

Initial Report

Families Know Best - December
2014 Last Modified: 12/12/2014

What is your county of residence?

#	Answer	Response	%
1	New Castle County, DE	20	65%
2	Kent County, DE	4	13%
3	Sussex County, DE	3	10%
4	Other - Pennsylvania Resident	2	6%
5	Other- New Jersey Resident	2	6%
6	Other- Maryland Resident	0	0%
	Total	31	100%

What is your child's disability or health condition?

Text Response
ASD
rare genetic condition, CP, multiple disabilities
Rett syndrome
Down syndrome
Autism
autism. Also, FTT, G-tube
ADHD
Type 1 Diabetes
Cp
Autism
Polymicrogyria. Left hemiparesis, epilepsy, developmental delays
autism
autism
Down Syndrome, Autism, Hearing Impairment
TBI
autism, asthma, sensory process disorder, immune deficiency

What is the age of your child?

Text Response
4
11
14
8
11
13
17
7
9
12
6
5
14 years old
10
18
9

Is your child 14 or older?

#	Answer	Response	%
1	Yes	9	29%
2	No	22	71%
	Total	31	100%

Do any of your child's doctors of other health care providers treat only children?

#	Answer	Response	%
1	Yes	9	100%
2	No	0	0%
	Total	9	100%

Have they talked with you about having your child eventually see doctors or other health care providers?

#	Answer	Response	%
1	Yes	5	56%
2	No	4	44%
3	Don't Know	0	0%
	Total	9	100%

Eligibility for health insurance often changes as children reach adulthood. Has anyone discussed with you how your child can obtain or keep some type of health insurance coverage as he/she becomes an adult

#	Answer	Response	%
1	Yes	3	33%
2	No	6	67%
	Total	9	100%

How often do your child's doctors or other health care providers encourage (him/her) to take responsibility for (his/her) health care needs, such as taking medication, understanding (his/her) diagnosis, or following medical advise?

#	Answer	Response	%
1	Never	4	67%
2	Sometimes	1	17%
4	Always	1	17%
	Total	6	100%

Please feel free to share any comments or concerns regarding transition.

Text Response

health care since we won't be able to go to Nemours/duPont, what type of program my child will be in during the day, how to find respite options

I am very scared about when my son becomes 18 and he will be kicked out of Nemours Pediatrics and AI DuPont Hospital. I will have to find someone to help me transition him into the adult care system. And what doctor will take a person with autism? I hope Practice Without Pressure will expand their care to include doctors.

I am concerned that my son is so low-functioning that he might not be able to get any sort of job. I am also concerned about where he will live as an adult. My son is not yet 14, though, so we have not yet looked into resources.

It stinks in schools - they are not following any kind of law

social security disability, medicaid transition, issues surrounding college

My pediatrician (Dr. E Giannoukos) sees patients through age 25, so I feel confident going through transition at age 18 and maintaining continuity in care through her.

It is scary and finding the correct adult Doctors has been complicated.

I am very scared about my son's transition from AI DuPont and Nemours. He is non-verbal autism with challenging behaviors and he loves his doctor at Nemours Pediatrics in Peoples Plaza and the AI DuPont Hospital. I met the transition coordinator at AI DuPont Hospital yesterday at a conference and will talk to her about this issue.

No discussion or information about transition

During the past 12 months, was your child delayed in getting dental care, test, or treatments that you or a doctor believed necessary? (do not include medical care or prescription medicines)

#	Answer	Response	%
1	Yes	13	42%
2	No	18	58%
	Total	31	100%

Which of there best describes the main reason(s) your child was delayed in getting dental care, tests, or treatments that you or a doctor believed necessary.
(Check all that apply)

#	Answer	Response	%
1	Couldn't afford care	2	15%
2	Insurance company wouldn't approve, cover, or pay for care	5	38%
3	Doctor refused to accept family's insurance plan	6	46%
4	Didn't know where to go to get care	2	15%
5	Services my child needed were not available in my area	7	54%
6	Waiting lists, backlogs, or other problems getting appointments	10	77%
7	Problems getting to doctor's office	1	8%
8	Language barrier	0	0%

Which of there best describes the main reason(s) your child was delayed in getting dental care, tests, or treatments that you or a doctor believed necessary.
(Check all that apply)

Other, please specify
no participating providers
Practice Without Pressure was closed down for a few months.
no participating providers
PWP closed for a few months