

# TASP ANNUAL REPORT

## November 1, 2019 – October 31, 2020

### **GENERAL TASP UPDATES**

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- Welcomed a new Board President, Dr. Julie Clockston, DSW
- Hired an Executive Director, Chelsea Tighe, M.Ed., at 30 hours/week beginning 2/1/20.
- Changed bylaws to update the composition of the Executive Committee to ensure there is always a parent/self-advocate represented at the highest board level in TASP.
- Added 2 new board members during the reporting period, and recruited 4 more for vote at the 2020 annual meeting (2 ultimately decided to join and are being voted in at the annual meeting 11/16/20).

### **OUTREACH**

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- **Website development and design**
  - Created and shared a plain language COVID-19 resource
  - In response to the pandemic, we created a COVID-19 resource page on our website, gathered pertinent resources, and updated and shared as needed
  - 3,949 sessions to the website (down 32% from the previous year)
- **Social Media Outreach**
  - Facebook access was limited to a small group of TASP employees/board members who put a plan in place for a social media strategy to increase TASP's presence and influence.
  - The plan was 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
  - Total FB posts for the reporting period was \_\_\_\_, versus \_\_\_\_ for the same time last year.
  - Engaged with 1,528 people via FB posts (an increase of 29% from the previous year)
    - 926 likes
    - 354 shares
    - 127 other interactions
    - 121 comments
- **MailChimp and mailings**
  - 629 contacts, 520 are subscribers

- Mailings included 19 eBlasts with topics like COVID-19 Resources, Mother's Day Giving Request, new TASP training and updates to that training, monthly TASP happenings, ADA celebration and giving campaign.
  - Total eBlasts for the reporting period was 19, versus 10 for the same time last year (90% increase).
  - Averaged 15% open rate and a 4% click rate (percentage of people who click the links in the emails or click through to our website).
  - Added 62 people to our mailing list this year (mostly from the embedded pop-up form on the website)
  - 31% of our subscribers are highly engaged and open our emails
- **Newsletter and Blog**
    - Draft newsletter developed with the Development Committee and phased in, with a shorter version shared in July, August, and September. The original goal was to send a newsletter every other month. Currently we've been able to send monthly and plan to continue that but would like to add original features (meet the board, parenting life hacks, original resources, and more).
    - Blog is still in the works.
- **Conference Attendance Outreach**
    - Due to COVID many of the conferences that TASP board members planned to attend were canceled.
    - TASP is an exhibitor at the upcoming 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.
- **Other**
    - TASP created an outreach video that we can use to share what we do and our message. The video is 2-minutes long and is currently hosted on both YouTube and Vimeo (<https://youtu.be/2DrXtBGF390>)
    - Researched Finance/Donation/Donor consultants and began discussions with Do Good Better Consulting to come on board in a short-term fashion to help TASP grow our donor base and develop a fundraising plan. This contract is still being considered by the Executive Committee and Finance Committees, and will be presented to the TASP Board at the annual meeting.

## **NEW INITIATIVES**

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- **Membership**
  - Membership categories approved by the board at the February 2020 meeting
  - The Development Committee worked on determining free vs. paid content and content development, including webinars, info sheets, tip sheets, etc.
  - Plan to roll out membership in October 2020 was pushed to Spring 2021 as we continue to gather and create membership materials.
  
- **Webinars**
  - Solicited input from the TASP board on webinar topics
  - Developed a 2021 webinar schedule, planning for free webinars every other month, and approved by board.
  - We are in the process of purchasing webinar software and developing a webinar protocol
  - Continuing to plan for the first webinar in January 2021
  
- **TASP Training: Working with Parents with I/DD**
  - The Education Committee worked this year to finalize the first TASP training
  - Developed website with FAQ and interest form
  - Mailings and social media posts to drum up interest
  - Started spreadsheet of interested people/systems
  - Converted the training to an online, interactive Zoom training due to COVID-19 travel restrictions and concerns. Re-did all fliers/websites, etc. to reflect the new offering and scheduled our first training for January.

## **ADVOCACY EFFORTS**

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- TASP joined over 50 national organizations to sign the The Education Taskforce of the Consortium of Citizens with Disabilities (CCD) letter to Congress strongly opposing any waivers to IDEA or the Rehabilitation Act during COVID-19. More info [HERE](#)
- TASP signs on to the AADMD Hospital Visitation petition which would make it possible for people with disabilities, particularly those with communication difficulties, to have a known person to support them in the hospital: More info [HERE](#)
- Promoted various webinars on advocacy efforts, including on on Passing Legislation for Parents with Disabilities, Brandeis, Robyn Powell and Kimberley Tissot (who passed cross-disability legislation in S. Carolina) via social media and eBlasts

- Maintained connection with NCIL Parenting Task Force, which required Susan’s getting an individual membership with NCIL
- Susan and Nikki meeting with the Disability Coalition in Seattle (by phone) to promote the Peer Navigator model; shared powerpoint from conference and final report to ACL by Dr. Patricia Nobbie
- 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 getting involved with the parent in the case mentioned above. Susan has been requested to create an advocacy curriculum for 12 parents from different cultures and offer it in person in the fall if COVID allows.
- Board members continued work in Seattle (Nikki continues to travel there)
- 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.

## **TASP RETREAT and ACTION PLAN PROGRESS**

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The TASP Board was able to accomplish 15 of the 21 tasks (71%) of the action items in the strategic plan from the 2019 TASP Retreat. The full report of retreat tasks and updates is attached, but some of the major action items and progress include:

- Updated the TASP mission
- Developed budget options and based on those TASP hired an Executive Director at 30 hours/week beginning 2/1/20.
- Developed membership categories, costs, and “take aways” and began collecting and creating original content for members.
- Developed a slate of webinars for 2021
- Created and began sending regular newsletters and other mailings
- Finalized a new TASP training, and pivoted to an online model when COVID-19 changed the landscape of in-person events. The first of these full-day virtual trainings is set for January 2021.
- Created a fundraising plan and implemented a few donor asks. This led to consulting a firm who can assist in our fundraising strategy and building our donor database.

## **COMMITTEE WORK**

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- **Education Committee**

Members: Nicole Brisson (Chair), Susan Yuan, Lindsay Brillhart, Ginny Cruz, Julie Clockston, Tom Robinson, Chelsea Tighe

The Education Committee has begun discussions about holding another conference. We have not formed an ad hoc committee and have decided that it is not in TASP's best interest financially to hold another conference at this time. We are looking into partnering with other organizations; however, COVID-19 is making this difficult given many conferences have been canceled or are now online. The committee will be following up with IASSID to see if we might be able to partner at their next conference. It does not look like partnering with AAIDD for their hybrid conference is a good fit, given their theme this year.

The Education Committee is continuing to review online resources to determine the need to speak with contributing individuals about intellectual property rights to determine what we can and cannot use and are considering developing internal policies related to intellectual property. However, legal guidance on this would be helpful. We have discussed bringing an attorney onto the board or looking into consulting with one but have not yet made a decision on this. We have drafted an Assignment and Transfer agreement to allow TASP to use Ginny's curriculum for training. She is in the process of reviewing it.

The Education Committee's main activity this year has been to revise Ginny's curriculum, "Parents with Developmental Disabilities" (now called, "Working Successfully with Parents with I/DD"). This training will build on professionals' skills when working with parents who have an intellectual and/or developmental disability. They will learn how to make accommodations and set goals to give parents a fair chance to parent. The training will be offered online and in person (when COVID-19 restrictions allow) starting in January 2021.

- **Developmental Committee**

Members: Betsy Misch (Chair), Chelsea Tighe, Lindsay Brillhart

The Development Committee's primary focus for the year has been the development and implementation of the Membership Plan.

**Membership:**

- Recommended to the Board that membership have only 3 levels: Individual, Advocate/Parent, and Business. Accepted by the Board and By-Laws were changed.
- Recommended that the Membership year run Jan-Dec. Accepted by the Board.

- Developed timeline for Membership roll out. In process and changed/updated as needed.
- Developed Membership costs related to level of Membership. Accepted by Board.
- Developed possible Membership benefits and began working on the process of creating and collecting those items.
- Recommended that TASP have 6 months of content before opening Membership.

### **Social Media:**

- Recommended that only specific Board members have access to our special media accounts and will be responsible for vetting content. Accepted by the Board – Members that have access are: Chelsea Tighe, Julie Clockston, and Denice Mock. Developed calendar and content for social media posts.
- Increased traffic to website and social media accounts using recommendations from Webixi.

### **Website:**

- Developed webinar content and schedule for 2021.
- Researched and chose webinar platform that would work for all committees
- Updated website regularly, and began a website content overhaul.

### **Other:**

- Gathered content from the Board for the website, social media, and Membership benefits.
- Developed a consistent “look/Brand” for all materials, handouts, and info sheets.
- Developed Newsletter format/look and began sending to our database.

- **Advocacy Committee**

Members: Susan Yuan and Bernadette Iriwn (Co-Chairs), Lindsay Brillhart, Heidi Haines, Ivanova Smith, Auguste Elliott (on leave of absence due to illness), Colleen Downs, Heidi Haines, Renee Jones – new members of the Advocacy Committee as of 10/13/2020

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

- COMPLETED --Develop an elevator pitch/message that can be modified for different groups and used for Development or Fundraising. Committee decided to use TASP Mission Statement as each component (education,

advocacy and support) can be expanded and modified for varying presentations and audiences.

*TASP as a non-profit is dedicated to enhancing the lives of parents with ID/IDD and their families through Education, Advocacy, and Support.*

- COMPLETED Develop an Advocacy Platform
  - Supporting and Maintaining the rights of people with disabilities to receive needed health care.
  - Encourage Child Welfare Agencies to help families creatively have visitations using, for example Zoom, Face Time, etc.
  - Join TASP advocacy efforts with other organization to ensure that we advocate for common advocacy goals as they align with TASP Mission
  
- COMPLETED Map of the connection of each Board Member -- Advocacy Committee joined with the Development Committee to develop and conduct a survey of Board Members
- In Progress – Committee will use the Outreach List started at the Retreat and add additional information gathered from the Board (see above) to identify what each could do and then start conversations with each group/agency/organization.
  - This activity/assignment was severely hampered by the Covid 19 virus (school closings, office closings, etc.) and unfortunately the illness of several members. This Committee did not formally meet till October, 2020. Committee started to address this assignment at their October meeting – plans for this will be developed and presented to the Executive Committee for approval.
- Additional Activities
  - Three new members were added to the Advocacy Committee at November meeting.
  - Susan Yuan (with Julie Clockston) completed a Parenting Assessment for a WA family whose children had been removed. She maintained close (almost weekly) contact with the Child Welfare Agency and the Attorneys who represented the family, and the family is being reunified. This success comes in the context of so many assessments carried out by TASP VP Nicole Brisson, across the country.
  - Advocacy Committee set a consistent meeting day and time for each month to ensure that meetings are held more timely.
  
- **Executive Committee**  
Members: Julie Clockston (Chair), Nikki Brisson, Lindsay Brillhart, Cathay Haarstad, Susan Yuan, Sue Jones, Bernadette Irwin, Chelsea Tighe

Retreat task updates included proposing and changing the TASP mission statement and recruiting new board members. Both tasks were completed,

although the EC continues to recruit new board members hoping to broaden the spectrum of members to outside the DD world.

Other activities for the reporting period included:

- Updated and finalized FY2020 budget
- Oversaw hiring of Executive Director, including developing a job description and assigning an ad-hoc committee to develop HR policies.
- Worked with Sue Jones and Massachusetts to be involved in new initiatives there, potentially bringing the Peer Navigation model. Sue kept the group updated on the MA Statewide Partnership for Supporting Parents Living with IDD, a collaboration across different departments and agencies. Many activities and RFPs are on hold due to COVID but, TASP has been added to MA Resources Directory.
- Proposed a change to the TASP bylaws ensuring there is always a parent/self-advocacy on the Executive Committee. Proposal was accepted by the board.
- Updated TASP general business practices and dealings to remain in line with current law (changed insurances from DC to Maryland, become a Foreign Business Entity in Maryland, updated TASP business name and addresses across multiple systems so they begin to match).
- Worked on board recruitment, and was able to add 2 new board members this year, with 2 more nominees for the 2020 Annual Meeting.

- **Fiscal Committee**

Committee Chair Name: Cathy Haarstad

Committee Members: Sue Jones, Susan Yuan, Cathy Haarstad, Pat Gross; Heidi Haines; Lindsay Brillhart

- Update on retreat-related activities/assignments:
  - Developed the annual working budget which was approved by the board. Board approved one of three options which included a salary for a new Executive Director (ED) position.
  - Made membership structure recommendations to the board which determined that TASP would be an informed membership organization.
  - Shared a list of board expenses for a three-year span.
  - Gave input on the fundraising plan developed by the ED.
- Main activities/tasks/outcomes during the reporting period:
  - Updated draft finance policies and sent for board approval.
  - Developed a working draft of personnel policies.

- Developed a financial log and obtained Quick Book Reports for all expenditures and balances.
- Reviewed donations and expenditures.
- Secured annual 990 tax report from accountant. Assured payroll taxes were paid on time.
- Discontinue unnecessary unemployment and auto insurance. Obtained refunds with help of ED.
- Set up a merchant account and managed all finances for the conference with help from tech support and ED.
- Assure that licensure with the state of Colorado was in good standing.
- Established temporary sick and annual leave policies for board review.

## **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.
  - Tom Robinson offered a direct parenting services training
  - Cathy Haarstad:
    - Included information on the capability of parents with I/DD in statewide training on supporting individuals with disabilities to develop safe and healthy social/sexual training.
    - Attempted to set up a meeting with state personnel who oversee support for parents with I/DD in ND. Had to postpone due to Covid.
  - Susan Yuan:
    - Completed an interview for a podcast in Vermont, *Abled and On the Air* with Lawrence Seiler. The topic was *Parents with Disabilities and Child Welfare*.
    - Served as reviewer for two journals (*Child and Youth Services Review* and *Families and Society*): 4 reviews completed
  - Dr. Julie Clockston:
    - Submitted abstract of dissertation research for the 2021 Social Work Science for Social Change Conference. SSWR 2021 conference acceptance will be announced this fall.
    - Publication: Jackson Clockston, J. M. (2019). *Perceptions of human service professionals and parents with intellectual disabilities: Action research* (Order No. 22585013). Available from ProQuest Dissertations & Theses Global. (2300629945).

- NASW-Co President recorded a promo on September 11<sup>th</sup> 2020 and will discuss TASP as well as legislation and programming for parents living with disabilities.
- 2020 presentations included:
  - “Metropolitan State University of Denver Social Work Student Field Day First Session” Presented as Keynote Speaker Metropolitan State University. Presented about Field Work, NASW and TASP Developmental Disabilities and Parents Living with IDD Denver CO
  - “Metropolitan State University of Denver Social Work Student Field Day Second Session” Presented as Keynote Speaker Metropolitan State University. Presented about Field Work, NASW and TASP Developmental Disabilities and Parents Living with IDD. Denver CO
  - “Colorado State University Social Work Student Field Day First Session” Presented about Field Work and NASW, TASP Developmental Disabilities and Parents Living with IDD Colorado State University, Fort Collins, CO.
  - “Colorado State University Social Work Student Field Day Second Session” Presented about Field Work, NASW Presented about Field Work and NASW, TASP Developmental Disabilities and Parents Living with IDD Colorado State University, Fort Collins, CO.
  - “I SLAY Virtual Girls Empowerment Camp” Presented about Mental Health and Public Health regarding COVID-19 and Racism, Fort Collins, CO.
- Attended the following trainings:
  - National Research Center for Parents with Disabilities: Supporting the Social Lives of Children of Disabled Parents
  - UT Health San Antonio Department of Psychiatry and the Texas Health and Human Services Commission Training Program:
    - Putting it all together: Support and Strategies for Direct Service Workers
    - Overview of other Medical Diagnoses Associated with IDD
    - Overview of Genetic Syndromes Associated with IDD
    - Functional Behavior Assessment and Behavior Support
    - Trauma Informed Care for Individuals with IDD
    - Co-Occurring Disorders: IDD and Mental Illness
- Ivanova Smith:
  - Presented to Kinderly about true inclusion

- Interview with New York Public Radio's RadioLab (it's aired a few times):  
<https://www.wnycstudios.org/podcasts/radiolab/articles/g-unfit>
  - o Sue Jones
    - Presentation at UMASS in Amherst at Arc National convention
    - Facilitated Parent Panel at TASP Conference
    - Part I and Part II Webinar Presentation on Parents w/ I.D.D. for The Arc MA, which was hosted by the newly formed MA Partnership for Supporting Parents with I.D. and DD. which Sue is a founding member.
- **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.):
  - o Tom Robinson:
    - Legal Aid Services liaison/advocate
    - Child Welfare services education/advocacy
    - Community education on behavioral resources for parents
  - o Lindsay Brillhart talked to her local Ohio DDS board to make them aware that people with disabilities need time to transition to a new SSA and should not be rushed into the process.
  - o Susan Yuan:
    - Named a 2020 AAIDD fellowship
    - Member, National Council for Independent Living, Parenting Task Force.
    - Contracted by Open Doors for Multicultural Families in Seattle to create a Leadership curriculum for family members from different cultures.
    - On-going consulting relationship, through Sage Haven Associates, with the Office of the Public Defender, Washington state, re: working with parents with disabilities.
    - Met with Washington state advocates to discuss Peer Navigation.
  - o Dr. Julie Clockston, Colorado State University Social Work Education external advisory board member recommended education regarding IDD and Parents living with IDD during the October 2020 meeting.
  - o Ivanova Smith:
    - Was instrumental in (and a primary complainant on) a complaint about discrimination regarding people with disabilities in prioritizing who gets medical treatment during the COVID-19 pandemic, which resulted in HHS/OCR putting out guidance to states.
    - Is part of the Bree Workgroup about reproductive health and is able to give recommendations on support for parents with disabilities to medical professionals by not supporting sterilization.

- o Sue Jones took part in the Massachusetts Partnership for Supporting Parents with I.D. and DD, of which she is a founding member.
- **Other work of TASP members** (*fellowships, research, assessments, direct services, etc.*):
  - o Tom Robinson completed Family Preservation services development and monitoring
  - o Cathy Haartstad:
    - Recruited one new potential board member.
    - Wrote a grant to the ND DD Council to translate the booklet “Living in an Adult World,” which provides information on the legal requirements of being an adult into an easy-read format.
    - Shared copies of the curriculum “Personal Self-Advocacy,” as requested in multiple states and Canada.
  - o Susan Yuan Conducted assessments, along with Dr. Julie Clockston, for four parents in the Seattle area, one of which is part of a complaint to the Office of Civil Rights of Health and Human Services. These were conducted through Sage Haven Associates.
  - o Julie Clockston:
    - Training with SAGE Haven Associates Dr. Brisson and Dr. Yuan trainers for my certification to become an assessor for competency based assessments for parents living with IDD and their families
    - Ongoing direct service provider in Colorado for individuals diagnosed with developmental/intellectual/cognitive disabilities 1996-current
    - Certified in QBS Safety Care
    - Teaching 7 college courses this fall/ winter 2020-2021 and will incorporated information about developmental intellectual cognitive disabilities, parents living with disabilities and general IDD information and awareness into my lectures. Sociology and Social Work courses.