

# TASP ANNUAL REPORT

## November 1, 2020 – October 31, 2021

### GENERAL TASP UPDATES

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- Added 2 new board members during the reporting period
- Change in leadership on the Education Committee from Nikki Brisson to Auguste Elliott (April 2021) to Lise Schellman (October 2021)
- Nikki Brisson has stepped down as TASP Vice President and the role in the process of being filled
- TASP had great success this year with our newest training, Working Successfully with PARENTS with IDD, but continues to seek out additional sustained funding opportunities.

### OUTREACH

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- **Website development and design**
  - Continually updated the website, changed pages, added and removed information as needed.
  - 9,317 sessions to the website (up 93% from the previous year) with 7,591 users (up 91% from last year) and 17,172 page views (increase of 77%)
  - 5,237 direct searches (up 162% from last year), with most traffic going to our home page, webinars, training for professionals, parenting tips, and trauma training (in that order)
  - 300 page visits came directly from Facebook (up 23% from last year), and 82 visits from 32 from LinkedIn
  - Largest age group visiting our website is those aged 25-34, followed by 18-24 year-olds
  - Received a Google Ad Grant for up to \$10,000 in search ads shown on Google searches. This is specific search ads, so that when someone searches for key terms on Google (like parents with disabilities, supported parenting, etc.), it would put TASP at the top of the list, driving traffic to our website. This should greatly increase web traffic to our site. More info about the grant here: <https://www.google.com/grants/>
  - 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
  - Posted and shared on social media 245 times during the reporting period. This is an average of 4.7 times/week with over 70% of posted content being original (not just sharing someone else's post). This is a 300% increase over the last reporting period, when we also posted almost zero original content.

- Facebook posts reached 6435 people during the reporting period, an increase of 65%.
- **MailChimp and mailings**
  - Added 585 people to our mailing list this year, more than doubling mailing list contacts to 1105 (from 520 last year)
  - 450% increase in eBlast mailings included, sending 85 eBlasts vs. 19 last year.
  - Total eBlasts for the reporting period averaged 7/month versus 1.5/month last reporting period.
  - Averaged 16% open rate and a 2% 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
  - Blog is still in the works but we created a monthly "Parenting Tips" series written by parents, for parents, that was shared via eBlast, posted on social media, and posted on our website.
- **Conference Attendance Outreach**
  - TASP was an exhibitor at the TASH Virtual Conference Dec.1-9 2020. This allowed our info and logo on their website and in conference materials and they will share our 2-minute promo video during conference breaks and online.
  - TASP also has two board members, Susan Yuan and Bernadette Irwin presenting at the TASH Virtual Conference. They are presenting on the Peer Navigation model used by TASP in the DC Project, and will promote TASP during their presentation.
  - Susan Yuan and Bernadette Irwin presented for TASP, on the topic of Peer Navigation, at the 2021 AAIDD Virtual Conference in June 2021.
  - TASP will be represented at the October Zero to Three conference, a new audience for TASP, in a presentation entitled "Assume Competence: Working Better with Parents with Intellectual/Developmental Disabilities and their Young Children."
- **Other**
  - TASP created a video featuring one of our parent/self-advocate board members that was shared prior to each training
  - Presented at the SARTAC weekly meeting on 4/29/21
  - Applied and was approved for permission to change our GuideStart information (for donation purposes). This required help from the Treasurer to change information within the IRS system.
  - Applied for and was approved for Charitable Giving through Facebook

- Applied for a Google Ad Grant of up to \$10,000 in ads per month
- Met with the Parents with Cognitive Challenges workgroup in Florida to join their discussion around services/supports for parents with IDD and how TASP could help
- Met with the Washington State Coalition around parents with IDD to share info about TASP and how we could help their work. This workgroup was formed at the 2019 TASP Conference and continues to meet quarterly.
- Joined Kentucky Coalition working on advocacy efforts around parents with IDD and shared some things TASP may be able to help with.

## **NEW INITIATIVES**

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- **Membership**

- Created schedule for rollout of resources
- Beta tested the site with all board members in April 2021
- Membership site built in spring 2021 with help from our web developers at WebIXI
- Membership was opened to the public in May 2021.
- New resources, training codes, all archived webinars, and more is added to the membership site on a regular basis.
- Development Committee continues to work on the best way to share information and get people engaged in membership.

- **Webinars**

- Purchased webinar software
- Created schedule of FREE webinars, every other month in 2021
- Promoted webinars through eBlasts and social media
- Through webinars, we were able to reach almost 400 people from 34 different states and 6 different countries.

- **TASP Trainings**

- **Working with Parents with I/DD**

- The Education Committee worked this year to finalize the first TASP training and roll it out to the first group in February 2021.
- This year we trained over 160 people across 8 trainings, generating an income of over \$40,000 for TASP
- Pre and Post attitude surveys show a positive change in attitudes towards parents with IDD after completion of the training.
- Grew our group of Independent Contract trainers to 9

- **Trauma**

- **Collaborations/Contracts**

- Contracted by the Center for Parent Information and Resources under the U.S. Department of Education, Office of Special Education Programs to

create 5 training modules on Parents with IDD. These modules will be part of their eLearning Hub for all Parent Center staff in 91 centers across the country.

- Began discussion around a potential collaboration with the International Le Leche League
- Collaborated with Brandeis on their reapplication for the NIDILRR grant for the National Research Center for Parents with Disabilities. In April 2021, TASP submitted a letter of support that we would collaborate to bring one training per year (for up to 20 people) and NRC would cover the cost.

## **ADVOCACY EFFORTS**

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- TASP joined national organizations to sign the LGBTQ/Disabled Parenting Rights Letter in April 2021. More info [HERE](#)
- Met with Kentucky Disability Rights Coalition in April 2021 to discuss their ongoing legislative efforts to pass a bill guaranteeing the rights of parents with disabilities
- Developed an Organizational Self Assessment Tool (OSA-TASP), 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)
- Stayed abreast of a class-action suit moving forward with a formal complaint to the Office of Civil Rights of Health and Human Services. Submitted in July, likely to go to Carla Carter. Included 3 cases, one of which is a parent who received a Competence Based Parenting Assessment done by Susan with consultation from Nikki.
- Broadened Seattle connections via Open Doors for Multicultural Families as Susan was contracted to create an advocacy curriculum for 12 parents from different cultures and offer it in person in the fall if COVID allows.
- Worked with Dr. Ed Feil, Research Scientist at the Oregon Research Institute and sent letters for support for his (subsequently funded) IES development grant (<https://ies.ed.gov/funding/grantsearch/details.asp?ID=4470>) in March, and his NIH grant (approval pending) on *Digital Healthcare Interventions to Address the Secondary Health Effects Related to Social, Behavioral, and Economic Impact of COVID-19* in August. TASP is serving on his Advisory Board for both grants, and has agreed to share info across our networks to help with recruitment.
- Sent a letter of support for the Access to Free Speech for All Act that would create a National Resource Center on Augmentative and Alternative Communication to serve the 5 million people in the United States who cannot rely on speech to be understood due to various disabilities and conditions. CommunicationFIRST worked closely with the

Association of University Centers on Disabilities (AUCD) and the Autistic Self Advocacy Network (ASAN), as well as the offices of Rep. Stephanie Murphy and Sen. Bob Casey on this revised bill, which was originally introduced by Sen. Casey in June 2019.

- Formally supported Massachusetts S.1083/H.1711 which would require judges to determine whether or not a parent’s disability causes actual harm to their child before they rely on the parent’s disability as a factor in a custody or parenting time determination. This bill will not cost the state money and may even save the state money by preventing unnecessary foster care placements in child welfare cases.

## **COMMITTEE WORK**

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- **Education Committee**

Members: Auguste Elliot (joined and Chaired as of April 2021), Nicole Brisson (Chair through April 2021), Susan Yuan, Lindsay Brillhart, Ginny Cruz, Julie Clockston, Tom Robinson, Lise Schellman, Chelsea Tighe

The Education Committee has completed all 2019 Retreat goals. The charge to develop internal policies related to Intellectual Property has been met with regard to current training offerings, but may need formalizing with regard to the material of non-Board members.

With regard to Education Committee Goals for 2021, they have been met, with the caveat that several of those goals are ongoing; i.e. development of the training menu, a virtual conference for 2022, monthly materials to Development for Membership, and the marketing of the Mental Health toolkit (for which we have asked help from the full board).

The Education Committee had a very productive year thanks to the direct contributions of many members and the unflagging organization and creativity of our Executive Director. The map of states represented in our webinars and trainings is a must-see on the website!

Highlights of the year include:

- “Working Successfully with Parenting with IDD”, Ginny Cruz’s original curriculum revised last year by the Committee, was presented numerous times. Numerous Board members have co-presented the curriculum and are available to do so going forward.
- Our first “Level II”. or advanced. training has been developed by Ginny Cruz entitled “Trauma, Parenting and Intellectual Developmental Disability: An Intra and Interagency Puzzle.” This half-day training will be presented for the first time on October 22.

- We are now able to offer National Association of Social Workers CEUs for the two aforementioned trainings, thanks to the patience and thoroughness of our Executive Director.
  - Our first “toolkit” has been developed. The Mental Health Toolkit, designed for therapists, is ready to be marketed to interested clinicians and clinical support staff.
  - Chelsea and Cathy submitted the first of many training modules in a contract with CPIR.
  - Committee members joined with other Board members in developing parent and provider informational materials for distribution to membership.
  - A sub-committee focussed on a virtual conference in 2022 has begun meeting and planning both content and logistics.
- **Developmental Committee**  
Members: Betsy Misch (Chair), Chelsea Tighe, Lindsay Brillhart, Lisa Simmons

The Development committee has completed almost of the tasks on our to-do list from the Retreat/Strategic Plan. Including developing a membership model and a membership site. The Committee still needs to re-define our role within the larger Board and draft new tasks for 2021-2022.

**Membership:**

- Developed a Membership site – Webixi and Chelsea.
- Membership officially opened 6/14/2021.
- As of today we have 34 memberships, half of which are Board members.
- Developed numerous tip-sheets and hand-outs for membership perks.
- Dev. Chair met with Education Committee to discuss their Membership submission commitment.

**Webinar Series:**

- Purchased Zoom Meeting software for webinars, etc.
- Developed protocols and word document for presenters of the free webinars.
- Developed 6 free webinars with consultation from the Education Committee.
- Developed an intro script for the host of the free webinars (Chelsea).
- Hosted and supported five of the six free webinars.
- Developing with Education a slate of webinars for the coming year.

**Marketing:**

- Discussed the need for Marketing to enhance membership numbers.
- Discussed and developed a Marketing plan.
- Applied for and received a Google Ad grant to support our outreach and marketing strategies.

- **Advocacy Committee**

Members: Bernadette Irwin and Susan Yuan (co-chairs), Chelsea Tighe, Julia Clockston, Coleen Downs, Lindsay Brillhart, Lise Schellman, Ivanova Smith, Kimberly Tissot

The Advocacy Committee worked towards completing all goal from the 2019 retreat, including an e;evator speech, and created and shared an Organizational Self ASsessment for Organizations.

Additional highlights of the year's work include:

- Susan Yuan continued her involvement with the NCIL Parenting TASK Force this year. She was instrumental in getting Kim Tissot from NCIL to join the TASP Advocacy Committee.
- Susan Yuan, Co-Chair of the TASP Advocacy Committee continues to consult with staff at Open Doors for Multicultural Families in Seattle.
- TASP continues to work with Seattle programs through consultation. Susan Yuan has completed several Parenting Evaluations (through Nikki) and has testified virtually with her results.
- All 52 UCEDD's were sent a packet that provided a survey that would help them determine their interest and capacity to provide services to parents with ID and the professionals who provide services for them.
- TASP Co-Chairs participated in a phone conversation with Early Intervention programs in Ohio to discuss how TASP could assist them in their program as parents with ID attend their programs
- Susan Yuan and Bernadette presented at TASH virtual conference in December 2020. We presented an over of the Peer Navigation model and reported on the DC Project. Participants were also invited to join TASP
- Susan Yuan and Bernadette presented at a TASP Webinar – overview of Peer Navigation and overview of the DC Project. Participants were also invited to join TASP
- Joined Lindsay Brillhart in a phone update regarding his book on Parents with Disabilities. Recommended that he also include Ivanova Smith in his book – he did contact her and she was included in his book
- Contacted La Lache International to discuss possible collaboration. Several phone calls and emails followed. Decided that what the wanted fell under the prevue of the TASP Education Committee. There

seems to be a breakdown in this transfer – Advocacy Committee and Education to discuss next steps.

- Bernadette and Susan presented over of Peer Navigation at AAIDD Virtual Conference on the Peer Navigation Model and the DC Project. Also shared information about TASP and invited participants to join.
- Several members of the Advocacy participated in other TASP Committee. Several are actively involved in the 2021 Min-Retreat meeting,
- Next steps will be developing a packet for DD Councils, CILS and P&A to help them gage their knowledge of serving parents with ID and possible collaboration with TASP

- **Executive Committee**

Members: Julie Clockston (Chair), Nikki Brisson, Lindsay Brillhart, Cathay Haarstad, Susan Yuan, Sue Jones, Bernadette Irwin, Chelsea Tighe

The Executive Committee completed remaining retreat activities and developed new goals for 2022 which were shared with the full Board. The EC has discussed outreach to potential board members, and assigned outreach of specific people to members of the EC.

TASP VP stepped down from her role so at the time of this report there is a vacancy in the Vice Presidency and in the Conference Subcommittee Chair position.

Other activities for the reporting period included:

- Discussion for increased recruitment and retention of parent self-advocates -BOD and membership. This is still an area of need.
- Appoint VP as liaison between committees to foster a connection and close the gaps. This is still needed.
- Discussion surrounding funding opportunities
- Completed Executive Committee Goals for 2021 adopted policies
- Discussed TASP Conference sustainability budget TBD discussion will continue.
- Finances are at a critical state discussion surrounding options for viability continue
- November retreat will primarily be spent on determining a solid plan for sustainability and growth of the organization.

- **Fiscal Committee**



Committee Chair Name: Cathy Haarstad  
Committee Members: Sue Jones, Susan Yuan, Pat Gross; Ginny Cruz, Chelsea Tighe

### **Administrative Activities Completed**

- The committee switched from meeting every other month to monthly.
- Meetings were held in: Nov. Dec. (2020) Jan. Feb. Apr. May June July Aug. Sept. (2021)
- Sue Jones resigned in Sept. 2021. Ginny Cruz joined in Aug. 2021.
- All minutes and finance reports can be accessed in Google Docs.
- Difficulty in obtaining a report on expenditures against the budget remained. (Chelsea worked with Joe Brusak on updating our account categories to align with the budget so that future reports can be available).
- The contract with Joe Brusak was updated in August 2021.
- Renewal of non-profit status in Colorado completed in Jan. 2021 – Fee paid.
- Evidence shows that the system of checks and balances put in place by the board continues to operate well as needed for both income and expenditures.

### **Financial Review Activities Completed**

- A finance log was reviewed in detail by the committee at every meeting.
- Balance sheets were also reviewed.
- Bank statements were reviewed.
- We continue to have limited notes entered for expenditures whenever the BOA makes a payment or withdrawal.
- Access to information in QuickBooks tends to lag but is updated when reminders are sent to the accountant.
- No significant misappropriation of funds were discovered.
- Both paycheck protection loans have been forgiven by the SBA.
- TASP remains fiscally solvent however, future income is difficult to predict and will probably be insufficient to sustain operations – especially payroll for the ED.

### **Financial Development Activities Completed**

- An online map that could be used to chart progress in building relationships in each state was shared with the ED and committee.
- A talking points document with embedded finance development strategies for use in outreach was developed and shared with the board.
- A handbook for fundraising was developed and is being reviewed by the committee.

- The FC discussed an actionable step that involves featuring self-advocates in stories or case studies. These could be motivating to potential members. No plans to develop this resource are in place. Next step is to discuss with the EC.
- A preliminary listing of how organizations can contribute to TASP was developed with steps on how to accomplish those activities was created.
- The advocacy committee was assisted to develop an assessment tool that UCEDDS could use to self-assess readiness to support parents with ID. The tool has been shared with all UCEDDS. This is a long-term financial strategy to build interest in TASP trainings.
- The F.C. recommends that TASP purchase marketing services and possibly email lists that we can use to expand interest in our services.
- Ginny found several resources from a Colorado non-profit organization that can be forwarded for future contacts.
- Pat will check with her contacts for EI in Florida and get the name of someone we could contact at the state level. Most of her contacts are local and she has invited Chelsea to participate on their local committee

## **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.
  - Lisa Simmons:
    - 2020 Presentations included - "Practical Ways to Support Parents with Disabilities" for Family Tree organization of parent educators; Final report to Developmental Disabilities Council of Oklahoma on 5 Year initiative to improve supports for parents with disabilities living in Oklahoma; "Supporting Parents with Disabilities in Healthcare Settings" for the staff of Variety Care clinics; "The Importance of Communication Support in Family Court" for 3 groups of paralegal professionals in Oklahoma; "Providing resources and communication support for parents with disabilities" for the directors of Oklahoma's multidisciplinary teams reviewing child abuse/neglect cases; "Tips and Tools when Working with Parents who Have Disabilities" - provided as a breakout session for the Child Abuse and Neglect Conference for staff involved in the child welfare system
    - Hosted trainings in Oklahoma - Virtual TASP training, "Working Effectively with parents with I/DD for Oklahoma parent support

agencies; Virtual training with Lynne Cardozo on Providing in person and virtual communication support for parents with disabilities interacting with the Oklahoma child welfare and family court systems.

- Auguste Elliott:
  - Discussions with officials at Vermont Department of Health regarding accommodations for parents with I/DD in their maternal mental health and prenatal programs. Inquiries to domestic violence network regarding accommodations/considerations, resulting in planned presentation in December.
  - In my role as National Trainer in Visit/Family Time Coaching, I have been a voice for parents with I/DD and incorporated resources and guidance into the training.
- Sue Jones:
  - Have begun conversations with an agency in Maine on developing a program to provide supports to parents with I.D.D.
  - In September will begin facilitating Parenting Groups for the Greenfield Housing Authority
  - Will be presenting at the Children's Trust Annual Conference in November on Virtual Supervised Visitation for Parents with I.D.
  - Facilitated a two part series on Working with Parents with I.D.D for the MASS Coalition on Parents Living with I.D.D (2019)
- Tom Working Successfully With Parents Who Have IDD training through TASP x5
- Susan Yuan:
  - Consultation and training with the team for a parent and children in WA state, coaching the parenting coach; consultation with a community service agency in RI regarding serving parents with i.d.; member of Sage Haven Associates, which conducts parenting skills assessments; assessments for 3 Vermont families including court testimony; reviews for 3 articles in related journals; design and conduct of Family Leadership Training for Open Doors for Multicultural Families in Seattle; presented at TASH and AAIDD Conferences; consulted on Peer Navigation with Parent/Child Centers in Vermont
- Lindsay talked about the book and my chapter has TASP in it.
- Cathay Haarstad:
  - I have included participants from the ND UCEDD in considering support for parents with I/DD as part of the planning towards their annual five year goals. They agreed to do this.
  - I engaged the US Department of ED in awarding a contract to TASP through CPIR to design modules on supporting parents with IDD for parent training and information centers in all 50 states.

- Colleen Downes attended the Endependence Center, Norfolk, VA 40th anniversary virtual celebration and shared information about TASP. I have also met with their advocacy staff and shared information about TASP.
- **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.):
  - Lindsay wrote a chapter in the book and included TASP
  - Sue Jones continued participation on the Mass Coalition for Parents Living with I.D.D.
  - Susan Yuan participated in State Standing Committee for Vermont Developmental Services; Assessment Task Force for Payment Reform in VT (got parenting added to assessment tool); court testimony for 3 parents.
  - Direct service contact with individual parents as a Behaviour Consultant
  - Colleen Downes shared information about TASP with the Long-Term Care workers at Senior Services of Southeastern Virginia since we service clients with disabilities and older adults.
- **Other work of TASP members** (*fellowships, research, assessments, direct services, etc.*):
  - Lindsay applied for a call for advocates to join the Disability Inclusion Fund (DIF) Grantmaking Committee, which is part of the Presidents' Council on Disability Inclusion in Philanthropy, and comprised of foundation presidents who are committed to disability inclusion as part of improving diversity, equity, and inclusion within philanthropy.
  - Sue Jones will be receiving the Fran Litman Award from the Children's Trust at their Nov 4th at The Children's Trust Annual Conference.
  - Tom received CARF accreditation for organization and worked as a Surveyor in the US and Canada
  - Auguste Elliott:
    - I have been working with a committee at Easterseals Vermont developing a handbook for coaching parents with IDD whose children are in state's custody (Family Time Coaching model). This is in its final stages of development and will be used throughout the state and beyond.
    - In my prior role at Easterseals Vermont direct intervention in supporting parents for whom the pandemic and virtual Family Times were challenging their bond with their children and their opportunities to make progress towards reunification.