

Supports & Services At A Glance

Data From Background Information

This information provided by agencies prior to visit (61.54% from case managers or service coordinators)

-The top 5 services people received over the past 4 years are:

1. Service Coordination
2. Transportation
3. Clinical services
4. Community participation
5. Facility based employment

-Types of transportation people use: Top 4 answers over 4 year averages:

1. Staff- 77.07%
2. Family- 32.39%
3. Agency Contracted- 20.75%
4. Ride- 13.81%

-Who owns the home where people live? Top 4 answers over 4 year averages:

1. Family/guardian/ friend-30.67%
2. Private agency- 28.49%
3. State or county agency- 19.56%
4. Person rents home- 15.14%

-53.93 of the people visited over the past 4 years have 24 hour supports

-Does this person have a representative payee or financial guardian? (4 year average)

- Yes- 62.99%
- No- 18.84%
- Don't know- 18.17%

•Data collected regarding self-directed supports and ICF vs HCBS Waiver is inaccurate. (see page 7 for clarification)

Data From Visits

-Of the people who have staff at work or a day program, only 5.02% say some staff or most staff are not nice and polite.

-Of the people who have staff at work or a day program, only 6.00% say some staff or most of their staff do not listen & do what they ask them.

-2008 only- Of your staff who helps you there [work/day program], why do you like them?

1. Helpful
2. Nice to me
3. They're fun
4. Friendship
5. Listens to me

•Of the people who have staff at home, 3.57% say some staff or most staff are not nice and polite.

-Of the people who have staff at home, only 3.66% say some staff or most of their staff do not listen/do what they ask them.

-2008 only- Of your staff who helps you at home, why do you like them?

1. Nice to me
2. Helpful
3. They're fun
4. They take me out
5. Friendship

-General problem solving: Who do you go to with a problem? Average, top 8 answers:

1. A specific staff
2. Whoever is with them, staff or family
3. Family
4. Person is unable to respond in any manner
5. Supervisor/Boss
6. Chose to tell no one
7. Draw attention by their actions
8. Friend

-If someone is bothering you at work/day program, who would you tell? Average, top 8 answers:

1. Tell specific staff
2. Tell the "Big Boss" (Agency Ex. Dir)
3. Do nothing
4. Tell family
5. By actions/draw attention
6. Tell someone else/be persistent
7. Tell another staff
8. Tell boss/Manager

-If someone is bothering you at work/day program, who would you tell? Average, bottom 8 answers:

Low to High: Call Quality Assurance, Go to the Human Rights Committee, Person cannot ask for help, Go to neighbor, Case Manager, Counselor, DDD Social Worker, Co-worker, File a grievance, Tell friends

-Do people help you learn new things? Average of 4 years: 74.82% Yes

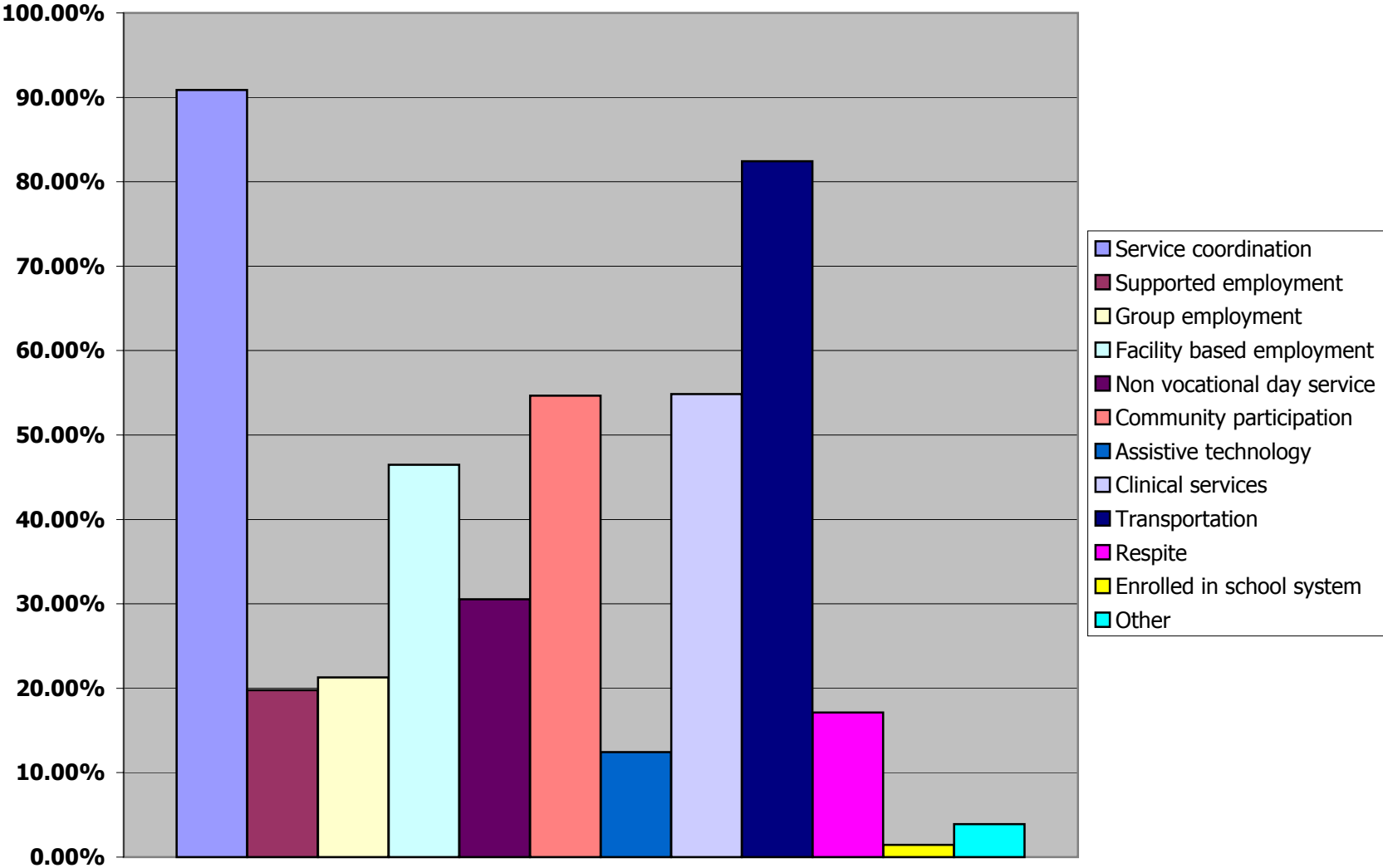
-Of the 274 people who answered they do not get or only sometimes get help to learn new things, 164 or 43.04 want help to learn new things

-84.27% of the people visited over 4 years say when they want to go somewhere; they can get a ride to go.

-52.81% of all people visited over 4 years answered they get all the services they need.

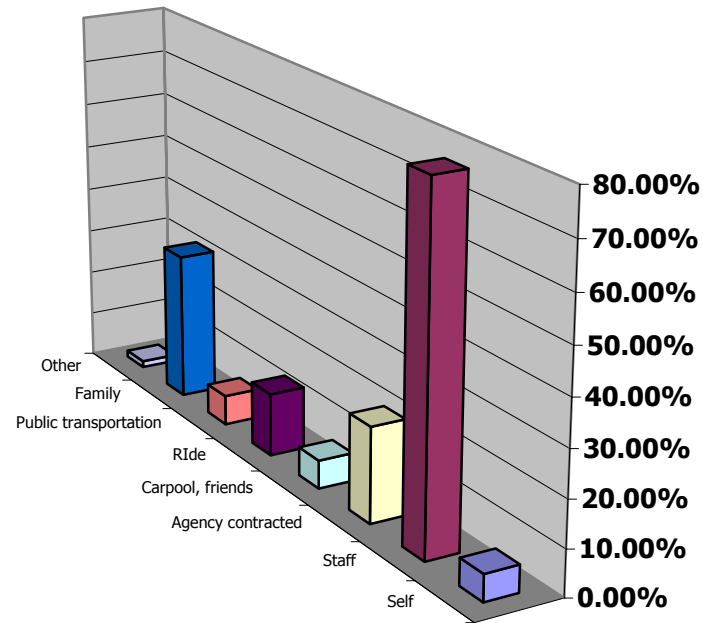
Types of Supports

What other paid supports and services does this person currently receive?
 (multiple responses possible)

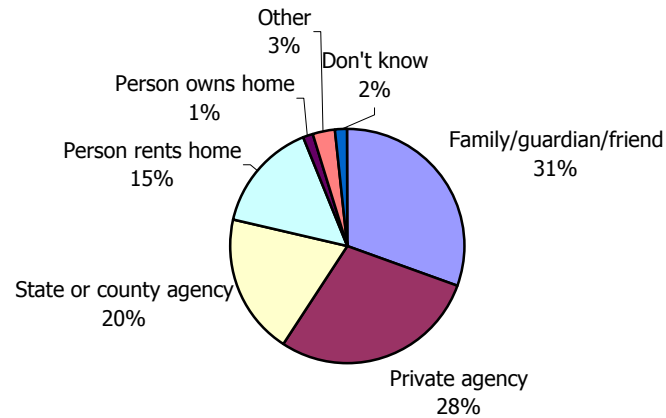


Types of Supports (continued)

What types of transportation does this person use?
(multiple responses possible)

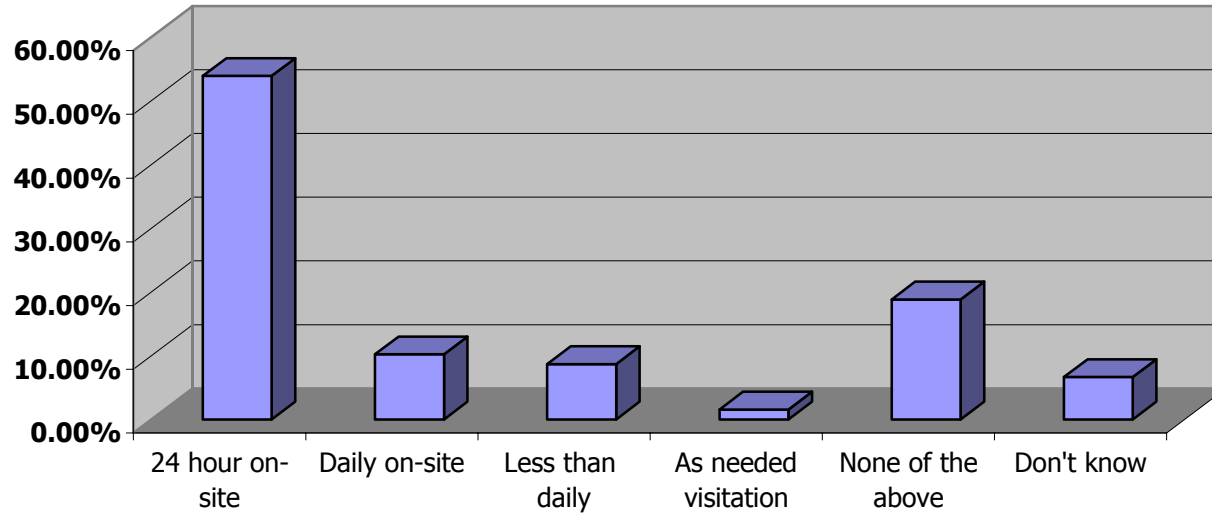


Who owns or leases the place where this person lives?

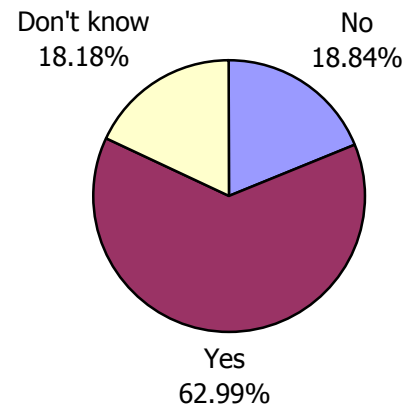


Types of Supports (continued)

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

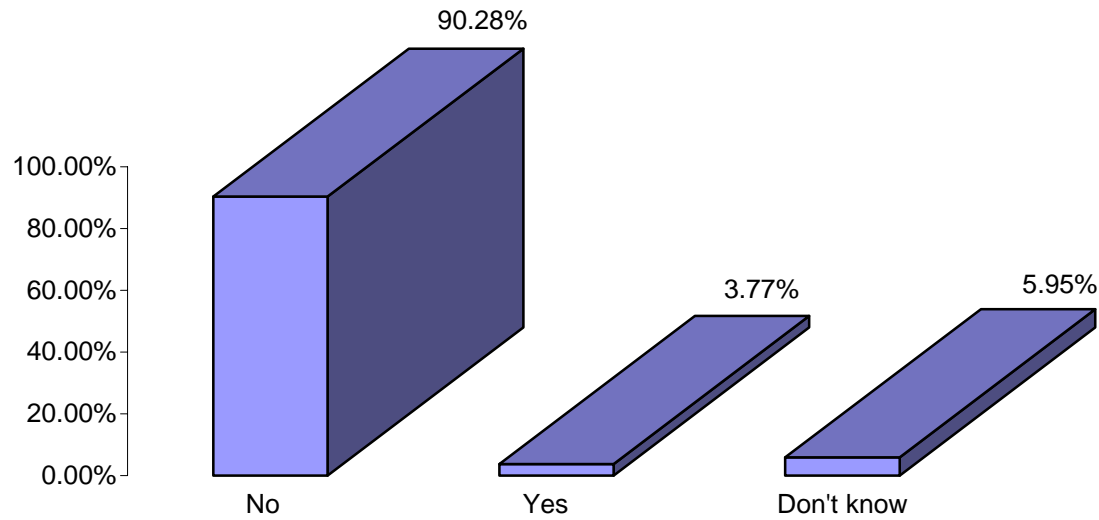


Does this person have a representative payee or financial guardian?

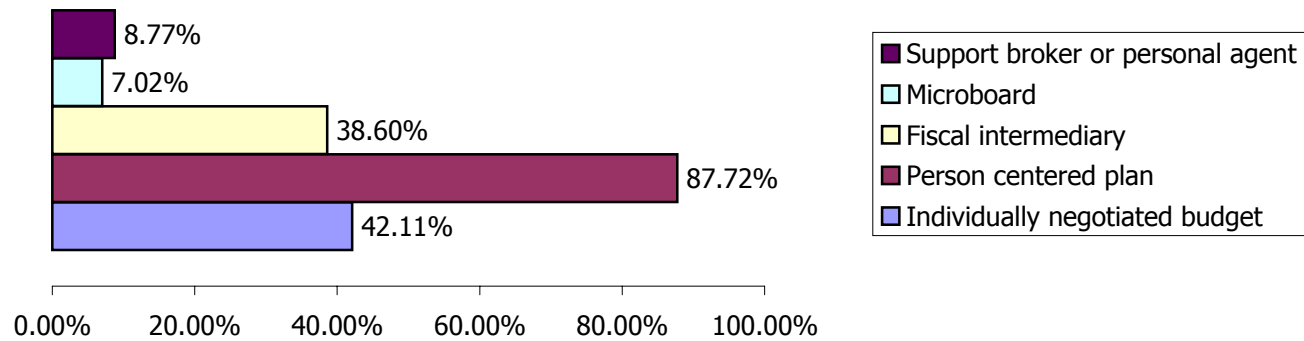


Types of Supports (continued)

Does this person currently use self-directed supports option?

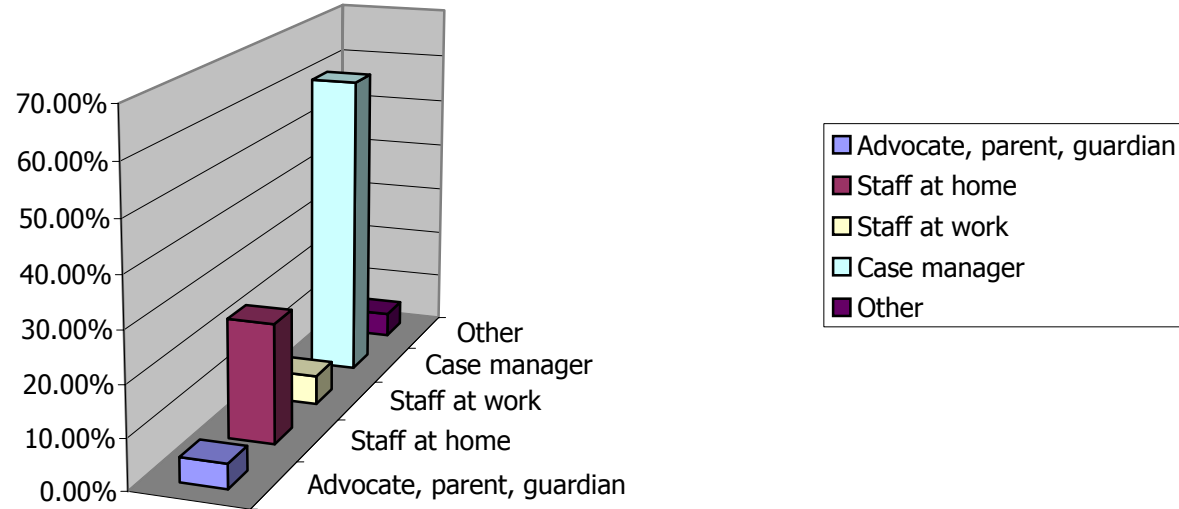


If yes, does this person currently have....
(multiple responses possible)

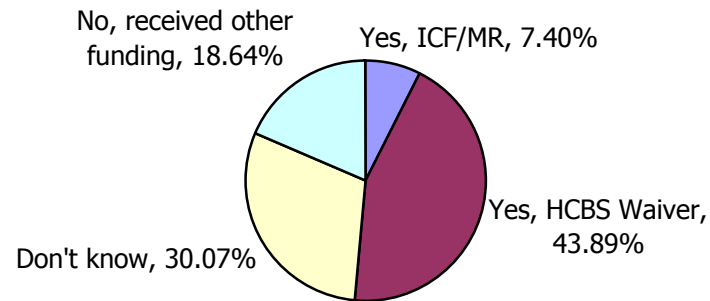


Types of Supports (continued)

Please indicate who provided this information:
(multiple responses possible)



Does the person receive ICF/MR or HCBS Waiver funding?
(multiple responses possible)



Types of Supports (continued)

Comments:

• Most people are receiving:

Service coordination: 90.88%
Supports for transportation: 82.42%
Community participation: 64.66%
Type of transportation: Staff: 77.07% Family: 32.39% Agency Contracted: 20.75%
At home, have 24 hour supports: 54.15%
Representative Payees: 67.99%
Family, Guardian, Friend or private agency own their home- 59.16%

•Some people are receiving:

Supported employment: 19.76% Respite: 17.12% Assistive Technology: 12.43%
People use this type of transportation: Self: 5.81% Carpool/friends: 6.21% Public transportation: 6.54% RIDE: 13.81%
At home has less than daily or as needed supports: 5.37%
No Representative Payees: 18.84%
People who rent their own home: 15.14% Own their own home: 1.39%

- Community participation is critical to friendship and developing natural supports. 64.66% of people have supports for community participation. How is participation defined? It can be support in making connections with community members to going for a ride or through the Dunkin Donuts drive through. We believe more focus on community building is a critical need.
- The use of staff for transportation has increased from 41.76% in 2005 to 53.73% in 2008. Transportation to an individual's preferred places and to develop community relationships is critical for people who cannot drive. No access means limited social connections and increased loneliness. RIPTA and RIDE are very important pieces to transportation.
- The HSRI data collected about self-directed supports and ICF vs. HCBS waiver is in question due to the way the question was asked or the knowledge level of the person filling out the background information form. Support staff, from our experience, can be out of the loop of information, so focused on the day to day, however, the question was worded by NCI and not in "Rhode Islandese", so the intent may have been misunderstood.

Annual Plans & Positive Support Plans

Annual Plan dates				
	2005	2006	2007	2008
No date	16	17	39	18
Span of annual plan dates	2/1/2002 to 6/24/2005	5/14/2004 to 3/27/2006	10/6/2004 to 8/15/2007	2/15/2006 to 6/5/2008

Examples of Goals (from background information) compared to Wishes (from visit)

Each agency is represented once in 4 year comparison.

2005					
In this [person's] plan, what are the 3 most important goals /objectives to the person we are visiting?			If you had 3 wishes, what would they be?		
Goal 1	Goal 2	Goal 3	Wish 1	Wish 2	Wish 3
Will maintain a predictable schedule that will incorporate all routines	Will successfully use picture system to choose community activities & communicate restaurant order	Will feel better	Get another job	Move to Florida	None
Community employment	Improve her computer skills	Take on responsibility in kitchen and as receptionist	Live with best friend	Go on a cruise	Get married someday
Medical desensitization, OT, PT exercises, medication regulation, dietary management	Help adapt to a less rigid home/mom visit schedule	Continue with enjoyed activities and try new ones at home and at day agency	_____ as a girlfriend	See his siblings who live out of state	His dad was alive (died 2 yrs ago)
Residential goal- continue living arrangement	Work goal- keep work same and job/hours	Personal goal- dad passed away this July- grief counseling. Wants to reconnect with cousin	Live with 1 or 2 people (smaller group of people)	Peace throughout the world	Cures for all medical illnesses
By 12/05 _____ will develop her ADL skills- cooking, cleaning, personal care	By 12/05 _____ will transition to her own apartment with a roommate	By 12/05 _____ will participate in 2 preferred recreational activities each week	Live with friend	Have a girlfriend	Be with friends from North Kingstown
_____ with staff assistance will prepare a meal 2x per month	_____ will continue to be involved with various community activities he enjoys 1x per month	No goal	To have maid service	Get out of the Iraq war	Get out to work more
Move to <u>agency_name</u>	Improve writing/reading	No goal	A swing	Something to drink while walking	Go to Washington DC
By 6/05 _____ will utilize bikes, treadmill, and basketball for a minimum of 30 minutes per session	By 6/05 _____ will continue his daily hygiene independently	By 6/05 _____ will continue in car store averaging no more than 3 prompts to stay on task	Wish _____ would come (to his visit)	A real car	Ride go-carts with _____

Annual Plans & Positive Support Plans (continued)

Examples of Goals (from background information) compared to Wishes (from visit)

Each agency is represented once in 4 year comparison.

2006					
In this [person's] plan, what are the 3 most important goals /objectives to the person we are visiting?			If you had 3 wishes, what would they be?		
Goal 1	Goal 2	Goal 3	Wish 1	Wish 2	Wish 3
Trip to Alabama to visit Mother and Angelica's Broadcast Center	Renew his marriage vows	Purchase a new speaker phone	Get GED	Go to Alabama	Get a good friend with his own religion
By 9/06 _____ will go on a vacation to NH- The Beacon	By 9/06 ____ and__ will commemorate many years of being together- have a celebration ceremony	By 9/06 _____ and __will live in a new apartment	Cook again	Go on a plane on vacation	Be happy with _____
By 11/06 _____ will be preparing meals with minimal staff assistance and will be swimming 1 day per week	By 11/06 _____ will be independently completing her hygiene routine	By _____ will prepare meals that are portioned and will prepare them with staff so she has meals already prepared for days that she doesn't have staff	Go on a cruise	Have a roommate	Have more staff hours
Will make more social contacts and make more friends	Will be more physically fit	Will find regular employment	Own house	Get married	Have kids
ADL's (hygiene, home living skills, etc)	Socially appropriate behavior	Work at center/community	Coke truck in the backyard	Live with parents	Meet news anchors from channel 10
To explore other video dating services (other than Unlimited Connections)	To increase participation in community activities on the weekends	Obtain new manual wheelchair	Girlfriend	Money	A son
_____ will connect with _____, _____, and _____ at least once a month	_____ will obtain at least one more community membership	Beginning 1/2006, _____ will begin to try at least six new in house activities	Unlimited amount of money	Go swimming with the dolphins	Spend a lot more time with her family and friends
No goal listed on BIF	No goal	No goal	Have good luck here	Being good at home	If rich, not work and take it easy

Annual Plans & Positive Support Plans (continued)

Examples of Goals (from background information) compared to Wishes (from visit)

Each agency is represented once in 4 year comparison.

2007					
In this [person's] plan, what are the 3 most important goals / objectives to the person we are visiting?			If you had 3 wishes, what would they be?		
Goal 1	Goal 2	Goal 3	Wish 1	Wish 2	Wish 3
To increase independence.	To hold down a good paying job	To enjoy improved relationships- have a girlfriend	Have own apartment	Have girlfriend and get married	Travel to see Elvis Presley's birthplace and Hall of Fame
Go to gym, manage health	See my son on a regular basis	Move out to the group home	My apartment	My own car and be able to drive	To have a lot of money to go shopping
No goals listed	No goal	No goal	Better weather	Lots and lots of staff	New wheelchair
Find a job	Learn how to paint	Spend time with friends and family	1 billion dollars	Pay off his family's mortgages & debts	Pay mom's doctor bills, buy his siblings their own home, buy the house he lives in
To increase independence.	To make progress with her service dog	To manage medical appointments & medication	Buy an accessible house	Own my own business doing arts & crafts	Go on vacation to Florida
_____ will learn to read and write at Adult Literacy classes	_____ will learn to cook healthy, balanced meals and snacks	_____ will get together with friends regularly- Ladies Day Club	Wish I could read	Go shopping for clothes	I wish I knew you better
_____ will continue to decrease instances of SIB and oppositional behavior	_____ will keep up and improve daily hygiene skills	_____ will continue musical and art activities	A boyfriend	Another job	To have a lot of money to go shopping

Annual Plans & Positive Support Plans (continued)

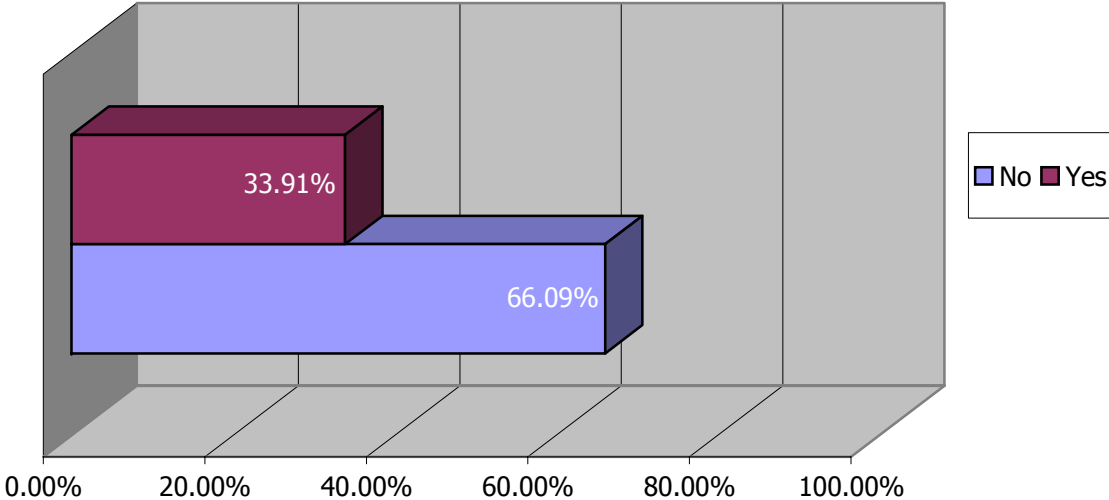
Examples of Goals (from background information) compared to Wishes (from visit)

Each agency is represented once in 4 year comparison.

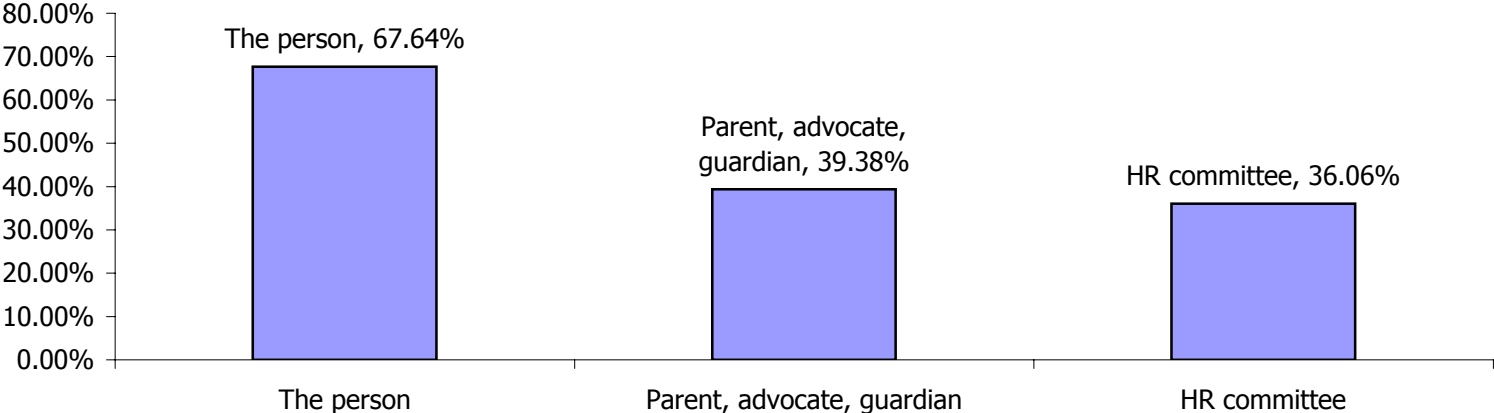
2008					
In this [person's] plan, what are the 3 most important goals /objectives to the person we are visiting?			If you had 3 wishes, what would they be?		
Goal 1	Goal 2	Goal 3	Wish 1	Wish 2	Wish 3
By 8/08 _____ will feed his fish on weekends	By 8/08 _____ will bathe without assistance	Maintenance- Vary in-home and community activities	Meet a nice Portuguese girl	More opportunities for physical exercise	March in parade
_____ will increase and improve his daily work production	_____ will remain in his seat	No goal	Travel to Miami	Music- listening, and going to concerts	Dance, not work, continue learning
Check writing skills	Register to vote	Visit Cheers bar in Boston	Win the lottery	Share my winnings with my sister _____	Go see my cousin in Ohio
Maintain physical support with all ADLs and personal care needs	Continue to visit with parents and help them as much as possible	Continue to promote business card design service	Make more money	See parents more often	We are not all that different from anyone else
_____will complete the chores on her ADL list daily	_____will increase her circle of friends by scheduling plans	_____will increase her day program opportunities weekly by trialing new activities on Mondays	Shopping with _____	Out to eat more	Another Billy Ray Cyrus concert
_____ will maintain part time employment at the YMCA, approximately 20 hours per week	To properly clock in and out for each shift	To follow all child safety standards	Win the lottery	Have a big wedding- 200 people	To have children someday

Annual Plans & Positive Support Plans (continued)

Does this person have a positive support plan?
(Not an annual plan)



If yes, who has signed off on the positive support plan?
(multiple responses possible)



Annual Plans & Positive Support Plans (continued)

Comments:

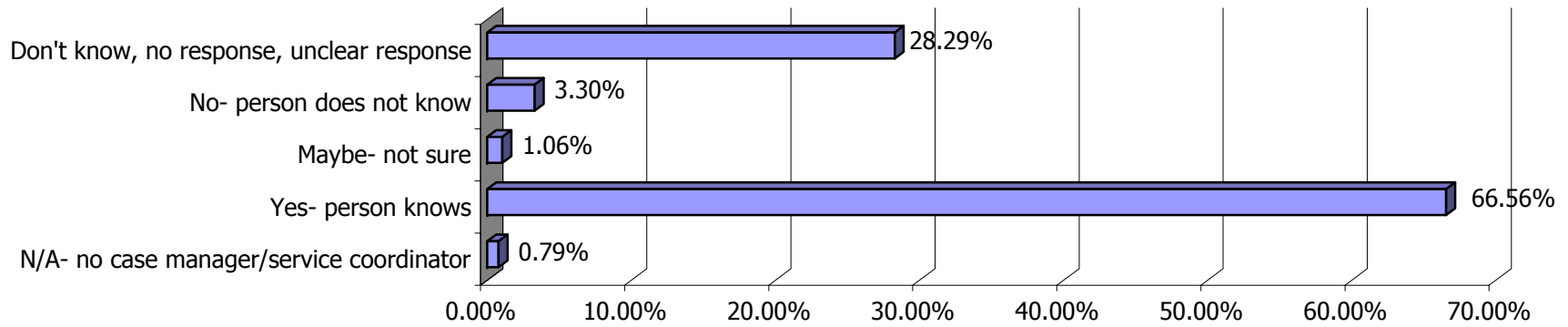
- Often at visits, people and their parents do not seem to know a person's annual goals or of the continuous movement of an annual plan throughout a year.
 - Many people visited, who seem very able to follow their plan, do not seem to be actively participating in it.
- Annual plans are required by DDD and CMS. Do the plans truly reflect a person's dreams, wants and needs? Are they goals we would write for ourselves?
- Wishes reflect what is important to us all: Relationships, having enough money, vacations and doing what we love.
- As people, we all need support to actively work toward our dreams. It is so important for people with disabilities to have encouraging, positive, and focused supports on their dreams so their world can be improved.

Vision without action is merely a dream.
Action without vision just passes time.
Vision with action can change the world.

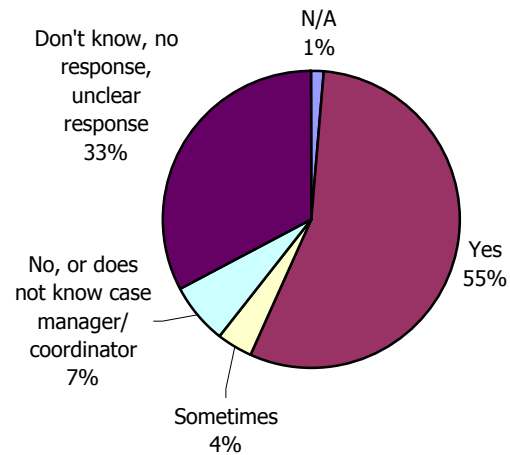
Joel Baker

Agency Coordinator and DDD Social Workers

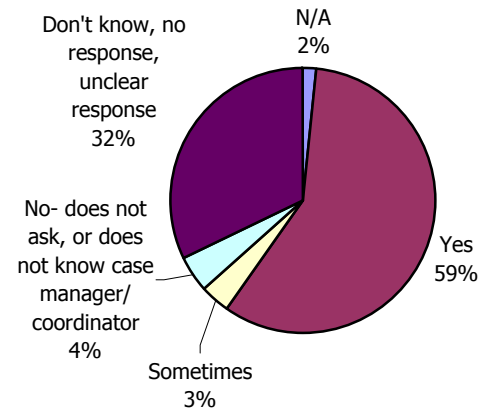
Do you know the person who coordinates your annual plan?



Does s/he ask you what you want?



If you ask for something, does s/he help you get what you need?



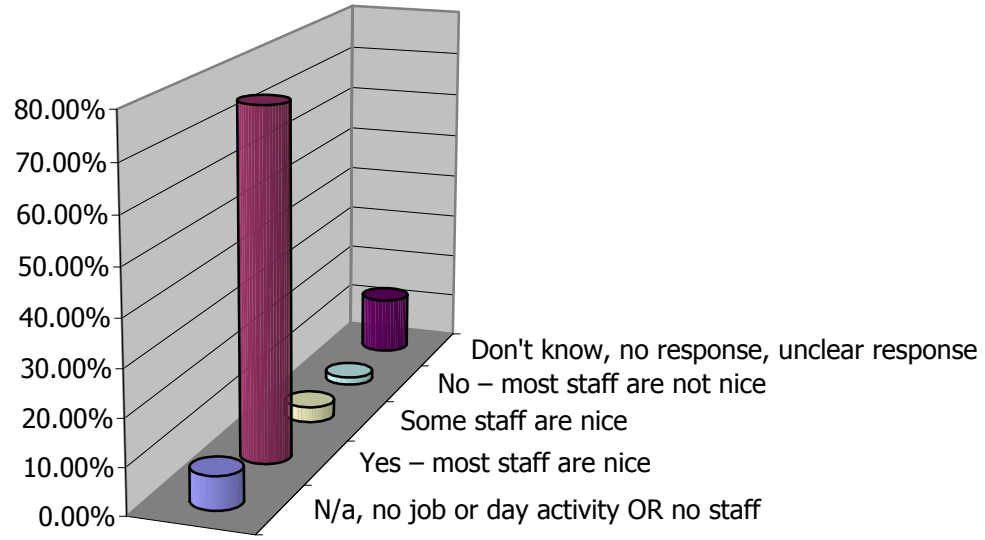
Agency Coordinator and DDD Social Workers (continued)

Comments:

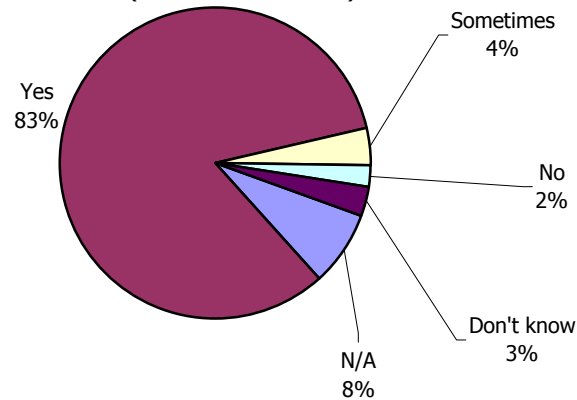
- Most people know the agency person who coordinates their annual plan.
- 235/250 or 94% of the people who know their case manager or service coordinator answered yes they are asked what they want by the coordinator.
- 236/250 or 94.4% of the people who know their case manager or service coordinator answered yes, if they ask for something the coordinator helps them get what they need.
- People and their families do not seem aware of community support hours and are unclear about what respite can be used for.
- Often young adults want to move, as their siblings do, out of their parents' home, but there are few options.

Home and Work/Day Program

**Work/Day Program- Do you have staff that helps you there?
Are they nice and polite to you?**

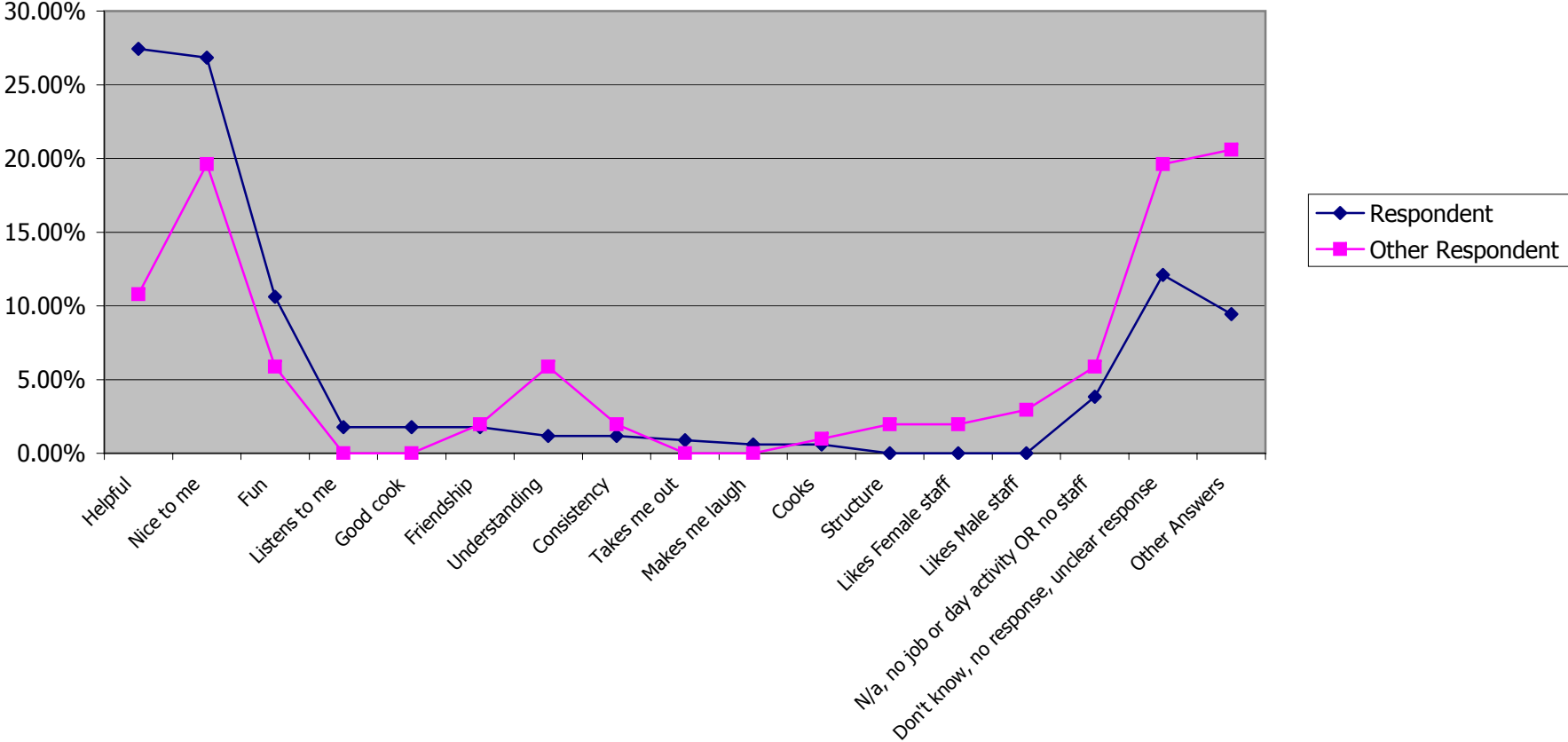


Work/Day Program- Does your staff listen carefully to what you ask them to do?
(not asked in 2008)



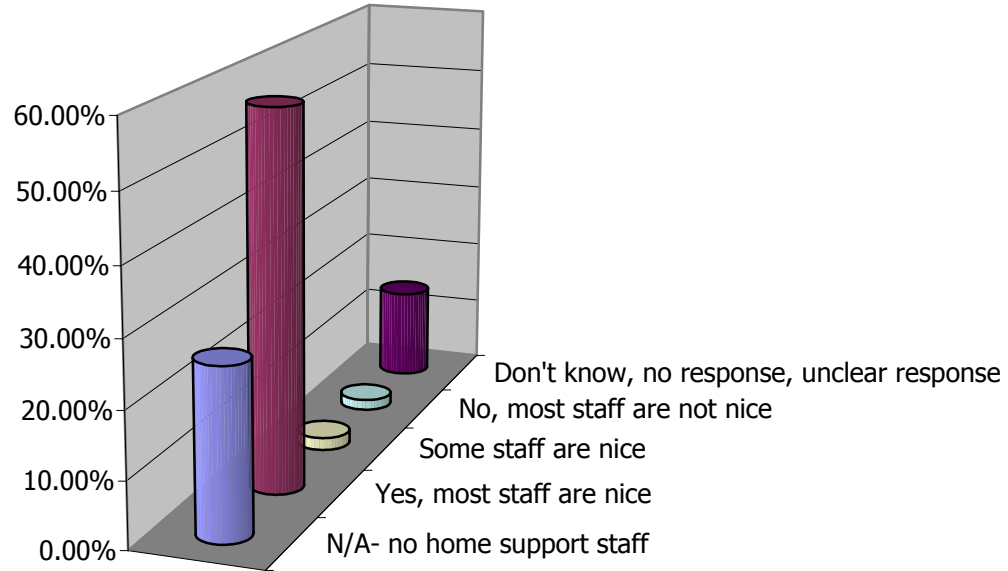
Home and Work/Day Program (continued)

2008 only- Of your staff who helps you at work/day program, why do you like them?

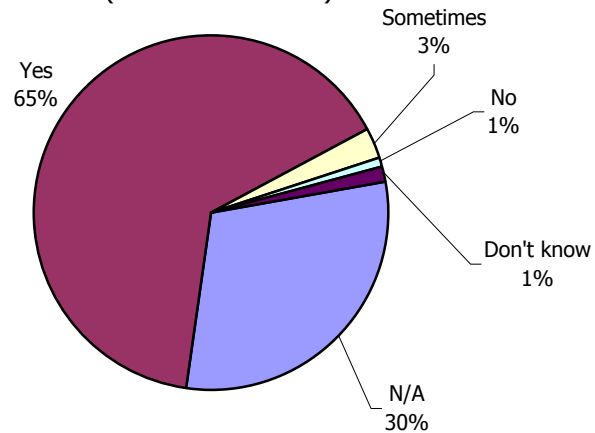


Home and Work/Day Program (continued)

**Home- Do you have staff that helps you where you live?
Are they nice and polite to you?**

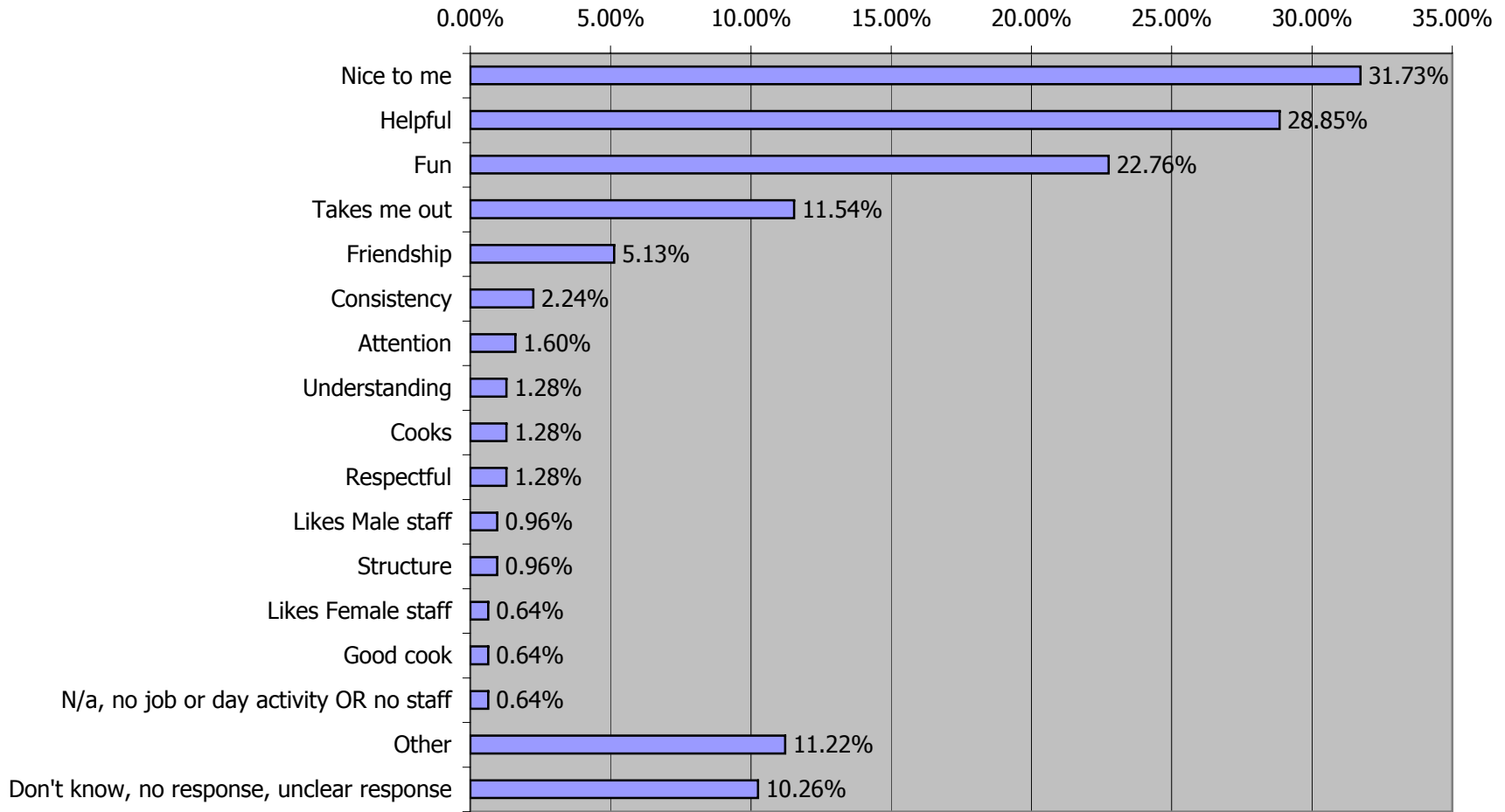


**Home- Does your staff listen carefully to what you
ask them to do?**
(not asked in 2008)



Home and Work/Day Program (continued)

2008 only- Of your staff who helps you where you live, why do you like them?



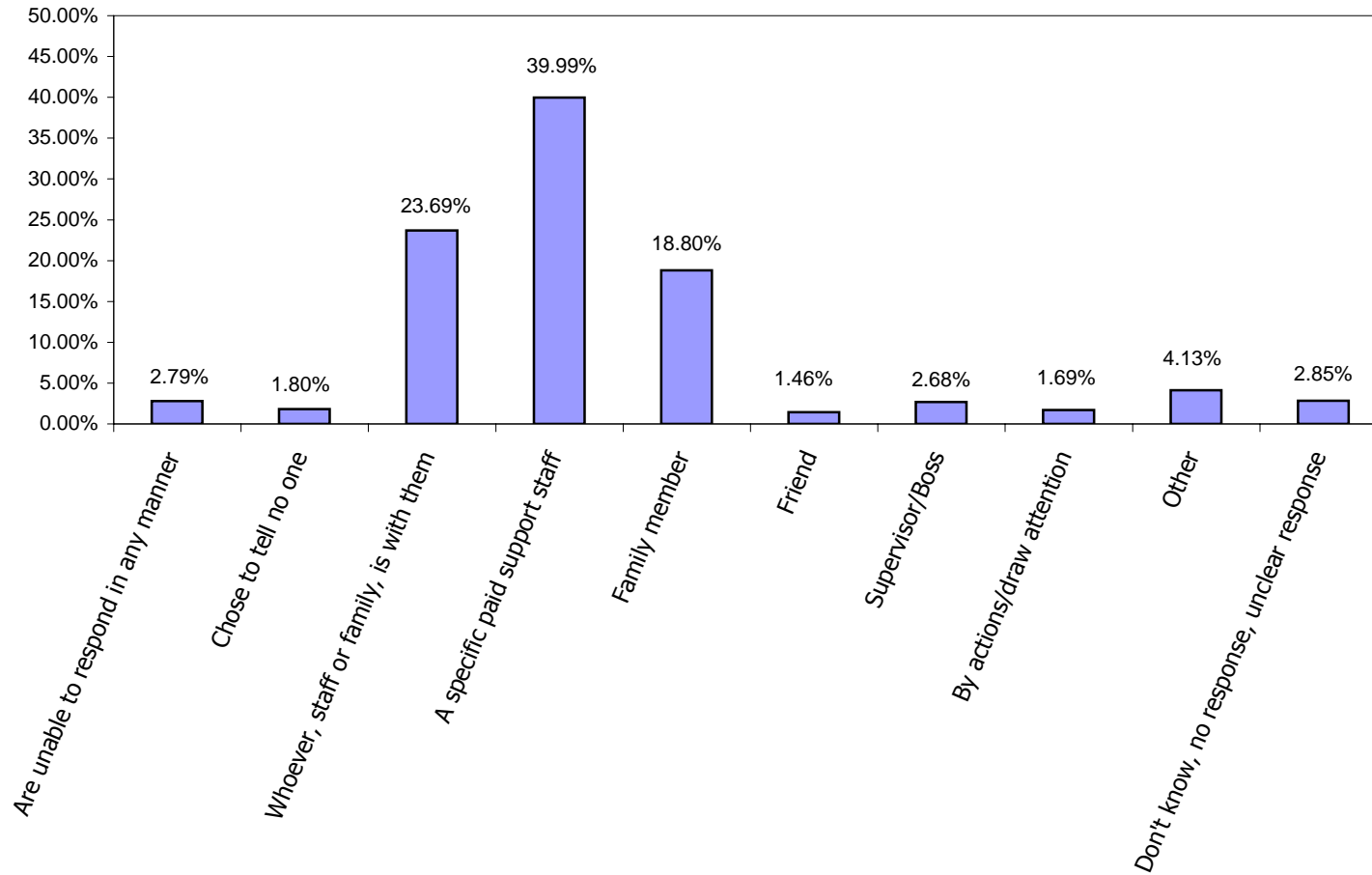
Home and Work/Day Program (continued)

Comments:

- Answers about staff were given by the people we visited, or family or staff if the person could not respond on their own. This may affect the accuracy of the data.
 - Data shows approximately 5% of the people visited are not happy with some or most of their staff.
- Qualities people like in staff at home and work/day program are kindness, helpful, fun and those who will take people out. A variety of answers, although less in numbers were given (in order of the number of responses): is understanding, friendship, consistency, male staff, gives me attention, female staff, cooks, respectful and is a good cook.
- In our observations, we feel many people understand the importance of maintaining a good relationship with their staff.
 - An ideal staff focuses on the person they support and assists this person to develop life experiences and relationships with non-paid community people based on the person's interests and gifts.
 - Bravo to the many wonderful support staff in Rhode Island.

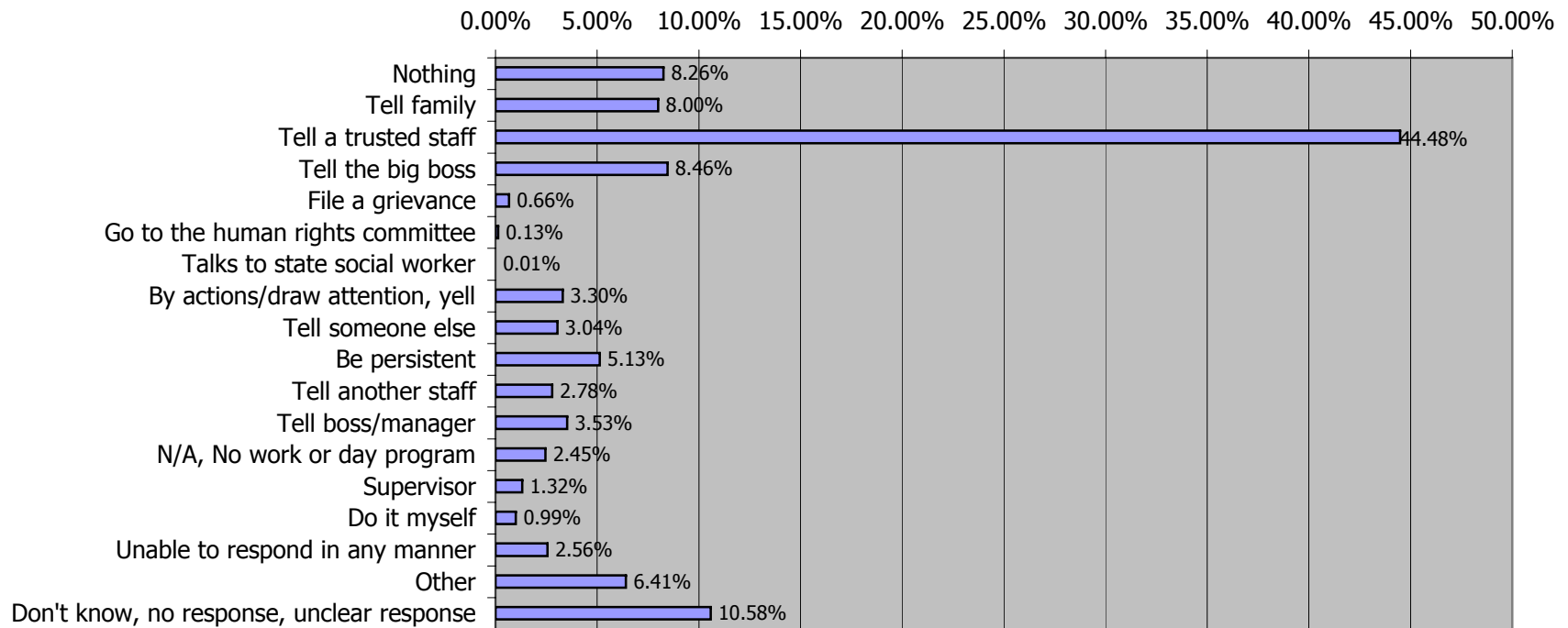
Problem Solving

Who do you go to with a problem?



Problem Solving (continued)

**If someone is bothering you at work (day program), who would you tell?
(multiple answers possible)**

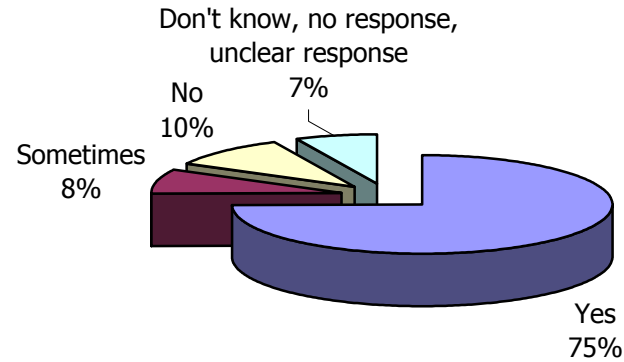


Comments:

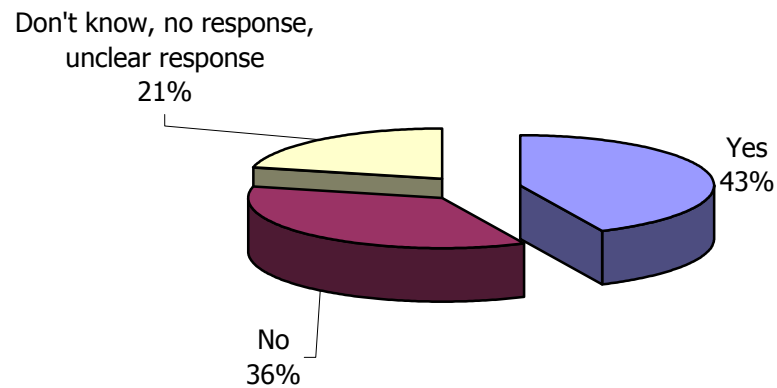
- If a person has a problem, most people, if able, would tell their staff or a family member or both.
- If a person has a problem, people do not seem to know options beyond telling staff or family.
- Advocating for one's self beyond an initial complaint is not prominent.
- People need more encouragement and knowledge to pursue a solution. If not, they give up and go with what is.

Access to Information, Learning, Assistive Technology, & Activities

Do people help you do or learn new things?



If not (10% of previous question), do you want (more) help to do or learn new things?



Access to Information, Learning, Assistive Technology, & Activities (continued)

Do you know how much money is spent on paying your staff? Do you know how much money is in your budget?

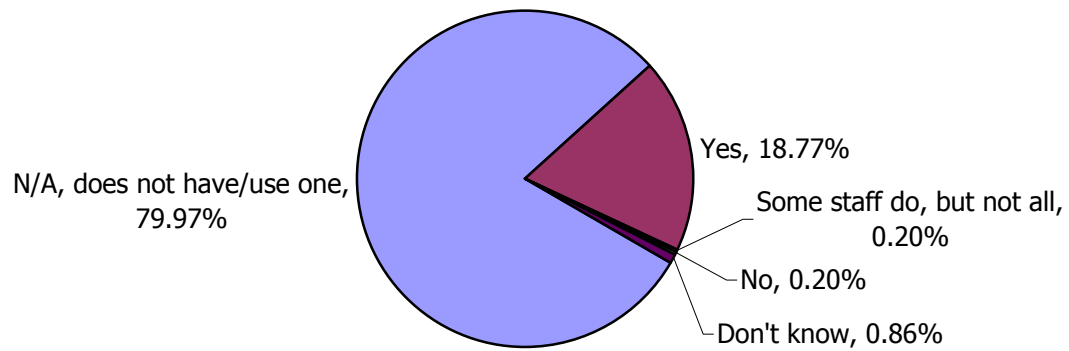
N/A- does not use self directed supports	94.32%
Yes	0.73%
Maybe, not sure	0.00%
No	1.72%
Don't know, no response, unclear response	3.24%

When you have your annual meeting, does someone tell you how much is in your budget?

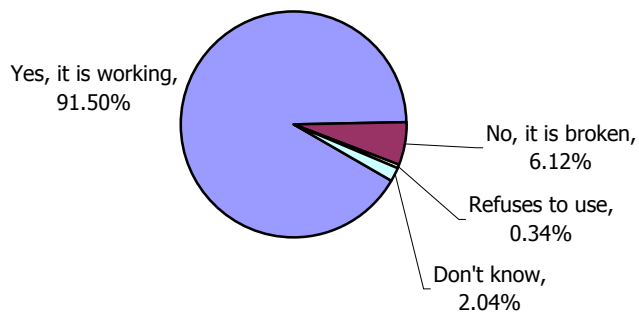
N/A- does not use self directed supports	94.32%
Yes	0.66%
Maybe, not sure	0.26%
No	1.52%
Don't know, no response, unclear response	3.24%

Access to Information, Learning, Assistive Technology, & Activities (continued)

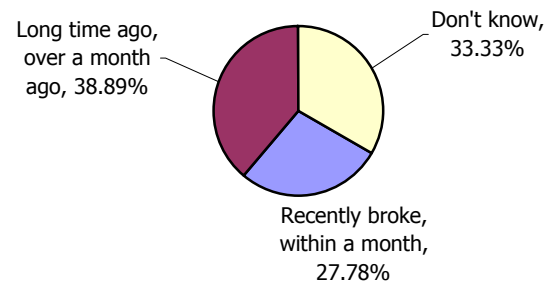
Does your staff help you use your assistive technology device?



Is your assistive technology device working?



If it is not working, how long has it been broken?



Access to Information, Learning, Assistive Technology, & Activities (continued)

Comments:

- There should be many opportunities to learn new things during a person's day program. Many have creative opportunities however, many do not. If there is time, what creates the lack of active learning? No supplies, lack of ideas on how to approach, no time for individualized activities, not enough staff support, etc.

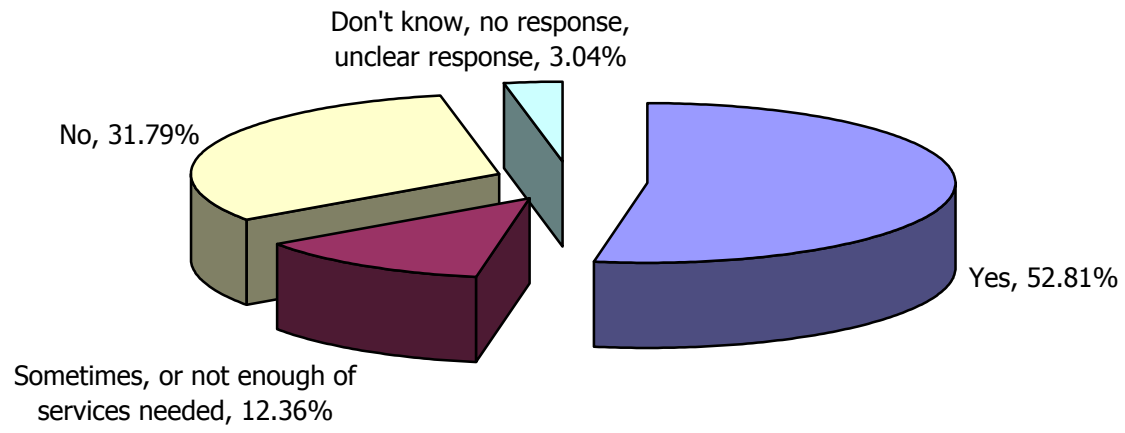
- 84.27% of the people visited say they have access to transportation when they want or need it.

- During our visits, it seems most people are not aware of how much money is spent to provide their support. Currently, people are getting this information in the mail, which can create new conversations, if the information gets to the person receiving services.

- We added the question about assistive technology to assess if people who have devices, have support to use it:
 - 303 people of the 1513 people visited, 93.73% answered yes, all their staff help them use it.
 - 18 people said their device was broken.

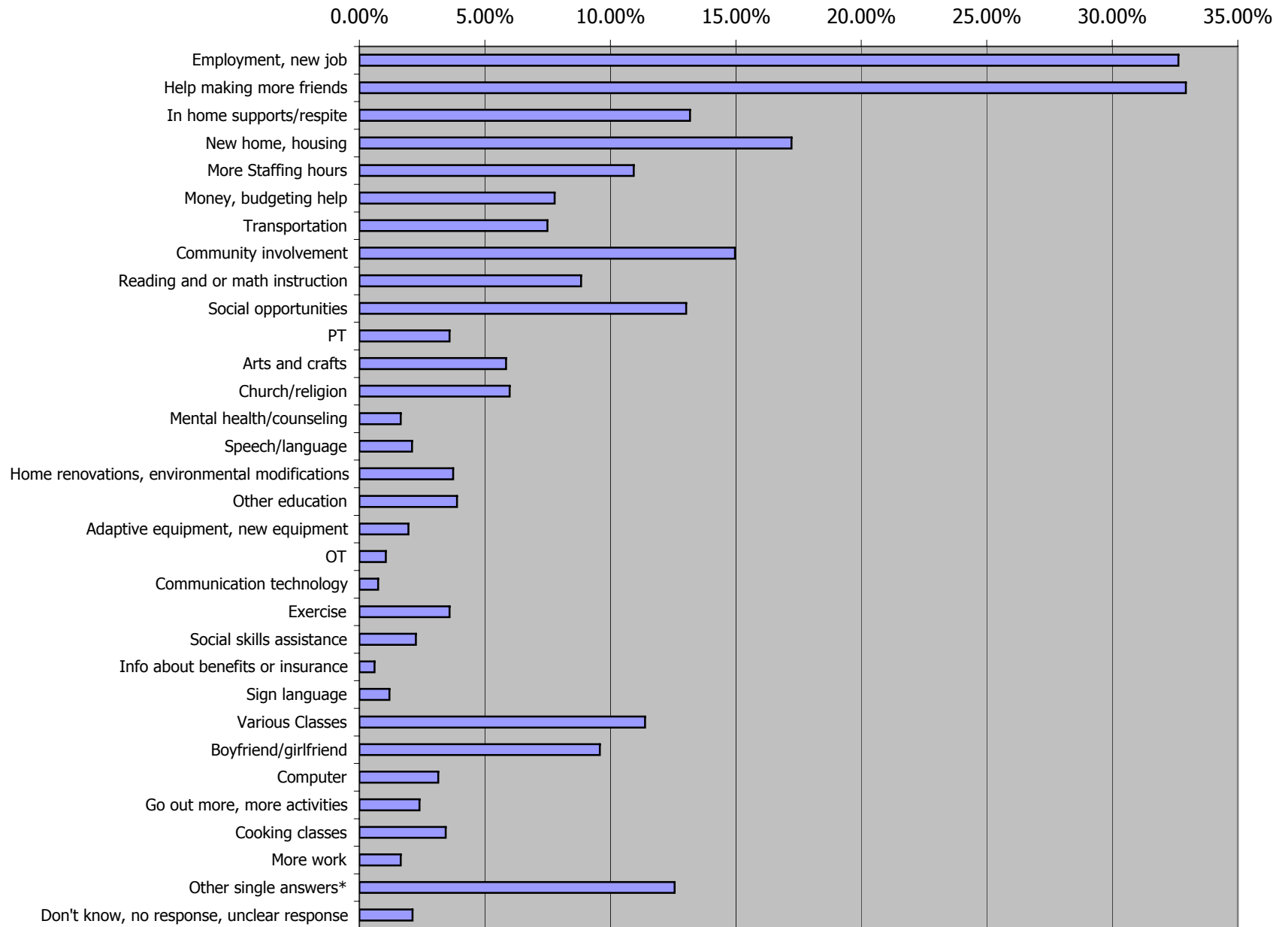
Need for Additional Services

Do you get the services you need?



Need for Additional Services (continued)

If not, what services do you need? (multiple answers possible)



*Other answers included advocacy opportunities, see family, own apartment, more money, and other single answers.

Need for Additional Services (continued)

Comments:

•52.81% of the people visited said they need more services. The top 5 service needs are:

1. Friendship development
2. Employment, new job
3. New home/housing
4. Community involvement
5. In home supports/respite

Next 10 service needs are:

Social opportunities
Various classes
More staffing hours
Boyfriend/girlfriend
Reading and or math instruction
Money, budgeting help
Transportation
Church, religion
Arts & crafts
Other education