

**CIDSO Meeting– General Membership Meeting**  
**April 20, 2023 7:00 PM. – virtual via zoom link**  
**Approved Minutes**

1. **Call to Order:** President Deb Presley called meeting to order at 7:02pm.
2. **Attendance - certify quorum:** (24 members as of 4/13/23; 9 “active”) Present were: Deb Presley, Diane and Bill Crutcher, Diane Walker, Kim Weber, Shelley Marquis, Bethany Romer – early departure, Mel Sculfield, and Sandy Bauer.
3. **Approval of Meeting Minutes: Deb**
  - a. January 31, 2023 Diane Crutcher moved approval of Draft Minutes. Mel Seconded. Passed unanimously.
4. **President’s Report: Deb**
  - a. **Library Book Walk Update:** Deb has still been working with the Normal library on our outside storybook walk project. Since the book we will be using does not come in ‘Big Book’ size, we cannot use the actual book pages. Therefore Deb must work with the publisher and sign-makers to produce the book walk posters. She has contacted them both but has not yet received publisher permission.
  - b. **Normal Public Library summer display:** Does anyone know where CIDSO’s large durable display panels are? CIDSO used to use these at educational events, galas, etc. Deb would like to use them for this disability-awareness-hunt project wherein visitors to the children’s library can go hunting for certain books that lead them to see various tables. The tables hold disability themed display boards/panels. Deb, the Crutchers and Sandy will pursue contacting leads and looking for the display panels. If we no longer have these panels, Deb will use other materials. Deb will also need photos of our children for the display. Diane has some, and members are encouraged to send any - particularly children at school - to Deb. We will consider other items for the table, brochures, freebees, etc. when Deb knows more about our space size.
  - c. **Renewal of Tax-Exempt Status** has been completed. Kim will put it in the CIDSO Google Drive.
  - d. **Use of physical address vs PO Box address.** Kim completed application for use of the physical address of the Normal Post Office for those times when we actually need it, such as forms, such as The Google address application. which will need changed from Crutchers to “200 W. North St. Box 595, Normal, IL 61761”. The title “Normal Post Office” is NOT needed. Otherwise always use the CIDSO, PO Box 595, Normal, IL 61761 address.
  - e. **Proposed switch from: [info@cidso.org](mailto:info@cidso.org) to [cidsofamilies@gmail.com](mailto:cidsofamilies@gmail.com).** Due to ongoing trouble with the [info@cidso.org](mailto:info@cidso.org) email address, Deb purposed that we use the functioning [cidsofamilies@gmail.com](mailto:cidsofamilies@gmail.com). (Any email coming through to [info@cidso.org](mailto:info@cidso.org) will forward into [cidsofamilies@gmail.com](mailto:cidsofamilies@gmail.com)) The timing is right for the new brochures. However, the [info@cidso.org](mailto:info@cidso.org) in digital places will need changed. For instance, we will need to reach out to Pam to change on Enrichment Funds app, and any other addresses she has access too. Diane W. will do all on the website that she can. Things that Pam can’t change on the website, Deb will give to Jason. The email address is to be published in lower case. Diane W will notify the CIDSO membership. Deb moved the switch be made and Diane C. seconded. Passed unanimously.

## 5. VP Report: Diane C.

- a. **IDDC:** Diane has sent us the Resource Committee test document that compiled the email and phone numbers of agencies that can impact the lives of CIDSO member families. The intent is to make this as user friendly as possible. The Advocacy Committee (3 members including Diane) will start testing this document with Fairview Elementary school (Normal) and the Baby Fold. It is to assess its helpfulness, ease of the format, etc. Later they will test it with other schools. A thank you to Diane was extended by Deb for this work. Deb also shared that Cedar Ridge Elementary is a Title 1 and Bilingual elementary school. Thus it could be a good school for the Advocacy Committee to consider for testing. The Resource and Advocacy Committees will also seek a District 87 school(s).
- b. **PATH update:** Diane received the annual notice to update CIDSO's information which she has completed. She will now reach out to PATH with the email address change to [cidsosofamilies@gmail.com](mailto:cidsosofamilies@gmail.com) in hopes of getting it changed before dissemination.
- c. **AFNAP meeting:** The Access and Functional Needs Advisory Panel (AFNAP) meets quarterly to ensure so that all residents are represented in emergency response planning. Diane will be representing people with Down syndrome. The next meeting is later this month. Deb would like to know how families are to access the Registry for updating their information within it. Diane will inquire. As well, she will also check for those in CILAs. Deb also asked if Diane will ask about triangulation of cell phone land lines as many land lines have been dropped. Without a landline for location identification, do they know where a cell phone is. Diane will report back with what she learns.
- d. **Website:** Diane shared the Google profile shows 270 views in March! She also thanked Diane W doing a wonderful job with the Website.
- e. **New brochure:** Diane sent the most recent text for the revised brochure which included feedback from Sandy and Deb. Also Angela has commented and Diane will include that as well. As it is CIDSO'S 50<sup>TH</sup> year, Diane will include a banner on the brochure. Deb stated that if we don't name the years (i.e. 1974 -2023/24) on the banner, it will not confuse readers as to which year, and therefore it will be applicable to 2023 and 2024. Next Diane will select and insert pictures and re-send to us, then on to the typesetter, then back to us, then to printer. All pics will be forwarded to Deb for Library display boards. There are great pictures!

6. **Treasurer / VP Funds Administrator Report: Kim/Shelley.** Financials went out today. On the Balance Sheet Detail, you will see the Trac Phone has 2 bills and Kim is seeking corrections from Trac Phone for this. When looking at the Balance Sheet Comparison vs Prior Year, you'll see there is more this year than prior year in checking and savings than in prior year. Looking at Profit/Loss, we have had more donations than usual, for instance, the hefty Finlen donation and the U of I Credit Union donation. The PayPal balance was transferred at the beginning of the year to clear out 2022. Administrative shows \$1809. However, \$1839.26 is correct. An accidental line item assignment of a bowling event check went into this line. Enrichment Fund expenses total has some of the 2022 expenses reflected in the balance. However, \$2377.39 is what we spent year to date. The Budget Spent line has the Bowling pizza expenditure that just hit there. Kim asked for any questions and there were none.  
In 2021 when the taxes were done, Rick filed for an extension. Now Illinois is saying we are late in sending in our info, and the fee is \$100 for this. Rick sent in documentation to support the filing. However, we have now just received another letter from the IRS which says "RE: Annual Report of Charitable Organization. Ending 12/31/2021". Yet at the bottom of the letter is says

'Please submit your \$100 late fee for fiscal year ending 12 of 2019'. Kim anticipates much time and difficulty straightening this out with IRS. Shelley shared that she has experienced something similar and paid it to avoid a penalty (even though it was not owed) and then the government refunded it. Seeking our input in resolving this, Kim was encouraged to consult with Rick again. Deb stated and Diane moved that if after consulting with Rick, he thinks the best course of action is to pay the \$100, Kim has the authority to do so. Diane Walker seconded. Motion passed unanimously.

Our US Bank CD matured on 4/4/23 and Kim was on vacation and unable to see the auto renew notification. Therefore, it automatically renewed for 11 months. As of yesterday, the interest rate for this CD is .05%. She will try to go talk them. Deb asked about penalty for early withdraw. Kim read the penalty conditions. Kim will follow up by going into the bank to explain our situation including the fact that the PO Box is only accessed about once a week and she was on vacation.

7. **Secretary Report: Sandy.** The CIDSO line had a call from a family that had moved away and now returned and inquiring about activities. When Sandy returned the call she had to leave a voicemail. There was no reply from the voicemail message, and Sandy only has the name of the caller.

#### 8. **Committee Reports**

- a. **Buddy Walk Report** (Kim or Angela). Kim reported the official date for the Buddy Walk will be 9/9/23 and will be held at Eastview Church again.
- b. **Advocacy** (Sandy). Sandy reported on the Electronic Visit Verification (EVV) method being put in place that affects those of us receiving the Medicaid Waiver for Home Based Community Services. This new system is NOT family friendly even though it may work well for agencies. Each state has the option to adopt EVV for live-in caregivers or not. Illinois is leaning towards adopting this method which is cumbersome and a hindrance to families who are live-in caregivers. Information was shared for contacting the state (DHS-DDD) to object to Illinois adopting EVV for live-in caregivers, and the dates for DHS-DDD to host Listening Sessions for the purpose of making our views and experiences known. Diane Walker has posted this info in our media.
- c. **Social Media / Family Outreach / Social** (Angela & Wendy) Shelley mentioned that Angela has posted the date for the Down for the Ride Motorcycle fundraiser as 6/11/23 on Facebook. Diane Walker will go to Facebook to copy it for our other media. The route will end in Creve Coeur, and our families are encouraged to attend the finish to show our appreciation and assist with socks sales and silent auction.  
*See \*\* after 'd.' for more Social Media/Family Outreach/Social discussion*
  - i. Birthday card outreach. Wendy not present to report.
- d. **New Parent** (Kim or Angela). Deb stated CIDSO got an email about a Chicago generated website that reaches out to new families via hospitals. Deb asked if Kim or Angela was familiar with this. Kim and Diane C said it was Angela. Diane C spoke with Angela about this new method of referral and outreach in terms of McLean county. Angela has said she will do this and get it to Diane W. Kim will contact Angela for an update. If we need a new page on the website to gather information using a form, we will use Pam.

\*\*Shelley shared that she has just seen on our Facebook a post from Maizee that there is going to be a Sign and Play in the Park, at McGraw on Jun 3<sup>rd</sup>. Maizee is assisting in the Family Outreach role. CIDSO is collaborating with Communication Junction for this as a Family Outreach activity.

Deb would like to coordinate things, like this, posted on FB would also be sent to Diane Walker to post to the on the Website. Diane W. doesn't put anything on the website unless she is directly asked to so. In terms of Facebook, Diane W manages CIDSO Facebook and Angela manages Parents and Caregivers Facebook. Kim updated that now Maizee also can post to Parents and Caregivers. Diane C. stated that things need to be shared under CIDSO umbrella. Kim stated that events and CIDSO activities on Parent and Caregivers FB should be shared with Diane W. for posting to CIDSO. Deb asked Diane W. to connect with Angela/Maizee and share that it's been discussed tonight that events going on Parents and Caregivers FB need to be shared with Diane W for posting to the CIDSO website. There are some members who don't access Facebook and rely on the website for events.

## 9. Old Business

- a. **Status of Updates to By-Laws and Critical Decision Matrix.** (Wendy/Diane C./Bethany)  
Diane has heard nothing from anyone, and thinks she should take this back as it has been almost 3 yrs. And the same is true of the Decision Matrix. Therefore this will be a big job to compile. Kim will check with Bethany to see what obstacle she has to doing this role, as Diane has offered assistance and a template. Deb inquired if Kim would also ask Bethany if she plans to do these tasks, and if not then CIDSO will need to find some to fill the General Membership position. Kim agreed and will get back to Deb.
- b. **Updates on Fundraising /Awareness Events We Know of:** Discussed in these Minutes at 8. Committee Reports, c.

## 10. New Business

- a. **Do we need a disclaimer for things posted on website, on our brochure, or on things sent out to members?**
  - i. "The information and resources provided by CIDSO ("we," "us," or "our") on [www.cidso.org](http://www.cidso.org) (the "Site") is for general informational purposes only. All information and resources on the Site are provided in good faith. However, we make no representation or warranty of any kind, express or implied, regarding the accuracy, adequacy, validity, reliability, availability, or completeness of any information or resources found on the Site." Having no objection this will be placed CDISO Facebook as pinned post, brochure, website, [CIDSOfamiies@gmail.com](mailto:CIDSOfamiies@gmail.com)

There has been no objection to this statement. Diane C has included it on the new brochure. Diane C suggests Diane W place it on the website's Resource page. Diane W agreed and will add it to our CIDSO emails in the signature section as well. It could also be a pinned post on the CIDSO Facebook.

- b. **Confirmation of criteria for what is posted on the website or sent out to members:** As a result of a political email request to share with our membership in March, the Executive Committee(EC) broadly asked itself about our criteria for what is posted and what is not. In appreciation for Diane W.'s management of much of our social/digital media, Deb asked she update the EC on what the categorizations/parameters are. Diane W. provided these in an email. Diane W. manages issuing information through 4 CIDSO social/digital platforms: CIDSOfamilies email account; CIDSObusiness email account; CIDSO Facebook; CIDSO website.  
Discussion was had on criterion for: individuals seeking personal support; The Arc info as an agreeable and trustworthy source for political/legislative information; fundraising competition.

It was concluded and confirmed that: an individual request for personal support or assistance would not be posted/distributed but responded to by the Executive Committee; political/legislative information vetted by the The Arc or other trustworthy entity can be posted; national fundraisers can be posted, but not local fundraisers, such as SOAR, Homes for Hope, etc.

Diane W. said that if anything ever gets posted that shouldn't, contact her and she can take it down.

- c. **50<sup>th</sup> Anniversary “celebrations” for 2024:** Deb wanted thoughts on how to commemorate and determine planning in this conversation.
- i. T-shirts? Tie in with Buddy Walk. Either only CIDSO or with the Buddy Walk? Deb asked Kim if there were restrictions on the Buddy Walk t-shirts. We can put our own t-shirts together for the Buddy Walk. Yet if we use Buddy Walk logo then we have to use their most recent logo.
  - ii. Pantagraph feature article on how long this has made it... who will make the contact? Diane and Bill should be interviewed because of their role in CIDSO. What about Bill Flick for a big feature? Bill Kemp (historian)??? Diane and Bill will pursue some kind of an option and get back to us. Maybe we could time around the Buddy Walk? October as Ds Awareness Month?
  - iii. WGLT? A WGLT reporter is on Kim's daughter's softball team and Kim will ask him.
  - iv. Family Dinner? And celebrate!  
(This -2023- is the 50th year. But 2024 was year one. But could stretch it out.)
  - v. Local advertising
  - vi. Contact and acknowledge Penny and husband Steve Schimpler as co-founders.

Reflection on the 4 daring, courageous, markedly determined parents, who naively thought they could whip the world. AND DID with so many positive impacts that kept so many from the same terrible experiences the founders went through! Diane W. said from day one she was aware that because of CIDSO, James would have opportunities, and she will be forever grateful.

So continue to brainstorm ideas between now and the next meeting. Deb welcomed us to email those around.

#### **11. Standing Business:**

- a. **Sharing resources that you use with your child that might help others.** No questions.
- b. **Open question to families – How can CIDSO help you?** No discussion.

**Adjourn:** Diane C moved adjournment at 8:46pm. Deb seconded.

**Next Meeting: 7/13/23 7p via Zoom.** Please note this is a Thursday, not Tuesday.

Sandy Bauer, CIDSO Secretary

Minutes approved at the 7.13.23 Meeting - seb