

NORTH DAKOTA STATE COUNCIL ON DEVELOPMENTAL DISABILITIES
MEETING MINUTES
SEPTEMBER 22, 2010
PIONEER ROOM
STATE CAPITOL BUILDING
BISMARCK, NORTH DAKOTA

Members Present

Darcy Andahl	Holly Major	Brenda Schmid
Brent Askvig	Jeremy McIntyre	Alex Schweitzer
Shirley Brennan	Marcia Kilzer	Mary Simonson
Tammy DeSautel	Pam Kolling	Mark Sloan
Tamara Gallup-Millner	Carol Olson	Diana Zietz
Richard Hickok	Bob Rutten	

Members Absent

Jane Haerter	Cindy Taylor
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Proxies

Darcy Andahl for Jane Haerter
Alex Schweitzer for Carol Olson in her absence

Staff Present

Andrea Peña
Bonnie Roth

A birthday song and wishes went out to Shirley Brennan who was celebrating her birthday today.

The meeting was called to order at 9:00 AM by Chairperson Mary Simonson. Roll call was taken, and a quorum was present.

The following proxies were accepted for those who could not attend the meeting:

Darcy Andahl for Jane Haerter
Alex Schweitzer for Carol Olson, when she was not present.

Darcy moved and Holly seconded that the Council accept the proxies.

A motion was made by Darcy and seconded by Marcia to approve the meeting agenda. Motion carried.

An approval of the July 22-23 meeting minutes was called for. Darcy asked that the minutes be amended to clarify she stated the Council should not have tunnel vision, but think outside the box when developing the next five year state plan. Darcy moved to accept the minutes with amendment, and Marcia seconded. Motion carried. Darcy moved and Shirley seconded to accept the August 18, 2010, Executive Committee minutes. No discussion. Motion carried.

Executive Director's Report:

Andrea Peña presented the Director and Financial Status reports.

Andrea stated the mid August state plan amendment was submitted to the Administration on Developmental Disabilities on time. The only change the Council had to submit was membership in which we added Holly. ADD is currently working on a new state plan template for the next 5 year state plan under the new commissioner, Sharon Lewis. Commissioner Lewis is moving forward for change. Mary and Diana will go to Orlando to the National Association of Councils on Developmental Disabilities meeting. The draft template will be available at that time as well as online. Notify Andrea if you want to provide feedback on the federal template draft.

During the summer, the Council was represented at the Americans with Disabilities 20-year rally at the Capitol by Darcy. Darcy stated the rally went well. Darcy gave out pamphlets, notepads, bags, and pens. There was a huge crowd. Carla Tice and group did a performance of Grease.

General Announcements: Save the date regarding housing issues Part 2 from the ND Housing Alliance. They hosted a meeting regarding housing problems last year which was well attended. They are hosting a second housing meeting on Wednesday, October 13, in Bismarck. Andrea will email more information if anyone wants it.

An Employment First Summit is being held. The DD Network is co-sponsoring this summit on October 15 in Bismarck. This is the first Employment First summit which the Council and DD Network have collaborated. Andrea encouraged everyone to attend.

At the July meeting, Brent stated the Council is required by law to have 60% parent and consumer representation. When Tammy D. was switched from the dual role as both a parent and state agency representative, the Council's percentage shifted to just below the required 60%. Another member will have to be added. When Sheryl Matney was here in July, she encouraged us to highly consider race, ethically and demographics of the new member as noted in the DD Act. Andrea has sent information to various organizations to recruit a member. If you have a potential candidate, contact Andrea, especially if they fit into any of the targeted areas.

2009 Budget:

The 2009 budget is highlighted in yellow. The administration portion of this budget has been closed out. On page 2, you will see that the Open Door Center has a small amount left and is spending down their funds via a contract amendment. Andrea granted an amendment for their after school program which ends June 2011. The Head Injury Association was granted a change to the direction of their funding and Andrea granted an amendment to December 31, 2010. The Arc of Bismarck and ND Advocacy Consortium are 2010 projects which were rolled to back to utilize the remainder of the 2009 monies. There are no concerns with utilizing the remainder of the 2009 budget on time.

2010 Budget:

The 2010 budget is highlighted in orange. The majority of these expenses have not changed since the July meeting.

Approval of the Proposed 2011 Budget:

Andrea shared the Executive Director's 2011 budget proposal with the Council. The member in-state travel will remain at \$7,000. Out-of-state travel will remain at \$8,500. The members' stipends will remain the same at \$2,000. The registration fees will remain the same at \$1,000. Conference expense is \$300. Printing/photocopying has been increased by \$500. NACDD anticipates the dues will remain the same at \$4,262. Meeting costs will be \$1,000. Telephone costs are being increased by \$200 for conference calls, as needed. Postage costs have increased to \$150. Supplies have increased to \$200, for additional state plan materials. ISD/Data processing will remain the same at \$1,000. Alternate format conversion is \$100. Office equipment is \$625, in which every third year the office computer is replaced. DSA services which covers the administration and fiscal management costs remain the same at \$19,600. The line item, Annual Report, was added to the budget at \$2,000. The discretionary expense is to pay for the facilitators for the remainder of the state planning process. The total FY 2011 administration is \$127,774.

It has been discussed for several meetings to contract a new staff for a salary of \$3300 per month which would start in August 2011. The forecast of income would be \$490,797; and total expenses are forecasted at \$162,313. Project requests are \$592,704 with a balance available for FY11 projects at \$328,484.

It was moved by Darcy and seconded by Diana to approve the FY2009 and FY2010 spreadsheets and the FY2011 budget proposal. No discussion. Motion carried.

By Laws:

Andrea e-mailed the by-laws to the Council members for review. Andrea stated the changes made during the July 22-23rd meeting are incorporated into the draft copy and shown in purple.

Starting on page 3, Item #6. The language was changed. It was recommended by Sheryl, our state plan facilitator, to change the wording and remove "of the federal administration on DD."

Bottom of page 3, section 1. It was recommended to take out the word "federal." It was also discussed that the Council have language in membership to make sure the Council has geographically represented members with diversification in race and ethnicity. This sentence was added.

Page 4, Membership. The paragraph was added covers h, i and j stating these requirements can be covered solely by the Executive Director of the Department of

Human Services or three separate state agency members representing each of these divisions.

Page 5, Article 7. The Council discussed language to be added regarding voting by non-Council members. This section now states that non-council members serving on council committees will be permitted to vote within the committee, but not at full Council meetings regarding official Council business.

Page 7, Section 6. This section is about meeting attendance and how it is counted. A section was added that states if someone is attending the meeting via conference call or other electronic means, they are counted in attendance for purposes of a quorum.

Section 7. Order of Business. This portion talks about casting votes. Votes may be given via conference call or other electronic means.

Page 8. Language was just cleaned up a little in the first paragraph. The second paragraph was crossed out and should not have been crossed out. This section mentions that our state gets one voting member for our national association (NACDD).

Discussion: Darcy questioned the portion in which we may not have enough members for a quorum. Andrea explained that the Council may still meet; but no votes can be made regarding items of business. **No proxies will be allowed in future meetings as stated in the by-laws** (page 7).

Diana moved and seconded by Brent that we accept the new draft of the by-laws.

Discussion: Brent questioned the blue highlighted guidelines from the last meeting. There were definitions stated at that time. Andrea stated the guidelines Brent spoke about are in the blue section of the by-laws draft which will be moved to the conflict of interest section of the operations manual. Andrea will present the draft of the operations manual before the December meeting, which will include the portion on conflict of interest.

Motion carried.

Brent asked for special recognition to those members who worked on the by-laws. The by-laws committee was: Diana, Mary, ad hoc member Bruce Murry (previous Council member), and Andrea. Andrea will get the by-laws printed and distributed to all the members.

Grant Applicant Presentations for FY 2011 Grant Funding Requests:

Andrea stated the Council received 20 applications this year compared to 26 last year. Nineteen of the 20 applications were eligible for review; one application came in late and did not qualify. The evaluation, scoring, and funding information spreadsheet was sent to all Council members and applicants received individual evaluations, so they

knew their composite score and that the minimum scoring was 75 to be considered for funding.

Upon review of the Summary Sheet of FY 2011 NDSCDD Grant Funding Requests & Amounts Recommended spreadsheet shows the score as well as the emphasis area, the organization, project name, if they were funded in 2010 and for how much, how much money they requested for 2011, how much the Executive Committee recommended and any notes. This spreadsheet is not as cumbersome when reviewing the various grants. Mary stated some of the recommendations that were made were driven by the amount of money the Council has available. Level funding was seen as the most appropriate way to use the Council monies this year. The Council's Executive Committee chose one project from each area of emphasis and then looked at merit before the recommendation was made. When one project from each emphasis area was chosen, the Committee started at the top and went through the process again. The Committee wanted to make sure they were accountable to the performance outcome measures in the state plan.

Quick Reminder: If you are affiliated with any organization such as a board member, etc. please re-cuse yourself from presentations and voting by removing yourself from the room. It will be noted in the minutes.

Project Presentations:

Presentations of FY 2011 project funding requests were given by representatives of organizations requesting Council funding. Council members reviewed their spreadsheet regarding the applications and the Executive Committee recommendations as project representatives presented their requests. Presenters then answered questions from Council members after their presentations.

The Arc of Bismarck – Partners in Policymaking – Joyce Smith

Joyce stated this was a continuation project. Her handout showed topics that have been used in their current project. Partners in Policymaking is an innovative, competency-based leadership and advocacy skills training program which is designed for adults with disabilities and parents of children with disabilities. The general goal is educating the participants to be in a positive relationship, and promote self-advocacy and systems change. This is an event with a series of eight (8) weekends of training totaling 128 hours over an eight month time period. Joyce noted that on page 8, the project has met and surpassed all target numbers, completed the training sessions, and provided advanced training for graduates. On page 5, is a narrative of activities that are provided. Community education is promoted and they collaborate with other agencies. The purpose and goals stay constant. Legislative session process training will start in the fall, and approximately 60 people are involved in drafting testimony and speaking. The Arc is proposing advanced training for July. Three performance outcome measures have been added.

The Arc has a community workshop throughout the state. There was a rally celebrating ADA at the Capitol. There was a good turnout as well as good press. An emergency

readiness training was done, and a video is available. They have a television series on Dakota Media access. Radio ads and billboards are still up.

Discussion: Andrea questioned Joyce regarding the TV series. Joyce stated that two episodes were filmed during the rally. The keynote speakers, Emma Sullivan and Juna Wentz, spoke on how the ADA affected their lives and families. L.I.S.T.E.N., Inc. self-advocates were interviewed. Veronica stated the upcoming episodes would have the spotlight on people who are active as parents, self advocates and will be included in community awareness. Right now, these interviews have been available in the Bismarck-Mandan area. Soon they will be seen in the Fargo, Minot, and Grand Forks areas on public access channels.

Andrea stated the Executive Committee questioned the information regarding the administrative and bookkeeper salaries. Joyce stated there is no administrative assistant – those costs are in-kind costs. The Executive Committee made a recommendation in regards to future funding –the Arc apply for a maximum of \$50,000 for the project per year. Brent stated he thought Partners was only an educational project; but apparently there is a large information dissemination of public awareness that goes on also. Brent questioned what portion goes toward the training session and what portion of the funding goes to public partners? Joyce stated that all money given by the Council goes to the Partners project. The other activities are done with monies received from various grants. Brent asked about page 6 and the additional disabilities activities. Joyce stated the billboards are from Council dollars.

Brenda asked how the numbers look in attendance for Partners for the training sessions. Joyce stated they write a grant for 25 people, and there has been good attendance. Partners is a national trade marked and specialized curriculum.

Diana re-cused.

ND Disabilities Advocacy Consortium – Disability Awareness Day at the Capitol – Jim Moench

Jim was not able to attend. Jim contacted Andrea this morning. If there are any questions, Jim could answer questions via e-mail. If the Council has questions regarding this grant, Andrea can contact Jim to get his response. On the evaluation summary form, the Executive Committee had three criteria questions regarding support data, board members of NDDAC and their responsibilities with this day and identification of income match.

Discussion:

Jim has not indicated to Andrea regarding his plans for retirement. Council money to the NDDAC ends on September 30, 2010. Andrea does not know if they have another source of funding at this time. Jim's position is only part-time right now. Andrea stated she doesn't know if they have money for Executive Director funds at this time. They are applying for other funding to support them as well.

Pathfinder Parent Center – Parent Involvement Conference Support – Cathy Haarstad

This funding is to help support the 2011 parent involvement conference. Pathfinder is partnering with DPI in seeking funding because of the cost incurred in bringing parents from all over the state to this conference. On the information sheet passed out at the meeting, it shows the emphasis area, goals, and expenses.

An additional column was added to the budget showing what percentage goes into the budget. About 60% of the funding goes directly to stipends or to parents statewide to attend the conference. Without funding from Council, it would be difficult to bring parents to the conference. Pathfinder would be forced to cut back to a regional conference, which would be difficult for parents and DPI to host instead of a state-wide conference.

Many schools and providers bring speakers to the conference. Parents are invited to join group activities. Sometimes it is very difficult to get to conferences because not only do they have to carve out the time, but they have to make arrangements for child care for their children for three days. Some families may not have the respite hours for this conference. The parents may have additional costs to care for the children that are not covered by Medicaid. Pathfinder can help parents get to the conference. Pathfinder is very grateful for previous funding. Parents continue to show up at the conferences and receive inspiration from the various speakers. This year's conference will focus on universal theme for learning.

Holly re-cused.

There was no discussion.

ND Center for Persons with Disabilities – Medical Home Care Coordination II

A handout was given to the Council regarding this representation. The presenter had a medical emergency and could not be present. This is a continuation grant which would be funding Phase II, with no funding needed after the completion of Phase II.

The Executive Committee had three questions regarding the grant. This is a continuation grant which was funded last year. This would be the last year for funding of this grant.

Question 1: Are the people listed in the target numbers for the performance outcome measures? Are these the same people as in Phase I, or a new group of people that the project would be reaching?

Response: They stated that they will expand to include additional stakeholders and partners. For example, Family Voices has expressed interest in having the modules available.

Question 2: With the continuing education model, will there ever be a need for an updated online program? If so, who will be responsible for the update?

Response: Yes, there will be a need for update in the future. Integrated services would be responsible for updates.

Question 3: Does this project have measures in place for sustainability? Has there been thought given to the lack of computer/internet accessibility for those in rural areas?

Response: If they do not have access, paper copies are available.

Tammy G. and Brent re-cused.

Discussion:

Brenda questioned how funding would continue after the grant is completed? Carol stated it was addressed in the application on page 6 and Andrea noted they are supporting this through continuing education fees.

Minot State University -- ND Center for Persons with Disabilities – The Mythbuster Project 2011 – Steve Peterson

This project began in October 2006. This is a 5 year collaboration with the Council and P&A. This project changed public perceptions using various marketing tools over the project such as theme development throughout the state, communities, and person-to-person campaigns. Steve prepared an overview for the Council members as well as a packet of samples of what has been done in year 4 for each member.

To summarize the plan for year 5: Mythbusters will sustain all three state-wide campaigns and complete the development of the speakers' bureau. The web site will be maintained. A hard copy flyer will be available also. Mythbusters will build on and complete the content of the awareness calendar that is inside the disability date book which includes printing, an updated hard copy and creating an electronic copy. Mythbusters also wants to make this information available for dissemination on a CD and on the web site. The date book was developed last year. The calendar goes to web site articles regarding social markets and disabilities. Mythbusters would like to make all the products available for replication.

Brent re-cused.

Discussion.

Andrea asked Steve for more discussion regarding the disability date book. Andrea stated it was a very good document. Steve said the disability date book will be put on line this year and updated soon. Mythbusters had their interns expand the calendar. Andrea questioned the purpose and background of the calendar. State stated it was a historical document on developmental disabilities from beginning of information to present. A copy is available for \$10. Andrea has a copy for anyone who would like to see it. Call NDCPD at 800-233-1737 Extension 3505 and ask for Steve or call Steve directly at 701-838-3505.

Andrea stated it's easy to read, easy to understand, and an interesting book. It is expected to be published by mid-May or June.

Family Voices of North Dakota -- Parent-to-Parent Project – Donene Feist

Through the Parent to Parent Project, Family Voices did a survey and discovered that 50% of those surveyed were more empowered and better able to cope with self-diagnosis, 80% received more social support, 100% had better acceptance of health issues, and 80% had less stress.

There were 219 parent follow up contacts last year. Family Voices continues to offer parent-to parent workshops in each region. A parent navigator program has been started and is incorporating five new teams this year in more rural areas.

Parent navigator teams are taking families and professionals and collaboratively working with regional areas on various issues. The mailing list, because of parent navigators, is about 5000 people and approximately 4000 e-mail newsletters are distributed. Family Voices is always looking for ways to partner with other organizations and hopefully expand. There are discussions with Sanford Health, Innovis, and March of Dimes.

Family Voices is working with more technology and trying to network families. They are partnering with other organizations to sponsor the leadership institute such as Federation of Families and Pathfinder. The leadership retreat will be in October this year, and they have invited parent leaders from across the state who have attended the previous institutes, experienced parent programs, and those who have regional and other leadership roles.

Family Voices is growing; therefore, they are looking for assistance from United Way funding. They have been successful with one grant in Williston. As far as sustainability, Family Voices received funding through DPI. Last year the Dakota Medical Foundation worked with Family Voices to help with fund raising. All Family Voices' staff are part time and include many volunteers. They are growing so fast that it is becoming necessary to have staff in each region. More and more families are learning about formal as well as informal supports. Feedback is always given. Family Voices encourages the parent leadership training.

Tammy G., Brenda and Tammy D. re-cused.

Discussion:

Andrea asked Donene to identify Family Voices staff:

Missy Baranko -- Dickinson

Vicki Peterson – Bismarck

Joan Karpenko – Grand Forks

Brenda Schmid – Fargo

Donene – Edgeley

Part-time in Minot – unknown at this time
Funding in Williston
Jamestown and Devils Lake are gaps that need to be filled.

Andrea asked if the October leadership retreat is their first retreat of this kind? Donene stated that this will be the first leadership retreat. The registration is about 60 who will attend; but invitations were sent to approximately 150. Child care will be provided at this retreat. Towards the end of the retreat, Family Voices will be using their Robert Wood Johnson monies for Penny and Pals who will be at Pumpkin Patch. Family pictures will also be taken.

Missy Baranko presented after lunch:

Travel is always difficult for persons with disabilities and very necessary. One of the goals is going to get the program to small rural areas that have interest in the program. This funding will help with support groups. They are using the Big Tent platform, which is similar to Face book, but it has more privacy. Missy is the moderator. This is a place for DD parents and consumers to post support work or community activities. They partner with other people and programs such as the hospital with parent-to-parent ventures.

ND Center for Persons with Disabilities – Consumer Participation in the 2011 NDACP Conference – Mary Mercer

Mary Mercer presented the ND Center for Persons with Disabilities – 2011 NDACP Conference project. This is a continuation project.

Mary thanked the Council for past conference support. Of the 412 participants at the conference last year, 15% were presenters and the rest were persons with disabilities and their families. They were supported through Council funding. Some of the speakers were from Wisconsin. Keith Jones presented a session on “Providers as a Cornerstone.” The presentation related to quality assurance, medical homes, special needs trusts, ethics, and facilitating the role of the personal advocate. They discussed work incentives and the benefits of them.

Andrea asked Mary to share a story regarding a self advocate. Mary stated that self advocates had many personal stories including Mr. Miller who still lives in his apartment. His visual impairment makes him a strong advocate. He works two part-time jobs and member of a self advocate group. Many advocates, including Mr. Miller, and providers thought the conference said their experience was informative and a good learning experience; they met many new people. They talked about the importance of rights.

The consumer satisfaction survey this last year showed increased levels of choice and control, opportunities, and their knowledge of rights. Next year’s conference will be in Fargo, ND.

Brent re-cused.

Discussion:

Brenda stated the conference also welcomes those persons who live in Minnesota. The registration is \$150 for 3 days; but there are also one-day presentation rates. Mary stated that the conference is very beneficial and has a wide variety of topics. Council members are free. Register by using the registration form and how many days you plan to attend. Mark the form as a State Council Member.

IPAT – Event Coordination for AT Expo/Self Advocacy Leadership – Jeannie Krull & Rhonda Wilson

Children, adults, and professionals who have attended, find the Expo beneficial. Vendors are there also to showcase their wares such as devices for the telephone, walkers, wheelchairs and other useful items. There are very few technology vendors in North Dakota. So, children, adults, family members, and professionals who serve individuals with DD have an opportunity to experience new technology devices at the AT Expo from vendors all over the United States. This Expo increases AT awareness. The Expo has free tables for support groups to help recruit members in their area and help with the needs in their areas.

Employment, SSI benefits, internet safety, and leadership will be added as topics to the Expo this year. A new feature this year will be the partnership through CTV and footage that will be televised for those people in North Dakota that are not able to attend. They will provide film coverage of the Expo and be featured on Disability Viewpoint. This is an awarding-winning show that has been aired in the Twin Cities area for 11 years. They can access footage on the internet and it's available on a DVD. This film coverage will also be accessed by public TV as well as on Prairie Public in Minnesota.

Jeannie addressed the questions that were posed to her by the Executive Committee. First, why is this position being expanded at this time? This position has expanded dramatically in 2008, which is why they contracted with an event planner in 2009-10. During those years, the Expo expanded further and still needs an event planning company as their previous planner does not do this function any longer. They are also looking for another funding source. IPAT, their previous funder, had program changes and reallocated their monies.

A breakdown for the event of coordination fee was requested by the Council. Their previous coordination services charged a flat fee to perform all the needed activities at the Expo. The duties and fees are shown on page 9. The Council requested a travel budget. The CTV group (shown on page 12) is the only group who will be traveling and they will do videotaping and interviews.

The last question asked by the Council is if this was the last year of funding, can IPAT sustain this project in the future? Jeannie stated that they have a list of other groups they will contact for help with future sustainability.

Discussion:

Andrea questioned Jeannie regarding the anticipation of another coordinator. Would the fee amounts match what another event coordinator would cost? Jeannie stated that they have sent out bids already.

IPAT offers scholarships for families with children or adults with disabilities as well as families and/or adults with care providers. Mary stated that the exhibit hall is open and free to everyone. She also shared that all Council members, because we sponsor the Expo, are admitted free. The pre-conference date is April 27, and the 28th is the conference day.

Brent asked how many people attended this conference last year? Jeannie stated that 570 attended last year, of which 80% were North Dakota families.

Community Living Services, Inc. – Transition Age Work Experience Project – Jeff Anderson

This is the second year for this project request. The project is a collaborative effort between the community, West Fargo Public School, and Fargo area schools that provides vocational support services. The project has job shadowing, job coaching, and aid for high school transitioning for persons with developmental disabilities.

This project allows West Fargo and area schools to collaborate community-based services and job placements for students with special services. The students are working with various skill levels and areas to help transition them to work areas. Areas would be implemented by IT managers and schools. Job placement will be undertaken by school-based educators, job coaching provided by COS specialists, Vocational Rehabilitation educators, and sports specialists who study the students and work on their skill level. The success will be measured by jobs obtained in the community and gainful employment. The ultimate goal is to successfully employ 22 transition age students with a job which is consistent with their ability and self-sufficiency this year.

To summarize, the handout given by Jeff has a revised budget asking for \$39,900 instead of \$45,000. Transition age work project has exceeded their in-kind match this year; therefore, the project has advanced a little faster. The agency is committed to this project and more time was given by the supervisor. Community Living Services will share this model with other schools to make it work statewide. This program is now included in area schools and not just the West Fargo Public Schools. Word of mouth has spread the growth of this program. The South Valley Special Education Unit is now receiving their services. Rural Cass County Schools have contacted them too.

The Executive Committee asked for explanation of the performance measures. During this time period, 27 students were served with 22 students gainfully employed, five (5) did not get employed, and one (1) quit the program. Originally the goal was to supply jobs to 15 students and they have now surpassed that number.

Discussion:

Alex questioned what the reason was for the five persons who didn't get served. Jeff stated that it had nothing to do with eligibility; but follow through. Community Living Services is taking the lead with these services and hopefully the school will pick up the funding later. Alex wondered if Vocational Rehabilitation was part of this project or will work with them? Jeff stated they don't work with VR. Brent recommended Jeff contact the new VR Director, Russ Cusack, about their program and see what help they can get from them. Marcia wondered about supervision of the students and how many adults supervise them? The project dollars are spent to allow agency staff to provide the support and have them go with the students.

March of Dimes North Dakota Chapter NICU Family Support Program – Karin Roseland

March of Dimes helps families through the overwhelming and catastrophic experiences of the NICU journey. Karin read a letter from a NICU family who stated they would like a handbook on how it will affect the family. The handbook would state how families will not be alone. Karin stated that the NICU is like "ground zero early intervention." The March of Dimes program offers parents some tools, empowerment, and preparation for transition. A March of Dimes employee stays at the NICU with the family to help comfort them and help their transition in and out of the NICU. .

Discussion:

Brenda questioned what type of support March of Dimes gives families after leaving the NICU? March of Dimes provides support to families by giving e-mail addresses and having contact with those families that were involved in the program. Bonding comes together with other parents who have previously gone through the NICU experience and befriend them. Tammy D. – parents are matched with March of Dimes training and mentoring. The March of Dimes works with a group of parents that has gone through the experience and befriends a family. March of Dimes has a web page with a section called "share your story." It is an online web page and post comments. Families get support that way. March of Dimes licenses and trains their staff.

Karin stated that March of Dimes is seeking funding from foundations and families to increase sustainability. They have increased their fund raising efforts also. Eventually these funds will roll into their operating expenses.

The Council asked if other NICU's have similar programs.

L.I.S.T.E.N., Inc. Self Advocacy Solutions – Carla Tice

Carla Tice, Project Director, stated the L.I.S.T.E.N group was on their way to Kansas City for the National Self Advocacy Conference. Carla stated that since 1991, she has worked in a civil rights movement called self-advocacy. SAS is an everyday occasion. At this time, this group is run by a part-time project director, 1 part-time state liaison, 2 staff team leaders who have developmental disabilities, and 2 self advocates who are

funded through the Lutheran Drop-In Center. Self advocacy supports people with disabilities and teaches them to speak up, know their rights, get the support they need, and promotes choice and independence for activity and inclusion.

The work of self advocacy, maximizes the opportunities for people with disabilities to remove the barriers in housing, employment, transportation, education, and accessibility. In the past eight (8) years, SAS has worked with self advocacy groups in North Dakota allowing self advocates to express themselves in tools of their choice such as statewide speaker's bureau, curriculum and conferences. They have had a very successful year in reaching their goals. They have worked closely with Partners in Policymaking, the Arc of Bismarck and enjoyed the Emergency Readiness Conference.

The Council had concerns regarding changes in the budget. The Council questioned how SAS reached the other parts of the state, primarily the western portion?

L.I.S.T.E.N provided training this year in difference settings. Four trainings were held in Minot, Valley City, and Dickinson, and presentations were provided, such as the Wizard of Oz.

Discussion:

L.I.S.T.E.N. is working closely with RSVP, Independent Living Center, and Second Story to best provide support to self-advocates. They are trying to set up a conference to serve self advocates in Dickinson. Andrea questioned if it would be possible to have staff regionally located throughout the state? Carla stated the problem is that part-time is too part-time. It would be hard to find persons who would work 10 hours weekly and need the funding for travel. Carla stated they will be doing more contracting with employees.

Presentations from Non-recommended Requests

Andrea stated that projects are invited to present if they scored 75 or above on their evaluation, but were not recommended by the Executive Committee.

Pathfinder Parent Center – Transition Planning for Students with Significant Support Needs - Cathy Haarstad

This is a new project. Pathfinder wanted to organize a resource for the state that show possible futures for people with significant work needs due to significant intellectual disabilities. Pathfinder is aware of a wide variety of transition materials that are available to families in North Dakota. But most of the materials that are available at this time are for support groups and persons with less significant disabilities. Families don't see some of the future activities in sight for their child.

This project would like to do statewide interviews with families and providers. Families do not see this is happening in other areas in North Dakota.

Cathy stated that the Executive Committee thought merit was not found in this project, as they scored low on it. Pathfinder felt their project had merit and gave a handout to each Council member. The Council felt this information was being given to families; but Pathfinder does not believe it is widely disseminated. The Executive Committee stated there was no statewide data provided. Cathy stated that every provider, family, and special education unit had to do a picture. It was based more on emotion than data. Activities were included in the proposal. They are looking for technical assistance in future applications. Pathfinder would like to see families have the richness of information on transition available to these challenged individuals; and because of this small population, they do not receive the information.

Cathy stated they secured an in-kind match at the last minute. They did not place this information on the application. The Executive Committee questioned the difference in pay for professional staff vs. parents. Pathfinder talked to the parents who have been recruited and asked what they wanted for reimbursement. Parents stated they did not want to be paid. Pathfinder stated they would pay them something for the grant and worked with them. The range of salaries for the professionals varied and decided on an average hourly rate. The parents would receive \$15 an hour; professionals would receive \$18 an hour.

There was no discussion.

Holly re-cused.

Minot State University – We’re Ready: Disaster Preparedness 2011 – Janet Green

Janet thanked the Council for the past years of support. Vicki Troftgruben has been working with this project the past year. She has been going throughout the state organizing focus group meetings. It is hard to get individuals with DD to come to these meetings. Anonymity and independence is important. MSU would like to develop a test program in Region II, focusing on the smaller rural communities and entice them to come with a 72 hour kit.

Janet stated that there was a change to budget by minimizing budget costs and reduce the staff. The original proposal was stating \$21,908 for their request and now requesting a reduction of \$6,000, making their request amount of \$15,547. They are helping individuals who live independently in their homes become prepared for a disaster.

Brent re-cused.

Summa Labore - Mary Stammen

Mary clarified resources that are already in existence and employed by some of the state agencies will be used. For example, a key story in the magazine handed out was

written by special education teachers North Dakota public schools. Free lance writers have also been used which can be found in North Dakota's free lance list as well as photographers. Twenty seven stories have been completed or are near completion already.

Sustainability had 2 points subtracted from the total. Publishing a magazine doesn't require a miracle. It requires dedication and determination. The use of a subscription-based business model by special interest magazines is well established and has been highly successful. Mary stated that originally advertising was going to be their main method of sustainability; but many didn't want to advertise. They wanted to pay for subscriptions.

There would be printed as well as digital editions of the magazine to help with dissemination as well as ask organizations and agencies who should get it.

It is difficult to visualize a periodical publication if you have not seen it. 25% of my requested funding (\$7,500) would help publish the first issue of the magazine and put it into the hands of people, who need it, want it, and others in the disability community.

Discussion:

There are success stories in the first pages which are the main focus. Bob stated that Summa Labore has approached DPI about disability funding through the Department of Special Education. It has been hard to get dollars for this project. There will be printing and mailing expenses.

Member Announcements:

Mary announced that there will be Head Injury Mentor Training in Fargo on October 29. The Head Injury group is in partnership with UND Rural Health and Sanford. If anyone is interested in becoming a mentor for Head Injury clients, please contact Rich Ott who is in Bismarck.

Holly stated there will be a Pathfinder Conference regarding parent Involvement Conference Support at the Seven Seas in Mandan, April 14-16, 2011. The information is in the Pathfinder application (#3).

BY-LAWS REMINDER: Carol questioned when the by-laws will go into effect. Brent stated they should not go into effect until the following day because there are proxies being used in today's meeting. Diana also noted that proxies have been approved and we should not want to go back.

Tammy D. moved and Carol seconded that the by-laws go into effect October 1st, 2010. No further discussion. Motion carried.

Next Meeting:

Friday, December 10, 2010 – Bismarck

10:00 a.m. - 5:00 p.m.

Agenda: Additional work on the state plan.

Diana stated she will be absent.

2011 Tentative Meeting Dates:

Brent offered an invitation to the Council to consider Minot for hosting a meeting and see their facility as well as other agencies. Bob also stated that visiting other cities and their facilities would be good for the Council and offered the school of the Deaf and school for the blind as options as well.

Tuesday, March 8, 2011 – 10:00 – 4:00

Friday, June 17, 2011 – 10:00 – 5:00

Thursday, September 15, 2011 – 10:00 a.m. – 5:00 p.m.

Friday, December 9, 2011 – 10:00 a.m. – 2:00 p.m.

Possible travel to other cities in March and/or June of 2012.

Diana moved to accept the meeting dates for 2011, and it was seconded by Darcy. No discussion. Motion carried.

Approval of FY 2011 Project Selection and Funding Requests

Council members began consideration of fiscal year 2011 project requests submitted to the Council. Roll call votes were taken on each project funding request.

A motion was made by Alex and seconded by Darcy to approve funding for the March of Dimes Project for the amount of \$22,750, which was recommended by the Executive Committee. In discussion, Tammy G. wanted to know if there is monitoring throughout the award. Andrea stated that the performance outcomes and measures are monitored. Motion carried.

Mary questioned if there are specific non-recommended projects that the Council needs to look at before the money is used?

A motion was made by Holly and seconded by Carol to approve funding for the Family Voices of North Dakota project for the amount of \$58,168, which was recommended by the Executive Committee. No discussion. Motion carried. Tammy G, Tammy D, Bob, and Brenda re-cused themselves.

A motion was made by Diana and seconded by Brent to approve funding for the Pathfinder Parent Center – Parent Involvement Conference Support for the amount of \$13,125, which was recommended by the Executive Committee. Motion carried. Holly re-cused. Bob abstained as there was agency co-funding.

A motion for discussion by Brenda and seconded by Tammy D. regarding the Pathfinder Parent Center, Transition Planning for Students with Significant Support Needs. Brenda stated this was a very good program and there is a desperate need for this transition program for this age group. A motion was made by Brenda and seconded by Shirley to approve funding for the Pathfinder Parent Center for the amount of \$31,409. Tammy D. stated this was a very important project, but she was wondering if support could be done with other educational departments. Brent asked if there is money for curriculum development for DD not for transition? Motion failed. Holly re-cused.

A motion was made by Tammy D. and seconded by Mark to approve funding for the Community Living Services, Transition Age Work Experience Project, for the amount of \$39,900, which was recommended by the Executive Committee. Mary stated she thought some of these people should be served by Vocational Rehabilitation. Motion carried.

A motion was made by Richard and seconded by Alex that the Council not fund the Minot State University – ND Center for Persons with Disabilities - We're Ready: Disaster Preparedness 2011 project. No discussion. Motion carried. Brent re-cused.

A motion was made by Darcy and seconded by Alex to approve the funding for the Minot State University – ND Center for Persons with Disabilities – Consumer Participation in the 2011 NDACP Conference for \$9,340, which was recommended by the Executive Committee. No discussion. Motion passed. Brent and Mary re-cused.

A motion was made by Diana and seconded by Darcy to approve the funding for the Minot State University – ND Center for Persons with Disabilities – Medical Home Care Coordination II Project – for \$20,272, which was recommended by the Executive Committee. No discussion. Motion carried. Brent and Tammy G. re-cused.

A motion was made by Pam and seconded by Darcy to approve the funding for the IPAT – Event Coordination for AT Expo/Self Advocacy-Leadership Workshop and Video Webcast – for \$22,607, which was recommended by the Executive Committee. Brent asked during the presentation about the funding for this project. In the discussion, Brent questioned if there is any funding for persons attending the Expo who may be out of state during the presentation. Andrea thought there was funding for out-of-state attendees. Mary was told that they must be a state resident to receive a stipend. Andrea stated that the stipend paperwork would not through the Council, but the entity the Council is granting to, there for, stipends for out of state attendees could be obtained. Motion carried.

A motion was made by Holly and seconded by Tammy G. to approve the funding for Summa Labore for a reduced amount of \$6,600 for one year. In discussion, Andrea stated that \$6,600 would be available by using the funds for the contracted employee and then the contracted employee could start in October vs. August. The Council does keep 5% of the BSGA in reserve. That amount does not have to be kept in reserve; but it has been recommended by the Council in the past in case there is a deficit. Bob sees this as a new voice and audience for clients with disabilities. A printed budget would be given to the Council in detail before the award is given. Mark stated that there's an extra \$1,000 remaining on the 2011 spreadsheet for the grants. Amended funding for \$7,500 was made by Holly and seconded by Tammy G., contingent on the corrected and verifiable budget for printing and mailing of the magazine. Motion carried. Carol re-cused.

A motion was made by Alex and seconded by Darcy to approve the funding for the Arc of Bismarck – Partners in Policymaking -- in the amount of \$73,275, which was recommended by the Executive Committee. No discussion. Motion carried.

A motion was made by Diana and seconded by Darcy to approve funding for the Minot State University – ND Center for Persons with Disabilities – The Mythbuster Project 2011 – in the amount of \$15,029, which was recommended by the Executive Committee. No discussion. Motion carried. Brent re-cused.

A motion was made by Brent and seconded by Richard to approve funding for the ND Disabilities Advocacy Consortium – Disability Awareness Day at the Capitol – in the amount of \$3,000, which was recommended by the Executive Council. In discussion, Andrea stated that the funding would be contingent on verifying the match. Andrea will e-mail them to get an answer. The amended motion to funding was made by Brent and seconded again by Richard, which is contingent on the match information. Motion carried.

A motion was made by Alex and seconded by Darcy to approve funding for the L.I.S.T.E.N., Inc. – Self-Advocacy Solutions – in the amount of \$50,000, which was recommended by the Executive Committee. No discussion. Motion carried.

The final total of expenditure was \$334,966.

REMINDERS: December 10th – next Council meeting at the Capitol. Proxies will no longer be accepted.

There being no further business, the meeting adjourned at 3:30 PM. Jeremy moved the Council meeting adjourned and it was seconded by Diana.