

Initial Report

Care Coordination

Families Know Best - May 2016

1 - What is your place of residence?

Answer	%	Count
New Castle County, DE	65.22%	15
Kent County, DE	13.04%	3
Sussex County, DE	13.04%	3
Other - Pennsylvania Resident	4.35%	1
Other- New Jersey Resident	4.35%	1
Other- Maryland Resident	0.00%	0
Total	100%	23

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

What is your child's disability or health condition?	Count
Autism	6
Down Syndrome	2
Cerebral Palsy	2
Diabetes	2
Orthopedic impairment	1
TBI	1
Epilepsy	1
Rett Syndrome	1
Multiple:	7
<ul style="list-style-type: none">- autism, motor deficits- autism, adhd, odd and now mood disorder, major depressive disorder and ptsd from attending an INCLUSIVE public middle school for 6th grade- Polymicrogyria- ADHD and anxiety- multiple disabilities, rare genetic disorder, CP- Autism, Asthma, Malabsorption Disorder, SPD- Neonatal abstinence syndrome	

3 - Please identify yourself.

Answer	%	Count
Mother	95.65%	22
Father	0.00%	0
Legal Guardian	4.35%	1
Foster Parent	0.00%	0
Other (please specify)	0.00%	0
Total	100%	23

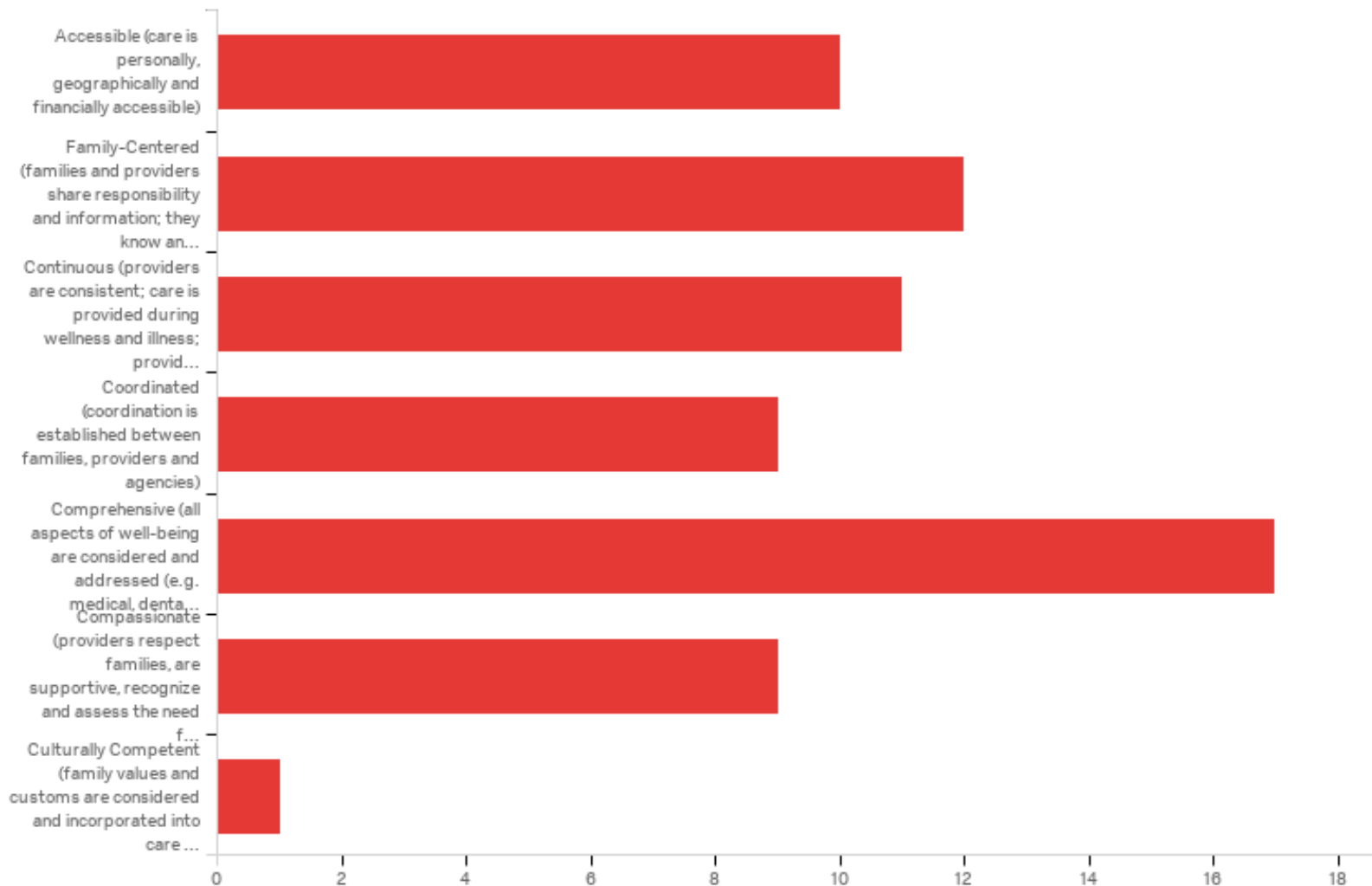
4 - What is your race/ethnicity? (Check all that apply)

Answer	%	Count
White	78.26%	18
Black or African American	8.70%	2
American Indian or Alaska Native	0.00%	0
Asian	4.35%	1
Native Hawaiian or Pacific Islander	0.00%	0
Other	13.04%	3
Total	100%	23

5 - Please rank what your ideal medical home model might be.

Question	1	2	3	Total
A medical home creates a team which can include youth, family, primary care provider, specialist(s), care coordinators and others. The team will deliver and coordinate the care both within the practice and with community providers and specialists.	52.38% 11	42.86% 9	4.76% 1	21
A medical home uses a team approach to chronic condition care including planned visits, coordination of complex services, co-management with specialists, and assistance with transitions - especially to adult services.	42.86% 9	33.33% 7	23.81% 5	21
A medical home knows its population. The practice has ways to identify children/youth who need extraordinary care. They know and remember their population of children and families.	4.76% 1	23.81% 5	71.43% 15	21

6 - Please indicate the 3 components of a medical home that are most critical to your child's care. Choose your top three. (n = 23)



7 - Of the topics below, what would you be willing to take action (e.g. go to a workshop, attend a webinar, etc.) to learn more about? Choose all that apply

Answer	%	Count
Your role as part of a medical home	47.83%	11
How to shape your medical appointment	8.70%	2
Preparing for a medical appointment	8.70%	2
Forming partnerships for care coordination	78.26%	18
Other (Please Specify) - availability of medicaid coverage for services, supplies, etc.	4.35%	1
None of these	13.04%	3
Total	100%	23

8 - What would you be willing to do to get "medical home" type services for your child? Choose all that apply

Answer	%	Count
Ask your primary care doctor whether his/her practice follows the medical home model	63.64%	14
Attend a workshop to learn more about medical home	54.55%	12
Search out care coordination services beyond your doctor's office	50.00%	11
Other (please specify) - Research the specific medical home model being used to see whether it seems appropriate.	4.55%	1
Total	100%	22

9 - Would you pay out-of-pocket for care coordination services if your doctor's office did not adequately provide them?

Answer	%	Count
Yes	17.39%	4
No	21.74%	5
Depends on the cost	60.87%	14
Total	100%	23

10 - Rank the transitions where extra assistance would be most helpful.

Question	1	2	3	4	5	6	7	8	9	10
Pediatric to adult healthcare services	45.45%	10	18.18%	4	13.64%	3				
Hospital stay discharge to home	4.55%	1	27.27%	6	36.36%	8				
Home care/illness to school	18.18%	4	22.73%	5	31.82%	7				
Primary care provider to specialists	22.73%	5	27.27%	6	18.18%	4				
Other (please specify)	9.09%	2	4.55%	1	0.00%	0				

11 - Of the activities that happen between medical visits/hospital stays, what takes you the most time to manage. Please rank from most time to least time.

Question	1		2		3	
General communication	21.74%	5	17.39%	4	4.35%	1
Prior authorizations	8.70%	2	30.43%	7	21.74%	5
Scheduling appointments - especially sub-specialists	13.04%	3	8.70%	2	17.39%	4
Contacting insurers	26.09%	6	13.04%	3	13.04%	3
Obtaining, refilling, arranging for prescriptions	17.39%	4	4.35%	1	13.04%	3
Obtaining/arranging for equipment	0.00%	0	8.70%	2	21.74%	5
Arranging in-home assistance/providers	8.70%	2	17.39%	4	4.35%	1
Other (please specify)	4.35%	1	0.00%	0	4.35%	1

11 - Of the activities that happen between medical visits/hospital stays, what takes you the most time to manage. Please rank from most time to least time.

Other (please specify)

The following two options do not apply

not really sure what you are talking about..."activities between medical visits/hospital stays"

finding available services

Getting hihgmark to accurately process and make payment for my out of network bills from my child's psychologist since ICD-10 began. He hasn't been paid by them since 9/2015! this is awful!

communication from doctors to school after surgery/hospital stay

paperwork for medicaid renewal and FMLA leave

12 - In the last year, what was the biggest barrier to receiving coordinated care for your child?

Answer	%	Count
Doctors not communicating with one another	21.74%	5
Lack of linkage with your child's school	8.70%	2
Insurance issues	26.09%	6
Difficulties in scheduling services/therapies	8.70%	2
Needing to continuously educate healthcare providers about your child	17.39%	4
Other (please specify)	17.39%	4
Total	100%	23

12 - In the last year, what was the biggest barrier to receiving coordinated care for your child?

Other (please specify)

My child is a medical marijuana card holder, and many doctors do not want to have that conversation

insurance issues...trying to explain to insurance why my child needs an extra or different than usual insurance (dental appts more than 2/yr, sensory issues leading to the need for 2 appts for what most can do in 1, etc)

Insurance, medical supply company, and doctors not communicating with one another.

n/a - Care had been coordinated appropriately

13 - Who should provide general information to you about the medical home model? Choose your top two

Answer	%	Count
Your social worker/ community care assistant	34.78%	8
Your primary care provider	65.22%	15
Staff in your primary care provider's office	26.09%	6
Specialists	17.39%	4
Your parent support group/ organization	4.35%	1
Your insurance company/ payer/ Medicaid	17.39%	4
Advocacy organizations	17.39%	4
Faith community	0.00%	0
Recreation programs	4.35%	1
Media and public health campaign (e.g. billboards)	8.70%	2
Other (please specify)	0.00%	0
Total	100%	23

14 - How would you want to receive information about the medical home model? Choose your top two

Answer	%	Count
In person meetings	30.43%	7
Website content	39.13%	9
Printed material	21.74%	5
Via email	52.17%	12
Mobile app	8.70%	2
Workshops	17.39%	4
Helpline telephone	0.00%	0
Webinar	13.04%	3
Via postal mail	17.39%	4
Other (please specify)	0.00%	0
Total	100%	23

15 - If you could make one change to the healthcare system that serves your child, what would it be?

Answer

24 hour care, when needed

Easier communication with insurer

Improvements to parent education

Better communication between doctors

Doctors actually talking to each other

More specialized providers

That they would recognize that children with disabilities might need more/different medical services, like 2 appointments to accomplish what insurance only pays for 1 appointment, or coverage of 3 dental cleanings a year because my teenage son doesn't have the fine motor skills to really brush his teeth effectively, etc

more communication between school and dr offices

Having primary care providers working with providers that will service my daughter when she can no longer see her provider when she reaches 21.

15 - If you could make one change to the healthcare system that serves your child, what would it be?

Answer

Improve communication between specialists

Please see number 11 comments under other category. This really has been a nightmare to navigate this year with Highmark!

Feeling that physicians themselves are more accessible, particularly specialists when you've got a medically complex child.

easier access to services and providers... Too many hands in the pot and the parent is stuck in the middle ... PCP needs to get the prior auth for DME... DME was rx'd by specialist, Parent must first find out where to get the DME, then has to contact the specialist to have them send rx to DME provider, then parent has to contact DME provider to see where the rx is to only find out that a prior auth is required, Parent has to contact PCP to get prior auth sent to insurance, PCP has to get notes and rx from specialist, Parent has to follow up with Specialist to see if they forwarded rx and notes to PCP, then parent is calling DME provider, PCP, Specialist, insurance, around and around and fighting over if the items/ services are even covered, then to see who dropped the ball, who still needs what from who to get the claim approved, it could be months if ever before child gets required services/ supplies.

Better communication

15 - If you could make one change to the healthcare system that serves your child, what would it be?

Answer

easier communication by email to psychiatrist

communication between all his providers

Insurance issues

Follow up care and resources

Make insurance easier to coordinate

That my insurance company didn't make so many mistake (approximately one out of every three explanations of benefits contains an error which requires my spending time on the phone during work hours to correct.)

16 - Please feel free to share any comments about Medical Home and Care Coordination.

Answer
There is not enough information to the public
I feel the family community in general doesn't really know what this is. We need to educate families
ours STINKS
Interested in attending workshops on this model.
The name "Medical Home" does not sound like what it actually represents - very confusing when a family first hears about it.
I thought EMR would have eliminated this run around. it should be easy enough for the insurance company to see what the pt needs and who pars w/ their company and they should arrange the services.
I spend more time on the phone trying to get prescriptions from Walgreens pharmacy
I would be somewhat leery of whether our health care information would be shared appropriately in a way which didn't lower security