

# **TASP ANNUAL REPORT**

## **October 1, 2021 – September 31, 2022**

### **GENERAL TASP UPDATES**

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- Added 3 new board members during the reporting period: 2 parent-self advocates and 1 returning founding board member.
- Change in TASP Board Leadership included:
  - Dr. Nicole Brisson stepped down as Vice President of the TASP Board and Lise Schelmmann was elected to the position.
  - In August, Dr. Julie Clockston stepped down from the Presidency, and Lise Schellman was elected to that position.
  - Lisa Simmons took over as Secretary in August.

### **OUTREACH**

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- **Website development and design**
  - Continually updated the website, changed pages, added and removed information as needed.
  - 13,259 sessions to the website. Up 42% from the previous year and 135% over 2 years.)
  - 10,823 users: up 54 % from last year and 145% over 2 years.
  - 22,037 page views: increase of 23% from last year, and 100% over 2 years.
  - 7,157 direct searches, with most traffic going to our webinars, trauma training, resources, and blog posts (in that order)
  - 543 page visits came directly from Facebook (up 55% from last year).
  - Largest age group visiting our website is those aged 25-34, followed by 18-24 year-olds
  - Continued our Google Ad Grant for up to \$10,000 in search ads shown on Google searches.
  - Re-established work on SEO, using a list of identified search terms
- **Social Media Outreach**
  - Continued the plan for regular, at least 3-4 times/week postings on FB
  - Schedule of posts put in place to enable us to create content ahead of time
  - In line with last year, we posted and shared on social media 260 times during the reporting period. This is an average of 5 times/week with over 85% of posted content being original (not just sharing someone else's post).
  - Facebook engagement was up 63% and posts reached 6,111 people during the reporting period.
  - Our FB page has a total of 1443 likes

- **MailChimp and mailings**
  - Added 458 people to our mailing list this year, 50% increase to 1578 (was 1120 end of last reporting period)
  - Sent 60 eBlasts this year
  - Total eBlasts for the reporting period averaged 5/month.
  - Averaged 20% open rate and a 4% click rate (percentage of people who click the links in the emails or click through to our website).
  - 20% of our subscribers are highly engaged and open the majority of our emails
  
- **Newsletter and Blog**
  - Sent ongoing, regular monthly newsletter
  - We converted our highly viewed monthly "Parenting Tips" series to a blog to increase accessibility, SEO traffic, and content. This year we created 12 blog posts by both parents and professionals.
  
- **Conference and Training Attendance Outreach**
  - TASP, represented by Sue Jones, Bernadette Irwin, and Susan Yuan, presented to a group of Maryland University Centers for Excellence in Education trainees and professionals on the topic of supported parenting.
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- **Other**
  - Took part in a meeting with a consortium of advocates and support partners from Washington state. This workgroup was formed at the 2019 TASP Conference and continues to meet quarterly.

## **NEW INITIATIVES**

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- **Membership**
  - After a slow roll-out and few paying members, TASP decided to close down its membership site in August 2022. Archived webinars were moved to a new shop on TASP's main webpage, and the Education Committee continues to work on what to do with the remaining resources.
  
- **Webinars**
  - Applied for and received a grant from the Maryland Developmental Disabilities Council to provide a series of 4 webinars in 2022.
  - Created schedule of FREE webinars with TASP Board members presenting on topics
  - Promoted webinars through eBlasts and social media

- Through webinars, we were able to reach 334 people who participated (and 634 people who registered and then became part of our network), from 45 different states and 7 different countries.
- **TASP Trainings:** all TASP trainings are certified by the National Association of Social Workers and have CEU credits, which were re-certified this year. They include:
  - **Working with Parents with I/DD**
    - This year we trained 47 professionals across 2 trainings (Oklahoma and Brandeis/Massachusetts).
    - Pre and Post attitude surveys show a positive change in attitudes towards parents with IDD after completion of the training.
  - **Trauma**
    - Our newest training for mental health professionals provides an overview of some of the puzzle pieces of trauma, parenting, and IDD, and puts them together in the form of a coherent treatment approach.
    - This year is was offered once as an open training.
- **Collaborations/Contracts**
  - Continued and completed the contract with the Center for Parent Information and Resources under the U.S. Department of Education, Office of Special Education Programs. This included creating 5 training modules on Parents with IDD. These modules will be part of CPIR's eLearning Hub for all Parent Center staff in 91 centers across the country.
  - Received a grant from the Maryland DD Council to host and plan a series of free webinars on the topic of supported parenting in 2022. These were completed in conjunction with TASP Board Members, and presented in January, April, July, and September.
  - Received a grant from the Self-Advocate Resources and Technical Assistance Center (SARTAC) to create resources for parents with IDD around getting their child vaccinated against COVID-19.
  - Contracted with the National Research Center for Parents with Disabilities at Brandeis University to provide 1 training/year around Working Successfully with Parents with IDD. Completed the first training in April of 2022.
  - Worked with UCEDDs in North Dakota and Maryland to get priorities for parents with IDD in their 5-year plans. TASP secured an MOU with Maryland to provide 1 training/year for professionals working with parents with IDD.

## **ADVOCACY EFFORTS**

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- Promoted TASP’s Organizational Self Assessment Tool (OSA-TASP) to DD Councils, UCEDDs, and more, to allow an agency, program or state department to examine support for parents with I/DD at the local, regional, and/or state level.
- Maintained connection with NCIL Parenting Task Force, which required Susan’s getting an individual membership with NCIL
- Attended meetings of the Disability Coalition in Seattle (via Zoom)
- Worked with Dr. Ed Feil, Research Scientist at the Oregon Research Institute on *Digital Healthcare Interventions to Address the Secondary Health Effects Related to Social, Behavioral, and Economic Impact of COVID-19*. TASP serves on his Advisory Board for both grants, and has agreed to share info across our networks to help with recruitment.

## **COMMITTEE WORK**

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- **Education Committee**

Committee Chair: Lise Schellman

Members: Lise Schellman, Ginny Cruz, Susan Yuan, Lindsay Brillhart, Tom Robinson

**Update on specific retreat-related activities/assignments:**

Our main goal until 5/2022 was to create new trainings and opportunities. With the changes in the strategic plan we put our energies into moving existing resources into tool kits and will ensure we have trainers available for existing trainings and develop new trainings as required.

**3-4 goals/priorities for the next year:**

1. Complete resource toolkits.
2. Present existing trainings.
3. Develop trainings as needed.
4. Provide resources for any consultations resulting from Organizational Self-Assessments

- **Developmental Committee**

Committee Chair: Betsy Misch

Members: Chelsea Tighe, Lindsay Brillhart, Lisa Simmons

**Update on specific retreat-related activities/assignments:**

The Development Committee had taken the lead on discontinuing our membership site and supporting the webinar series. The Committee had begun to develop a marketing plan, however as the priorities of TASP changed, the Committee dropped this priority.

**Main activities/tasks/outcomes:**

- Discontinued Membership site

- Met with Advocacy and Education to prioritize goals.

### **3-4 goals/priorities for the next year:**

1. Finalize social media plan - who will be responsible for this if/when Chelsea is no longer ED.
2. Create system for developing resources
3. Define ongoing goals

- **Advocacy Committee**

Members: Bernadette Irwin and Susan Yuan (co-chairs), Sue Jones, Lindsay Brillhar, Ivanova Smith, Dorothy Hannigan, Colleen Downs, Lise Schellman, Lisa Simmons

### **Update on specific retreat-related activities/assignments:**

- IMPLEMENT SELF-ADVOCATE LED GRANTS AND PROJECTS
  - A video (three sections) was developed along with a Resource Section, and Tip Section. Advocacy Committee member Lindsay Brillhart along with Bernadette Irwin presented the video and provided a brief overview of the project on September 29, 2022, to SARTAC.
  - The three components of the video were: SHOULD I GET MY CHILD VACCINATED; PREPARING YOUR CHILD FOR THE VACCINE, AND WHERE AND HOW DO I GET MY CHILD VACCINATED.
  - TASP will continue to maintain contact with SARTAC to learn of additional opportunities for grants and projects that we may participate in.
- TASP WILL USE TASP-ORGANIZATION SELF-ASSESSMENT WHEN NEEDED TO PROMPT TRAINING NEEDS AWARENESS
  - TASP will follow-up with the UCEDD's who were contacted this year along with the remaining UCEDD's. Also, the Committee is developing work plans for contacting and maintaining contact with the DD Councils, The Protection and Advocacy group, and the Independent Living Centers. Every correspondence will reference the TASP-SA tool.
  - Committee is in the process of identifying States where legislative or potential legislative activity is taking place -- all these encounters will emphasize using the Self-Assessment tool to raise awareness and for potential training that we could of
- SEND TRAINING MATERIALS TO UCEDD'S/DD COUNCILS AND OTHERS
  - Committee members will present a Work Plan at next AC meeting for how this task will be implemented
- RECRUIT AND ENGAGE SELF-ADVOCATES. BY DEVELOPING STRATEGIES TO ENGAGE AND SUPPORT PARTICIPATION ON BOD OF DIVERSE SELF-ADVOCATES.
  - TASP has invited three self-advocates that attended the National Developmental Disabilities Council annual conference this summer (Susan Yuan. Sue Jones and Bernadette Irwin presented at this

conference. Lindsay and Bernadette Irwin had one phone conversation with the three new self-advocates to answer the questions about TASP. They will complete the paperwork after our Annual Meeting and then the Board will vote on their acceptance.

- AC will also maintain close contact with the new Leadership Committee, headed by Tom Robinson, to ensure that the self-advocates are supported in their new role.
- IDENTIFY STRATEGIES TO ENGAGE AND SUPPORT PARTICIPATION OF DIVERSE SELF-ADVOCATES ON BOD
  - Committee Chairs will maintain contact Tom Robinson who will Chair the Self-Advocates Leadership to ensure that all self-advocates are engaged and growing in their new role on the BOD
- SUPPORT SELF-ADVOCATES TO CARRY OUT ACTIVITIES TO SUPPORT PARENTS WITH I/D
  - A portion of each monthly AC meeting will be devoted to targeted conversations about potential projects that the self-advocates have an interest in that would advance TASP Mission and services available to parent with I/DD

**Main activities/tasks/outcomes:**

- \* TASP Advocacy Committee met monthly
- \* Planned and participated in TASP Retreat on November 18, 2021
- \* Presented virtually with Sue Jones at ISSIDD Conference on November 24k 2022-- provided overview of TASP
- \* Participated in several SABE/SARTAC monthly meetings
- \* Advocacy Committee researched and develop a video presentation along with Tips and Resources in response to a request from SARTAC
- \* AC Chair participated in several planning phone calls with MD UCEDD on how TASP and the UCEDD could collaborate -- eventually TASP written in to their 5-year plan for conducting training (topic to be determined later)
- \* AC Chair along with two AC members presented an overview of TASP at the KKI/UCEDD Summer Training Program
- \* AC Chair participated in several Zoom meetings with TASP grant writer
- \* AC Chair along with two members AC Committee presented at the NACDD in DC on July 20, 2022 -- overview of TASP with emphasize on TASP-OSA
- \* AC Chair along with two AC members planned and participated in a phone conversation with Alison Barkoff, Jennifer Thomas and Jill Jacobs on August 31 to discuss the development of a designation of a Project of National Significance for Parents with I/DD
- \*Identified three new self-advocates who will join the BOD after our Annual Meeting. Each of these individuals have extensive background in positions with their State's DD Councils. Two are from Nevada and one is from Michigan.

**3-4 goals/priorities for the next year:**

1. Support newly formed leadership committee to ensure that self-advocates are productive and enjoying their contribution to TASP's mission
2. develop and implement work plans to work with UCEDDs/DD Councils/Centers for Independent Living/Protection and Advocacy Centers and others to offer training of TASP-OSA to increase TASP's income
3. Identify and develop work plans to contact at least two states who are considering legislation to enhance their services to parents with IDD or to protect parents with i/dd from abuse of their civil rights. This would result in a process that could be replicated in other states.

- **Executive Committee**

Chair: Julie Clockston (through 8/22/22), Lise Schellman (as of 8/22/22)

Committee Members: Cathy Haarstad (Treasurer), Lisa Simmons (Secretary elect as of 8/22), Lindsay Brillhart (Parent Self-Advocate), Sue Jones (Senior Board Member), Bernadette Irwin (Senior Board Member)

**Update on specific retreat-related activities/assignments:**

- One new self Advocate has been elected to the board and 3 new recruits are interested.

**Main activities/tasks/outcomes:**

- SPAN/CPIR contract (Cathy/Chelsea)  
We have a contract for 5 modules, \$2000/each over the next 14 months.
- Mini retreat in November – Facilitator Moses Perez  
Leadership  
What's Important for TASP?  
Spend wisely  
Brainstorming to Fund These Priorities  
DEI as priority and also opens doors to more funding opportunities
- Recruit Self Advocates.  
Priorities changed as financial situation became more challenging.
  1. August 2021; how do we fund TASP to continue to build as a business
  2. Dec 2021; DEI emphasis recommended in Retreat
  3. April 2022; Recognition that business/sustainability plan was not tenable, and focus on DEI while highly important needed to take back seat to sustainability
  4. May 2022; Developed new Strategic plan with understanding we would need to end contract with ED by July.

5. July; Developed new strategic plan based on financials that included continuing contract with ED

**3-4 goals/priorities for the next year:**

1. Continue to refine Strategic plan and build Community Model
2. Support work of Finance, Education, Development and Advocacy Committees as they change to adjust to new model
3. Ensure tasks ED has done in the past are assigned to current members.

● **Fiscal Committee**

Committee Chair Name: Cathy Haarstad

Committee Members: Mary Mercer, Sophie Cates, Pat Grosz, Joe Brusak, Cathy Haarstad, Chelsie Tighe, Virginia Cruz (recently resigned)

**Update on specific retreat-related activities/assignments:**

- Reviewed, updated and shared a tool with TASP members on how to engage partners in a dialogue about providing financial support to TASP.
- Developed four contract funded CPIR training modules (with Chelsea Tighe) on supporting parents with IDD.
- Sought funding from the Dryfus foundation and edited grant applications for the Niles foundation. Also sought funding from the Kellogs Foundation. Held planning discussions related to that application with representatives from Michigan.

**Main activities/tasks/outcomes:**

- Held four committee meetings to review bank statements, finance logs, balance statements and profit and loss statements.
- Developed a community business model for TASP in light of changing financial conditions.
- Helped to find and secure a grant writer for TASP.
- Reviewed and proposed a new budget for the upcoming year.
- Worked with the ED and Executive Committee to assign committee responsibility to all tasks currently completed by the ED.

**3-4 goals/priorities for the next year:**

4. Update the finance committee membership
5. Develop a tool for seeking committee support with projects or making budget access requests.
6. The tool must be simple to understand and easy to use, written in plain language for access by self-advocates. Update the listing of executive responsibilities.



## **WORK BY TASP BOARD MEMBERS TO ADVANCE TASP'S MISSION**

- **Outreach:** ways TASP Board Members engaged and educated the public about parents with I/DD. This could include training/presentations you gave, published articles, conferences you attended and/or presented at, podcasts, podcast interviews, other interviews, etc.
  - Susan Yuan:
    - Advocacy training for Open Doors for Multicultural Families (Seattle); two cohorts of families from 8 different linguistic groups, 1 cohort for staff, and consulting on advocacy curriculum for Self-Advocates.
    - Keynote speaker at Canadian Angelman Syndrome Conference (coming in October)
  - Betsy Misch:
    - Completed trainings at The University of Massachusetts for their Brain Sciences Department
    - Worked on the Mass Partnership for Supporting Parents Living with ID/D
    - Worked on the Brandeis NIDILRR Grant
  - Lisa Simmons:
    - 10/15/21 - Provided handouts for child welfare staff training: Intervention idea sheets on 5 disability categories and digital Child Welfare Desk Reference on Supporting Parents with Disabilities. Also offered consultation on complex cases.
    - 11/22/21 – Provided training for OUHSC Research Staff on “Supporting Parents in Their Homes as they Participate in University Sponsored Research Projects”.
    - 1/10/22 provided a 90-minute training for the Children First staff at the Oklahoma County Health Dept.
    - 1/24/22 provided a 1-hour professional rounds training on “Supporting Parents with Disabilities in Healthcare Settings” for the OUHSC Psychiatry Dept
    - Coordinator for the Oklahoma Communication Support Project
    - April, 22 – Provided a 1-hour virtual training on Complying with the Americans with Disabilities Act in the Courtroom. This training covers how to accommodate individuals with disabilities as courtroom participants and is appropriate for all judicial staff and courtroom participants.
    - 4/7 and 5/5/22 Partnered with The Association for Successful Parenting (TASP) to provide training on “Working Effectively with Parents who have I/DD”. This is a 6-hour interactive training that was offered to Child Welfare staff, CASA volunteers, and legal aid offices.

- 4/28/22 provided 90-minute training for the JC McCarty Care Team on ways to support and communicate more effectively with parents who have an intellectual disability.
  - Distributed 200 bench cards sharing information about reasonable accommodations for individuals with disabilities to legal aid offices and CASA programs across the state.
  - 5/4/22 Provided legal staff from Still She Rises with information and resources so that they can better support clients with disabilities.
  - 5/9/22 provided resources for understanding I/DD to assist Wichita Tribe and Dr. Tom Teasdale as they launch a project to support individuals with I/DD who may be experiencing dementia.
  - 8/16/22 Provided the Department of Human Services nursing staff with resources and strategies to assist them as they provide medical education to parents with intellectual disabilities who are raising children with chronic health conditions.
- Cathy Haarstad:
  - Provided a one hour virtual training on TASP to program managers employed by North Dakota Department of Health and Human Services.
  - Shared various TASP materials with personnel at the local University of Excellence and provided consultation as they developed a new five year plan.
- Tom Robinson:
  - Trained service providers who work with IDD parents in northern British Columbia
  - Administered and provided resources for Family Preservation Program involving at risk families in isolated, rural communities
- **Advocacy:** ways our board members spoke on behalf of or in support of parents with I/DD. This could include participation and collaboration on boards, commissions, or other systems work (advisory councils, task force, trainee, fellow, etc.):
  - Susan Yuan took part in:
    - State Standing Committee for Developmental Services (VT), Payment Reform Advisory Committee (DS, VT), Assessment Team, (Payment Reform)
    - Board of Directors, Upper Valley Services
    - Fellow, AAIDD
    - Presenting at TASH Conference
    - Presented, along with Bernadette and Sue, at NACDD Conference
    - Me2 Orchestra (for people with mental illness and those who support them; Burlington Civic Symphony; VT Mahler Festival Orchestra

- The Vermont Communication Support Project, Advisory Committee. VCDR--(VT Coalition for Disability Rights).
    - Working with Vt legislator Theresa Wood to draft legislation restricting restraint and seclusion (we got regs about a decade or more ago, but they aren't strong enough).
  - Lindsay Brillhart took part in the Family Children's First Council for my county in Ohio and spoke about the work of TASP.
  - Colleen Downes took part in the Wight Special needs Task Force – a task force that addresses the needs of the persons with disabilities.
  - Betsy Misch worked on the Mass Partnership for Supporting Parents Living with ID/D.
  - Lisa Simmons:
    - Provided consultation on 13 cases to assist family support professionals to include reasonable accommodations as they assisted parents with disabilities.
    - Conducted outreach to CASA programs and Legal Aid attorneys across the state of Oklahoma to raise awareness about the need for communication support for parents with intellectual disabilities.
  - Cathy Haarstad shared information with various groups in ND on the Organizational Self-Assessment Tool.
  - Tom Robinson served as an in-service facilitator for ethics and best practices in work with families
  - Bernadette Irwin maintained communication throughout the year with Aaron Bishop and Matt McCullough. Both these allies remain available to provide advice and guidance to TASP.
- **Other work of TASP members** (*fellowships, research, assessments, direct services, etc.*):
    - Susan Yuan completed parenting Skills Assessments, through both SageHaven Inc. and Yuan & Associates, LLC.
    - Lindsay Brillhart is taking part in a research project with Brandeis about mom's that have premature babies and talking about how to get services for kids when younger, as well as working on another Brandeis project.
    - Colleen Downe is a Special Olympics Volunteer and a member of the Virginia Caregiver Committee.
    - Tom Robinson served as a CARF International accreditation surveyor in the United States and Canada.