



THE WISCONSIN CONNECTION

The Newsletter of the Prader-Willi Syndrome Association of Wisconsin, Inc.

Mission: The mission of the Prader-Willi Syndrome Association of Wisconsin, Inc. is to Educate, Advocate and Support persons with Prader-Willi Syndrome, their families and professionals in meeting the challenges of this disability.

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Mike Larson

Vice President:

Jenny Lucas

Secretary:

Pat LaBella

Treasurer:

Tom Scheidegger

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Barb Dorn

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Wisconsin Moving Ahead on Participant-Directed Support Plans

Reprinted: Community Services Reporter February, 1998

Dane County, one of Wisconsin's Robert Wood Johnson Self-Determination project sites, has developed a plan to act as a partner with persons receiving specialized supports in determining how to best use the funding allocated on their behalf. The plan has recently been submitted for public review.

The goal is to change the organizing principle for managing public developmental disabilities dollars from a series of contracts between government and provider agencies to a process in which each individual creates a plan to obtain the support they require within an individualized budget keyed to his or her own needs. The new structure will allow the county to offer participant-directed supports to all adults who enter the service system or receive additional needed support during 1998, and to begin work on transitioning individuals now receiving community or institutional services to a person-centered, individually-budgeted approach.

Expected Outcomes. This fundamental change in how Dane county organizes and pays for developmental services and supports will have a significant impact on: (a) personalizing supports; (b) strengthening

& creating relationships; (c) possibly saving money; (d) reallocating funding over time towards people on the waiting list for services; (e) reinforcing the county's intent to be partners in supporting choice; (f) reinforcing the county's commitment to community services; and (g) sending the message that the county values individual capacities.

System Structure. Each person entering the Dane County service system will be assigned an individual rate-range based upon his or her need for support within a calendar year. The county will pilot the following approach and expects to learn from it and adapt it on an ongoing basis. For each individual, a base amount will be established and dollars will be added or subtracted in accordance with individual need and circumstances. This individual rate will be comprised of the following four components that will be combined to provide an "expected rate" (the cost of support the county would expect to spend on a given individual):

* **The 24 hour support need**, which will establish the direct support required by an individual, taking into account the hours that the person can function independently.

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Notes from the President

By Mike Larson

Well, it's time to gear up for the PWSA(USA) National conference. This year the conference is in Columbus, OH. It always surprises me how many representatives attend the national conference from WI. This year promises to be another great lineup of speakers and activities. Thanks to the Ohio chapter for their willingness to take on this challenge. I recently learned that the 2001 International Prader-Willi Syndrome Organization (IPWSO) conference will be in the U.S., possibly as close as MN. This is not finalized yet but this would be a tremendous opportunity for WI people to attend and be able to make contacts with others around the country and from all over the world. I get email from many people around the world dealing with PWS and it always amazes me how small the world really is. I get to see that another person on the other side of the world has many of the exact same problems and concerns about their son or daughter that I have about my son Alex. It also shows that there are many more people that need to be educated about PWS. Like in today's business world, it now needs to be a global effort. And that's why the IPWSO can be of great importance.

Father's Day is coming up quickly. Since becoming a father myself I have found this to be the best holiday of the year. If being a father is not tough enough, I think the father of a child with PWS has a special challenges. Along with the typical family stresses, the father of someone with PWS also needs to have "extras"...An extra dose of support for his spouse and Mother of his children, an extra dose of support for the non-typical situations of his child with PW and the extra dose of fatherhood that is needed for the other children in the family. So this Father's Day give all Father's the love and appreciation they deserve for their role as the foundation of the family. For me this is one of the greatest responsibilities I have ever had but one of the most rewarding.

Earl Weaver, longtime manager of the Baltimore Orioles and member of the Baseball Hall of fame, once said: "Until you're the person that other people fall back on, until you're the one that's leaned on, not the person doing the leaning, you're not an adult. You reach an age when suddenly you realize you have to be that person. It could be elderly parents, children...anything. But one day you realize, 'It's me. I've got to be the rock.'"

Mostly, being a good dad is about being the rock.

Mike ☺

A Big Thank You to Everyone At ODTC

On behalf of the entire organization, we would like to thank the staff and residents of ODTC for putting on a spectacular dance. Not only were we entertained by a disc jockey, but we also enjoyed games and face painting. Many people had a great time dressing for the tropical theme. Grass skirts and flowered shirts were found everywhere. For those who were unable to attend – you missed a great time. Once again, thanks ODTC for all your hard work and decorations. We also want to acknowledge the Wisconsin State Journal – Empty Stocking Club Grant for helping us make this event possible.



Happy 6th Birthday PWSA of WI, Inc.

As of June 25, 1998, PWSA of WI, Inc will be celebrating its 6th birthday. Boy have we come a long way!. Barb Dorn who houses the "office" in her home is having a hard time keeping up with the many requests for information as well as providing support and on-site training. "The phone rings an average of 5 times a day now. It used to be 5 times a month" she reports. And with the phone calls usually comes requests to either advocate or educate for the person or family with PWS. Written responses and meetings are also frequently needed for follow up. Schools, residential agencies, vocational agencies as well as parents are looking for the answers in understanding how to best support and help the person who has this disability.

"Many professionals are surprised to hear they can FAX me information or reach me on our email. They are also surprised at times when a child answers the phone too". Running the office has become a real family affair.

Barb (and Don) run the office out of their home and have done so now for 6 years. "You name it; we do it. Our office attempts to support people with PWS in any way that needs to be done. I attend school meetings; meet &/or talk with Directors of Developmental Disability Services from numerous counties trying to secure the most appropriate

services for the person with PWS. I talk to physicians and make forward progress in coordinating and securing funding so we can continue with quality trainings. There is never a dull moment.

Once again – **HAPPY BIRTHDAY!!**

PWSA of WI, Inc now has its own email address:
pwsawi@itis.com



LOOKING FOR VOLUNTEERS

You've heard it from the President; you've heard it from Oprah; and you have even heard it on Nickelodeon. What is it? Get out and volunteer!!!! Our organization is without exception – we need your help too. There are lots of opportunities to get involved – a little bit or a bit more. We especially need volunteers to fill our officer vacancies that will be coming up this fall. Please review their descriptions and estimated time commitments and consider trying it out. We all realize how precious time is these days but the more people we can get to help – the less time any one person has to invest. Please share your talents and your time. We really need your help to keep our organization up and going.

1998-2000 PWSA OF WI OFFICERS NEEDED

President - Principal officer of the organization & presides at meetings of organization's membership. Communicates such matters and makes suggestions to promote welfare & increase usefulness of organization. Serves on Chapter President's Advisory Board of PWSA (USA) which meets 1 time per year.

Time Commitment: Varies. Coordinates and chairs 2 officer/board of director meetings per year & 1-2 parent meetings.* Participates in 2 social activities and 1-2 large trainings per year. (*This is a shared expectation of all officers)

Vice-President- Acts as backup to president in case of absence or illness. Performs duties as assigned by

president.

Time Commitment: Varies. Attends 2 officer/board of director meetings per year & 1-2 parent meetings.* Participates in 2 social activities and 1-2 large trainings per year. (*This is a shared expectation of all officers)

Secretary- Has responsibility to give notices; keep record of proceedings; to attest documents and perform other such duties.

Time Commitment: Varies. Attends and takes minutes at 2 officer/board of director meetings per year & 1-2 parent meetings.* Participates in 2 social activities and 1-2 large trainings per year. (*This is a shared expectation of all officers)

Treasurer- Responsible for the financial integrity of organization. Keeps records of all moneys received and expended. Establishes controls and checks for financial transactions. Reports financial status to PWSA(USA). Prepares annual budget and financial statement.

Time Commitment: Approximately 1 hour per week of recording and banking activities. Attends 2 officer/board of director meetings per year & 1-2 parent meetings.* Participates in 2 social activities and 1-2 large trainings per year. (*This is a shared expectation of all officers)

If you are interested in volunteering or know someone who might be able to help us out, CONTACT BARB DORN AT PWSA OF WI, INC. OFFICE. (608)-845-9597 OR EMAIL AT pwsawi@it is.com

PLEASE – WE NEED YOUR HELP!!!!!!!!!!!!!!

Other Volunteer Opportunities

We also need your help at any of the following events. Remember, sharing your time makes things so much easier for others.

September 17th Training (Held at Ramada Inn-I-90, Madison)

Help at registration table 7:30 am – 9:00 am.

Looking for 2 people to help at registration table 9:00 am 10:00 am 1 person to cover late arrivals.

Help at table for sale of books & other resources. 1 person 10-10:15 am & 1 person 12:30 – 1:00 pm.

****CONTACT BARB DORN IF YOU CAN HELP.**

November 7th Parent Training (Held at RFDF
Community Living in Madison)

Help at registration table 9:30 – 10:00 am. Looking for 2 people.

Childcare volunteers. Looking for 3 people to work 9:30 – 12:00 and 3 people to work 1:00 – 3:00 pm. Will have activities and snacks provided.

****CONTACT BARB DORN IF YOU CAN HELP.**

NEWSLETTER EDITOR: We are looking for someone to help us with the layout and mailing of our newsletter. Officers help with article contribution. Labels for mailing are provided. Will assist and train.

CONTACT BARB DORN (608)-845-9597 OR
MIKE LARSON (920)-749-1174 IF INTERESTED

FUNDRAISING CHAIR PERSON: We are looking for someone to help us with planning ideas to help us raise funds for our organization. Any ideas open for consideration.

CONTACT BARB DORN (608)-845-9597 OR
MIKE LARSON (920)-749-1174 IF INTERESTED

Happy Fathers Day-June 21

A Letter to Dad

There are many things I'd like
To tell you, face to face,
I either lack the words or fail
To find the time and place.
But in this special letter, Dad,
You'll find, at least in part,
The feelings that the passing years
Have left within my heart.
The memories of childhood days
And all that you have done,
To make our home a happy place
And growing up such fun!
I still recall the walks we took,
The games we often played;
Those confidential chats we had
While resting in the shade/
You make my world a better place,
And through the coming years;
I'll keep these memories of you
As cherished souvenirs.

Author Unknown

Moving (Continued from page 1)

The Support Broker allocation will be based on current use of case management time for individuals that require a given level of support. It is anticipated that the time allocation for support brokers will be similar to that of case managers. Support brokers will be independent of the agency providing direct services and will work with brokerage firms (see below);

* **Housing** which will be determined by using available information for typical rental units and will be calculated by geographic locations. The base assumes that two individuals with disabilities will live together; and

* **Personal living funds** will be established using federal/state guidelines for a household of two to determine the base amount including utilities, food, clothing, transportation and discretionary funds. Once the base is established, additions might include co-payments for medical assistance, specialized transportation, special dietary needs, custom fit/made clothing, etc. Subtractions would include earned income, trust earnings, or other funds readily available for the person's use.

Developing Personal Support Plans and Individual Budgets. Within the rate provided, every participant will develop a person support plan, which will include:

- How the individual wants to live (where, what type and amount of support is required, how they spend their time);
- Elements of an individual's life which are "non-negotiable";
- Who will provide support;
- Budget describing which goods, services and supports will be purchased;
- The "outcomes" the individual expects from service providers
- Identification of and response to health care needs; and
- Identification of existing and potential risk factors.

The Money Flow. According to the plan, the most cost-efficient way to manage the flow of money will

be through the creation of Support Brokerage Firms. These agencies will be responsible for: (a) "housing" support brokers; (b) paying the bills of service providers; and (c) contracting with professional employment agencies to act as the employer of record in handling taxes, worker's compensation, and other benefits for individuals who provide support to a participant outside of a provider agency.

Quality Assurance. The plan includes a multifaceted approach to assuring that people living in the county's communities feel safe and secure. The main elements of the approach include:

- assurance that each individual has people in their life who care about them;
- individual support plans reflect persons non-negotiable and health & safety needs;
- procedures to report incidents of abuse and neglect
- an active support broker for each individual
- a resource committee to review, analyze and provide feedback on identified problems;
- a report card on providers;
- a strong self-advocacy presence;
- mentors who have experience and can offer support; satisfaction surveys and focus groups; and periodic system-wide performance review.

Target Population. During 1998, Dane County plans to phase-in participant-directed services for at least the following groups of individuals: (a) all adults who enter the system upon graduation from high school; (b) all adults who receive additional services as a result of participating in a waiver program; (c) all adults who return to local communities from institutions; and (d) any other adults who receive services for the first time.

- **Timelines and Goals.** By July 1, 1998, the county hopes to have:
 - developed at least 2 support brokerage firms;
 - established a pilot structure for setting individual rates;
 - established a revised and expanded system for assuring safety and promoting quality;
 - created a working relationship with one or more

- professional employment agencies
- established the funding and payment mechanisms to pay for services and supports provided through individual budgets;
- established the minimum criteria for an individual support plan;
- established a process for education and training of support facilitators; and
- convened a work group on family and children's participant-directed services.

For more information: Contact Dennis Harkins, Dane County Dept of Human Services, 1202 North Port Dr. 3rd Floor, Madison, WI 53740; (608)-274-6014.

COMMENTS FROM BARB DORN, EXECUTIVE DIRECTOR PWSA OF WI., INC.

"Not only is Dane County looking at this service model, but so are Winnebago and LaCrosse Counties.

Each county however has its own version of how they will administer it. You may hear it called "Participant-Directed Service" or "self-determination". They are both the same. I advise parents of all children to learn more about this model especially parents of adults who live in these counties.

We do have a 16-page handout that describes the Dane County proposed plan in more detail. You can contact our office to obtain one."

1998 PWSA of WI, Inc. MEMBERSHIPS

The following individuals are members of the PWSA of WI., Inc. We post this list as a thank you for all of you who have shown support to our organization. A membership is one way to say you support the person who has PWS in your life as well as an investment in their future. Through our organization we strive to **SUPPORT, ADVOCATE AND EDUCATE** on behalf of those who were born with this disability as well as those who are a part of their lives. It is never too late to become a member.

Lorraine Ablor
 Scott & Janice Adams
AGAPE OF APPLETON INC
 Susan Allison
 Laverne Becker
 Lorraine Beirl
 Robert & Kathleen Bomber
 Kevin & Anne Bresnahan
 Jon Cardarella
 CHILDREN'S HOSPITAL OF WI
 GENETICS CENTER
CHURCHILL HOME
 COMP SYSTEMS – NEW HAMPTON GROUP
 HOME
 CREATIVE COMMUNITY LIVING SUPPORT (CCLS)
 COMMUNITY TIES PROGRAM
KAREN CZEBOTAR
 DANE CTY HUMAN SERVICES/ADULT COMM.
 SERVICES
 Lisa Danelski
 Carol Dern
 William & Gloria Doherty
 Don & Barb Dorn
 James & Judy Dorn
 DREAMWEAVERS, INC
 Mr. & Mrs. Orville Endres
 FAMILY SUPPORT & RESOURCE CNTR – MADISON
 Miriam Farley
 Lori Fay
 Robert & Teresa Fischer
Robert & Jane Fritsche
 Gary Girdaukas
Louise Guido
 Chris Gursky
 Tom & Agnes Hughes
 HUMBOLT WORKSHOP INC
 BRUCE JENSEN
Tom & Bonnie Jones
 Yvonne Jones
 Madonna Kieffer
 Bonnie & John Kraft
 Richard & Victoria Kral
 Katie Kranjac
 John & Pat LaBella
Sarah & John Larkin

Mike and Mary Lynn Larson
 Lee & Shirley Larson
 LAURA BAKER SERVICES ASSOC
Kristin Lay
 John & Cathie Lehman
 Mike & Luci Liebe
 Rose Lopez
Arlan & Dorothy Lothe
 Robin & Jenny Lucas
Cindy Ludtke
 Helen Lynch
 DIANE LYTTON, PhD
Peter & Jane Majcherek
 Jan Marcou
Linda Martin
 Cindy Mattison
 Donald Morgan
 Robert & Pat Nelson
 Marshall & Sylvia Nickelson
 ODC - MARK HOHENWALD
ODTC - LIZABETH MOSER
ODTC - JACKIE STONER
 Cindy Organ
 OUTAGAMIE COUNTY – DD UNIT
PARAGON INDUSTRIES, INC
 Karen & James Plosczynski
 Sue Polasik
 RESPONSIVE EMPLOYMENT SERVICES
 RFDF COMMUNITY LIVING
 Nick & Wanda Scheidegger
 Tom & Judy Scheidegger
 Hazel Schuster
 Laura Ellen Schutz
 Raymond and Yvonne Seeley
 Mr. & Mrs. Duane Spice
 Richard Stark
 William Stege
 Russell Stuczynski
 Beatrice Sturm
 Rosalie Tillmann
 MARC WILLIAMS
 Gladys & Tom Yuenkel
 Gary Ziegelbauer

Coming Soon....

PWSA of WI Summer Picnic

When: August 22, 1997

Where: Appleton, WI

NO COST!!**EVERYONE IS WELCOME!!****Details will be coming soon**

Boosting Your Kids' Self-Esteem

The following statements are proven boosters to kids' self-esteem. Keep a copy of this list where you can read it every day.

I listening to my kids and acknowledge their feelings.

- ◆ I am clear and consistent about discipline. I use "I" statements to express my thoughts and feelings and I avoid "you" statements that blame, shame, label or ridicule my kids.

I use the same good manners with my kids that I would with an adult. This means saying "please" and "thank you."

- ◆ My behavior with my kids leaves no doubt in their minds that they are loved.

I trust my kids and I always keep my promises, so my kids will trust me too. I don't make promises I can't keep.

- ◆ I am quick to compliment my kids.
- ◆ I am teaching my kids right from wrong.

I help my kids set their own goals.

I understand that both my kids and I make mistakes. I am not afraid to say "I'm sorry" when the mistake is mine.

I encourage my kids to be independent, but I make sure I'm available if they need me.

I am teaching my kids valuable lessons, such as problem solving, communications, sharing and respect for themselves and others.

I honor each of my kids' unique abilities and personalities, allowing them to be different.

I encourage my kids to pursue what they're good at, not what I wish they were good at.

I refrain from comparing my kids to someone else, even to a sibling.

I take care of myself so I have plenty of energy for my kids.

MARK YOUR CALANDER

The next Meeting of the PWSA of WI.

November 7, 1997
Parents Training Day

This will be a special day designed for parents of individuals with PWS.

Place: RFDF Community Living
2875 Fish Hatchery Rd
Madison, WI 53713
608-274-4353

Date: Saturday November 7, 1998
Time: 9:30 am- 3:00 p.m.

Cost: Free to members / \$15 to nonmembers but will include 1 yr membership
Registration deadline: Friday October 23, 1998

Come, Learn and Share. Everyone is welcome!

Prader-Willi Syndrome Association of WI, Inc.
305 Amanda Way
Verona, WI 53593