

1111 Cornwall Ave. #205
Bellingham, WA 98225
360-715-0170
1-866-284-8444 (toll free)
360-715-8522 fax
email: parentcoaltn@nas.com
www.arcwhatcom.org
Issue No. 05-03



May 2003

16 Friday—Bellingham

Spring Sibshop—ages 7-13,
Ceramic Painting. Call 360-255-6402

19 Monday- Bellingham

Parent to Parent Support meeting 7:00
WCEL, 2001 H St, call 360-255-6402

21 Wednesday - Bellingham

PACT Training. 9am - 3pm St. Luke's
Community Health Education Center. Call
360-715-0170

30 Friday—Bellingham

Alstrom Syndrome Benefit Gala, B'ham
Ferry Terminal 7-11pm. Call 715-1889

June 2003

2 Monday - Bellingham

The Arc Board of Directors meeting. 4 - 6
pm. 360-715-0170.

3 Tuesday - Bellingham

Whatcom ICC Council At Large meeting.
12:00-1:30. Brigid Collins Family Center.
Call 360-715-0170.

9 Monday - Bellingham

Whatcom County DD Advisory Board
meeting. 4:30 - 6 pm. 1000 N. Forest
St. 360-676-6829.

10 Tuesday - Seattle

Self Advocates in Leadership (SAIL).
1 - 4 pm. Hilton SeaTac 360-715-0170

14 Saturday-Anacortes

Father's Day Weekend Picnic!

Call: Mike Etzell at 360-679-7350 or
Washington State Father's Network at
425-747-4004 ext. 218

16 Monday-Bellingham

Parent to Parent Support meeting 7:00
Preschool Sibshop

July 2003

8 Tuesday - Seattle

Self Advocates in Leadership (SAIL). 1 -
4 pm. Hilton SeaTac 360-715-0170

12 Saturday-Bellingham

Parent to Parent Family Picnic Call 360-
255-6402

14 Monday - Bellingham

Whatcom County DD Advisory Board
meeting. 4:30 - 6 pm. 1000 N. Forest
St. 360-676-6829.

21 Monday-Bellingham

Parent to Parent Support Meeting. 7:00
pm. WCEL, 2001 H St.,

Reminder - The Arc Board will *not* meet
in July.



Washington State Fathers Network Statewide Conference

Here is a chance to attend a great day of learning and training! The Steering Committee of the Washington State Fathers Network (WSFN) encourages you to attend the June 7th conference and offers the following Top Ten Reasons:

10. The food is great and the amount is virtually unlimited.
9. The Capitol Hill area of Seattle is a hoot, with surprises every hour.
8. The price can't be beat; just \$45 gets you breakfast and a great lunch plus superb workshops and a keynote address, and tons of printed resources to help your child.
7. Full and partial scholarships are available; we can help with transportation and also provide limited childcare. We can find you no-cost housing if needed. Thus, there should be no excuses about cost.
6. The 16 workshops cover a broad range of topics vital to families raising children with special needs, whether your child is 16 months or 16 years.
5. Our outstanding afternoon presenter is Norman Kunc. Norman believes that people with developmental disabilities reflect the diversity of the "human community" and that we need to focus on each person's unique gifts.
4. The camaraderie among men is tremendous. You might not know any one when you arrive, but we guarantee that will not be the case when you leave. You will have countless chances to network and make friends.
3. The laughter is contagious; there are few places where humor is so abundant, and so needed.
2. We need your support. The WSFN has grown tremendously in the past few years. Your attending will be proof that this program has value to you and your family.
1. **The number one reason to attend is to learn from other men. If you've attended before, come again knowing other men will learn from your experiences.**

Contact: Washington State Fathers Network (425)-747-4004 ext. 4286
<http://www.fathersnetwork.org>

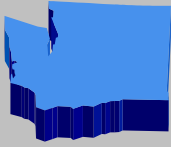


Mike Etzell and team at 2002 event

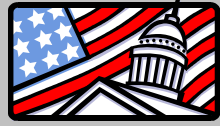
Dads: Everyone welcome!

Everyone is invited to the 20th annual Father's Day Weekend picnic June 14th!! Come for the day or camp for the weekend. The picnic will be at the group camping area of Washington State Park, in Anacortes. Grills and charcoal will be provided, simply

bring what you want to eat and a dessert to share. Sponsored by WSFN and hosted by Ed Green and a few other Anacortes dads. For more information about camping and the picnic contact Mike Etzell at 360-679-7350 or WSFN at 425-747-4004 ext. 218
Hope to see you there!



**The Latest in Washington D.C. and
Washington State - Toll Free Legislative Hotline:
1-800-562-6000**



DESPERATE TIMES — DESPERATE MEASURES

Guest Editorial: Tracy Vandewall, Director & Jack Kingery, Board President, Pierce County Parent Coalition for Developmental Disabilities

As we work together to develop more opportunities for our loved ones it is important we are mindful of the past, present and future. By investing in our understanding of the circumstances that have impacted the lives of people with developmental disabilities we can help identify and overcome challenges and barriers that will allow all citizens to be valued members of our society. We have a responsibility to be informed on issues of importance to others affected. As an example: one of our greatest achievements over the last three decades has been our willingness to challenge the way we view institutional care. By doing so we have seen significant positive differences in the lives of our loved ones and their families. With that said, there are some challenges that remain that like families do not believe can be met outside of a 24 hour care environment offered by our state RHC's. For those families there is more work to be done to insure the health and safety of those we serve. Within our interests I would hope that we are always willing to affirm the fears of others whose circumstance and beliefs may be different from our own without denying their preference and need as they perceive it.

The legislature is considering closing Fircrest School, a Residential Habilitation Center (RHC) for those with significant developmental disabilities in Shoreline (ESB5971). It is incumbent upon them to take into account the many consequences of such an action before making a decision and setting a devastating precedent for all concerned.

Lawmakers have failed to provide a choice from the spectrum of options needed and adequate funding as promised in 1997 and residents of Fircrest are now being expected to pay the price for their (lawmakers) negligence in dealing with the issues in a thoughtful planned way. We acknowledge the potential for consolidation and/or closure of an existing RHC if the market no longer supported their existence, which has yet to be determined. In our state reduced populations are the result of the illegal practice of denying access to those eligible and in need by DSHS for over a decade (Federal CMS audit finding)

Regardless of perspective, the fears of those involved are real. Fear and despair of those 262 individuals' parents and guardians who value the supports and often lifetime of services, including 108 with skilled nursing needs, they have received at Fircrest School, who would be displaced.

Fear and despair of the 9000 individuals and their families who have been waiting for years to receive the supports they need for respite, employment, and residential alternatives in their communities, that they are being told will be made available only if institutions close.

Fear and despair on the part of state staff and professionals who have provided for the residents that, in part, will be unemployed.

Fear and despair of community employment providers and those participants who are at risk of losing 1,400 prevocational placement opportunities and no new funding for our 1300 graduating students if the legislature adopts the Governor's recommended budget.

Fear on the part of interested decision-makers in the Shoreline community who believe they will benefit by the state's disposing of this very valuable property which would allow for the expansion of commercial development and further increase property tax revenue the city needs.

Our allegiance is to the people and families affected by such a proposal and maintaining the long-term benefit of the fiscal and human resources we have invested in on their behalf. The Pierce County Parent Coalition for Developmental Disabilities' mission includes our commitment to value the perspective of all of our members regardless of where they reside. Our efforts have included the privilege over the years of working with all of the various organizations concerned including those with national agendas that promote either the elimination or promotion of institutional care throughout the United States. (PC)2 leadership remains committed to individual family choices and beliefs first, rather than organization agendas, when determining how to best meet the needs of our loved ones, including the personal choices available those who would prefer non-institutional environments.

Although \$30+ million is a large sum and a trust is essential, it represents only 2-3% of our current DDD budget, against \$500 million dollars worth of unmet need of the 9,000 who are waiting. With the costs of such a closure now being recognized it is questionable if there would be any savings in the first biennium. The sale of Fircrest cannot possibly be represented as sufficient to meet this need. In our current crisis-driven system, every dollar of projected saving is being re-spent by one group in need at the expense of another, while commitments to provide adequate funds are non-existent without increased revenues or different legislative priorities. The current land value will not decline if a more thoughtful approach is presented next year.

Be they residents of Fircrest or the thousands waiting who are equally as deserving of help, to rob one in haste to serve another is a dangerous precedent today and in the future. We expect Pierce County legislators will offer a more responsible approach to meeting the needs of individuals with developmental disabilities in Washington State.

State Legislative Update

It's not over, folks. The legislature failed to complete its business by the close of regular session, and Governor Locke has called for special session to begin May 12th. In the meantime, budget conferees will be sorting through the sticking points between the House and Senate proposals and arrive at a budget that the legislature can pass when it returns in May.



Guidelines for Writing or Reporting about People with Disabilities

As we communicate we have the opportunity to shape the public image of people with disabilities. The terms we use and the way that we portray people with disabilities will either create a straightforward positive view of people with disabilities or a negative portrayal that reinforces unfair stereotypes. To help you to make better choices in terms of language and portrayal the Publications, Research and Training Center on Independent Living from the University of Kansas offers the following **Guidelines**:

- When determining the appropriate terminology to use, **put people first**. Instead of saying blind man, say man who is blind. Instead of saying autistic girl, say girl who has autism. This puts a focus on the individual, not the particular functional limitation.
- Do not focus on the disability** unless it is crucial to a story. Avoid tear-jerking human interest stories about incurable diseases, congenital impairments, or severe injury. Focus instead on issues that affect the quality of life for those same individuals, such as accessible transportation, housing, affordable health care, employment opportunities, and discrimination.
- Do not use generic labels** for disability groups, such as "the retarded," "the deaf." Emphasize people, not labels. Say people with mental retardation or people who are deaf.
- Emphasize abilities**, not limitations. For example: uses a wheelchair/braces, walks with crutches, rather than confined to a wheelchair, wheelchair-bound, differently-abled, birth difference, or crippled. Similarly, do not use emotional descriptors such as unfortunate, pitiful, and so forth.

For many more helpful tips and to see the entire publication of the guidelines you can find it on the web at <http://www.lsi.ku.edu/lsi/internal/guidelines.html> or call (785)864-4095.

The Dignity of Risk



- What if you never got to make a mistake?
 - What if your money was always kept in an envelope where you couldn't get it?
 - What if you were never given a chance to do well at something?
 - What if your only chance to be with people different from you was with your own family?
 - What if the job you did was not useful?
 - What if you never got to make a decision?
 - What if the only risky thing you could do was act out?
 - What if you couldn't go outside because the last time you went it rained?
 - What if you took the wrong bus once and now you can't take another?
 - What if you got into trouble and were sent away and you couldn't come back because they always remember your trouble?
 - What if you worked and got paid \$.46 an hour?
 - What if you had to wear your winter coat when it rained because it was all that you had?
 - What if you had no privacy?
 - What if you could do part of the grocery shopping but weren't allowed because you couldn't do all of the shopping?
 - What if you spent three hours every day just waiting?
 - What if you grew old and never knew adulthood?
 - What if you never got a chance?
- From Linda Stengle's book *Laying Community Foundations for Your Child with a Disability*.

DOWN SYNDROME OUTREACH E-MAIL LIST

Down syndrome Outreach is setting up an e-mail list for members of the local Down syndrome community. The e-mail list will not be moderated; however postings will be restricted to members only. The list will be used as an additional means of advertising and planning Down syndrome Outreach events. Contact: Tracey Finch, Down syndrome Outreach Coordinator at 360-650-0221 or trace@nas.com

One Volunteer's Story!

My name is Robin Childs. I am 22 years old. I graduated from Meridian High School. I volunteer at The Arc of Whatcom County. My job is to answer the phone every Friday. I work on the Newsletter. I insert, fold, use the tri-fold machine and put labels on the newsletter. I am looking for a paid position doing office work. *Robin is assisted by Kulshan Supported Employment, 360-676-9010.*

Heart and Hands & Other Volunteer Awards

On April 27 the Whatcom Volunteer Center recognized outstanding volunteers in our community. Among this years' award winners were Nancy Briegel and Rose Formichella, nominated by Dana Little, Administrative Assistant for The Arc. Dana noted that Rose and Nancy "... have become 'regulars' in our office—part of our Arc family—they have been volunteering on a regular basis since Spring of 2002. Each morning when they arrive... they are prepared to work. Rose and Nancy have been integral in turning our office into a more friendly, welcoming and organized place. They never fail to bring a smile to our office when they grace us with their presence."

We congratulate Rose and Nancy, and thank all The Arc volunteers recognized at the annual meeting May 2nd: Heather Abernathy, Sara Achey, Robin Childs, Alan Foytek, Adam Garman, Allison Hahnel, Eric Johnson, Meleah Korver, Tony La, Matthew Masters, Kim Menninga, Erica Miller, Cathrine Morgan, Tom Nelson, and Tobi Tommaney.



Ray Briegel; S. Jewell, Executive Director; Award Winner Nancy Briegel; Marguerite Ryan, Board Secretary; Award Winner Rose Formichella and Joe Formichella at the Heart & Hands Awards.

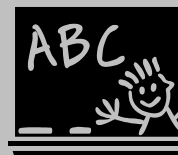
Get Involved!



HELP US TO SERVE YOU BETTER.....

The Arc of Whatcom County, with funding from United Way and the Whatcom County Developmental Disabilities Program, furnishes you with this free Parent Coalition monthly publication. Please take a moment to read and respond to the questions below so we may improve how we serve you. Respond by fax to 360-715-8522; or mail to 1111 Cornwall #205, Bellingham, WA 98225. Thank you.

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I am satisfied that the information I receive from The Arc of Whatcom County has allowed me to access and/or build on services					
Because of the information/training/advocacy support I receive from The Arc I have broadened my understanding of developmental disability issues.					
Because of The Arc I am a better advocate for myself/other with a developmental disability					
I have been able to use the information I received from The Arc to help educate myself/others about issues relating to developmental disabilities.					
The Arc helps me to better navigate services, enabling me to be more involved in my community and increase independence.					
Circle the answer that most closely fits:					
I spend this much time per month working on issues related to developmental disabilities:	>5 hours	4-5	1-3	0-1	Never
The person with a developmental disability I am concerned with is:	<0-3 yrs	3-20	21-35	35-50	>51
Where does your family member with a developmental disability live?	With parent	Adult Family Home	Their own apartment w/support	Does Not Apply	Other:
Have you ever attended Advocacy Day in Olympia?	Yes	No			
Do you respond to legislative alerts? Provide your e-mail address if you would like to be added to our e-mail legislative alert list: _____	Almost Always	Sometimes	Only when it applies to my family	Almost never	Don't Care
One thing I would like to see The Arc do more of is: _____ _____					
I would like to see more newsletter articles on these subjects (choose as many as apply): Other: _____ _____ _____	Legislative Housing Residential	Human Interest Current Events	Special Ed IEP's	Family support	Choice Self-Determination



Summer Camps!



There are dozens of camp opportunities for people of varying ages that have developmental disabilities. The following are just a few options that are available in a directory produced by Children's Resources Center and the Center for Children with Special Needs at Children's Hospital and Regional Medical Center. To find the camp that best fits your needs consult the detailed Summer Camp Directory found online at: <http://www.cshcn.org>
To receive a copy in the mail call toll free (866)987-2500, option 4



POWER SOCCER!

Power soccer is a wonderful opportunity for users of power chairs to socialize with their peers and play an exciting sport. In addition to building fine and gross motor skills, power soccer allows players to develop team spirit and teaches cooperative play. It is also a terrific chance for players and parents to network with others. Players of all ages and abilities are welcome. Contact Caroline Chamblin (360) 380-1084 chamblins@earthlink.net

Camp Fire USA, Samish Council
2217 Woburn St. Bellingham, WA 98226
(360) 733-5710 <http://www.campkirby.org>

Ages: 6-17
Siblings: yes
Cost: \$270/week
Dates: 6/29 - 8/9, 2003 (7 weekly sessions)
Serves children with: Physical disabilities, learning and developmental disabilities, behavior disorders, and other medical conditions

Camp Kirby Location: Samish Island

Camp Fire USA
8511 15th Ave NE Seattle, WA 98115
(206) 461-8550 info@campfirecpsc.org

Ages: 18 and under **Siblings:** yes
Cost: call for details
Dates: Memorial Day Weekend 2003
There are wheelchair accessible cabins
Serves children with: physical disabilities, learning and developmental disabilities, behavior disorders, and general medical conditions

Camp Sealth Location: Vashon Island

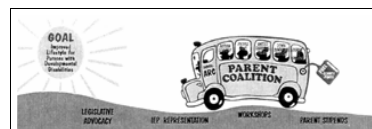
Social Security Administration Plans to Update Rules

The Social Security Administration (SSA) is planning to update and revise the rules it uses to evaluate "mental disorders," including mental retardation, in both adults and children who apply for Social Security disability benefits or Supplemental Security Income (SSI) payments based on disability.

SSA's "Listing of Impairments" specifies the detailed criteria, bodily system by bodily system, that SSA uses in determining whether an applicant meets the statutory eligibility criteria to receive SSI or SSDI disability benefits. Even relatively minor changes in SSA's criteria for qualifying for SSI or SSDI benefits on the basis of mental retardation can affect whether thousands of children or adults nationwide are determined eligible to receive federal income maintenance payments.

The loss of SSI eligibility means that groups of individuals may lose categorical eligibility for Medicaid benefits, meaning, for example, that states can no longer claim federal funding on their behalf if they are enrolled in a waiver program or ICF/MR services. Before drafting any revisions, SSA is asking interested people and organizations to send them comments and suggestions for revising the rules they use to evaluate mental disorders. SSA is also interested in any ideas you have about how to improve their programs for people who have mental disorders, especially those who would like to work full-time or part-time with supports.

The Social Security Administration will accept your comments online at <http://policy.ssa.gov/pnpublic.nsf/LawsRegs>, by e-mail to regulations@ssa.gov; by fax to (410) 966-2830; or by letter to the Commissioner of Social Security, PO Box 17703, Baltimore, MD 21235-7703 **no later than June 16, 2003.**



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1-866-284-8444 (toll free)
email parentcoaltn@nas.com or arc2@nas.com.

Newsletter Production Staff:
Harshpreet Walia, Robin Childs,
Rose Formichella, Nancy Briegel,
Tobhiyah Tommaney,
Cathrine Morgan

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The Arc of Whatcom County Board of Directors
Steve Johnson, President
Lisa Rolston, Vice President
Marguerite Ryan, Secretary
Marilyn Miller, Treasurer
Jan Carlson, Michele Hill, Kristina Hoffman, Connie Knau,
Susan Larson and Emily Kahlstrom
There are currently two vacancies.

Executive Director
Susan Jewell
Office Manager
Dana Little
OFFICE HOURS:
9 am - Noon, Monday-Friday



THE ARC OF WHATCOM COUNTY

1111 Cornwall Avenue #205
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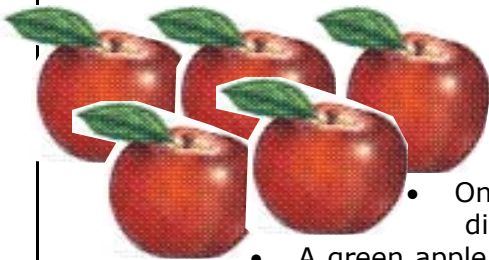


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CHOICE & SELF-DETERMINATION

People with developmental disabilities and their families want services and supports delivered by a system that allows us choice and control over our own lives.



Disability is Natural

What do apples have to do with disability?

- One of the five apples is green - one American in five is a person with a disability.
- A green apple is more like red apples than different. An individual with a disability is more like people without disabilities than different.
- Apples are natural. Having a disability is a natural condition of the human experience.
- The sun shines equally on all the apples in the bowl, and it's time for the light of inclusion, opportunity, freedom, and dignity to shine equally on all people—including people with disabilities.

In the United States today, we have an array of laws, which guarantee legal equality for people with disabilities. With all the laws and services, why do so many people with disabilities (and their family members) remain excluded from the mainstream of society, relegated to second-class citizenship? Because—contrary to popular belief—neither laws nor services can provide what people with disabilities really need: inclusion, dignity, freedom, friendships, participation in community, and many of the other ordinary, but precious, elements most people take for granted.

The greatest obstacles people with disabilities face are old attitudes and perceptions that create social and environmental barriers. And these barriers—based on long-standing myths and prejudices—keep many children and adults with disabilities socially isolated, physically segregated, and excluded from the mainstream of American society.

What will it take to ensure people with disabilities live real lives: being included, having friends, enjoying both the rights and responsibilities of citizenship, participating in and contributing to their communities, and, in general, living typical, ordinary lives?

1. A gentle rebellion against old attitudes and perceptions.
2. A new way of thinking about people with disabilities.

It's time for revolutionary common sense!

Disability is Natural!

<http://www.disabilityisnatural.com>