

# Initial Report

## State Services/Division of Public Health- Maternal and Child Health Bureau

Families Know Best - April 2018

# 1 - What is your place of residence?

Answer	Count
New Castle County, DE	18
Kent County, DE	4
Sussex County, DE	2
Other - Pennsylvania Resident	0
Other- New Jersey Resident	1
Other- Maryland Resident	0
Total	25

2 -

What is your child's disability or health condition?	Count
Autism Spectrum Disorder	8
Down syndrome	2
Developmental delay	1
Mild intellectual disability	1
Medically fragile	1
Type 1 Diabetes	1
Cerebral palsy	1
Genetic disorder	1
Multiple:	
Autism (also severe cognitive disability)	1
Autism/ADHD	1
ASD, ADHD,SPD	1
Autism coppled with ADHD	1
Autism, SPD, Asthma, Immune deficiency disorder, malabsorption disorder	1
Rare genetic syndrome, CP	1
CP, seizures	1
Polymicrogyria - hemiplegia, epilepsy, developmental delay	1
Co-occurring Down Syndrome and Autism, Obstructive sleep apnea	1
Total	25

### 3 - What is the age of your child?

Answer	Count
0-4 years old	3
5-11 years old	8
12-21 years old	13
over 21 years old	1
Total	25

## 4 - Please identify yourself.

Answer	Count
Mother	25
Father	0
Legal Guardian	0
Foster Parent	0
Total	25

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

Answer	Count
White	17
Black or African American	2
Hispanic, Latino, or Spanish Origin	1
Asian	3
American Indian or Alaska Native	0
Native Hawaiian or Pacific Islander	1
Other (please specify)	1
Total	25

### Other (please specify) - Text

multi-racial - this question does not allow you to click all that apply

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

Answer	Count
Yes	17
No	8
Total	25

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

**No (please explain below): - Text**

Usually, but communication devices and other tools he needs are not always covered

Appeals Are brutal

Inadequate orthodontia thru private insurance

need coverage for specialized therapies with no copayment

needs physical motor skills therapy, not PT, but it doesn't cover motor skills development as he really needs

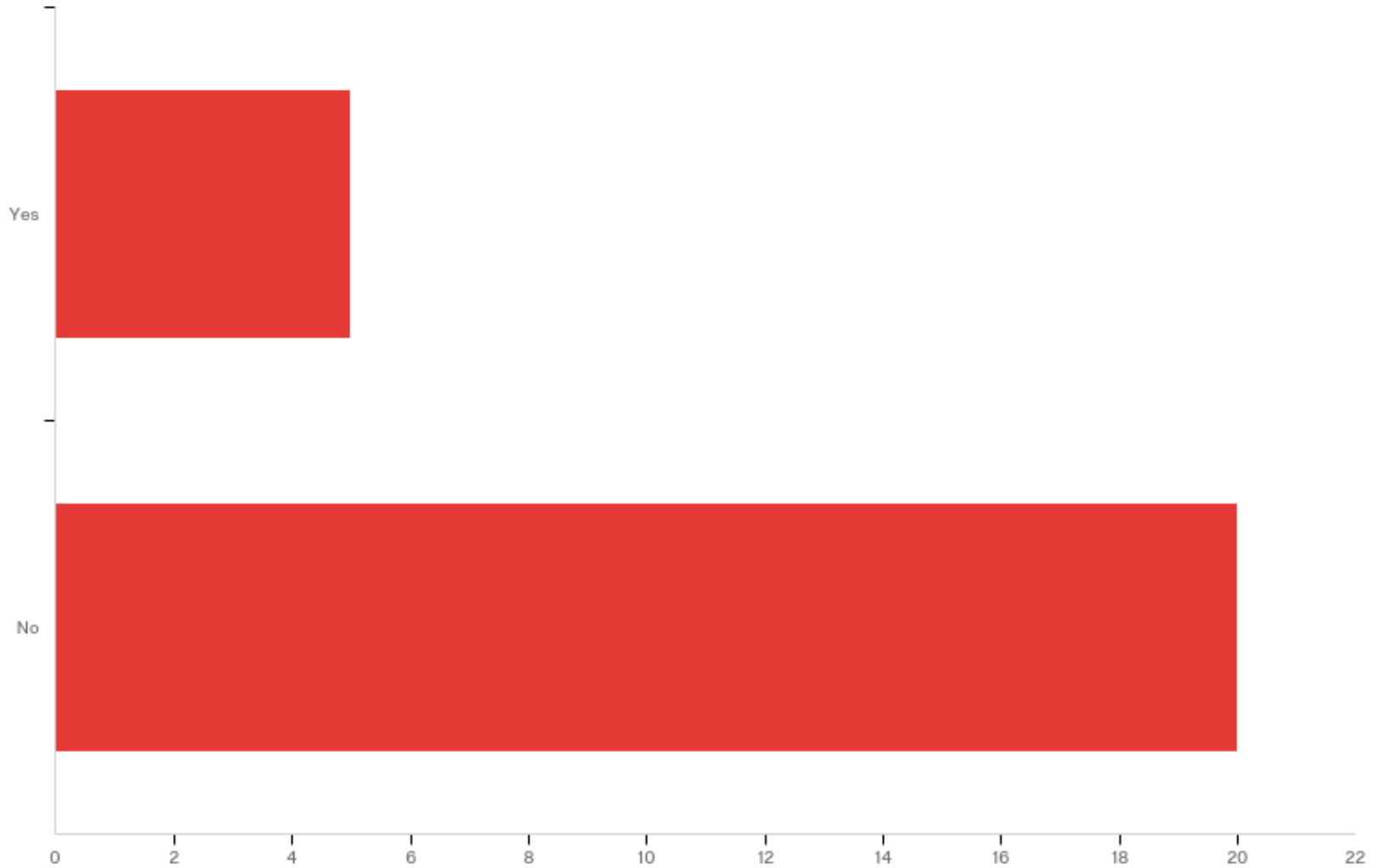
I have paid for 13+ years for high priced Specialty health services, not covered by either insurances for Speech.

Because my child condition is very rare and new, I always have to fight to get the right services.

no participating providers / prior approval needed for everything and no follow thru by PCP/ Other provider



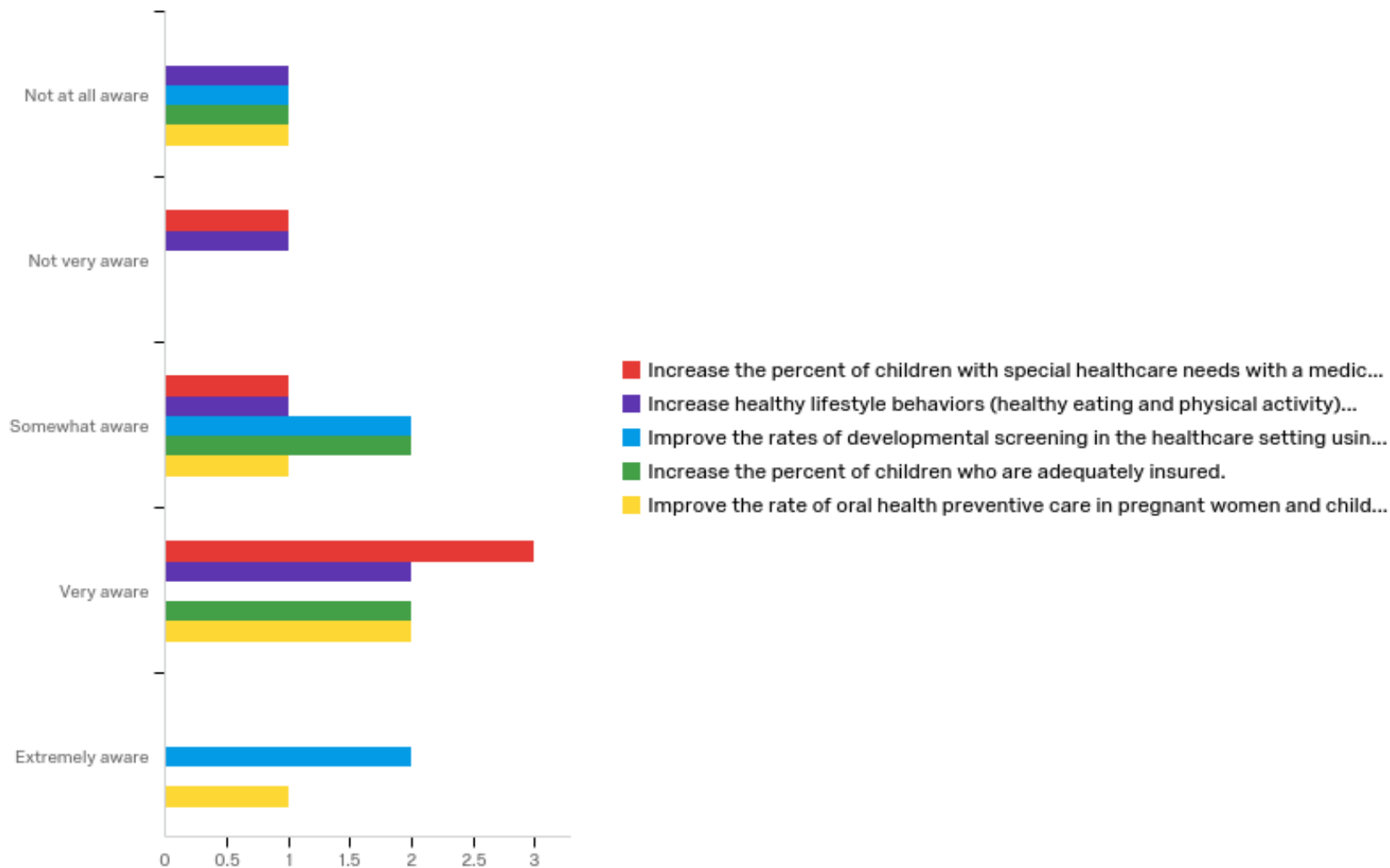
# 7 - Are you familiar with the priorities of the Delaware Division of Public Health/Maternal and Child Health Bureau?



7 - Are you familiar with the priorities of the Delaware Division of Public Health/Maternal and Child Health Bureau?

Answer	Count
Yes	5
No	20
Total	25

8 - Please indicate your level of awareness of the following priorities within the DE Division of Public Health/Maternal and Child Health Bureau which relate to children with special healthcare needs.



9 - Are you aware that the Children and Youth with Special Healthcare Needs Program is housed within the Delaware Division of Public Health/ Maternal and Child Health Bureau?

Answer	Count
Yes	6
No	19
Total	25

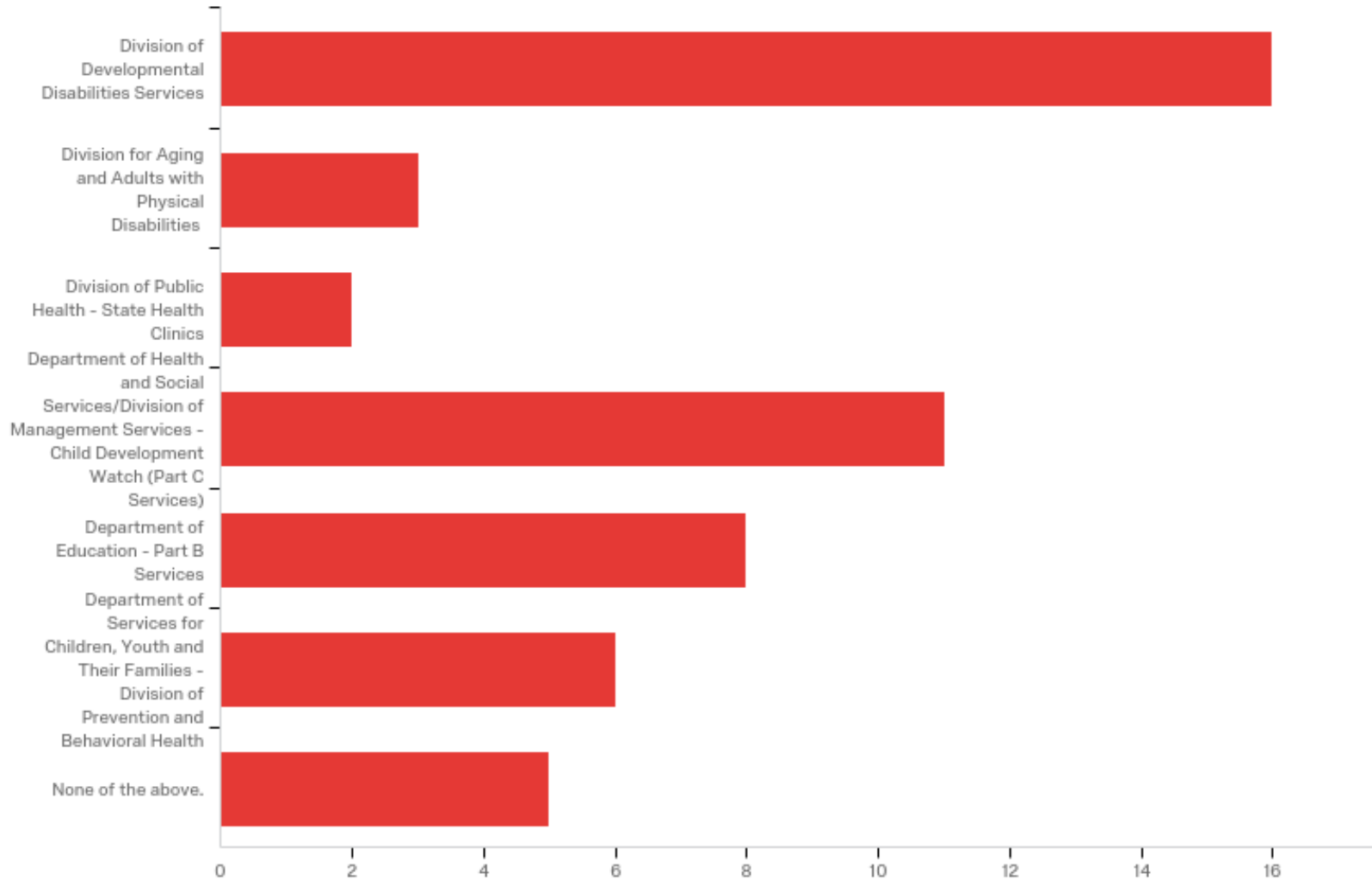
10 - Are you aware that the Family SHADE Project is funded through the DE Division of Public Health/Maternal and Child Health Bureau?

Answer	Count
Yes	5
No	20
Total	25

11 - Please indicate if you are aware of the services available to your child within the following state agencies (check all that apply).

Answer	Count
Division of Developmental Disabilities Services	16
Division for Aging and Adults with Physical Disabilities	3
Division of Public Health - State Health Clinics	2
Department of Health and Social Services/Division of Management Services - Child Development Watch (Part C Services)	11
Department of Education - Part B Services	8
Department of Services for Children, Youth and Their Families - Division of Prevention and Behavioral Health	6
None of the above.	5
Total	51

11 - Please indicate if you are aware of the services available to your child within the following state agencies (check all that apply).



12 - Please indicate whether you have received or are receiving services from the following state agencies for your child with a special healthcare need/disability:

