

CIDSO General Membership Virtual Meeting April 20, 2021

Minutes Approved with Corrections

1. **Call to Order** was made by President Deb Presley at 6:01pm.
2. **Attendance - Certify Quorum.** Present: Wendy Boswell, Bill Crutcher, Angela Hedican, Michelle Newbold. And Executive Committee: Diane Crutcher, Sandy Ginther, Shelley Marquis, Deb Presley, Kim Weber, Bethany Romer (encountered some temporary trouble getting in and staying connected). To date, the 2021 Membership is at 25. A Quorum was declared by Deb.
3. **Approval of January 19, 2021 minutes.** There were no concerns or corrections voiced about the Draft Minutes. Diane moved Minutes be approved and Michelle seconded. Passed unanimously. Draft 1.19.21 Minutes Approved.
4. **President's Report** – Deb. Redbird Reader update. Kelli's report stated that for the Spring 2021 virtual semester there are: 13 participants and 26 tutors; 8 weekly sessions and an orientation for tutors; whole group and breakout sessions weekly; parent and participant reviews were favorable including the importance of having an activity to connect with others during the pandemic; examples of participant chosen activities were research about Broadway, recipes, caring for a baby, writing short story. For Fall 2021 semester, Kelli needs 9 or more participants for the program to be viable. Still unsure what ISU and/or Illinois will do with COVID guidelines concerning onsite in-person sessions especially given potential concerns of bringing outside individuals who are not ISU students into Milner Library. Kelli is securing tutors in hope of the program's continuance either virtual, in-person or a hybrid. Diane stated what a good program this is and how purposeful it is. Others agreed. Deb added that the virtual format has been helpful to increase participants communication skills. The fee for Fall semester will be proportionate to the number of participants. Its expected that Kelli will put something out about interest in a Fall semester.
5. **VP Report** – Diane.
 - a. Diane continues to update the metafile, and will update tomorrow about tonight's meeting. It is now averaging 15-20 views a week.
 - b. Request from PATH for updates to its information about CIDSO was provided by Diane. Its lengthy - about 15 pages – which makes it very informative.
 - c. Diane needs more photos of our children/adult children for the metafile. Please send to Diane and she will send back a permission form.
 - d. Autism Society has a display trail of about 30 sign boards placed in Carden Park. The poster display tells about what Autism is and tells a story about a child. Maybe we could do this about Down syndrome? Constitution Trail would be a wonderful posting location – it takes a long stretch of land. It could be posted in one location for a while and then another. It could be displayed in conjunction with our fundraisers – and with a few fundraising posters weaved into the display. We still have the sign boards from previous Buddy Walks with Down syndrome facts. This project idea was received with much enthusiasm. If we have a member who wants to become Active or just volunteer to do this project,

it would involve getting pictures on foam board (or a different weatherproof material) that Bill Edwards at the Copy Shop could produce, as well as getting permission from our cities for posting. Bill and Diane have pictures of some of the Autism display, but will get them all so volunteers can understand the whole display. It appears the Autism display may have used a book to guide their message. There may be a book out there on DS to assist the design the of our display. For those who sent in photos for the new CIDS0 brochures and are willing to have them used in this project, please send Diane an email stating permission for use in the sign board display as well. When the Crutchers have obtained photos of the whole Autism display, Deb will send email request out (and maybe put a splash on the website) to seek those who may have an interest in leading this project.

6. **Treasurer/VP Funds Administrator Report** -Kim, Shelley. All should have the financials which Diane sent out for Kim this morning. They are self-explanatory, but if any questions, let her know. Looking at the 2020-2021 Balance Sheet Comparison for quarter one, we are down a little from 2020. The Profit and Loss comparison Administration line is high because of \$455 insurance charge that will be pulled out for itemization later, and storage that was paid as yearly vs. prior monthly. Enrichment Funds expenses are down significantly. There was an overlap of 2020 reimbursement requests that arrived in 2021. In quarter two, CIDS0 received about \$1400 from Shelley's father-in-law memorials. Donations in quarter one included such items as an Explore BloNo RobDob's donation, Amazon Smiles, Network for Good. 2021 Budget review included such things as 2021 Summer Picnic site rental, Enrichment Fund – lagging some submissions that will come out in quarter two. Deb commented that we encourage Active members to submit request for Enrichment Fund as soon as possible for an actual accounting of how much our liability is for coverage.
 - a. 1980 CD update: Kim reported on this last meeting but there were no funds in the CD.
7. **Secretary Report** -Sandy.
 - a. A call was received on the CIDS0 phone by a mother in southern Illinois of a 44-year-old daughter who has brain cancer. The mother has to make a life vs. quality of life decision and is looking for families who have had this experience.
 - b. Sandy has made some head way on getting this past year's protocol decisions in to our Matrix, but is behind on uploading Minutes into the Google storage.
 - c. Thank yous will be going out to donor's memorial for Glenn Marquis.
8. **Old Business**
 - a. Update on birthday cards: Wendy received the Birthday cards from the printer, and displayed one on the screen. She has sent 5 cards out, and commented how helpful the Copy Shop was. She will continue this project.
 - b. "Explore Blow/No Challenge" fundraiser update - Angela and Wendy.
 - i. 13 teams registered! 3 Headliners sponsors at \$1000. 7 Stop Sponsors at \$350. 3 Stop Sponsors that did in-kind for prizes. Angela was able to get all website and graphics donated. She thinks the net will be \$5,600.
 - ii. It was FUN! Shelley got lots of comments and questions from her FB posting. How about advertising at 2021 Buddy Walk?

- iii. Wendy and Angela debating if World Down Syndrome Day is the best time for this fundraiser.... Competes with Spring break, etc.
 - iv. The social media aspect was worthwhile for the businesses. Wendy commented businesses had fun coming up with the challenges.
 - v. Diane commented that even if out of town (as they were) you can support a team for just \$65.
- c. Update of Committee positions: Deb.
- i. Advocacy & Resources – Sandy Ginther
 - ii. Communication Administrator – Diane Walker
 - iii. Social Media Administrator – Angela Hedican
 - iv. **Community Outreach –**
 - v. Family Outreach – Kim Weber, Angela Hedican
 - vi. Social Chair – Jayna Vroman, Angela Hedican
 - vii. Self Advocates – Abbey Heins, Kirsten Boswell
 - viii. Conflict Resolution Committee – Angela Hedican, Diane Crutcher, Wendy Boswell
 - ix. If anyone has an interest in the Community Outreach position, PLEASE email Deb as no-one has stepped into that yet.
- d. Family Outreach Update: Angela has: met with a mom with a prenatal diagnosis and gave her some information; connected with a mom who's adopting; delivered a New Baby Basket to a family with a 2-month-old.

Other Updates:

- Diane reported that a longtime family of CIDSO reconnected for assistance with having their adult daughter moved from an out-of-town IFCD placement into a Bloomington Normal CILA. With Diane's assistance and a little help from Sandy, this move occurred.
- Sandy reported the CIDSO cell phone had a call from an older mother in southern Illinois who is looking for a family who has experienced brain cancer with a midlife adult child. She wants talk to a family, not an association, not-for-profit or entity. While not aware of any families in our group, Sandy told her that she would check at this meeting. They have a very difficult decision to make concerning treatment, quality of life, and length of life. With no experience among those present, discussion determined Sandy should reach out again and re-iterate that such entities as Park Ridge Adult Down Syndrome Center, St. Louis Parent Group, and the national groups could lead her to a family with similar experiences.

After these reports, it was noted that CIDSO advocacy stretches from early intervention to late life issues.

9. New Business:

- a. Deb received an email from the McLean County Health Department Behavioral Health that referred to collaborations. Deb checked with the Executive Committee. Diane spoke of her experiences with the MCHD 377 Board which deals with Developmental Disabilities. A paradox exists that members of the

Board cannot be people who have received 377 funded services. Deb will get back to MCHD to ask for more information about what it is seeking. Spring Health was asked about as a collaboration but opinion was that this was not really a CIDSO collaboration.

- b. Increasing Active membership for CIDSO. Diane stated we have the same 9-10 folks that kind of do all our work. How can we involve more? Should each of us reach out to somebody? Active member commitment statements were due 1/31/21 (although a grace period can be extended past the deadline). The number of Active members commitment statements has not increased since the 1/19/21 meeting, remaining at 8 Active members (equating to a current \$24,000 budget impact). Bill suggested that when COVID allows, it's good to invite potential individuals/families to in-person social settings. Kim and Angela reported that our new member, Crystal Morris from Clinton, with a one-year old son, put together a local Walk in March and split the proceeds with CIDSO 50/50 and a Clinton Not-for-Profit issuing CIDSO a \$450 money order. Sandy will send her a Thank You.
- c. Increase membership with other interested parties. Wendy suggested CIDSO consider what the Arkansas group does to attract interested parties. Their members invite their friends and contacts (business, health, etc.) to become interested parties. Their meetings and fundraising include the families of both those with and without Down syndrome. (In the long past, CIDSO has had interested parties who joined us in meetings and our work.) Deb expressed the more the merrier. The Crutcher's friends, the Cochrans, is an example. Bill pointed out that these folks need a reason, and something for them to do - where they can see the benefit of their involvement. It was suggested to get a sub-committee that over the next several months drafts an ambassador program with some 'rules and opportunities' and how they would be a part of us, how we would make them want to be a part, and what they would be doing. A call for volunteers was offered, but no response from those present. Wendy will bring research from the Arkansas group to our next meeting. For now, we can call this project 'Friends of CIDSO'. Deb suggested Wendy could try to get others involved and report out at our next meeting.
- d. Supported employment in B/N: Deb. Marc eliminated the Supported Employment (SE) program due to lost funding and COVID. Wendy thinks DRS is reaching out to Bridgeway. Others defined Bridgeway as only for MI, and with poorer quality and types of services than Marc's program had. Diane reported that Bridgeway is exploring opening to DD, but that process can take a year. Thus currently the only SE services for our area are in Pekin (TCRC) and Peoria (EPIC). They only occasionally interview, however they don't have any relationships with local employers. SE here is set back perhaps 20 years. It was suggested CIDSO connect with Marc. Diane shared more background of her contact with Ann Taylor, VP over SE, who said they lost MCHD 377 Board funding. They had to make cuts with the loss of about \$250,000. Marc is looking for funding to bring back SE. This impacts our members, Mindie, Kirsten, James, Kathy, and others with a SE contract with Marc. So even if our members would get called back to

work, they would be going back without a job coach or support after not working for up to a year. Right now there does not seem to be anything we can do.

- e. Purchase of library book. Deb came across an important book "Mental Wellness in Adults with Down Syndrome (McGuire and Chicoine of the Adult Down Syndrome Center in Chicago) for \$20.97 and would like CIDSO to purchase and donate it to the Bloomington Public Library. Diane so moved and Sandy seconded. Passed unanimously. Bill and Diane will go look at Bloomington Public library to see how our book contributions are embedded in the building. From looking online, Deb sees what books the library has purchased in addition to the ones we have donated. It was suggested that if talking to staff at the library, Bill and Diane might ask them if the library could pull together a display for October National Down Syndrome month with these books and maybe something about CIDSO.
- 10. Other Business.** None brought forward.
- 11. Adjourned 7:08pm** with motion by Diane and second from Michelle.

Minutes Approved with corrections at 7.20.2012 General Quarterly Meeting