

Initial Report

# Parent Training Opportunities

Families Know Best - January 2018

# 1 - What is your place of residence?

Answer	Count
New Castle County, DE	13
Kent County, DE	4
Sussex County, DE	1
Other - Pennsylvania Resident	1
Other- New Jersey Resident	1
Other- Maryland Resident	0
Total	20

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

What is your child's disability or health condition?	Count
ASD	8
Down Syndrome	2
Traumatic Brain Injury	1
Rett Syndrome	1
Type 1 diabetes	1
Cerebral Palsy, seizures	1
Mild Intellectual Disability	1
Genetic Condition cdk13	1
Multiple:	
Rare genetic diagnosis, CP, multiple disabilities	1
ASD, motor deficits	1
Polymicrogyria with hemiplegia and epilepsy/developmental delay	1
autism, OCD, FTT	1
Total	20

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

Answer	Count
0-4 years old	2
5-11 years old	7
12-21 years old	10
over 21 years old	1
Total	20

## 4 - Please identify yourself.

Please identify yourself. - Selected Choice	Count
Mother	20
Father	0
Legal Guardian	0
Total	20

## 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)	0
Total	20

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

Answer	Count
Yes	17
No	3
Total	20

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

Primary alone would be inadequate. We also have Medicaid which seems to cover most of what our primary does not.

Neither ins cover residential placement.

Genetic condition causes severe delay in speech and feeding difficulties. he is not getting feeding support nor aac support. low body tone needs pt. no getting it also. usic has lot of impact on development of neurological issues but in delaware music therapy is not considered as therapy.

## 7 - Who provided your child's diagnosis?

Answer	Count
Physician	14
Psychologist/Social Worker	3
Birth-to-Three Program	1
Local School System	2
Other. Please specify.	0
Total	20



## 8 - Were informational resources provided at the time of diagnosis?

Answer	Count
Yes	14
No	6
Total	20

## 9 - What resources were provided?

Answer	Count
Print material from a local support organization/agency	5
Print material from a national support organization/agency	6
List of support organizations with contact information	7
Peer support information	2
Other - Please specify.	4
Total	24

## 9 - What resources were provided?

### Other - Please specify. - Text

Verbal

At the time of actual diagnosis a few year ago, Info on genetic diagnoses, but we had to find specific info on the internet.

Recommendation to read Temple Grandin's books

Medical

## 10 - Did you feel the resources provided were adequate?

Answer	Count
Yes	10
No. Please specify.	4
Total	14

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

No resources outside of medical recommendation.

We were in a hospital in Delaware and most support info was for programs there - we live in south jersey.

Tough to answer - it's a process over time. As you meet people (medical specialists, families, school resources, etc) they each lead you to more resources.

Needed to do online research and talk to specialists.

11 - Have you ever received information about parent training focused on raising a child with a disability or special health care need?

Answer	Count
Yes. Please specify the type of training.	8
No	12
Total	20

**Yes (please explain below): - Text**

Family voices, Autism Delaware, PIC

Most recent: Mandatory training

PIC - Autism Behavioral training

Info from Del Family Voices and PIC

12 - Did you ever attend a parent training focused on raising a child with a disability or special health care need?

Answer	Count
Yes	8
No. Please specify why you did not attend.	0
Total	8

## 13 - Did you find the training helpful/beneficial in raising your child?

Answer	Count
Yes	7
No. Please specify.	1
Total	8

14 - Have you ever received information about a parent training around your child's Individualized Family Service Plan (IFSP) or Individualized Education Plan (IEP)?

Answer	Count
Yes	8
No	12
Total	20



## 15 - Did you ever attend a parent training around your child's IFSP or IEP?

Answer	Count
Yes	7
No. Please specify why you did not attend.	1
Total	8

16 - Did you find the training helpful/beneficial in understanding your child's IFSP or IEP?

Answer	Count
Yes	6
No. Please specify.	1
Total	7

17 - Have you ever received information about a parent training regarding services/benefits available to you and your child (i.e. SSI, Medicaid, respite care, etc.)?

Answer	Count
Yes	11
No	9
Total	20

18 - Did you ever attend a parent training regarding services/benefits available to you and your child (i.e. SSI, Medicaid, respite care, etc.)?

Answer	Count
Yes	11
No	0
Total	11

19 - Did you find the training helpful/beneficial in learning about services/benefits available to you and your child?

Answer	Count
Yes	9
No. Please specify.	2
Total	11

## 20 - What other parent training opportunities would you be interested in?

- medical marijuana program, recreational activities
- General living with a special needs child training
- best websites to find information for your state
- Respite, ideas on how to handle your larger/older non-mobile child, recreational ideas, assistive technology, behavior, new research findings
- To have training about what services my child is eligible for and where to find this information.
- Behavioral
- Now that my sons getting older, most of the other parent trainings you mentioned
- benefits, supports available to families
- Managing transitions to middle and high school and beyond
- challenging behaviors
- Job training for him, teen opportunities, sexuality and how to handle puberty
- meeting social needs
- SSI
- Behavior management
- information about transitioning into the adult world
- Getting financial assistance for private education without lawsuits