

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. 03-03



## March 2003

### 17 Monday - Bellingham

Parent to Parent Support Meeting. 7 pm. 2001 H Street. Whatcom Center for Early Learning. Child care provided. 360-255-6402.

### 19 Wednesday - Olympia

AdvocacyDay-Transportation-Learn about the legislative process in person. 10-3pm. Call Arc: 1-888-754-8798 ext. 105

### 26 Wednesday - Olympia

Advocacy Day-Current Issues- 10 - 3pm. Call the Arc: 1-888-754-8798 ext. 105

## April 2003

### 2 Wednesday - Olympia

Advocacy Day- Budget- 10am - 3pm. Call the Arc: 1-888-754-8798 ext. 105

### 7 Monday - Bellingham

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

### Tuesday - Seattle

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

### 9 Wednesday - Olympia

Advocacy Day-Health Care-10am - 3pm. Call the Arc: 1-888-754-8798 ext. 105

### 12 Saturday - Bellingham

Medicaid Personal Care (MPC) Parent/ Provider training. 9 - 3 pm. 1111 Cornwall Ave. #204. 360-715-0170.

### 14 Monday - Bellingham

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

### 14 Monday—Bellingham

Abusive vs Healthy Relationships for adults with developmental disabilities, family, staff & caretakers. 6:30-8:30 pm. Call Gina @ Evergreen: 671-5898

### 16 Wednesday - Olympia

Advocacy Day-Session Wrap-up-10-3pm. Call the Arc: 1-888-754-8798 ext. 105

## May 2003

### 2 Friday—Bellingham

Arc annual membership meeting/pizza party 5:30-7:00 p.m. Call 715-0170

### 5 Monday - Bellingham

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

**Note: Call 715-0170 for People First - new meeting dates!**



## Max Higbee Community Recreation Center

### Goodbye, Maureen. Welcome, Kelli!

For over ten years in Whatcom County, Maureen Call has made interesting and fun things happen for people with developmental disabilities as director of the Max Higbee Community Recreation Center. Maureen retired at the end of November, 2002. Maureen's planning skills, commitment and enthusiasm were used to help the Center's board of directors find her replacement.



Maureen Call



Kelli Wold

Kelli Wold, who grew up in Bellingham, became the new director on December 1, 2002. "I love it!" she says enthusiastically. "It's exactly what I was hoping for, and more." Kelli has ten years' experience working with youth programs (birth to age 12) at the Skagit Valley YMCA, serving as Youth and Family Director for the past two years. She's been a Special Olympics swimming coach, and has also coached an inclusive swimming program, and is a graduate of Western Washington University's Outdoor Recreation program.

Maureen knows the answer to the frequent question: who are Max and Priscilla Higbee?! Max Higbee headed the Special Education department at Western Washington University for years.

By all accounts, Max was a soft-spoken man who worked with schools and parents and the vocational workshops to increase social opportunities for individuals with developmental disabilities. He and wife Priscilla helped found the "Drop-In Center", originally on State Street. After he died in 1991, the program was renamed The Max Higbee Community Recreation Center - affectionately known as Max's Place.

Maureen has made it a practice to see the person instead of the disability label they are given. Safety and medical

issues are of course a priority, but labels are not. Building confidence is another priority. The opportunity to build constructive friendships is a boost to self-confidence. Doing things out in the community is another confidence booster. And a reliable program is important to build parent and family confidence.

"She has come to know the members so well," says former board of director's member and parent Sandy Lane, "always with understanding and caring. She has contributed so much to the program all these years."

"Maureen will be greatly missed," says current board of directors president Amanda Grove. "Her dedication and commitment to the mission of the center is

truly inspirational. She has fostered a strong sense of community amongst the members. Through hard work and integrity, Maureen has provided a valuable service to this agency and our community.

"We look forward to working with Kelli Wold," adds Amanda, 'who brings her own unique talents, skills and vision to our community."

Kelli encourages anyone who's interested in the program to stop by. "Come down and check things out," she offers. "Families are always welcome. I look forward to meeting participants, and also their parents or guardians or caregivers. Everyone's welcome." In addition to Kelli, the Center is staffed by Kip Koegel, along with volunteers Theresa Quinn, Brenna Elder-McCoy, and Megan Elder-McCoy.

During 2003, participants will be involved in a variety of activities at the center, as well as activities in the community, which included attending a concert during the holidays. An overnight camping trip is being planned, and rehearsals will soon begin for a planned production of "Snow White." Don't miss it!

Reported by J. Wilke

Max Higbee Community  
 Recreation Center  
 315 Halleck St.  
 Bellingham  
 360-733-1828

Weekend program  
 Friday & Saturdays  
 5 - 9:30 p.m.



# The Latest in Washington State Toll Free Legislative Hotline: 1-800-562-6000

Don't know who your legislator is? Go to: <http://dfind.leg.wa.gov/dfinder.cfm>

## Considering the Future of Residential Habilitation Centers (RHCs)

### What are RHCs?

RHCs are defined in state law as state operated facilities for persons with developmental disabilities. Current RCW specifies five RHCs: Fircrest School, Rainier School, Lakeland Village, Yakima Valley School, and Frances Haddon Morgan Children's Center.

### How Big are the 5 RHCs?

Name	Location	Total Beds	Residents
Fircrest School	Shoreline	279	271
Rainier School	Buckley	399	394
Lakeland Village	Medical Lake	259	251
Yakima Valley School	Selah	120	111
Frances Haddon Morgan Center	Bremerton	56	55
Total		1113	1,082

### How old are residents? RHC residents are aging:

Average Age: Fircrest - 47 , Lakeland - 47 , YVS - 38 , FHMC - 30

### RHC Residents have Different Levels of Family Contact:

Weekly	86	8%
Monthly	209	20%
Quarterly	280	26%
Yearly	307	29%
Never	181	17%
Total	1,063	100%

### Resident Families Live at Different Distances from the RHC:

25 Miles	347	33%
50 Miles	242	23%
100 Miles	158	15%
Distant	219	21%
Very Distant	96	9%
Total	1062	100%

### Institutional Rate is Now 1/6th the Rate of 1970:

DD Institutional Population - 1970: 4000 , 2003: 1080  
State Population - 1970: 3,413,250; 2003: 6,041,700

### Why is RHC Population in Decline?

Preference for Community Living, mainstreaming education system, development of supports for families, and increasing RHC costs.

### How does Washington's RCH population Compare with other States?

In 2002, 17 out of every 100,000 U.S. residents live in public institutions for persons with developmental disabilities. Washington's rate was 20 out of every 100,000 residents. Washington's rate declined 55% from 1977 to 2000. The U.S. rate fell 68%. If the trend continues, RHC Population will fall to 625 by 2012. In order to comply with the intent of ADA we could not provide new placements only in RHCs. Several years ago, when offered a choice, 2 people picked living in RHCs and 20 people picked living in the Community.

### RHC Cost in FY 2002:

RHC Costs about \$390 per resident day and Community Costs about \$308 per resident day.

### Why are Costs Less in Community Settings?

Cost Area	Institutions	Community
Facilities	Institutional Construction and excess facilities	Residential Construction and just what is needed
Labor costs	Higher labor costs with many specialized jobs	Lower labor costs and fewer specialized jobs
Specialized Services	May be less costly for residents who need daily MD, RN & Therapies	May be more costly if needed daily

### Conclusions:

The long-term downward trend in RHC population will continue. The legislature will eventually be faced with the decision to consolidate and close one or more RHCs. We have excess facilities for the current RHC population and increasing portion of the RHC budget is supporting those fixed costs.

### What are the Fiscal considerations if the Legislature decides Consolidation and Closure of an RHC?

The approach and speed of downsizing; the threshold of consolidation and the disposal of surplus assets.

*Senate Ways and Means Committee*

*January 30, 2003*

*Presentation by Brian Sims*

*Committee Staff*

*(related story on pages 3 & 5)*



## Group homes option for some

*Pamela Brice, Shoreline/Lake Forest Park Enterprise editor*

Michael Dahlager, 47, has cerebral palsy and communicates with the help of a computer with symbols for words that can be put together to form sentences. Lori Seitz, 38, has a pervasive developmental disorder, autism, and communicates with the help of a communication assistant; whose finger Seitz uses to point to letters on a board, spelling out her answers.

Both Dahlager and Seitz live in a community home run by SL Start in Shoreline with two other roommates and 24-hour assistance. Both say they are much happier in the community living environments than at the state institutions Fircrest and Ranier, where they lived for several years.

Both also say it's been a tough road getting to this point.

From ages 3 to 5, Dahlager received services at Fircrest in Shoreline and lived there from ages 5 to 7, coming home on weekends. He spent his teen years at Ranier School, near Buckley. While waiting for the United Cerebral Palsy center to open in Shoreline, he moved to a nursing home in Bellevue then to the center, his mother Willa Dahlager, said.

"They were so anxious to get these folks out of an institution that they didn't plan in the community, the churches were not ready and the community was not ready," she said.

Michael Dahlager's experience with one residential provider was a "nightmare" she said, declining to say more.

Thanks to the help of a case manager with social services, he was finally "freed" and has "the power of choice" now at SL Start's supported living program, Willa Dahlager said. Her son participated in selecting the home he lives in, and his roommates, through SL Start.

"Here is really better, there are less people, and I like the big house," Michael Dahlager said.

Seitz moved from home to Fircrest when she was 14 years old, her father, Jerry Seitz, said.

The decision from home to Fircrest came when her mother died, and her safety was threatened because she was taking to wandering away from her special education classes at school, into the neighborhoods, he said.

Lori Seitz lived there a couple of years, then moved to a group home for children in Kenmore. When she turned 18, she had to leave the home because she was no longer a child, and moved back to Fircrest.

"I was lost inside there," Lori Seitz said, "I lost hope for so long."

She moved to another group home and it worked out well, until the management changed. At one group home, Lori Seitz says she was raped.

"I need respect and patience and it's up to the bosses. If they don't make it happen, I am in hell, at Fircrest or at a group home," she said.

"My experience has been that the services they get depends on who runs the group home," her father said.

Lori Seitz said at other group homes and at Fircrest, she was always in trouble for her compulsive disorder. "They had rules that meant us being trained to make us 'act right,'" she said. "Imagine if you could not go to Starbucks for coffee, and instead you had people bugging you all the time to quit doing behavior you couldn't help, think how it is an insult inside. Why make you feel bad if you can't do something? Why not just help and be kind instead?"

Lori Seitz says she is much happier in her present living situation.

"I am human, and they understand me. I am a woman, an adult, I can say 'treat me right' and Debi and Sylvia make it happen."

Many of the states developmentally disabled adults live in a community homes, with assistance provided by the state. At their peak in the 1960s the institutions housed over 4,000, today there are just over 1,000 disabled residents living there.

The population decline at institutions like Fircrest was caused by a significant philosophical change in perspectives regarding services for the developmentally disabled. A 1999 U.S. Supreme Court decision requires states place persons with mental and developmental disabilities in the "least restrictive setting possible and appropriate."

Washington state contracts with service providers, mostly non-profit organizations, to provide community living programs, said Marybeth Poch, regional director of the Division of Developmental Disabilities. She recognizes that there will always be a need for institutions — they have their

place and should not be closed down altogether.

Sylvia Furstenberg, branch director of SL Start said, "The purpose of the move to community living is for them to be an integral part of the community, to have rich and healthy lives and provide them with some form of power of control over their lives.

"Some things so wonderful we take for granted that people in institutions don't have experience with, like being in a room while dinner is being cooked. At the institution, food is rolled around on a cart," she said.

But Furstenberg admits, community living programs have had difficulty with high turn-over, and service consistency over the years.

Consistency of services is of concern for lawmakers as well. There is also high staff turn-over — from 54 to 60 percent in the residential setting, according to a 2001 Department of Social and Health Services study. And because state workers at the institutions are unionized, their salaries are 45 percent higher than their counterparts in the community.

Furstenberg says funding is a key concern for the providers of residential services. "Choice is mandated in federal law, and the state is obligated to offer the opportunity to move into the community. The state legislature has to prove they are willing to commit the dollars and long-term support to people in the community," Furstenberg said.

Parents and advocates of residents living at Fircrest argue that, for those that require extensive care, the state should continue to provide it at institutions.

"In community homes these vulnerable people would be lost," said Phil Scheier, whose son lives at Fircrest. "My son wouldn't last a month in a community home, with all of his problems and special needs."

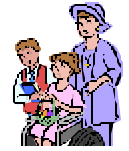
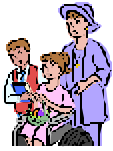
Furstenberg said she understands those concerns.

"We need to be very thoughtful and respectful of what's best for each individual. We could replicate homes for the medically fragile, but it could cost more than it does at Fircrest."

-Reprint permission granted from The Shoreline/Lake Forest Park Enterprise



# Get Involved!



## CREATING COMMUNITY - Meaningful, inclusive recreation in our community

### **Can everyone take part in meaningful, inclusive leisure time activities in our community?**

In 2002, Amanda Grove, Recreation Coordinator of Bellingham Parks and Recreation, and Jill Heckathorn, Instructor in the Recreation Program at Western Washington University, began a study, funded by the Whatcom County Developmental Disabilities Program, of barriers to meaningful and integrated leisure activities for people with developmental disabilities.

The study began with interviews conducted by trained WWU Recreation students in 17 focus groups that included over 120 people with disabilities, their families, support staff and recreation service providers, all discussing priorities and problems in being involved in community recreation. Feedback from participants was as diverse as the individuals themselves, but themes revolved around issues of transportation, program costs and information.

Information from the focus groups led to the development of three projects to increase leisure involvement and success:

The first is publication of "Creating Community: Increasing Leisure Opportunities for Persons with Developmental Disabilities." This booklet gives ideas for creating, developing and maintaining recreational programs that are fully inclusive of individuals with developmental disabilities. While intended primarily for people who develop recreation programs, the information in this booklet can be useful to any organization striving for inclusive recreational activities and supports.

A second outcome has been three classes in "Self-advocacy and Leisure" for individuals with developmental disabilities. In these sessions, individuals had the opportunity to identify activities they enjoy, list the resources available to support

their involvement, make a plan to maximize their independence, and start taking part in desired activities. The feedback from participants was very positive, and led to Bellingham Parks and Recreation's winter "Let's Go Out" 3-session program, giving participants a chance to choose a community activity, make a plan, and put the plan into action by going out together and participating in the activity.

A third outcome of this study is a self-guided "leisure audit" – ways to explore and encourage more diverse and more independent leisure activities at home.

### Excerpt from "Creating Community":

Inclusion is:

- Having the same choices and opportunities in recreation activities that other people have;
- Being a valued customer and a welcomed participant in community recreation programs, regardless of ability levels;
- Providing the necessary individual adaptations, accommodations, and supports so every person can benefit equally from a recreation experience in the community with friends;
- The belief that diversity is valuable and not just something to be tolerated or accepted;

*Focus group participants voiced the need for more information about how to sign up for programs in the community. Some ways to increase accessibility are:*

- Clearly advertise the different ways that registration is accepted;
- Make phone-in registration as easy as possible; offer to mail program and registration information;
- Provide assistance in completing forms. Provide space and time for people to complete forms at their own pace;
- Train registration staff on these accessibility issues.

*Reported by J. Wilke*

## **Washington Assistive Technology Foundation Access Fund Loans**

The Access Fund offers low-interest loans to individuals with disabilities and their families for purchases of assistive technology (AT) and home and vehicle accessibility modifications.

**What can Access Fund Loans be Used For?** Access Fund loans can be used to purchase any device that maintains or improves functional capabilities. Examples include: Hearing Aids, Closed Circuit TV's, computers with Braille or speech output, and computers with adaptive equipment. Loans also can be used to purchase related services such as AT evaluations, training, extended warranties and equipment set-up, maintenance and repair.

**Who can apply for Access Fund Loans?** Washington residents for disabilities or their families for the benefit of Washington residents with disabilities.

**How Much Can I Borrow?** \$250 to \$5000.

**What is the Interest?** 6 %

**Are there Loan Fees?** The loan fee is 1% of the amount you borrow, a minimum of \$25. We also ask you to pay for your credit check and filing fees.

**How Do I Apply for A Loan?** Contact us for an application packet via phone or e-mail.

Complete the loan application and financial information and submit it by mail, email or fax. You will need to provide an invoice or invoices detailing the AT you want to buy and copies of your most recent tax return or other verification of income.

**What Happens After I submit My Application?** Your application will be reviewed by our staff to see if it is complete and/or if we have any questions. We will request a credit report. The Board will make their decision within 30 days of receipt of a completed application.

**What Criteria will be Used to Decide if I get a Loan?** Both program eligibility and ability to repay must be established. Program eligibility is established by showing that (a) you have a disability and (b) the item you wish to purchase qualifies as "assistive technology." Ability to repay is evaluated on the basis of your income, expenses, current debt levels, availability of other resources and your credit history. No matter what your income, we will do our best to help you qualify. Loan funds can be combined with other resources so we also will try to help you identify other sources of funding.

**Where can I get an application?** Frances E. Pennell, Exec. Director  
206-826-1038 or 1-800-214-8731  
fpennel@seanet.com  
Learn more: <http://www.watf.org>

## **Bonnie Bergan Memorial Northwest Women's Hall of Fame**

Bonnie Bergan has been selected for posthumous induction to the Northwest Women's Hall of Fame. Bonnie will join an impressive group of women who have elevated the quality of life in the Northwest through their work and commitment to volunteerism, mentoring, the arts, health care, and human rights.

The celebration will be held at Northwood Hall, four-thirty in the afternoon on March 23<sup>rd</sup>.

We invite you to join us at Northwood Hall on March 23<sup>rd</sup> at 4:30 p.m. For tickets please contact: YWCA (734-4820).

The time has come to adapt a new way of thinking, one founded on the premise that the community belongs to everyone, and everyone – regardless of level and type of ability – belongs to the community.

*S. Schleien, 1993*



## Call to Action!

Send a message to preserve funding for people with developmental disabilities. Senate Bill 5971 has been proposed to consolidate state DD institutions and use proceeds from the sale of Fircrest property to establish a trust that will help meet the needs of more than 9000 children and adults with developmental disabilities.

SB 5971 avoids harmful cuts to services and continues to support the 262 residents of Fircrest in their choice of residential placement. SB 5971 takes a positive step forward for people with developmental disabilities and their families. Ask your legislator to please create a positive future for people with developmental disabilities and their families.

Contact The Arc at 715-0170 or 866-284-8444 for a blue postcard pre-printed and ready to mail this message to your legislator.

## COMPUTER GRANTS— ACT NOW!!

Grants of technology equipment for individuals and organizations are now available from the Beaumont Foundation through a class action award and they must distribute \$350 million over 5 years of Toshiba branded equipment.

There are 3 grant categories—community grants, education grants and individual grants.

There is virtually no proposal writing involved, the only documentation needed is proof that the individual is disabled. **Deadline is March 31, 2003**

Contact: [www.bmtfoundation.org/grants](http://www.bmtfoundation.org/grants)  
Beaumont Foundation of America,  
P.O. Box 209000, Austin, TX 78720-9000  
1-866-505-2667

## Reauthorization of IDEA (Individuals with Disabilities Education Act)

There is a good chance that the U.S. Congress will address the reauthorization of IDEA this session. The results of the November election will have a significant impact on the process. Senator Ted Kennedy is no longer the chair of the Education Committee. There are several pieces that we must pay attention to, the first and probably most significant, is the *No Child Left Behind* act. It is clear that this will be the filter that anything related to education will flow. There are some good things in this act, there are also some red flags. The second piece we need to know about is the President's Commission on Excellence in Special education. The recommendations in the report from this commission will be the driving factor in IDEA reauthorization.

The reports' three major recommendations were:

1. Focus on results - not on process.  
(watch out for short term goals and "benchmarks" disappearing)
2. Embrace a model of prevention not a model of failure  
(Kids with LD may not receive Spec. Ed services. Question: will funding for prevention be paid for by Spec. Ed or through regular funding?)
3. Consider children with disabilities as general education children first  
(this is a funding issue- not necessarily a Least Restrictive Environment issue)

Other recommendations we want to pay attention to are:

- Reducing the paperwork burden  
(Question: will our children be protected?)
- Simplifying the identification process  
(to 3 categories)
- Encouraging innovative approaches to parental involvement and parental choice  
(think: school vouchers)
- Support general education and special education teachers through training and better education
- Prevent disputes and improve dispute resolution  
(Are parental rights addressed?)
- Reforming special education finance and funding  
(promotes safety net funding and high risk pooling)
- Improve the impact of research findings  
(Will only "proven" methods be used? Research takes many years, will our kids have to wait?)

Further info: <http://www.reedmartin.com>, <http://www.nclb.gov>



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email [parentcoaltn@nas.com](mailto:parentcoaltn@nas.com)  
or [arc2@nas.com](mailto:arc2@nas.com).

**Newsletter Production Staff:**  
Harshpreet Walia, Sara Achey,  
Adam Garman, Kim Lynch, Matthew  
Masters, Robin Childs,  
Jennifer Wilke, Rose Formichella,  
Nancy Briegel & Eric Johnson

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Dana Little  
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9 am - Noon, Monday-Friday



# THE ARC OF WHATCOM COUNTY

1111 Cornwall Avenue #205  
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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.*



## MARCH IS DEVELOPMENTAL DISABILITIES AWARENESS MONTH

The Arc of Whatcom County, an affiliate of the nation's largest volunteer based organization dealing solely with life-long issues of developmental disabilities, marks Developmental Disabilities Awareness Month this month. During March, The Arc of Whatcom County joins chapters of The Arc around the country in engaging in a media and public awareness campaign aimed at bringing issues concerning people with developmental disabilities and their families to the public.

To recognize Developmental Disabilities Awareness Month, Mark Asmundson, Mayor of the City of Bellingham and Pete Kremen, Whatcom County Executive have been asked to sign a joint proclamation declaring March 2003, Developmental Disabilities Awareness Month.

"Developmental Disabilities Awareness Month is an opportunity for The Arc to draw attention to issues affecting people with developmental disabilities and their families and to media to point out some of the positive contributions of people with developmental disabilities in our community life," said Stephen Johnson, Arc Board President. "We invite the people of Whatcom County to learn more about The Arc and its mission during the month of March each year. By devoting one month to public awareness, we hope to enlist more community support of our mission and values."

Chapters of The Arc around the country are embarking on a public awareness campaign this month to

bring attention to their programs and activities. Through advertisements, media coverage, and public service announcements in newspapers, on radio, and on television, The Arc hopes to reach millions of people with its message of inclusion for people with developmental disabilities.

The Arc has adopted a set of Core Values that will serve as guiding principles of the national association and its affiliated chapters. These values include: People First, Democracy, Visionary Leadership, Community Participation, Diversity, and Integrity and Excellence. For more information about The Arc, visit our national website at [www.thearc.org](http://www.thearc.org); our state website at [www.arcwa.org](http://www.arcwa.org); our local website at [www.arcwhatcom.org](http://www.arcwhatcom.org)

The mission of The Arc of Whatcom County is to improve the quality of life, increase the independence, and assure the full inclusion in the community of any persons with a developmental disability.

The vision of The Arc of Whatcom County is to be an effective resource, a strong advocate, and a dedicated base of support for individuals with developmental disabilities and their families.

The Arc of the United States is the nation's leading organization on developmental disabilities. The Arc has over 120,000 members within approximately 1,000 state and local chapters, and represents the membership on advocacy and programmatic issues pertaining to developmental disabilities.



Passages: We celebrate the lives and mourn the loss of  
Jeremy Robert Price, Kathleen Lois Waite,  
Daniel Aaron Godwin, Alice Irene Lloyd