

Families Know Best Survey- February 2013

Topic: Transition

What is your child's disability or health condition?

Text Response
Traumatic Brain Injury
high functioning autism
multiple disabilities, CP
Down Syndrome, hearing impaired
PDD-NOS, Ehlers-Danlos Syndrome
Rett Syndrome
Dandy-Walker Malformation (mental retardation)
right hemisphere polymicrogyria, left hemiparesis, epilepsy, developmental delay
Trisomy 21
Down Syndrome, PDD-NOS, Hearing Impairment
Autism
brain disorder similar to severe cp
Autism Spectrum Disorder

What is your county of residence?

#	Answer	Response	%
1	New Castle County, DE	8	62%
2	Kent County, DE	2	15%
3	Sussex County, DE	0	0%
4	Other - Pennsylvania Resident	2	15%
5	Other- New Jersey Resident	1	8%
6	Other- Maryland Resident	0	0%
	Total	13	100%

Is your child 14 or older?

#	Answer	Response	%
1	Yes	3	23%
2	No	10	77%
	Total	13	100%

Has your pediatrician or primary care provider discussed transition to an adult provider for when your child ages out of pediatric care?

#	Answer	Response	%
1	Yes	0	0%
2	No	3	100%
	Total	3	100%

Has any medical specialist discussed transtion to an adult provider for when your child ages out of pediatric care?

#	Answer	Response	%
1	Yes	1	33%
2	No	2	67%
3	My child does not see any specialists	0	0%
	Total	3	100%

Are you aware that you can contact your insurance provider (case manager) for assistance with transition?

#	Answer	Response	%
1	Yes	2	15%
2	No	11	85%
	Total	13	100%

Does your child have the following? (check one):

#	Answer	Response	%
1	Individualized Education Plan (IEP)	2	100%
2	504 Plan	0	0%
	Total	2	100%

Did your child's school perform any transition assessments (vocational/ educational)?

#	Answer	Response	%
1	Yes	1	50%
2	No	1	50%
	Total	2	100%

Did your child's school provide you with a transition family/student survey?

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

Did your child move from Early Intervention Services to school-based services?

#	Answer	Response	%
1	Yes	9	75%
2	No	3	25%
	Total	12	100%

What would have helped to better prepare your child for that transition?

Text Response

A bullet list of issues that needed to be addressed including some information on the emotional difficulties of moving from such an insulated experience to a more widespread delivery of services.

My child is now an adult (28) Until we moved to DE 2 years ago, no one had EVER mentioned transition services

It would have been helpful to have a helpful and knowledgeable Family Support Coordinator.

The transition from early intervention was smooth.

A school system without a "one size fits all mentality" . We decided to move from Red Clay to Colonial.

more visits to the classroom and with the therapists she would be seeing at the school

Smoother transition from Child Watch to Special Education within the school district.

that transition was handled well. A visit to the school ahead of time would be my only suggestion.

School outreach; direct communication between early intervention and school

Does your child receive Medicaid benefits?

#	Answer	Response	%
1	Yes	9	69%
2	No	4	31%
	Total	13	100%

Do you know at what age your child's Medicaid coverage ends?

#	Answer	Response	%
1	Yes	2	22%
2	No	7	78%
	Total	9	100%

Do you know about possible benefits for which your young adult may be eligible? (Medicaid, Social Security Income, SSDI)

#	Answer	Response	%
1	Yes	7	54%
2	No	6	46%
	Total	13	100%

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

Text Response

I recently took a course on transition through Houlston Institute sponsored by Autism Speaks. This 12 week online course was a wonderful course to help anyone (parents, teachers, administrators, etc).

We need to ensure that multiple points of contact (i.e., doctors, therapists, schools, etc.) know to start stressing transition at an early age, not when the child is about to transition out of their current services.

Thanks to Anne @ Family Voices, we see Dr. Jennifer LeComte and she is the best doctor we have EVER had! She not only sees our disabled adult but my me and my husband as well.Thank you Anne!!

I contacted the school district myself in order to prepare my daughter for transition from EI to school.

I do not have any knowledge yet regarding SSI benefits or transitioning after graduation. I think the school supplies that information once she reaches age 14.

I am using the assistance of the "transition of care" team at Nemours, along with the school district.

I'd like to see earlier involvement by both DDDS and DVR vs child's senior year. I'd like both agencies involved where applicable

It does not exist in s hooks in DE