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## Smart Health for Autism in Northwest Ohio Survey Summary [Slides]

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# Smart Health for Autism in Northwest Ohio Survey Summary

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# Executive Summary

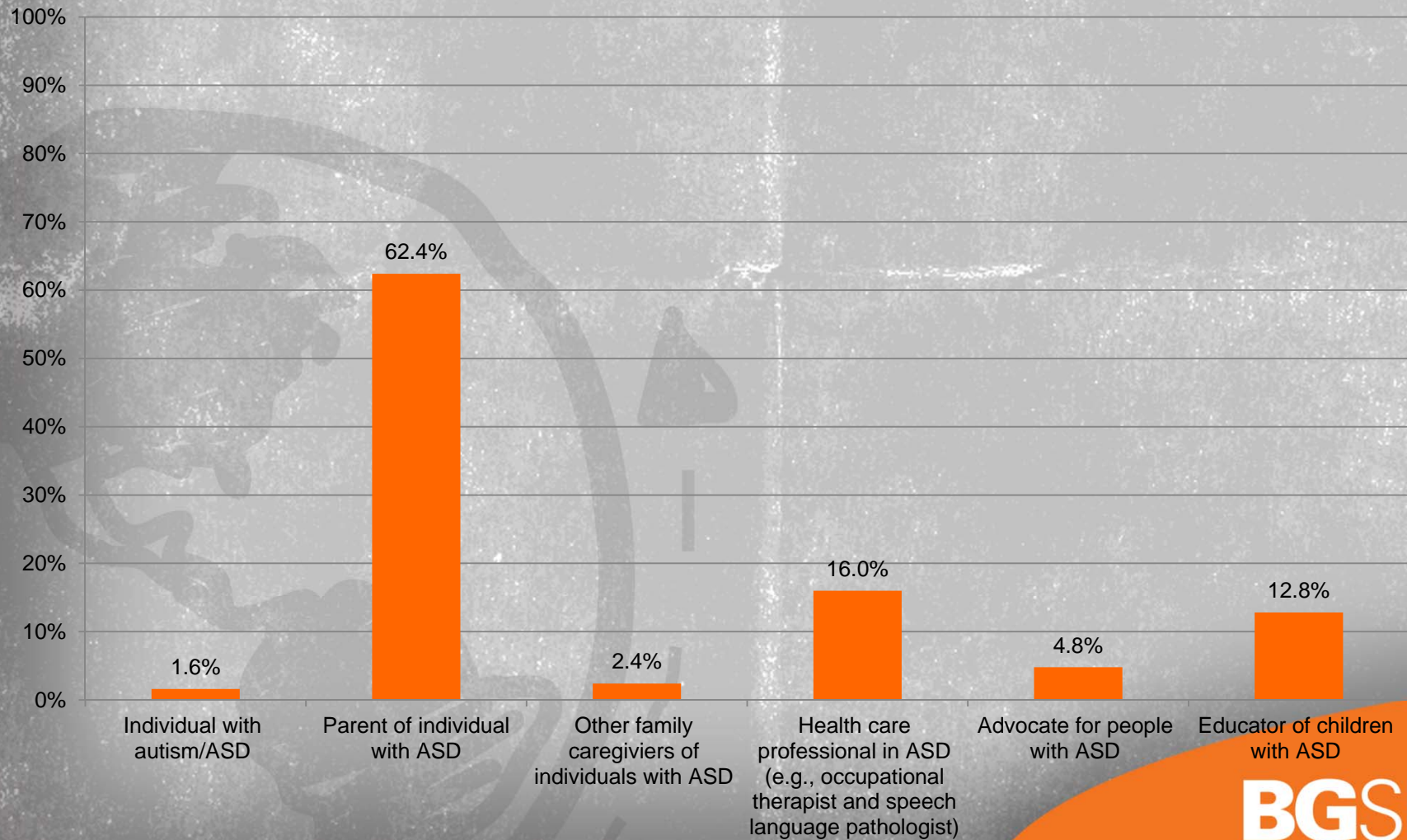
- **The study showed no major differences between parents and professionals in their information environment assessment.**
- **Parents rated other parents as the most trusted source of information; professionals rated parents as their second most trusted source.**
- **Parental factors such as information needs, age and income were found to be best predictors of support services used.**
- **Media, especially web sites, were most frequently used sources for information.**
- **Results indicate the importance of accessibility of services and high quality information.**



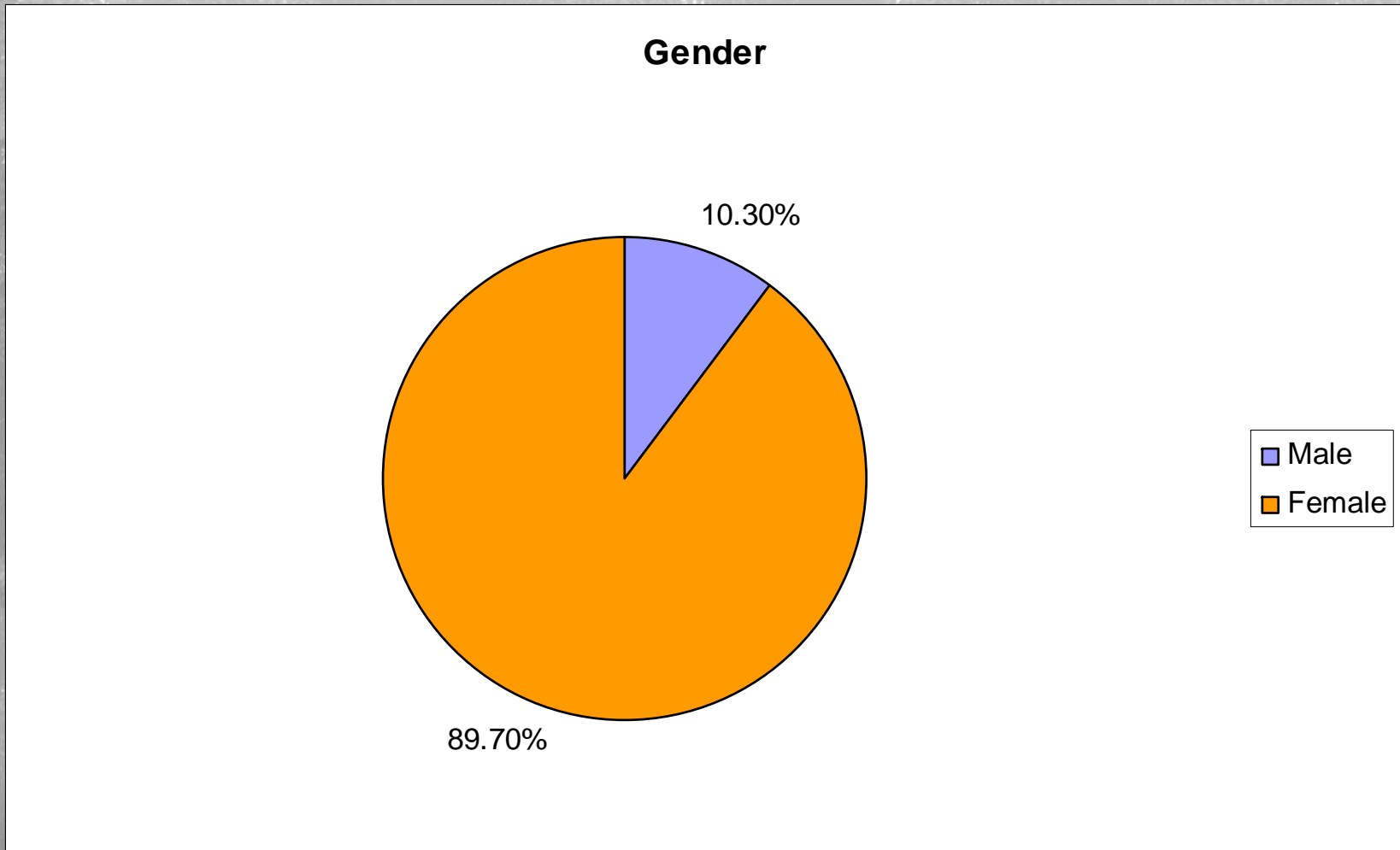
## Method

- A web survey of the e-mail listserv subscribers of Autism Society of NW Ohio from February 1 to March 15, 2011
- A total of 250 valid responses were received
- The respondent distribution basically mirrored the list composition estimates of Autism Society of Northwest Ohio: 66.4% (n=170) of the respondents were family members, caregivers and individuals with ASD, and 33.6% (n=80) were professionals.

# Respondents' Relationship with ASD

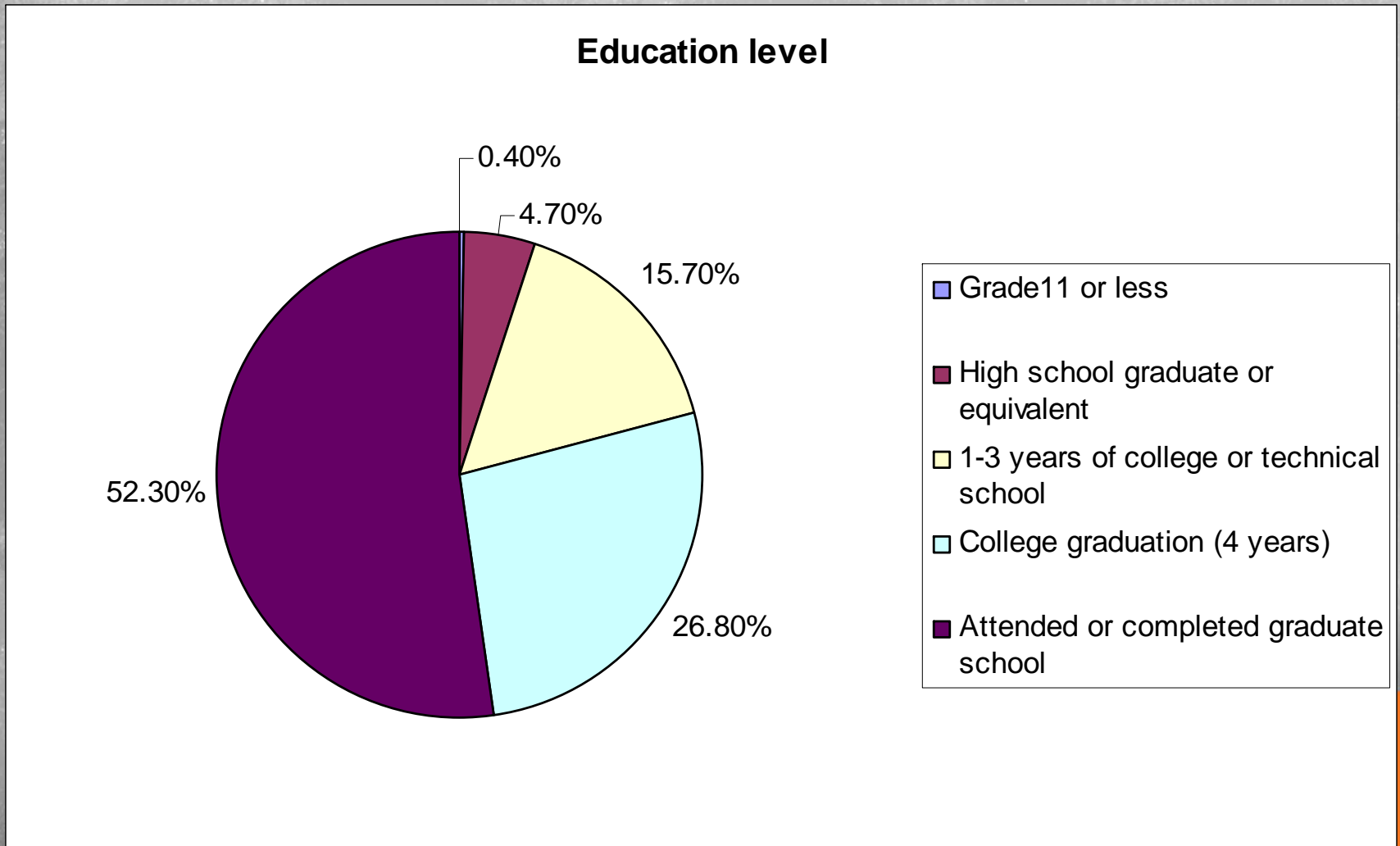


# Most Respondents are Females

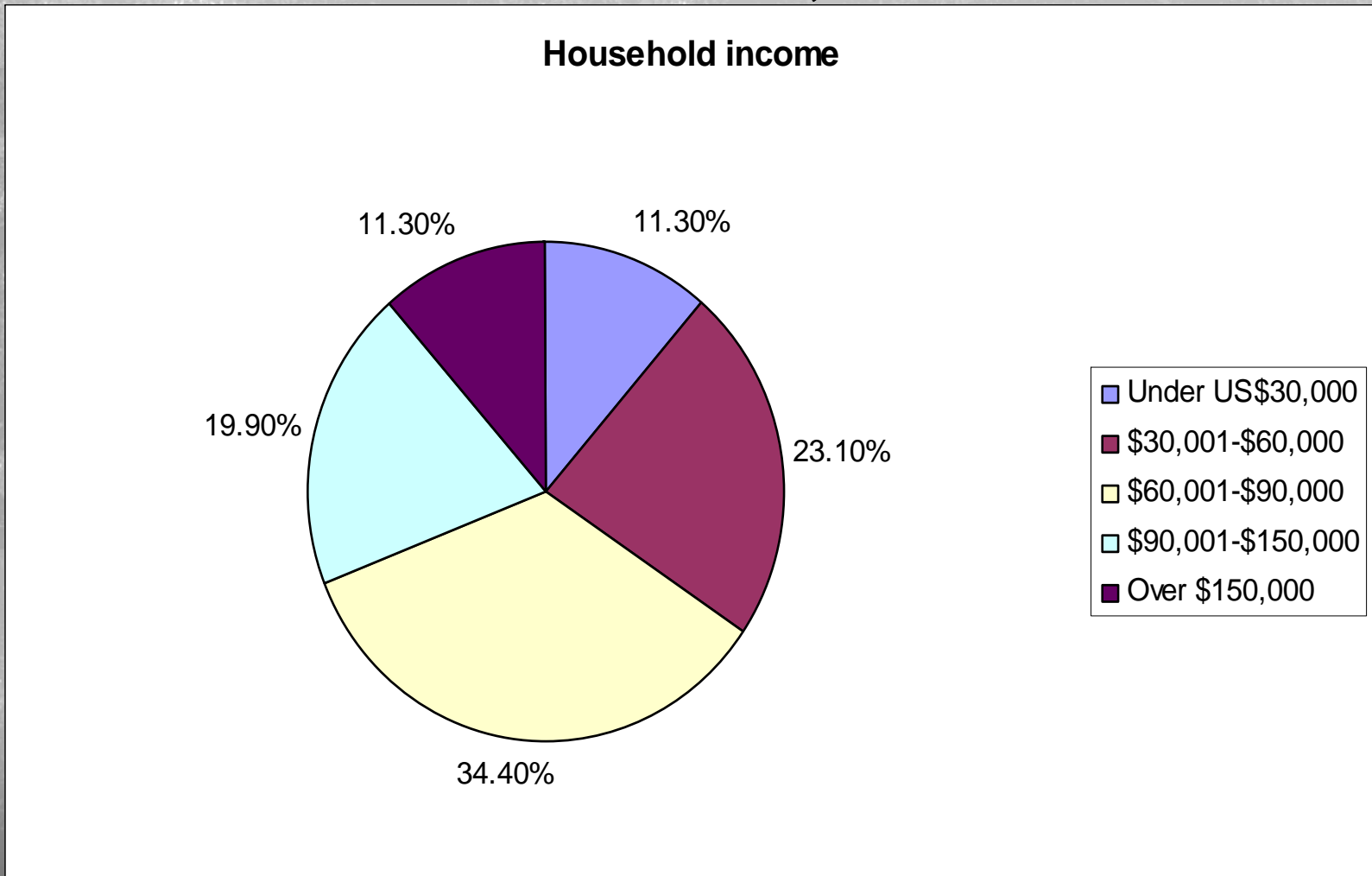




# Most Respondents are well-educated



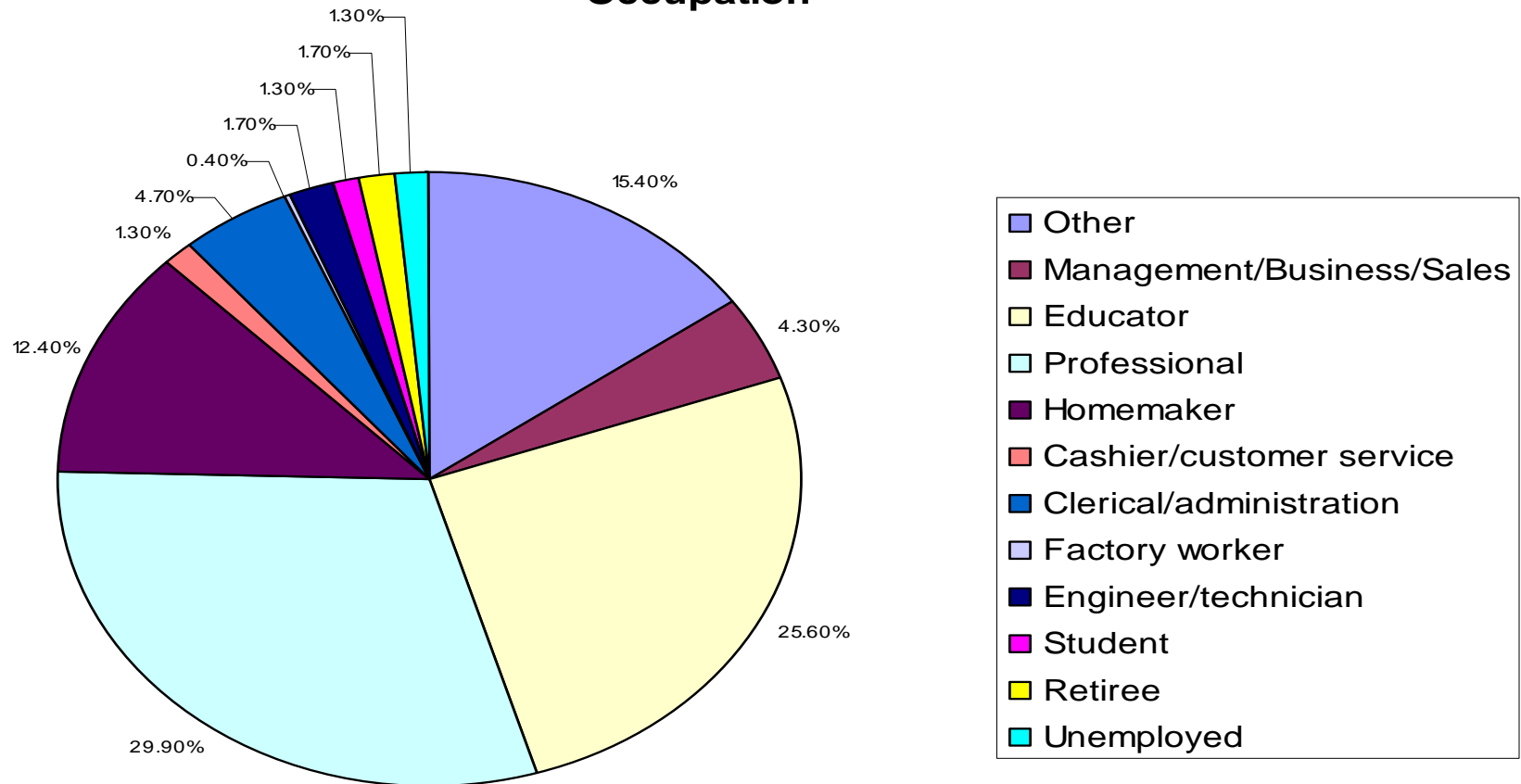
# 31% of respondents' income is above \$90,000



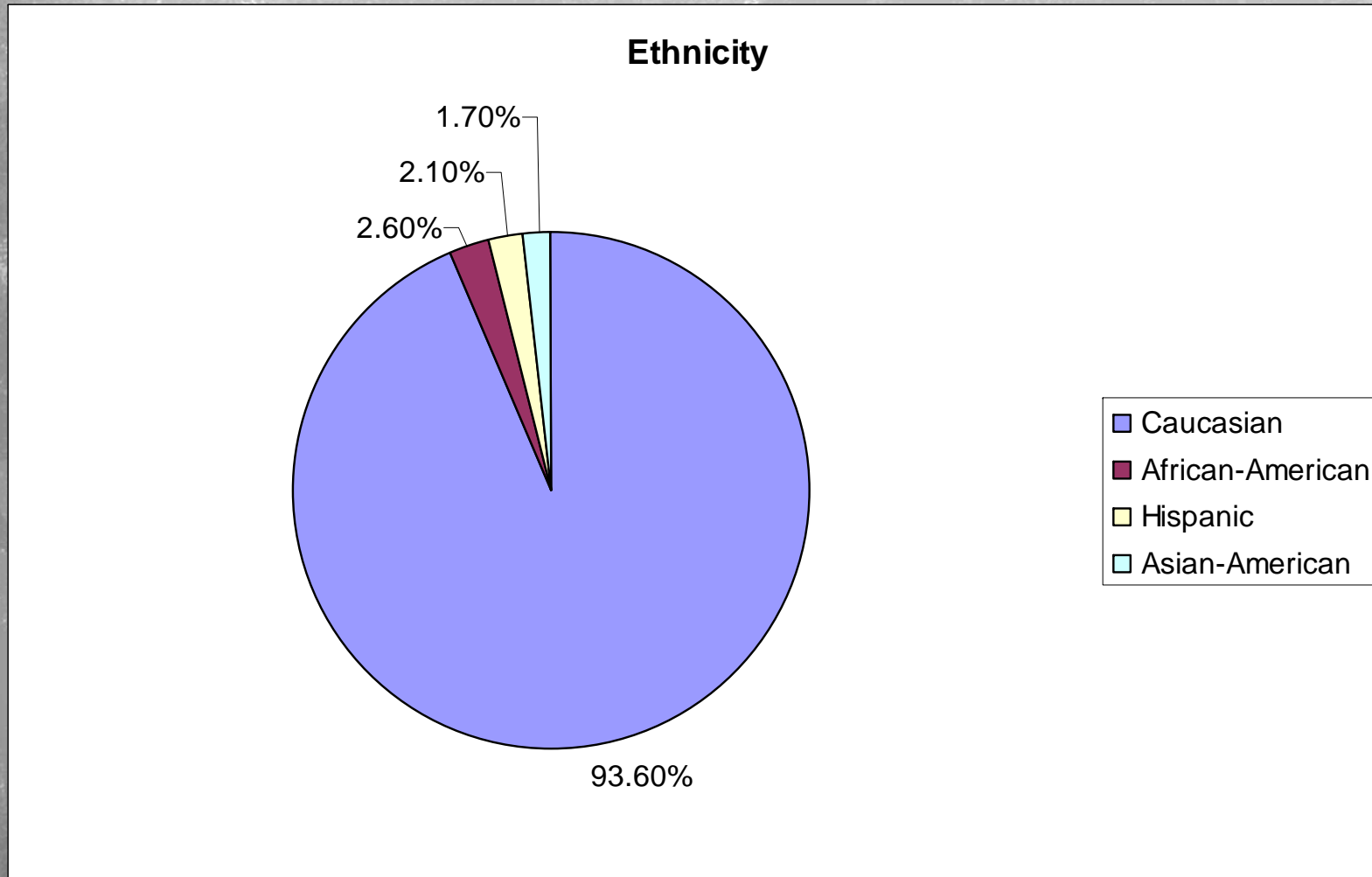


# Professionals, Educators and Homemakers are the most common occupations of respondents

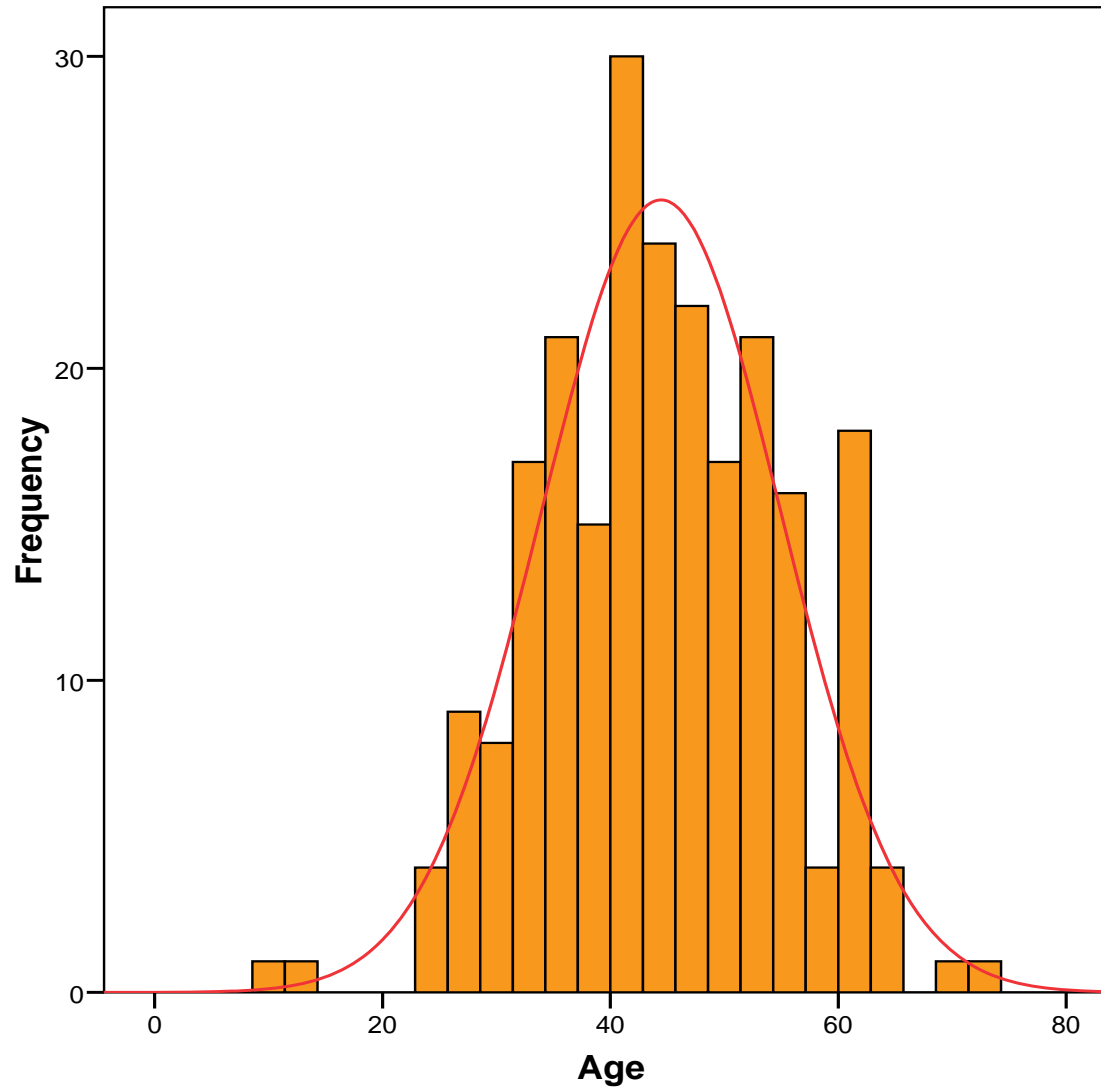
Occupation



# 93.6% of Respondents are Caucasians



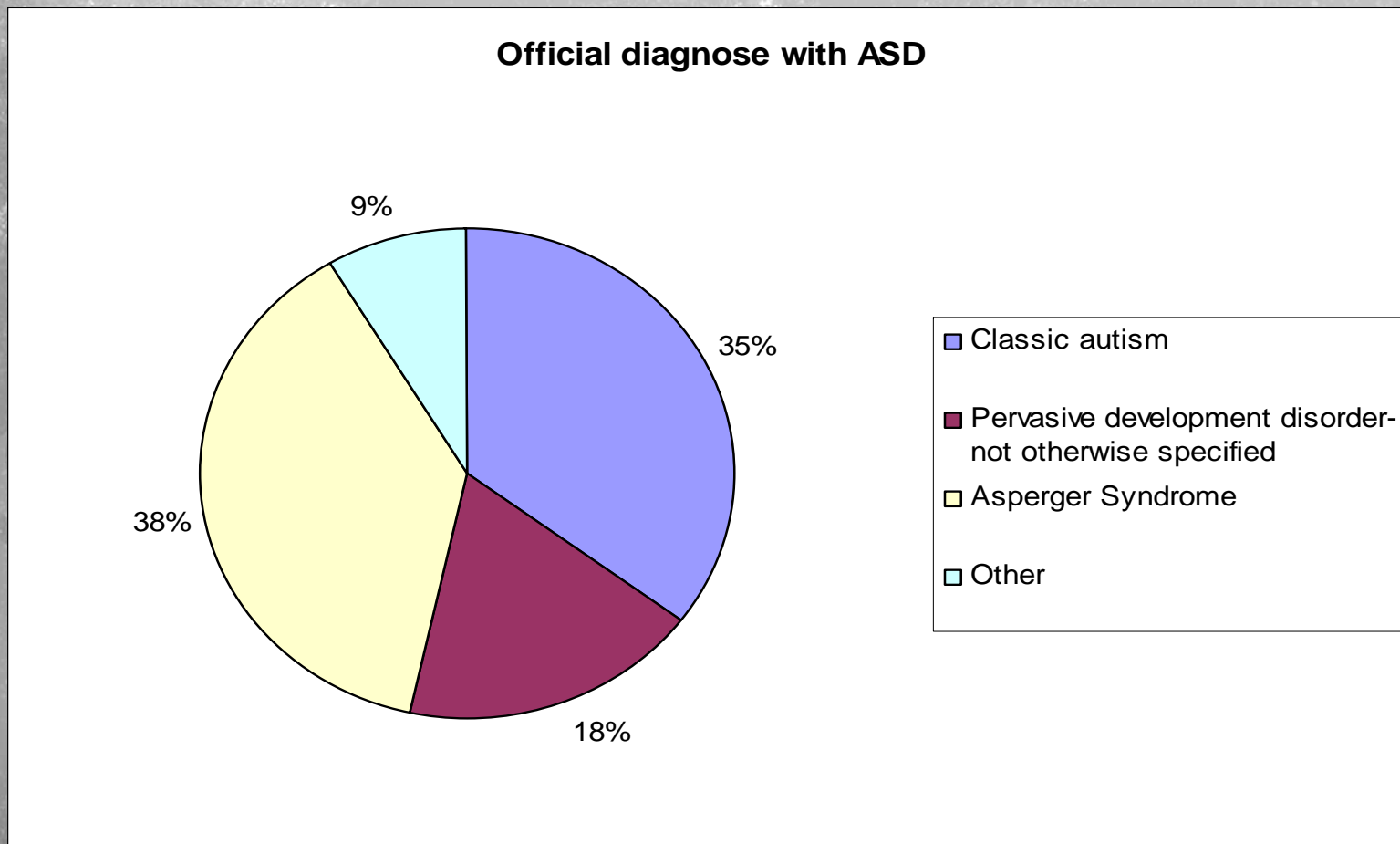
# Respondents' average age is 44.45 years old



Mean =44.45  
Std. Dev. =10.501  
N =234

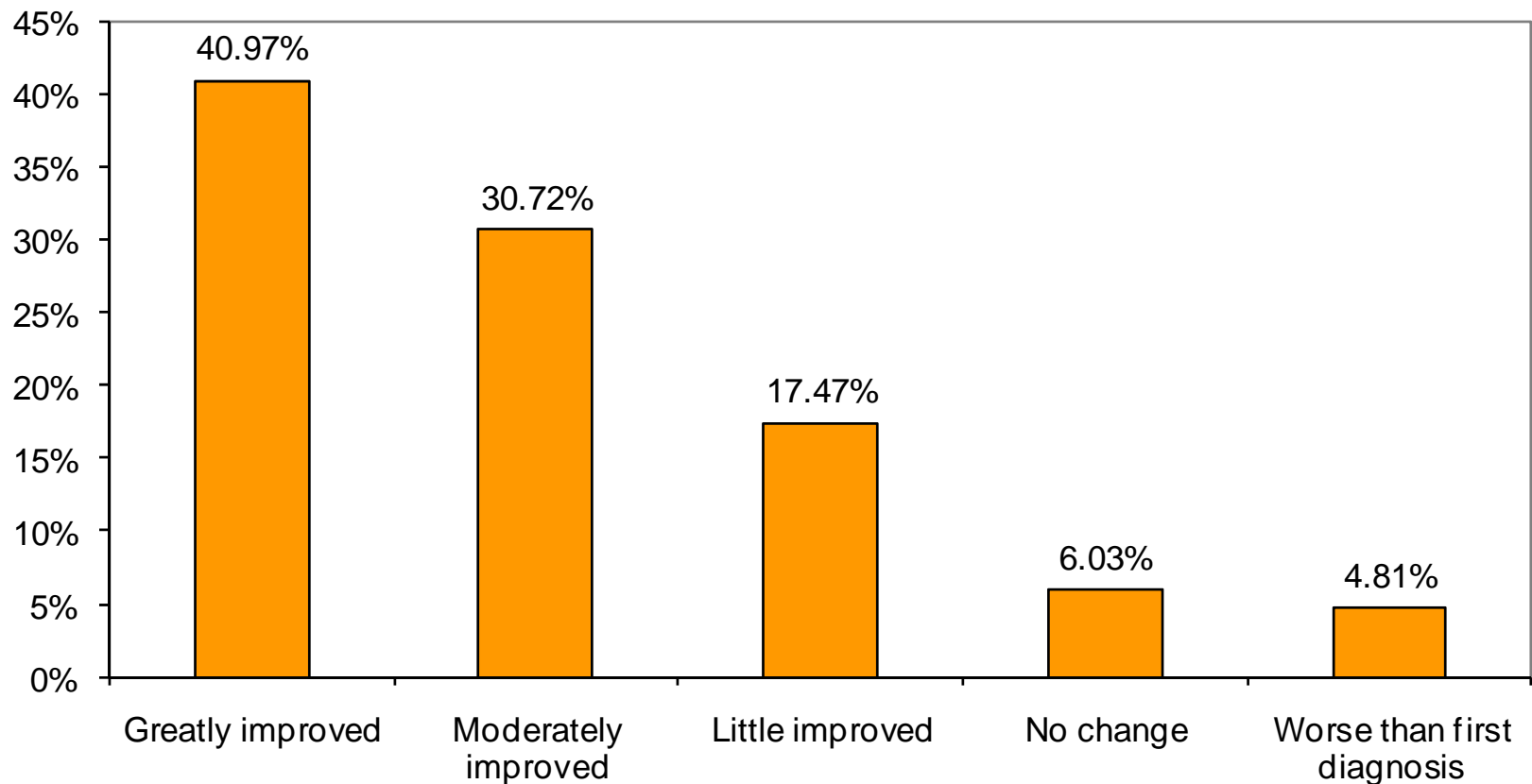


# Asperger Syndrome and Classic Autism are the most common diagnosis



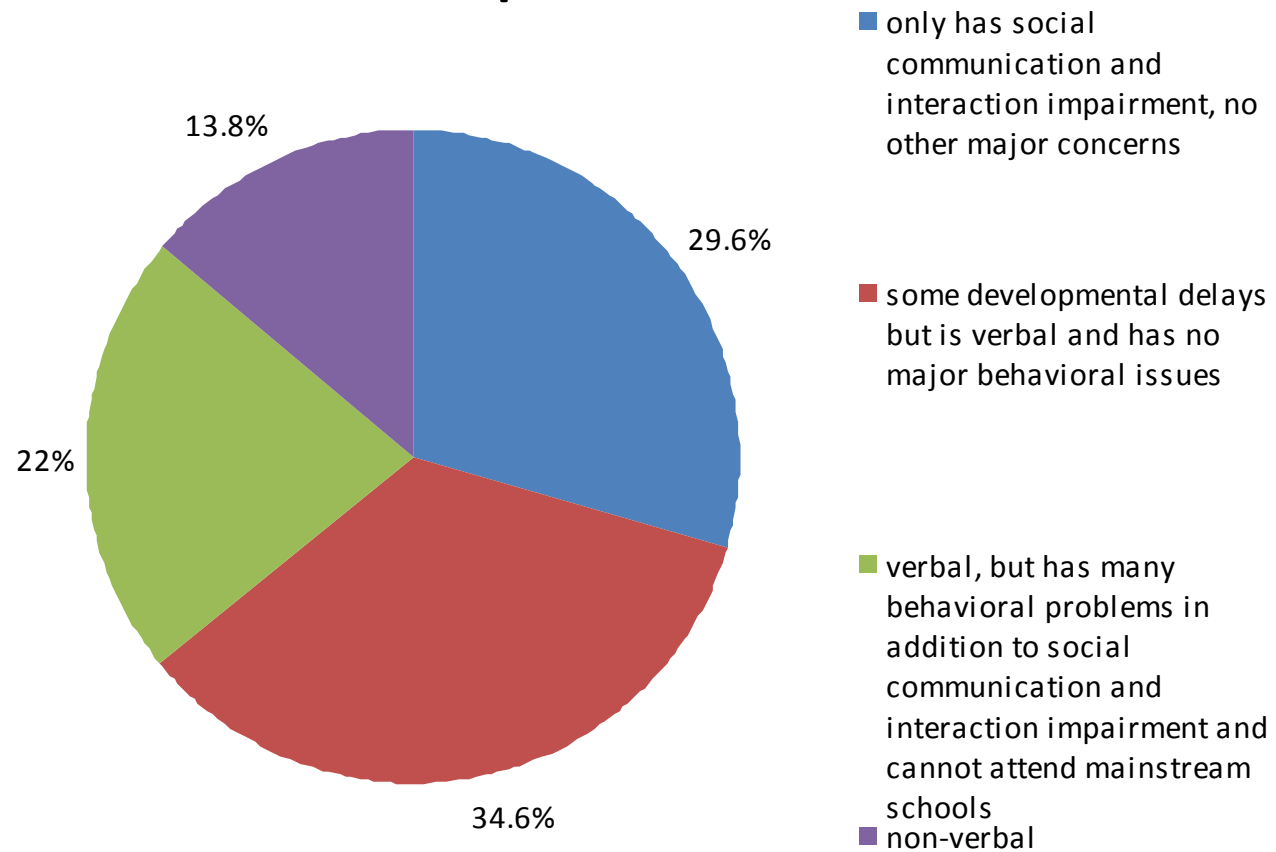
# Most parents/caregivers see improvement in their family members since diagnosis

Progress compared to the first diagnosed with ASD



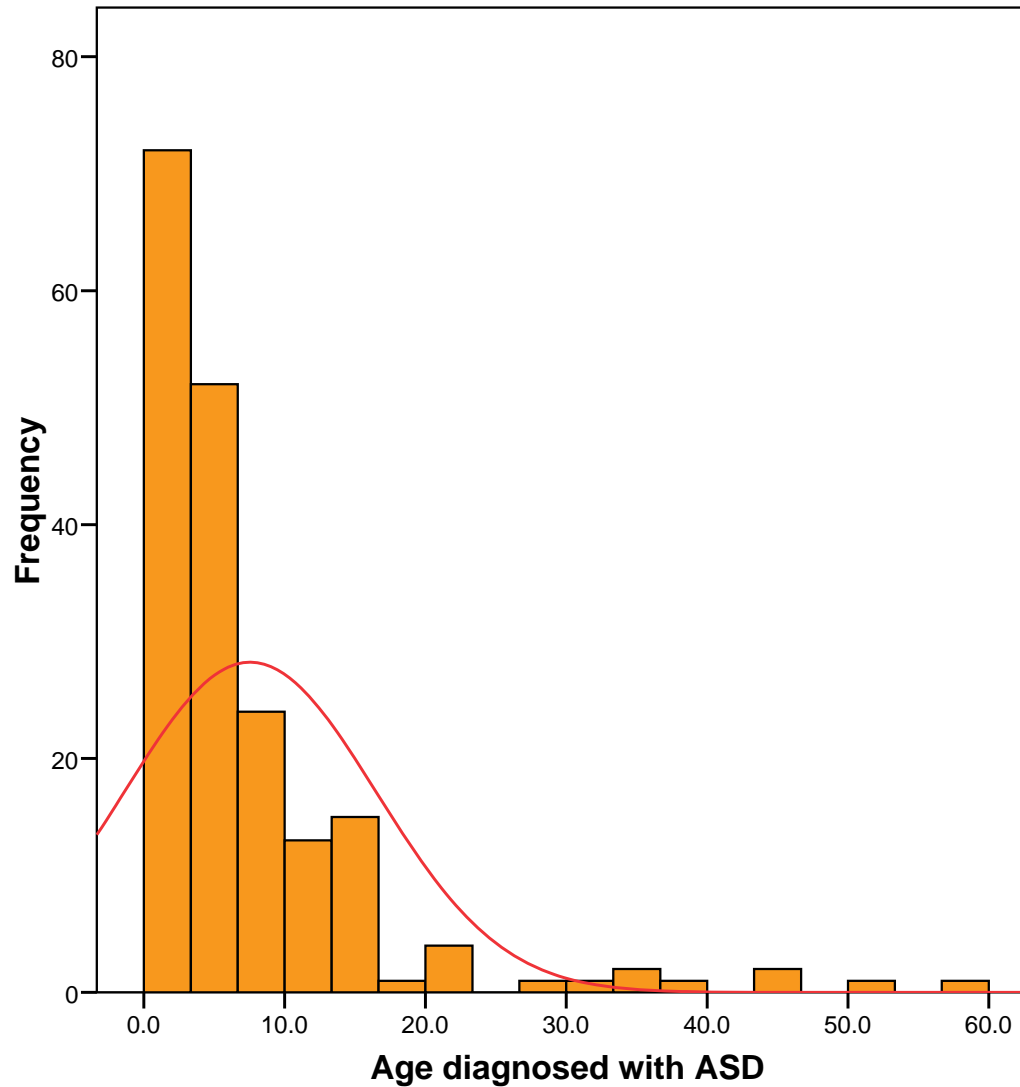
# Most ASD Individuals have Moderate Impairment

**Best description of ASD condition**



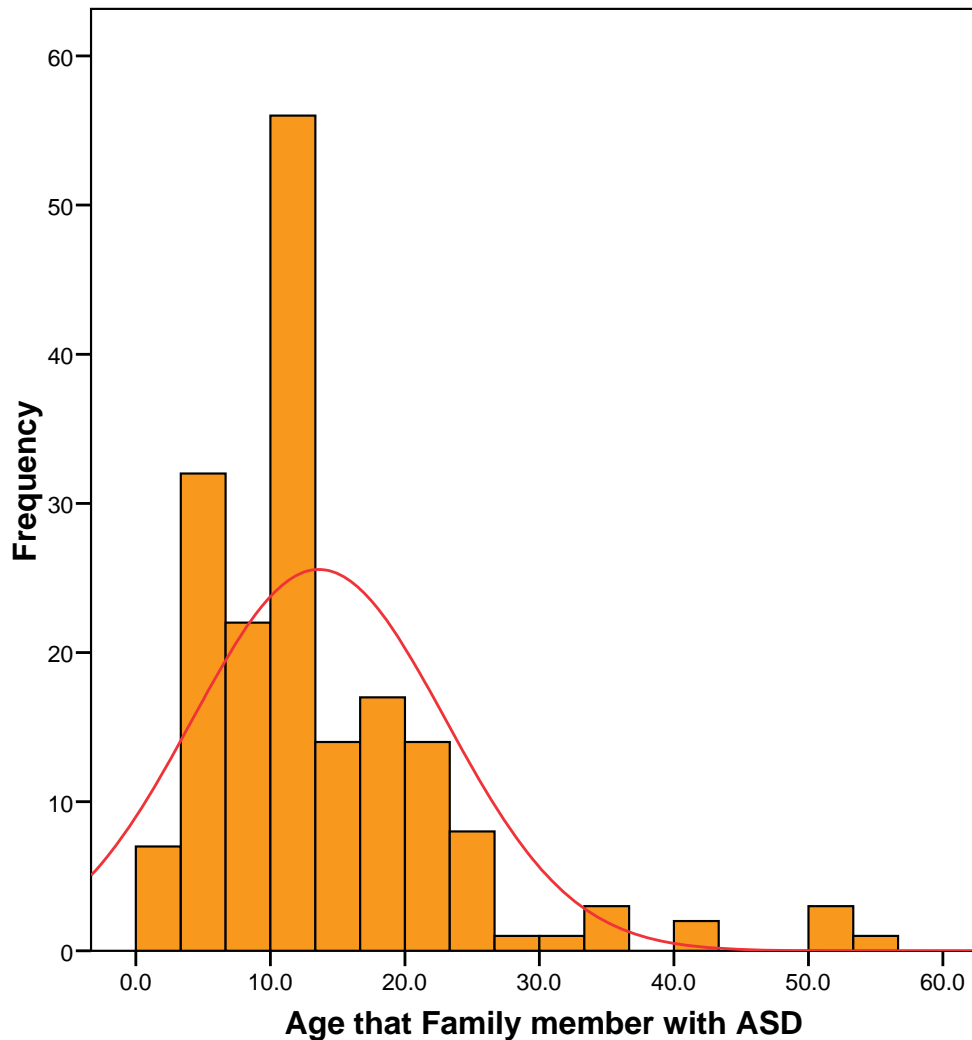


On average, ASD Individuals were diagnosed at 8 years old



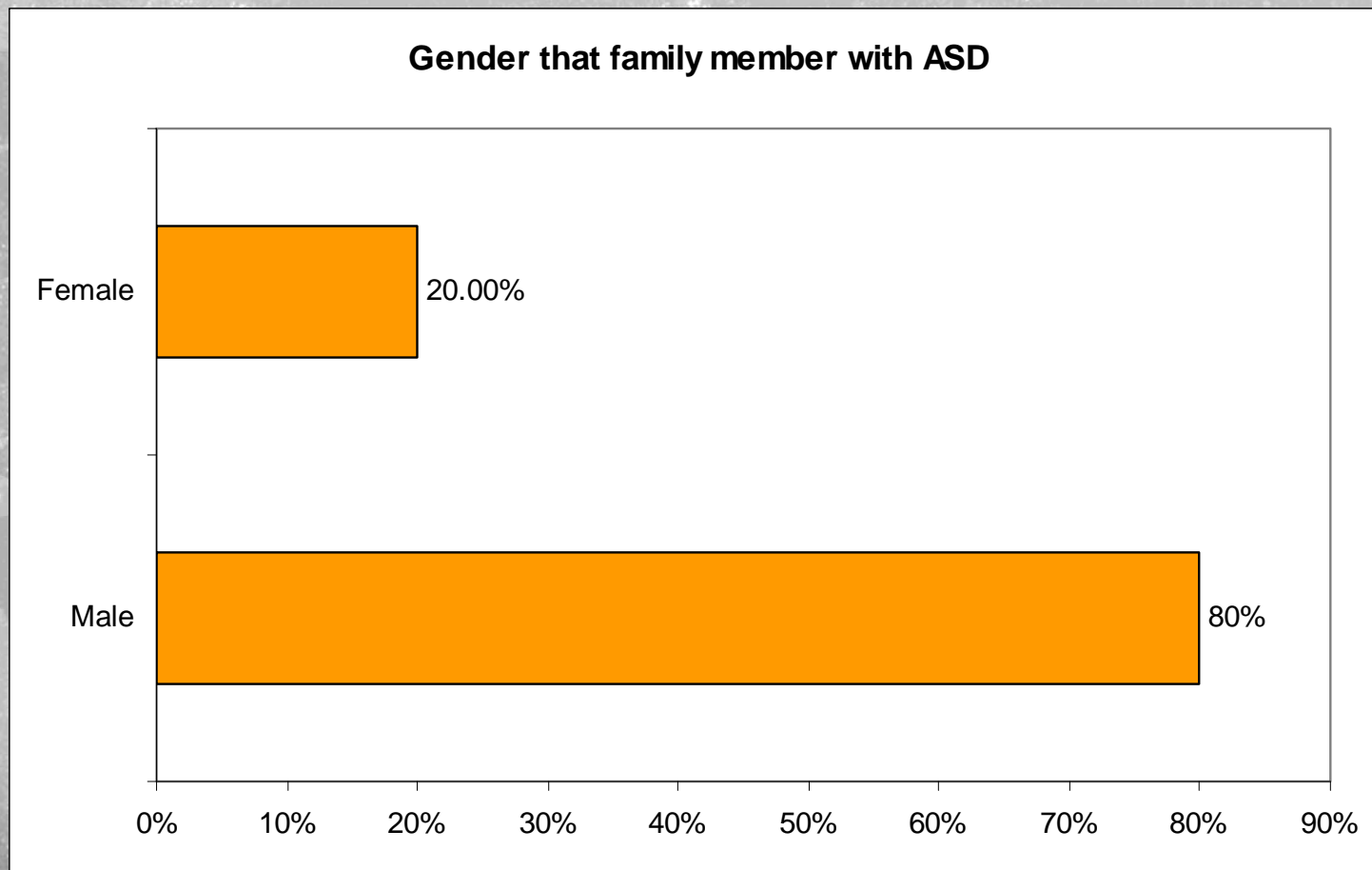
Mean = 7.55  
Std. Dev. = 8.95  
N = 190

# The current age of individuals with ASD on average is 14 years old



Mean =13.61  
Std. Dev. =9.413  
N =181

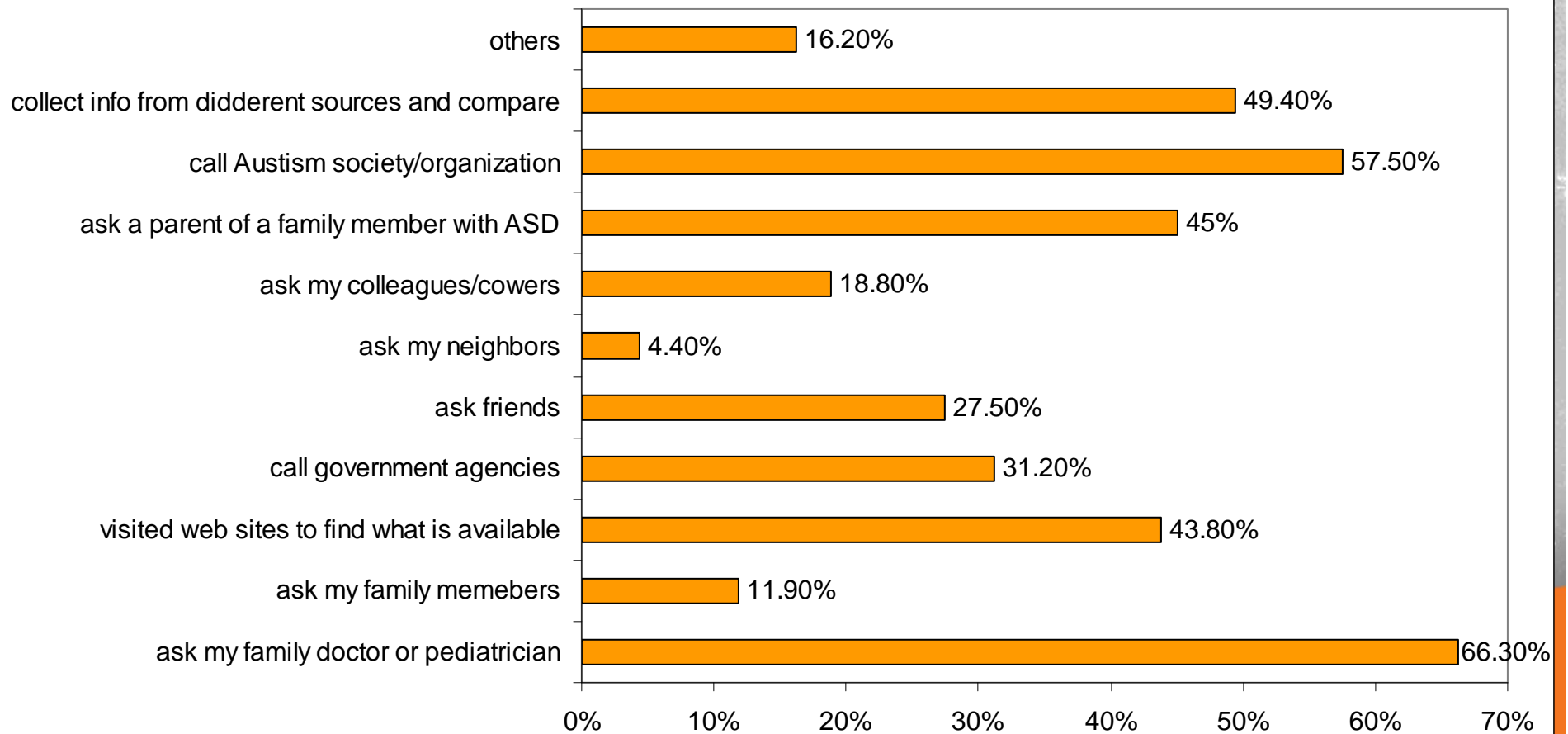
# Male to Female with ASD Ratio is 4:1



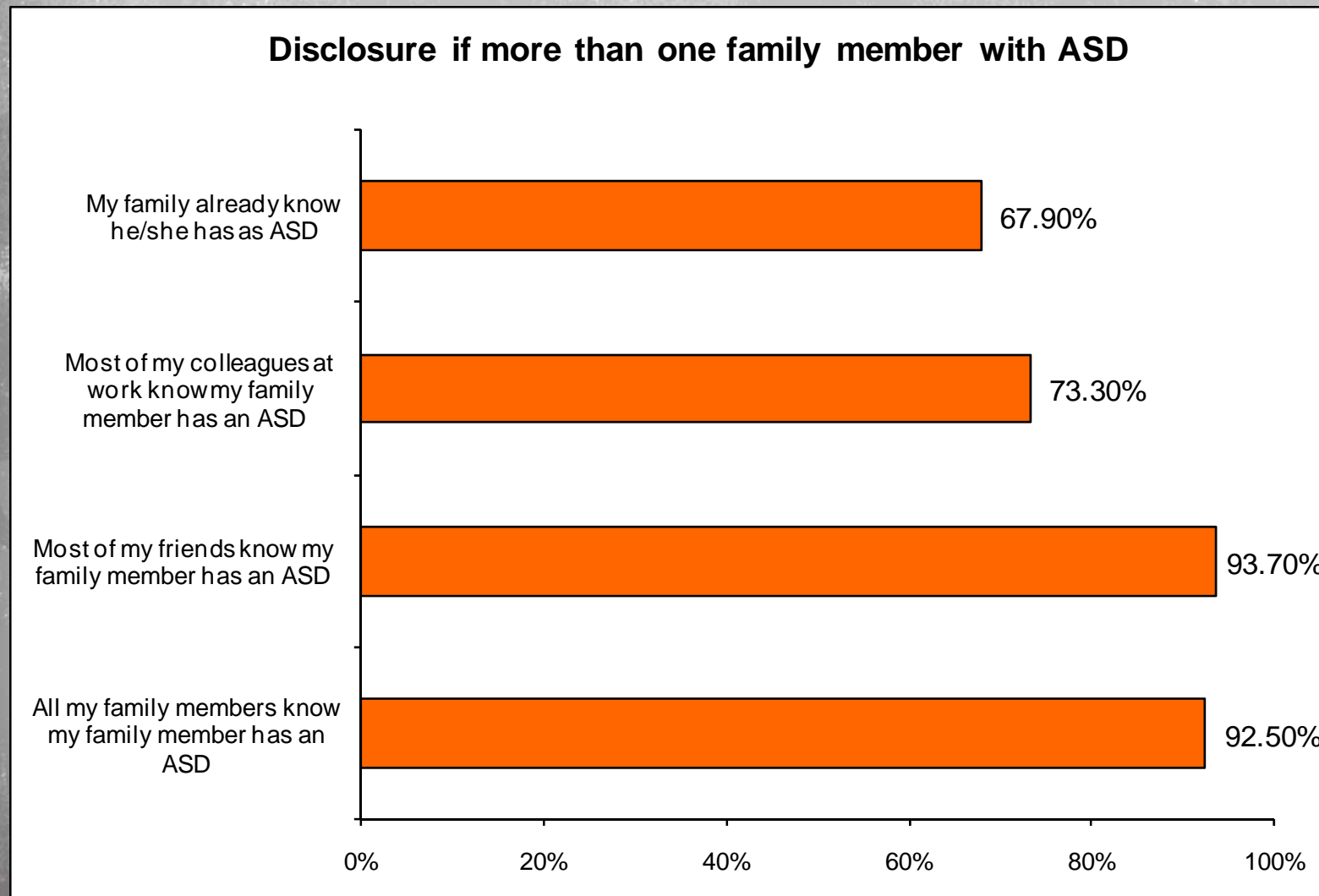


# Family Doctor, Autism Society and Other parents are most common sources for parents to seek for referral of ASD service providers

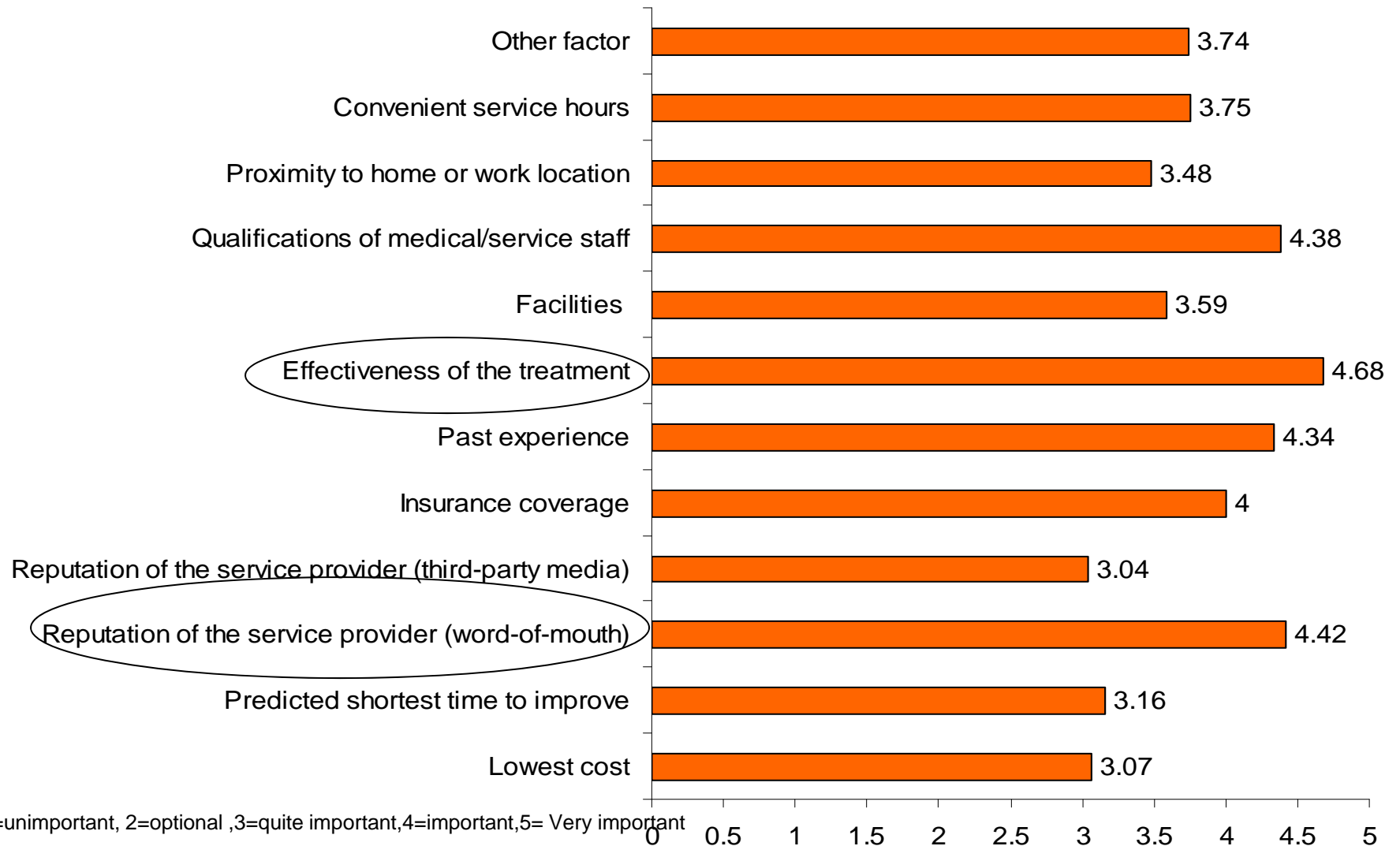
Choice of a service with ASD



# Friends and Family Members are disclosed of the ASD diagnosis

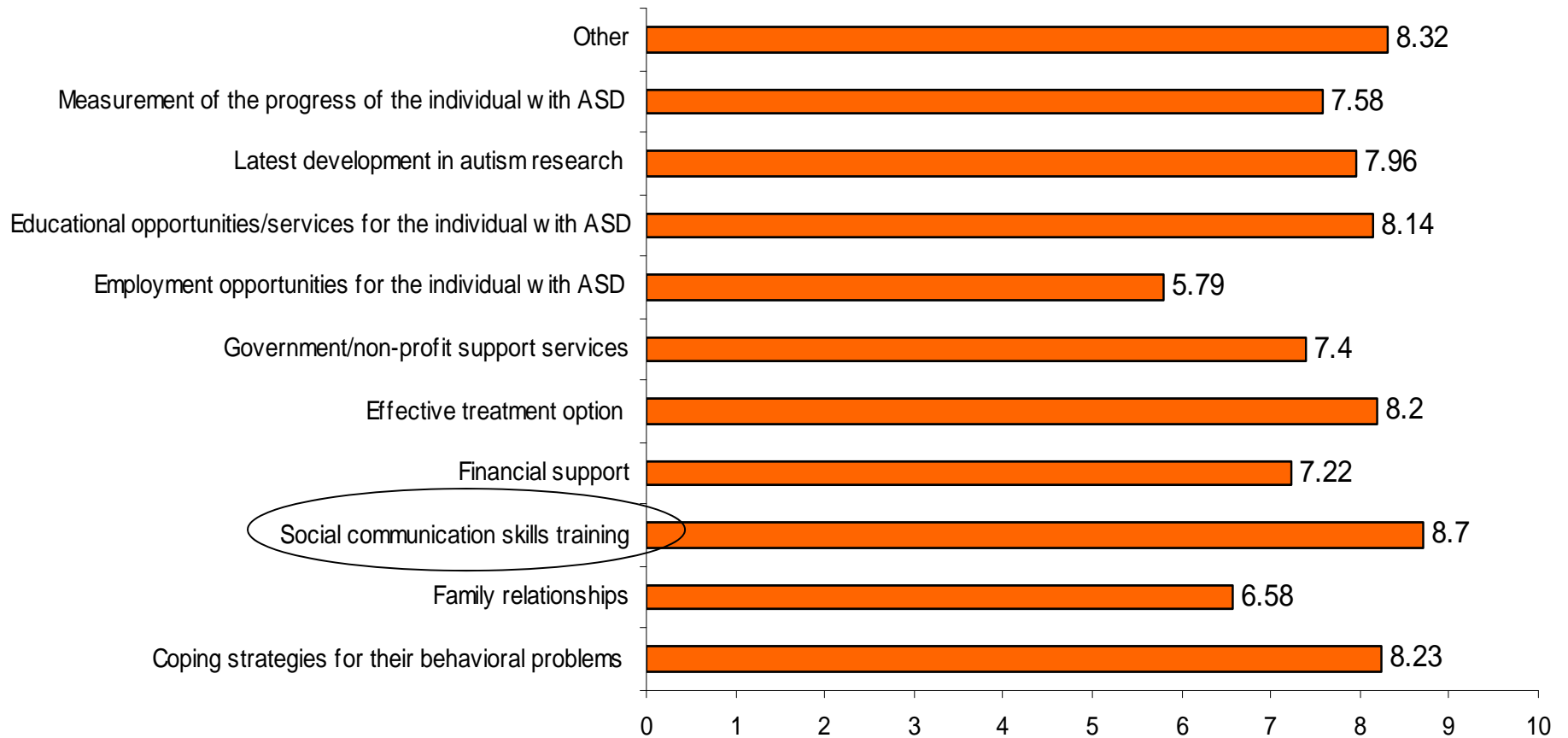


### Important factors affecting the choices of ASD treatment/service





### Rating of the type of information needed to raise/provide ASD service to family member/student/client with ASD



10 is most needed, 1 is least needed

# Other information needs (1)

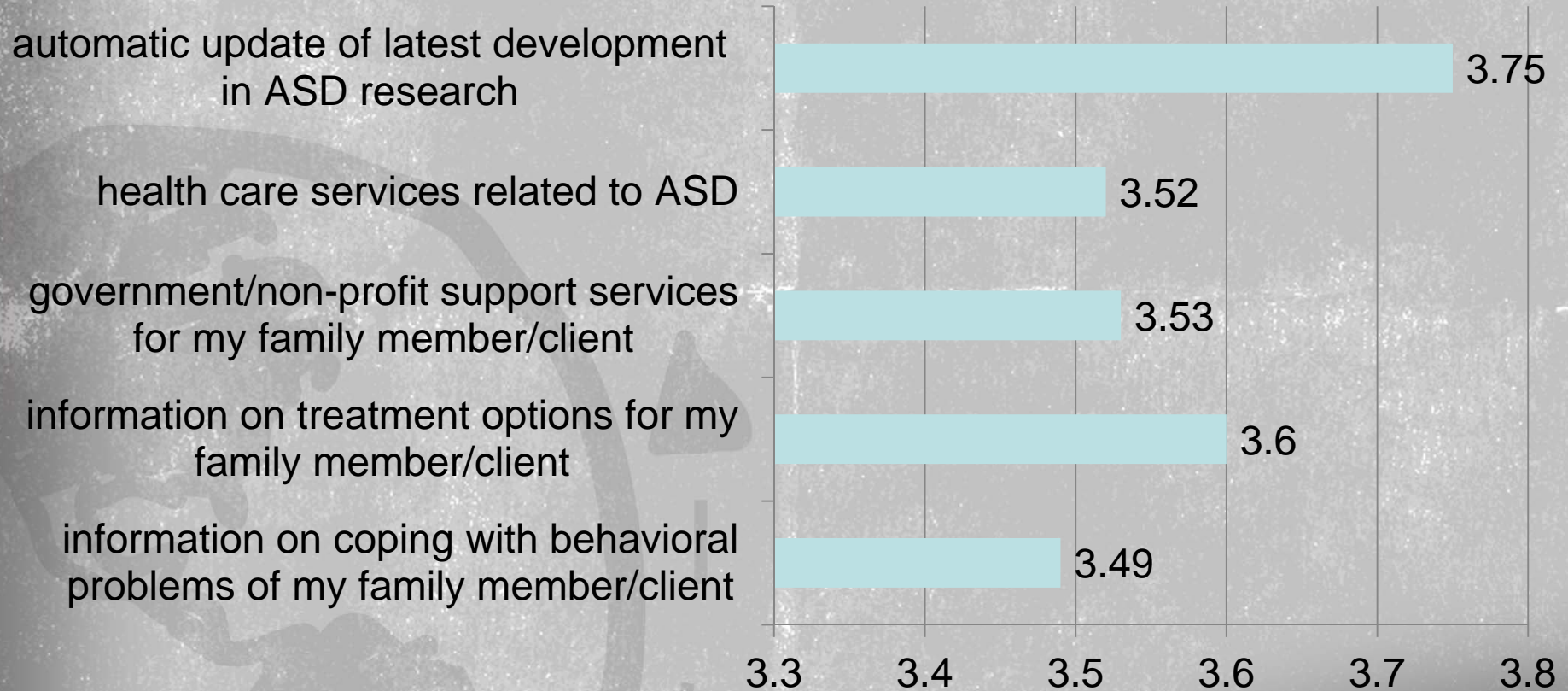
- ABA programs in the area that are done well.
- Affordable activities for him to be involved in.
- A decent set of doctors with experience with autism
- Adult socialization and interaction
- Affordable diagnostic services for adults; assistance for undiagnosed adults
- As we do not qualify for aid & insurance does not pay; programming this group can afford
- Collaboration efforts home districts; providers;
- Family cooperation with public schools
- Daily sensory processing diet at home - guidance to implement and support diet
- Expanding diet/health financial help or help so they can live more independently in society.



# Other Information Needs (2)

- How to get the government system to work
- individuals to volunteer/get paid for services in our home based program
- local support Medical needs
- support/ prescription plan qualified psychiatrist that understands ppd; along with adhd and anxiety; depression
- 2 x Respite services
- speech language therapy support for adults
- Test to see if employable and/or can succeed in college  
Training for public educators so they have greater awareness and understanding
- Health insurance
- Help for middle class w/ ADOS & LD testing;
- How to use technology-iPods
- Healthcare resources

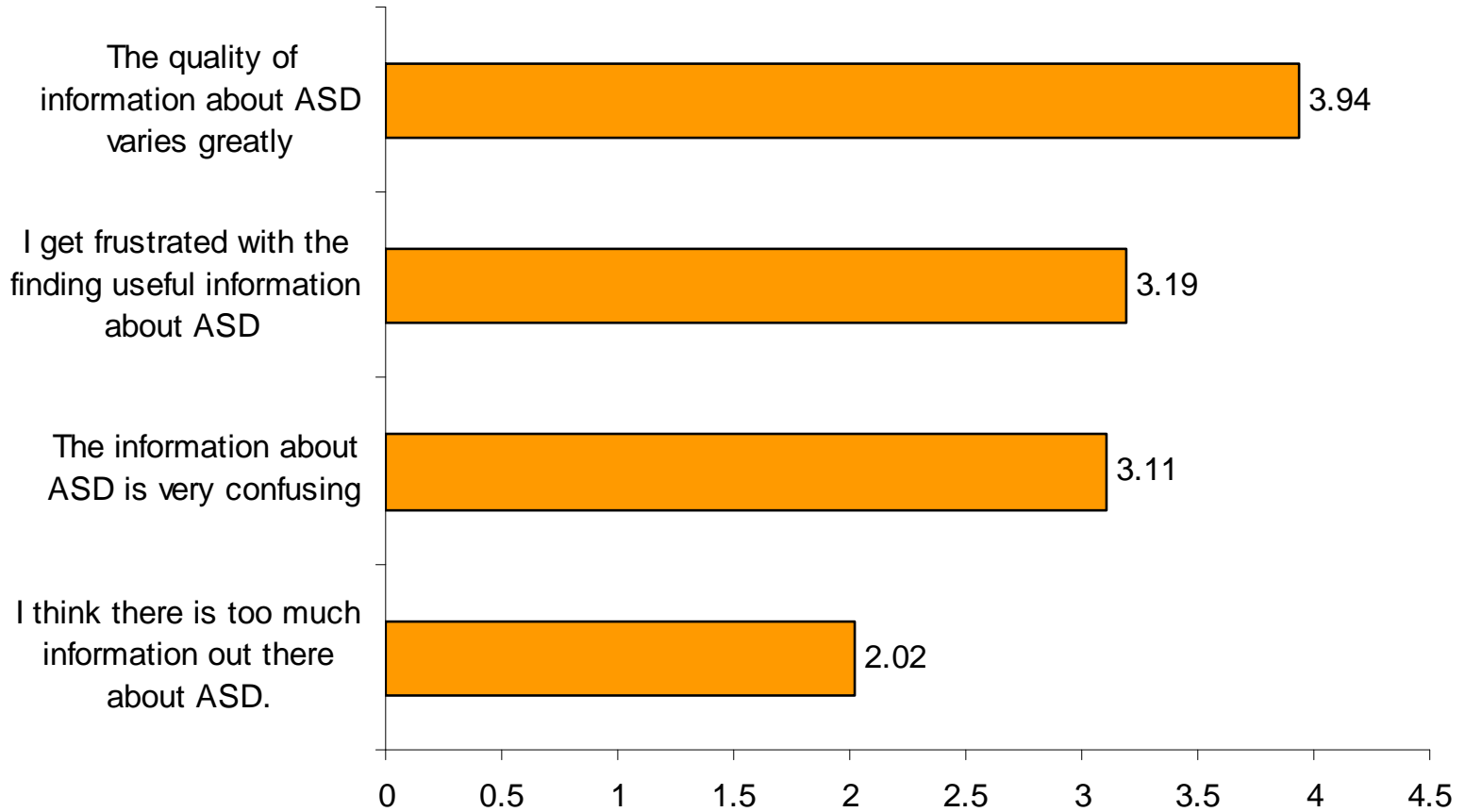
## Update of latest development in ASD research most needed for immediate access



1=strongly disagree, 2=disagree, 3=neutral, 4=agree, 5=strongly agree

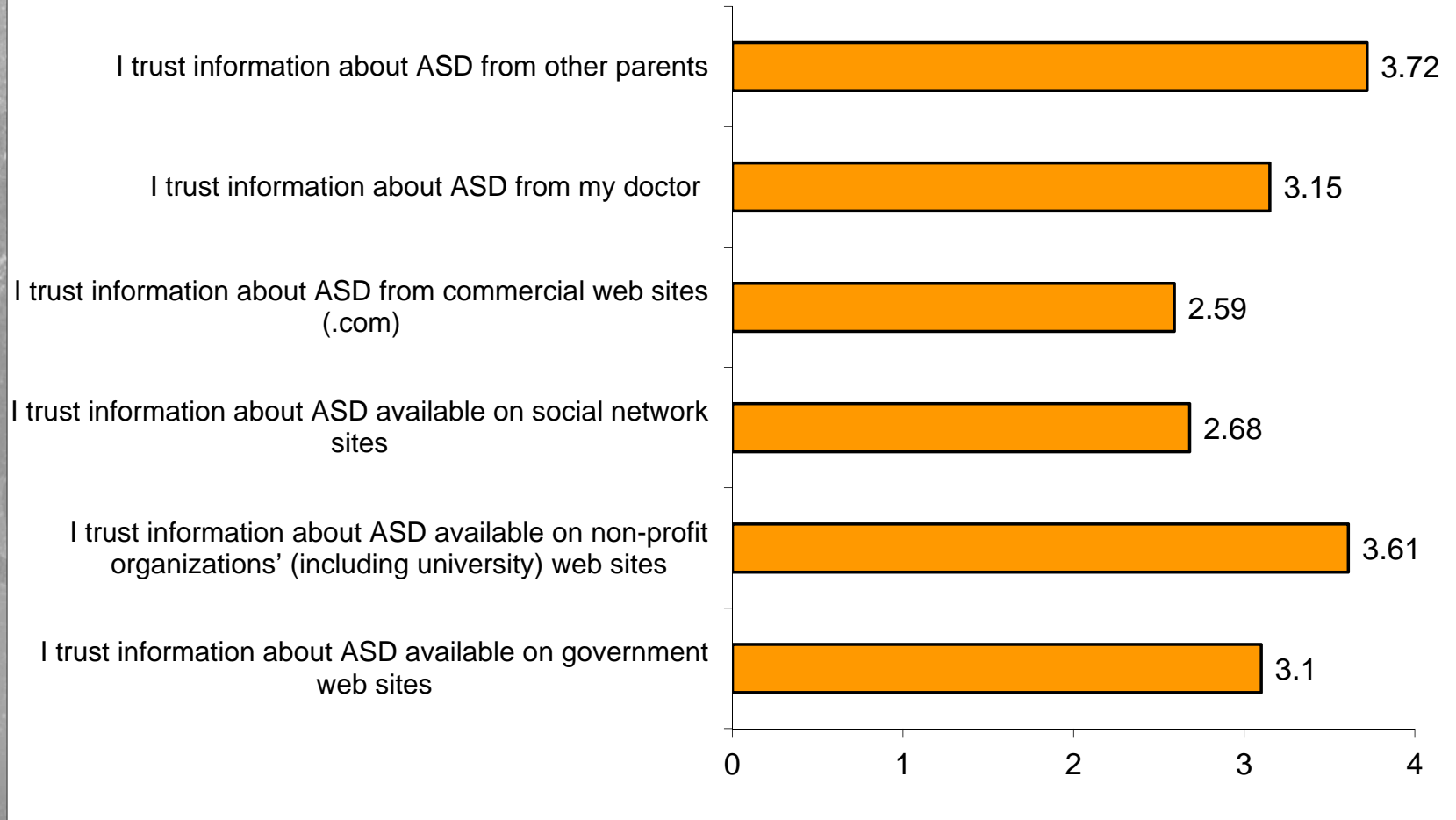


### Assessment of ASD information environment in general



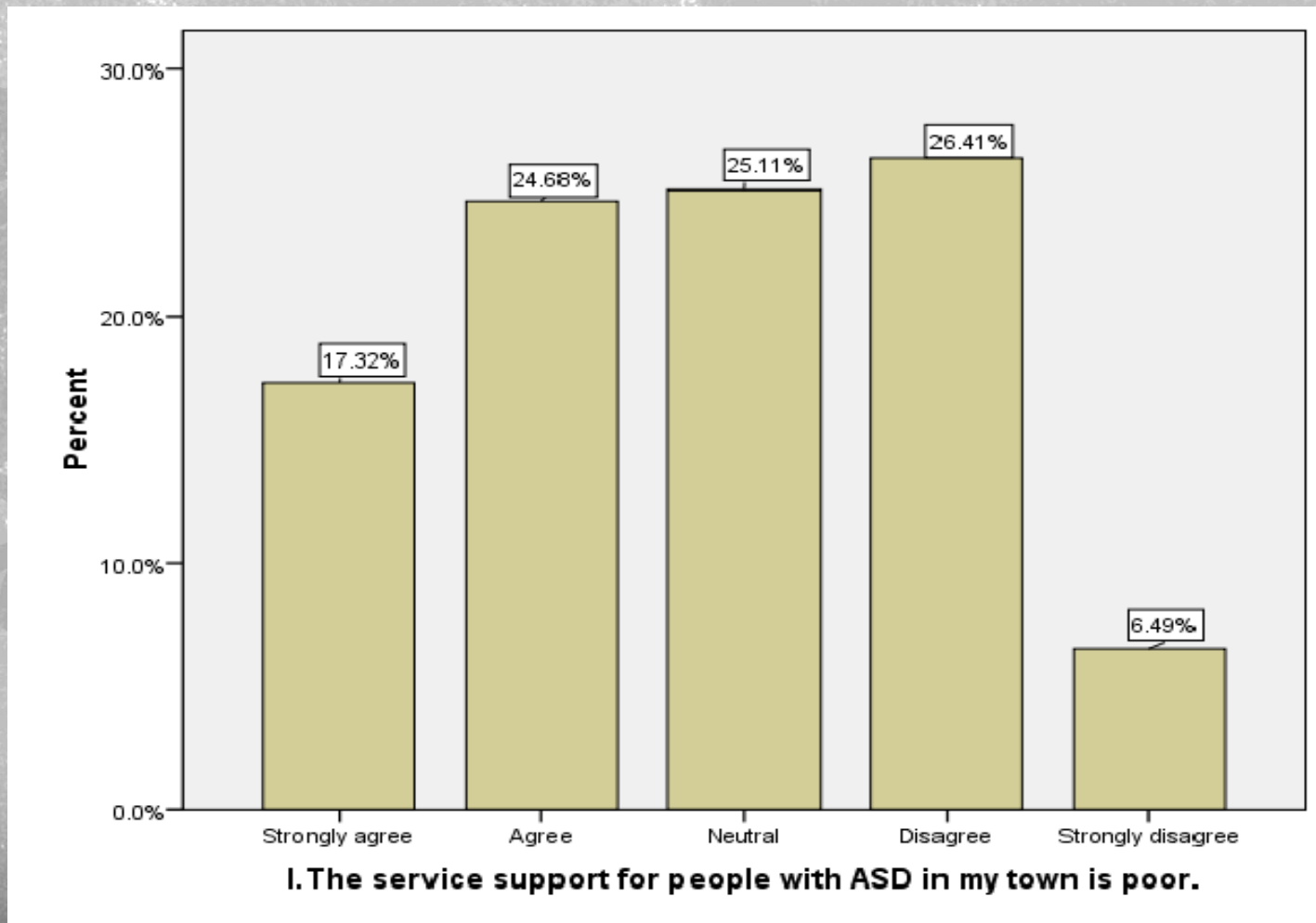
1=strongly disagree, 2=disagree ,3=neutral,4=agree,5=strongly agree

### Trust in different information sources



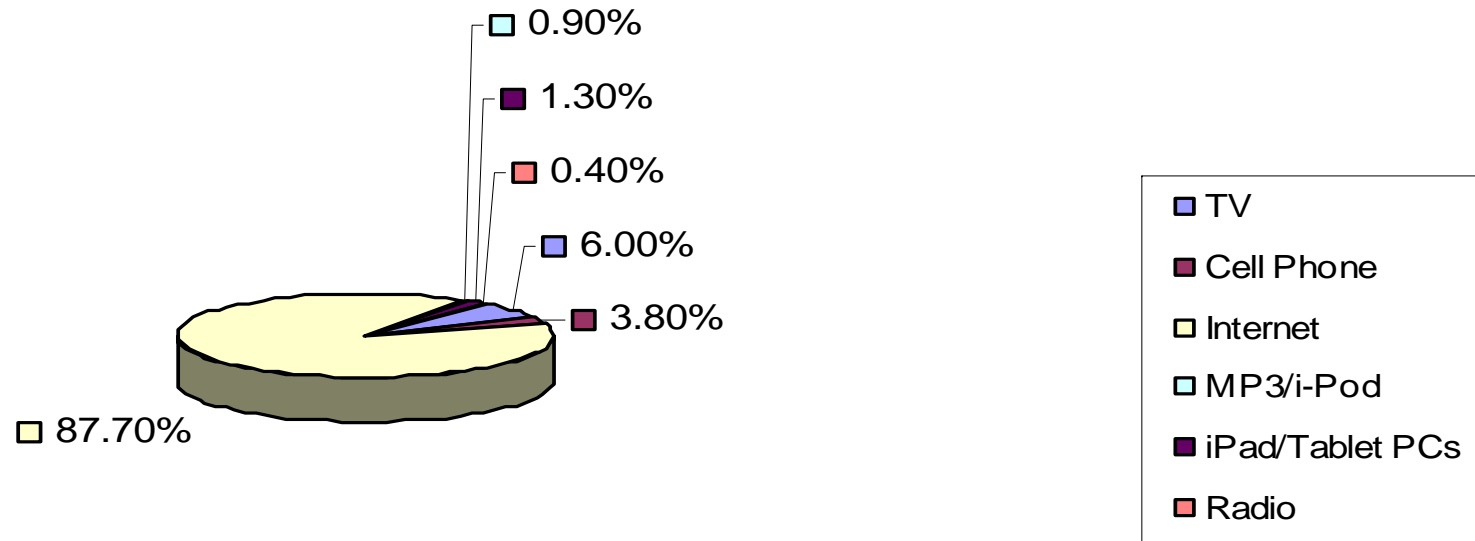
1=strongly disagree, 2=disagree, 3=neutral, 4=agree, 5=strongly agree

# Quite Divided on Rating of Local Support Service



# Internet is the Most Convenient Medium

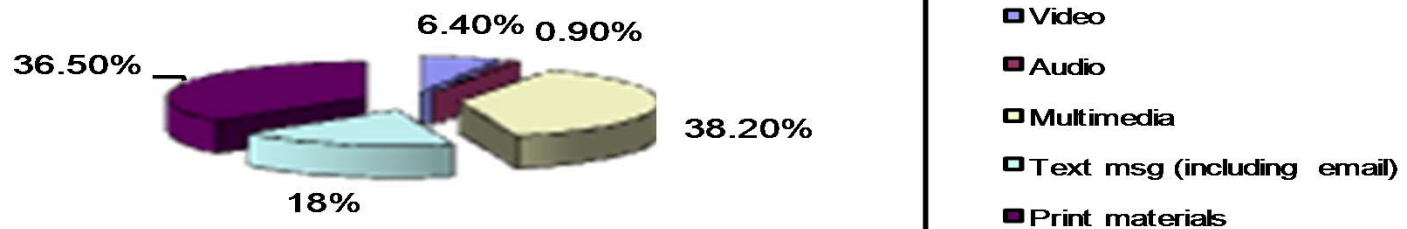
Most convenient media accessing to ASD info.



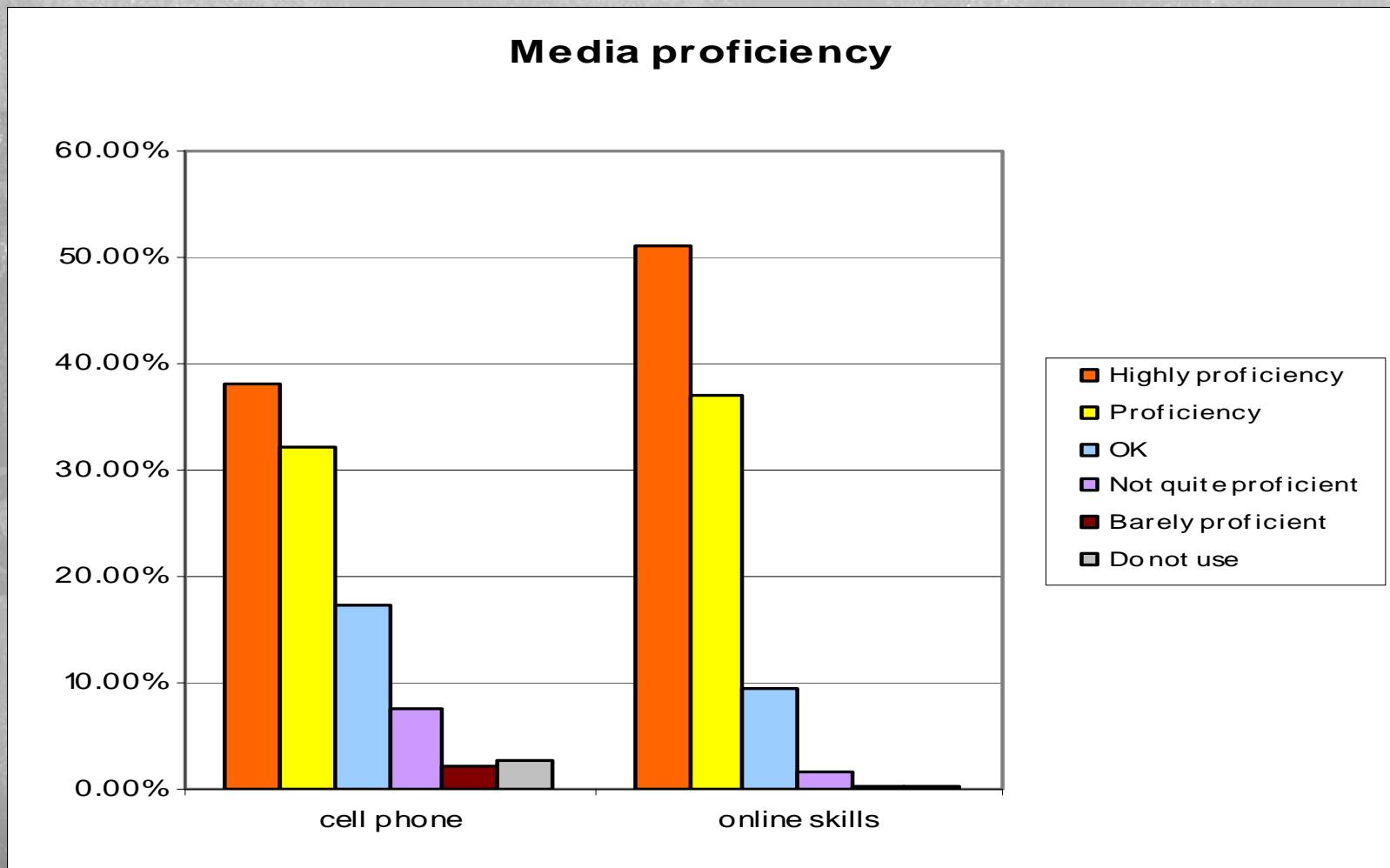


# Multimedia and Print Materials most wanted formats

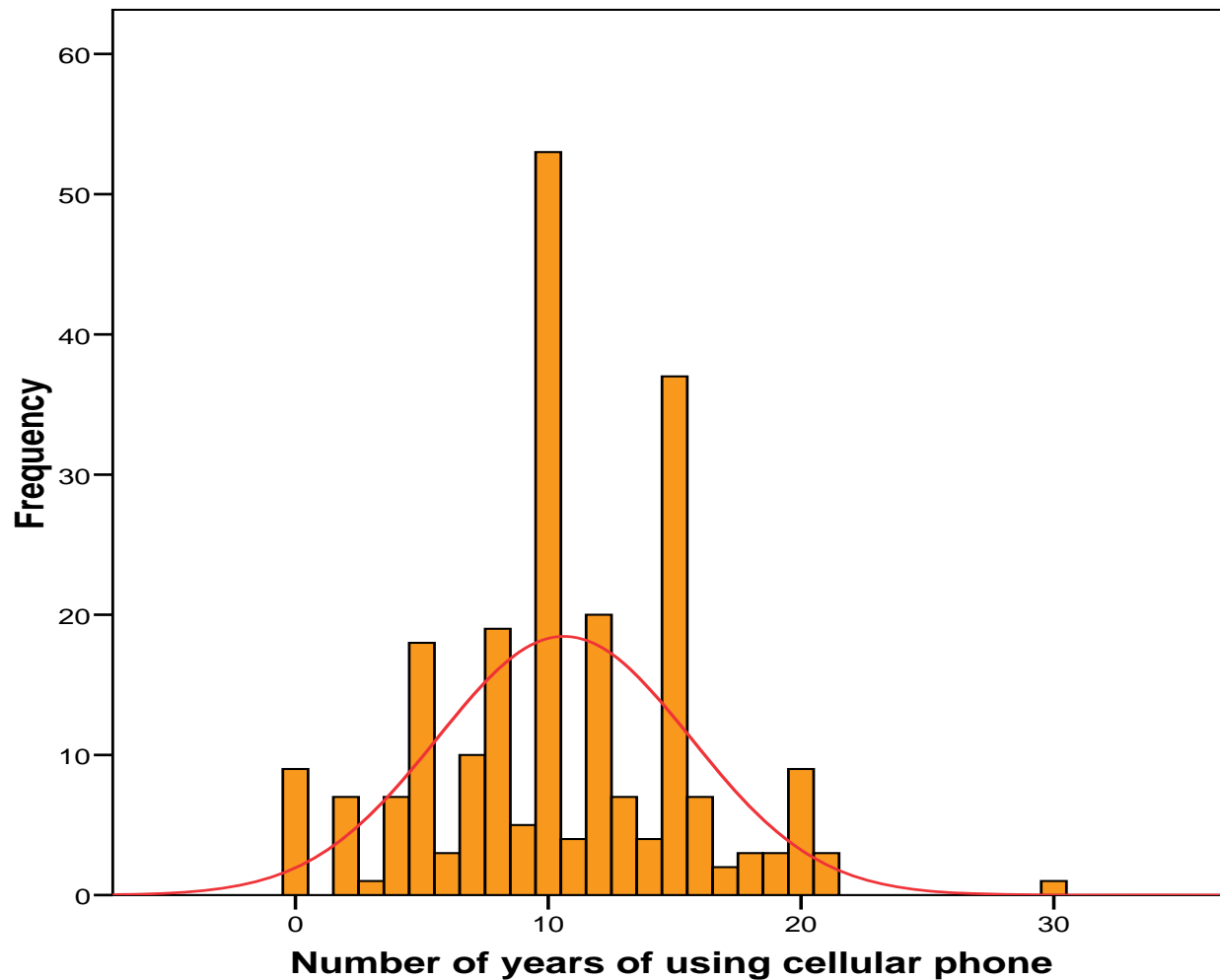
**Most wanted content format**



# Respondents rated themselves as highly proficient in online search skills, and less in cell phones

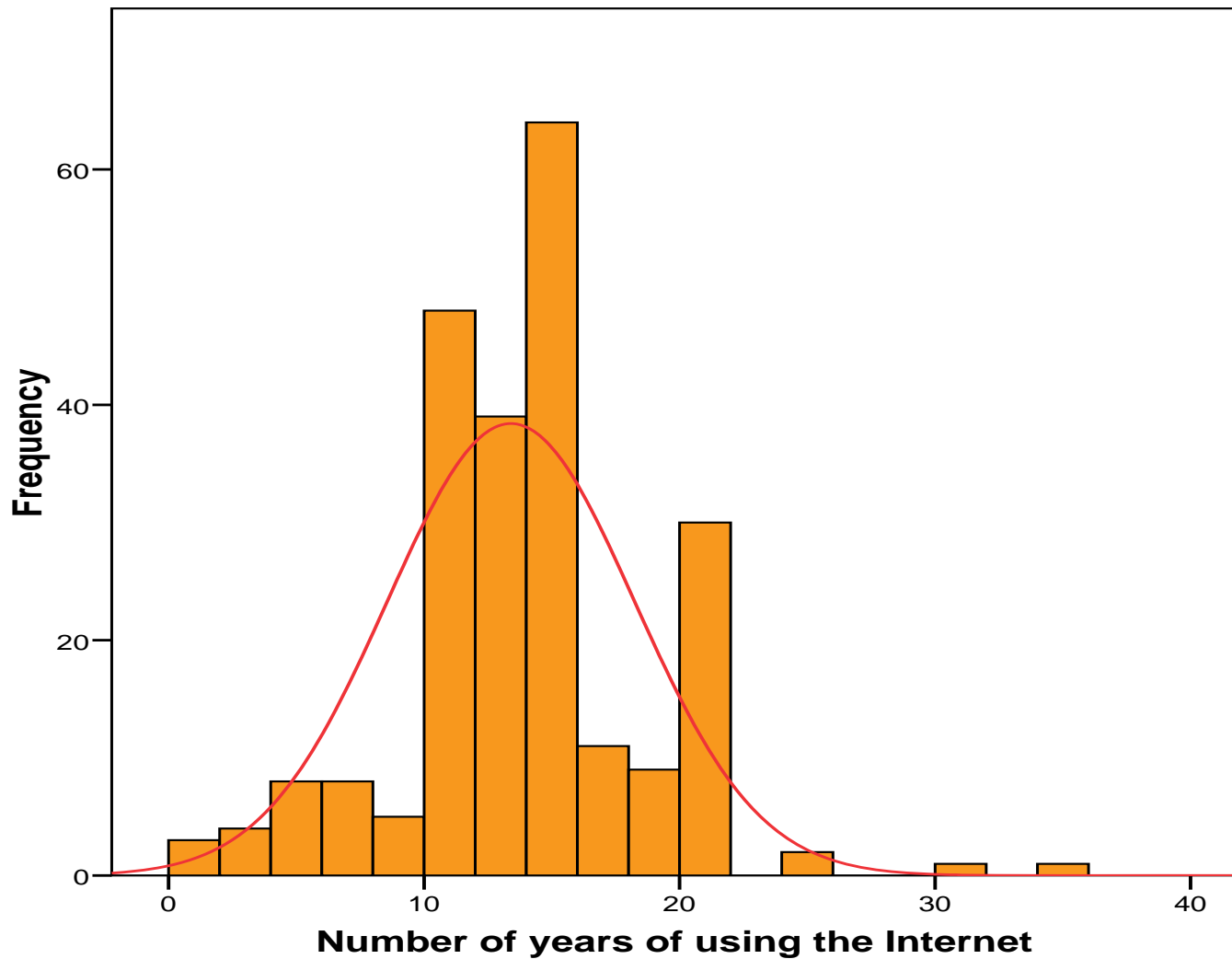


# On average, they used cell phones at least 10 years



Mean =10.63  
Std. Dev. =5.015  
N =232

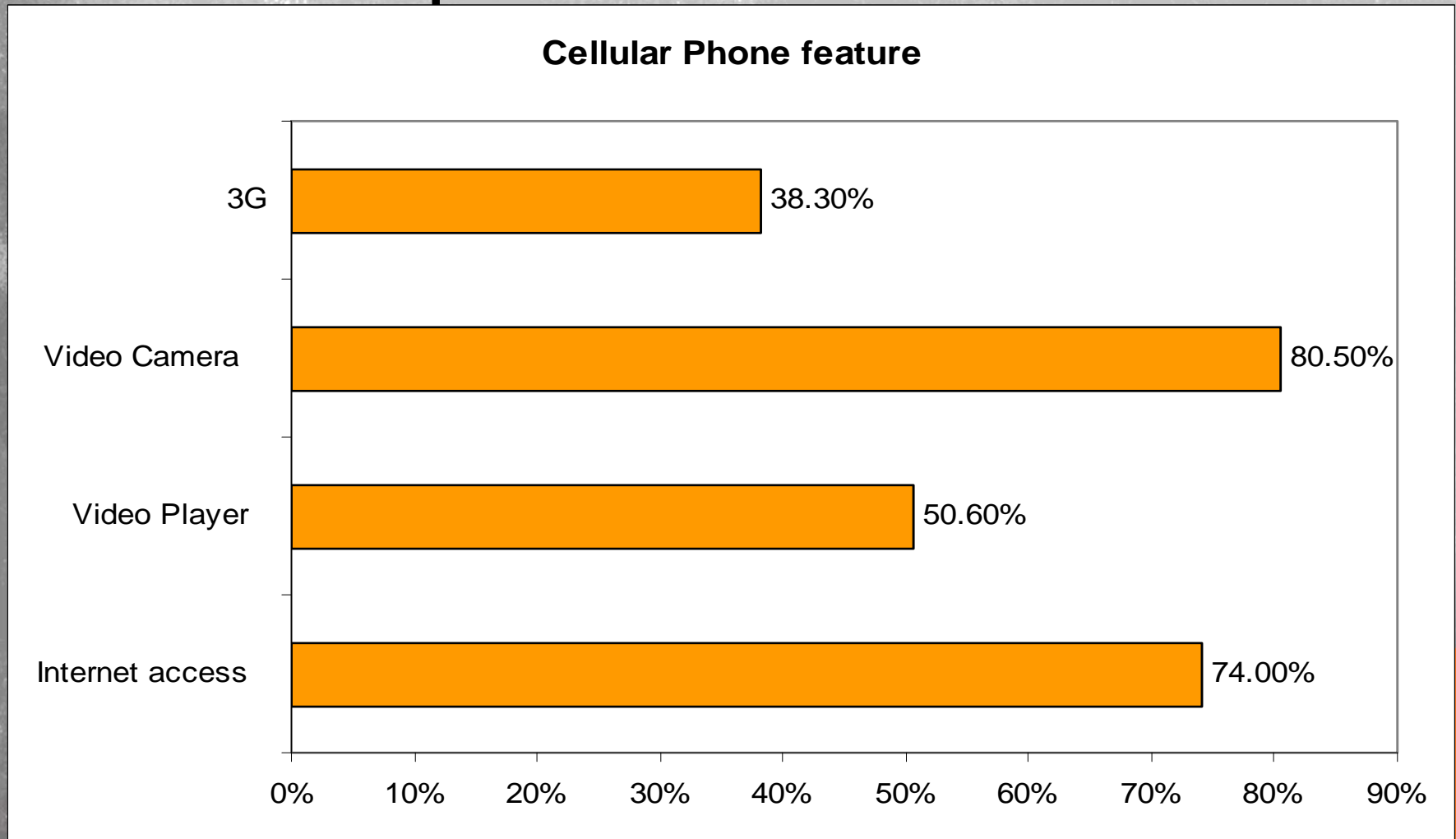
## Respondents also on average have 13 years or more experience using the Internet



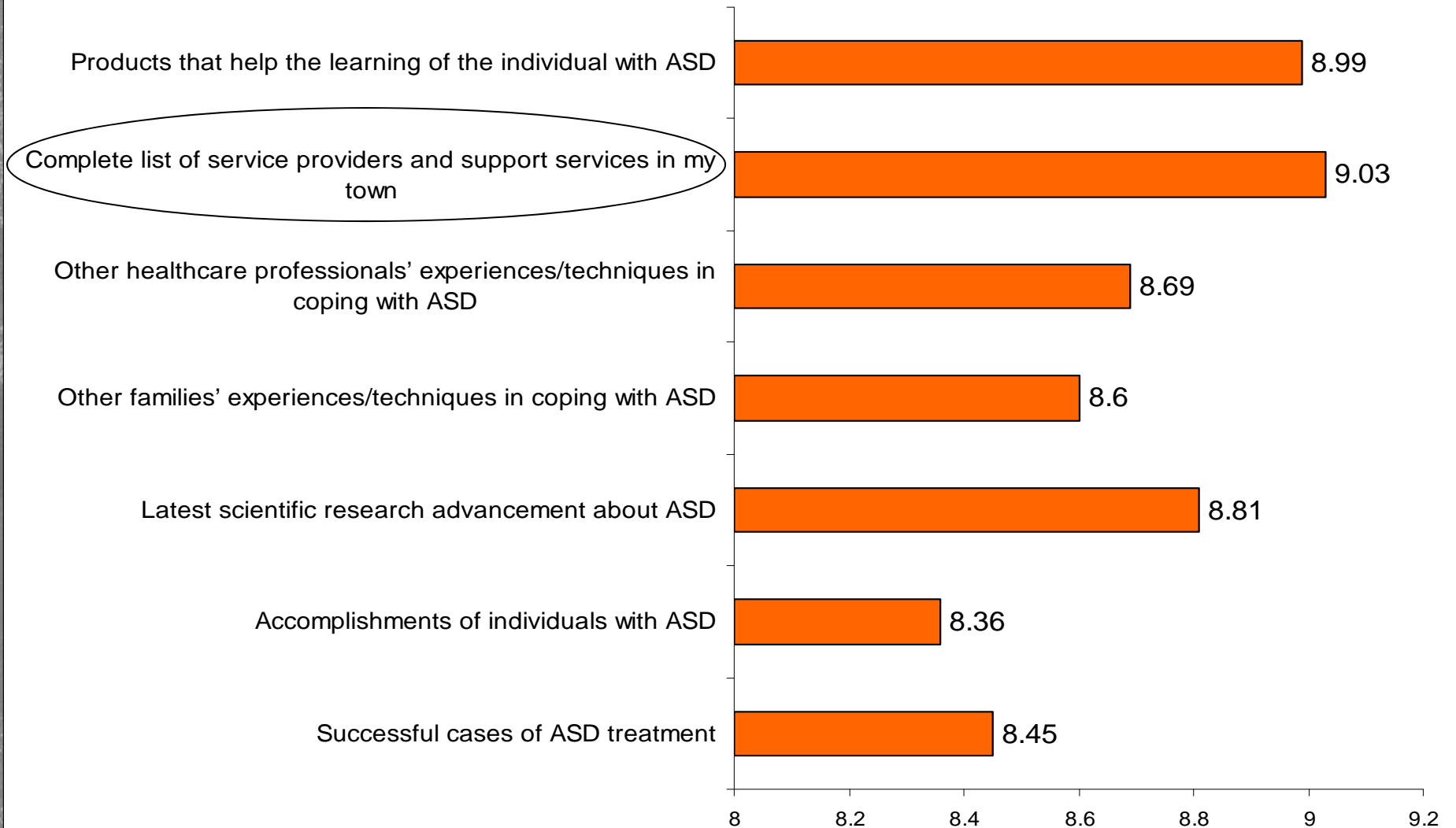
Mean = 13.4  
Std. Dev. = 4.841  
N = 233



# Video Camera is a Common Feature of Respondents' Cell Phones

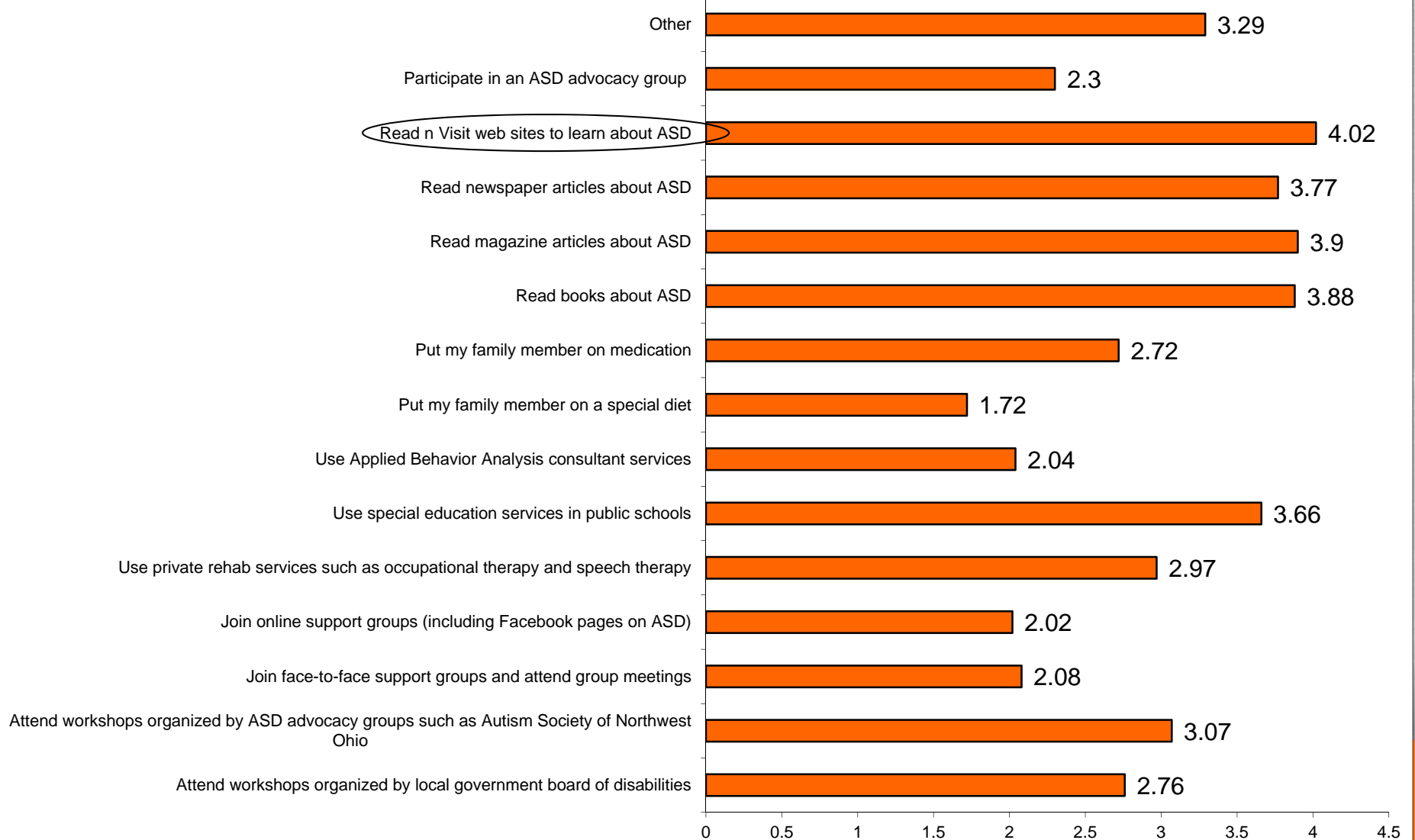


### Ratings of interested content



10 is you are most interested in it. 1 is you are not interested in it

### Current methods of coping with child's/sibling's/client's ASD



1=never, 2=Seldom, 3=Sometimes, 4=Frequently, 5= Very frequently

# Other coping strategies

- Attend all school meetings; IEP's conferences
- 2 x Attended BGSU autism certificate program
- Can't participate in anything outside of home because single parent and child can't stay alone at night
- connect with other Sunrise Program families and support from Autism Treatment Center of America
- DAN! Protocol - can't currently afford; but was very helpful w/ behaviors and stimming
- Drink alcohol. pray. sleep.
- Friends/support system.
- tried to use special ed for my child but wasn't allowed in
- Journal Articles
- Love them with all my heart; and cope with ups and downs by going out with them to have fun
- look for biological treatments that seem to meet her needs read research articles pertaining to autism
- Speak with other parents about ASD in a casual setting
- There is very little support in my city
- take courses on-line (DIR Floortime)
- talk with friends of children
- teaching certificate in ASD
- Use psychological services video recording of techniques/ teaching about behavior and characteristics
- Visit psychologist with ASD family member
- Went back to school to receive my Masters in Special Education and a Certificate in ASD from BGSU



# Individuals with ASD's Comments and Concerns

- *“would like adult social groups for meeting people and socializing. Would like help in being able to live on own and maintain apartment or home and take care of myself; or a living complex for people like myself similar to what is there for older people; like apartments with an office with a social worker and maintenance people etc; and rents based on income to help us get on our own.”*
- *“You should include transgender as a category; a large percentage of the transgender community is ASD (I am). There is very little out there for adults that are AS in the way of services. Many of us could help younger AS individuals with;It gets better and you can compensate and use your AS to good purpose.”*
- *“I think there needs to be more focus on work abilities and the positives; not just the negatives. I think more people need to be talking to the business and companies about the needs but yet the positives of people with asd.”*
- *“I wish I had somewhere I could go where people would understand me and not criticize me for not being good with people. “*

Source: IR offices

## Parents' and Professionals' Comments and Concerns about ASD (1)

- *“we are at a place now where we need very little services/outside help. when our child was first diagnosed; we had tremendous need for information and research and means for finding services at that time. “*
- *“The amount of information on autism is staggering. The quality of the information is a matter of opinion and perspective. After 12 years raising my son; he is the single most source of joy; pride; love; growth; strength in my life. I have fought docs; schools; "professionals"; etc and used "alternate" interventions. Now (as of 1 month ago) he's in typical public school...every day I pray he has a good day. If he's got any symptom of illness...he doesn't go. The risk is too great...he'll freak; hit someone; and the progress slides back 2 years. ILLNESS BRINGS BACK regressed AUTISTIC behaviors. At 180 LBS and 5'5" he has hurt people in autistic rage. He takes 3 meds a day (inc Prozac); plus supplements. Keeping him home from school too much has obvious detriments. Academic; social; schedule; FINANCIAL (I can't work); between siblings (why does he get to stay home?); but SAFETY and maintaining progress are core motivators. I make every decision; 100s of times a day; on Safety and Maintain or Promote Progress.”*
- *“There is a high demand for the 7-13 age group for Children with Aspergers/Autism/ASD to have before/aftercare and transportation to and from school. There is no alternatives for transportation if you choose to opt out of public transportation?”*



## Comments and Concerns about ASD (2)

- *“I think there needs to be more focus on work abilities and the positives; not just the negatives. I think more people need to be talking to the business and companies about the needs but yet the positives of people with ASD”*
- *“I am an art educator who has used art projects with great success for teaching all subjects to individuals with ASD. I would like to see more research done on this subject.”*
- *“Unfair that insurance companies exclude autism coverage; need greater services available for ASD and affordable services and services that are more local; need greater direction and where to go for help”*
- *My biggest concern are most on the autism spectrum are becoming adult and there is no job for them. How can they afford insurance once they reach the age where they can no longer be under their parents. Parents continue to advocate for them and it seems like finding help is a constant struggle.“*
- *“It has been difficult to find service providers who are competent in; and able to regularly/consistently provide; services for sensory processing disorder. Many don't seem to understand this prominent aspect of ASD.”*



# Comments and Concerns (3)

- *“We need a more clear; concise; user friendly way to navigate the services available for those affiliated with ASD in our community.”*
- *“People on the autism spectrum are a growing population. I am concerned that while there is more information available; services have not become available. Schools nearly inhibit parents from getting information. Many children are being overlooked and end up labeled as unruly or criminal. “*
- *“It is very difficult to get and hold a job with ASD. Either we can't play the politics required. We are "too smart". Or; if we identify ourselves as ASD we are treated as retarded even with an IQ of 147. Government agencies are have been useless. Schools wanted to treat the kids are retarded. I homeschooled them. My son did college level astronomy in the 8th grade but a local therapist told him he was lazy because he home schooled and didn't have his GED. He has Rheumatoid arthritis and told him he was lazy because he couldn't work. Don't even get me started about the horror of 4-H.”*
- *“It would be helpful to be able to utilize programs online. It is difficult to get to seminars after school; this is when we have therapies; Dr. apptmts and much homework to finish. The middle class really need help financially. Insurance does not pay for many things for people with ASD. Suppliments; ADOS testing; and Learning disabilities are non covered items. The schools are supposed to be able to assist in these areas; but it is difficult to get them to respond to requests; let alone get a qualified person to test if they agree to it.”*



# Comments and Concerns (4)

- *“WE have tried many doctors/services in the area and have not been happy with any of them. They tend to treat all with aspergers the same but through group sessions we have seen they are very different. Insurance won't pay for services outside area. Need help for those entering workforce and/or college.”*
- *“Would love to have family counseling to learn how to best handle a child with PPD but don't know of providers. also; any good psychiatrists in northwest ohio that specilizes in PPD? We need more social skill groups for these kids”*
- *“schools in the area don't seem to know what resources there are to help individuals with asd.”  
It seems that the schools in the wood county area need a place they can turn to. Toledo is too far for many of the families and school systems here to go to the lectures and gatherings”*
- *“Our insurance coverage is poor for mental health services and we can't afford to pay out of pocket”*
- *“Social skills trainings and workshops for general education teachers on strategies is critical!”*
- *“We live in a rural area. There are few if any services in our area. People including professionals are ignorant of Autism and how to treat my son. Very few have the knowledge; training; or patience to handle my son safely. Public schools; board of DD and others have done more harm than good in treating my son. Tens of thousands of dollars have been poured out between public school and medicad services and very little has been done to help my son. by the time the funding trickles down to the actual caregivers little if any training has been done. They don't know what to do because they have not been trained and lack knowledge and experience”.*



# Comments and Concerns about ASD (5)

- *“One of my concerns is too many org's & agencies that provide so-called information or advocacy yet very few provide "real" legal representation – thus; creating serious gaps in how or what can be provided to students. Although vital; information provided is only good as of the knowledge gained being accepted. For parents; that presents a serious problem legally. More often than not; their child(ren) will receive less or worse; nothing. In the education world it is that precious time of opportunity to learn that is lost; and so too; at that point; the child. From personal experience; if a parent goes up against a LEA they are more than likely going up against highly expertise and paid attorneys? Advocates don't have a prayer. They are great for support but in reality are; for the most part; a waste of time when it comes to legal issues. Secondly; the disconnect between the education world and research and development and new services - assessments that show more effective development or outcomes but are the least afforded in elementary or secondary education. Even if parents are up on the new research and development; it doesn't mean that a LEA knows or will consider using. Third; people have this misconception that "autism" is new. Having a child nearing 20 I can say that we are not part of some rad' seeking family hopping on the coolest boogey board catching the latest psycho wave. Parents seeking "real" answers to "real" issues seek help for “real” answers. Once some recognition did materialize about autism it seem to perpetuate a whole other world; a science world; that has for the most part alienated the patient and families who actually need them. For my family and me we feel as though we are placed once again in a bubble even though; by all appearances; an area of great concern and interest. Lastly; if a professional goes in his/her chosen field which happens to include children; one needs to separate oneself apart from all else. LEA's need to be concerned about true results that provide the greatest impact in learning; not skirt it along. And parents need to understand that a disability doesn't mean unable or requiring the best or most. And both need to recognize that society's future is heavily dependent on their cooperation with each other.”*