

Learning the Impact of a disability on the person/child/family

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(LEND)

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Background

- Based on my personal experience, there seems to be a need to have more professionals in dialogue with families and persons with disabilities regarding the nature of their disability.
- In my experience, as a child, I had limited knowledge of my disability and why I received certain services. For example, I didn't know about the side effects of my disability and why certain services/treatments would help.
- This lack of understanding led to frustration, both from the disability and from lack of communication with me about my disability. Without a solid foundation/understanding of your disability, you don't have a path forward to success. I was told "do this" or "this is best", but no one motivated me by telling me about how these services and skills would help me.

Purpose

- How do parents and people with disabilities learn about their disability?
- Do they get communication from professionals who are providing services to them about how the service would help them?

Methods

- Two surveys were developed: One for parents of children with disabilities and one for people with disabilities.
- These anonymous surveys were sent to graduates of Partners in Policymaking and the CT ARC lists. In addition, they were disseminated to the youth at CT-KASA. Over 500 were sent out through Survey Monkey.
- 30 Families responded and 17 people with disabilities responded.

Self Advocate responses: Who gave you the information about your disability? (Check all boxes that apply)

• Answered: 17 Skipped: 0

ANSWER CHOICES	RESPONSES	
Parent(s)	70.59%	12
Other family member	23.53%	4
Doctor	76.47%	13
Other service provider	47.06%	8
Friend	0.00%	0
Support groups	11.76%	2
Other people with disabilities	17.65%	3
No One	0.00%	0
Other (please specify)	23.53%	4
Total Respondents: 17		

Self Advocate Responses: Who explained the therapies, special education and other services and the reasons for these services?

- Answered: 17 Skipped: 0

ANSWER CHOICES	RESPONSES	
Parent(s)	47.06%	8
Other family member	23.53%	4
Service provider	52.94%	9
No One	17.65%	3
Total Respondents: 17		

Parent Responses: How did you learn about your child's disability? (Check all that apply)

- Answered: 29 Skipped: 1

ANSWER CHOICES	RESPONSES	
I learned on my own	68.97%	20
resources from friends or others	34.48%	10
Internet	44.83%	13
Resources from othr professionals	62.07%	18
Support group	13.79%	4
Meetings/conferences	41.38%	12
Other (please specify)	24.14%	7
Total Respondents: 29		

Parent Responses: How did your child participate independently in making decisions about the services or supports he/she needs. (Check all that apply)

• Answered: 29 Skipped: 1

ANSWER CHOICES	RESPONSES	
Went to the IEP meeting	55.17%	16
Saw the doctor alone	20.69%	6
Went to social events/recreational events alone	24.14%	7
Went to other events	27.59%	8
Went to leadership training	17.24%	5
Other (please specify)	55.17%	16
Total Respondents: 29		

Discussion

- Professionals do not engage with people with disabilities about the impact of their disability and the rationale for certain services.
- Parents learn about their child's disability from many, many sources. Most learned on their own, from the internet or at conferences, in addition to hearing from professionals.
- Youth with disabilities are not engaging independently in their IEP meetings, visits to doctors or other events where they might learn more about their disability.
- More professionals need to engage with youth and adults with disabilities about their disability, the impact of their disability, their services and the rationale for services.
- Most importantly, all this discussion will help youth and adults with disabilities know how to build good lives with the challenges they have.

QUESTIONS?