

**Building on Collaboration to Improve Services for Children and Youth with Autism Spectrum Disorders  
and other Developmental Disabilities: Need Assessment Survey Report**

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## **Introduction and Methods**

In late 2011, the Autism Spectrum Disorders project distributed a needs assessment survey to three groups of individuals in Delaware: 1) Parents/guardians of children with autism spectrum disorders; 2) Caretakers of adults with autism spectrum disorders; and 3) Adult self-advocates with autism spectrum disorders. Each group received a slightly different version of the survey. In all, 271 parents/guardians of children with autism spectrum disorders, 91 caretakers of adults with autism spectrum disorders and 19 adult self-advocates with autism spectrum disorders completed the survey.

### **Needs Assessment Survey Instrument**

The needs assessment survey included questions addressing the following themes:

- 1) Receiving a diagnosis and follow-up care.
- 2) Barriers and limitations to accessing health care.
- 3) Employment challenges for adults with autism spectrum disorders.
- 4) Family impact.
- 5) Service needs.
- 6) Unwanted outcomes.

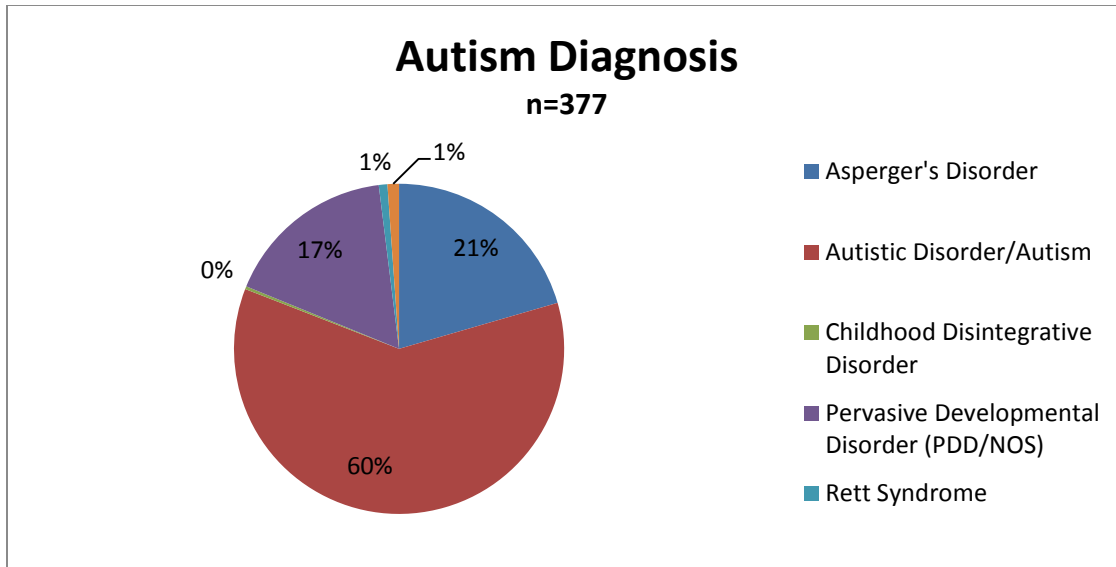
The survey was modeled after a similar survey distributed in Pennsylvania by the Center for Autism Research. Survey questions were modified slightly to apply to Delaware. Modifications included asking questions about Medicaid providers and how far families traveled to see a provider.

This survey was distributed in late 2011 in both paper form and online. A paper copy was sent via mail by the Delaware Department of Education and Delaware Division of Development Disabilities Services and links to the survey were included on websites for the Center for Disabilities Studies, Autism Delaware, Parent Information Center and Delaware Family & Voices. In addition to including a link on their website, Autism Delaware also sent a link to the survey via their list-serve. Information about the survey and a link was also included in a newsletter published by Project Bridge.

A statement at the beginning of the survey instructed parents/guardians of children and caretakers of adults to either fill out a separate survey for each child with autism, or, if only filling out one survey, to complete questions for their oldest child with autism. Adult self-advocates with autism were instructed to answer questions regarding their current situation.

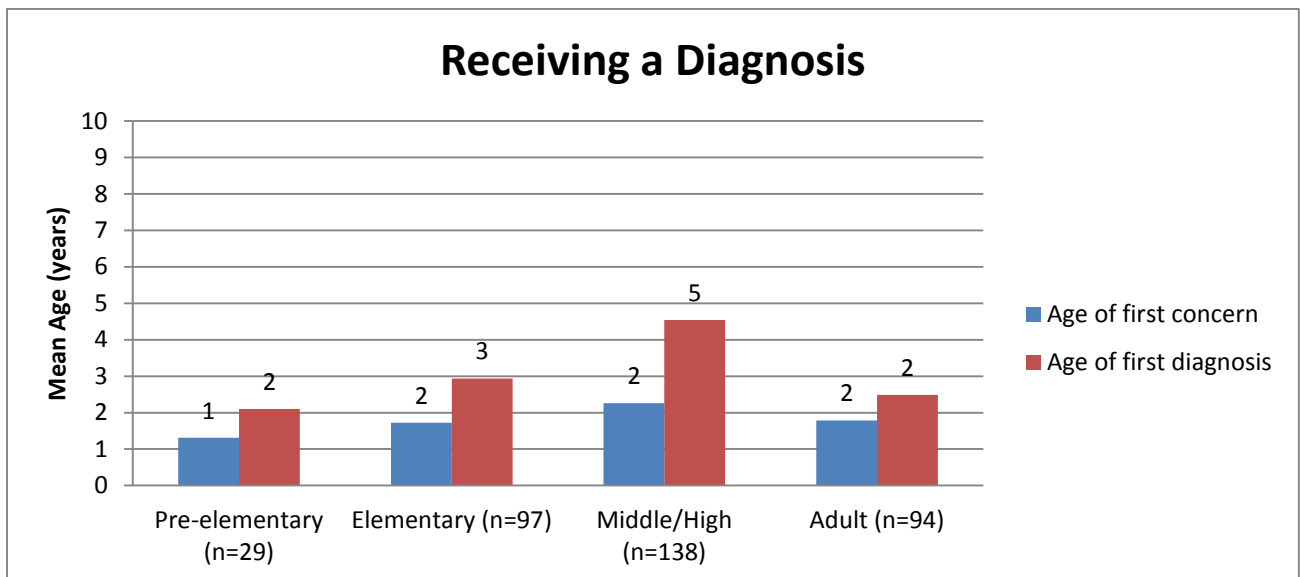
### **Data Analysis**

Analysis and reporting of the survey data was conducted by staff at the Delaware Education Research & Development Center and modeled after the Pennsylvania Autism Needs Assessment report produced by the Pennsylvania Department of Public Welfare. The data presented are meant to give a picture of the issues surrounding treatment, services, employment outcomes and the impact of having a child with autism spectrum disorder on care takers and family members in Delaware. Data are presented in frequencies and percentages. Examples of substantive interpretations of data are presented below each chart.



**“60% of those who reported a primary diagnosis, reported “autistic disorder/autism...”**

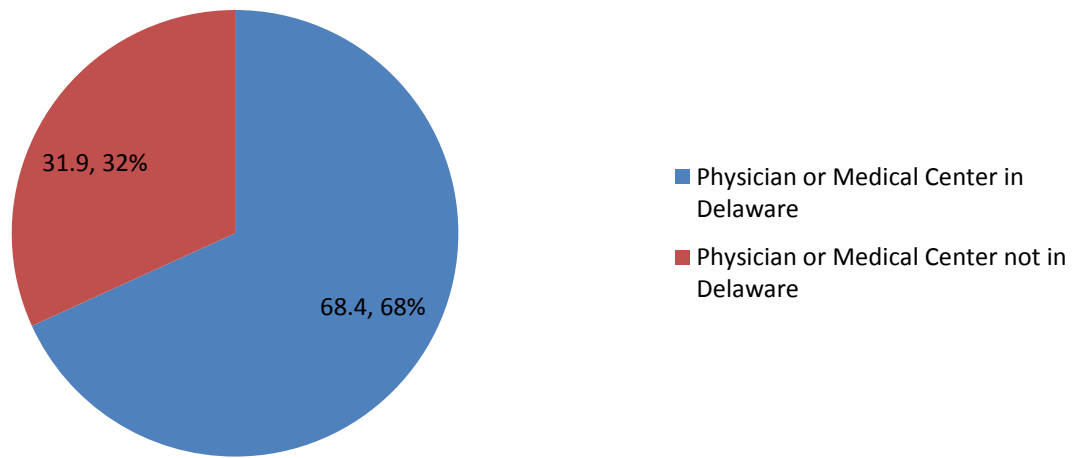
Autism diagnosis statistics calculated by combining the frequencies for the school age, adult and adult individual surveys. Comments made in the “other” category were not included or re-coded.



**“Among the children who are now pre-elementary age, the mean age of first diagnosis was 2.1 years...”**

Age of first concern and Age of first diagnosis derived from school age and adult surveys (not assessed in adult individual). Mean age was calculated for each age category. Results are depicted in means. I kept the decimal places because it is mean age. Vertical Axis altered to represent 10 point scale.

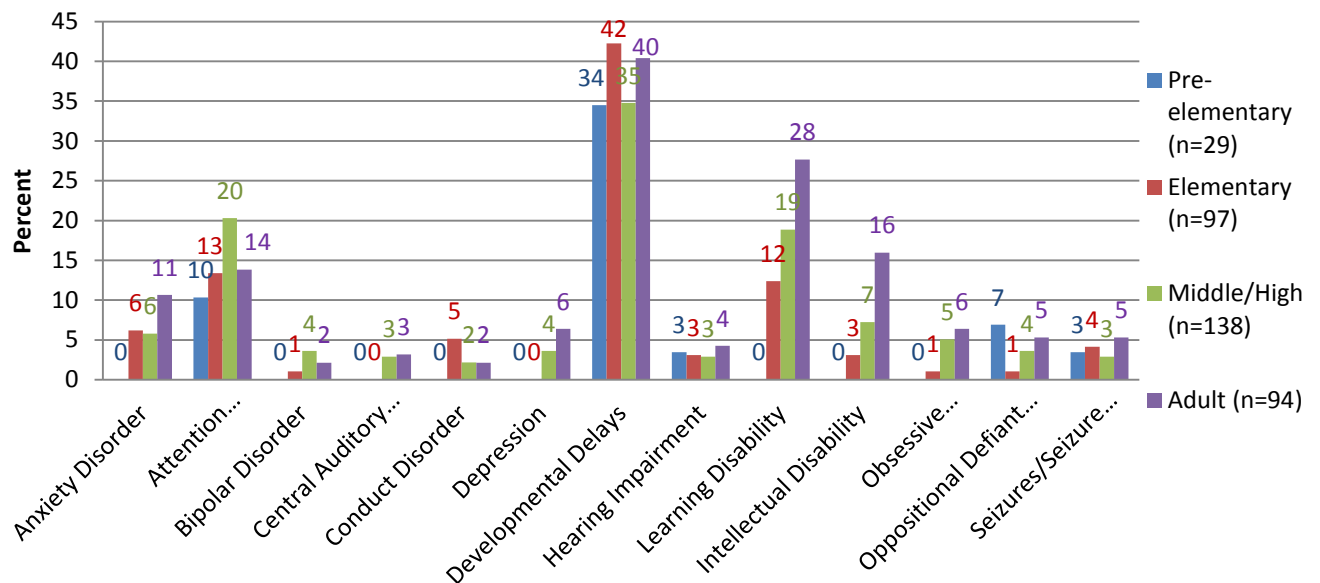
## Where did your child receive his/her diagnosis?



**“32% of those who reported to have received their diagnosis outside of Delaware...”**

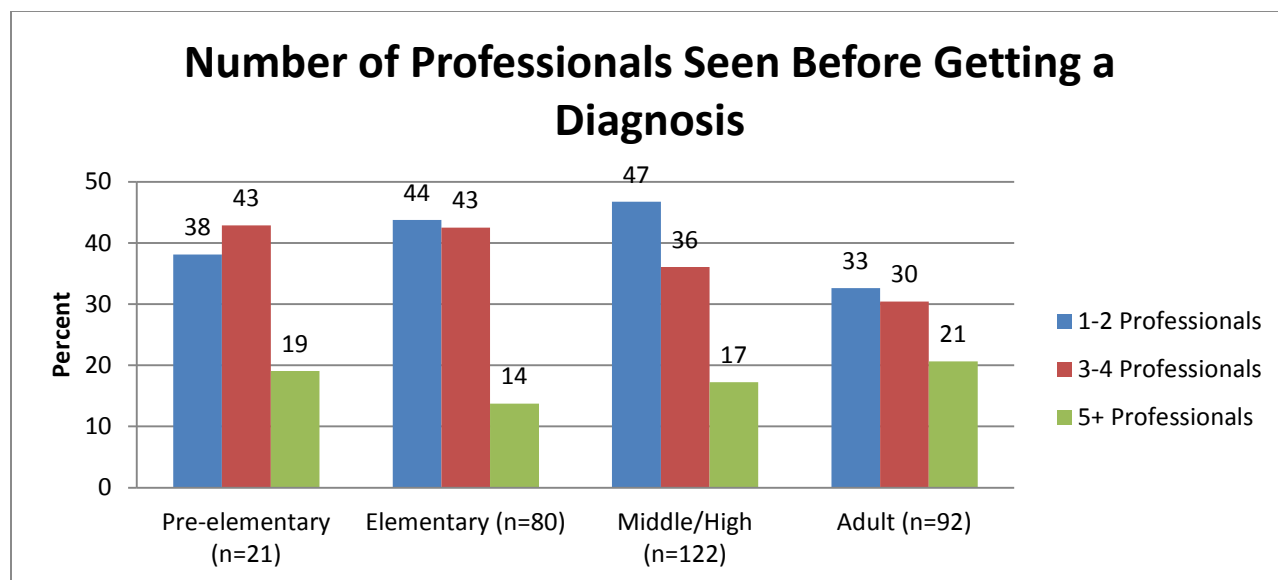
Data derived from school age and adult surveys (not assessed in adult individual). N=314

## Prior Diagnoses



**“35% of parents/guardians of middle/high age students report developmental delays as a prior diagnosis ...”**

Prior diagnoses data derived from school age and adult surveys (not assessed in adult individual). Disorders arranged in ascending order by % reporting.



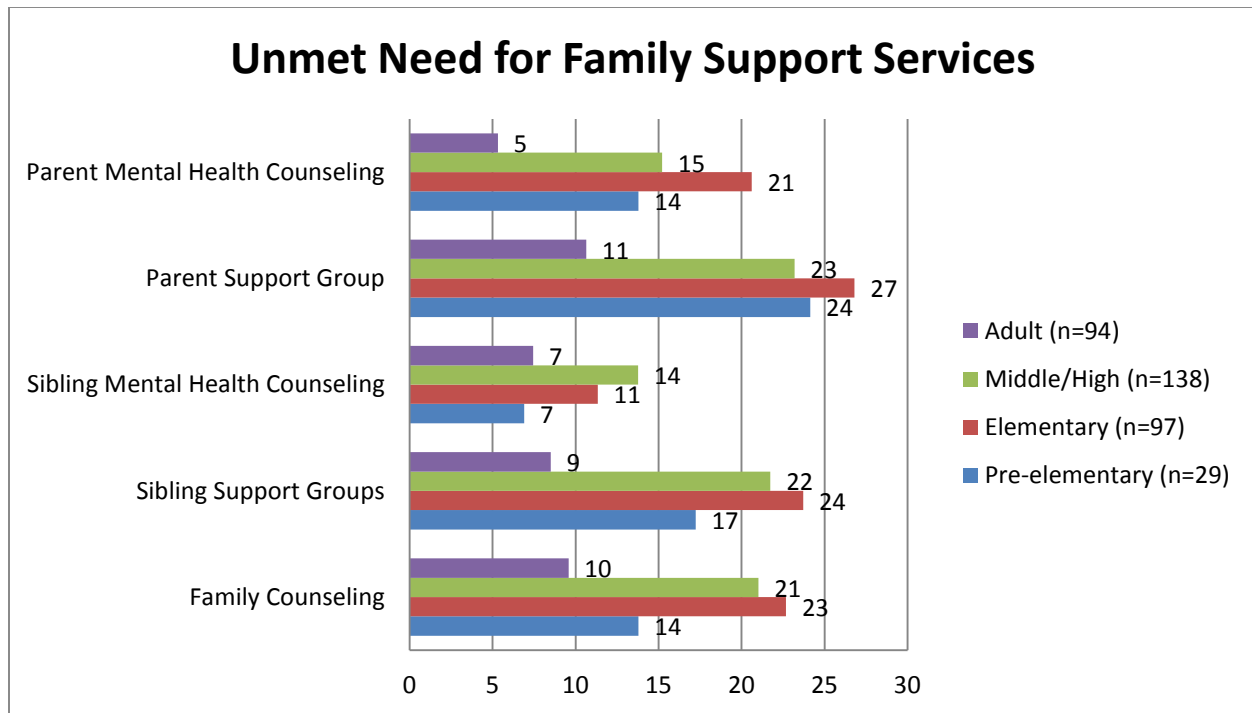
**“Among the middle/high age category, 47% saw 1-2 professionals before receiving a diagnosis...”**

Data derived from school age and adult surveys (not assessed in adult individual). Vertical axis altered to represent a 50 point scale.

Follow-Up Services by Age Group				
Age Group	Pre-elementary (n=29)	Elementary (n=97)	Middle/High (n=138)	Adult (n=92)
Follow up Appointment	8 27.6%	42 43.3%	58 42%	39 42.4%
Referral for Assessment	8 27.6%	34 35.1%	33 23.9%	22 23.9%
Referral to Treatment	5 17.2%	16 16.5%	25 18.1%	20 21.7%
Referral to Early Intervention	18 62.1%	49 50.5%	56 40.6%	42 44.6%
Referral to Support Groups	5 17.2%	32 33%	30 21.7%	21 21.7%
Referral to Website, Literature	6 20.7%	36 37.1%	40 29%	9 9.85
None	3 10.3%	10 10.3%	15 10.9%	14 14.1%

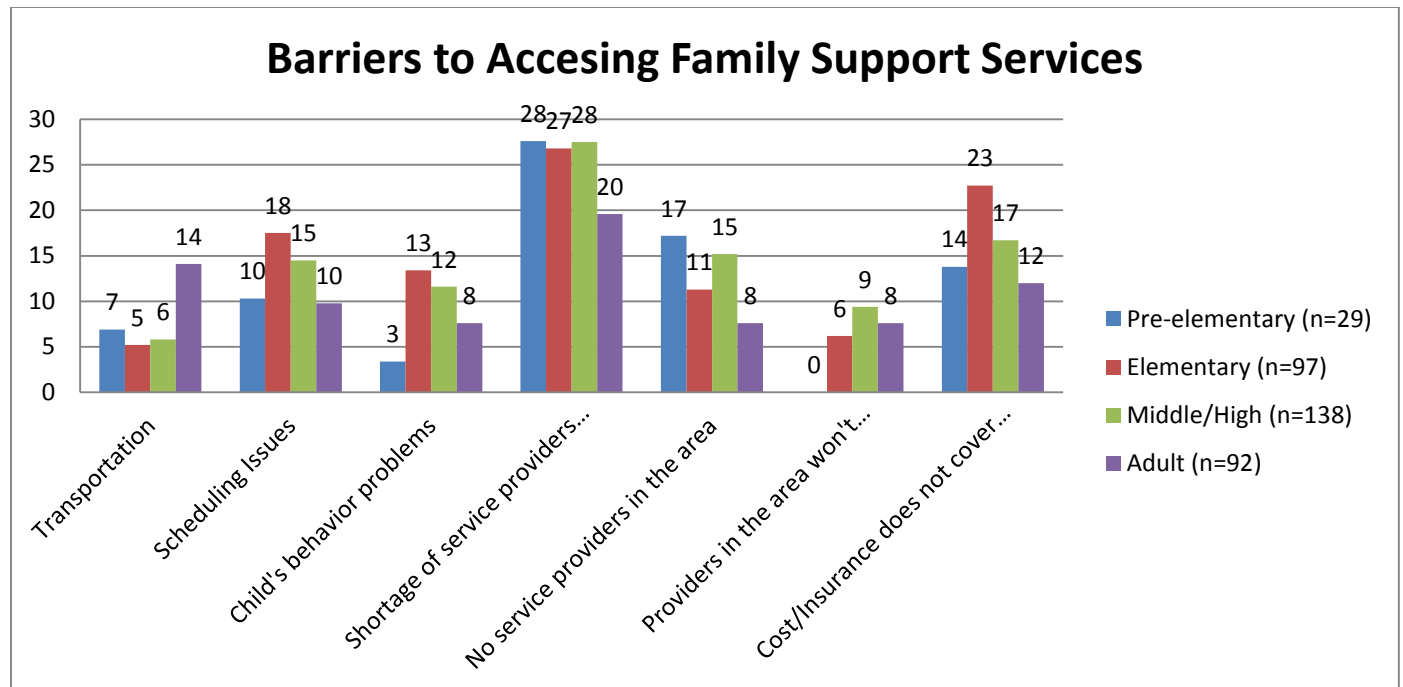
**“Of those caring for pre-elementary children, 17.2% are referred for further treatment...”**

Derived from school age and adult, not assessed in adult individual. Sample size represents the number of people who responded to this question.



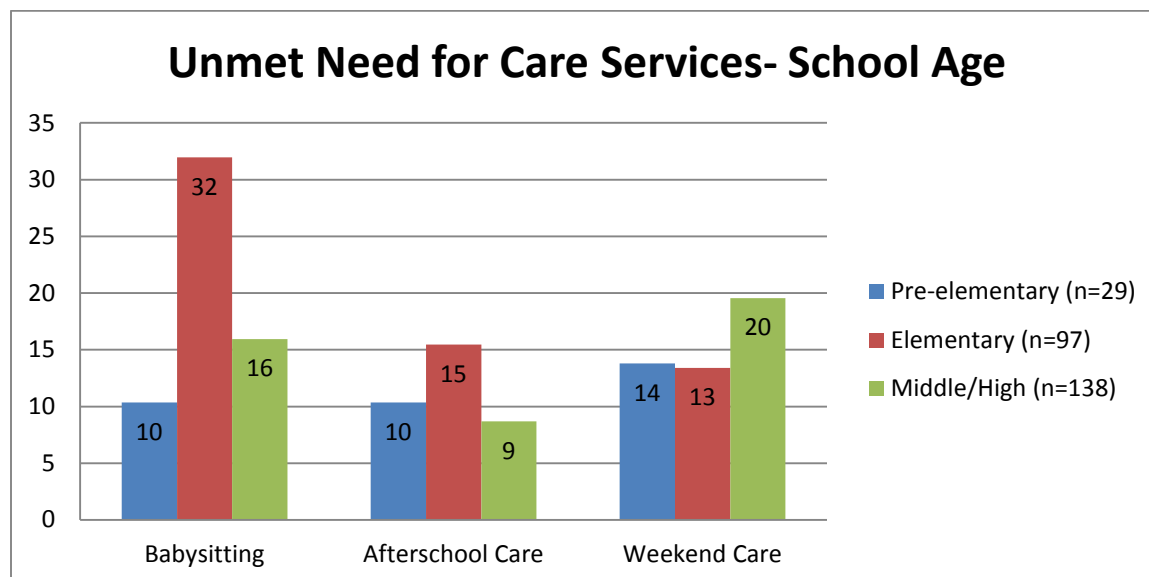
“27% of caregivers of elementary aged children report an unmet need for parent support groups...”

Data derived from question #48 (school age and adult). “Unmet need” calculated by combining ‘my family is receiving but needs more’ and ‘my family is not receiving, but needs.’



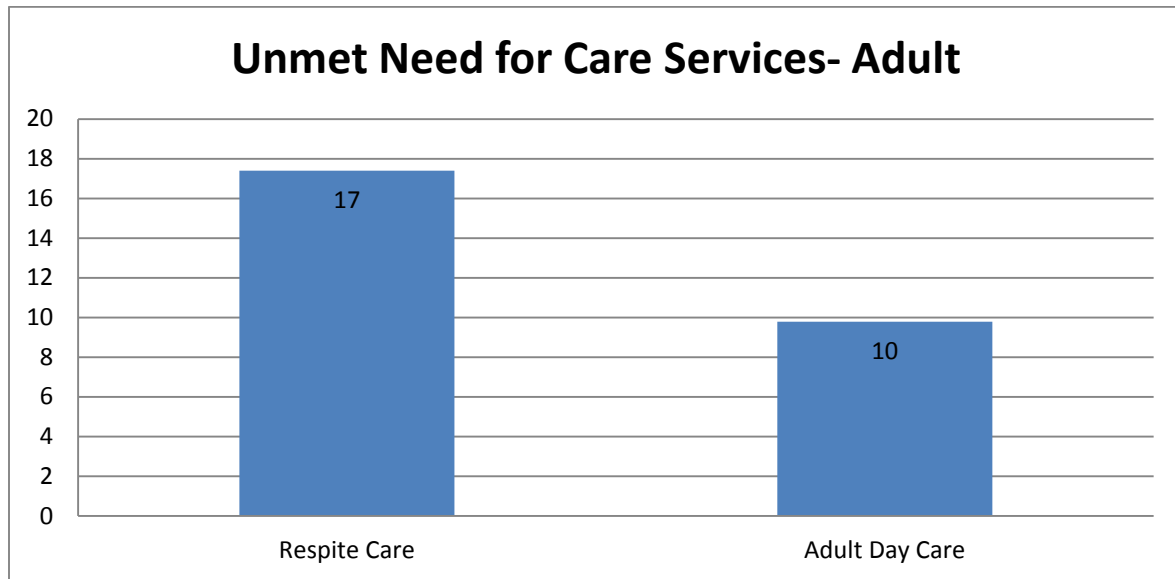
“28% of caregivers of pre-elementary children report a shortage of service providers in the area as a barrier...”

Data derived from question #51 (school age and adult).



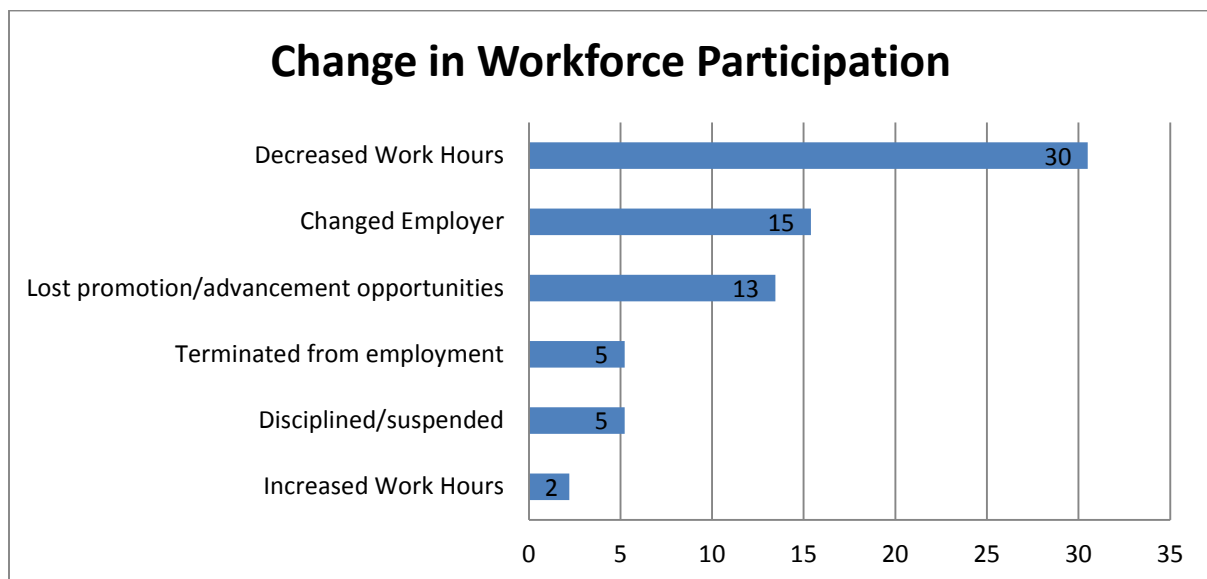
“32% of caregivers of elementary aged children report an unmet need for babysitting...”

Data derived from question #48 (school age). “Unmet need” calculated by adding ‘my family is receiving but needs more’ and ‘my family is not receiving, but needs.’



“17% of caregivers of adults with autism report an unmet need for respite care services...”

Data derived from question #48 (adult). “Unmet need” calculated by adding ‘my family is receiving but needs more’ and ‘my family is receiving, but needs.’

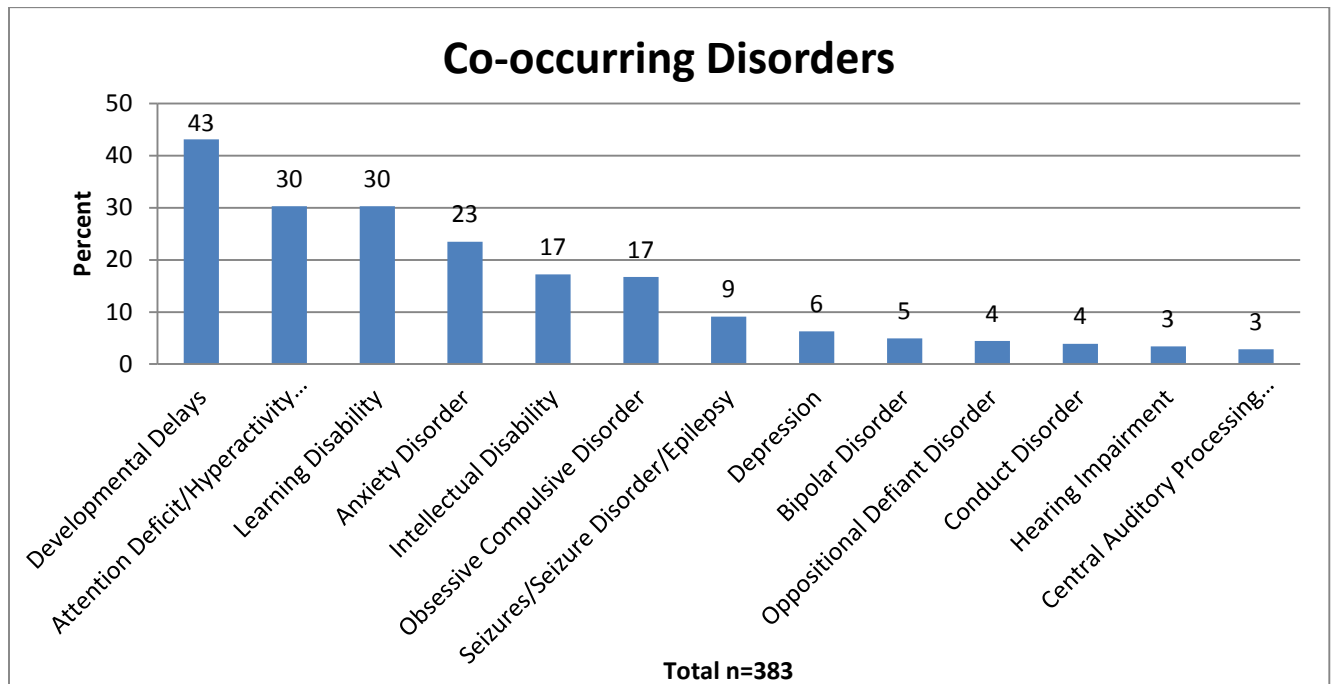


“31% of caregivers of children and adults with autism report a decrease in work hours...”

Data derived from question #36 (school and adult).



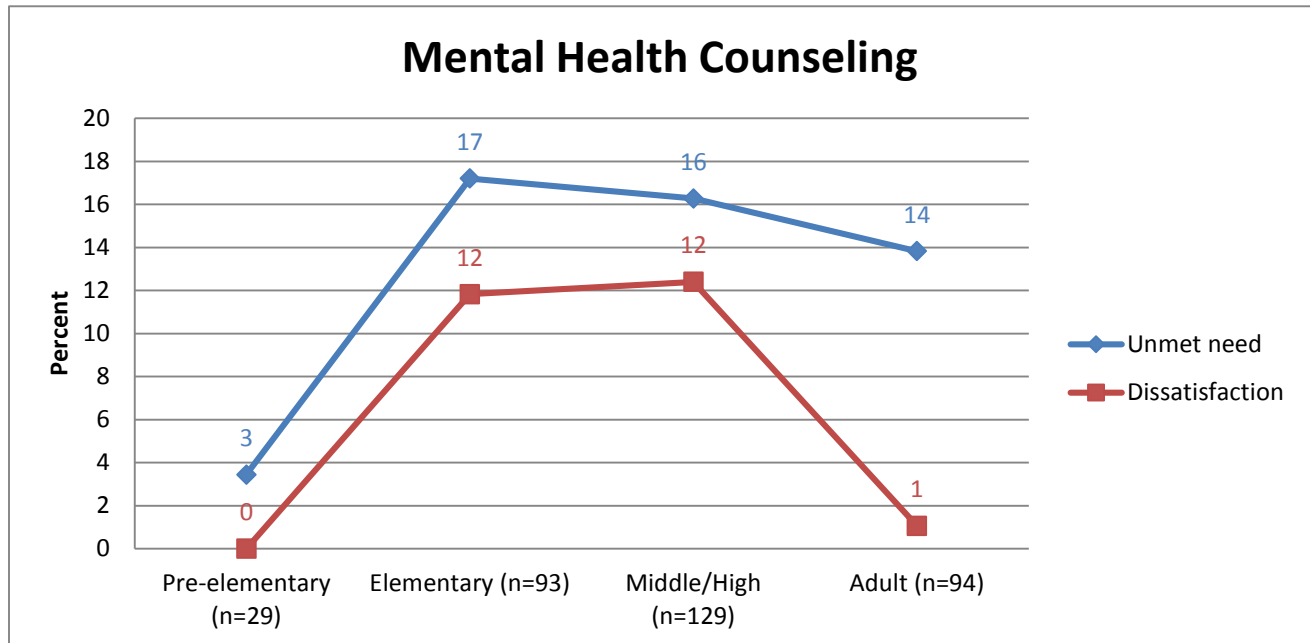
- Grant Number: H6MMC22713  
- Building on Collaboration to Improve Services  
for Children and Youth with Autism Spectrum  
Disorders and Other Developmental Disabilities  
- University of Delaware's Center for Disabilities  
Studies  
- Annalisa Ekbladh



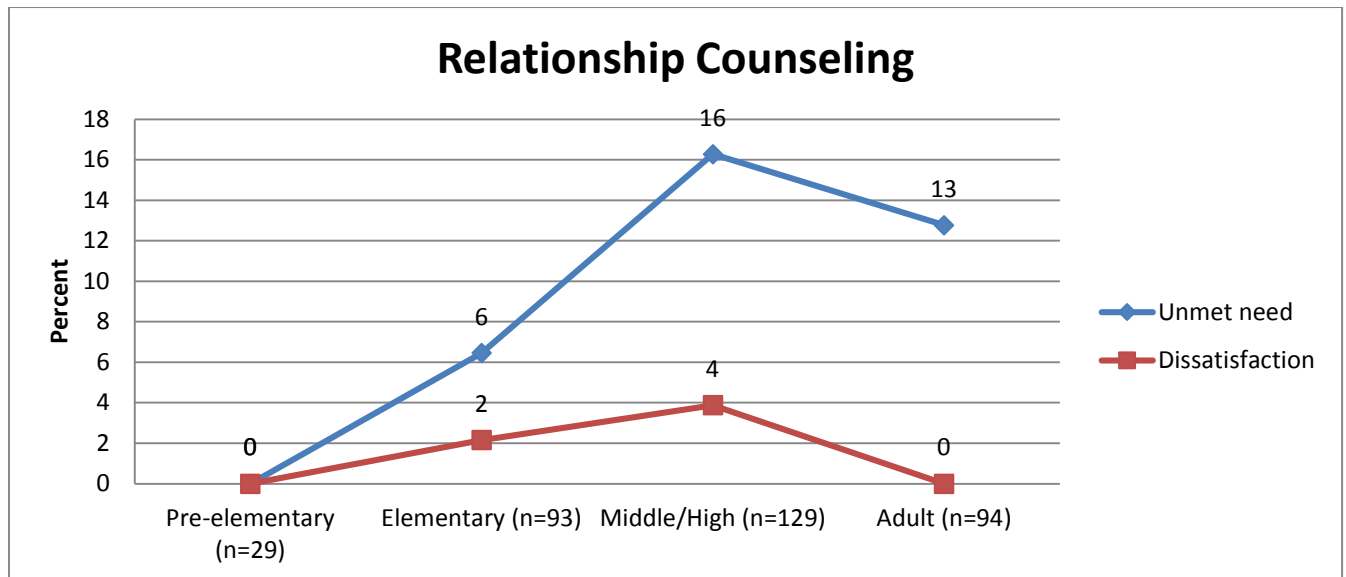
**“Of those reporting a co-occurring disorder, 43% report developmental delays as the co-occurring disorder...”**

Co-occurring disorders statistics were calculated using Question #15 from the school age survey, #15 from the adult survey and #9 from the adult individual. Disorders put in descending order by %. N=383

Data sources: school age, adult, adult individual.



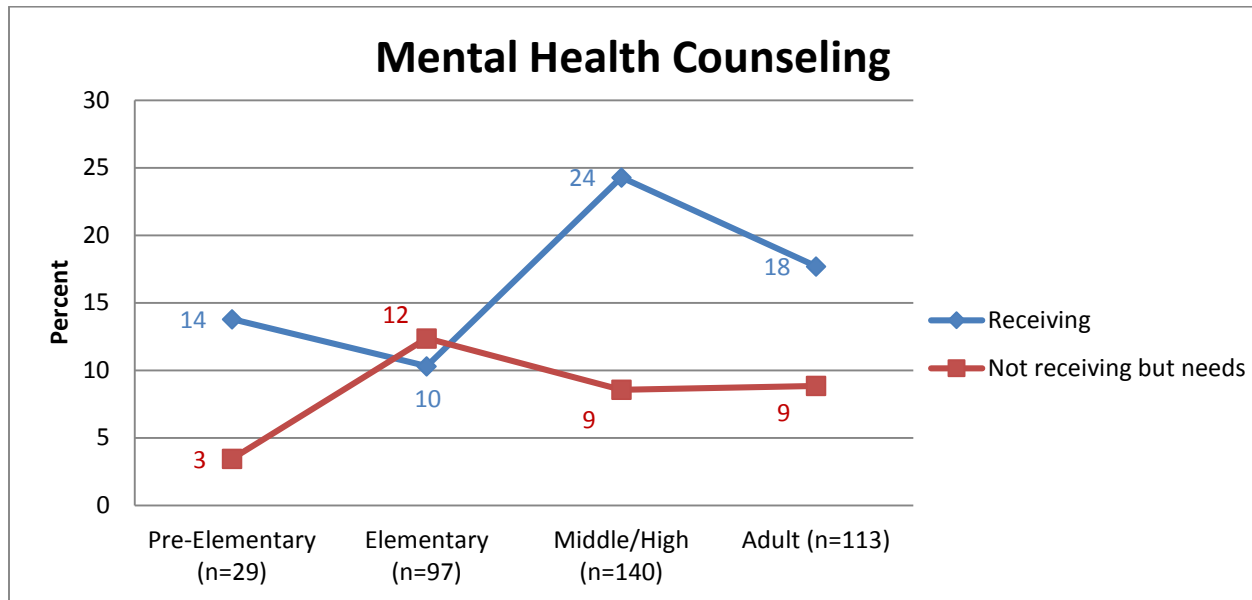
**“16% of parents/guardians report an unmet need for relationship counseling for their middle/high school age children ...”**



**“6% of parents/guardians report dissatisfaction with relationship counseling for their elementary age children ...”**

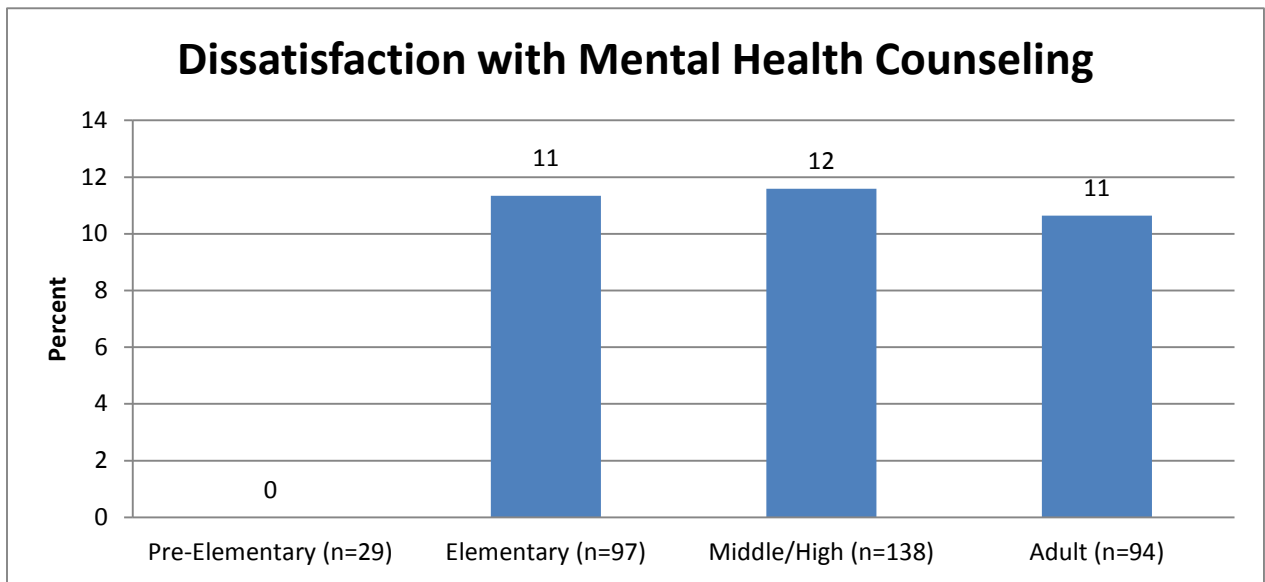
“Mental health counseling” and “Relationship counseling” (questions 44 and 46, school age and adult-satisfaction not assessed in adult individual). Previously reported in one chart entitled “mental &

emotional health services”- statistical problems led to separating the two items out. ‘Unmet need’ is calculated by combining items: “my child is receiving but needs more” and “my child is not receiving, but needs” (Question 44 school age). ‘Dissatisfaction’ is calculated by combining items: “disagree” and “strongly disagree” (Question 45 and 46 school age and adult). Crosstabs were calculated by age category for both ‘Unmet need’ and ‘dissatisfaction.’ Data sources: school age, adult (individual does not assess satisfaction so I left out).



**“12% of parents/guardians report that their elementary age children are not receiving but need mental health counseling....”**

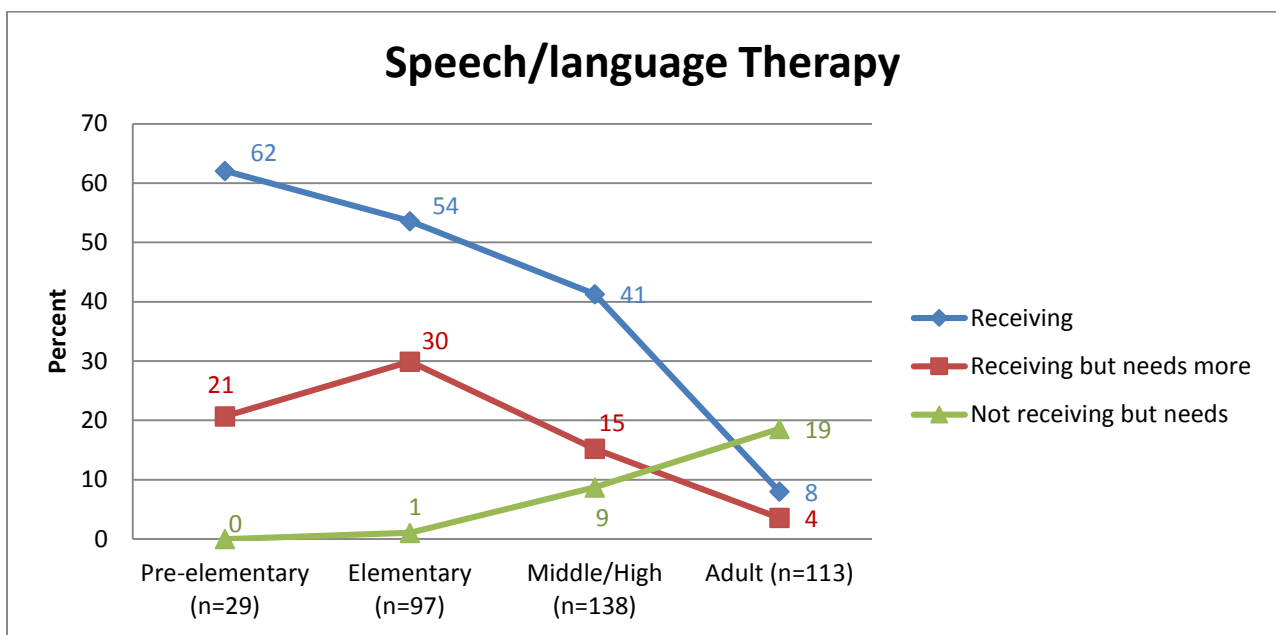
Mental Health Counseling graph was calculated using Question #44a (crosstab)- categories: “My child is receiving” and “My child is not receiving, but needs.” Age groups: Pre-elementary, ages 0-4; Elementary, ages 5-10; Middle/High, ages 11-21; and Adult, ages 22+. (Data sources: school age, adult and adult individual)



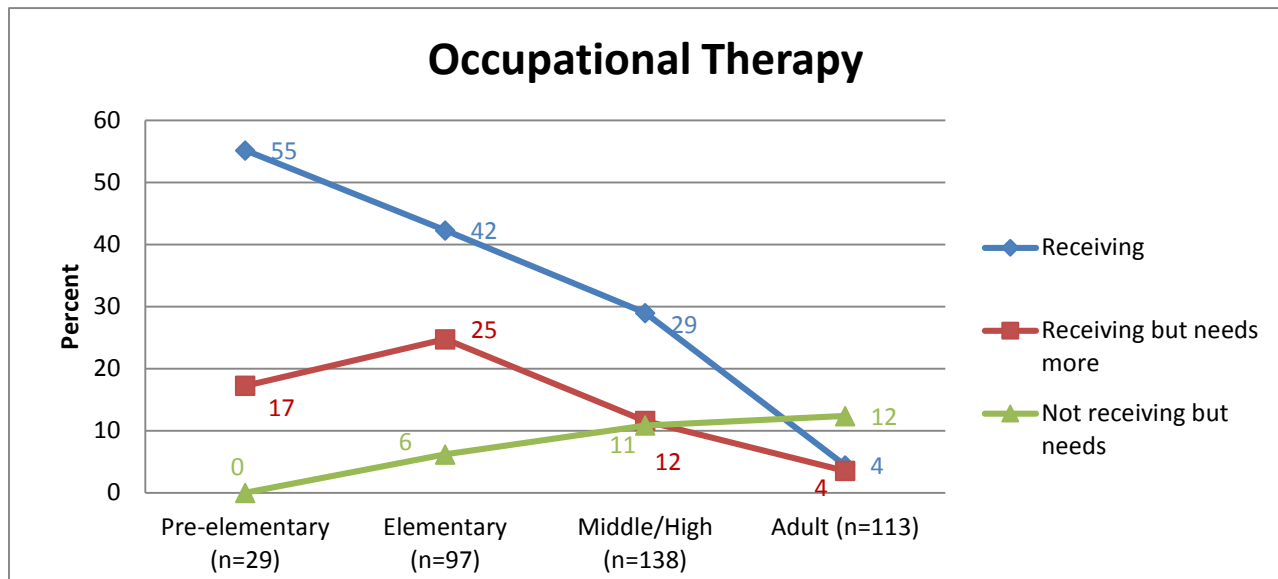
**“11.3% of parents/guardians report dissatisfaction with mental health counseling for their elementary age ...”**

Dissatisfaction with mental health counseling calculated using Question#46a (This service is effective in meeting my child’s needs) in school age and adult survey. Crosstabs were used to divide dissatisfaction by age (in school age). Disagree and Strongly disagree categories were combined, results represented in percentages.

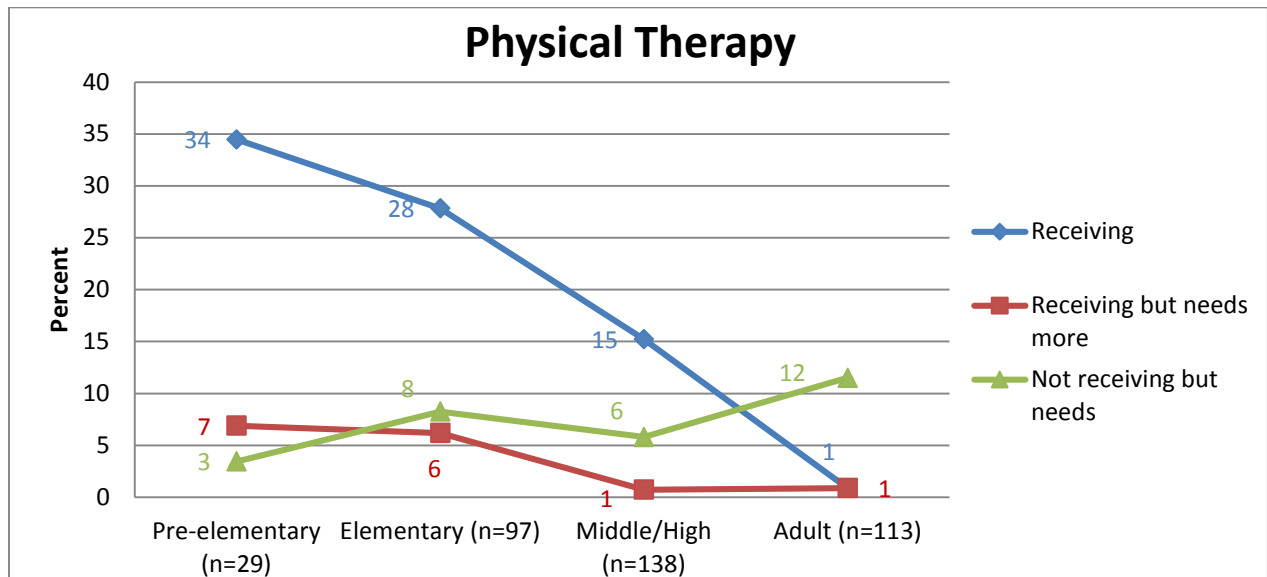
### Functional Therapy Services



**“41% of parents/guardians report that their middle/high school age children are receiving speech/language therapy...”**



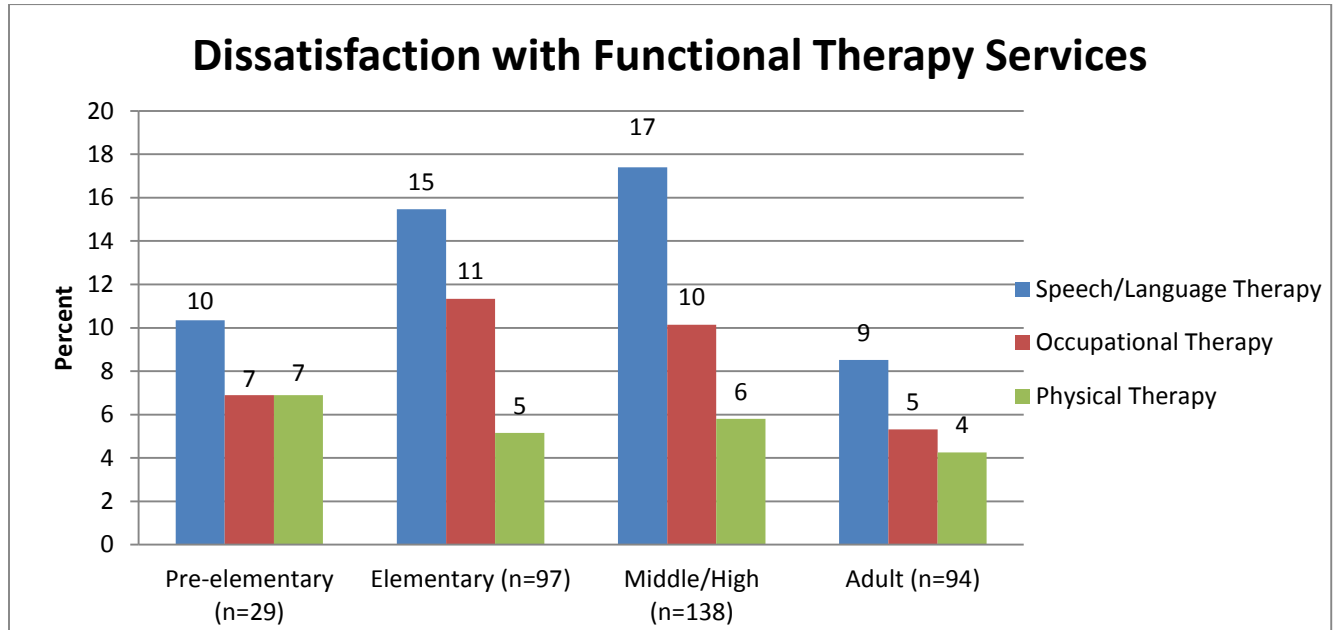
**“25% of parents/guardians report that their elementary age children are receiving, but need more occupational therapy...”**



**“34% of parents/guardians report that their pre-elementary children are receiving physical therapy services...”**

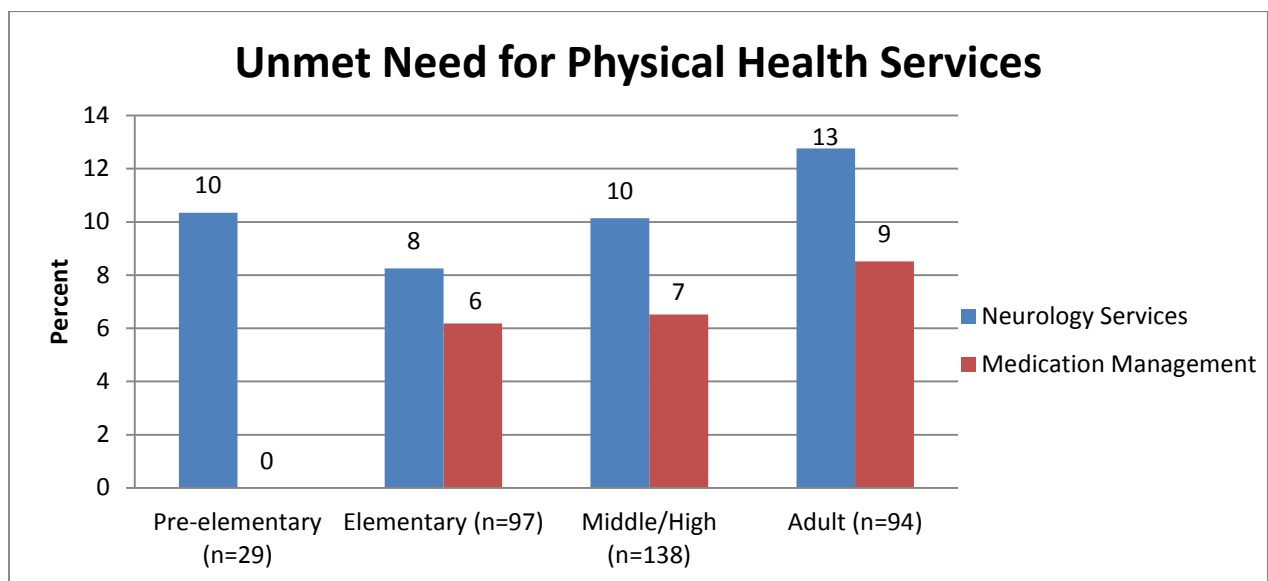
Functional therapy (speech/language, occupational and physical therapy) tables calculated using #44b,c and d (school age and adult), #35b, c, and d (adult individual)- items ('speech/language therapy,'

‘occupational therapy,’ and ‘physical therapy’). Crosstabs were calculated using age group and need items (listed in chart).



**“17% of parents/guardians report dissatisfaction with speech/language therapy that their middle/high school age students receive...”**

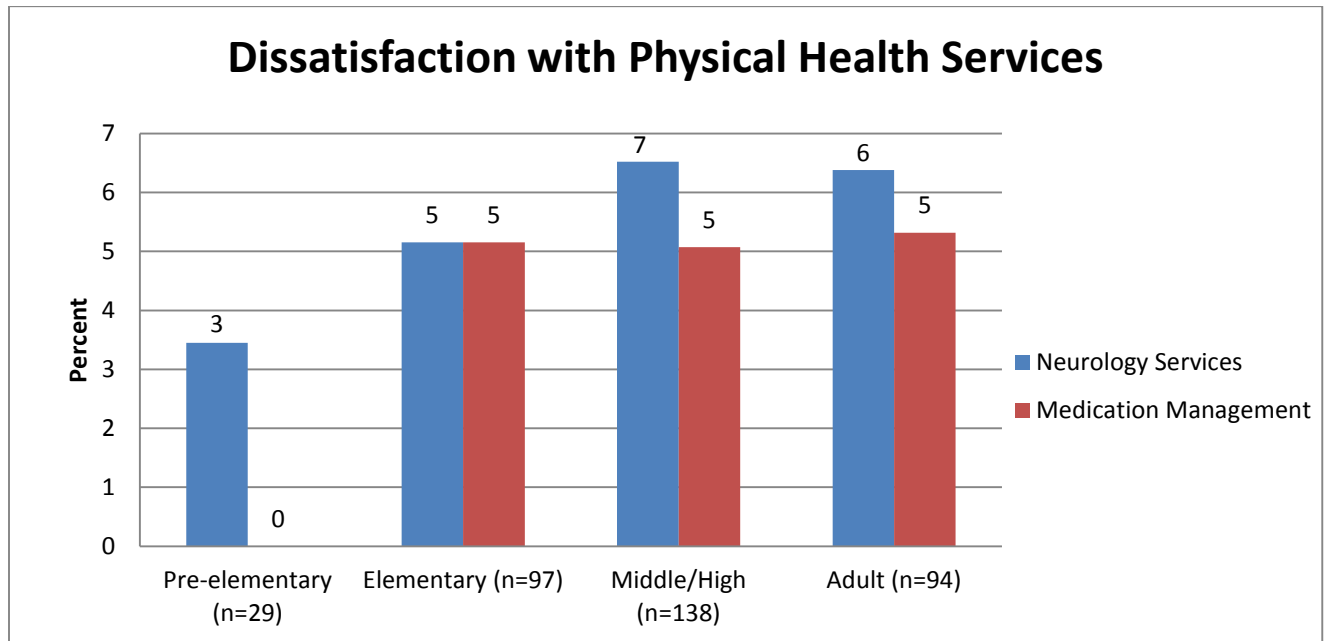
Calculated using question 46 from school age and adult surveys. Dissatisfaction calculated by combining “disagree” and “strongly disagree” responses.



**“13% of adult individuals with autism report an unmet need for neurology services...”**

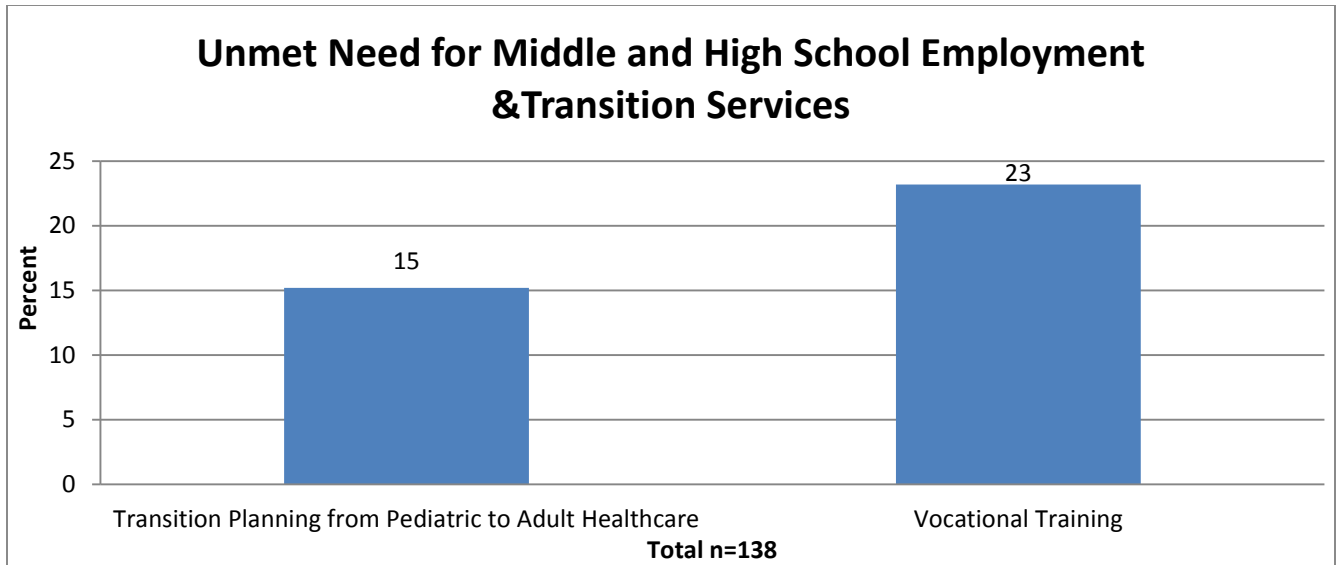
## Service Needs

Physical Health Services include items: “neurology services” and “medication management.” Unmet need includes items “my child is receiving but needs more” and “my child is not receiving but needs”- combined together (Question 44j and k, school age; Question 44 j and k adult- items not included in adult individual).



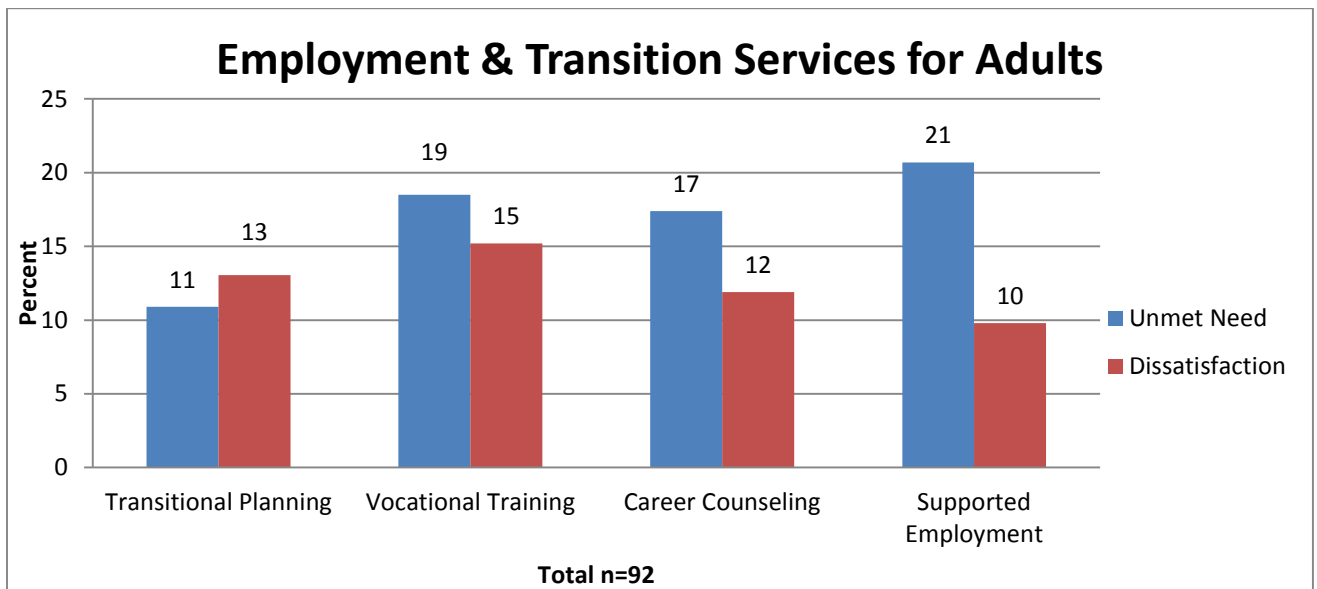
**“7% of parents/guardians report dissatisfaction with neurology services their middle/high school age children receive...”**

Data derived from question 46 school age and adult. Dissatisfaction calculated by combining “disagree” and “strongly disagree” for neurology services and medication management.



**“23% of parents of Middle/High school age children report an unmet need for Vocational Training...”**

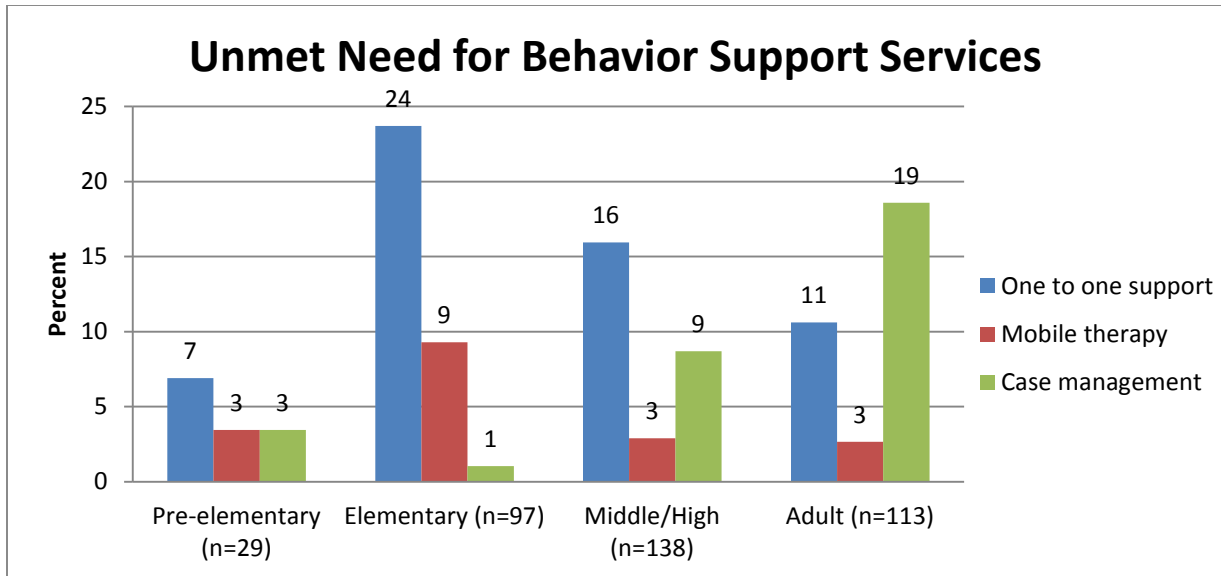
Employment & Transition Services derived from question 44, school age. Unmet (question 44) need calculated by combining “my child is receiving, but needs more” and “my child is not receiving but needs.” Results depicted in percentages for middle/high school students only.



**“Thirteen percent of individuals caring for adults with autism report dissatisfaction with transitional planning...”**

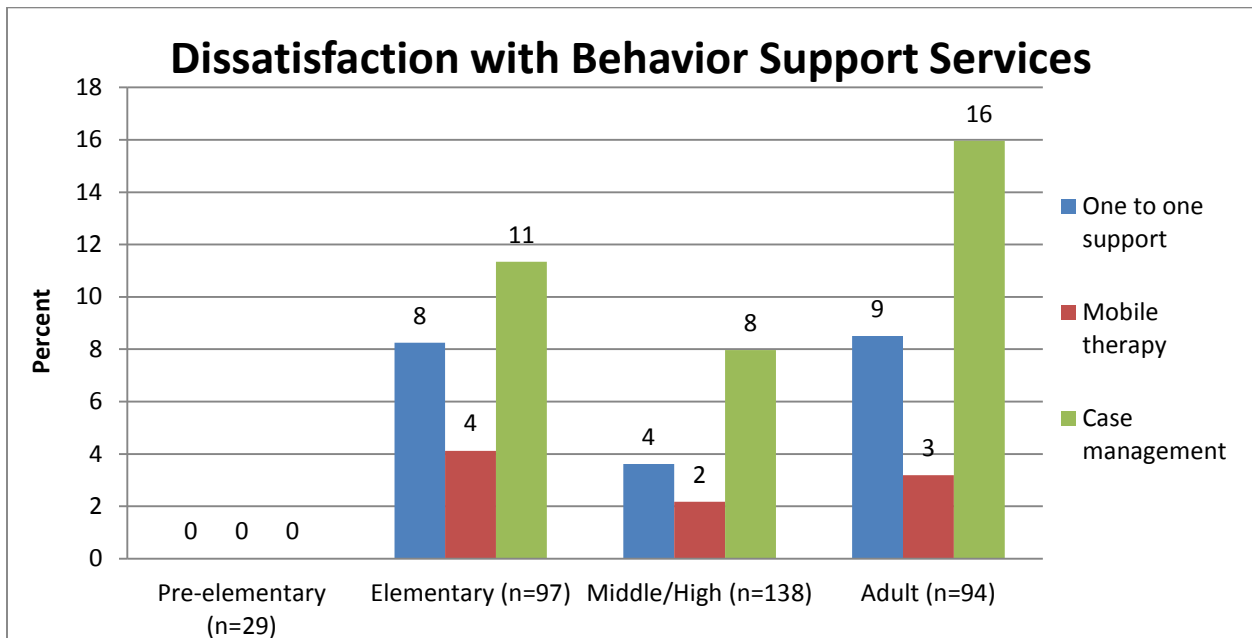
Unmet need calculated by combining “my child is receiving, but needs more” and “my child is not receiving but needs.” Dissatisfaction was calculated by adding “disagree” and “strongly disagree” question 46. These services only included in adult, not adult individual.





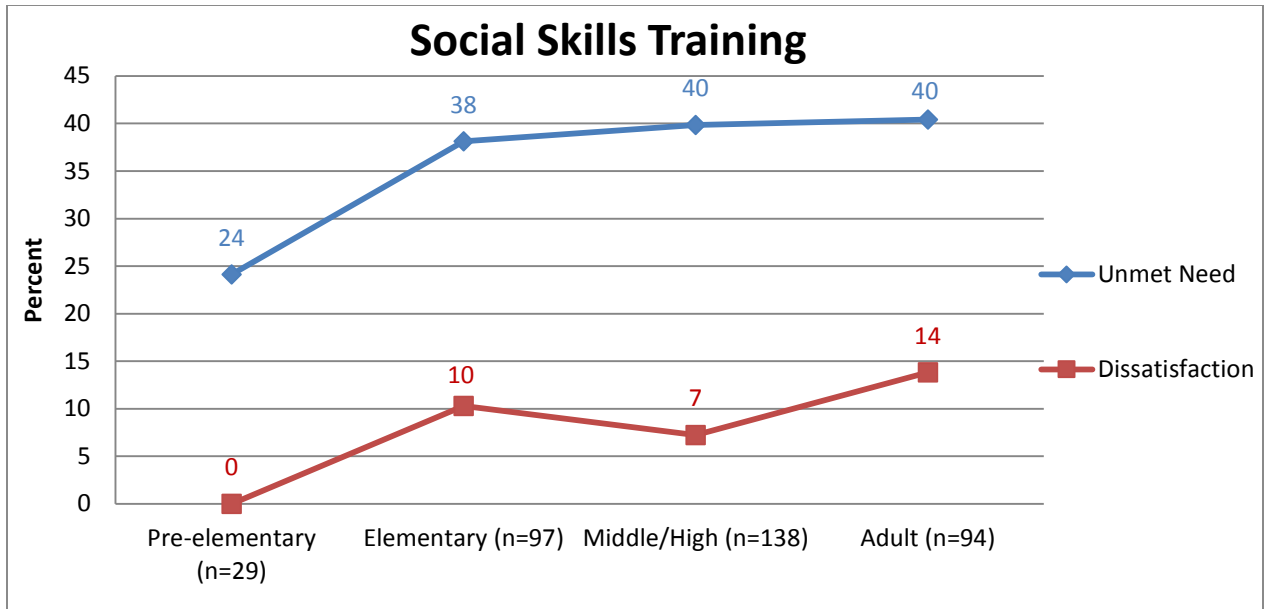
**“24% of parents/guardians report an unmet need for one to one support for their elementary age child with autism ...”**

Behavior support services derived from school age, adult and adult individual. Unmet need calculated by combining “my child is receiving, but needs more” and “my child is not receiving, but needs.” Question 44 school age and adult; question 35 adult individual.



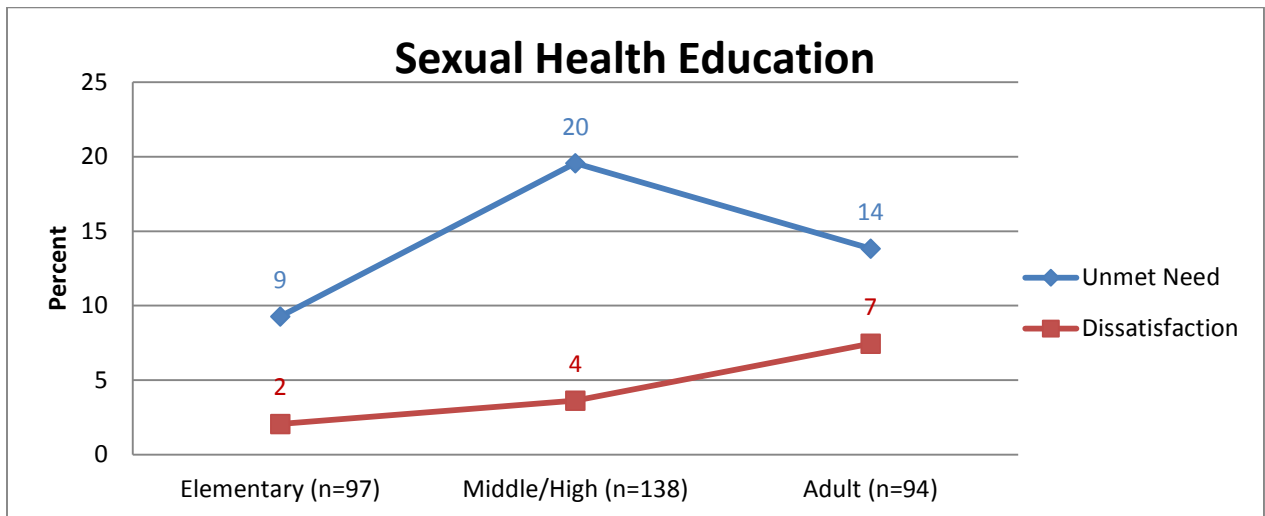
**“16% of adults report dissatisfaction with case management....”**

Behavior support services derived from question 46, school age and adult (satisfaction was not assessed for adult individual). Dissatisfaction calculated by combining “disagree” and “strongly disagree.”



**“24% of parents/guardians report an unmet need for social skills training for their pre-elementary age ...”**

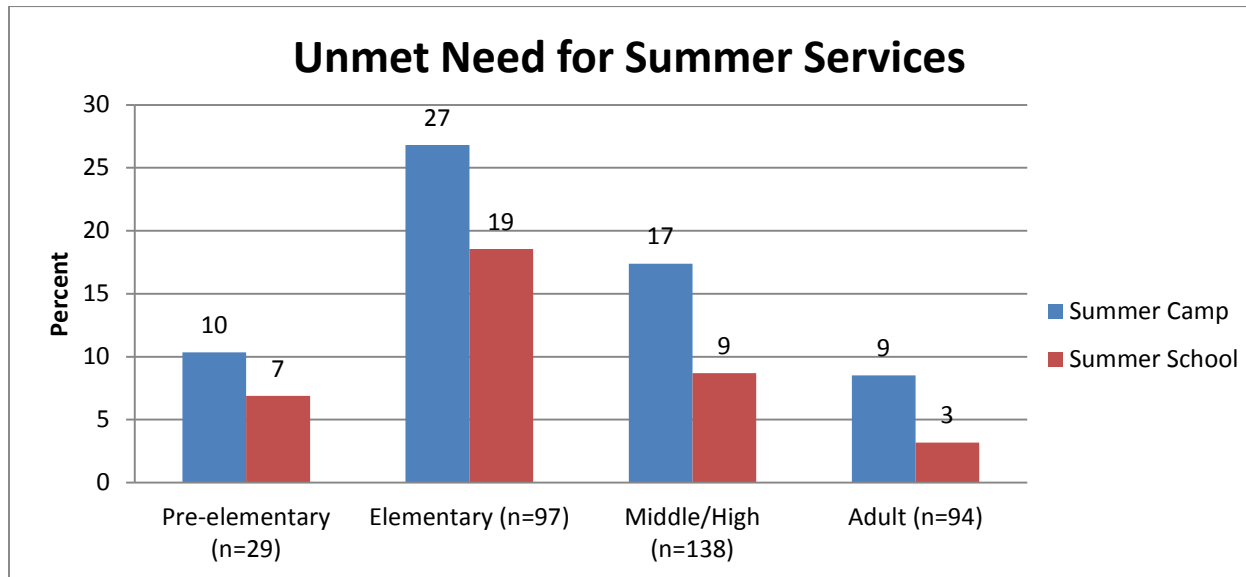
Social skills training derived from question 44 and 46, school age and adult. Dissatisfaction calculated by combining “disagree” and “strongly disagree.” Unmet need calculated by combining “my child is receiving, but needs more” and “my child is not receiving, but needs.” Data sources: school age and adult (dissatisfaction not assessed in adult individual, so not using any of that data here).



**“20% of parents/guardians report an unmet need for sexual health education for their middle/high age child with autism ...”**

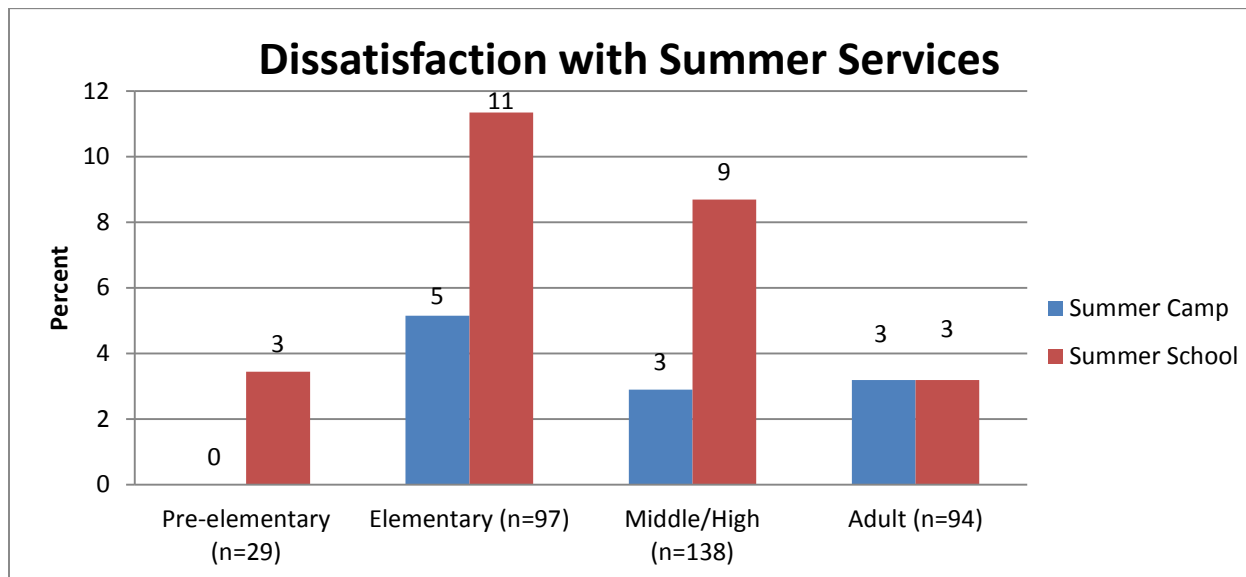
Sexual health education derived from question 44 and 46, school age and adult. Unmet need calculated by combining “my child is receiving, but needs more” and “my child is not receiving but needs.”

Dissatisfaction calculated by combining “disagree” and “strongly disagree” - question 46. Adult individual not included in analysis because it does not assess satisfaction levels.



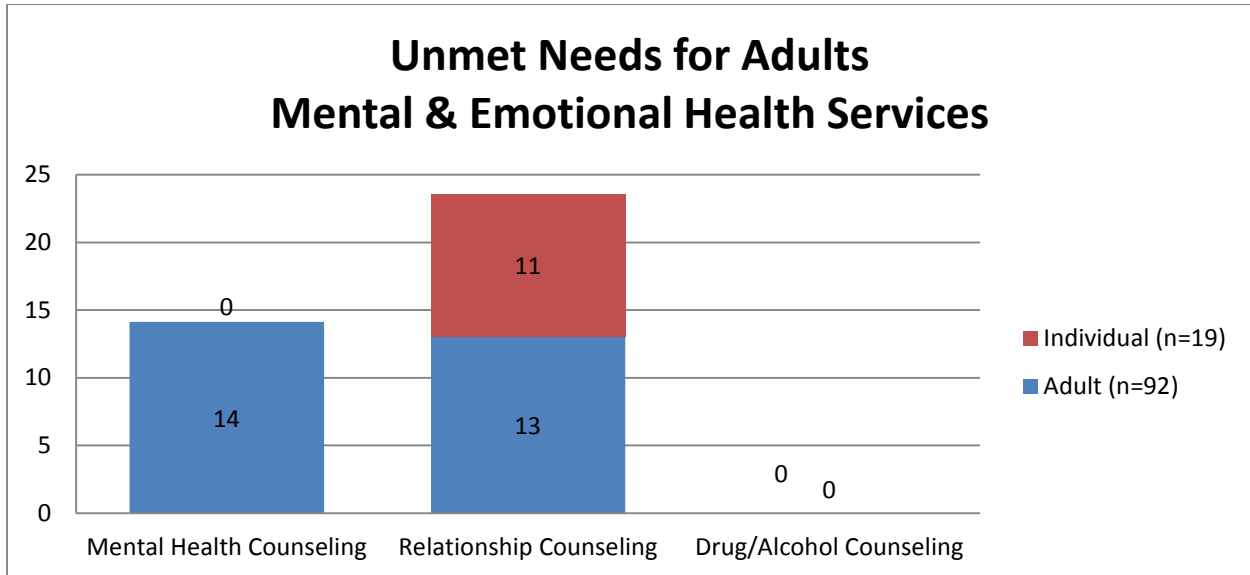
**“27% of parents/guardians report an unmet need for summer camp for their elementary students ...”**

Summer services data derived from “summer camp” and “summer school/ESY” items, from questions 44 and 46, school age and adult. Unmet need calculated by combining “my child is receiving, but needs more” and “my child is not receiving but needs.”



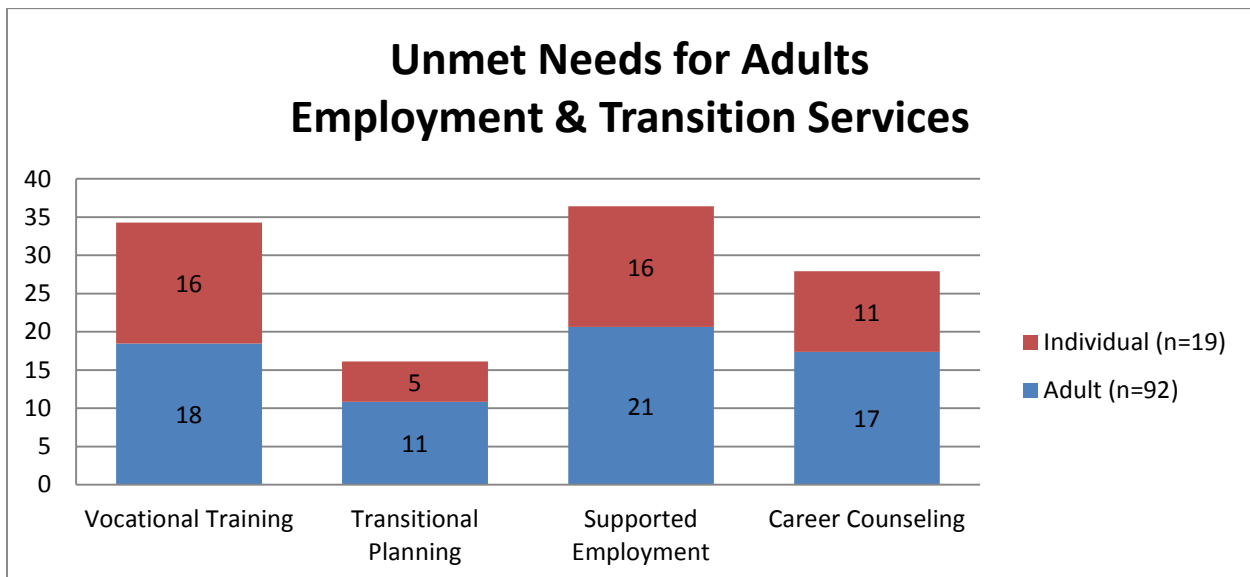
**“11% of parents/guardians report dissatisfaction with summer school for their elementary students ...”**

Dissatisfaction by combining “disagree” and “strongly disagree” - question 46. Adult individual not represented because dissatisfaction was not assessed.



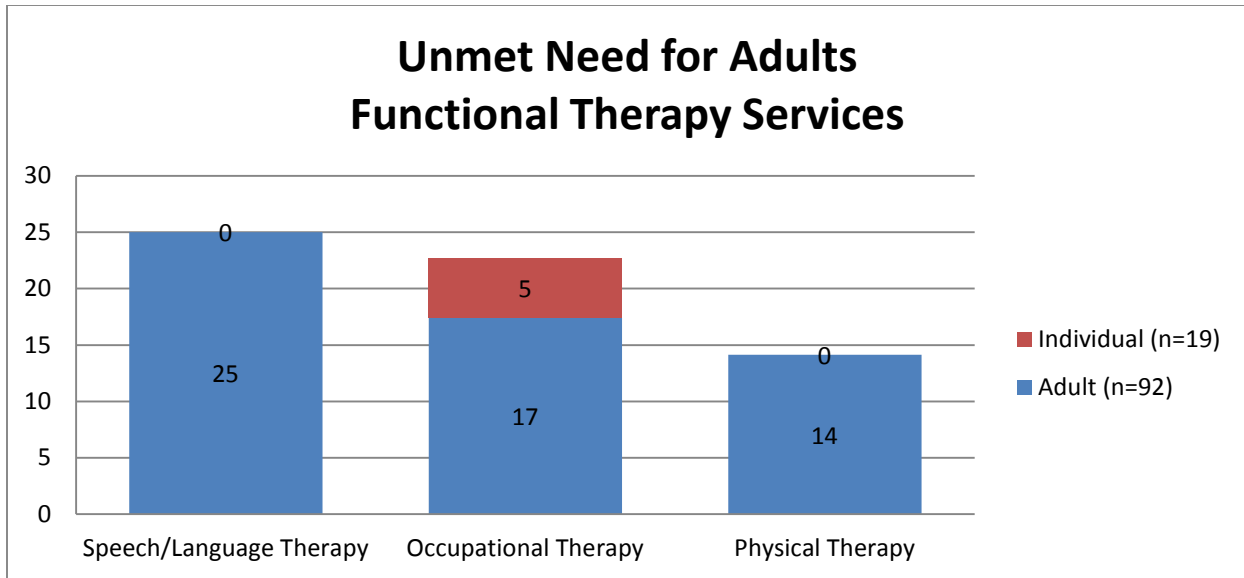
**“11% of adults who answered for themselves report an unmet need for relationship counseling...”**

Unmet need calculated by combining ‘my child is receiving but needs more/I am receiving but need more’ and ‘my child is not receiving but needs/I am not receiving but need.’ Question 44 adult, question 35 adult individual.



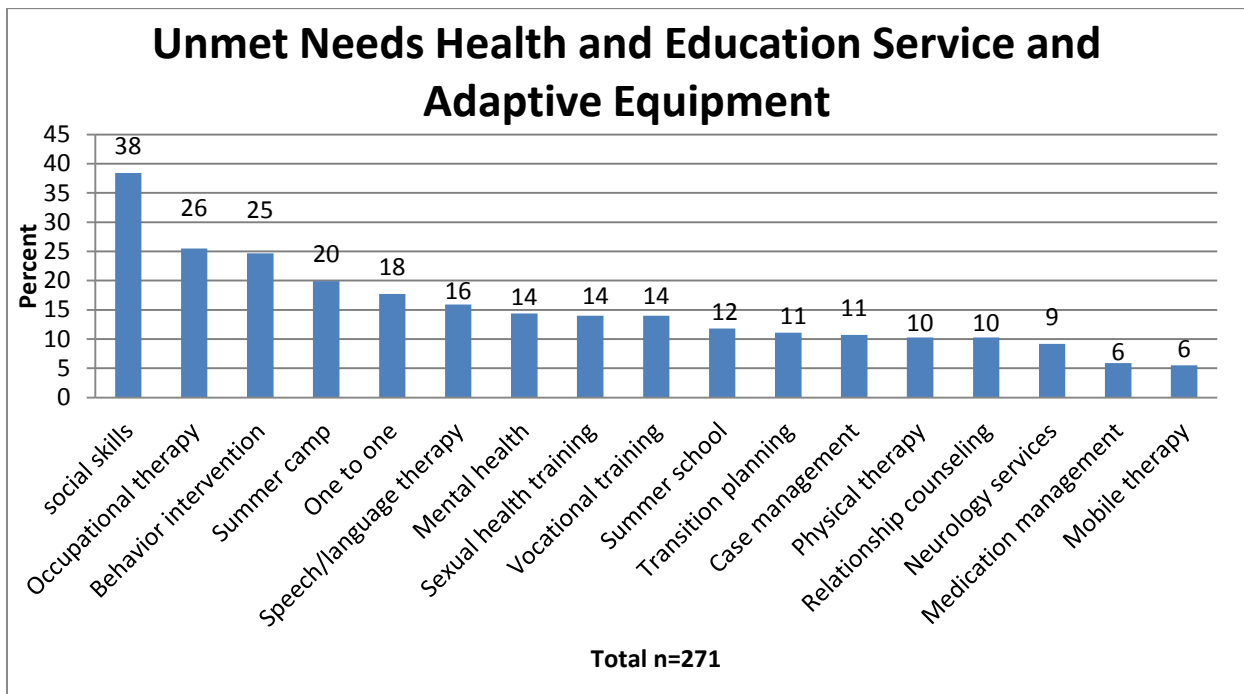
**“34% of all respondents to adult surveys report an unmet need for vocational training...”**

Employment & transition services items derived from Question 44 adult, question 35 adult individual. Unmet need calculated by combining “receiving, but need more” and “not receiving, but need.”



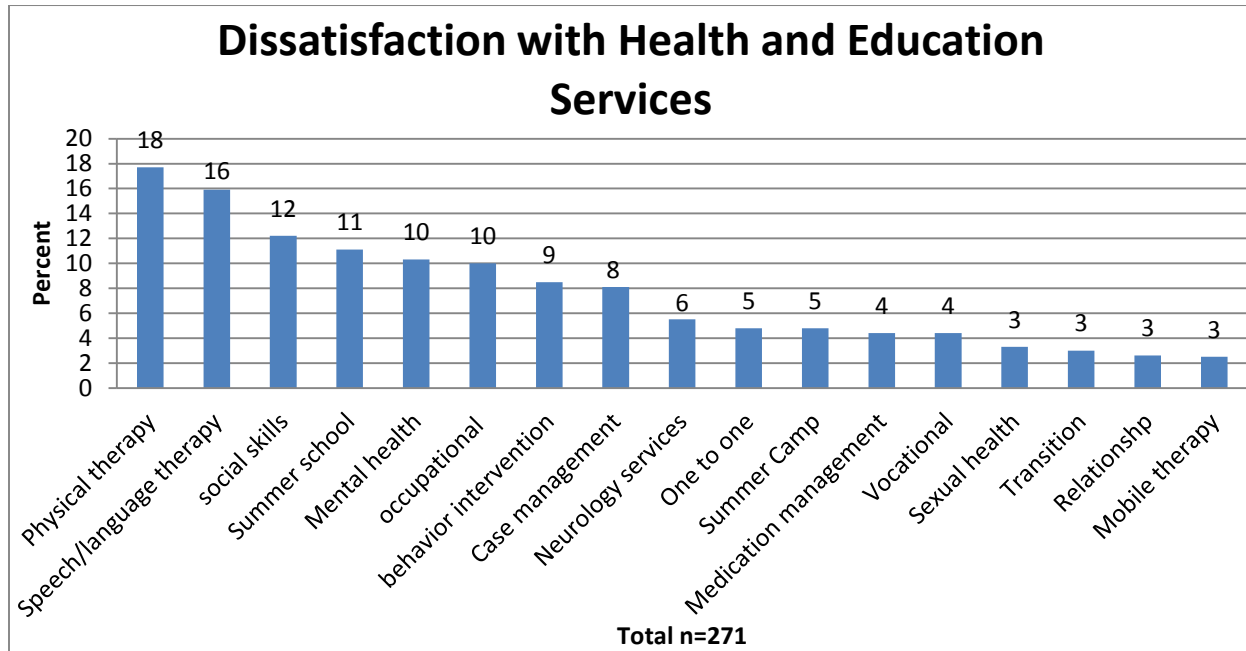
Functional therapy items include ‘speech/language therapy,’ ‘occupational therapy’ and ‘physical therapy.’ Question 44 adult, question 35 adult individual. Unmet need calculated by combining “receiving, but need more” and “not receiving, but need.”

Educational services, which was depicted in the PA report was not calculated because the items were not present across both the adult and adult individual.

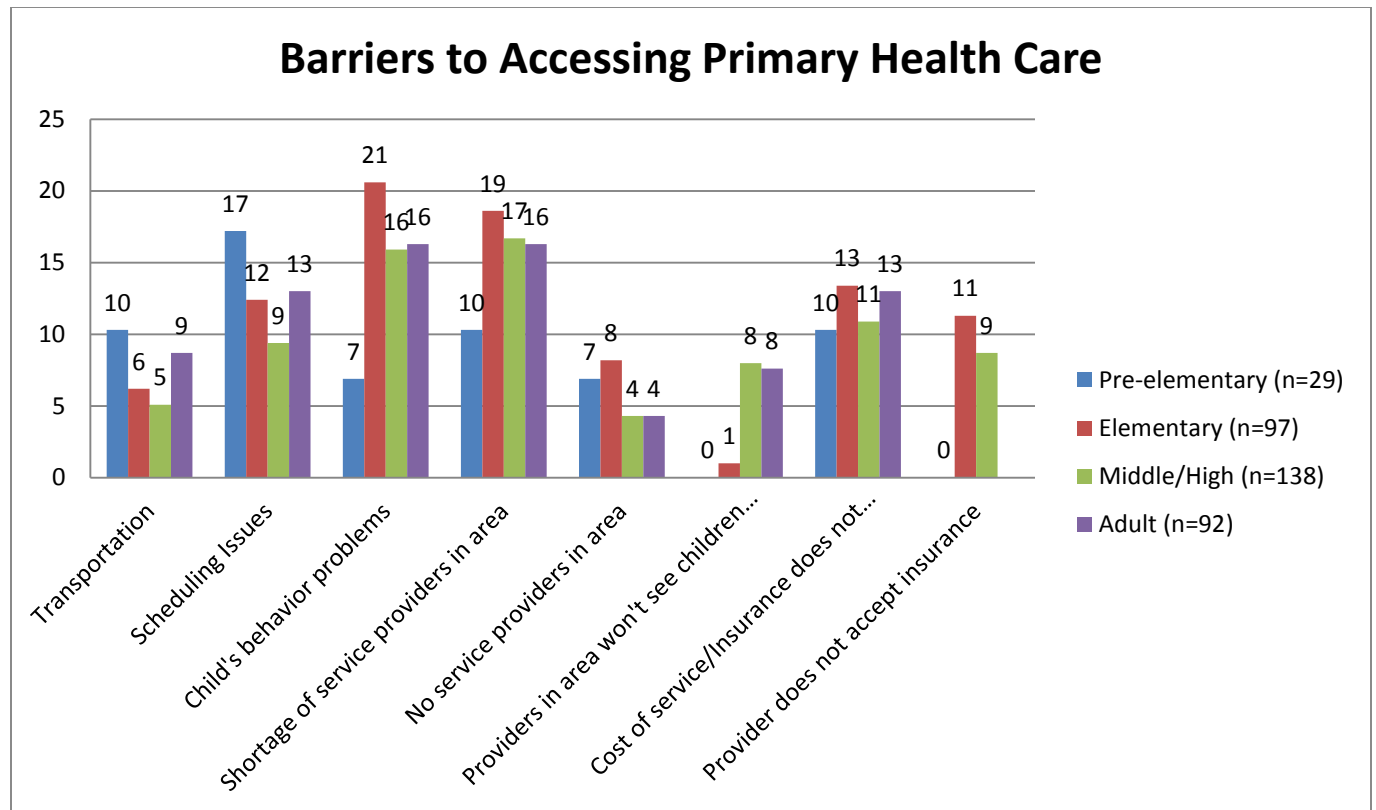


## Service Needs

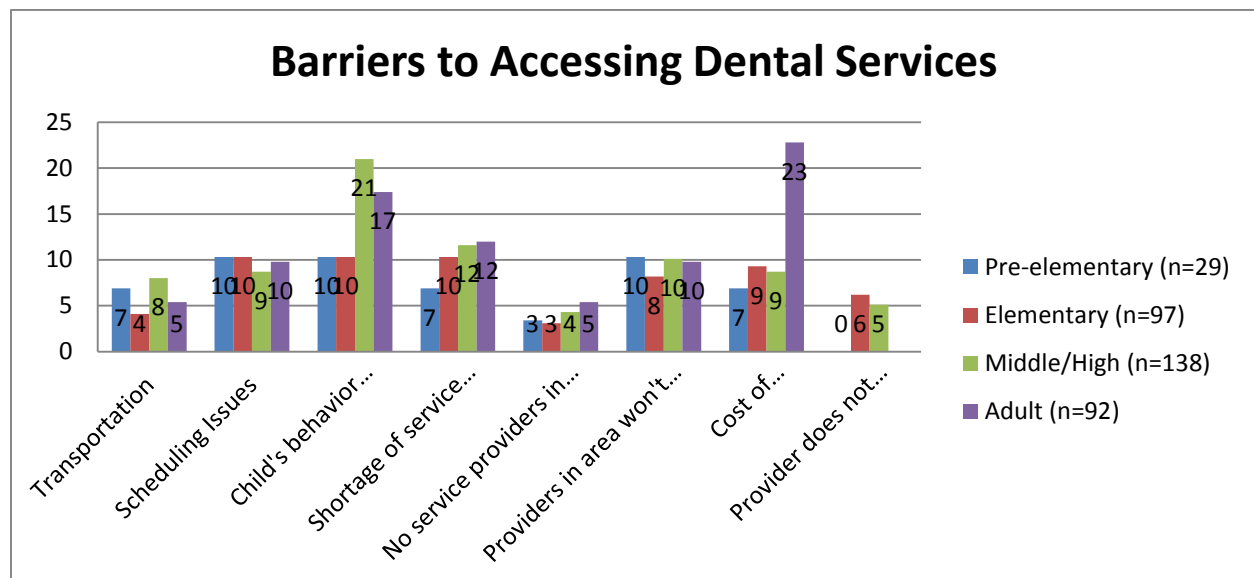
Overview of percentage reporting unmet needs by health and education service and adaptive equipment. Unmet need calculated by combining “my child receives, but needs more” and “my child does not receive, but needs.” Sorted in ascending order, reported as percent. School age survey only.



Overview of percentage of people reporting dissatisfaction with health and education services. Dissatisfaction calculated by combining “disagree” and “strongly disagree” for question 46, school age. Sorted ascending order, reported as percent. School age survey only.

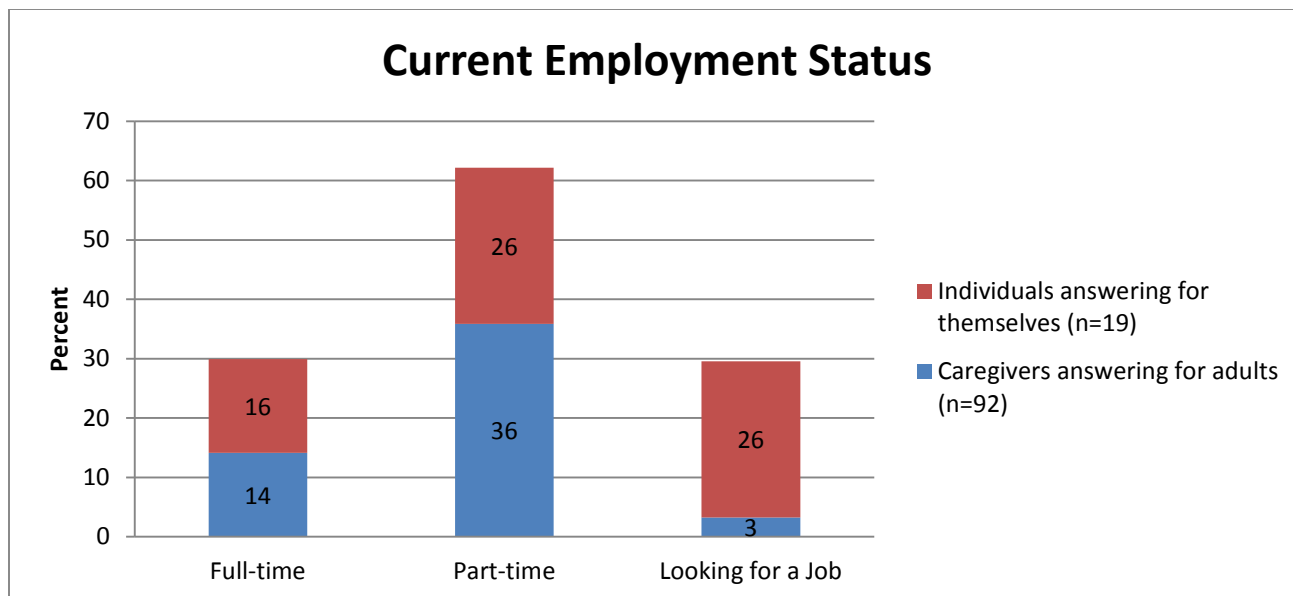


“10% of caregivers of pre-elementary children cite transportation as a barrier to accessing primary health care...” Data derived from question #43 (school age and adult).



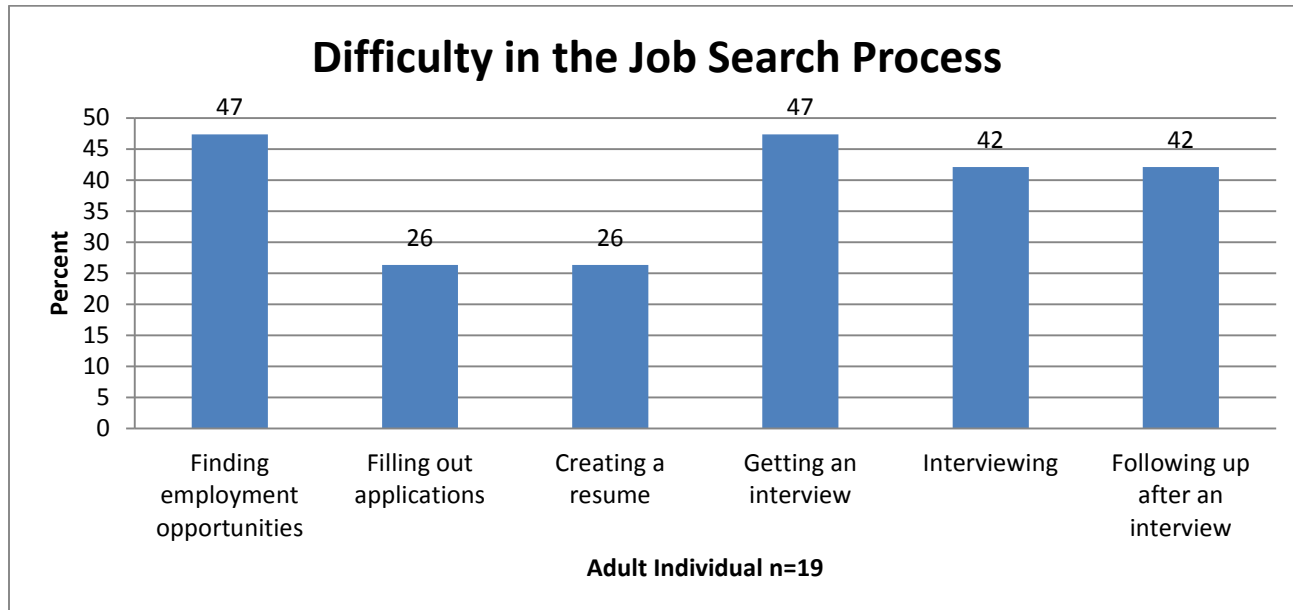
“7% of caregivers of pre-elementary children cite transportation as a barrier to accessing dental services...”

Data derived from question #43 (school age and adult).



**“Of those individuals answering the survey for themselves, 26% are employed part-time...”**

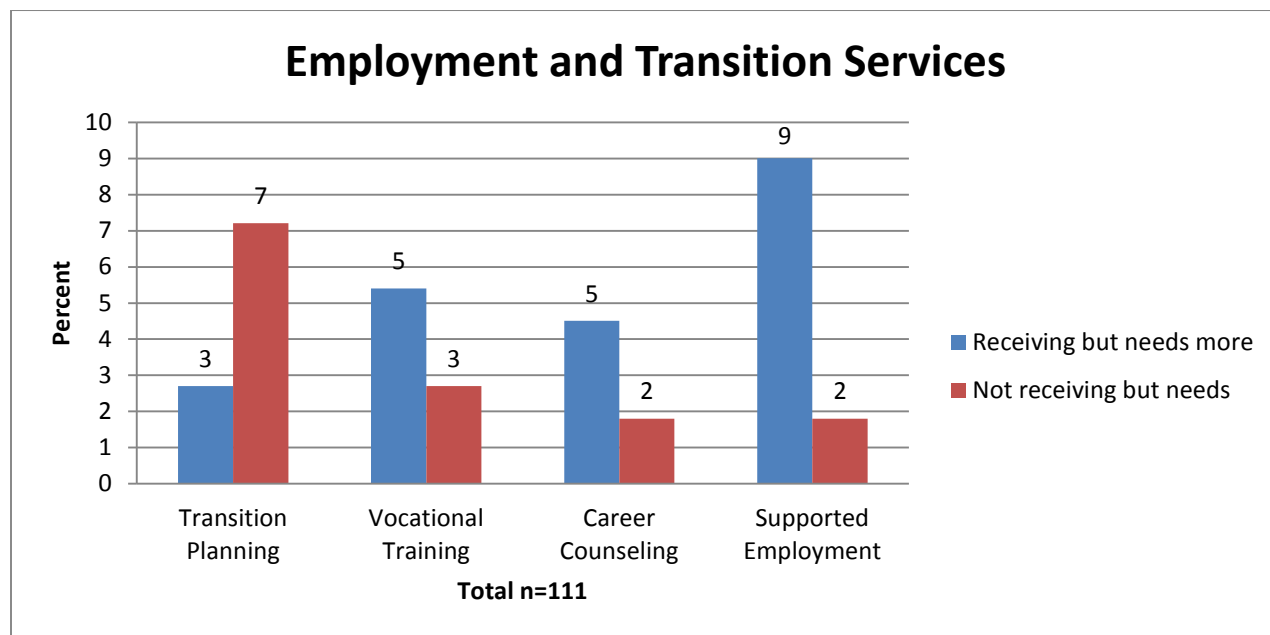
Data derived from adult and adult individual. Adult included response categories: part-time with support, part-time without support, full-time with support, full-time without support. The part-time categories were combined and the full-time categories were combined. Vertical axis altered to represent 70 point scale.



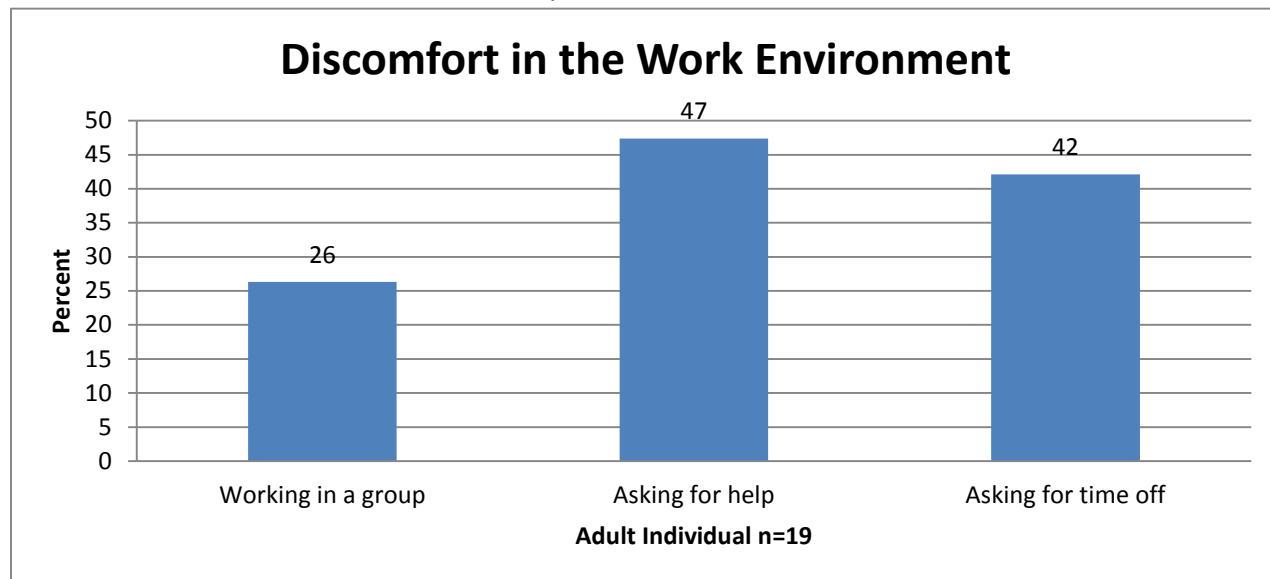
**“47% of adults (answering the survey for themselves) report difficulty in finding employment opportunities...”**



Data derived from adult individual, not assessed in adult. Response categories for each category included “very difficult” and “difficult”- these two were combined. Vertical axis altered to represent 50 point scale.

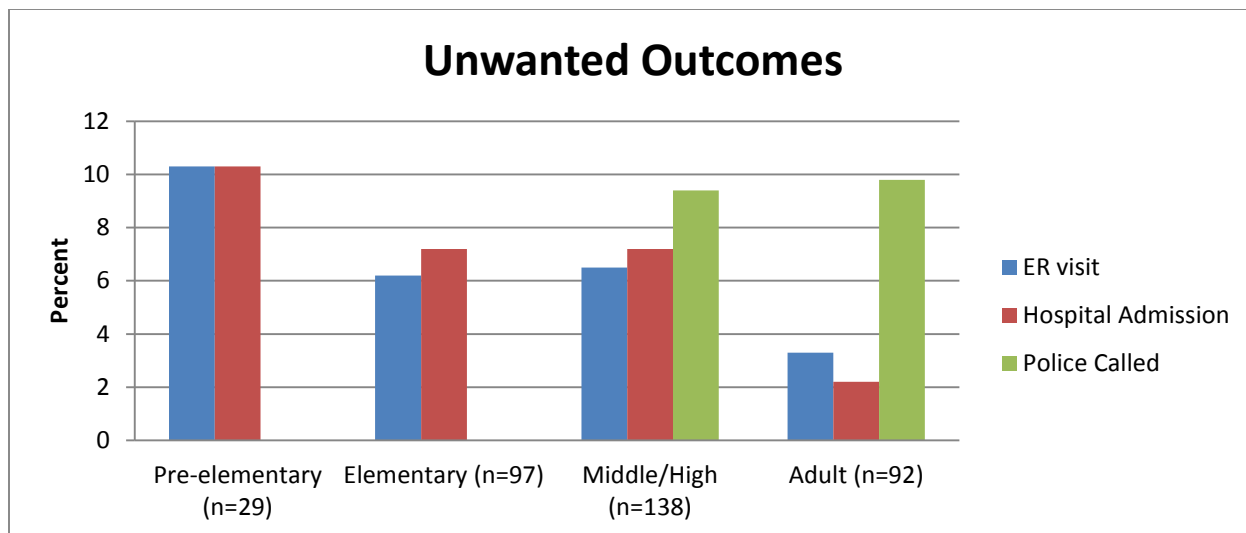


**“7% of adults report that the person in question is not receiving but needs transition planning...”**Data derived from adult and adult individual surveys.



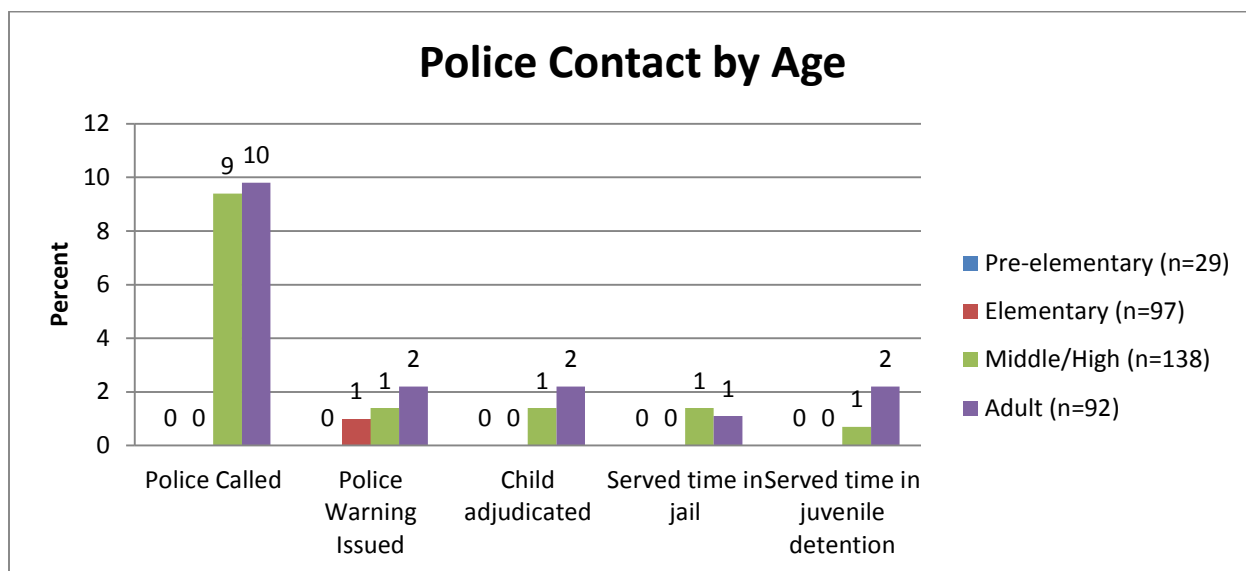
Vertical axis altered to represent 50 point scale. **“26% of adults answering the survey for themselves report difficulty working in a group...”**Data derived from adult individual, not assessed in adult.

Discomfort in work environment calculated by combining “disagree” and “strongly disagree” categories for each statement on question 23. Asking for help calculated by combining “I feel comfortable asking my peers for information or help” and “I feel comfortable asking an authority figure for information or help.”



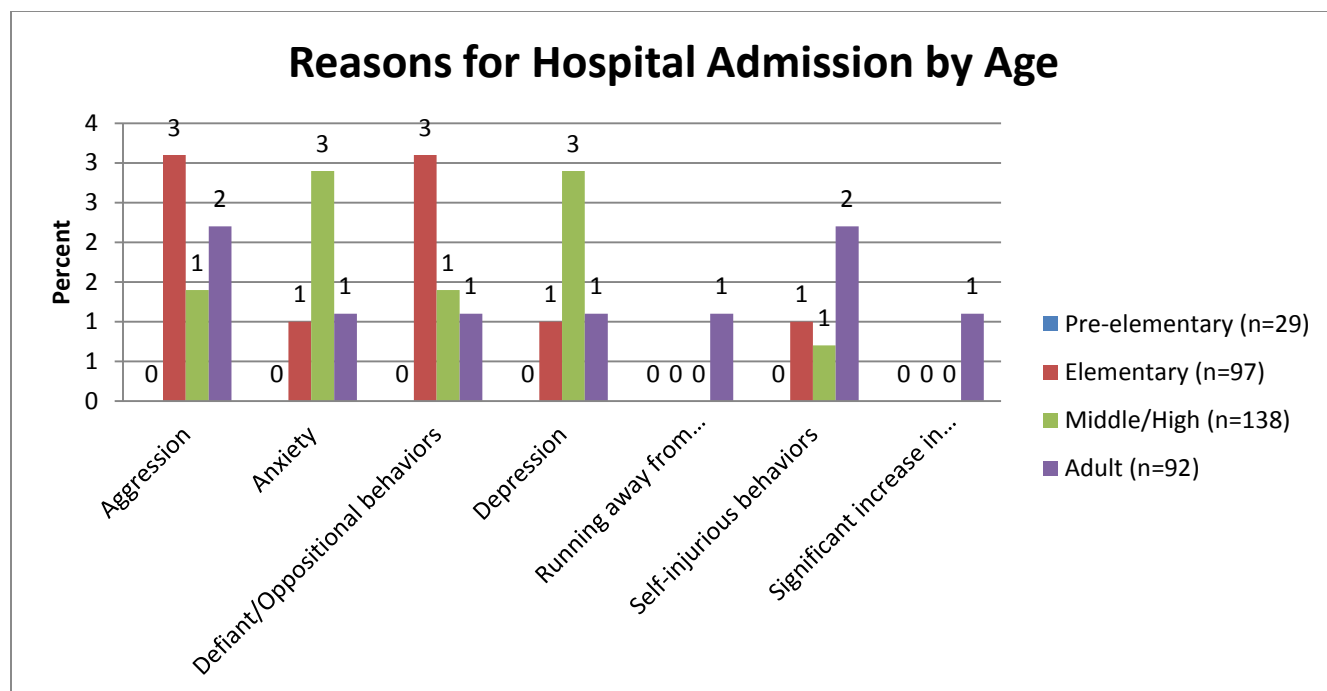
“9% of caregivers of adults report calling the police...”

Data derived from question #27, 28 and 34 (school age and adult).



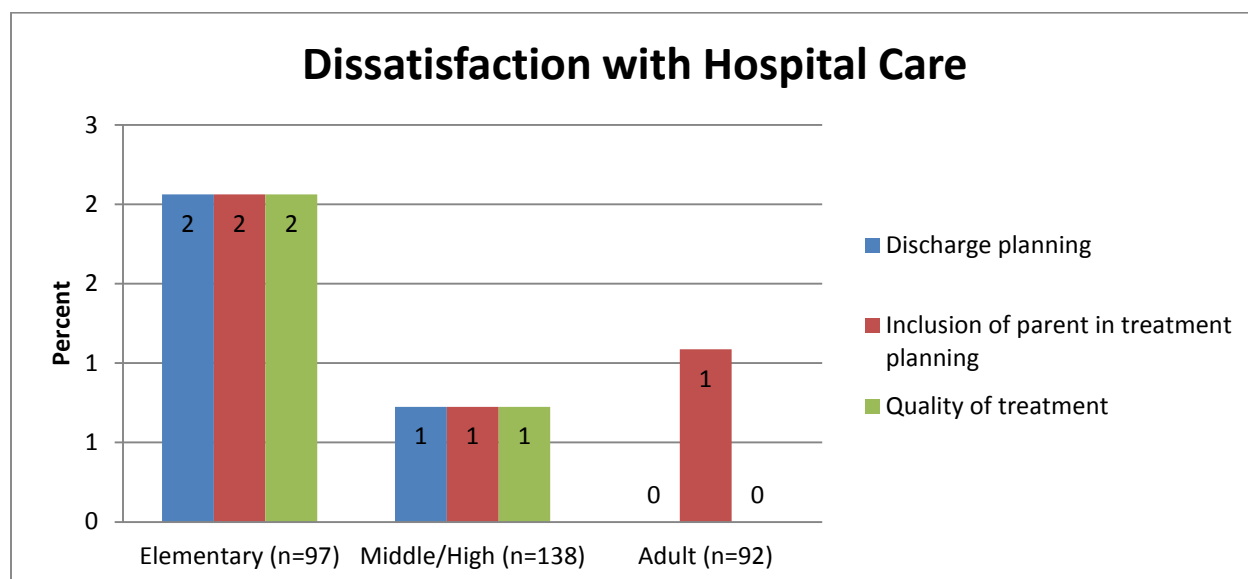
“9% of caregivers of adults report calling the police...”

Data derived from question #34 (school age and adult).



“3% of caregivers of elementary children report aggression as the reason for their child’s hospital admission...”

Data derived from question #28a (school age and adult).



“1% of caregivers of adults with autism report dissatisfaction with the inclusion of parent in treatment planning...”

Data derived from question #28b-d (school age and adult). Dissatisfaction calculated by adding 'dissatisfied' and 'very dissatisfied.'