



TSC Alliance Constituency

October 2023

RELEVATION 



Background & Objectives



- The first TSC Alliance Constituency Study was conducted in 2002. Based on the findings from the study, organizational strategic goals and objectives were set and new constituent services and programs have been instituted.
- The management and Board of Directors of the TSC Alliance launched additional constituency studies in 2010 and 2018 to gauge the organization's performance and determine constituents' unmet needs.
- Specific objectives of the 2023 TSC Alliance Constituency Study were as follows:
 - To gauge the performance of the TSC Alliance in meeting constituents' needs, living up to the organization's mission and managing expectations during and after the pandemic;
 - To determine awareness, usage, and opinion, of various TSC Alliance resources, programs and events, as well as how those have changed over time;
 - To understand the challenges faced by individuals and families impacted by TSC, including medical, community and social services, and to identify where there are still unmet needs; and
 - To prioritize the organization's strategic goals and direction.

Methodology



- Online Survey
- Field Dates: January 18 – April 1, 2023
- Sample = 502 total respondents
- Respondent Qualifications:
 - 13 years old or older
 - Individuals with TSC, parents or caregivers of people with TSC, and researchers/medical practitioners with an interest in TSC or in the care of people with TSC.

Methodology Cautions

- It is important to note that this survey was not designed to derive a reliable projection of the *overall* sentiment of the constituency of the TSC Alliance, but rather to understand the motivations and opinions *within* certain groups (such as individuals with TSC, parents/caregivers, and researchers/medical practitioners), and to enable comparisons *across* such groups.
- Specifically, the survey respondents do not represent all of the TSC Alliance constituents, and the proportions of those we did reach may not represent the actual proportions of the constituent in the “real world.” (For example, donors who are not personally related to individuals with TSC, or those who are not the main caregivers of a person with TSC were excluded.) In addition, respondents were self-selected and completed the survey online. It is important to keep these qualifications in mind when this report refers to “constituents.”
- As researchers, we find that respondents who self-select may have an inherent bias toward the topic, either strongly positive or strongly negative.

Summary of Findings



Constituent Profile

- Just over three quarters of respondent to this research are female (79%) as has been true in prior waves. The vast majority (76%) are primary caregivers (most often parents of Individuals with TSC) which form a larger subset of responding constituents than previously.
- 4 in 5 Primary Caregivers indicate TSC was diagnosed within the first 2 years although over half of Individuals with TSC state diagnosis occurred at 4 years +. Individuals with TSC are almost equally a mix of independent, dependent and semi-dependent. On average, individuals with TSC are marginally older on average than in 2018.
- The largest proportion of Provider respondents continue to be neurologists, followed by researchers or scientists, but in 2023 Epileptologists and Geneticists played a greater role.

TSC Symptoms, Challenges and Care

- Overall, half of constituents indicate they are satisfied with the care they receive from healthcare providers. This cannot be compared to prior waves because of a slight change in methodology. Just over half report it is hard to find TSC specialist close to home.
- Just over one third believe the TSC providers they rely on are knowledgeable.
- Skin manifestations, Epilepsy and Intellectual Disability/Developmental Delay are the most prevalent issues affecting Individuals with TSC (currently or ever). Epilepsy comes up more often for Individuals <20.
- In 2023, Behavior issues, sleep disorders, psychiatric problems, reproduction/family planning concerns and learning disabilities are most difficult to manage, in that order.

Summary of Findings (continued)



TSC Symptoms, Challenges and Care (continued)

- Educational issues are the most weighty non-medical symptom affecting the highest proportion of individuals with TSC (most notably for those <20). followed more distantly by accessing social/recreational programs.
- The majority use a TSC Clinic (64%) with the Clinic of Cincinnati named most often at 18%. Lack of a clinic within driving distance is the greatest deterrent to using a clinic.

Relationship with the TSC Alliance

- Over four in five (89%) have contacted the TSC Alliance within the past 4 years which is comparable to 2018/2010; half of those contacting did contact within the past 3 months. Providers report contacting more often than other groups in 2023, although this base size is small. The major catalysts for contacting are getting medical information/resource guidance/general information or event information.
- The major reasons for non-contact are 1) using other resources and 2) the belief that TSC Alliance could not help, despite help being needed.
- The majority of people contact TSC Alliance via the website or email with a reduction in calls versus 2018.
- 80% are satisfied with their most recent TSC Alliance contact which is comparable to 2018. Very few give negative ratings regarding their most recent contact and reasons center on an inability to connect and/or get the specific answer they needed.
- The percentage of Participating Constituents who donate remains constant to 2010 & 2018 research with Primary Caregivers most likely to donate. One fifth expect to increase donations next year.

Summary of Findings (continued)



TSC Alliance Resources and Communication

- The TSC Alliance website and TSC Clinics are relied on most for TSC information.
- Social media and search engines are utilized less often than in 2018 as are calls to TSC Alliance.
- Individuals with TSC indicate they use the website most often, Primary Caregivers TSC Clinics most often and Providers overwhelmingly turn to PubMed.
- Awareness of TSC Alliance website, Perspective, Facebook Discussion Group, Informational Brochures and TSC Matters eNewsletter are all above average and usage as a function of awareness of all resources is high across the board. Awareness of Facebook Discussion Group appears slightly down relative to 2018 as is reported usage.
- Awareness of the World TSC Conference, Events and Teleconferences/Webinars is highest with the World Conference and Teleconferences/Webinars showing growth relative to last wave. In general, reported attendance at any event, in person or virtually, is similar to 2018; non participation is driven by lack of proximity, personal scheduling and/or cost.
- Frequency of TSC Alliance website usage has slightly eroded (with over half now using less often than once every 4 months) since 2018. But the website is credited with offering useful info for newly diagnosed, upcoming events, fundraising & donation opportunities & latest research with at least 3 out of 4 indicating they Strongly or Somewhat Agree.
- In terms of emails, roughly 3 in 4 Constituents read and open TSC Alliance emails and feel they are informative but this is down marginally compared to 2018. At the same time, fewer Constituents complain about the volume of emails than in the past.

Summary of Findings (continued)



Perceptions of/Reactions to the TSC Alliance

- Constituents continue to regard TSC Alliance very highly overall on the job it is doing in fulfilling its mission. “Excellent” ratings are at parity to 2018 and again, an additional one third rate it “Very Good”. But there is some uptick in “Good” ratings this wave at the expense of “Very Good”. This can occur as an organization grows.
 - As was true in the past, Providers appear to rate TSC Alliance slightly higher than those with TSC or Primary Caregivers.
- Just over 3 in 5 (63%) believe the TSC Alliance has improved in fulfilling its mission over the past 5 years which is similar to the past two waves.
- The main reasons for improved perceptions, both volunteered by more than 30%, are the availability of more/new information & better communication and the advancements made in treatments/research/medical improvements.
- Constituents were asked what positive and negative associations they have with respect to TSC Alliance.
- Nearly all select at least one positive descriptor with the Top Descriptors = Supportive, Professional and Caring (which are the same 3 as in 2018). The positive descriptors selected least often this year to describe TSC Alliance include Well-funded, Cutting edge and Indispensable (in 2018, technologically advanced fell into the bottom 3 but not this year). Slightly fewer select any of the negative descriptors in 2023 (30%) with “under-funded” again the one selected most often.

Summary of Findings (continued)



Perceptions of/Reactions to the TSC Alliance (continued)

- Providing thorough and timely response by staff, easily understood information & literature, and volunteer opportunities to raise awareness & funding continue to be service areas where TSC Alliance gets strongest marks.
- TSC Alliance website, Informational brochures, Perspective and TSC Alliance Navigator Guides net the best ratings, all of which outperform the conference/event ratings.

Future Guidance/Focus

- Needs & expectations of TSC Alliance remain greatest for learning about TSC medical issues, supplying information on TSC Clinics, and new research/clinical trials. Getting information on TSC Clinics moved into second place this wave.
- The minor slippage to “Good” ratings overall versus “Very Good” could be a watch out. Some issues identified in the research include bolstering TSC Now podcast, TSC Navigator, and Private Facebook Discussion Group, Inspire online community, and Multicultural gatherings/meetup ratings which all fall well below average.
- Among those who suggested areas for improvement, the principal ones cited were putting people first and increased local support/involvement.
- Increasing funding for TSC clinical trials, Staying abreast of legislative issues and Increasing funding for TAND research are the **top** priorities for Activities To Pursue/Continue. Four others score above average: Referral vehicle, Providing latest info on non-medical issues, Push for state funding, Serving as Connection vehicle, and Raising awareness nationally.

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Detailed Findings

Constituent Profile



- Constituents, at least those participating in the survey, skew female although Providers skew Male
- Relative to prior waves, participants in 2023 over-represent Individuals with TSC and Primary Caregivers versus Providers and Other Connections (the latter were excluded this year)

	Total	Connection with TSC/TSC Alliance			Age of TSC Alliance Individual		
		Individual with TSC	Primary Caregiver	Provider	Under 13	13-19	20 and Over
	n=502	n=112	n=381	n=30	n=144	n=85	n=238
Female	79%	73%	82%	52%	87%	74%	78%
Male	21%	27%	18%	48% BC	13%	25%	22%
Mean Age	47.9	40.5	49.7	51.3	43.0	47.0	50.9
United States	90%	94%	90%	80%	88%	91%	92%
Other	10%	6%	10%	20%	13%	9%	8%
Urban	30%	35%	29%	30%	31%	28%	29%
Suburban	24%	27%	24%	17%	24%	24%	26%
Rural	34%	30%	36%	27%	32%	38%	36%
Midwest	22%	18%	23%	20%	24%	32%	18%
Northeast	15%	21%	13%	20%	10%	14%	19%
South	31%	27%	33%	30%	38%	33%	28%
West	21%	29%	20% D	7%	17%	12%	27%
No region found	10%	6%	10%	23%	13%	9%	8%

Constituent Profile (continued)

- Respondents were principally Caucasian
- The overwhelming majority of survey respondents were Primary Caregivers, generally relatives or other close connections. This has been true in prior waves as well

	Total n=502	Connection with TSC/TSC Alliance			Age of TSC Alliance Individual		
		Individual with TSC n=112	Primary Caregiver n=381	Provider n=30	Under 13 n=144	13-19 n=85	20 and Over n=238
White	87%	86%	88%	86%	86%	90%	88%
Asian	5%	6%	4%	14%	4%	6%	4%
Indigenous American or Alaska Native	2%	1%	2%	0%	1%	2%	2%
Black or African American	2%	3%	2%	0%	1%	2%	2%
Other	7%	6%	7%	7%	10%	4%	6%
Relative of an individual with TSC	75%	16%	98%	3%	99%	96%	61%
Individual with TSC	22%	100%	5%	3%	-	4%	46%
Provider	6%	1%	1%	100%	-	-	1%
Friend/Neighbor/Acquaintance/Guardian/Caregiver	2%	-	2%	3%	1%	-	1%

Primary Language

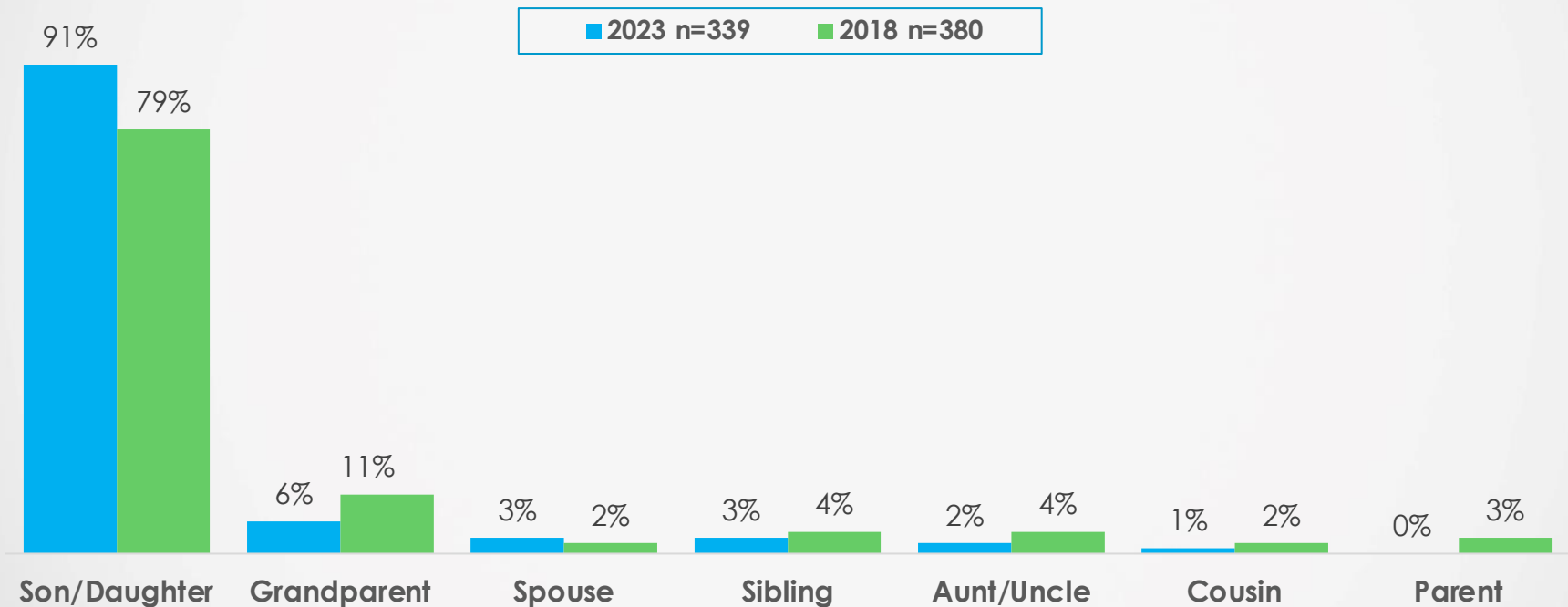
- Virtually all survey participants credit English with being their primary language
- No differences are observed in secondary language. Since participants self-select and the survey was offered in English, this should not be surprising

	<u>Total Participants</u> n=502	<u>Primary Caregiver</u> n=39
English	98%	9%
Spanish	5%	5%
Chinese (including Mandarin, Cantonese, Hokkien and other varieties)	1%	1%
French	0%	3%
Tagalog (including Filipino)	0%	0%
German	0%	0%
Russian	0%	0%
Arabic	0%	0%
Vietnamese	0%	0%
Korean	0%	0%

Relationship To Individual With TSC



- As in the past, when the individual with TSC is a relative, the relationship is usually one of parent to child
- This is more pronounced in 2023 than in 2018 where grandparents played a slightly larger role

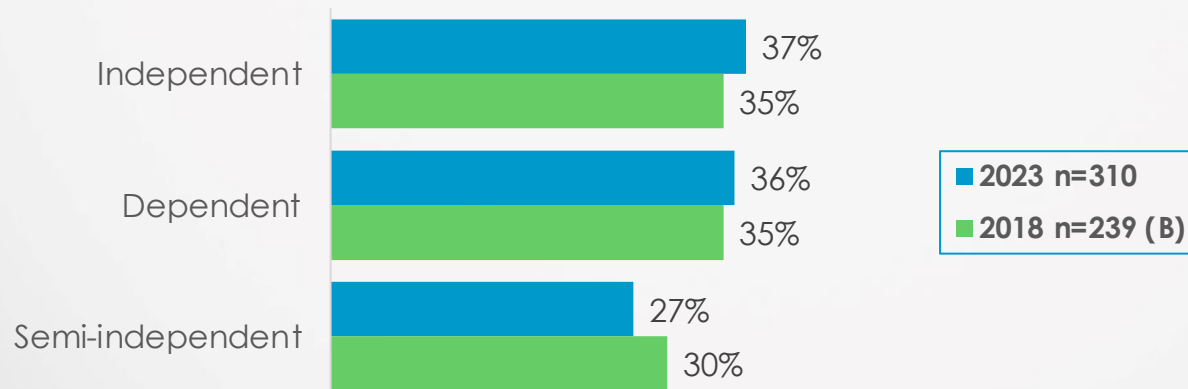


Profile Of Individuals With TSC

- The individual with TSC is on average slightly older this wave than in 2018 but equally likely to be various stages of independence
- Primary Caregivers report the age of the Individual with TSC diagnosed as 12 months or younger while Individuals, themselves, are most likely to indicate 4 years+



Independence Among TSC Individuals Older Than 13 (Limited to Caregivers)

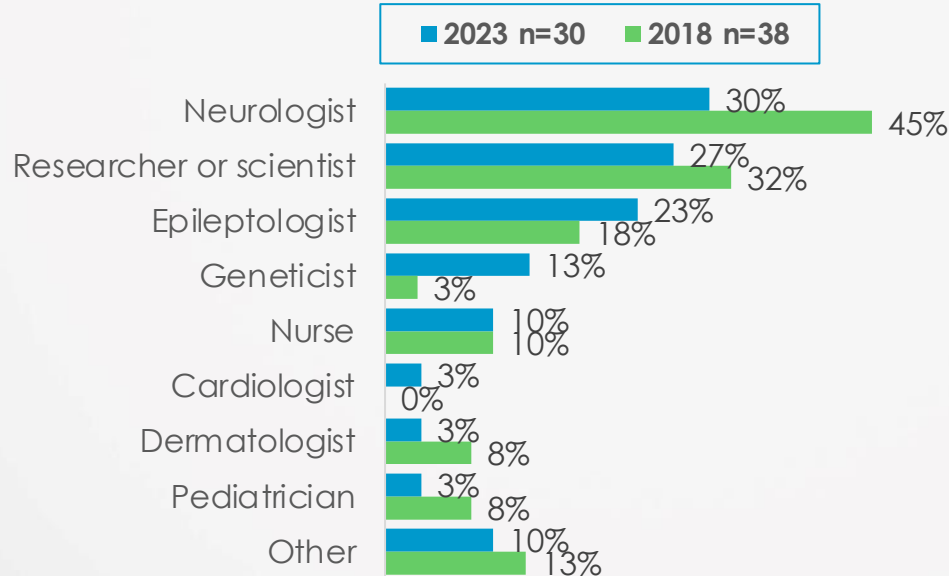


AgeTSCPerson. What was the age of the person with TSC in years as of his/her last birthday? Depends. In terms of your day-to-day needs, would you describe yourself as independent, dependent, or semi-independent?/In terms of his/her day-to-day needs, would you describe this person as independent, dependent, or semi-independent? Diagnosis1. How old were you when you were diagnosed with TSC?

Qualitative Profile Of Healthcare Professionals: Professional Capacity

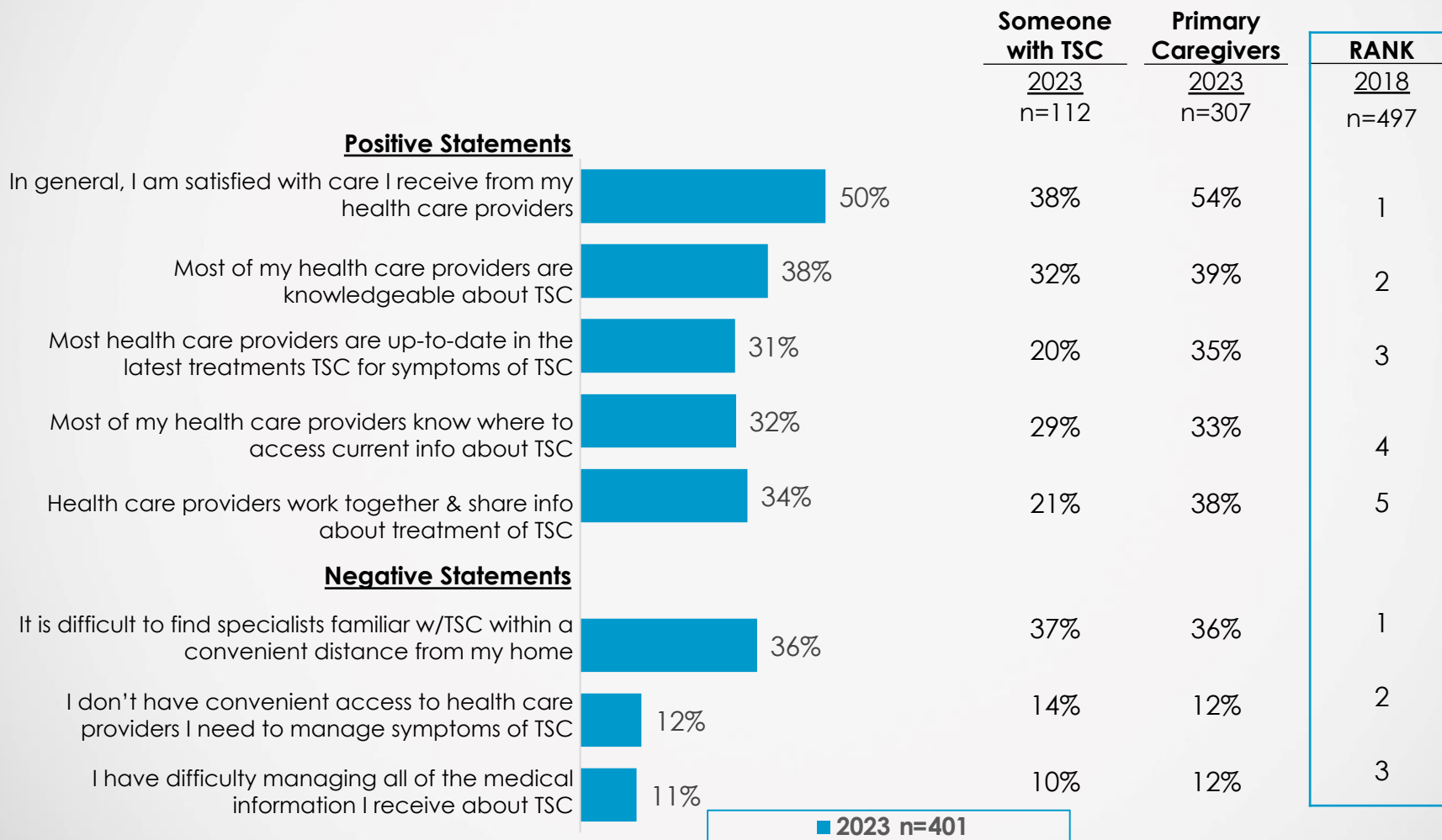


- Neurologists and Researcher/Scientists continue to make up the largest groups of Provider survey participants this wave but Epileptologists and Geneticists are represented more than before



Attitudes Toward TSC Healthcare

- Satisfaction and belief in provider knowledgeability, current treatments and access remain strongest
- The difficulty of finding specialists continues to be the biggest challenge

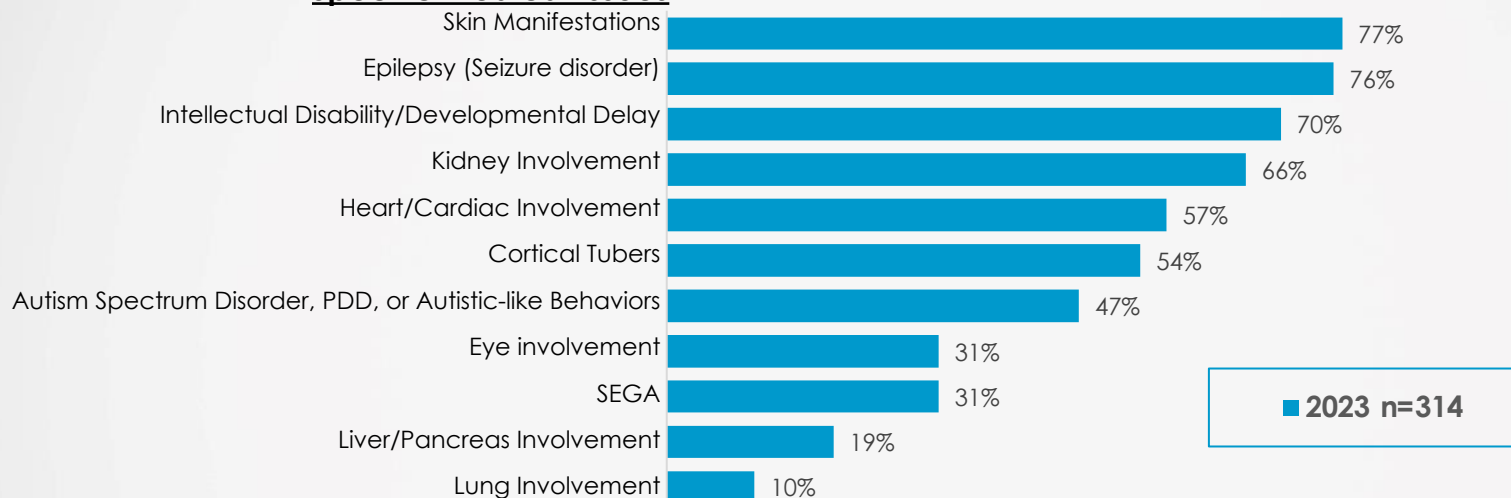


TSC Medical Symptoms Currently or Ever Experienced by Individual with TSC

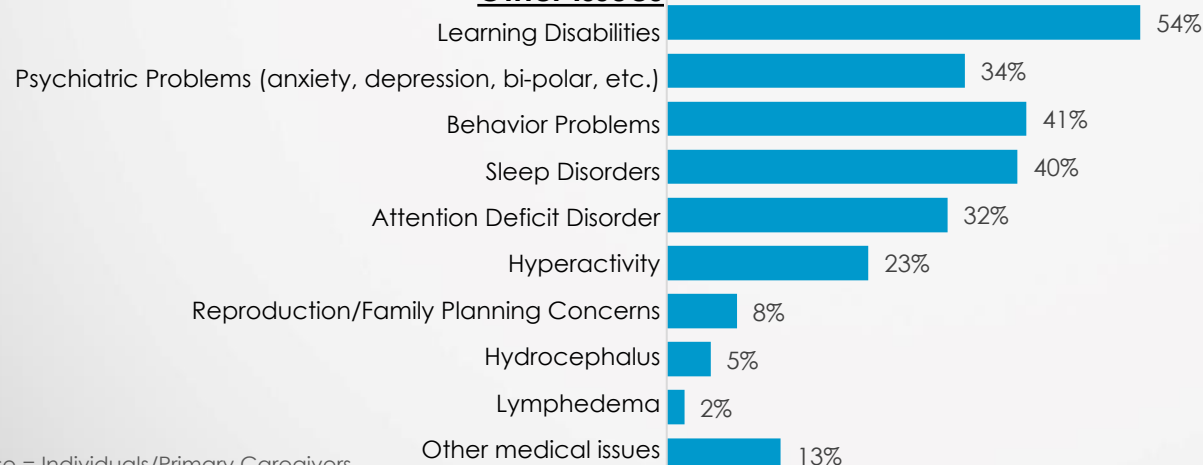


- Skin manifestations, Epilepsy and Intellectual Disability/Developmental Delay are the most prevalent issues affecting Individuals with TSC

Specific Medical Issues



Other Issues



Base = Individuals/Primary Caregivers SymptomsA[x]. Please select all TSC-related medical symptoms and issues that you, yourself, have ever experienced.

Symptoms Currently/Ever Experienced by Age



- Many conditions are similar across Individuals With TSC ages, however, liver/pancreas & lung involvement, psychiatric problems, and reproductive/family planning concerns are more prevalent for those 20+ while heart/cardiac involvement are more common among those <13

Other	<u>Under 13</u> n=126	<u>13 - 19</u> n=74	<u>20+</u> n=209
<u>Specific Medical Issues</u>			
Epilepsy (Seizure disorder)	93%C	95%C	70%
Skin Manifestations	78%	93%AC	85%
Intellectual Disability/Developmental Delay	75%C	76%C	56%
Cortical Tubers	72%C	74%C	53%
Heart/Cardiac Involvement	67%BC	41%C	27%
Kidney Involvement	55%	65%	69%A
Autism Spectrum Disorder, PDD or Autistic-like Behaviors	52%C	62%C	38%
Eye involvement	38%	41%C	30%
SEGA	31%	42%C	29%
Liver/Pancreas Involvement	5%	9%	17%A
Lung Involvement	1%	1%	27%AB
<u>Other Issues</u>			
Learning Disabilities	58%	82%AC	49%
Behavior Problems	44%	51%C	36%
Sleep Disorders	32%	39%	41%
Attention Deficit Disorder	29%	43%AC	24%
Psychiatric Problems (anxiety, depression, bi-polar, etc.)	25%	54%A	53%A
Hyperactivity	23%C	19%C	11%
Hydrocephalus	5%	3%	4%
Reproduction/Family Planning Concerns	2%	8%A	12%A
Lymphedema	0%	1%	5%
Other medical issues	7%	7%	18%A

Base = Individuals/Primary Caregivers

SymptomsA[x]. Please select all TSC-related medical symptoms and issues that you, yourself, have ever experienced.

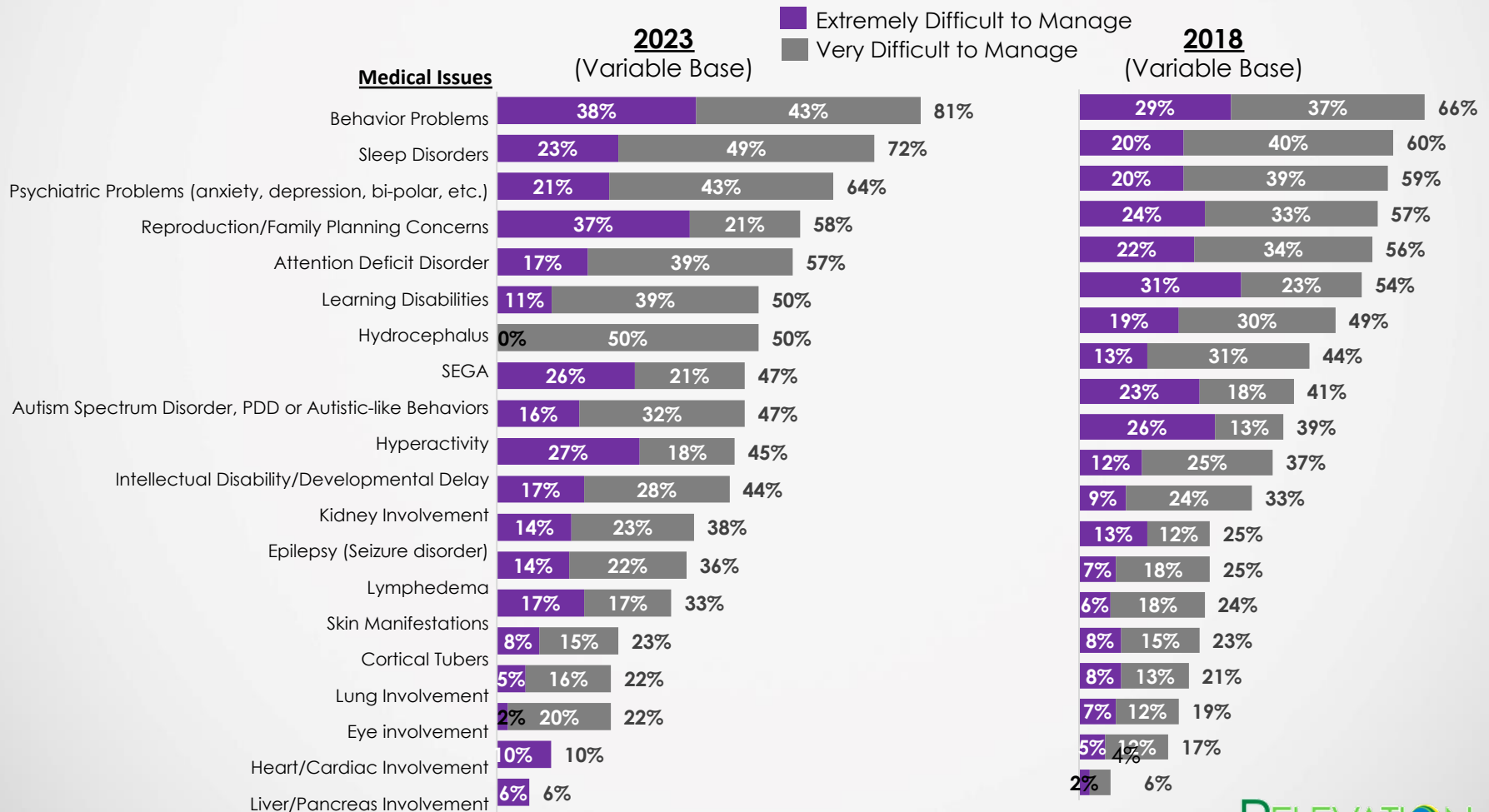
SymptomsC[x]. Earlier you said that you are primarily responsible or share responsibility for the care of an individual with TSC. Please select all

TSC-related medical symptoms and issues that this person has ever experienced.

Challenge of Managing Medical Symptoms



- Behavior problems, Sleep disorders and psychiatric problems are reportedly most challenging to manage. NOTE: not directly comparable to 2018 because questions were handled different, but the rank order is the same

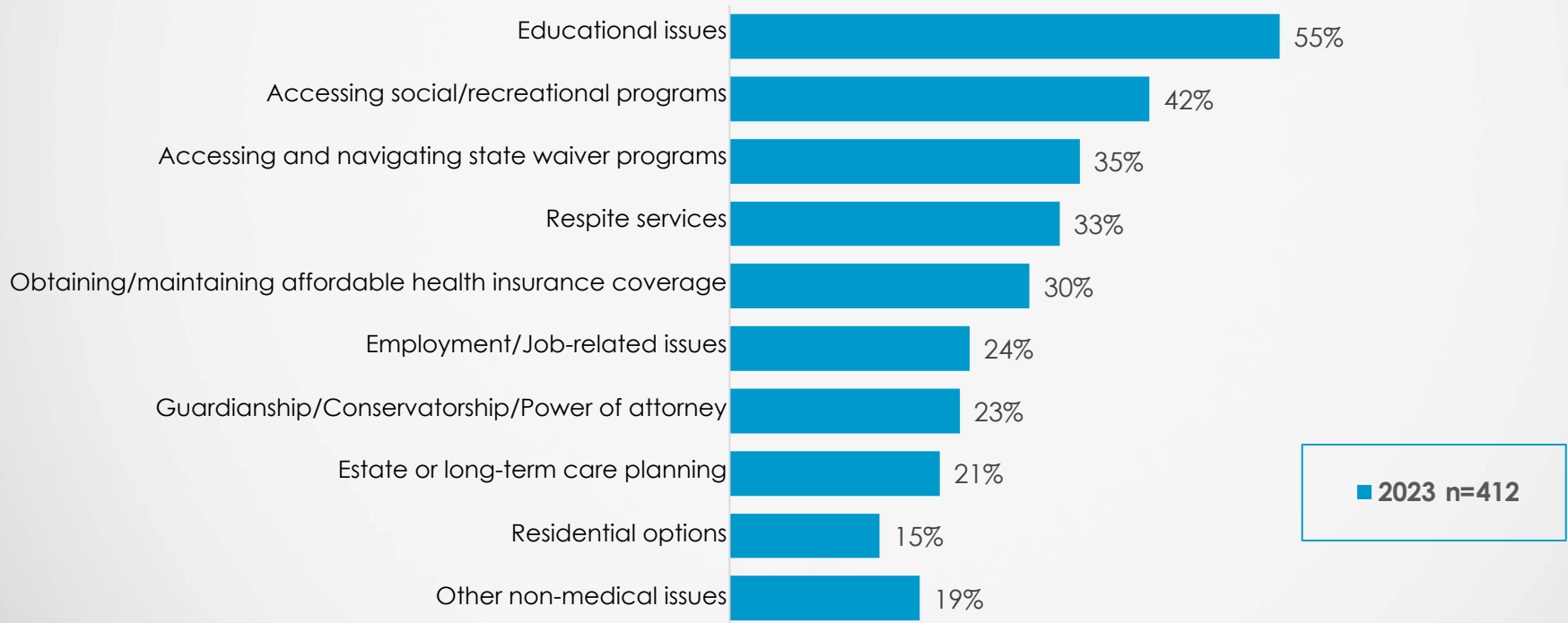


WorstA/C. Please rate these medical symptoms and issues according to how difficult you find them to manage or cope with, where "5" means "Extremely Difficult to Manage" and "1" means "Less Difficult, Easy to Manage".

Non-Medical Symptoms Currently or Ever Experienced



- Educational and accessing social/recreational programs are the non-medical symptoms faced by the most Individuals with TSC
- Estate/long-term care planning are currently or ever experienced much less often



SymptomsB[x]. Please select all TSC-related non-medical issues that you, yourself, have (1) ever experienced, and (2) currently experience.
SymptomsD[x]. Earlier you said that you are primarily responsible or share responsibility for the care of an individual with TSC. Please select all TSC-related non-medical issues that this person has ever experienced.

Base: Total (n=351)

Non-Medical Symptoms Currently or Ever Experienced by Age



- Non-medical symptoms vary tremendously based on age
- In general, Accessing social/recreational programs, Accessing/navigating state waiver programs, respite services, employment/job-related issues and Guardianship/conservatorship come up more in 2023 across the board than in 2018

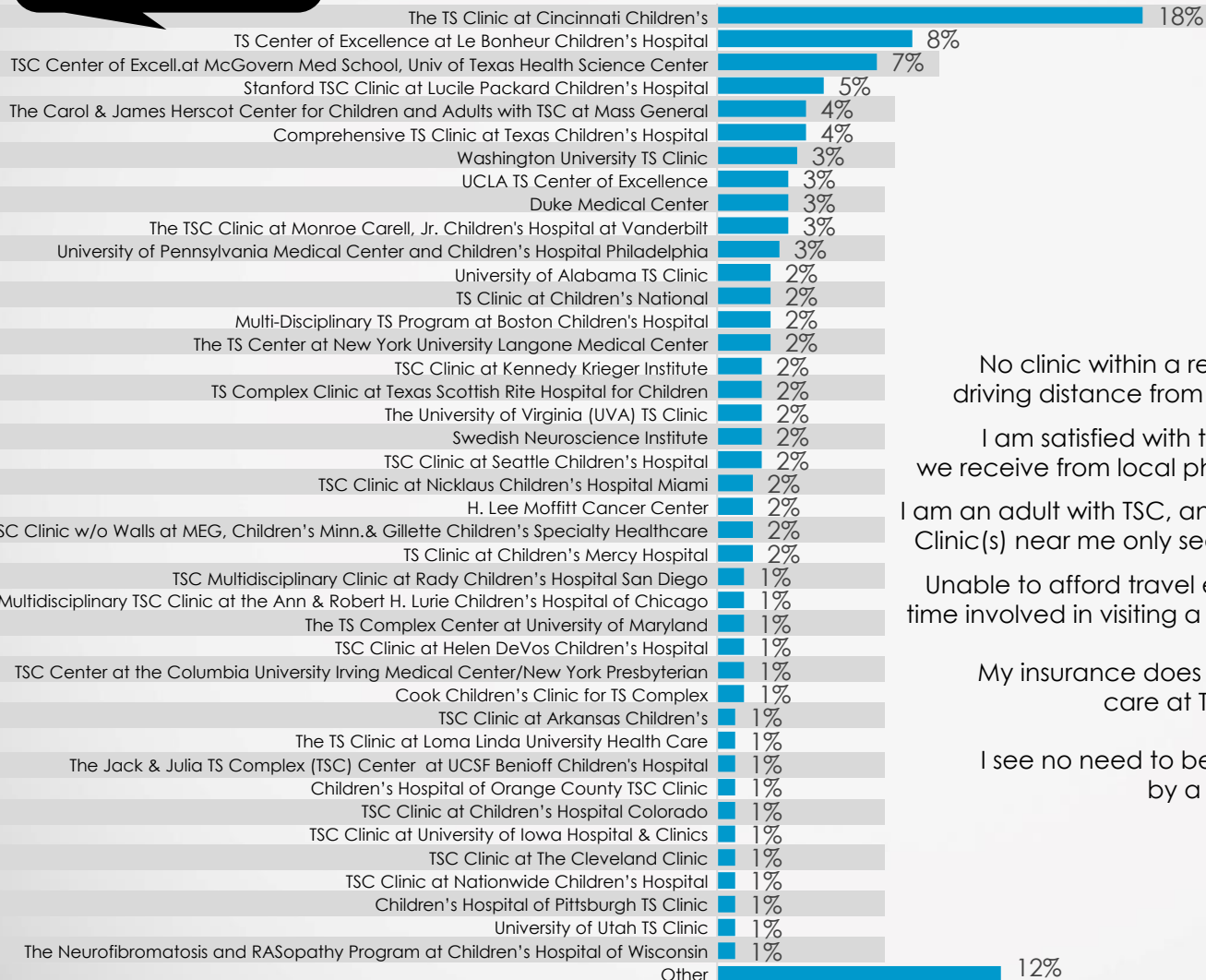
	2023			2018		
	Under 13 n=126	13 - 19 n=74	20+ n=207	Under 13 n=126	13 - 19 n=71	20+ n=99
Educational issues	65%	84%	39%	62%	67%	28%
Accessing social/recreational programs	39%	54%	39%	28%	37%	31%
Accessing and navigating state waiver programs	36%	42%	32%	25%	30%	23%
Respite services	29%	43%	31%	19%	31%	20%
Obtaining/maintaining affordable health insurance coverage	29%	18%	34%	27%	39%	30%
Estate or long-term care planning	14%	28%	23%	7%	22%	23%
Employment/Job-related issues	9%	16%	35%	2%	7%	29%
Guardianship/Conservatorship/Power of attorney	5%	26%	33%	1%	24%	24%
Residential options	2%	8%	24%	4%	15%	16%
Other non-medical issues	19%	8%	22%	9%	9%	15%

TSC Clinics Using for Medical Care/Treatment & Reasons for Not Visiting Clinic

64% are using a TSC clinic (fewer than reported in 2018)

TSC Clinics Using for Medical Care/Treatment

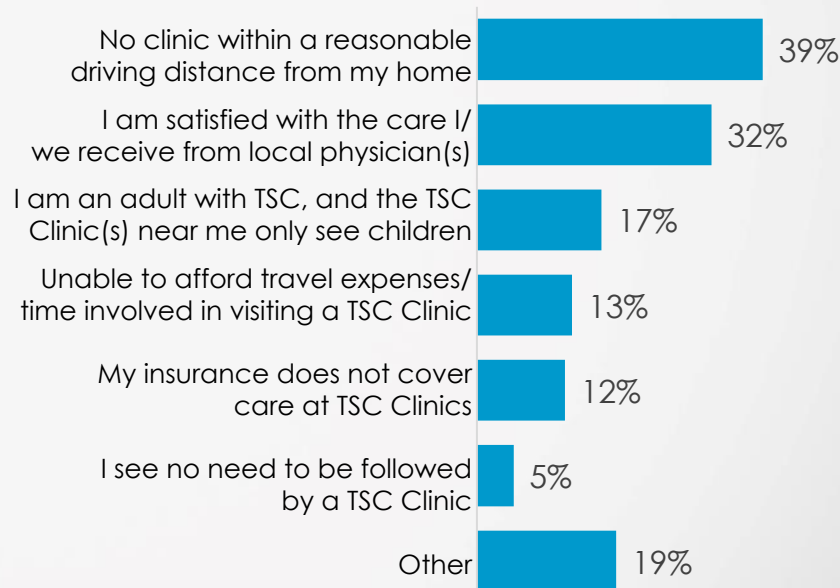
n=262



36% are NOT using a TSC clinic

Reasons for Not Visiting Clinic

n=145

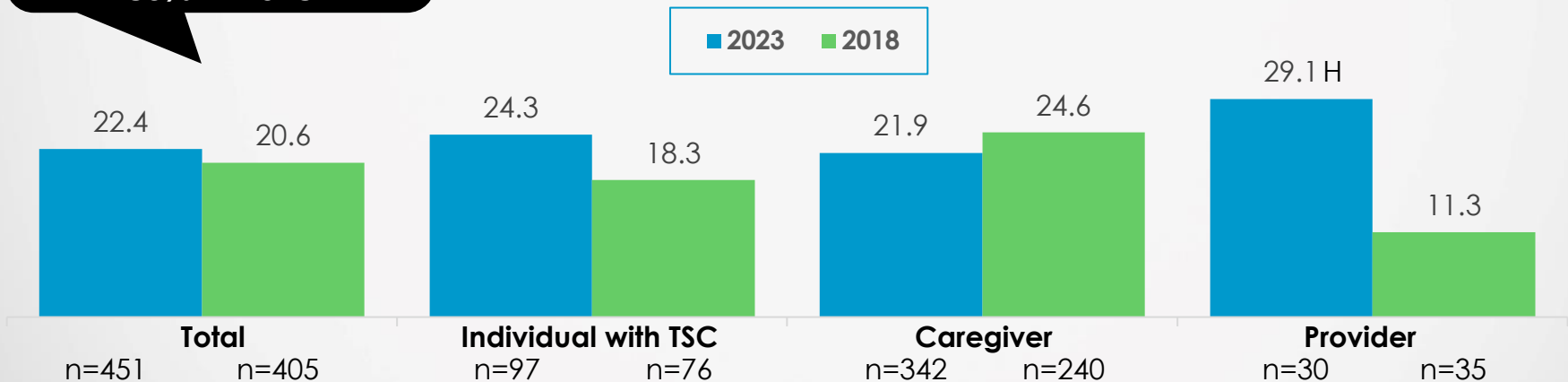


Frequency of Contacting TSC Alliance

- Providers in 2023 contacted TSC Alliance more often on average than in 2018
- The percent who report ever contacting the organization is higher than prior waves, possibly due to Covid

89% Have Ever Contacted TSC Alliance compared to 83% in 2018

Frequency of Contacting TSC Alliance



Reasons for Contacting TSC Alliance



- Leading reasons to contact TSC Alliance include: getting medical information/resource guidance/general information or event information
- Looking for local support or connecting with other healthcare providers, along with volunteering/organizing fund raising are not major catalysts for contacting TSC Alliance

	<u>Ranked 1</u>	<u>Ranked 1/2</u>
	n=450	n=450
To get medical information/guidance to resources	22%	39%
To get general information about TSC or the TSC Alliance	14%	29%
To find out about an event relating to TSC or the TSC Alliance	10%	24%
Related to the volunteer work I do for the TSC Alliance	10%	13%
To donate to the TSC Alliance	9%	18%
To get information about clinical trials	8%	17%
To locate a TSC Clinic or local physician	8%	16%
To get non-medical advice/information	5%	15%
To find out about educational rights and advocacy	5%	8%
To find out about volunteering	2%	5%
To locate local support	2%	8%
To find out how to organize fund raising for the TSC Alliance	1%	2%
To connect with other healthcare providers	1%	1%
Other	4%	4%

Not Contacted TSC Alliance

- Roughly one in 10 survey participants report never contacting TSC Alliance which is lower than prior waves
- Fewer attributed this to “Haven’t had a need” in 2023 than before with a corresponding rise in “didn’t think TSC Alliance could help”

Reason(s) For Never Contacting TSC Alliance

	<u>2023</u>	<u>2018</u>
	n=51	n=113
Used other resources instead of TSC Alliance	24%	22%
Didn't think TSC Alliance could help me though I needed help	22%	12%
Haven't needed anything from the TSC Alliance	20%	56%
TSC Alliance was not helpful the last time	2%	2%
Unsure/NA	6%	--
Other reason	12%	15%

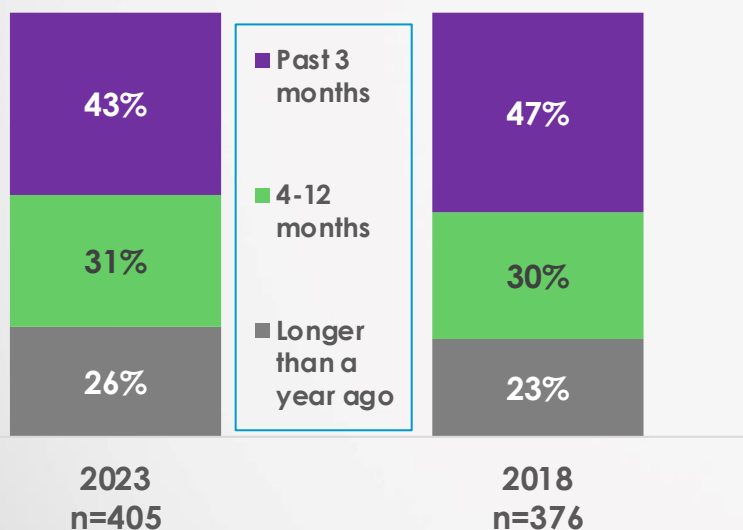
Sources Used Instead of TSC Alliance

	n=502
Doctor/Hospital/Healthcare facility	13%
Local or General TS Clinic	11%
Facebook	8%
Epilepsy Foundation	8%
Internet/Other online websites or searches	5%
Other Parents/Friends	5%
Google	4%
TSC Alliance/TSC website	3%
Childrens Hospital	3%
Neurologist	3%
LAM Foundation	2%
Epilepsy-related website/group	2%
Local or General TS Group/Organization	2%
NORD	2%
University	2%
Medical Journals/Research/Studies	2%
Autism-related website/group	2%
NIH.gov	2%
Mayo Clinic	1%
PubMed	1%
Disability-related website/group	1%
Other Social Media	1%
The Arc	1%
Autism Speaks	1%
Other	9%
NA/None	25%

Last Contact Details.

- The majority of constituents contact TSC Alliance via the website or email with a reduction in calls versus 2018 but a correspondingly lift in Conference calls
- Recency of contact has changed little since 2018

Most Recent Contact With TSC Alliance



Type of Contact

	2023 n=405	2018 n=376
Website	31%	30%
Emailed	27%	27%
Conference call	12%	5%
Called	9%	15%
Posted on TSC Alliance social media site	5%	6%
Community Alliance Rep	5%	4%
Text Message	2%	2%
Posted on TSC Alliance community support page	2%	3%
Social media App	1%	2%
Posted on TSC Alliance's Twitter or Instagram page	0%	NA
Went in person to the TSC Alliance offices	0%	NA
Mailed a letter to the TSC Alliance	0%	NA
Other	4%	5%

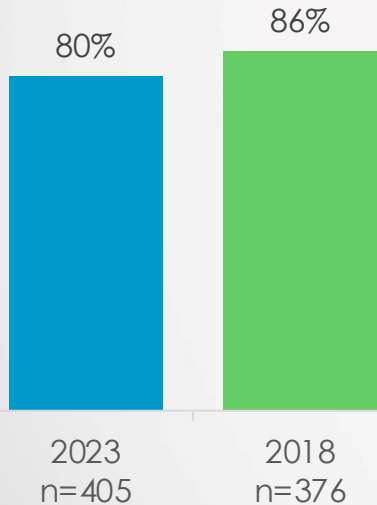
Satisfaction with Most Recent Contact

- Satisfaction erosion continues a slight downward trajectory since 2018 and 2010 before that although it cannot be attributed to a significant level across groups
- This could be the result of satisfaction erosion we see across all categories post Covid

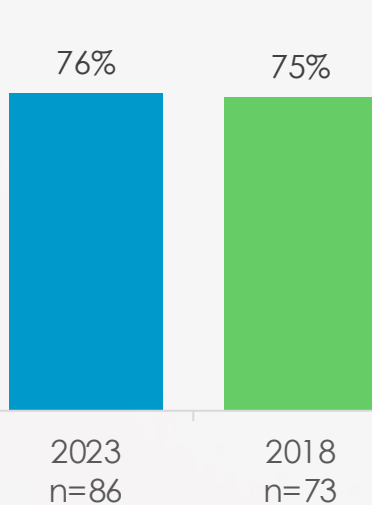
■ 2023 ■ 2018

Top 2 Box Satisfaction

Total



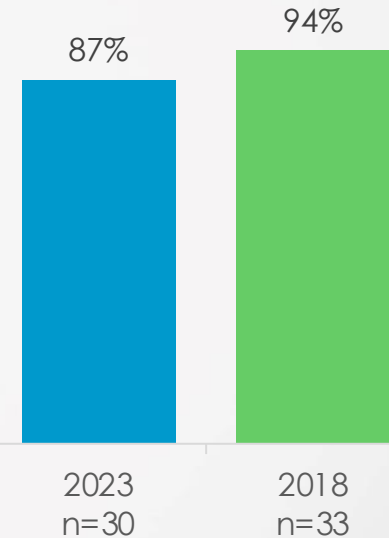
Individual with TSC



Caregiver



Provider



Reasons For Gave Negative Rating For Last Contact



Have tried to contact TSC via various emails with minimal response. Have had to call multiple times to get in touch with the correct person.

I asked about finding a TSC clinic near me. They sent me on a long phone tag with Seattle Children's and Swedish. Swedish didn't even know they had a TSC clinic at first. I don't live in Seattle, I live 4 hours away. Swedish is just different Drs with no collaboration(that's what I was told.) I can't get all appointments done together. I'd have to go separately for each specialty. Please don't call it a clinic if it's the same care I get everywhere else.

There was no help they could give for an adult patient and radiation issues.

I called and requested help with my daughter's Sabril script, the current contact was unavailable so I left a message. I didn't hear back so followed with an email. I didn't hear back so tried to call again, emailed other members and nothing ever returned over the course of three weeks.

I didn't get what I wanted

I got a noncommittal answer. I used to get off the record doctor recommendations. I'm looking to move and my sons TSC is complex with severe health issues. I need a REAL clinic not like the one in Philly. It took me years to educate all his doctors and Philly does not have a clinic just neurologists in a large academic organization. Only offers neurology and does not fully understand nephrology issues related to neurology issues.

Listened to sessions from the conference. Specifically the ones concerning adult services and care/living options. I left feeling even more depressed, confused, hopeless. The speakers spent more time talking about everything bad about the future. Offering little in the way of options or where to turn. They talked about planning for the future, but then told how everything they planned fell apart. So do I take that as a warning of what not to do, or try this option anyway? Hopeless.

The assistance with the IEP meeting was not beneficial.

Timeliness of response. It took three follow ups and 8 day wait time. Incomplete response. No follow up on issues. Suggestions taken wrongfully (as criticism instead of positive reinforcement and growth opportunity)

I wasn't able to reach anyone. I never received a response.

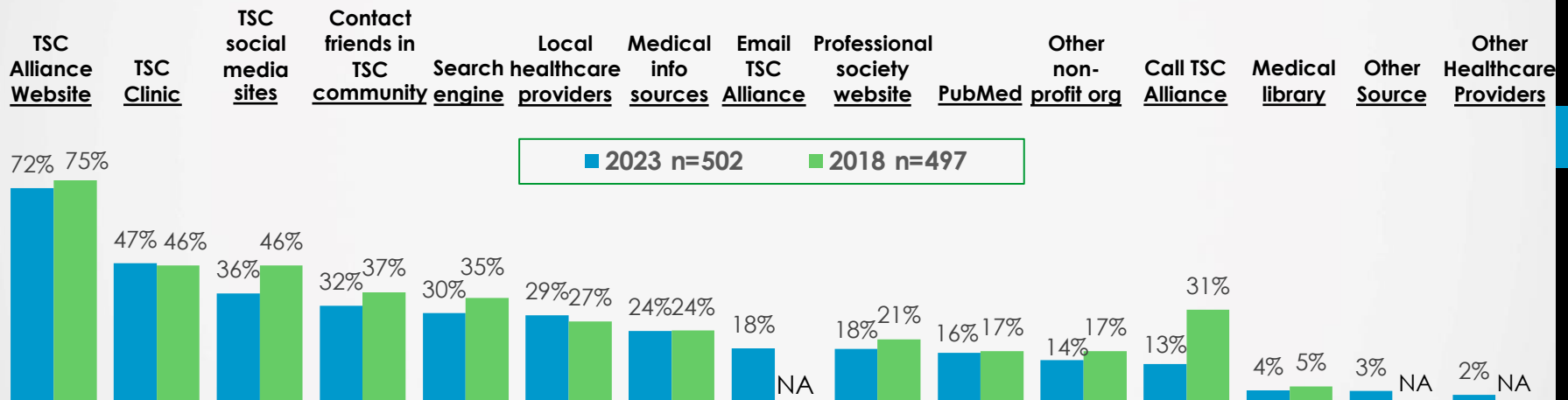
Offered little local assistance

There was no follow up and I still don't have answers.

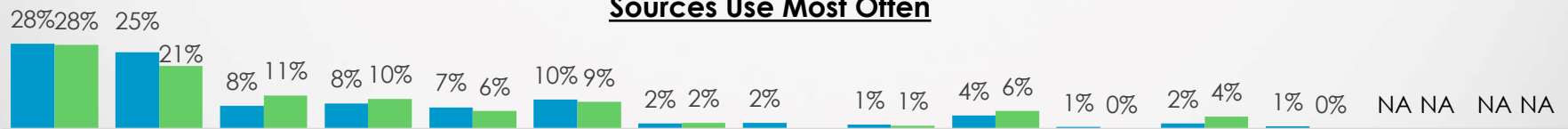
Sources Use & Rely On Most

- TSC Alliance website and TSC Clinics are sources regularly go to and use Most Often
- As was true with contacts, phone is declining; TSC Social Media sites are also down relative to 2018

Sources Use



Sources Use Most Often



Source Rely On Most (continued)

- Primary Caregivers rely on TSC Clinics as an information source more than Individuals with TSC or Providers
- PubMed is the dominant source for Providers

Sources Use Most Often

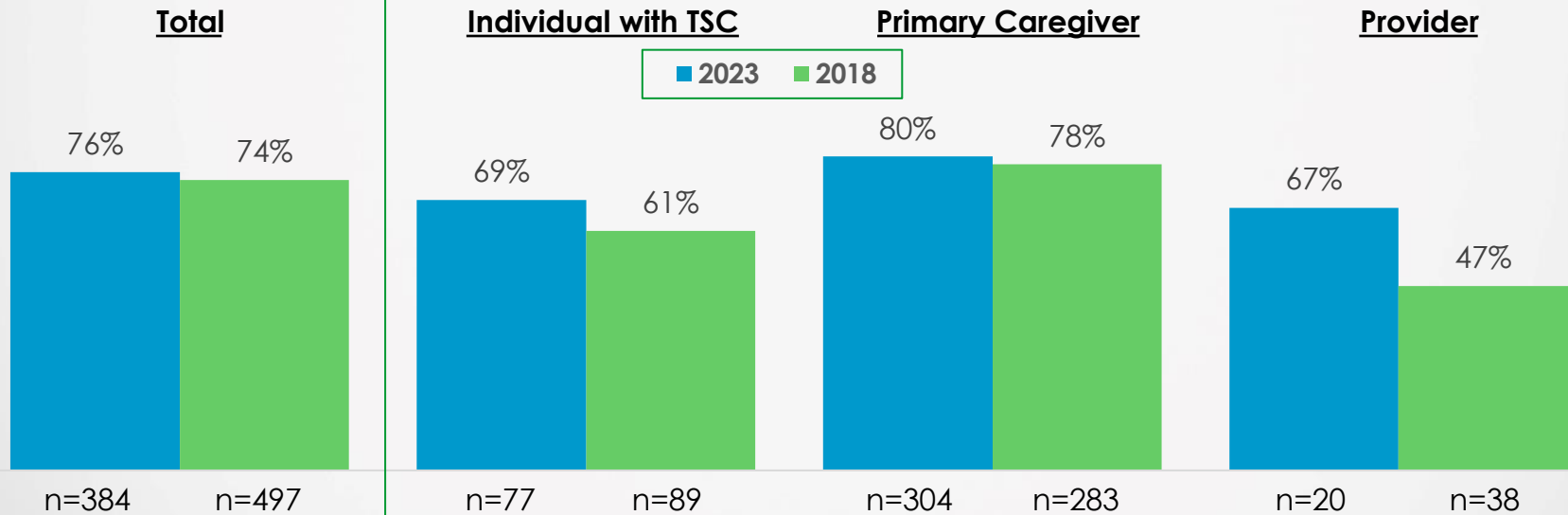
	<u>Individual with TSC</u>		<u>Primary Caregivers</u>		<u>Provider</u>	
	<u>2023</u> n=112	<u>2018</u> n=88	<u>2023</u> n=381	<u>2018</u> n=281	<u>2023</u> n=30	<u>2018</u> n=38
TSC Alliance Website	30%	35%	28%	32%	30%	16%
TSC Clinic	20%	11%	29%	24%	0%	4%
PubMed	3%	1%	2%	1%	50%	66%

Donations

- The percent of Constituents who claim to have ever donated remains the same as in prior waves with the highest incidence of donating among Primary Caregivers; the percent who expect to donate the same amount next year also remains the same along with those who anticipating increasing their donation

**20% will increase
72% will stay the same
8% will decrease**

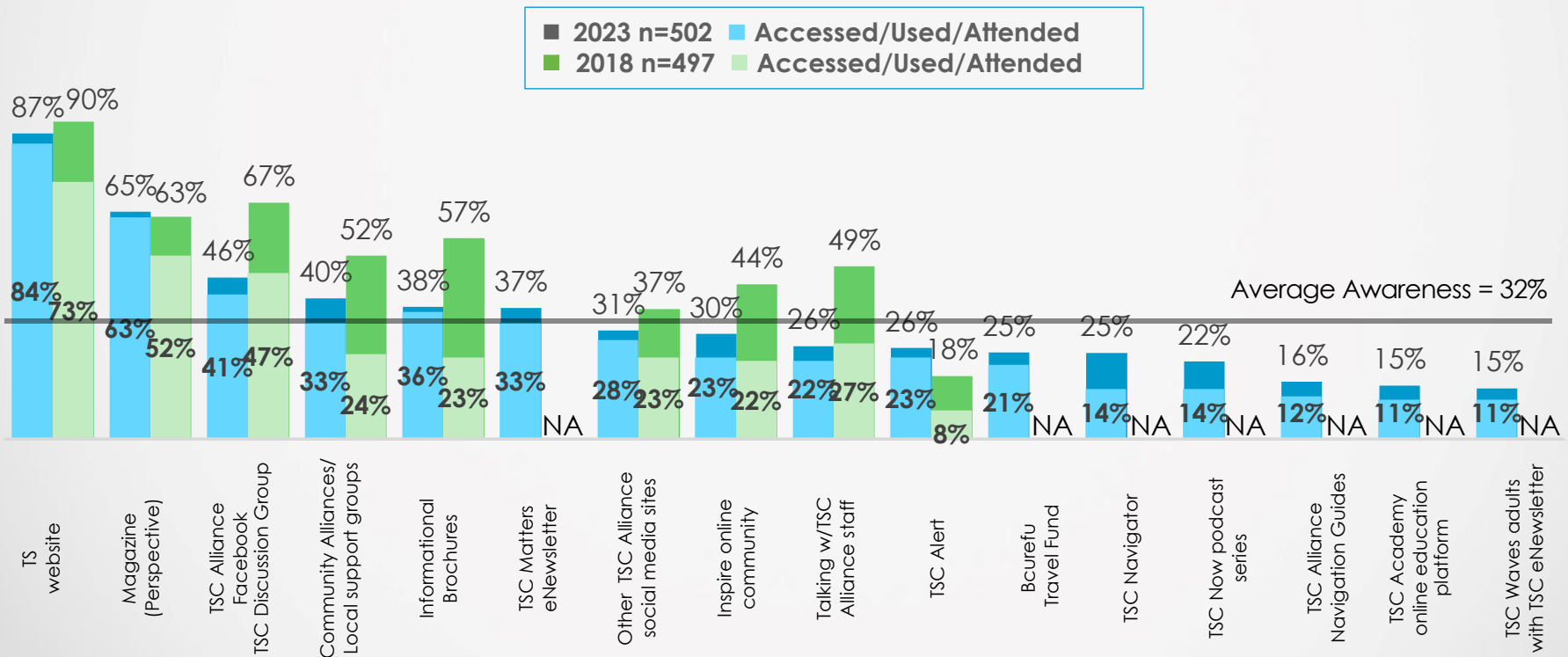
Donation for Next Year
(384)



Awareness & Usage of TSC Alliance Resources



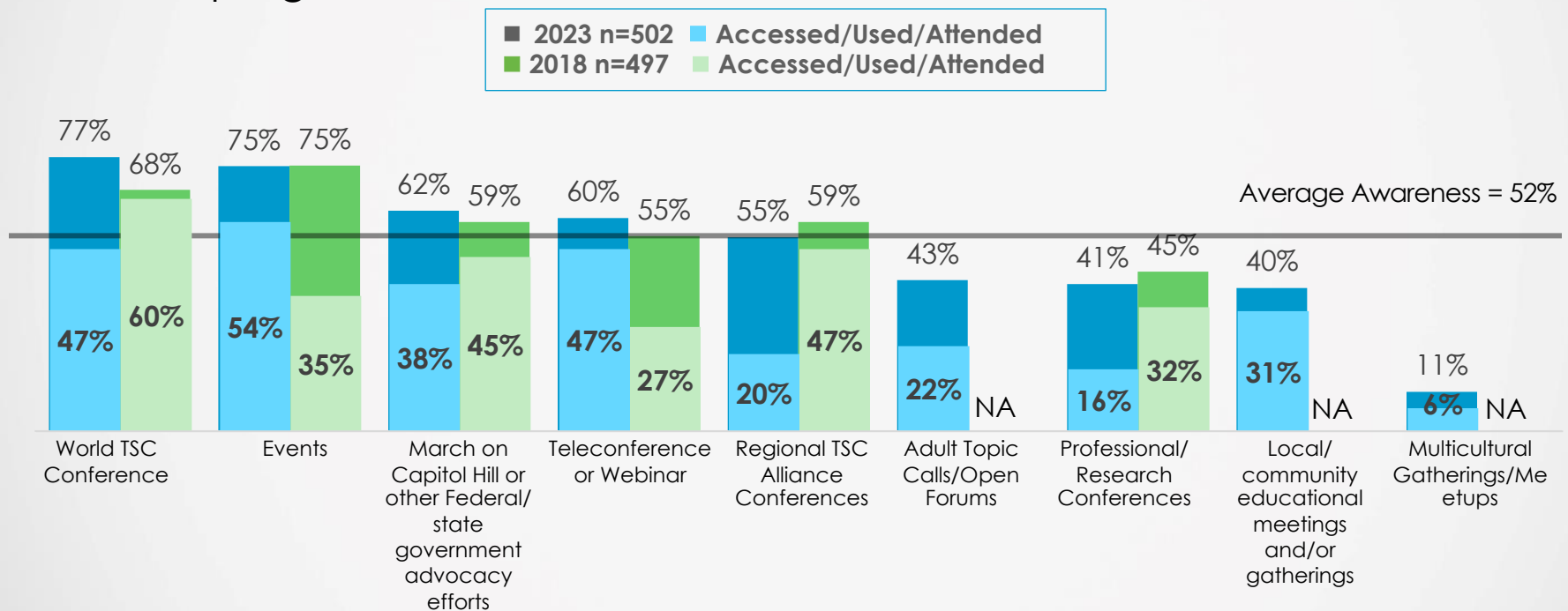
- Awareness of TSC Alliance website, Perspective, Facebook Discussion Group, Informational Brochures and TSC Matters eNewsletter are all above average
- Among those Aware, usage/access of resources is high across the board
- Awareness of Facebook Discussion Group is down relative to 2018 as is reported usage



Awareness & Attendance/Usage of TSC Alliance Events & Programs



- Awareness of the World TSC Conference has grown along with Teleconferences/Webinars have increased
- Awareness of Multicultural gatherings/meetups is low relative to other events/programs



SourceAwareB[x]. Following is a list of events and conferences sponsored or conducted by or in association with the TSC Alliance. Which, if any, of these have you ever heard of?

SourceUseB[x]. And which of the following, if any, have you accessed, used or attended in the past year?

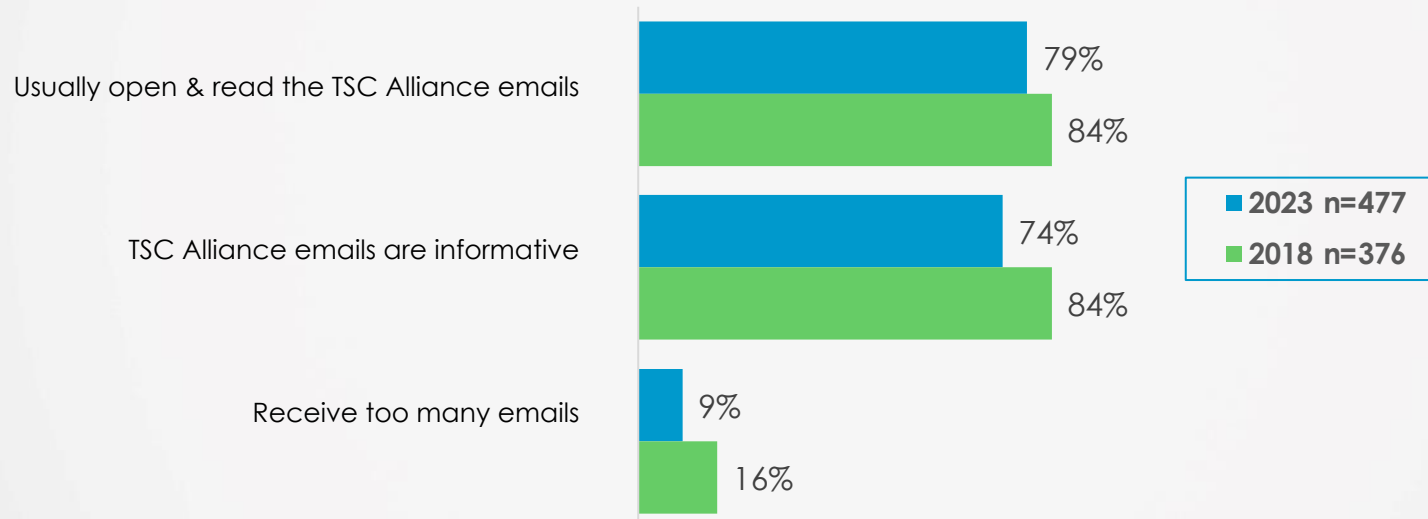
Benefiting Ratio is calculated by dividing each resource's 'use' score by their 'aware' score

Email Communication

- Opening and reading TSC Alliance emails dropped for the 2nd time versus 2018 and 2010; perceptions of emails as informative have also declined
- Complaints about the volume of emails, however, have decreased

Feelings About TSC Alliance Emails

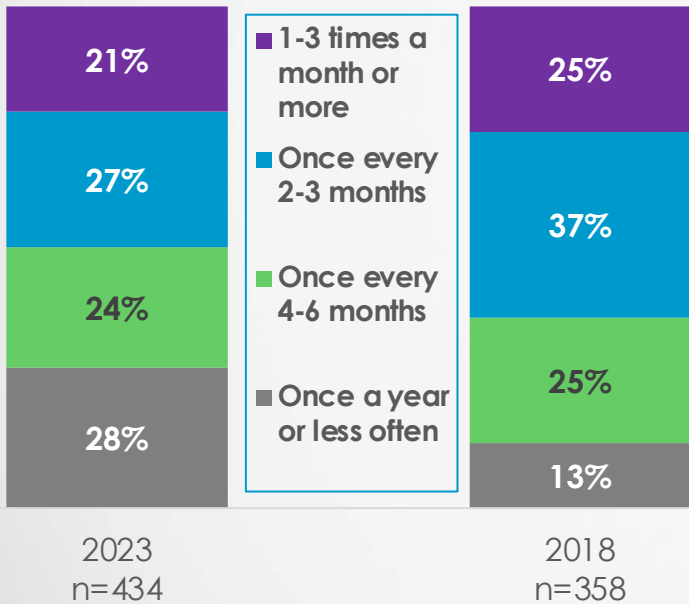
(% Agree Strongly/Somewhat)



TSC Alliance Website

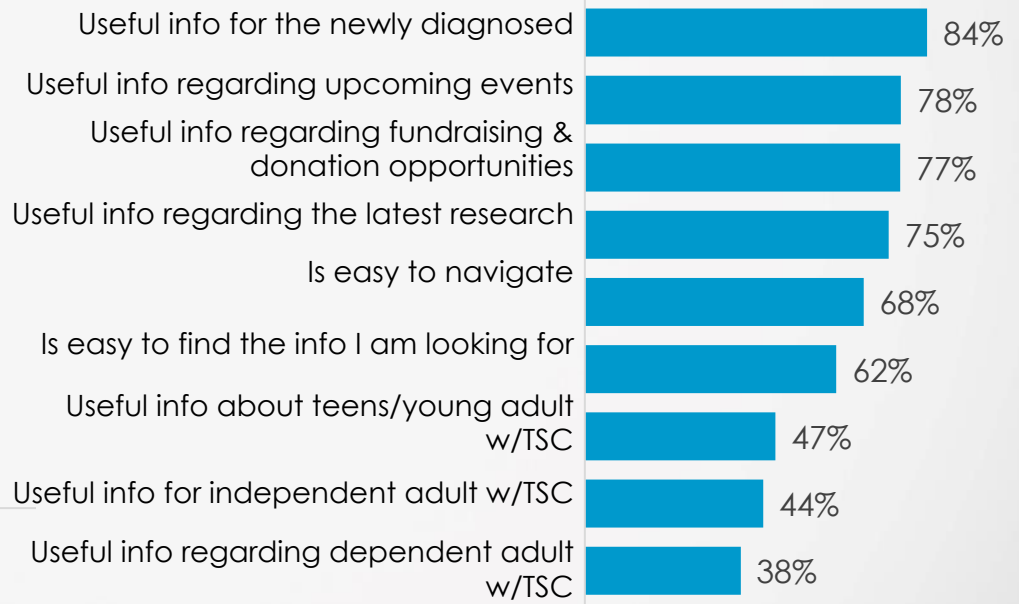
- Frequency of TSC Alliance website usage has slightly eroded (with over half now using less often than once every 4 months) although the website is credited with offering useful info for newly diagnosed, upcoming events, fundraising & donation opportunities & latest research

TSC Alliance Website Usage



Feelings About TSC Alliance Website

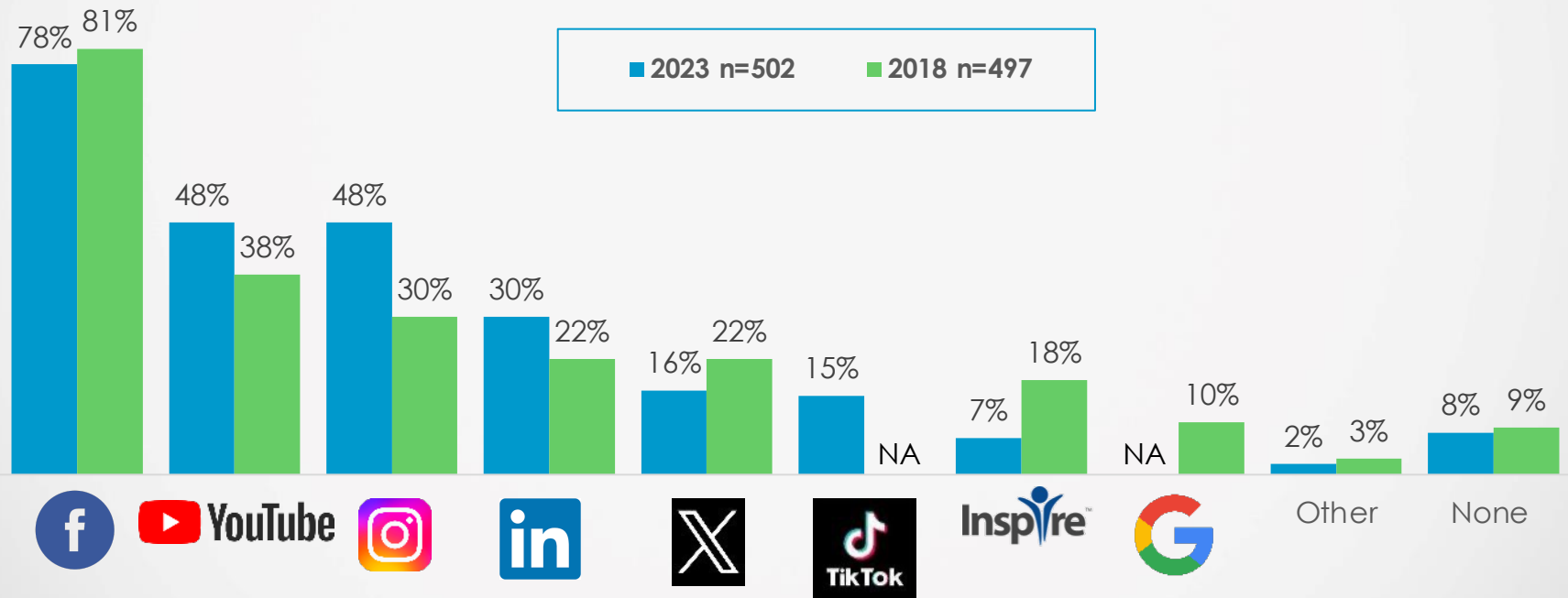
(% Agree Strongly/Somewhat)



WebsiteUse. Earlier, you said you have heard of the TSC Alliance website. How often do you visit www.tscalliance.org? WebStatements[x]. Following are some statements about the TSC Alliance website. For each statement, please indicate how much you agree or disagree.

Social Networking Site Usage

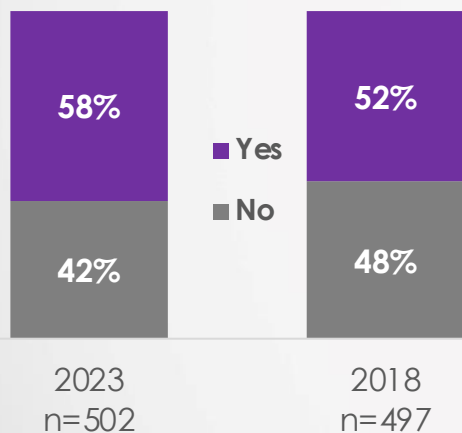
- Facebook continues as the key social networking site used for any purpose, followed by YouTube and Instagram
- YouTube, Instagram and LinkedIn have gained ground versus 2018 while Twitter and Inspire have correspondingly lost usage



Attending Events

- Claims of ever attending TSC Alliance event have stabilized 2018 to 2023 compared to 2010
- As in the past, reasons for not attending events center on lack of proximity, personal scheduling and cost

Ever Attended TSC Alliance Event



Reason(s) for Not Attending a TSC Alliance Event

Reason	Individual with TSC		Primary Caregivers		Providers	
	2023 n=57	2018 n=57	2023 n=147	2018 n=114	2023 n=12**	2018 n=24*
No event near me	47%	58%	54%	48%	**	25%
Too busy to attend	30%	28%	23%	27%	**	62%
Not able to afford to attend	25%	40%	21%	32%	**	12%
Issues with transportation	16%	NA	12%	NA	**	NA
Not aware of any events	11%	18%	10%	11%	**	12%
Concerned about COVID-19	9%	NA	7%	NA	**	NA
Not interested in events	11%	5%	3%	7%	**	8%
Physical limitations	7%	NA	3%	NA	**	NA
Event is hard to get to	9%	NA	2%	NA	**	NA
Other reasons	12%	7%	14%	15%	**	8%

■ 2023 n=209 ■ 2018 n=240

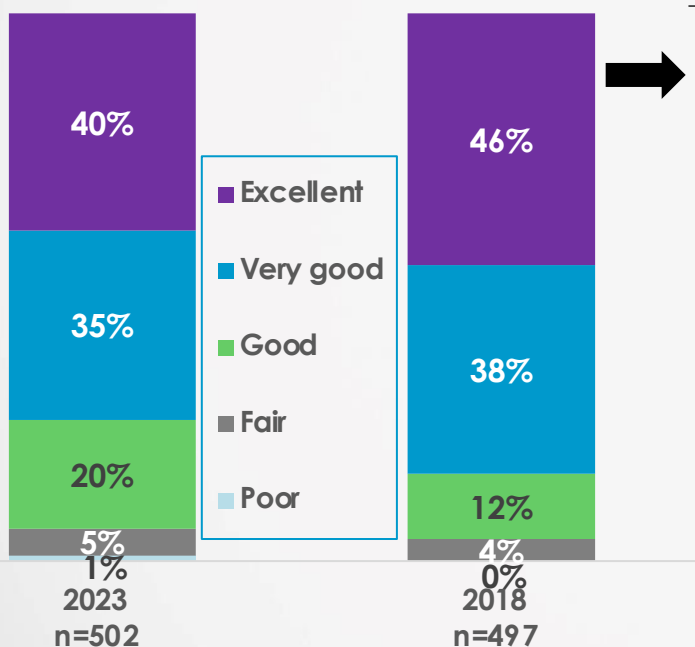
*Caution: Small Base; **Base too small to analyze

EventEver. Have you ever attended any of the TSC Alliance events such as Step Forward to Cure TSC walks, Comedy for a Cure, Golf Tournament, or local community fundraising events whether in-person or virtually? WhyEventNever1[x]. [IF EventEver = 2] Why have you **not** attended any **in-person** TSC Alliance events? A/B, C/D/E/F/G/H indicate significantly higher than corresponding group at the 90% confidence level. *Small base

TSC Alliance Ratings/Improvements

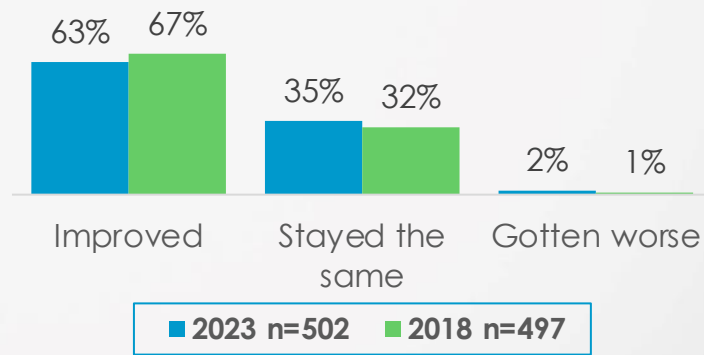
- Overall “Excellent” Ratings of TSC Alliance fulfilling its mission have stayed the same but “Good” Ratings have grown at the expense of “Very Good” Ratings; at the same time perceptions of improved have held constant
- However, “Excellent” Ratings have slipped among Primary Caregivers and Providers

Overall TSC Alliance Rating



Someone with TSC		Primary Caregivers		Providers	
2023	2018	2023	2018	2023	2018
n=112	n=89	n=381	n=283	n=30	n=38
40%	42%	39%	47%	47%	CDEF

TSC Alliance Improvement



TSAGrade. Overall, how would you rate the TSC Alliance in terms of how well it fulfills its mission: “To find a cure for tuberous sclerosis complex while improving the lives of those affected”?

TSATrend. Over the past 5 years, do you think the TSC Alliance has improved, stayed the same, or gotten worse in terms of its success in fulfilling its mission?

Reasons For TSC Alliance Improvement Fulfilling Mission



- Perceptions that TSC Alliance has improved in fulfillment of mission are principally More/New information/better communication and Advancements in treatment & research/medical improvements

Improved

n=315

More/New information readily available/Better communication	34%
Advancement in treatment and research/Medical improvements	32%
Increased involvement/Advocacy	26%
Increased Visibility/Awareness	24%
Better website/social media upkeep/tech mentions	16%
More/better fundraising	13%
More Medical Assistance	10%
Teleconferences/webinars help me feel more connected	8%
Better/more staff	7%
General improvement	5%
TAND tools/checklist mentions	3%
All Other	1%
Don't know	8%

Reasons/Feedback Re Experience

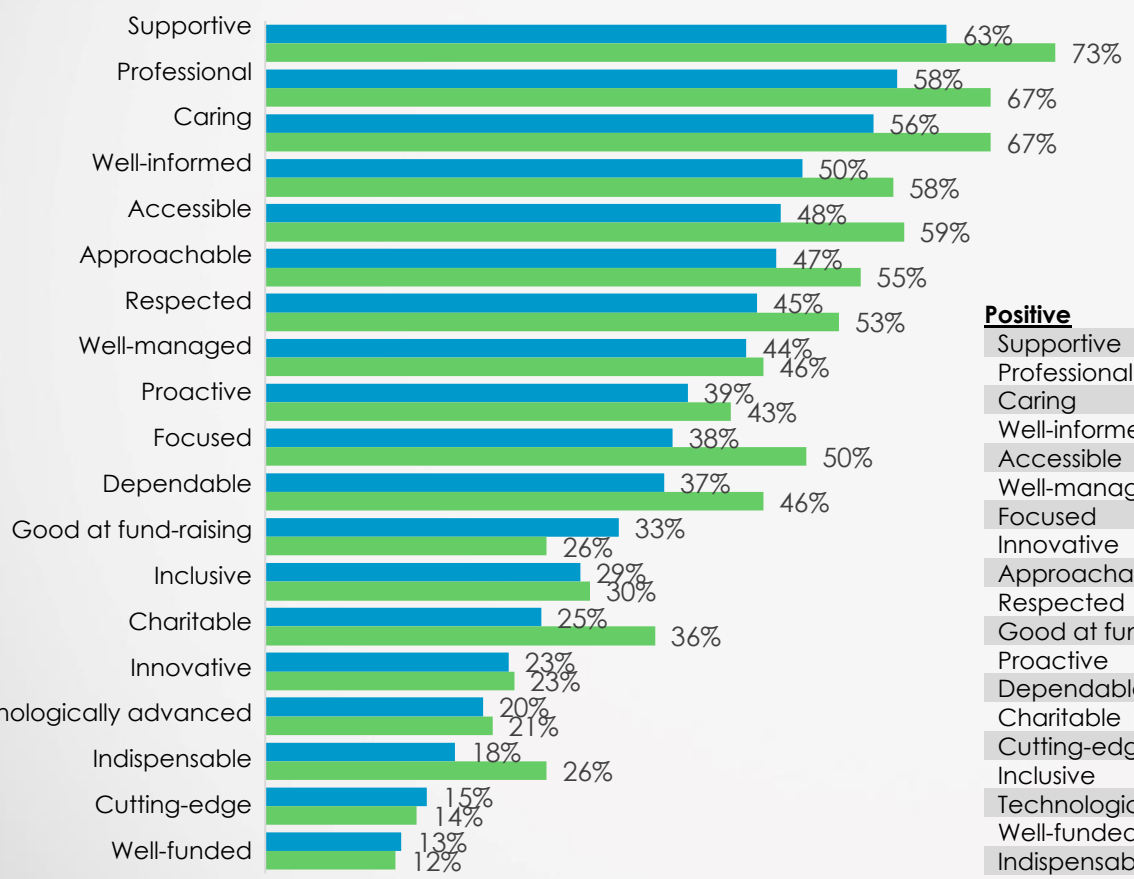
- Those who think TSC has gotten worse in fulfilling its mission credit that to lack of putting people first and doing enough locally in terms of support and involvement

<u>How to Improve</u>	<u>#</u>
Put people first	6
Local Support/Involvement	6
Adult services/information	3
Better organization/structure	2
Funding	1
Covid-19 mentions	1

TSC Alliance Positive Descriptors

- In 2023, Constituents selected fewer individual positive descriptors than in prior waves although they were equally positive overall. Only “Good at fund-raising” was selected more often than 2018

92% Selected At Least One Positive Descriptor



■ 2023 n=502
■ 2018 n=497

Positive	2023		
	Under 13 n=13	13 - 19 n=216	20+ n=238
Positive	92%	93%	89%
Supportive	62%	66%	61%
Professional	54%	57%	57%
Caring	54%	52%	59%
Well-informed	46%	51%	46%
Accessible	46%	47%	49%
Well-managed	46%	41%	43%
Focused	46%	37%	37%
Innovative	38%	20%	22%
Approachable	38%	45%	48%
Respected	38%	40%	48%
Good at fund-raising	31%	33%	32%
Proactive	23%	37%	40%
Dependable	23%	35%	38%
Charitable	15%	26%	25%
Cutting-edge	15%	15%	11%
Inclusive	15%	30%	27%
Technologically advanced	8%	19%	20%
Well-funded	8%	10%	12%
Indispensable	8%	17%	18%

TSC Alliance Negative Descriptors

- Constituents were equally likely to choose one negative descriptor about TSC Alliance as in the past
- Under-funded still ranks as the most selected negative descriptor about TSC Alliance, although it has seen a significant drop in mentions for the second consecutive wave

30% Selected At Least One Negative Descriptor

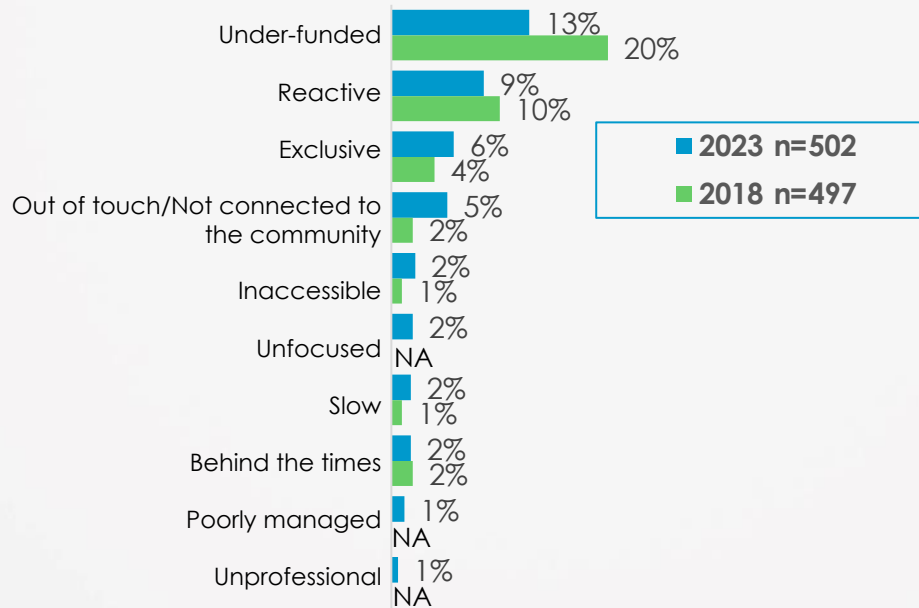


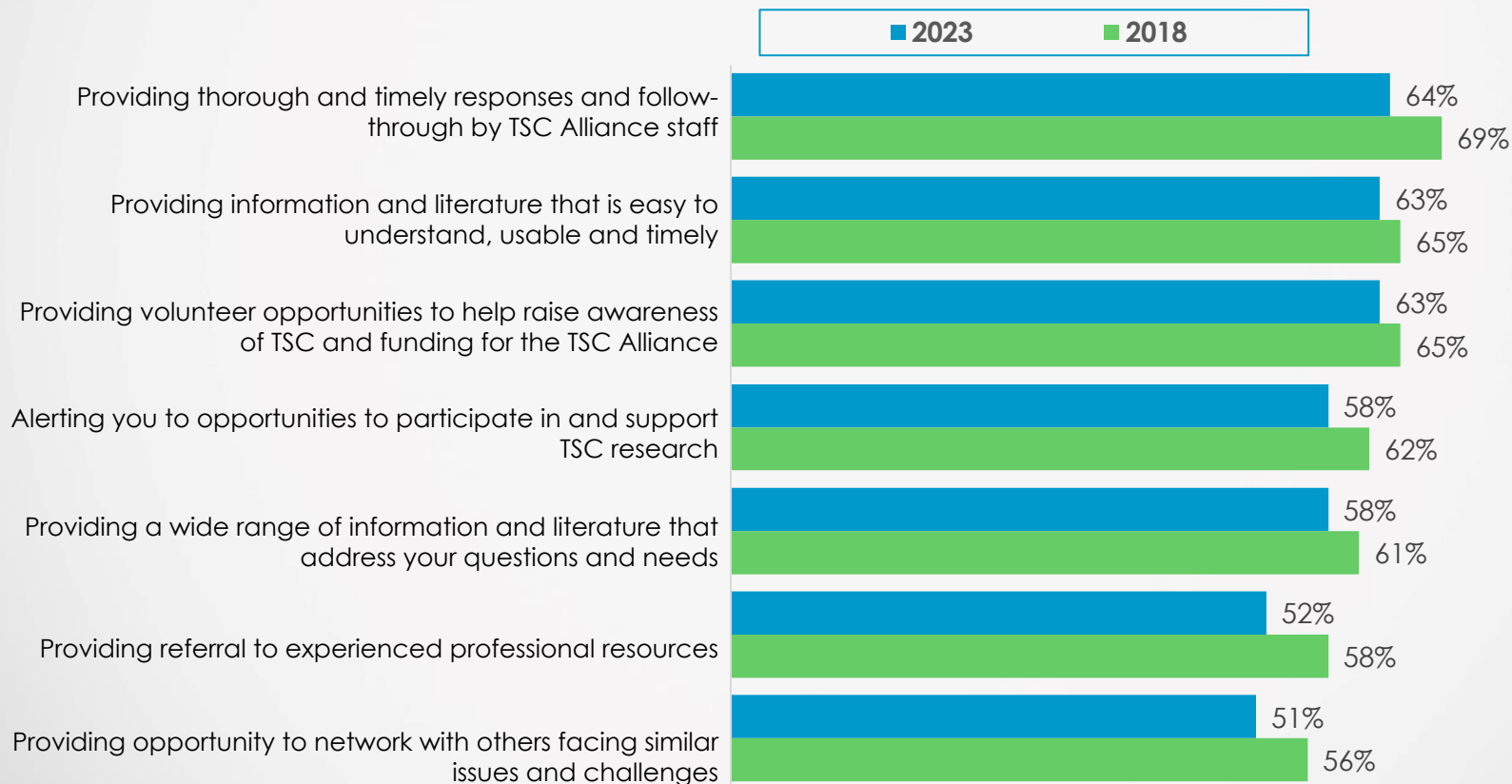
Table shows 5%+ mentions
 TSADescribe[x]. Which, if any, of the following words describe the TSC Alliance?

Ratings of TSC Alliance on Selected Services

% Rated Excellent or Very Good



- Thorough, timely responses & follow-through by TSC Alliance staff along with Providing info and literature that is easy to understand/timely and volunteer opportunities to raise awareness & funding lead in positive service ratings

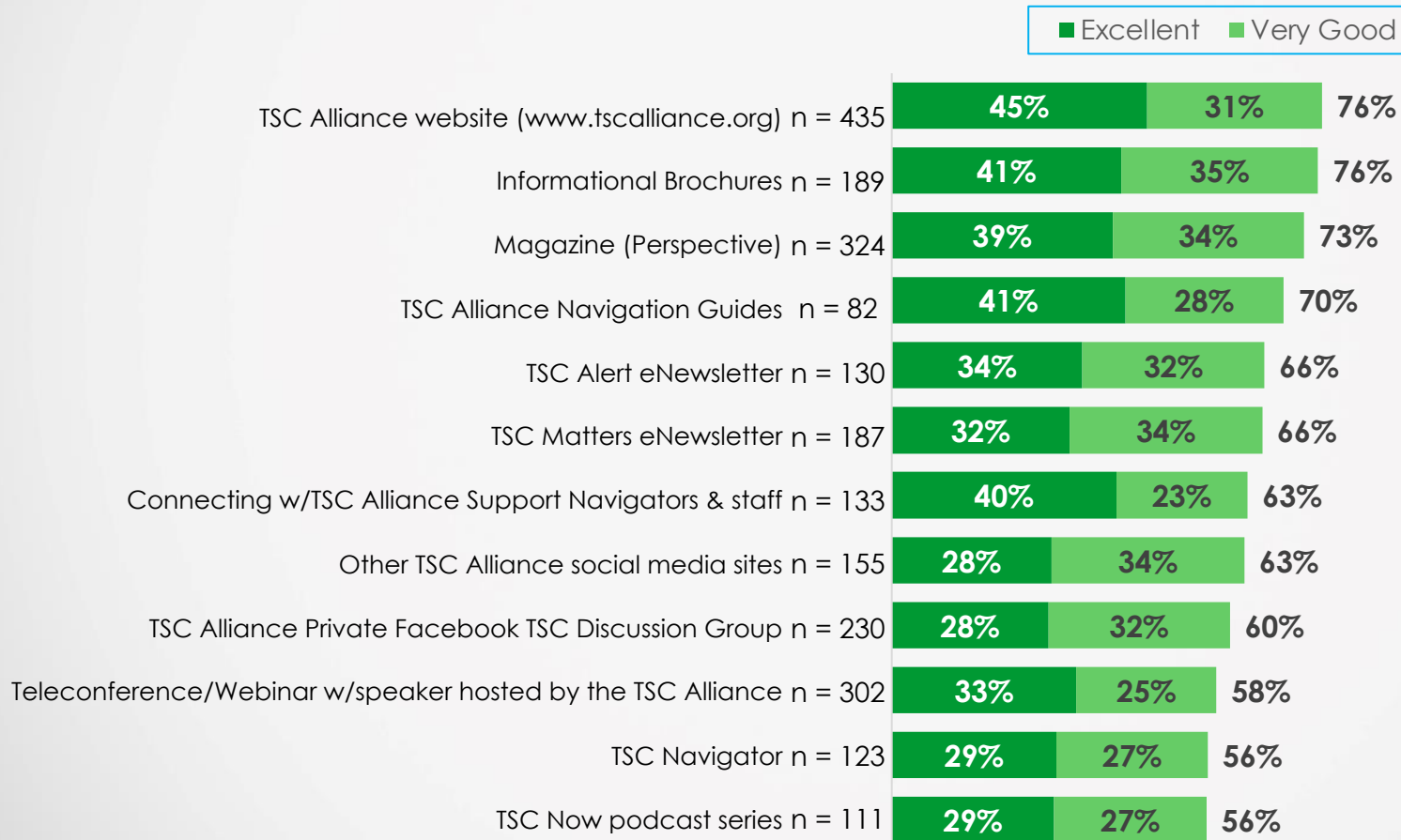


Base: Variable (Users)
Resources. Based upon your personal experiences over the past 3 years, please rate the TSC Alliance according to how well it has provided the services listed below.

TSC Alliance Offering Evaluation

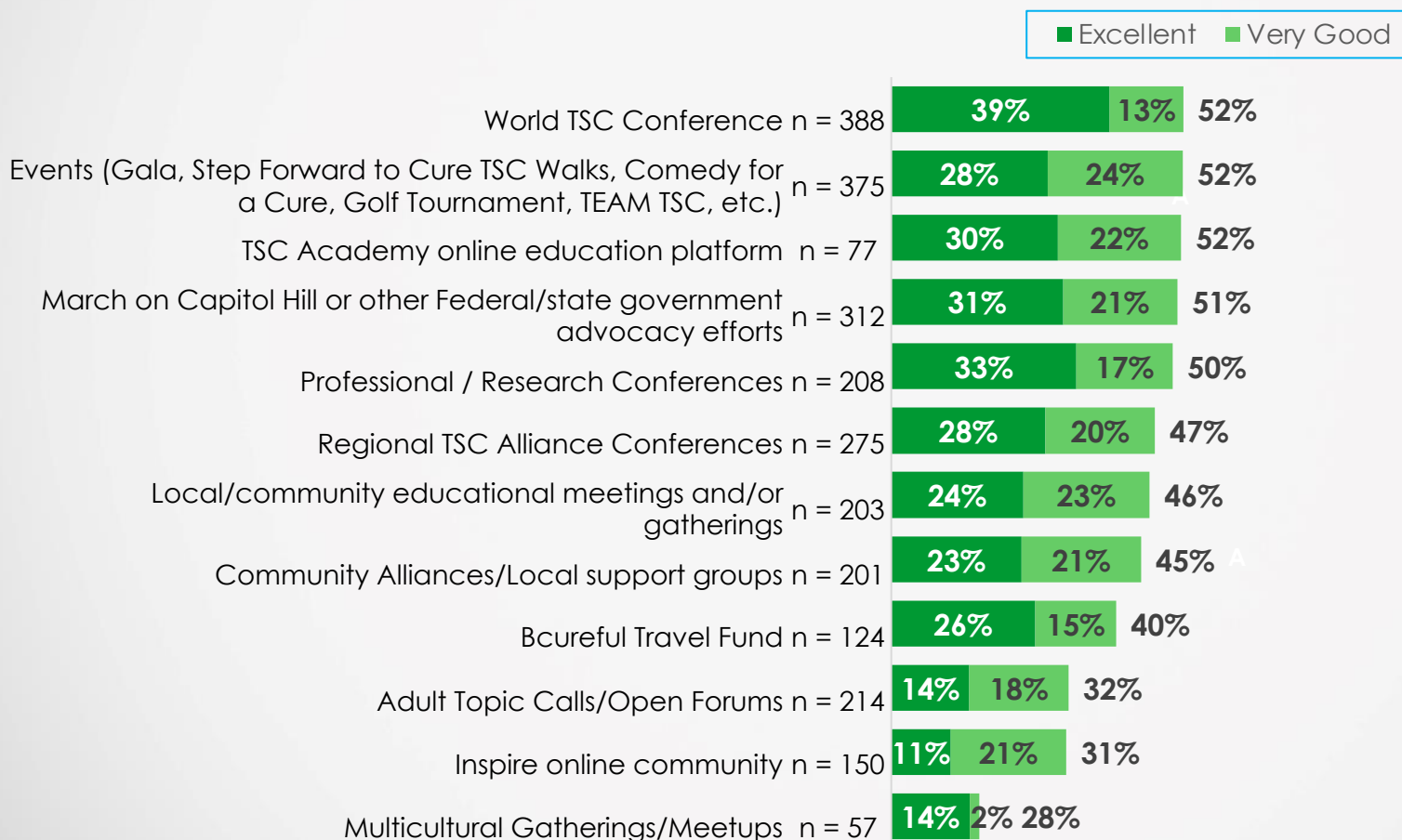


- Constituents are strongly positive (with Excellent ratings 40%+) toward the TSC Alliance website, Information brochures, TSC Alliance Navigation Guides, and connecting with TSC Alliance Support Navigation & staff



TSC Alliance Offerings (continued)

- At least half of Constituents taking advantage of social offerings rate the World TSC Conference, Events, TSC Academy online, the March on Capitol Hill and Professional/Research conference “Excellent” or “Very Good”

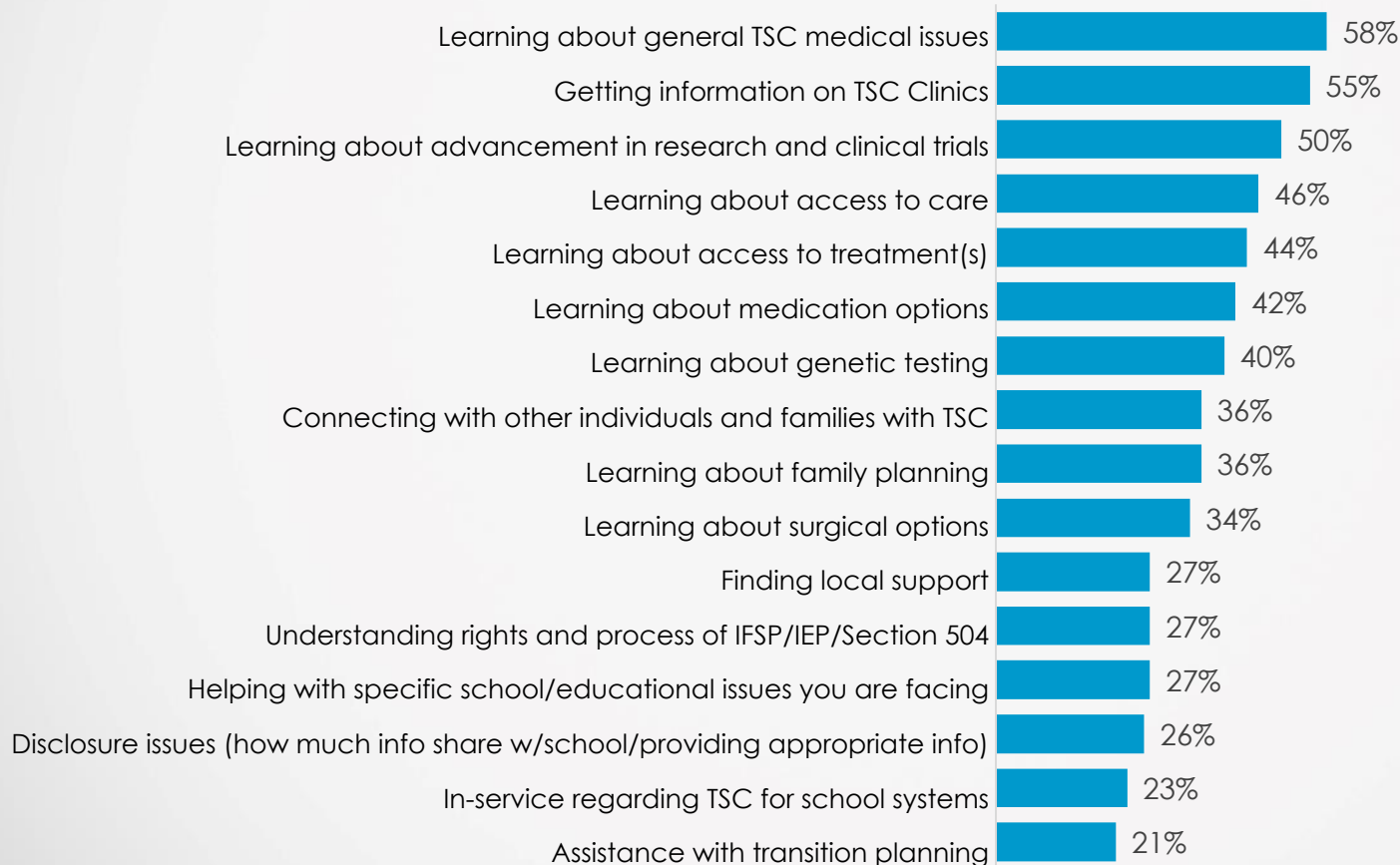


Top 2 Box Ratings of TSC Alliance in Helping Meet Individual Needs



- At least half of Constituents with a need give TSC Alliance Excellent/Very Good ratings on helping individuals “learn about TSC medical issues”, “get information on TSC Clinics” and “learn about research/clinical trial research advancements”

2023



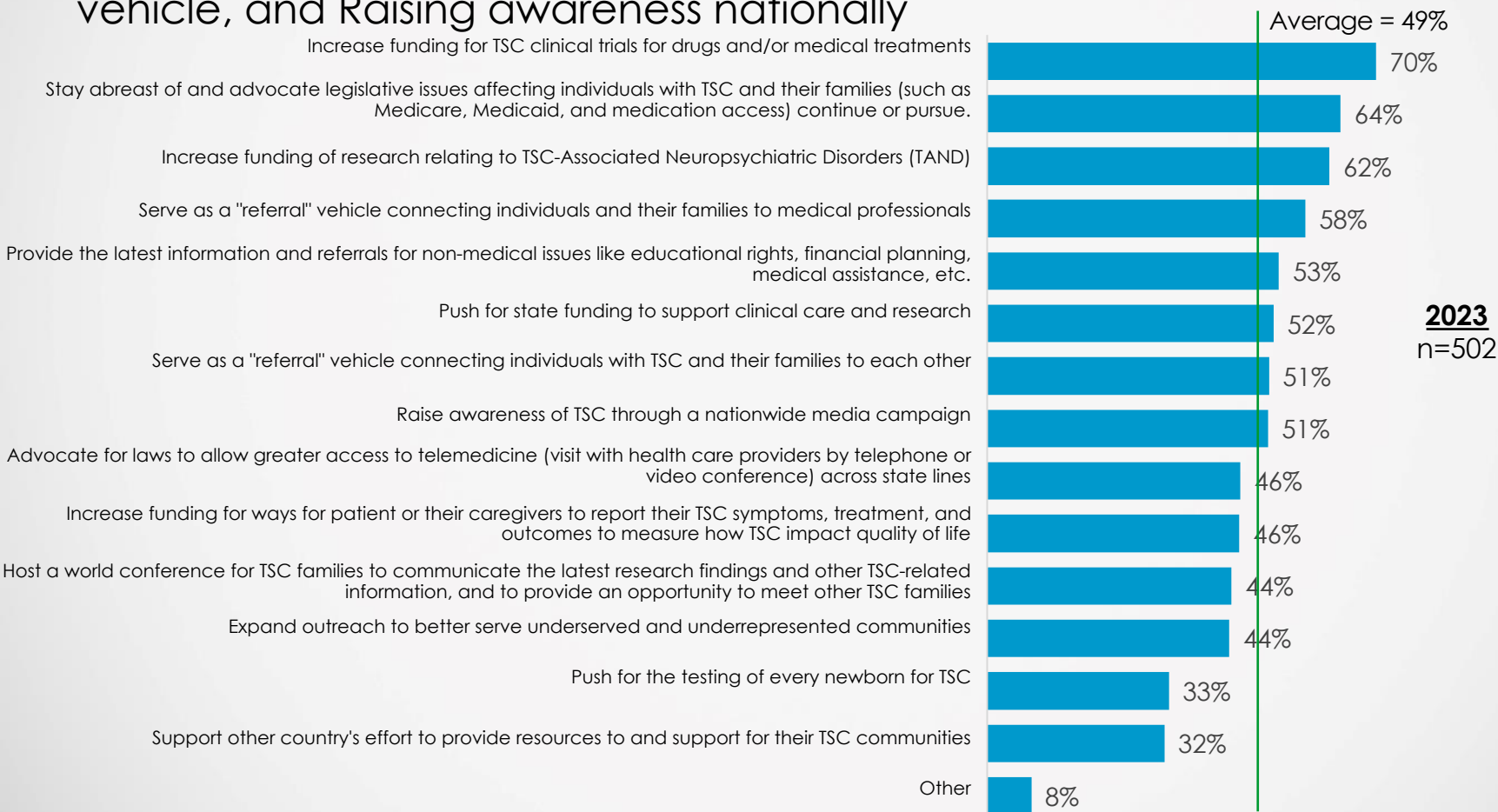
Top 2 Box Ratings of TSC Alliance in Helping Meet Individual Needs (continued)

- Education and family support issues, along with “gathering information about independent living options”, net lower Excellent/Very Good ratings among those with an applicable need



Activities to Pursue

- Increase funding for TSC clinical trials, Staying abreast of legislative issues and Increase funding for TAND research are the priorities for Activities To Pursue. Four others score above average: Referral vehicle, Providing latest info on non-medical issues, Push for state funding, Serving as Connection vehicle, and Raising awareness nationally



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