NAVIGATING MULTIPLE SYSTEMS
PARENT/FAMILY MEMBER/CAREGIVER SURVEY RESPONSES
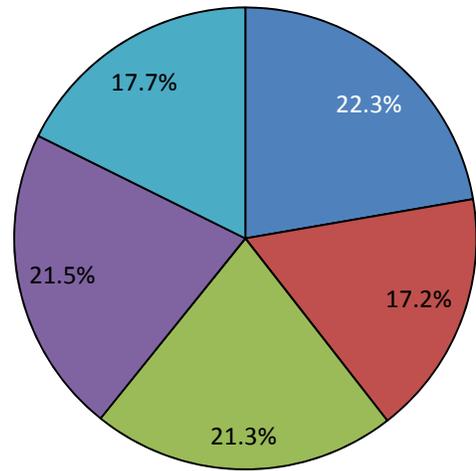
Purpose of Survey

The Navigating Multiple Systems Initiative is a statewide collaboration led by the New York State Council on Children and Families with funding from the New York State Developmental Disabilities Planning Council.

The purpose of this survey was to learn from parents and providers about the types of information that were useful to them in obtaining services for children across multiple systems. Particular emphasis was placed on ways user-friendly technology could serve as an information resource.

Overview of Respondents

- The web link to the survey was shared with respondents who were involved in parent advocacy organizations and other agencies. The survey was completed by parents, family members and caregivers via a web-based survey. A total of 462 individuals responded.

- The majority of respondents identified themselves as parents (75%) and family advocates/peer supports (28%).*

- About one in three (36%) of the individuals who responded as 'other' were grandparents, great grandparents or other family members (e.g., siblings, aunts, uncles).

- Many respondents were affiliated with *Parent-to-Parent in NYS* (21.7%) and/or *Families Together in NYS* (19.3%); 22% were unaffiliated.

- Other frequently cited affiliations that were not included in original listing were *Finger Lakes Parent Network* and *RAPP.*

Region of Respondents

- 22.3% Western New York
- 17.2% Central New York
- 21.3% Hudson River/Capital Region
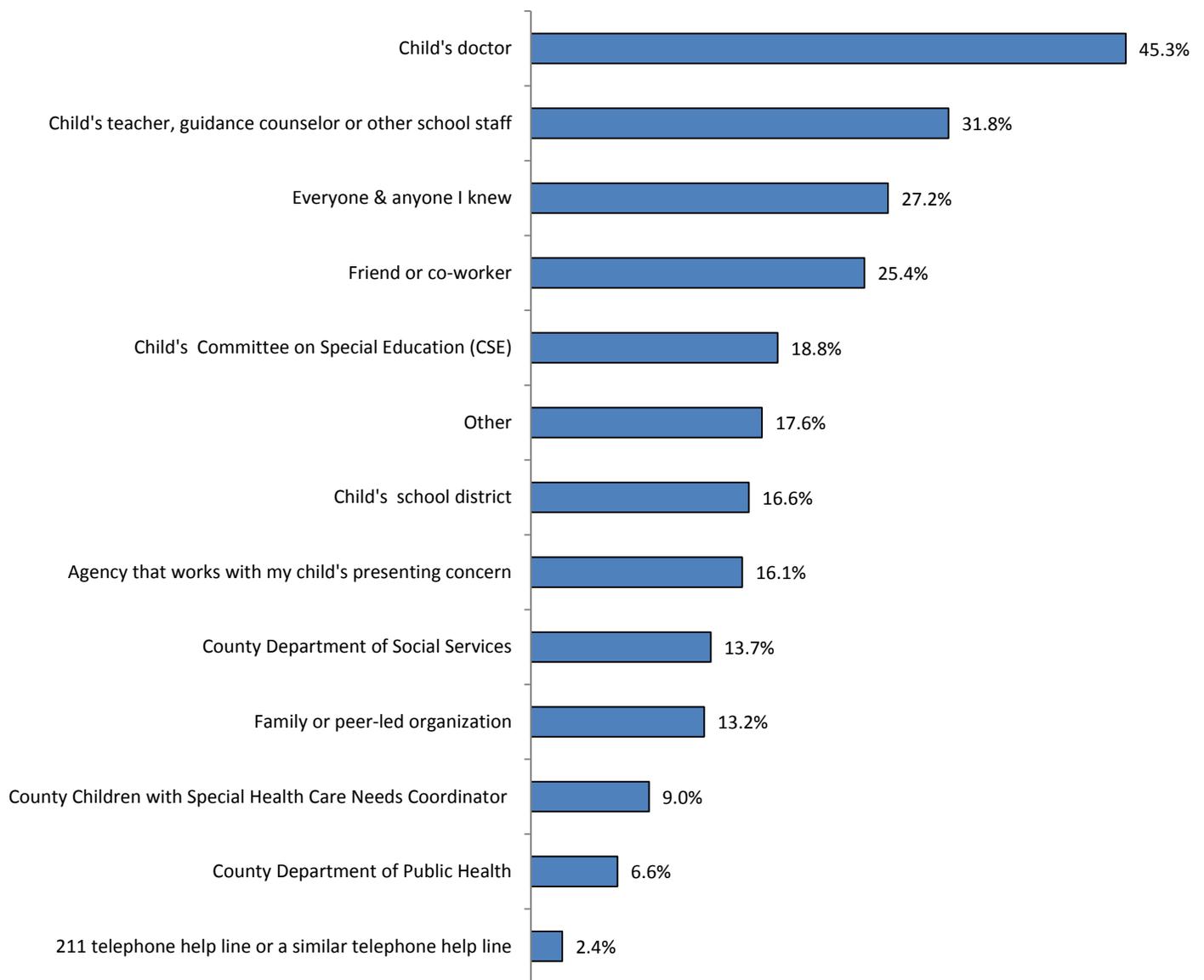- 21.5% New York City
- 17.7% Long Island

■ Western New York
■ Central New York
■ Hudson River/Capital Region
■ New York City
■ Long Island

*Does not sum to 100%; reflects multiple responses.

Initial Supports

- When respondents first recognized the need for assistance, they tended to seek help from physicians or professionals in education, such as teachers, guidance counselors and the Committee on Special Education. While most respondents tended to navigate through traditional routes for assistance, it was recognized that there was no one clear route, as indicated by the fact that 27% of respondents discussed this with "everyone and anyone [they] knew."

- Respondents with children whose needs may have been more apparent at birth (e.g., Down syndrome) did not make the initial contact with service systems. Instead, hospital staff assisted with referrals.

- Among those respondents who selected "other," about one in eight initially sought information and assistance through the internet.

Resources Contacted When it was First Determined Child Needed Assistance

Resource	Percentage
Child's doctor	45.3%
Child's teacher, guidance counselor or other school staff	31.8%
Everyone & anyone I knew	27.2%
Friend or co-worker	25.4%
Child's Committee on Special Education (CSE)	18.8%
Other	17.6%
Child's school district	16.6%
Agency that works with my child's presenting concern	16.1%
County Department of Social Services	13.7%
Family or peer-led organization	13.2%
County Children with Special Health Care Needs Coordinator	9.0%
County Department of Public Health	6.6%
211 telephone help line or a similar telephone help line	2.4%

Barriers Frequently Experienced

- The survey highlighted potentially common barriers that families may encounter and below is a summary of the experience of the respondents. The responses underscore the challenges encountered when family members of children with multiple needs contact specialized systems of care—the specialized expertise of staff and unique features of each system become barriers rather than assets.

- Generally, respondents providing "other" information indicated challenges associated with a lack of services and lack of knowledge about services (among service providers as well as parents).

- Examples of barriers pertaining to specific needs included translation services and supports for siblings.

Barriers Encountered

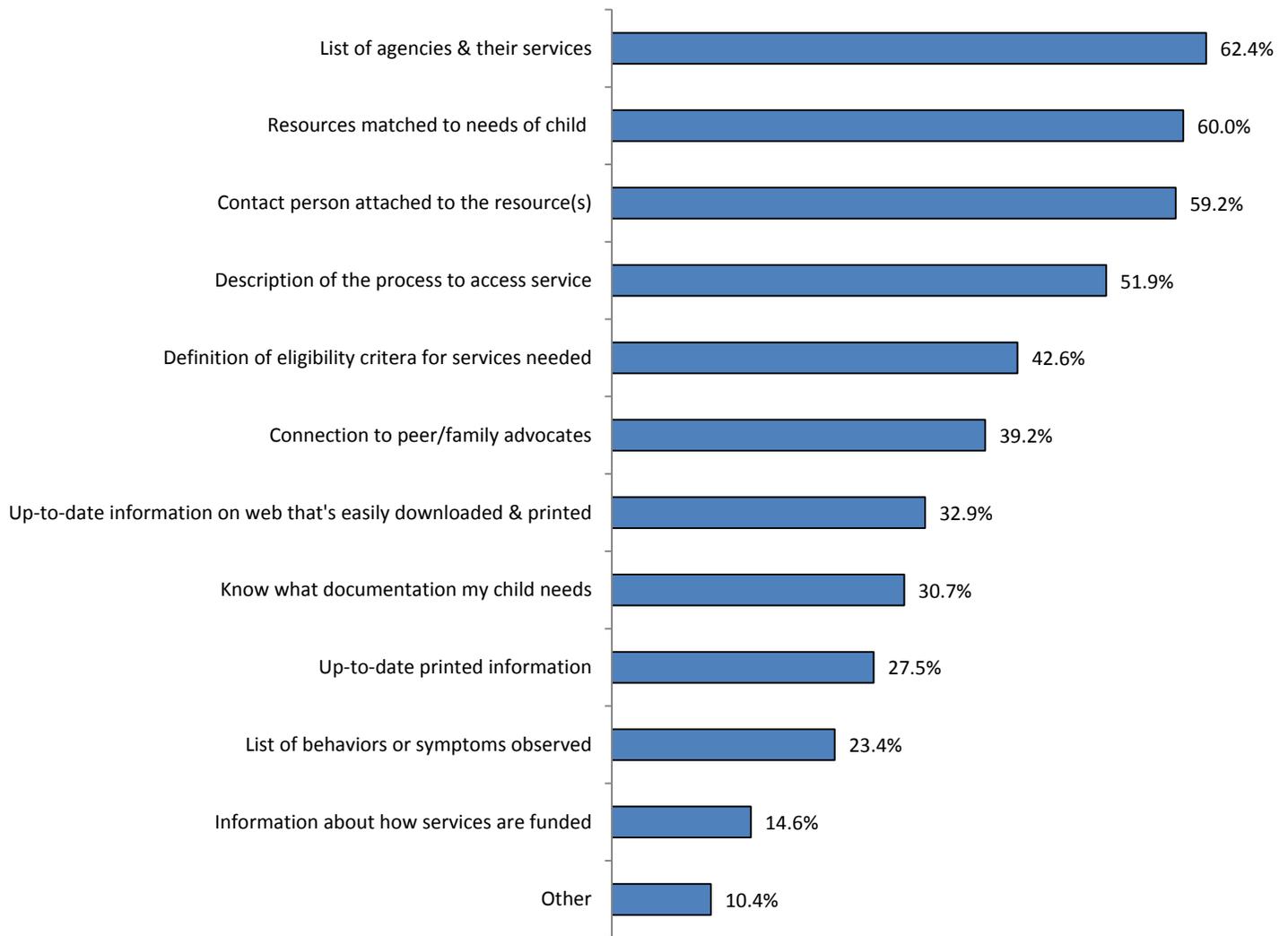| Barrier	Percentage
Contacted multiple agencies.	57.7%
People contacted not familiar with range of available services.	48.8%
Delay between request & receipt of services.	45.8%
Different eligibility requirements for needed services.	44.5%
Help provided by fragmented patchwork of agencies.	42.2%
Went to multiple websites.	36.4%
Different documentation required by each agency.	35.6%
Treatments/supports did not fit child's needs.	32.4%
Calls/e-mails not returned.	26.5%
Other	19.7%
Technology-based information inadequate.	15.4%
Family members not involved in meetings.	11.1%

- Among the responses provided, respondents indicated that personal persistence was fundamental to accessing services.

- It was also noted that knowing what to ask and how to ask it (i.e., use correct terminology) helped them navigate the system more successfully.

- The need for direct contact with knowledgeable individuals clearly is a vital factor to successful system navigation. The contact with other parents, support groups, peer supports or information and referral services was noted the benefit of face-to-face contact as well as via the internet.

- The value of self-advocacy (continuously promoting the needs of their children) and access to training were two aspects of successful navigation cited by respondents who offered "other" comments (e.g., lay advocacy, training through Wildwood).

Factors Related to Successful Navigation

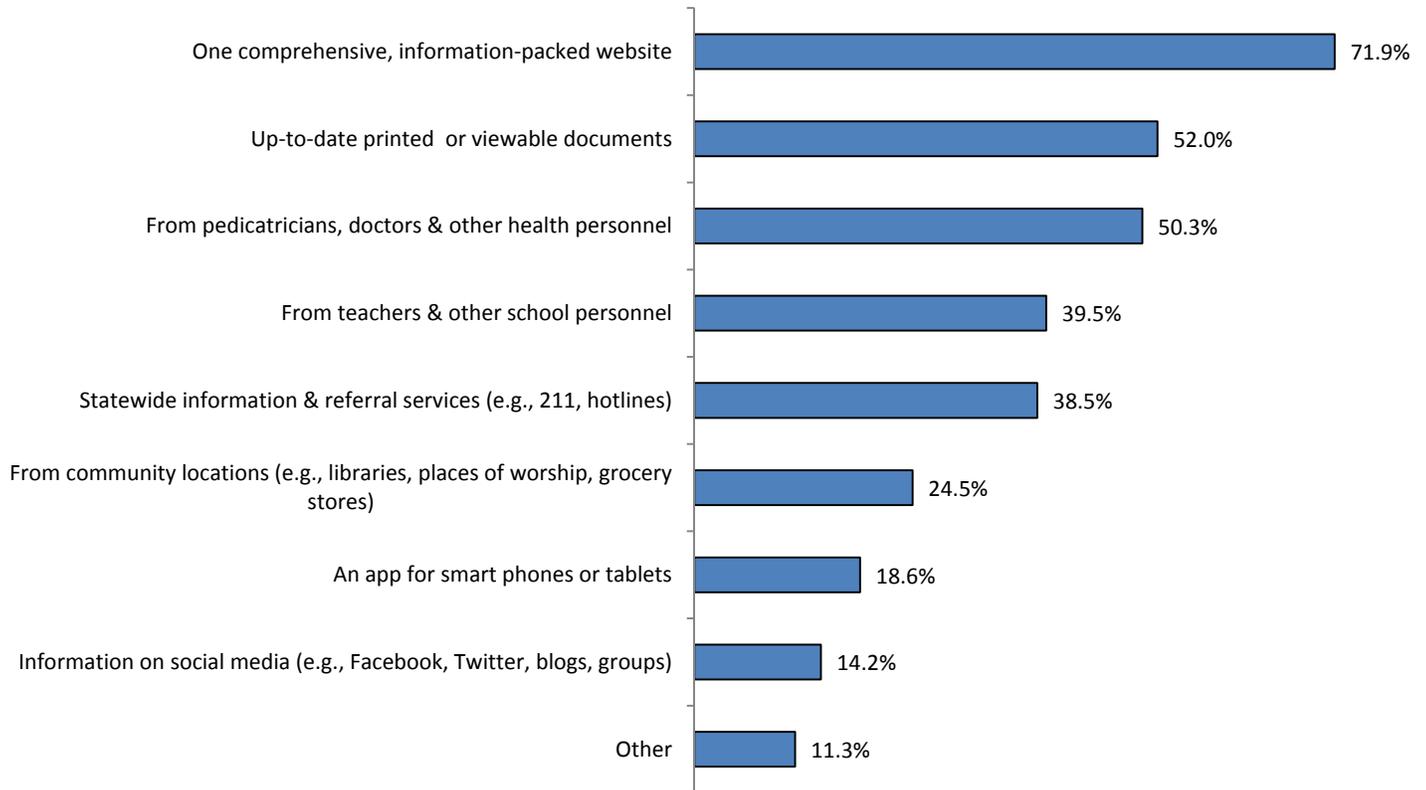| Factor	Percentage
My persistence	81.7%
Learn what to ask	68.2%
Find helpful/ knowledgable person	67.5%
Learn specifics of programs & services	59.7%
Learn the terminology	48.2%
Talk to a parent advocate/partner	47.5%
Use websites	31.9%
Connect with information & referral service	26.8%
Talk to a peer support/mentor	26.0%
Find helpful on-line tool	15.3%
Other	13.1%
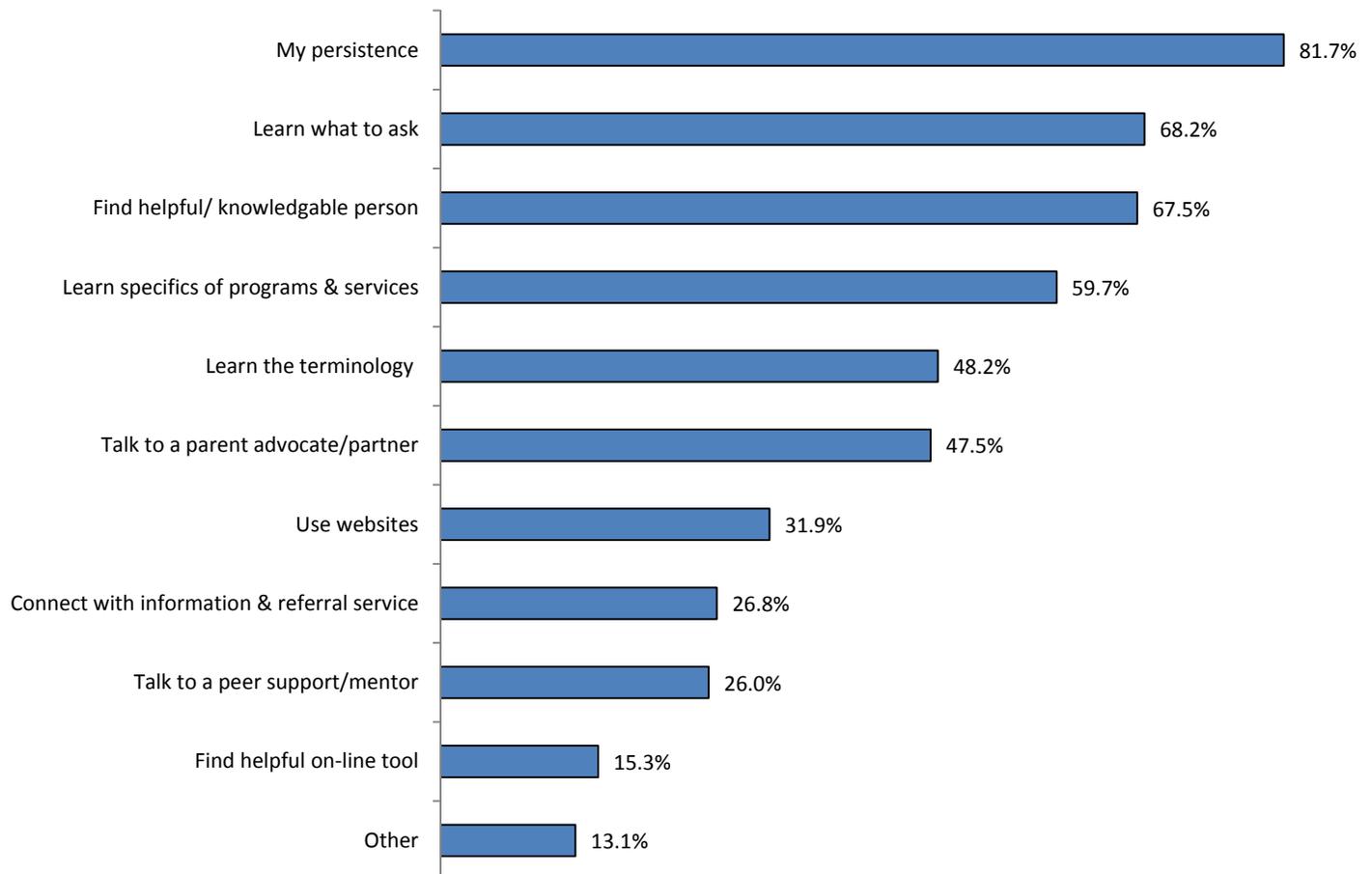
- Respondents shared suggestions regarding the types of information and assistance that has been and would be helpful to them. The suggestions highlighted the value of being able to receive comprehensive information through a single resource.

- "Other" responses underscored the reality that personal circumstances become increasingly complex due to such as: dedicated funding streams, need for service across multiple systems, and lack of available resources within the county or school system where one resides.
    o About two in five responses (39%) reflected the need for **personal interactions**, either with advocates, other parents, or well-trained and bilingual staff, who could help navigate the system.
    o Comments also reflected the need for structural modifications that would promote better collaboration across systems.

Information Useful for Navigating Multiple Systems

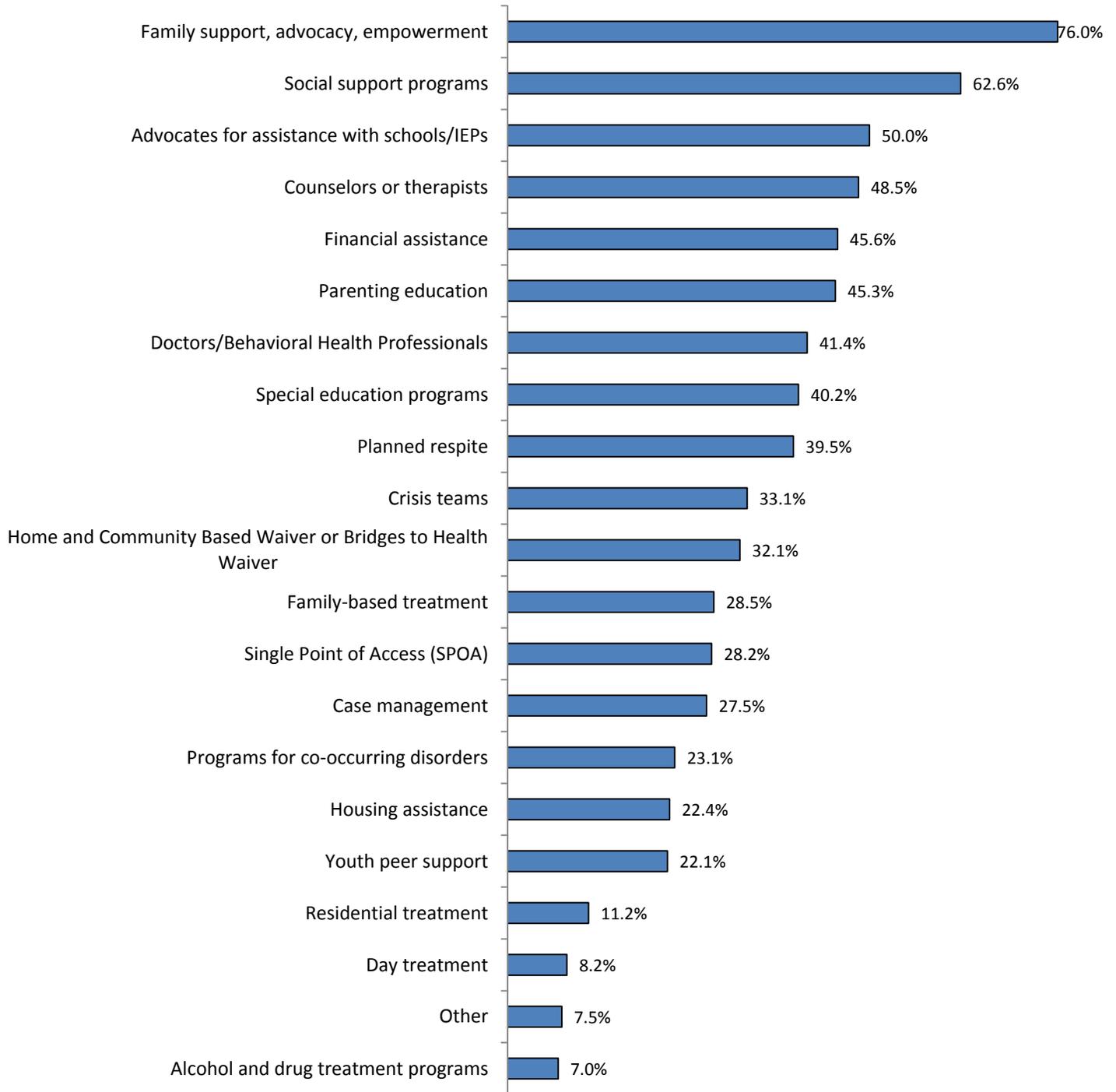| Category	Percentage
List of agencies & their services	62.4%
Resources matched to needs of child	60.0%
Contact person attached to the resource(s)	59.2%
Description of the process to access service	51.9%
Definition of eligibility critera for services needed	42.6%
Connection to peer/family advocates	39.2%
Up-to-date information on web that's easily downloaded & printed	32.9%
Know what documentation my child needs	30.7%
Up-to-date printed information	27.5%
List of behaviors or symptoms observed	23.4%
Information about how services are funded	14.6%
Other	10.4%

Preferred Way of Getting Information

- Among the options provided, respondents indicated they valued being able to gather information from a single website that had a range of information. Similarly, they were interested in using various forms of technology.

- About 46% expressed an interest in having personal contact in addition to a rich, technology-driven resource.

Category	Percentage
One comprehensive, information-packed website	71.9%
Up-to-date printed or viewable documents	52.0%
From pedicatricians, doctors & other health personnel	50.3%
From teachers & other school personnel	39.5%
Statewide information & referral services (e.g., 211, hotlines)	38.5%
From community locations (e.g., libraries, places of worship, grocery stores)	24.5%
An app for smart phones or tablets	18.6%
Information on social media (e.g., Facebook, Twitter, blogs, groups)	14.2%
Other	11.3%

Areas Where Additional Information Would be Helpful

- Respondents reviewed various service settings and identified those areas where, based on their experiences, access to additional information would be helpful. Of particular note:
    - Respondents clearly valued information received from individuals who shared their experiences as noted by the fact that about three in four (76%) identified information from family support and advocacy as helpful.
    - Half of the respondents (50%) reported the need for advocates who could provide assistance with schools and IEPs;
    - Information pertaining to financial assistance was identified as helpful for almost half the respondents (46%)
    - About two in five respondents (40%) noted the benefit of information related to planned respite while one in three (33%) recognized the need for more information regarding crisis teams.

Access to Additional Information Would be Helpful

Category	Percentage
Family support, advocacy, empowerment	76.0%
Social support programs	62.6%
Advocates for assistance with schools/IEPs	50.0%
Counselors or therapists	48.5%
Financial assistance	45.6%
Parenting education	45.3%
Doctors/Behavioral Health Professionals	41.4%
Special education programs	40.2%
Planned respite	39.5%
Crisis teams	33.1%
Home and Community Based Waiver or Bridges to Health Waiver	32.1%
Family-based treatment	28.5%
Single Point of Access (SPOA)	28.2%
Case management	27.5%
Programs for co-occurring disorders	23.1%
Housing assistance	22.4%
Youth peer support	22.1%
Residential treatment	11.2%
Day treatment	8.2%
Other	7.5%
Alcohol and drug treatment programs	7.0%

- Respondents rated features of a web-based information resource they would find most helpful. There was considerable agreement regarding the value of a comprehensive web-based resource that allows users to map resources and access printed materials.

- The one area that showed greatest variability was related to translation tools. Although 47% of respondents did not rate translation tools as useful, another 39% did. This may indicate that most individuals do not need this type of resource; however, among the small group of people who do, this would be quite beneficial.

Ratings of Features of Web-based Resource

Feature	Helpful or very helpful	Not helpful or would not use
Web-based service resource directory with mapping ability to locate resources -- accessed by computer, phone, tablet	86.6%	3.4%
Comprehensive website that's a portal/navigator to resources for multiple systems	86.1%	4.7%
Printed resource guides	85.6%	3.7%
Access to talk & text support line for families & youth	74.2%	14.3%
Acronym dictionary	69.9%	10.4%
Webinars with cross-system information; stored online, archived	69.4%	15.2%
Electronic communications (e.g., newsletter, social media)	66.3%	12.6%
Informational videos	60.8%	19.5%
Mobile apps with push technology for events ,etc.	47.7%	31.1%
Tools that use translation/interpretation services	38.5%	47.2%

Legend:
- ■ Helpful or very helpful
- □ Not helpful or would not use