

## Parent to Parent of Colorado

C/O UCP of Colorado  
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A service of UCP of Colorado

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## Annual Report

Fiscal Year July 2009 – June 2010

- Parent to Parent of Colorado connects families of children and adults with disabilities or special health care needs in communities across Colorado.
- Vision: It is our vision that parents and their sons and daughters are integral, valued members of society with a voice in shaping their chosen communities.\*
- Mission: We are a parent initiated, parent controlled, organized group that builds inclusive communities, takes effective and constructive group action, and supports each other on the journey of parenting our sons and daughters with special health care needs or disabilities.

### SOME HIGHLIGHTS FROM 2009-2010

- P2P had an opportunity to be part of 9News HelpLine in August. Thanks to collaborating organizations Peak Parent Center, Denver Metro Community Parent Resource Center (CPRC), Autism Society of Colorado, Arc of Arapahoe/Douglas, and EMPOWER Colorado. We took 150 calls in about two hours.
- Susan Blumberg, Parent to Parent Board member and volunteer extraordinaire, was honored by CP of Colorado as Volunteer of the Year.
- Through our contract with Colorado Department of Education (CDE), staff member Karen Rutledge audited school district websites for special education resources for parents. The majority of administrative unit (AU) websites in Colorado do not include special education resources for parents. Data was gathered on all AU websites and analyzed for reference to either PEAK Parent Center, Parents Encouraging Parents (PEP) conferences, Parent to Parent of Colorado, a special education handbook or other items. This information was shared with CDE.
- Karen and Dianne were able to participate in a day-long CDE workshop regarding Indicator 8, which speaks to whether schools facilitated parent involvement as a means of improving services and results for children with disabilities. Ideas and suggestions were generated. We are looking forward to reading the session summary.
- Parent to Parent continues to collaborate with PAD-CO (Parents of Adults w/ Disabilities in Colorado) and Colorado Cross Disabilities Coalition (CCDC). In the June, we presented a paper entitled **Position Paper Regarding the Federal Matching of Colorado County Developmental Disability Mill Levy Funds** to Rep. Kefalas and other interested parties. A second meeting is being scheduled.
- *Family Enrichment Event* – September 2009, **12th Annual Family Enrichment Event – Journey Forward Side by Side**





**Approximately 120 people in attendance** for the FREE picnic (a \$10 per family donation was suggested). Board member, Susan Blumberg and family designed a 'get to know each other' game with prizes for participants. This year we featured "Let Our Kids Shine Talent Showcase' and had five participants.

The concessionaire at Washington Park offered families ½ hour rides on a bicycle built for eight. Scott 'T' photography granted participants a complimentary photo shoot with a free 5X7 portrait per family. Great raffle items were given away. The event was advertised in both the newsletter and on the listserv. The picnic this year was organized by a committee of board members who donated much time to make this a successful event.

The Step Above Award went to Amy Fung for going beyond the call of duty on behalf of children with disabilities.

### Advisory Board & Staff

- The **Advisory Board for Parent to Parent consists of 11 parents** of children preschool through adult, bringing both their parent and professional expertise of various systems, including education, policy, developmental disabilities, cultural perspectives and mental health. Our board members volunteer their time. We review our 3-year plan each January to make sure that we are reaching toward our outcomes.
- P2P resides within Statewide Services and is directed by Patty Skolnik of Citizens for Patient Safety. Currently P2P has one full-time staff member and two part-time staff members:
- Dianne McNamara focuses on coordinating P2P activities, database management, editing and publishing the website, newsletter and resource documents.
- Renee Walbert's primary responsibilities are 1-1 parent matching, listserv moderation, Facebook group, and following policy issues.
- Karen Rutledge's work centers on outreach, information and referral, support groups and the annual Family Enrichment Event.
- Deon Gillespie coordinated activities for the African American Leadership project until December 2009 when the grant term ended.
- We share in attending meetings, conferences, trainings; preparing presentations; and participation on various committees.
- We continue to be supported by the resources and staff provided by UCP of Colorado.

<b>Advisory Board Members</b>
Susan Blumberg, Denver / Counseling, Parent
Lorene Devine, Highlands Ranch / Part C, Parent
Gerrie Frohne, Lakewood / Self-Determination, Parent of an Adult
Deon Gillespie / African American Parent Leadership, Parent
Heather Greene Denver / African American Parent Leadership, Parent
Carol Meredith, Littleton / Arc of Arapahoe & Douglas, Parent
Lori Parker, Aurora / Parent
Yvette Plummer, Aurora / Denver Metro Community Parent Resource Center, Parent
Kristina Sawycky, Colorado Springs / Part C, Parent
Carla Tave, Denver / African American Parent Leadership, Parent
Brenda Tuttle, Fort Collins / Northern Colorado, Parent

### Funding

For a copy of P2P's budget, please email [dianne@p2p-co.org](mailto:dianne@p2p-co.org). P2P receives funding through a variety of sources.

- *Grants* - Grants and funding were received from CDE Part B (Assistance for Education of All Children with Disabilities) and Colorado Developmental Disabilities Council (CDDC) Multi-Cultural Grant.
- *Fueling the Journey* - Annual November/December Online Fund Raising Campaign under the direction of Karen Rutledge.

- *Donations* - Collected through donation link on the P2P website and Exceptional Parent Magazine link, which generates funds when people subscribe through the link.
- *Supporters* – Advertisers on our webpage and in our newsletter.
- *10<sup>th</sup> Annual Mother's Tea* - Held at the Westin Tabor Center in May 2010. Proceeds from the event are shared among the Statewide Services of UCP. P2P staff is pro-active in soliciting donors for this event.
- *Volunteers* - **781 volunteer hours** include Board member contributions (meetings, listserv, fundraising activities); conference table volunteers; support parents used for 1-1 parent to parent matches; and annual picnic volunteers.
- *UCP of Colorado Support* – Includes grant writing support and funding for the shortfall in the budget. We appreciate all of their encouragement and financial assistance.

### Mutual Support

- Parent to Parent works to connect families to other families throughout the state and to provide resources and information to parents on various issues. Active involvement by members comes about through 1-1 matching, on the listserv, at the capitol, in support groups, at P2P Board meetings and in communities.

The Beach Center on Families and Disability at The University of Kansas conducted a national survey in 1988 of Parent to Parent programs to determine the effectiveness of parent to parent support. The results indicated that such support increases parents' acceptance of their situation and their sense of being able to cope. Based upon significant data, the research team recommends that Parent to Parent support should be an essential component of a comprehensive family support system as it is unique and cannot come from any other source.

**Parent to Parent of Colorado, following best practices as outlined by P2P USA, rounds out this continuum of support providing parents with one-to-one emotional and informational support from another parent who has been there.**

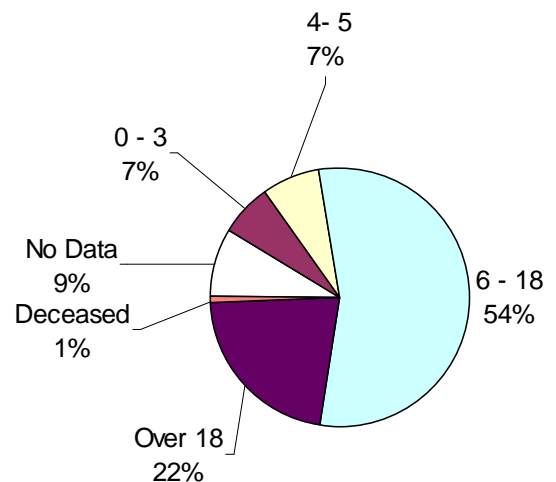
- *Membership* - **2262 members, with 283 new parent members this year.** Our membership represents parents of children of all ages as seen in the chart to the right.
- *Matching* - One of Parent to Parent of Colorado's main activities is 1-1 matching and support. **We saw a 35% increase in the number of matches (129) over last year based upon criteria, such as disabilities or parent issues. A completed 1-1 match can take up to 5 hours of staff time.**

Additional informal matching occurs informally on our listserv and our Facebook group. The numbers above reflect the "hard" matches that are directly facilitated by P2P staff.

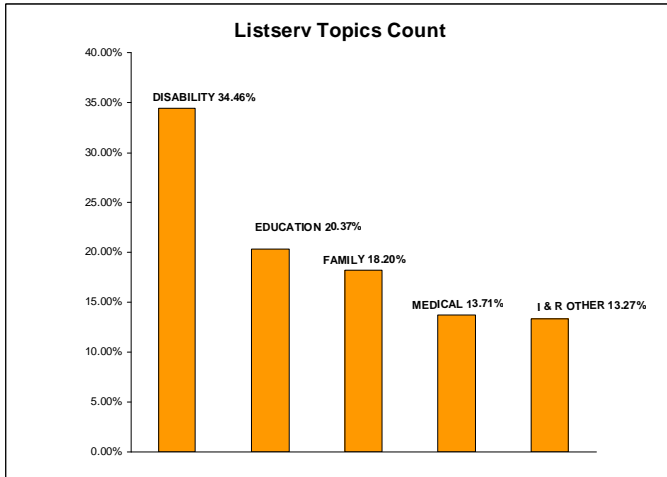
- *Information and Referral* - **P2P staff made 4495 contacts with information and referral on both our English and Spanish phone lines and over the Internet.** Of those contacts, 13% were professionals.

We distributed *Where Do I Start? And Where Do I Start? Disability Specific Resources*. Both are available in English and Spanish. **These guides are published on websites and used throughout the state by parents, school districts, CCBs, Early Intervention programs, support group facilitators and more.**

**Sons/Daughters by Age 06/10**  
Age Distribution of Children Represented by P2P Parents



A list of Parent Training Opportunities for the Denver metro area is compiled and distributed monthly to P2P listserv, PEP participants, school district special education coordinators, Child Find coordinators, Arc staff, Early Intervention staff, PEAK mentors and others for further dissemination. It has even been seen on a bulletin board at The Children's Hospital.



**Fifty-four wisdom files** (an assemblage of information from parents and other sources on requested topics) are now accessible on the P2P website. New ones added this year are Service Dogs, Lactose Intolerance, Information about SSI and Suggested Neuropsychologists.

- *P2P-CO Listserv* – A study on Internet Parent Support Groups (IPSG) found that a striking outcome of IPSG participation was improved caregiver-child relationship. P2P listserv parents provide each other parent leadership, educational advocacy and help in navigating the various systems. Support and encouragement abounds.



**P2P's listserv (1255 members) is always listed in the Top 10 Yahoo groups under our specific category (641 listings) with an average of 560 posts per month.**

Listserv moderator, Renee Walbert, is responsible for ongoing administration of the listserv including moderating, updating membership requests and making sure that everyone plays nice in the sandbox. She also sees that responses to parent questions are made in a timely manner.

**Educationally, emphasis is placed upon the importance of parent-professional partnerships and the value of inclusive education.** We partner with PEAK Parent Center and the statewide PEAK mentors to make sure that educational questions are answered with their expertise.

### Community Building

- *Website* – [Parent to Parent website](#) attracts **6978 visits per month**. A search engine for the site was added.

The [Resource Storeroom](#) was reconfigured this year with its own navigation bar. Topics most asked about by parents are organized into categories for ease of access to information. Each page is sorted into Colorado  and National links and indicates whether it has been recommended by a P2P parent .

**One hundred seventy-two websites are linked to the P2P website** with 13 new since June 2009. Among the new links are Northwest Colorado BOCES, Eagle County Schools, Colorado Links for Mental Health, Early Childhood Connections –Gunnison County and Education.com – Colorado State Disability Resources.

- **Facebook** – As expected, there are many younger families connecting via the Facebook page who have not yet connected to the more traditional listservs. Facebook is becoming an effective tool for marketing as well as information sharing. Renee migrated our P2P Facebook page to a Facebook Fan Page which now has 263 'likes.'
- *Newsletter* – [Newsletters](#), edited by Dianne McNamara, are published thrice yearly and available for downloading on the P2P website. All articles are written by parents. The Board Corner appears in every issue.

*Summer 2009 Newsletter Highlights*  
**The Words that Sting** by Jenny Fischer  
Orphaned in the Medical World  
My Secret About Inclusion: Coming out of the Closet  
Report Card On CDE's ESLU Goals

*Winter/Spring 2010 Newsletter Highlights*  
**Leaders Emerge from Parent Leadership Training**  
by Renee Walbert & Deon Gillespie  
To Pull or Not to Pull, That is the Question  
Are You Watching Your Language  
Assistive Technology Funding Sources

*Fall 2009 Newsletter Highlights*  
**My Child at an IEP Meeting?** by Charmaine Thaner  
ALPHABET SOUP TIME AGAIN! Changes to CDASS, SLS and COMP

- *Multicultural Outreach*

Collaboration with El Grupo Vida allows P2P to continue outreach to Spanish-speaking families through the P2P-CO-Hispano listserv. Maria Cabral graciously replies to phone messages left on the P2P Spanish line.

Through a grant from Colorado Disabilities Planning Council, we completed the 3<sup>rd</sup> year of a grant in conjunction with the Denver Metro CPRC to provide training in educational advocacy to our African American Parent Leadership participants. **A total of forty parents were trained through the program.**

- *Additional Outreach*

**Parent to Parent sent 167 "Parents are Talking" letters** complimenting individual schools, teachers, special education directors, community providers and medical personnel mentioned in a positive way on the P2P-CO listserv. P2P resources are included in the letter.

Outreach at The Children's Hospital includes talking with physicians and distributing informational packets about P2P and statewide resources. With the help of Senator Suzanne Williams, we made a key contact at Children's Hospital whom we will continue to follow up with. We also have made key contacts at the Rocky Mountain Hospital for Children at Presbyterian/St. Luke's Medical Center.

Presentations are made to Children's Service Coordinators within Early Childhood Connections several times a year.

We updated the professional database which included outreach to Arcs, single entry points and disability specific organizations.

- *Support Groups and Support Group Training – P2P annually updates our 4-page brochure entitled Colorado Parent Support Groups* in which the 131 support groups are organized by area of the state. The brochure was emailed to each P2P member and is also available on the P2P website.

As parents request, we send out a packet with information on how to start a support group. Staff also attends support groups for presentations on P2P as requested by support group leaders.

**Karen presented and conducted a survey at three parent support groups on Parent Engagement and Involvement.** The parents surveyed represented five school districts and children from 3 to 18 years old with a wide range of disabilities. A total of 15 surveys were completed. Some participants in these support groups were parents of non-school age children and, therefore, didn't complete the survey.

Over half the responses indicate that these school districts provide little, if any, information to parents about trainings and opportunities. Knowledge of and then participation in trainings and community organizations is the avenue by which parents get involved. Parents indicate that their best information comes from support groups, Parent to Parent of Colorado, Mobilizing Families workshops, Autism Society, the Arcs, CCBs and resources online.

- *Collaboration, Conferences and Meetings – P2P staff attended numerous meetings, trainings and conferences* where we provide information not only on P2P, but also PEP, PEAK and EMPOWER as noteworthy supports for parents. **We interacted with 2150 individuals throughout the year.**

- As a sampling, we attend meetings and have presentations for **CSEAC**, Mobilizing Families, JFK Family Advisory Council, Conference on Inclusive Educations, school district SEACs, Denver Interagency Transition Team, Courage to Risk, CICC and the **Legal Conference sponsored by CDE.**

- **Presentations at both PEP conferences centered on the topic of Parent Leadership.** We consider PEP to be one of the finest places to interact with parents who are seeking support and we value this conference as an important means for parents to learn much information in a short amount of time. **We follow up with PEP participants who have asked to "stay connected" by sending them a P2P welcome packet and an invitation to the P2P listserv. They are also added to our P2P database and thus receive the P2P newsletter.**
- Our participation in the National P2P Director's listserv continues to keep us informed of what is happening in the larger parent to parent community.

### Constructive Group Action

- *P2P-Policy Listserv* – **The policy listserv has 258 members** with an average of 43 posts per month. The P2P-Policy listserv is more active during the legislative session, however with the changes in the health care system this year, the activity level increased this year.
- *Public Policy* – The climate in our state has changed as resources become less available. There has been a movement in the DD world for less transparency and fewer partnerships. This has caused misunderstandings and flailing by parents as they patch together opportunities for their children in light of shrinking resources. We continue to offer factual information and creative ideas for parents to use. P2P kept abreast of the restructuring of the DD waivers and Colorado Fiscal Policy and reported to our members.

This year we initiated the 'Red Notebook' opportunity postings, an invitation to our members to bring their Red Notebooks with their son or daughter's picture on it to identify us as parents when attending meetings, especially at the capitol.

P2P relies on our veteran policy makers for their contribution in keeping up with and understanding the issues brought before the legislature and on various committees. Specifically this year members have been attending the Conflict of Interest Committee meetings and reporting back to the group at large. Renee Walbert also testified for the Michael Skolnik Medical Transparency Act.

- Additionally, we collaborate with Colorado Cross Disability Coalition and the ARC of Colorado as well as local Arcs and pass on their policy alerts to both of our listservs to inform our members of policy issues that affect our children.
- Parent to Parent participated in the Developmental Disabilities Summit in August 2009. Constituents from policy, advocacy, service providers, CCBs, mental health disability specific organizations, etc. gathered for this huge undertaking. Out of the Summit different committees were formed. Dianne participated in the Core Values committee which concluded its task in February. Next steps for Summit participants are being formulated.

### Summary

The National Quality Caregiving Coalition recently reported that caregivers are 14% more likely to rank their quality of life as fair or poor. And 30% do not know where they would turn to for information on short and long-term care. In David Braddock's 2005 State of the State study, it was found that 61% of persons with intellectual disabilities receive care from family members. Taken together, those statistics would cause one to sit up and think, "What could we offer to help the caregivers?"

P2P offers the following:

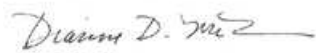
- Connects families to other families through database
- Provides resources and information to parents on many levels
- Reinforces parents' rights and ability to make decisions for their sons and daughters
- Helps parents to acknowledge their own ability to contribute to the well-being of their child from infancy through adulthood
- Organizes neighborhood support groups to bring parents together to create solutions for their own communities
- Provides listserv for parents to connect and share information via the Internet

- Supports opportunities for participation of individuals with special health care needs or disabilities in community activities and organizations
- Works to build inclusive schools and communities
- Promotes opportunities for information sharing
- Enhances meaningful participation in developing public policy that affects families' daily lives
- Presents opportunities to influence schools, organizations and communities to be more responsive to individual and family requests
- Works to add to the knowledge and sensitivity of people who serve families
- Furnishes legislative action alerts

Every year Parent to Parent of Colorado meets these outcomes with excellence and integrity.

**The work that we do alleviates some of the parent-as-caregiver stresses felt by our members. Whether parents ask for information on school issues, medical issues, behavior issues or just plain old day-to-day issues that families must deal with, Parent to Parent is available with resources and support with the goal of helping parents create a world that accepts our children with compassion, understanding and respect.**

Respectfully submitted,



Dianne McNamara  
Parent to Parent of Colorado  
Lead Project Coordinator

\*It is noted that the word "parent" is used throughout this document, but the reality is that we have parent members who are grandparents, foster parents and siblings. We wish to acknowledge this fact.