

Initial Report

Care Coordination and Communication
Families Know Best - October 2016

1 - What is your place of residence?

Answer	%	Count
New Castle County, DE	65.00%	13
Kent County, DE	15.00%	3
Sussex County, DE	10.00%	2
Other - Pennsylvania Resident	5.00%	1
Other- New Jersey Resident	5.00%	1
Other- Maryland Resident	0.00%	0
Total	100%	20

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

What is your child's disability or health condition?	Count
Autism	7
Down syndrome	2
TBI	1
Trisomy 21	1
CP, seizures	1
Rett Syndrome	1
Type 1 Diabetes	1
PTSD	1
Multiple:	5
ADHD, mood disorder, ODD	
Hemiplegia, epilepsy, developmental delay	
Autism (also life threatening allergies, failure to thrive, and ADHD)	
Autism, asthma, SPD	
Autism,ADHD,ODD & depression	

3 - Please identify yourself.

Answer	%	Count
Mother	95.00%	19
Father	0.00%	0
Legal Guardian	5.00%	1
Foster Parent	0.00%	0
Other (please specify)	0.00%	0
Total	100%	20

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

Answer	%	Count
White	80.00%	16
Black or African American	10.00%	2
American Indian or Alaska Native	5.00%	1
Asian	10.00%	2
Native Hawaiian or Pacific Islander	0.00%	0
Other	0.00%	0
Total	100%	20

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

Answer	%	Count
Yes	57.89%	11
No If response is No, please explain:	42.11%	8
Total	100%	19

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

No If response is No, please explain:

limited OT sessions in a year

I dislike how long it can take to get medical equipment approved through my child's insurance. Most of the time it's something she needs quickly, so we end up purchasing the item.

Limits on therapies, issues getting autism covered, no coverage for specially designed physical fitness for those w motor deficits. No coverage for devices that help in multiple ways, like iPads that can help w communication, skills modeling, organization, and digitizing writing and

limits to number of therapy visits compromise quality care to the child. Need year long service.

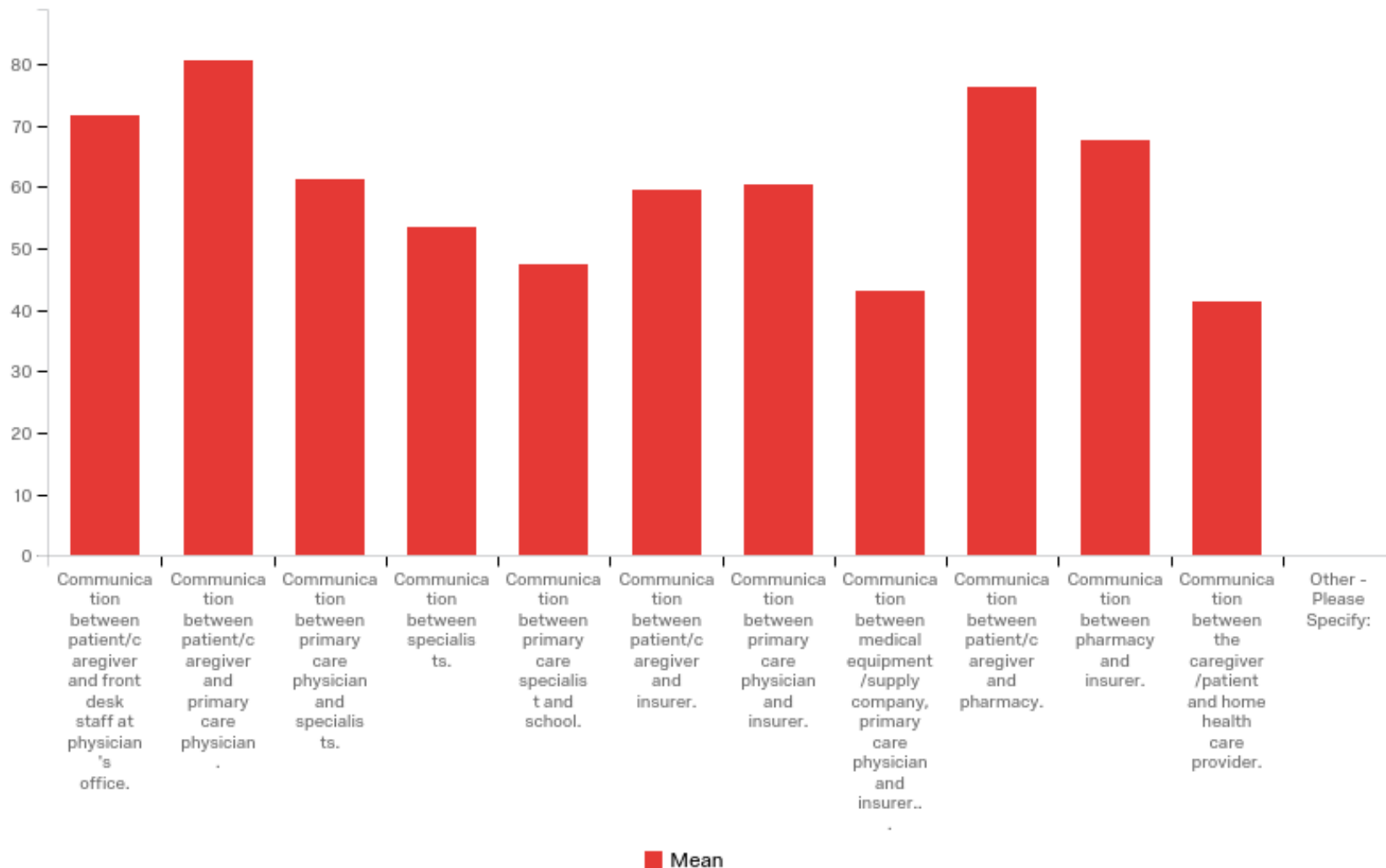
no coverage for special therapeutic equipment and tx or specialists who are not available in state

other than weekly mental health therapy, "outside the box" therapies such as medical massage and music therapy is not covered and no wrap-around services

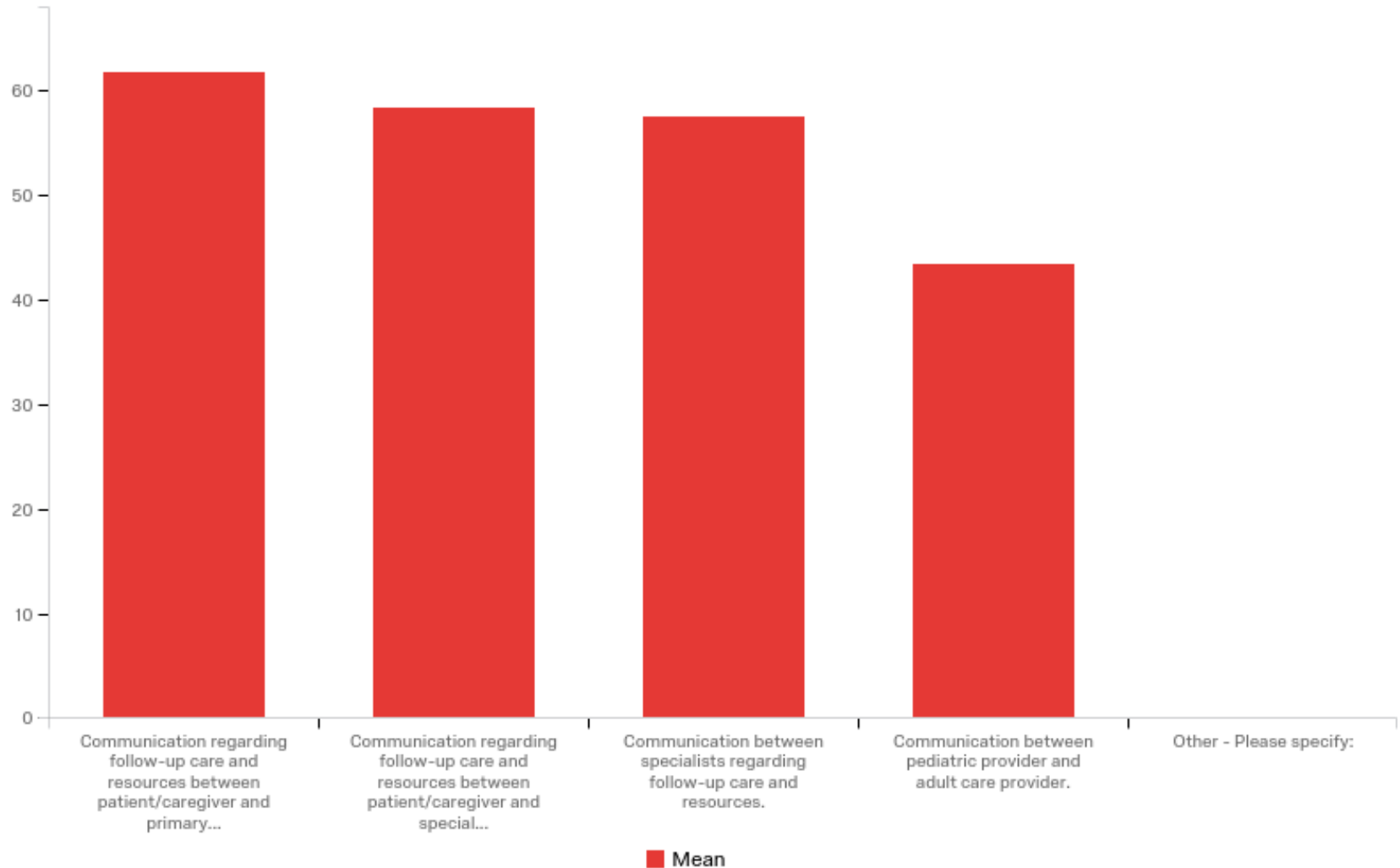
Although I worked on the SB for Autism Insurance and have run a Home ABA program with BACB for 20 years, the Bill does not benefit my son.

Our primary insurance would NOT be adequate; however, together with Medicaid her needs are usually met.

6 - What percentage of the time do you find communication to be effective, in the following categories, when trying to obtain medical/health care services for your child? (n = 20)



7 - What percentage of the time do you find communication to be effective when discussing the following transitions in care for your child?



8 - Please indicate the other points where communication around your child's medical/health care services could be improved.

If you could make one change to the healthcare system that serves your chil...

often no f/u from from front desk, communication not relayed. Privacy not always respected; personnel from institutions can call & get info. I find Nemours services to be the exception in most cases; they usually follow up thru completion & send communication to PCP, their privacy policies upheld to the utmost.

Communicating regarding insurance, billing codes, costs of medical services PRIOR to the service, communication to family regarding script formularies

Specialist and school

schools, social workers, dfs, respite services, community resources,

Mostly between the doctor, insurance, /mans medical supply company

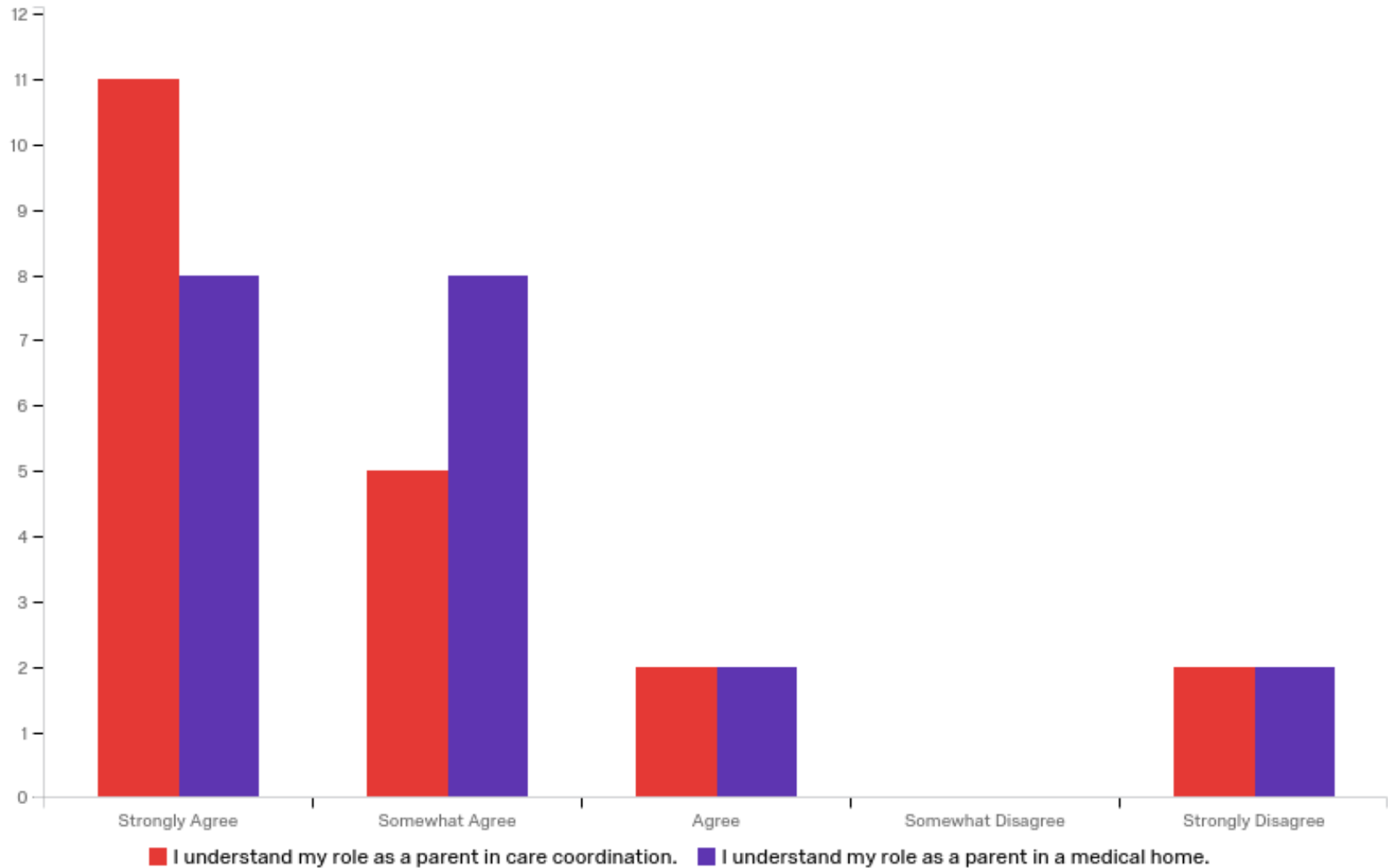
Follow up care, respite providers, transition coordination providers and who takes what insurance

Communication between therapists and insurance is extremely poor, and it is consistently the insurance company's fault -- they don't read the statements provided by the therapist's office. (They consistently misprocess a day's therapy as a single billing unit, despite having the fact that the statements have "multiple billing units per day" on them in three separate locations.)

Between doctors from different organizations such as DuPont with Chop staff.

Everywhere, I honestly don't think any of my sons health professionals talk to each other, EXCEPT his AIDupont primary care dr and his AI DuPont psychiatrist

9 - Please indicate your level of agreement with the following statement:



10 - Please feel free to share any comments about Medical Home, Care Coordination and Communication.

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Often takes repeated attempts to ensure needs are met; makes it very hard to get needs for child met because other health issues pop up

It's not fully explained to most families what this is, exactly, w specifics

I indicate my child's PCP to every other professional and hope they forward their findings back to the PCP so I consider that to be the "Medical Home" but that's about it, any and everything else I'm on my own to find, research, reach out, make appointment, find coverage/transportation/babysitter for siblings etc etc

I'd really feel better if I thought our medical home was a stable one where everyone stays current and contacts each other