

The Arc of New Jersey Family Institute Spring 2014 Family Survey

Executive Summary

Background/Introduction

Throughout 2009 the Family Advocacy Program (FAP) held joint presentations with The Division of Developmental Disabilities (DDD) on “Navigating the New System.” From these presentations it became apparent that there was a lack of data regarding the needs of families caring for a family member with intellectual and developmental disabilities (I/DD). In response to this need, the FAP created a survey in 2010 to gather information and to guide the program’s outreach. The survey was distributed to families via email distribution lists and shared on websites. The FAP used the information collected from that survey to develop the Program’s goals and objectives.

In 2014, The Arc of New Jersey Family Institute (FI) was established to expand the supports and services of the Family Advocacy Program, and to address the concerns and issues of families of individuals with (I/DD). It was important for The Family Institute to recognize the issues and concerns of the past survey, but also to recognize that the service systems for individuals with I/DD are ever-changing. Many families were switched from DDD to the Department of Children and Families (DCF) without any transition or explanation. And, with the impending roll-out of fee-for-service and the Supports Program, families now had new concerns and worries.

In order to gain a perspective of the new concerns families are experiencing, The Family Institute updated the 2010 survey and distributed it to help identify what families need now. The survey remained confidential and was posted online for 2.5 months. The survey was distributed through the FAP networks, forwarded to every local county chapter of The Arc and all major disability related organizations and community partners, and shared countless times on family support group Facebook pages.

A total of 631 respondents completed the survey. Of those participants more than 100 were added to the FAP network.

The results of the survey below help identify the areas of interest and needs of families but also the best approaches for providing this information. Following the survey results are recommendations for the direction The Family Institute should take in addressing the issues of concern to families.

Survey Limitations

There are several survey limitations which need to be kept in mind when looking at the results. While the results may be representative of what families need or want, it is best not to assume it is a full representation of families across the state of New Jersey.

- The survey was distributed to families connected with The Arc of NJ, a local county Chapter of The Arc or possibly some other community agency. While it was encouraged that people forward the survey to other families, the predominant population of respondents came from families already engaged with the community.
- The survey was posted online, so families without access to the Internet or not comfortable using online applications could not participate.
- The survey was only available in English.
- Some of language utilized in the survey may be new for families and a guide, or key, was not utilized to explain what certain terminology meant or represented.
- Many of the questions required families to choose from a list of pre-identified answers. For instance, when families were asked to rate levels of concern on issues, the issues were already identified. This may cause families to choose items they wouldn't normally select and/or not identify other areas of concern.

Despite the limitations, the survey provides great insight into the issues and concerns of families caring for a loved one with I/DD and how The Family Institute can address those concerns and help support families in navigating the service delivery system.

Part 1: Demographics

Questions 1-6 ask respondents to identify their county of residence, their relationship to the person with I/DD, where that person lived, and the person with a disability's age and diagnosis.

Q1: What is your relationship to the individual you care for with an intellectual and developmental disability (I/DD)?

Answer Choices	Responses	
Mother/Father	90.79%	572
Sibling	6.51%	41
Grandmother/Grandfather	1.90%	12
Aunt/Uncle	0.79%	5
Total		630

Q2: What is the age of the individual you care for with I/DD?

For this survey, we felt it was important to break the ages down by eligibility age ranges for services. The age breakdowns were: 0-3 (Early Intervention), 4-13 (Special Education/DCF), 14-21 (transition/DCF), 22-50 (DDD), and 50+ (DDD/Senior Services).

Answer Choices	Responses	
0-3	1.27%	8
4-13	16.98%	107
14-21	24.76%	156
22-50	52.38%	330
50+	4.60%	29
Total		630

Q3: What county do you reside in?

- In the previous survey from 2010, the county of residence was omitted. The Family Institute felt it was important to identify where families lived so that we could address areas of concern geographically. Every county was represented quite evenly except Salem County (0), and Hudson (5) and Cape May (8) Counties. The largest number of respondents came from Middlesex County (58), Morris County (57), Camden County (54) and Somerset County (53).

Q4: Does the individual you care for with I/DD live within your home?**Q5: If no, where do they reside?**

- Since housing has been a big concern across the state of New Jersey, we felt it was important to know how many people with I/DD were residing within their family's homes. Of the 631 participants, 549 families indicated that their family member with I/DD lives with them. Of the 71 who identified an out of home residence, most live in a group home (21) or a supported apartment (12), some reside in residential treatment facilities, specialized institutions or developmental centers (23) and some live on their own or with other friends or family (15).

Q6: Please identify the diagnosis of the person with I/DD

- Respondents were allowed to select more than one diagnosis. Many respondents also used the comment field on this question to list specific syndromes or disabilities not identified. The majority of individuals were diagnosed with Autism Spectrum Disorder (237 or 43%), Intellectual Disability (208 or 38%) or Processing Communication Disorder (104 or 19%).

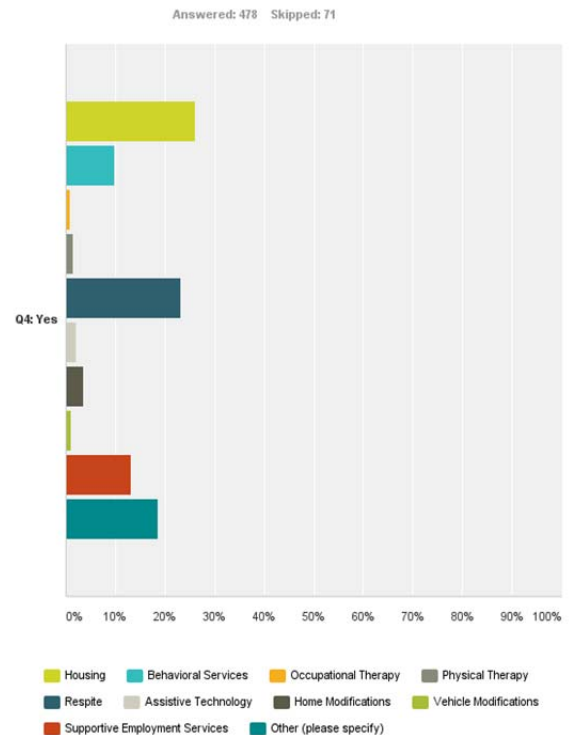
Answer Choices	Responses	
Autism Spectrum Disorder (Including Aspergers/PDD-NOS)	43.33%	237
Processing/Communication Disorder	19.01%	104
Cerebral Palsy	15.90%	87
Down Syndrome	14.81%	81
Fetal Alcohol Spectrum Disorders	1.28%	7
Fragile X Syndrome	1.83%	10
Intellectual Disability	38.03%	208
Mental Illness	6.95%	38
Spina Bifida	1.28%	7
Traumatic Brain Injury	2.56%	14
Vision Impairment	6.76%	37
Hearing Impairment	5.85%	32
Speech Impairment	17.55%	96
Total Respondents: 547		

Part 2: Issues and Concerns

Questions 7-14 ask respondents questions related to supports and services for the family member with I/DD.

Q7: If you could have any one service of your choosing tomorrow, what would it be?

- The most significant response choices included:
 - Housing (147)
 - Respite (113)
 - Supported Employment (74)
 - Behavioral Services (54)
 - “Other” Responses: Transportation, Speech, and Socialization/Recreational Activities.
- For respondents who indicated in Q4 that the individual with a disability lived in their home, 125 respondents indicated Housing and 112 respondents indicated Respite.



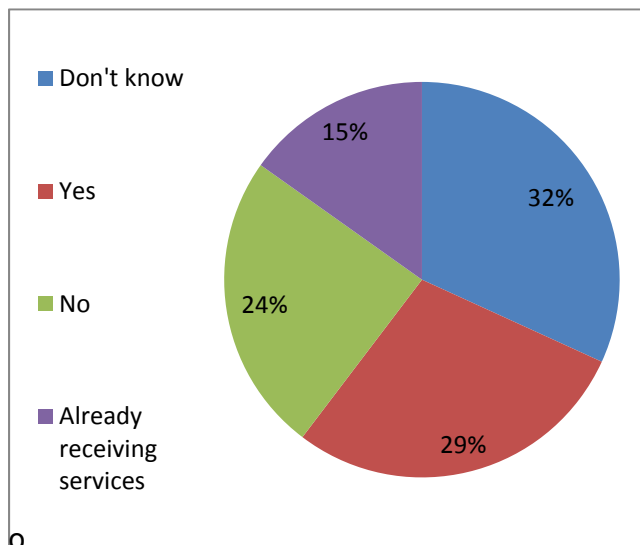
- Q8: Rate your level of concerns for the following services**
 - Respondents were asked to indicate if they were not concerned, a little concerned, indifferent, concerned or most concerned about 17 specified issues/concerns. Answers were tabulated to create average ratings for each area of concern.
 - The average ratings for each category were very closely scaled. There was only a 2 point different between the highest and lowest rated issues.
 - The ranking of concerns were:

Qualified Providers (4.29)	SSI (3.74)
Housing (4.12)	Community Care Waiver Waiting List (3.70)
Family Support Services (4.04)	Day Program (3.64)
Support Coordination (3.95)	Medicaid/Medicare Eligibility (3.60)
Safety Within the Community (3.94)	Transition from School to Adult Life (3.41)
Transportation (3.92)	Transition from DCF to DDD (3.29)
Fee For Service (3.83)	Healthy Sexuality (3.19)
Supported Employment (3.80)	Early Intervention (2.29)
Case Management (3.77)	

- **Q9: If you could change two things about the system or services for people with I/DD, what would that be?**

- This was an open-ended question
- A response matrix was developed to group respondent's answers into categories.
 - There were no trending response from age category 0-3
 - Families of those ages 4-13 indicated:
 1. More transparency from DDD regarding the availability of services.
 2. Training of non-disabled community members about I/DD
 3. Advocacy on behalf of individuals with I/DD.
 4. Assignment of a Case Manager from birth to help family navigate the system, more "hand holding" through the process.
 5. Quicker processing and attention of application and requests
 - Families of those ages 22-50 indicated:
 1. Less delays with housing, more information, choices and availability
 2. Improved quality of care
 3. Clear, simplified application process, less paperwork
 4. Access to services with waiting
 5. The way transportation is offered and organized
 - Families of those ages 50+ indicated
 1. Housing
 2. More guidance and assistance from case managers
 3. Less changes to programs that work (Real Life Choices, Self Direction)

- **Q10: Is your loved one on the waiting list for the Community Care Waiver (CCW)?**



- 32% of respondents didn't know, 29% of respondents indicated their loved one had never applied for the CCW, 25% of respondents indicated yes and 15% of respondents indicated their loved one was already on the CCW.

- **Q11: If your loved one is on the waiting list for the CCW, what are they waiting for?**

- Respondents could choose more than one answer.
- Of the 123 respondents who answered the question, 103 indicated they were waiting for housing and 31 indicated they were waiting for respite.

- **Q12: What services does your family member currently receive?**

- Respondents could choose more than one answer.
- Of the 179 respondents, 92 indicated day program and 71 indicated respite.

Answer Choices	Responses	
Behavioral Services	10.06%	18
Occupational Therapy	3.91%	7
Physical Therapy	2.79%	5
Respite	39.66%	71
Assistive Technology	2.23%	4
Home Modifications	2.79%	5
Vehicle Modifications	2.79%	5
Supportive Employment	17.32%	31
Day Program	51.40%	92
Transportation	26.82%	48
Housing	12.85%	23
Total Respondents: 179		

- **Q13: Do you feel these services are appropriate to your family member's need?**

- 61% indicated yes, 30% indicated no and 8% were not sure

- **Q14: Have you heard of the DDD upcoming Supports Program?**

- Of the 480 respondents, 48% indicated no, 39% indicated yes and 13% were unsure.

Part 3: Information Dissemination and Education

Questions 15 – 23 related to the kinds of information families were looking for and how they wanted to receive this information.

- **Q15: If you could only choose one method, how would you like to receive information about things going on in the DD community?**

- It is important to note that this survey was distributed electronically, so the majority of families were already utilizing electronic media. Families not connected to the internet were likely not participants of this survey.
- Of the 480 respondents, 365 selected email and 79 selected mail.
- In the age groups covering 0-21, most families reported utilizing **social media** as their primary way of accessing information (Facebook, Twitter) or school events.

- **Q16: What topics would you attend if offered as an in person workshop?**

- Families of those ages 0-3 were most interested in Special Needs Trusts
- Families of those ages 4-13 were interested in SSI Eligibility, Medicaid/Medicare Eligibility, Special Needs Trust, Advocacy Training, Guardianship and Individual Support Plans.
- Families of those ages 14-21 were most interested in Transition from school entitlements to Adult Life, Individual support Plans and How to Prepare, Fee for Service, Self-direction & Support Coordination
- Families of those ages 22-50+ would attend in-person trainings on Fee for Service, Self-Direction, Service Delivery Systems and Support Coordination

- **Q17: What topics would you participate in if offered as a Webinar?**
 - Families of those ages 0-3 were interested in Medicaid/Medicare and Special Needs Trusts.
 - Families of those ages 4-13 and 14-21 were equally interested in all the topics offered (aside from Early Intervention).
 - Families of those ages 22-50 were mostly interested in Self-Direction, Fee for Service and Support Coordination.
 - Families of those aged 50+ were interested in Fee for Service, Medicaid/Medicare Eligibility and Support Coordination
- **Q18: How many miles would you travel for a free workshop or seminar?**
 - 31% of respondents indicated they would travel 5-10 miles and 31% indicated 15-20 miles. 25% of the respondents indicated it would depend on the topic.
- **Q19: What prevents you from attending workshops, webinars and trainings?**
 - 376 of the 480 respondents indicated time/location/day of the week. 158 respondents indicated lack of a sitter or respite care.
- **Q20: How do you connect to other families of individuals with I/DD?**
 - Out of 480 responses, 157 indicated they do not connect with other families. 142 indicated support groups and 123 indicated social media.
 - 118 respondents indicated “other”, and listed social activities, Special Olympics and recreation programs.
 - Families of those aged 22-50+ indicated that they are not connected to other families. They attend workshops or may socialize with families from when their children were in school but the majority do not have connections to other families in their community.
 - Families of those ages 0-22 connected equally through social media and school events.

	Support Groups	Social Media (Facebook, Twitter, etc)	School Events	Workshops/Trainings	I don't connect with families	Other (please specify)	Total
Q2: 0-3	25.00% 1	50.00% 2	25.00% 1	0.00% 0	0.00% 0	0.00% 0	4
Q2: 4-13	40.24% 33	52.44% 43	37.80% 31	17.07% 14	24.39% 20	7.32% 6	147
Q2: 14-21	31.85% 43	28.89% 39	35.56% 48	25.93% 35	29.63% 40	22.96% 31	236
Q2: 22-50	26.23% 64	15.98% 39	9.02% 22	18.85% 46	36.07% 88	31.56% 77	336
Q2: 50+	6.67% 1	0.00% 0	0.00% 0	13.33% 2	60.00% 9	33.33% 5	17
Total Respondents	142	123	102	97	157	119	480

- **Q21: How did you hear about The Arc of New Jersey Family Advocacy Program?**
 - The majority of respondents indicated they had heard of the Program from The Arc of NJ website, through a local county chapter or they were forwarded information from another person or organization.
- **Q22: What additional supports do you feel you could use as a caregiver?**
 - 480 respondents answered the question. They could choose more than one answer.
 - Support groups (243)
 - Support groups were highest selection, particularly in Northern NJ counties.
 - Counseling (174)
 - Counseling, as well as support groups, was indicated in Central NJ, while South Jersey indicated the highest selection of counseling.
 - “Other” (192)
 - Responses included Respite, Workshops, Transparency of DDD and Housing
- **Q23: If you are not currently signed up for the Family Advocacy program, please indicate your contact information**
 - Approximately 138 respondents signed up for the Family Advocacy Program
- **Q24: Additional comments**
 - 90 respondents left additional comments. Many thanked The Arc of New Jersey. Many expressed the need for help in general or related specific issues and problems with their family member.

Part 4: Recommendations for The Arc of New Jersey Family Institute

- Families are overwhelmingly interested in having **educational advocacy** reintroduced as a service of the Family Institute. Families expressed confusion about the IEP process and their rights. Families felt they would benefit from webinars and/or educational materials to help walk them through what they need to know. This was supported both by the survey, in person support group comments and phone calls to the FI.
- Families would benefit from a **master resource list on The Arc of New Jersey and The Family Institute websites** that provide county based links to reputable agencies and activities throughout New Jersey.
- Many families reiterated that there are **too many organizations** engaged in the same activities. They expressed that they felt it was difficult to keep abreast of everything and know what is most important and helpful. The Family Institute is working with Autism NJ, among many other organizations, to share information and hopefully streamline supporting and advocating for families.
- Families indicated a need for the **roles of government entities** to be clarified. The Family Institute recommends creating documents that help families navigate through the systems.
- The Family Institute recommends having **information** on how to become eligible for services, and how to obtain Medicaid and SSI, and why these are important.
- Re-advertising webinars every 6 months, or close to graduation time, will help reach new families entering the system.
- The Family Institute recommends **clarifying the differences between The Arc of New Jersey and Local County Chapters of The Arc**. Many families and professionals would benefit from clarity on the structure of the organization, and which office to contact regarding issues, concerns and advocacy.
- **Outreach to families who are not connected electronically**. Compile a list of those families to send important updates that are pertinent to their loved ones via US mail.

- Continue to **develop relationships with support group facilitators, families and family mentors** across the state of NJ. Clearly, by the survey results, the southern counties of NJ are less connected to The Arc of NJ.
 - From in-person meetings in Northern New Jersey, it was clear that it is imperative to have someone available to translate. There are many Spanish speaking support groups that can be tapped into and those families need the information.
- Work with the Planning for Adult Life Program in establishing an **ongoing webinar series** that addresses these surveys findings but also can reach families of those over age 21.
 - Create materials to help prepare families in completing assessments (DDRT/NJCAT)
- Develop and maintain **easy to understand and transparent information on the website** regarding all topics of concern for families. (i.e. Housing, Family Support Services)
 - It is recommended to break the information down by age group so that families can easily identify the categories most useful to them.
 - It is recommended, based on “other” comments from the survey that families are looking for clear explanations of the language utilized by DCF and DDD. An “alphabet soup” of definitions has been created for the website and should include any and all language, abbreviations and acronyms that families may come in contact with when working within the service delivery systems.
- Over 1/3 of families who completed the survey are interested in attending support groups. **Linking families to established supports groups or developing local support groups** is necessary to connect and empower families.
- Families indicated that they could benefit from counseling. The Family Institute should **research resources for families to find qualified counseling professionals** that work with the I/DD population. If possible, The Family Institute could help foster these relationships with professionals or support families with grants.
- Families indicated they **need** more “Family Support Services” from DDD. The Family Institute should **work with the Family Advocacy Program in training families to become more active and involved in advocating** for more services and transparency.
- The Family Institute should develop a plan to reach out to younger families.
 - Develop mechanisms to connect with pediatricians, hospitals, child special health services, etc.

The 5 Highest Concerns of Families Surveyed

1. **Lack of clear information on how to access services and navigate the service systems**
 - Keeping up to date and trusting the information source
2. **Housing Issues**
 - Planning for housing and “how to” information
 - Transparency and a thorough analysis of the CCW and waiting list
 - Data that supports need for future housing
3. **Educational Advocacy**
 - IEP support and Parental Rights information
4. **Supports Program**
 - Support Coordination Interim Policy issues
 - Low individual budgets
 - Budgets limited to month by month (use it or you lose it)
 - Self-Directed Day Program budgets limited to 3-4 days a week
 - Fee for Service
5. **Quality of care**
 - Training for direct care staff
 - Direct Support Professional Issues (compensation, turnover)