

Initial Report

Families Know Best - February 2015

1. Please identify yourself.

#	Answer	%
1	Mother	95%
2	Father	5%
3	Legal Guardian	0%
4	Other (Please Specify)	0%
5	Foster Parent	0%
	Total	100%

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

#	Answer	%
1	White	86%
2	Black, African Am., Negro	5%
3	Asian/ Pacific Islander	9%
4	Hispanic, Latino, or Spanish origin	0%
5	Native American	0%
6	Other (Please Specify)	0%

3. What is your child's disability or health condition?

Text Response	#
Diabetes	3
Rare genetic syndrome, CP, multiple disabilities	1
Autism (ASD)	5
Down Syndrome	2
Cerebral palsy	1
Autism & ADHD	2
Rett Syndrome	1
Dandy-Walker Malformation	1
ADHD	2
Polymicrogyria	1
autism, asthma, SPD, Malabsorption disorder	1
Traumatic Brain Injury	1
autism, allergies, G-tube, FTT	1

4. What is the age of your child?

#	Answer	%
1	0 - 4 years old	5%
2	5 - 11 years old	45%
3	12 - 21 years old	50%
4	Over 21 years old	0%
	Total	100%

5. What is your place of residence?

#	Answer	%
1	New Castle County, DE	68%
2	Kent County, DE	18%
3	Sussex County, DE	5%
4	Other - Pennsylvania Resident	5%
5	Other- New Jersey Resident	5%
6	Other- Maryland Resident	0%
	Total	100%

6. During the past 12 months, did your child need a referral to see any doctors or receive any services?

#	Answer	%
1	Yes	45%
2	No	55%
	Total	100%

7. Was getting referrals a big problem, a small problem, or not a problem?

#	Answer	%
1	Big problem	10%
2	Small problem	20%
3	Don't Know	10%
4	Not a problem	60%
	Total	100%

8. Does anyone help you arrange or coordinate your child's care among the different doctors and services that he/she uses?

#	Answer	%
1	Yes	5%
2	No	95%
	Total	100%

9. Does a doctor or someone in a doctor's office provide this help arranging or coordinating your child's care?

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

10. During the past 12 months, have you felt that you could have used extra help arranging or coordinating your child's care among the different health care providers and services?

#	Answer	%
4	Yes	52%
5	No	48%
6	Don't know	0%
	Total	100%

11. During the past 12 months, how often did you get as much help as you wanted with arranging or coordinating your child's care? Would you say never, sometimes, or usually?

#	Answer	%
1	Never	45%
3	Sometimes	55%
4	Usually	0%
5	Don't know	0%
	Total	100%

12. Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with the communication about care coordination among your child's doctors and other health care providers?

#	Answer	%
1	Very satisfied	20%
3	Somewhat Satisfied	30%
5	Somewhat Dissatisfied	15%
6	No communication needed or wanted	10%
7	Very Dissatisfied	25%
	Total	100%

13. Please feel free to share any comments or concerns regarding coordination of your child's care.

Text Response
We've chosen to have our primary pediatrician in the same hospital system as our specialists which decreases my need to coordinate communication
Not all practitioners share willing with others.
Hipaa is being used as a way to keep coordination from happening and costing taxpayers and private consumers \$\$\$\$
Very rarely informed if there actually is a case manager when it comes to Medicaid.
Our pediatrician has a special care coordinator that goes out of her way to assist our family
We try to use the chop network as much as possible so everyone can access her chart easily
we get no help coordinating. it is very confusing and pediatrician sends us back and forth with specialists. Pediatrician will not deal with diabetes at all.
we have been lucky with our services for our son. i had a heads up on the AiDupont medicaid problems with the one company and i knew to switch to blue cross blue shield before the yr started

14. During the past 12 months, was your child delayed in getting prescriptions and/or prescription medicines that you or a doctor believed necessary?

#	Answer	%
1	Yes	48%
2	No	52%
	Total	100%

15. Which of these best describes the main reason(s) your child was delayed in getting prescriptions and/or prescription medicines that you or a doctor believed necessary. (Check all that apply)

#	Answer	%
1	Couldn't afford care	0%
2	Insurance company wouldn't approve, cover, or pay for care	80%
3	Doctor refused to accept family's insurance plan	10%
4	Didn't know where to go to get care	0%
5	Services my child needed were not available in my area	10%
6	Waiting lists, backlogs, or other problems getting appointments	0%
7	Problems getting to doctor's office	0%
8	Language barrier	0%
9	Couldn't get time off work	0%
10	Couldn't get child care	0%
11	Other, please specify	20%

15. Which of these best describes the main reason(s) your child was delayed in getting prescriptions and/or prescription medicines that you or a doctor believed necessary. (Check all that apply)

Other, please specify

Pharmacy out of stock

needed pre approval on a medicine. only had to wait a day for it to be resolved