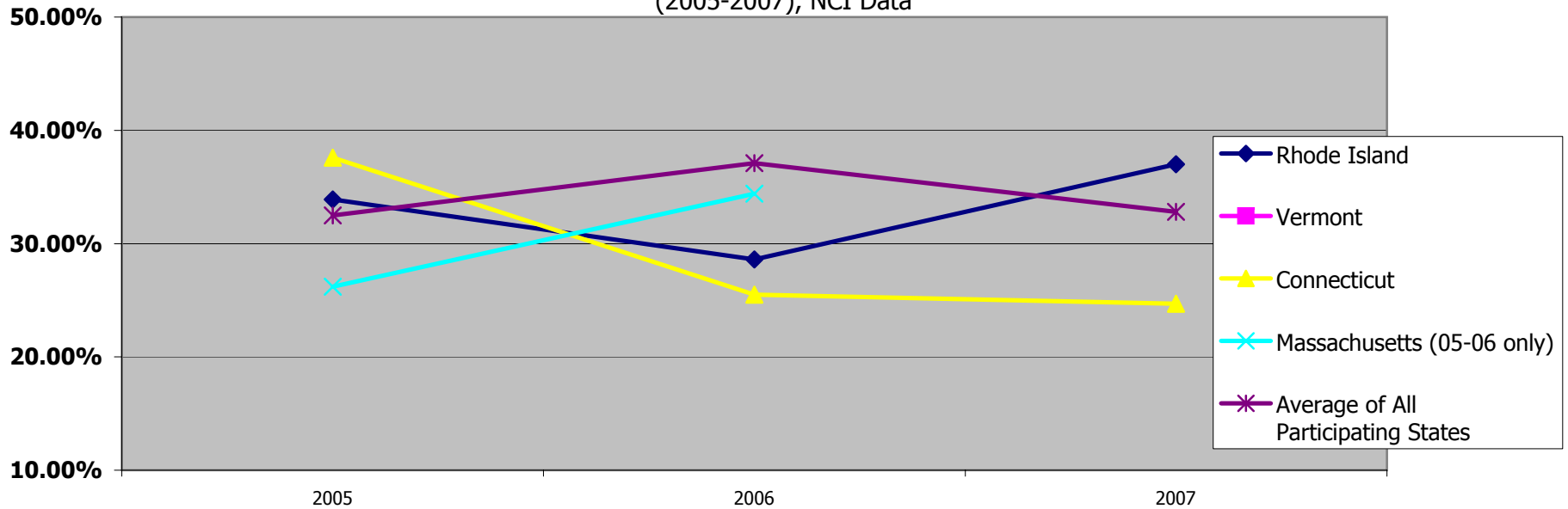
How many places did you visit before moving here?

Question answered on Background Information Form



Percent of People Who Looked at More Than One Home

(2005-2007), NCI Data

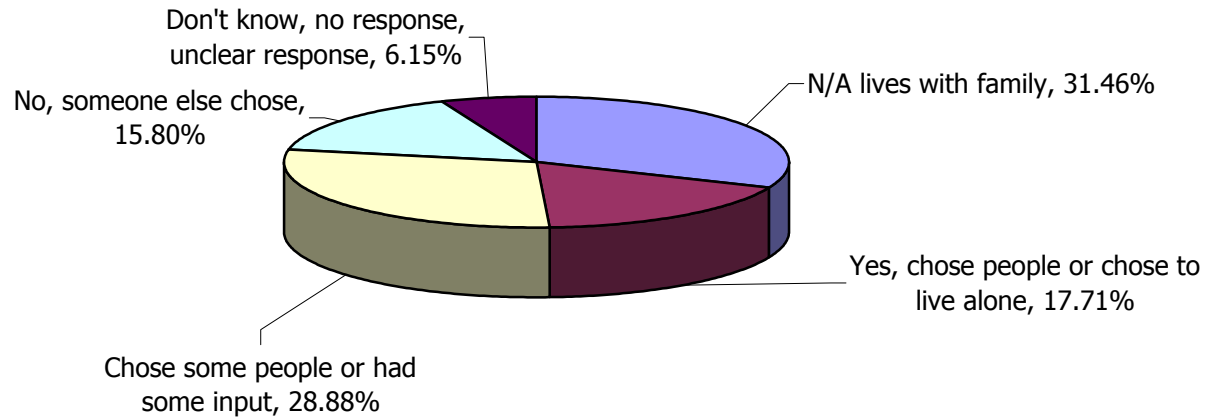


Rhode Island ranked 7.34 out of 17.67 participating states
(3 year average, variable number of states per year, per question)

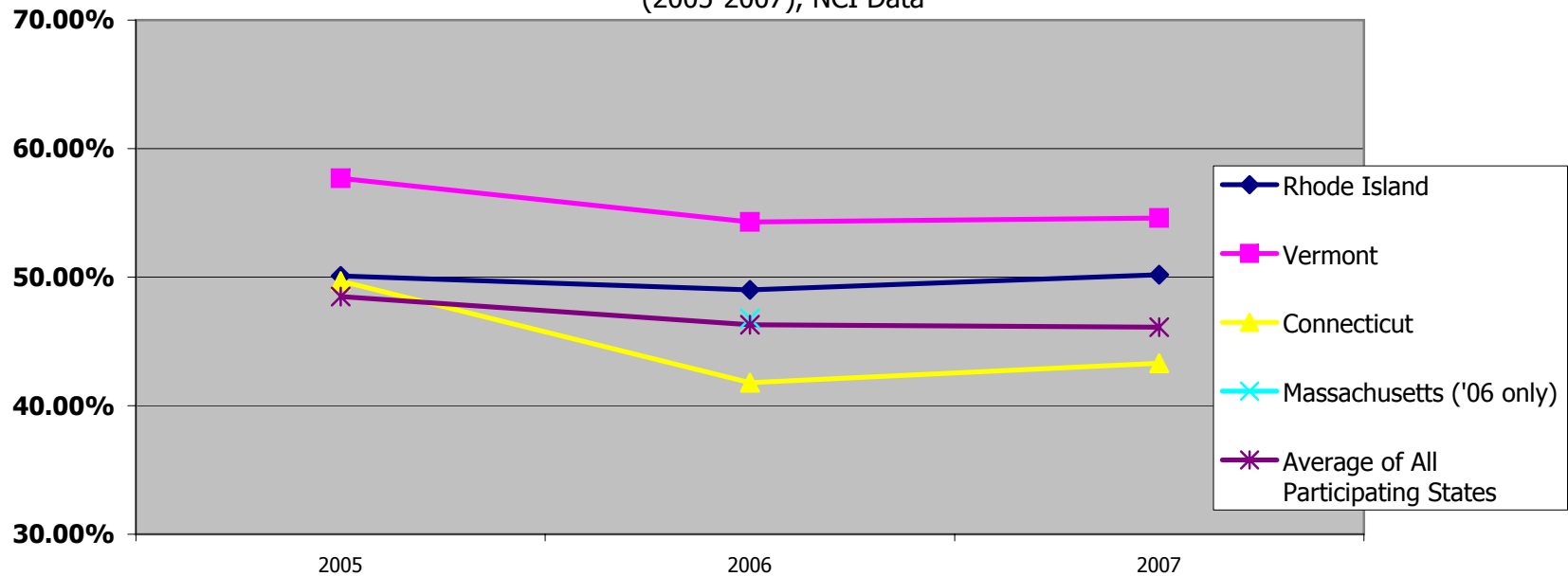
Choose People You Live With

Did you choose (or pick) the people you live with, or did you choose to live by yourself?

Question answered at the visit.



Percent of People Who Choose People They Live With
(2005-2007), NCI Data

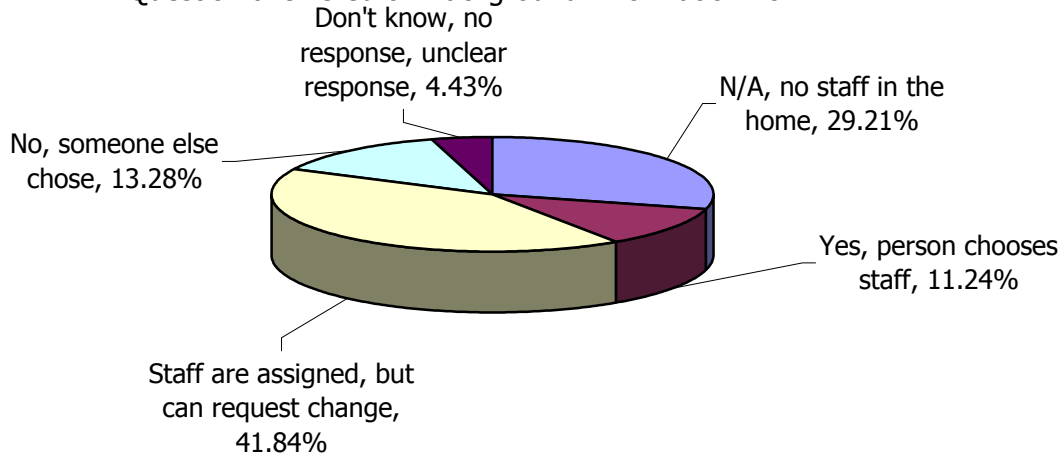


*Rhode Island ranked 5.34 out of 17.34 participating states
(3 year average, variable number of states per year, per question)*

Choose Who Helps You at Home

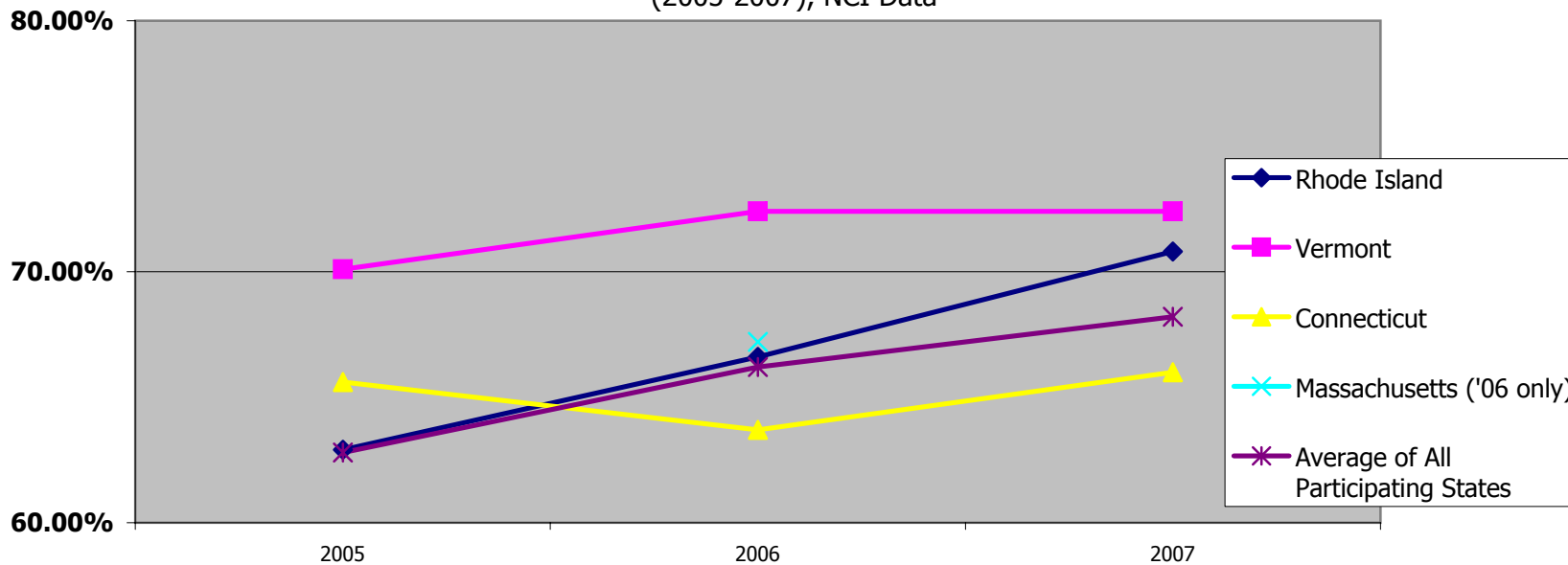
Did you choose (or pick) who helps you at home?

Question answered on Background Information Form.



Percent of People Who Choose Staff Who Help Them at Home

(2005-2007), NCI Data

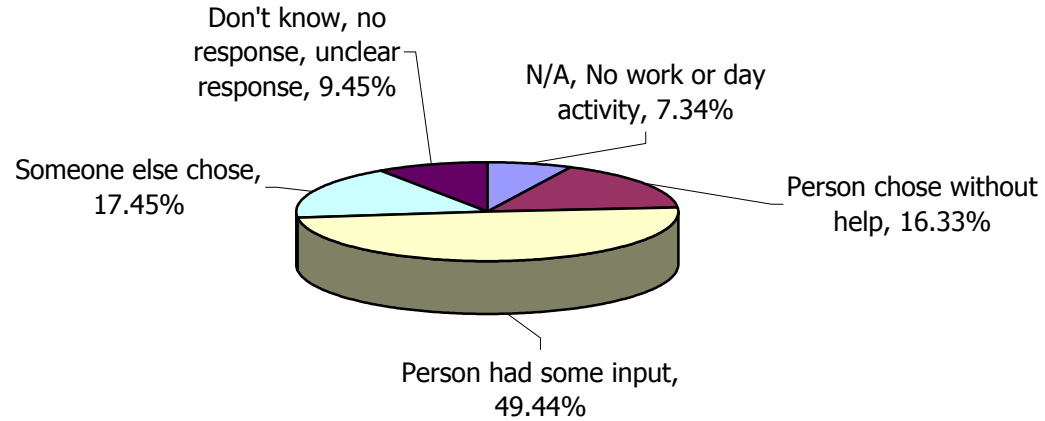


Rhode Island ranked 5.67 out of 17.34 participating states
(3 year average, variable number of states per year, per question)

Choose Place Where You Work

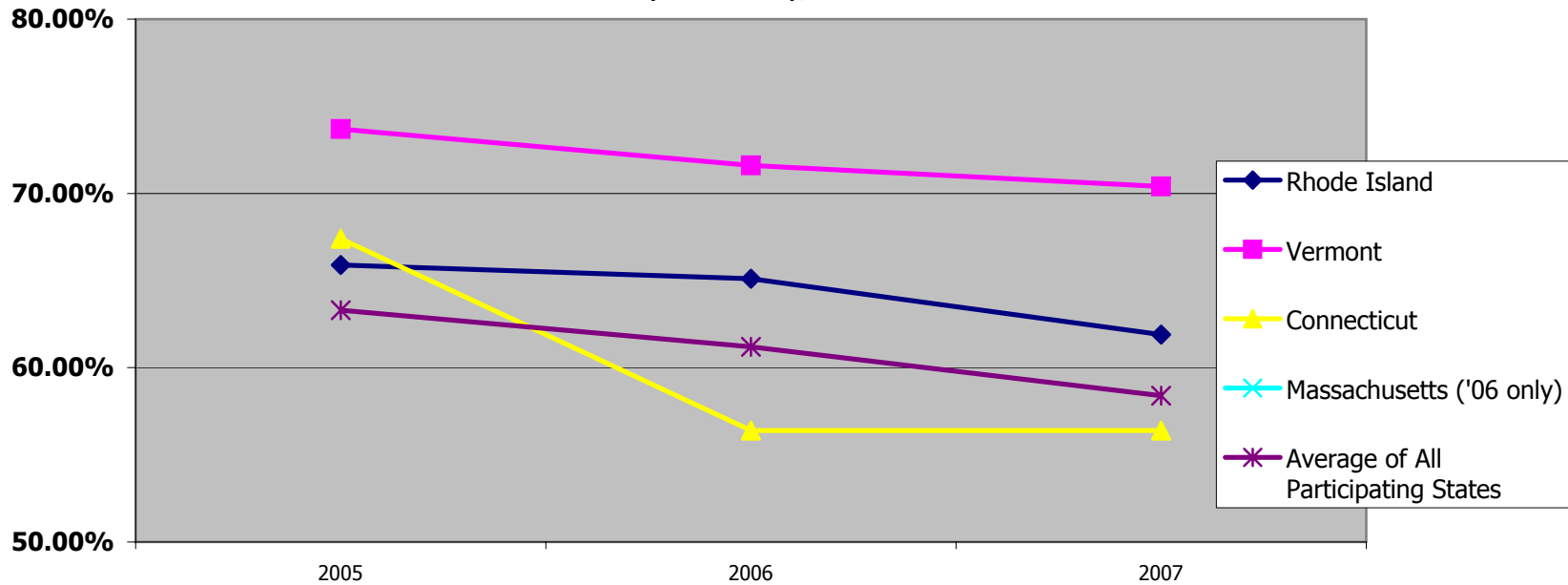
Who chose (or picked) the place where you work (go during the day)?

Question answered at the visit.



Percent of People Who Chose Place of Work or Day Activity

(2005-2007), NCI Data

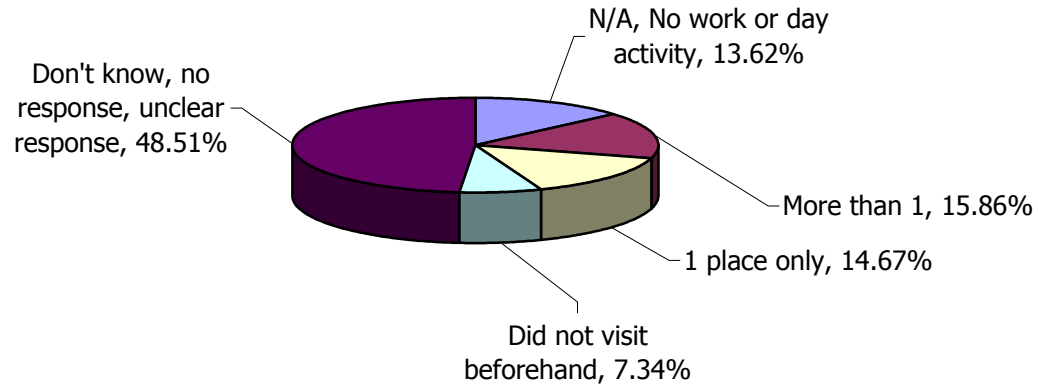


*Rhode Island ranked 5.34 out of 17.34 participating states
(3 year average, variable number of states per year, per question)*

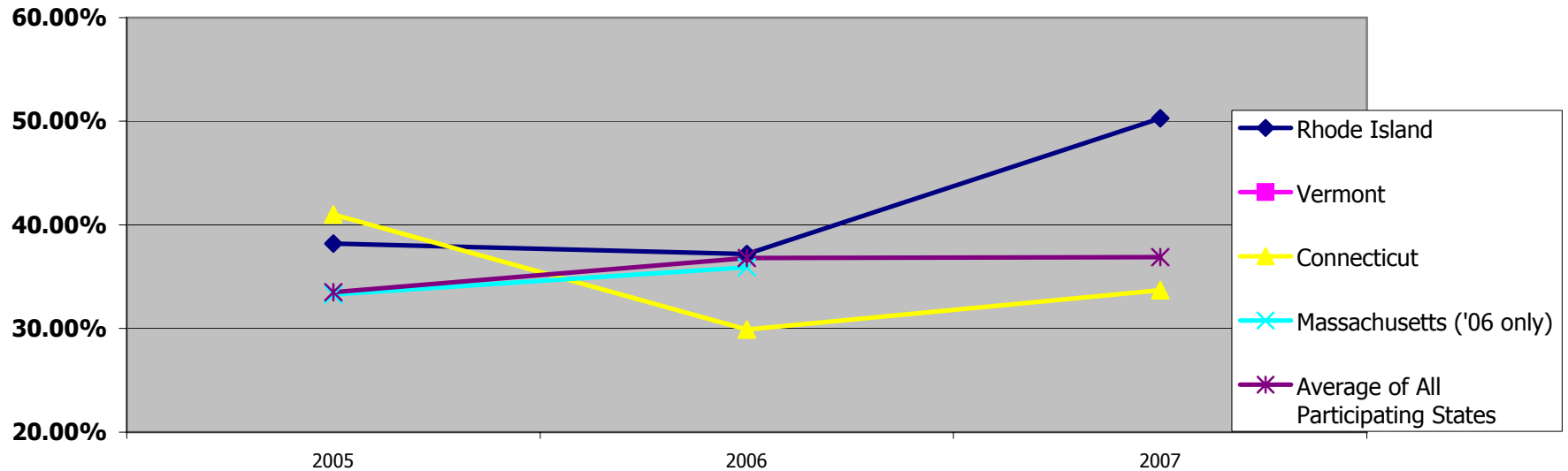
Places Visited Before Working Here

How many places did you visit before working here?

Question answered on Background Information Form



Percent of People Who Looked at More Than One Job (2005-2007), NCI Data

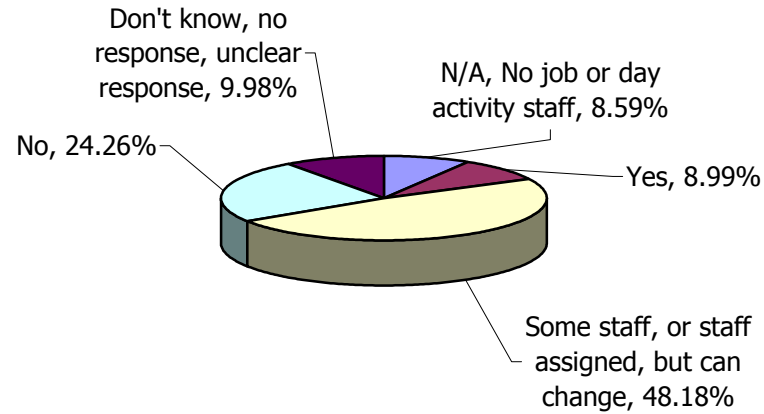


Rhode Island ranked 6th out of 17.67 participating states
(3 year average, variable number of states per year, per question)

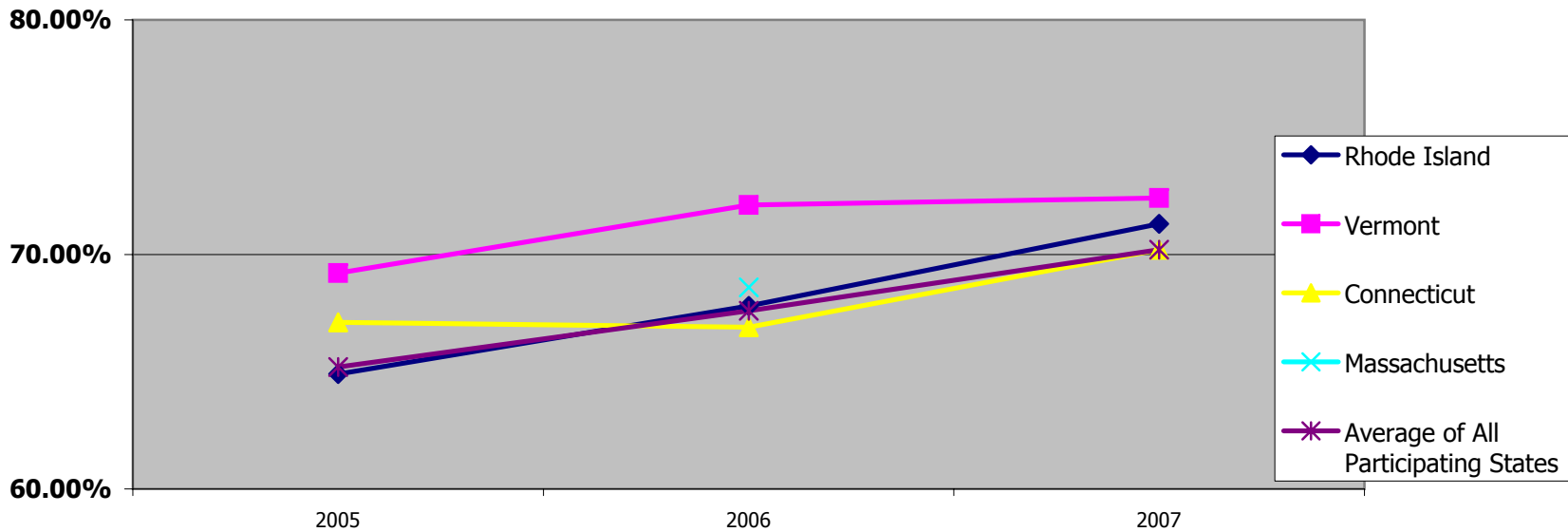
Choose Who Helps You at Work

Did you choose (or pick) who helps you at work?

Question answered at the visit.



Percent of People Who Choose Staff Who Help Them at Work or Day Activity
(2005-2007), NCI Data



*Rhode Island ranked 10.67 out of 18 participating states
(3 year average, variable number of states per year, per question)*

Human Rights, Life Choices and Self-Advocacy

Comments:

- In 2005, we added questions about mistreatment to our questionnaire so we moved 3 difficult NCI questions, with HSRI's permission, to the background information form. The 3 questions moved are:
 - 35. Who chose the place where you live?
 - 36. How many places did you visit before moving here?
 - 42. How many places did you visit before working here?

- Choice of home: An average of 22.21% of the people visited did not have a choice in where they live, however in 2008 the percentage is 26.92%. We feel this is another indicator of the state's budget deficits impacting major life decisions. Compared to other states from 2005-2007, RI is above the average of participating states.
 - NCI data shows from 2005-2007 an average of 31.17% Rhode Islanders looked at more than 1 place to live. Unless a person has an expressed desire to move out of their family's home, it is unclear if in the past people knew of other housing options. Is the number of people living in their family home due to their choice or because they have not been presented with choice? As choice and money decline, more adult children with disabilities will be living for longer periods with their families.

- Choice of staff at home: This NCI question did not include these response options: person is part of the interview process, interviewees visit the people at home before hired so interactions can be observed, etc. This question does not give us the information needed to assess how much a person participates in hiring their staff.
 - Choice of work or day activity: An average of 17.45% of the people visited did not chose their work or day activity. NCI data shows from 2005-2007 and average of 41.9% Rhode Islanders looked at more than 1 job and/or day program.

- Choice of staff at work/day program: Again this NCI question did not include these response options: person is part of the interview process, interviewees visit the people at work before hire, so interactions can be observed, etc. This question does not give us the information needed to assess how much a person participates in hiring their work/day program staff.

- Options for individuals wanting to move out of their family home are shrinking. Rhode Island does not have enough affordable housing.
 - Individuals and families sometimes make choices of day service based on proximity to home rather than interest

- Many more people are receiving in-home day supports. In-home day supports can and do work for people, but may sometimes reduce the opportunities for a change in environment. Being in your home with housemates and home staff can limit connections to community unless supports are focused on the individual and organized to keep people actively engaged in satisfying activities.