

Initial Report

Families Know Best – November 2015

Parent to Parent Support

What is your child's disability or health condition?

| Text Response |
|--|
| Autism |
| Autism |
| diabetes |
| Cp, seizures |
| Traumatic Brain Injury |
| autism (also failure to thrive and potentially life-threatening allergies) |
| Autism, adhd, odd |
| ASD |
| Down Syndrome |
| ADHD and anxiety |
| Polymicrogyria (hemiplegia, epileptic, developmental delay) |
| Type 1 Diabetes |
| Autism, SPD, Asthma, Immune deficiency |
| autism |
| autism, ADHD, motor deficits |
| mental health behavior issues & ADHD |
| Cognitive Delays and diagnosed with Down Syndrome |
| Rett syndrome |

Please identify yourself.

| # | Answer | % |
|---|------------------------|------|
| 1 | Mother | 94% |
| 2 | Father | 0% |
| 3 | Legal Guardian | 0% |
| 4 | Other (Please Specify) | 6% |
| 5 | Foster Parent | 0% |
| | Total | 100% |

What is the age of your child?

| # | Answer | % |
|---|-------------------|------|
| 1 | 0 - 4 years old | 0% |
| 2 | 5 - 11 years old | 50% |
| 3 | 12 - 21 years old | 50% |
| 4 | Over 21 years old | 0% |
| | Total | 100% |

What is your place of residence?

| # | Answer | % |
|---|-------------------------------|------|
| 1 | New Castle County, DE | 61% |
| 2 | Kent County, DE | 17% |
| 3 | Sussex County, DE | 11% |
| 4 | Other - Pennsylvania Resident | 6% |
| 5 | Other- New Jersey Resident | 6% |
| 6 | Other- Maryland Resident | 0% |
| | Total | 100% |

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

| # | Answer | % |
|---|-------------------------------------|-----|
| 1 | White | 83% |
| 2 | Black, African Am., Negro | 11% |
| 3 | Asian/ Pacific Islander | 6% |
| 4 | Hispanic, Latino, or Spanish origin | 0% |
| 5 | Native American | 0% |
| 6 | Other (Please Specify) | 0% |

When you first learned your child's diagnosis, did you have the opportunity to talk to a parent of a child with the same diagnosis?

| # | Answer | % |
|---|--------|------|
| 1 | Yes | 60% |
| 2 | No | 40% |
| | Total | 100% |

Would you have liked the opportunity to talk to another parent of a child with the same diagnosis?

| # | Answer | % |
|---|--------|------|
| 1 | Yes | 75% |
| 2 | No | 25% |
| | Total | 100% |

Have you received any support/ assistance from other parents in the past?

| # | Answer | % |
|---|--------|------|
| 1 | Yes | 56% |
| 2 | No | 44% |
| | Total | 100% |

After your child's initial diagnosis, WHEN would you have liked to be connected with a parent of a child with the same diagnosis?

| Text Response |
|---|
| The same day |
| Immediately |
| about a month after. Right at diagnosis it was too overwhelming |
| 1 month |
| As soon as possible. |
| as soon as possible |
| ASAP |
| initially |
| Within a month |
| I didn't find it necessary as I was very familiar with the diagnosis and it's implications. |
| As soon as possible |
| After a day or so, that way I had a little bit of time for it to sink in. |
| ASAP |
| same week |
| immediately |
| Birth |
| Within 6 months |

Please slide to indicate the degree to which other parents can be a helpful resource for INFORMATION.

| # | Answer | % |
|----|--------|------|
| 0 | 0 | 0% |
| 1 | 1 | 0% |
| 2 | 2 | 6% |
| 3 | 3 | 0% |
| 4 | 4 | 0% |
| 5 | 5 | 0% |
| 6 | 6 | 0% |
| 7 | 7 | 18% |
| 8 | 8 | 18% |
| 9 | 9 | 12% |
| 10 | 10 | 47% |
| | Total | 100% |

Please slide to indicate the degree to which other parents can be a helpful resource for support.

| # | Answer | % |
|----|--------|------|
| 0 | 0 | 6% |
| 1 | 1 | 0% |
| 2 | 2 | 0% |
| 3 | 3 | 0% |
| 4 | 4 | 0% |
| 5 | 5 | 0% |
| 6 | 6 | 0% |
| 7 | 7 | 6% |
| 8 | 8 | 24% |
| 9 | 9 | 12% |
| 10 | 10 | 53% |
| | Total | 100% |

Besides one-on-one support, please rank your preferences for parent to parent support & information.

| # | Answer | | | | | | Total Responses |
|---|------------------------|----|----|----|----|----|-----------------|
| 1 | support groups | 8 | 6 | 1 | 3 | 0 | 18 |
| 3 | events/activities | 5 | 4 | 7 | 2 | 0 | 18 |
| 5 | social media | 3 | 5 | 5 | 3 | 2 | 18 |
| 6 | other (please specify) | 0 | 0 | 1 | 2 | 15 | 18 |
| 7 | conferences/workshops | 2 | 3 | 4 | 8 | 1 | 18 |
| | Total | 18 | 18 | 18 | 18 | 18 | - |

WHO would you expect to tell you about parent support opportunities? Check all that apply.

| # | Answer | % |
|---|---|-----|
| 4 | doctor | 83% |
| 5 | other health care provider | 61% |
| 6 | school | 56% |
| 7 | condition specific organization (e.g. Autism Delaware, Down Syndrome Association, etc.) | 67% |
| 8 | state agency/ case worker | 50% |
| 9 | other (please specify) | 11% |

What type of helpful INFORMATION have you received from other parents?

| Text Response |
|--|
| Hospitals, specialists, therapies, ducal groups, networking, education techniques, respite, provuders |
| Recreational |
| school info, info about doctors |
| Online support, their past experiences, what to expect |
| Resources availkable, how they have coped and things they have found helpful1 |
| None from officially trained support parents; from others I have received information about services and advice about how to handle situations with my child |
| About the DDDS services in our state |
| where to send child for support services |
| Future specific steps need to take |
| nothing really |
| Online support groups relating to hemiplegia - school and self care issues |
| resource names and contacts, tx options |
| services, insurance coverage, iep goals, medication, events and activities |
| resources, trends, names of who to call who can really help, emotional support, "you are not alone" |
| related agencies, home care advice, medical advice, |
| General information about things to expect |
| Recommendations for doctors, equipment, funding, daily routine information |

Did you know that Delaware has a Parent to Parent program through Delaware Family Voices?

| # | Answer | % |
|---|--------|------|
| 1 | Yes | 41% |
| 2 | No | 59% |
| | Total | 100% |

Please feel free to share any comments about parent to parent support.

Text Response

I think that this is a critical missing piece for people with kids with diabetes. I would have liked for AI to help with this. It would be great if doctors would ask on an ongoing basis if you need support. Not just at diagnosis. My support needs have changed as time has gone by

Difficult finding similar diagnosis to be able to meet in person

I like it to be varied- at least one parent in my same town/school district with child with same disability, and then a broader range- parents in other counties so I can also hear "up here they do this!" and learn different options

nonjudgement zone best part. parent group, however, has been unstable.

During the past 12 months, was your child delayed in getting prescriptions and/or prescription medications.

| # | Answer | % |
|---|--------|------|
| 1 | Yes | 39% |
| 2 | No | 61% |
| | Total | 100% |

Which of these best describes the main reason(s) your child was delayed in getting prescriptions.

| # | Answer | % |
|----|---|-----|
| 1 | Couldn't afford care | 14% |
| 2 | Insurance company wouldn't approve, cover, or pay for care | 86% |
| 3 | Doctor refused to accept family's insurance plan | 0% |
| 4 | Didn't know where to go to get care | 14% |
| 5 | Services my child needed were not available in my area | 29% |
| 6 | Waiting lists, backlogs, or other problems getting appointments | 14% |
| 7 | Problems getting to doctor's office | 14% |
| 8 | Language barrier | 0% |
| 9 | Couldn't get time off work | 0% |
| 10 | Couldn't get child care | 0% |
| 11 | Other, please specify | 43% |

Other, please specify

delays from company in getting supplies

the location was too far away and too expensive with tolls and gas

pharmacy not familiar with how to correctly key in for coverage