

Initial Report

Transition/Legal Services –
Special Needs Planning
Families Know Best - October 2017

1 - What is your place of residence?

Answer	Count
New Castle County, DE	12
Kent County, DE	5
Sussex County, DE	2
Other - Pennsylvania Resident	1
Other- New Jersey Resident	0
Other- Maryland Resident	0
No Answer	1
Total	21

2 - What is your child's disability or health condition?

What is your child's disability or health condition?	Count
ASD	8
Mild intellectual disability	1
Genetic condition cdk13	1
Type 1 Diabetes	1
Down Syndrome	1
Rett Syndrome	1
Multiple:	8
Moderate Intellectual Disability and Down Syndrome	
High functioning Autism, ADHD, depression	
rare genetic diagnosis, CP	
PTSD, ADHD, depression	
autism, asthma	
autism, cognitive impairment, OCD	
Autism, spd, asthma	
Down Syndrome, Autism	

3 - What is the age of your child?

Answer	Count
0-4 years old	2
5-11 years old	7
12-21 years old	11
over 21 years old	1
Total	21

4 - Please identify yourself.

Please identify yourself.	Count
Mother	19
Father	1
Legal Guardian	1
Total	21

5 - What is your race/ethnicity? (Check all that apply)

Answer	Count
White	15
Black or African American	2
Hispanic, Latino, or Spanish Origin	0
Asian	3
American Indian or Alaska Native	0
Native Hawaiian or Pacific Islander	0
Other (please specify)	1
Total	21

Other (please specify)

multi-racial

6 - Do you consider your child's health insurance coverage to be adequate to meet your child's needs?

Answer	Count
Yes	13
No	8
Total	21

6 - Do you consider your child's health insurance coverage to be adequate to meet your child's needs?

No If response is No, please explain:

My son needed Residential Treatment facility placement for his severe rage and aggression, and neither of his insurance would cover it.

He's there now tho, because he started showing the same behaviors in his public school and they finally decided they would pay for it so he could still get educated without interfering with other students learning.

Unable to access ABA in the home through Medicaid provider Himark

Unable to access orthodontic care through Medicaid despite urgent medical needs

My son has severe feeding difficulties and speech difficulties but I am not getting feeding therapy and appropriate speech therapiesmy

No providers in area, no coverage for therapy or aides

usually for his medical needs, but not for assistive technology and sometimes the fight for adaptive equipment

Our primary alone would not be adequate. Having Medicaid as a secondary helps meet her needs.

Health insurance does not cover diapers or is limited on certain therapies

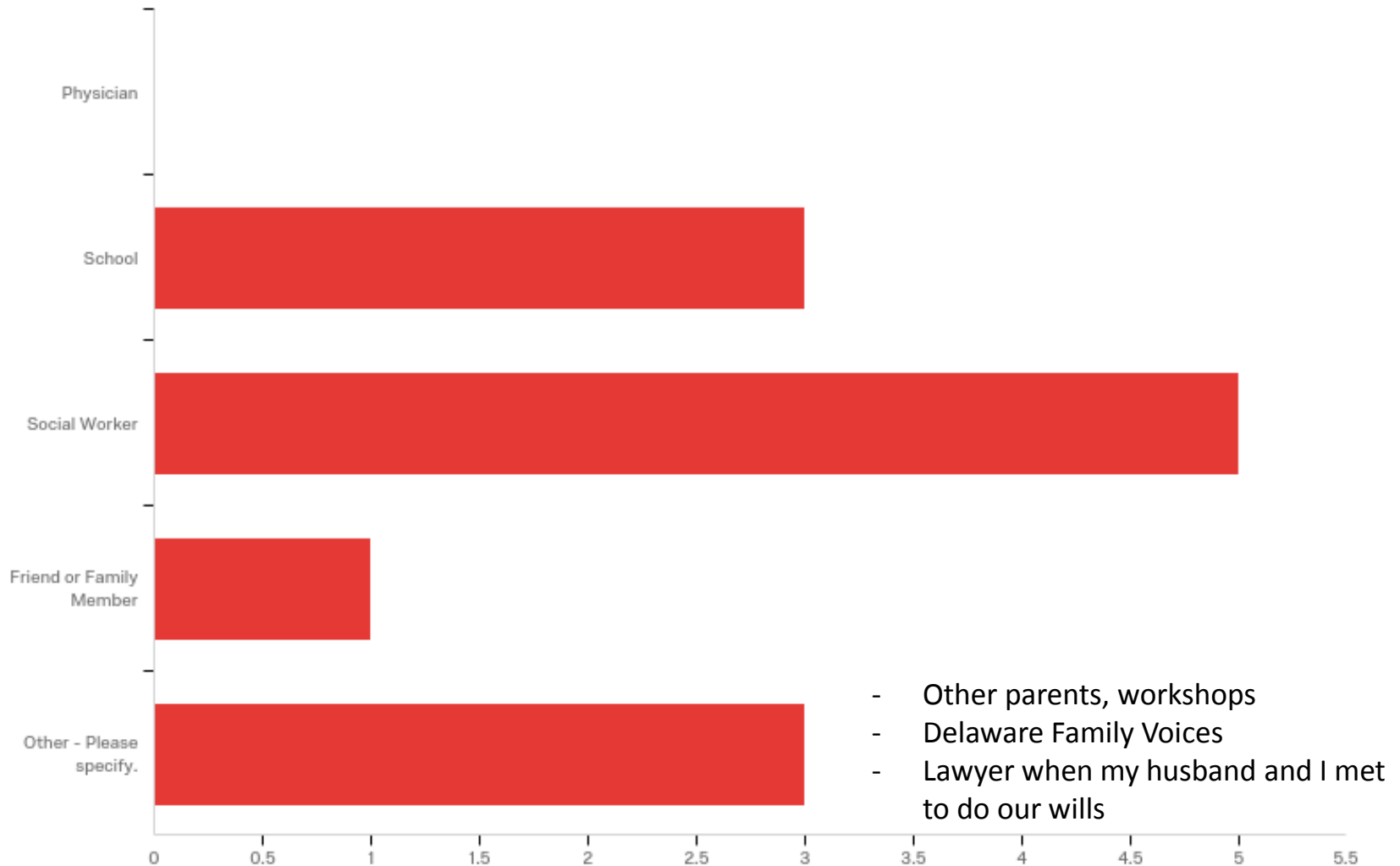
7 - Do you understand the difference between guardianship, medical power of attorney, financial power of attorney and supported decision making?

Answer	Count
Yes	13
No	8
Total	21

8 - Has anyone ever discussed guardianship with you?

Answer	Count
Yes	12
No	9
Total	21

9 - Who provided information to you about guardianship?



10 - Do you have guardianship in place for your child?

Answer	Count
Yes	3
No	9
Total	12

11 - What is your child's age and disability?

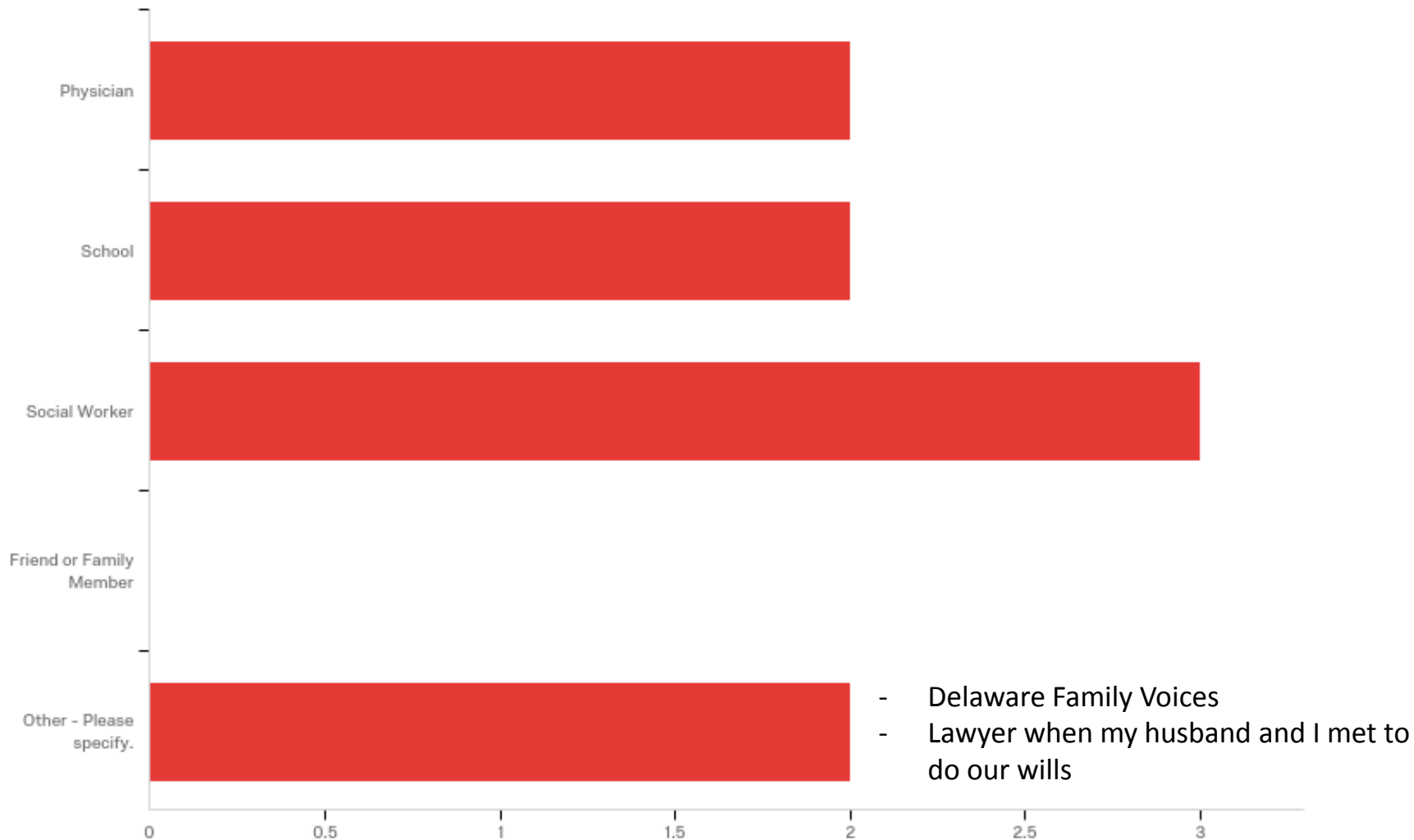
(Y = Yes answer to previous question)

How long did it take to be able to see the mental/behavioral health profess...
16, autism
8 years autism - Y
Age - 17 Autism Spectrum Disorder
22 autism
20, Moderate ID, Down Syndrome - Y
9, Type 1 Diabetes - Y
13, Down Syndrome, Autism
15 Autism, severe cognitive impairment, OCD
8 PTSD ADHD depression
14 - rare genetic dx, CP, multiple disabilities
17 Rett Syndrome
14

12 - Has anyone ever discussed medical power of attorney with you?

Answer	Count
Yes	9
No	12
Total	21

13 - Who provided information to you about medical power of attorney?



14 - Do you have medical power of attorney for your child?

Answer	Count
Yes	1
No	8
Total	9

15 - What is your child's age and disability?

(Y = Yes answer to previous question)

What services does your child require?

8 years autism

age - 17 Autism Spectrum Disorder

22 autism - Y

20, Moderat ID, Down Syndrome

9, Type 1 Diabetes

9 Autism

13 Down Syndrome, autism

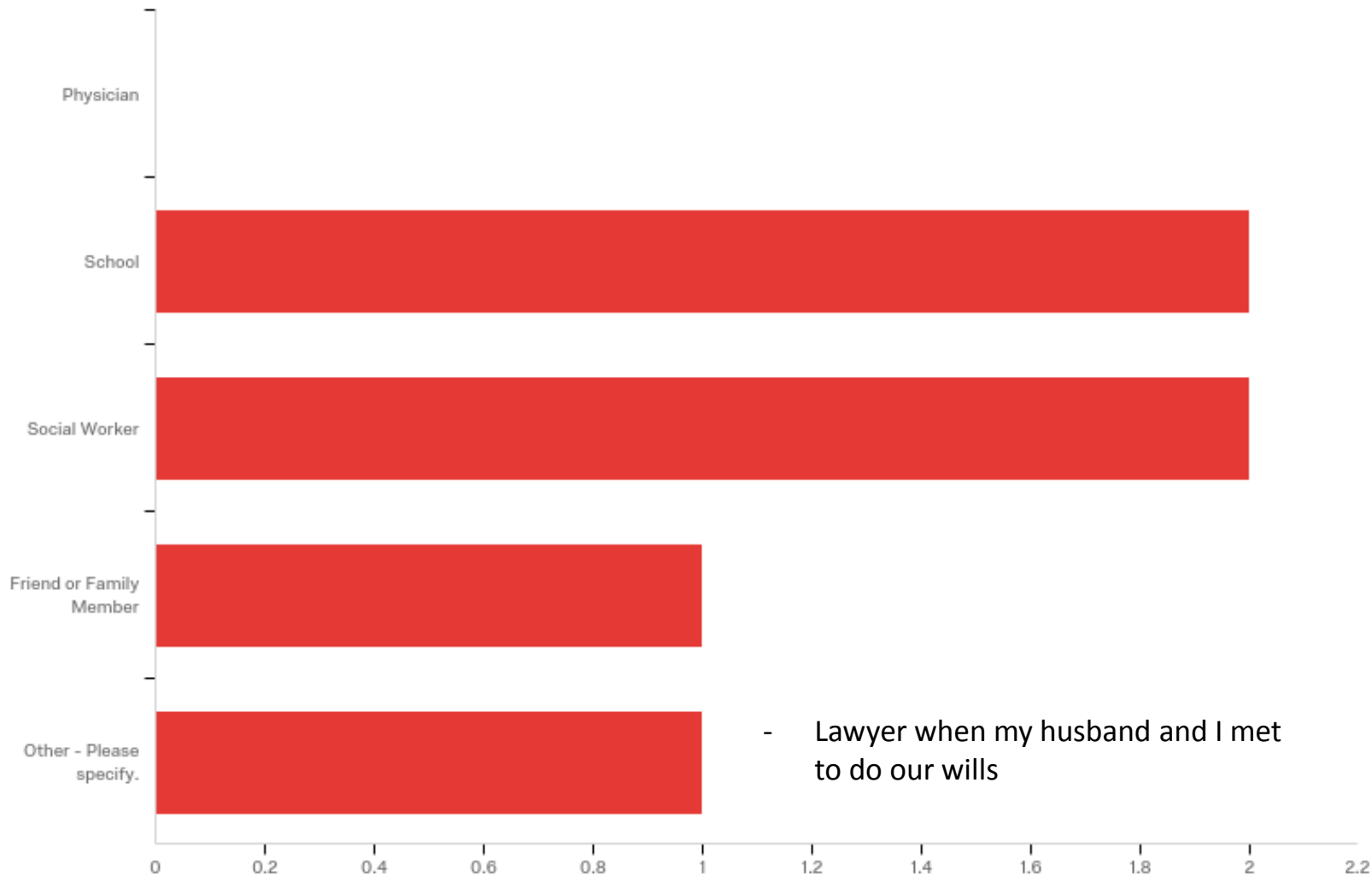
15. Autism, severe cognitive impairment. OCD

14 - rare genetic dx, CP, multiple disabilities

16 - Has anyone ever discussed financial power of attorney with you?

Answer	Count
Yes	6
No	15
Total	21

17 - Who provided information to you about financial power of attorney?



18 - Do you have financial power of attorney for your child?

Answer	Count
Yes	0
No	6
Total	6

19 - What is your child's age and disability?

(Y = Yes answer to previous question)

Where are you receiving services (i.e. name of organization, location of or...

8 years autism

Age - 17 Autism Spectrum Disorder

14 mild intellectual disability

9, Type 1 Diabetes

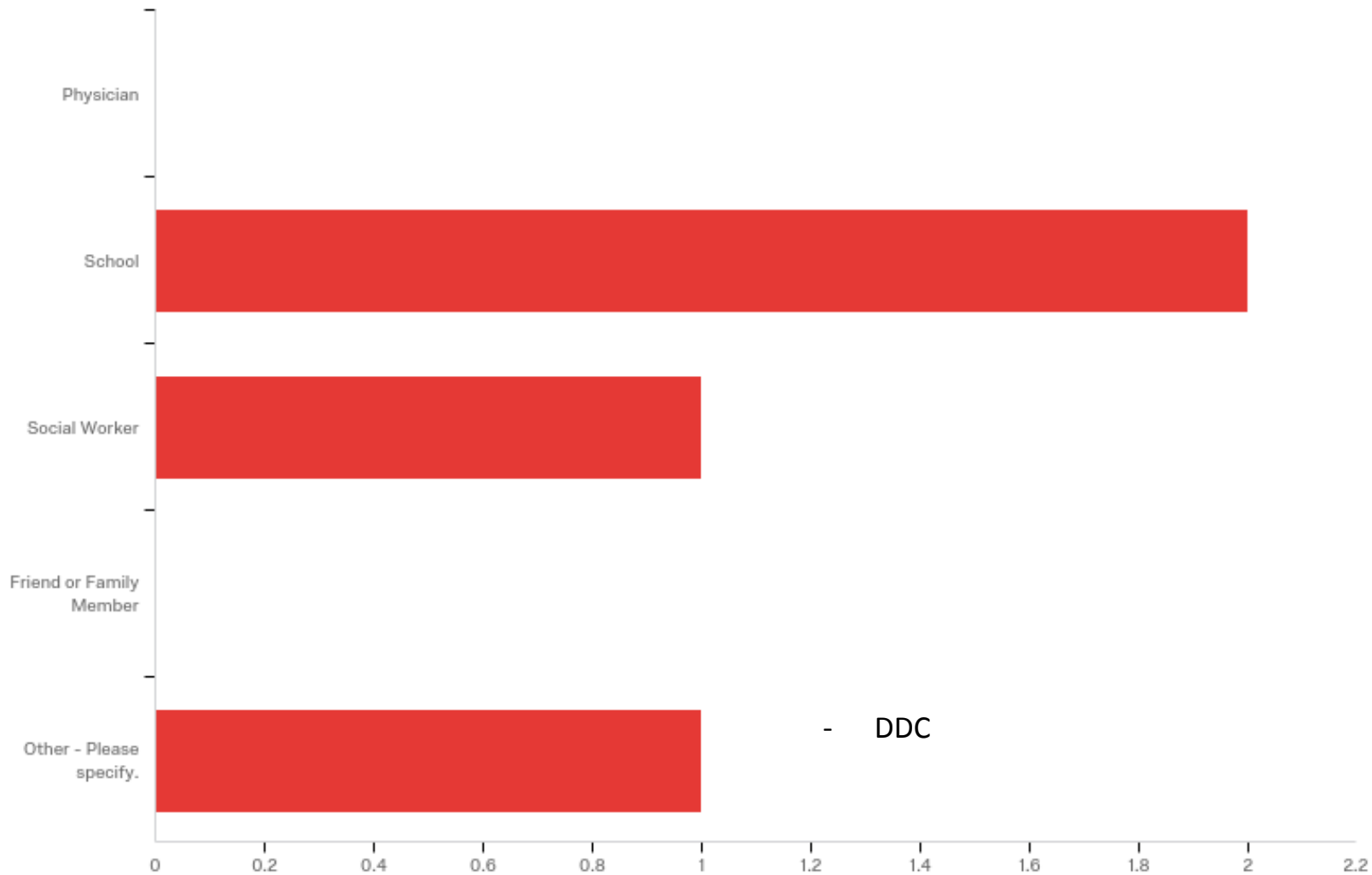
13 Down Syndrome and autism

15. Autism, severe cognitive impairment. OCD

20 - Has anyone ever discussed supported decision making with you?

Answer	Count
Yes	4
No	17
Total	21

21 - Who provided information to you about supported decision making?



22 - Do you have supported decision making in place for your child?

Answer	Count
Yes	2
No	2
Total	4

23 - What is your child's age and disability?

(Y = Yes answer to previous question)

What needs does your child have that you feel are currently unmet?

16, autism

8 years autism - Y

Age - 17 Autism Spectrum Disorder

14 mild intellectual disability - Y

24 - Is there any other information you would like to share in regards to transition and legal services for your child?

Is there any other information you would like to share in regards to suppor...

not many professionals out there are talking to parents about these options. No official paperwork for supported decision making is yet available, to my knowledge. Want to do it, just no way to do it yet!

I KNOW there are plenty of presentations and meetings being held constantly about this information, I just haven't attended them because my sons only 13 and I have plenty of time to learn that, right now I'm focused on my sons CURRENT behaviors

parents and caregivers need to know more

I feel lost and unprepared

How our social security is effected by our disabled child

Trusts and able account info

My son is still too young to have any of these in place. I do plan to complete all of the paperwork in a few years.

I need more information on everything

25 - Would you like to know more about the legal tools that are available to you and your child to make decisions as they transition into adulthood?

