



Welcome, Parent to Parent!

Parent to Parent moves to The Arc.

We at Parent to Parent are so enthusiastic about our recent move to The Arc of Whatcom County. We look forward to the partnership between organizations and hope to serve more families as our community continues to grow. The Arc has been a pillar in our community; their educational workshops and programs support the over 2,000 persons with developmental delays, disabilities, and ongoing healthcare needs and their families in Whatcom County. We also look forward to connecting with the Parent Coalition, Down syndrome Outreach, and the Young Adult Self-Advocacy programs. We will continue to provide personal support during the challenging times and celebrate your child's successes alongside you.

-From Parent to Parent

Parent to Parent Holiday Party

On December 3rd, Parent to Parent held our annual Holiday Party for families in our community. We welcomed a total of 211 guests throughout the course of the day. Families were able to enjoy a meal and meet with others. We had a wonderful visit from Santa Claus, and each child had their picture taken. Our Super Sitters worked at multiple craft tables with children and had a sensory area available. We sincerely appreciate Inner Child Studio for donating their time and bringing Legos and crafts for the kids. The party was a success largely due to the assistance of our wonderful volunteers and Helping Parents. We appreciate the time and effort put in to make our Holiday Party a safe and inclusive event. Big thanks to Bellingham Parks and Rec for co-sponsoring the event, and to Santa Jim and his family for being a part of the fun. We would also like to thank the Bellingham Food Co-op, Trader Joes, Target, McKay's Pizzeria, Costco, and Starbucks for their generous donations.

How to reach Parent to Parent

Karlene Umbaugh, Program Coordinator: (360) 715-0170, ext. 302, or KarleneU@arcwhatcom.org
Melissa Abraham, Parent Assistant: (360) 715-0170, ext. 301, or MelissaA@arcwhatcom.org
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FEDERAL CHANGES MAY IMPACT DISABILITY LIFELINES

Medicaid, the Affordable Care Act (ACA), Supplemental Security Income (SSI), Social Security, Medicare, and civil rights laws like the Americans with Disabilities Act (ADA) are lifelines for people with I/DD and their families, providing benefits, supports, and civil rights protections that help make community living possible. These federal programs provide the key to community living and inclusion for people with I/DD across the nation. Several current proposals put these programs at risk including cuts to SSI, ACA repeal, and block grants or caps for Medicaid. On these two pages, you'll find information about these lifelines and resources to stay informed so you can speak up about your interests or concerns.

Supplemental Security Income (SSI)

- Enacted in 1972 to reduce poverty by providing a floor under the often extremely low incomes of seniors and people with disabilities.
- Today, SSI provides essential income support to about 8.3 million people across the U.S., including 2.2 million seniors and 6.1 million children and adults with some of the most severe impairments and illnesses.



SSI Reduces Poverty

- Nearly two in three SSI beneficiaries live in families with incomes at or below 150 percent of the federal poverty level – but without SSI, over nine in 10 would.
- When a child becomes eligible for SSI, household poverty falls by 11 percent, on average.
- SSI lifted over 4.2 million people out of deep poverty in 2012.

*DON'T CUT OUR
LIFELINE*

SSI Improves Health

- Most states find SSI beneficiaries categorically eligible for Medicaid, helping beneficiaries access medical care to maintain or improve health and prevent worsening of medical conditions.
- SSI benefits also help pay for nutritious food, travel to medical appointments, and medical expenses.

SSI Reduces Homelessness and Institutionalization

- SSI provides a reliable stream of monthly income that helps people with disabilities live in the community.
- Without SSI, many beneficiaries would face homelessness or be forced into institutions.

SSI Helps Families Raise Children with Disabilities and Improves Outcomes

- SSI helps low-income families offset some of the often-extraordinary costs of raising a child with a disability.
- Helps replace lost income when a parent must take time off or reduce work hours to care for the child.
- Families raising children with disabilities are more than twice as likely as other families with children to face material hardships such as homelessness, food insecurity, and utility shutoff.
- SSI is cost-effective, allowing families to care for children with disabilities in their own homes instead of in costly institutions.
- SSI benefits also help families increase a child's opportunity to achieve an independent, rewarding, and productive life, including work in adulthood.

The Affordable Care Act: How People with Intellectual and/or Developmental Disabilities (I/DD) Benefit from the Affordable Care Act (ACA)

- The ACA expanded access to health care for individuals with intellectual and/or developmental disabilities.
- Access to consistent and reliable healthcare is imperative for individuals with I/DD.
- ACA created much-needed reforms to health insurance.
- Addressed systemic discrimination.
- Expanded coverage.
- The ACA allowed states to extend their Medicaid programs to childless adults earning up to 138% of the federal poverty level. This change has provided coverage to millions of people, including individuals with I/DD and other disabilities and chronic health conditions who were not otherwise eligible for Medicaid.
- The ACA provided federal money to support Medicaid expansion. The additional federal contribution to expanding Medicaid has helped more people access health care without harming the existing programs that provide supports and services to people with I/DD.
- Several provisions of the ACA were designed to assist states to invest in community-based long term supports systems instead of costly and outdated institutions. These include the Community First Choice Option (CFC) in Washington State.

Selected Examples of Provisions of the ACA that Impact the Lives of Individuals with I/DD:

1. Strong nondiscrimination provisions and health insurance reforms such as:
 - Banning the exclusion of people from health insurance coverage based on pre-existing conditions;
 - Preventing insurers from charging people with disabilities and health conditions significantly more for health insurance coverage; and
 - Eliminating annual and lifetime caps on health coverage.
2. Requiring a more comprehensive benefit package which includes rehabilitative and habilitative services and devices, mental health and substance abuse disorder services including behavioral health treatment, and critical prescription drug coverage;

3. Expanding access to health insurance in a number of important ways including:

- Medicaid expansion to childless adults;
- Expanding mental health parity provisions;
- Requiring coverage for dependents until age 26;
- Creating health insurance market places; and
- Improving accessibility of medical diagnostic equipment.

4. Expanding access to long term supports and services by creating the Community First Choice Option allowing states to provide comprehensive participant-directed home and community based attendant services and supports as part of their state Medicaid plan.

Impact of ACA Repeal on Medicaid:

- Repeal of the ACA would take away coverage from those who have received it due to Medicaid expansion.
- Repeal would undermine the basic health and long term supports provided by the Medicaid program.
- Destabilize the Medicaid program in the 32 states that have expanded Medicaid. Many states would be forced to make tough choices about eligibility and access to services and supports.

The Outlook for Medicaid in 2017: Facing Cuts, Block Grants or Per Capital Caps?

What is Medicaid?

- Medicaid is the nation's health insurance program for people with disabilities and low-income populations.
- The program currently covers over 10 million non-elderly people with disabilities.
- Medicaid is a lifeline for most people with significant disabilities.
- For many people with intellectual and developmental disabilities (I/DD), Medicaid generally is the only source of funds for them to live and work in the community with friends and families and avoid more costly and segregated nursing homes or institutions.
- Nationwide, state, and federal Medicaid together provide over 75% of the funding for services for people with I/DD.
- Medicaid is currently a jointly funded program with matching state and federal funds.
- When a state spends funds on providing eligible beneficiaries with services, then the state is guaranteed reimbursement from the federal Medicaid program at the state match rate.
- If a state increases its Medicaid spending, the Federal funding will also increase.

What is a Medicaid Block Grant?

- A block grant provides states with a set amount of federal money to fund its Medicaid program.
- A block grant would effectively end the flexible state and federal partnership.
- States would be responsible for covering the costs beyond the federal allotment, shifting costs to states.
- This may force states to reduce eligibility, limit services and supports, cut reimbursement to providers, or any number of methods to save money in the Medicaid program.

What is a Medicaid Per Capita Cap?

- Under a Medicaid per capita cap, the federal government would set a limit on how much to reimburse states per enrollee.
- Unlike a block grant approach, which provides a fixed amount of federal spending regardless of enrollment, payments to states could reflect changes in enrollment.
- However, a per capita cap model would not account for changes in the costs per enrollee beyond the cost growth limit. To achieve federal savings, the per capita growth amounts would be set below the projected rates of growth.
- A per capita cap would have a similar effect on the level of funding available to the state as the block grant approach.

What is at Stake for People with Intellectual and Developmental Disabilities?

States will receive less federal support to administer Medicaid if either or both of these approaches are enacted into law. While there is no way to be certain about what states would do if faced with block grants and reduced federal funds, we know there will be real life consequences for people with I/DD, such as:

- Losing home and community-based services and supports.
- Losing other critical services such as personal care, prescription drugs, and rehabilitative services. Medicaid usually is the only way people can get access to durable medical equipment like wheelchairs or prosthetic devices, as well as assistive technology.
- Unnecessary institutionalization.
- Shifting the costs to individuals or family members to make up for the federal cuts.
- If cost sharing levels are increased, people may be forced to forego lifesaving treatments, therapies, and medical care.
- Losing the entitlement to Medicaid. Currently, if a person meets the eligibility requirements (generally poverty, age, and/or disability), he or she is entitled to the services available under the state Medicaid program. People could lose all access to health care services.
- Children will lose valuable screening, services, and therapies if the Early and Periodic Screening, Diagnosis and Treatment benefit is dismantled.

Keep up to date on Federal Issues through The Arc US

Visit The Arc's **Action Center** to get information on elected officials, issues, legislation, candidates and elections: <http://cqrcengage.com/thearc/>

Sign up for the **Capitol Insider** to stay informed on the latest federal news: <http://cqrcengage.com/thearc/app/register?2&m=10985>

The **Public Policy** page has summary and background information on various issues: <http://www.thearc.org/page.aspx?pid=2400>

Source: <http://www.thearc.org/what-we-do/public-policy>

Community Events

ASK THE ADVOCATE WORKSHOP *Strategies for Support: The Art of Aging Well*

For parents & caregivers

6-8pm, Tuesday, January 17
The Arc of Whatcom County
2602 McLeod Road, Bellingham



Adults with developmental disabilities are living longer, healthier, more meaningful lives. Dealing with aging, planning, and end of life issues with people with intellectual disabilities is a growing challenge and an opportunity to focus on relationships, connections, and community. Join us and a panel of family members as we share strategies, resources, and support.

Please RSVP by January 12th: (360) 715-0170, ext. 303, monicab@arcwhatcom.org. Limited supervised care for family members is available on a first-come, first-served basis with RSVP by January 12th.



My Way Matinee: Sensory-Friendly Films

Regal Barkley Village Stadium 16 IMAX & RPX has announced their new line-up of sensory-friendly family movies. These

shows will be presented with the lights turned up and the sound turned down to accommodate those guests who may need a less intense viewing experience and are specifically for those guests who may need more freedom of movement or expression when enjoying a film. Tickets: \$6.50. Films will be shown at 10:30am on the following Saturdays:

January 14: Sing

February 11: A Dog's Purpose

March 11: Lego Batman

April 8: Boss Baby

Barkley Village Stadium 16 IMAX & RPX
3005 Cinema Place, Bellingham
(360) 527-1320
www.REGmovies.com

Spin Dance

6-8pm, Monday, January 16
Bellingham Senior Center
315 Halleck Street, Bellingham



Bellingham Parks and Recreation, The Max Higbee Center, and Whatcom County Parks sponsor monthly dances for individuals with disabilities. At the SPIN Dances, you can always count on lively music provided by local bands or DJ's, a healthy snack at intermission, and FANTASTIC company! All persons age 14 and over are invited for music, dancing, and fun! For information, call Amanda: (360) 778-7000.



Saturday, February 11

Max Higbee Center
1210 Bay Street #102, Bellingham
Registration/Package Pick-Up: 8am-9:30am
Race begins at 10am

Roses are red, violets are blue, we're running a 5k and you should come too! This Valentine's Day weekend, grab a pal, furry friend, or special someone and run your heart out at Max Higbee Center's "Hearty Party" 5k! This community event benefits Max Higbee Center, a non-profit organization providing recreational services to teens and adults living with developmental disabilities. Support a great cause and join the party for the 4th annual 5k with beautiful views of Bellingham Bay and Zuanich Park. The fun will continue with a hearty after-party at Boundary Bay Brewery.

For info, email sadie.maxhigbee@gmail.com or call (360) 922-2450.

P2P Support Meeting

7-8:30pm, Monday, February 13
The Arc of Whatcom County
2602 McLeod Road, Bellingham



Join other parents of children with developmental delays, disabilities, and ongoing health care needs in a comfortable, confidential setting for mutual support. Free on-site child care available for those who RSVP by February 10th: (360) 715-0170, ext. 302, or KarleneU@arcwhatcom.org.

Announcing the Autism 200 Series Schedule for 2017



Autism 200 is a series of 90-minute classes for parents and caregivers of children with autism as well as teachers and community providers who wish to better understand autism spectrum disorder. Faculty from Seattle

Children's, the University of Washington and community providers teach the classes. Classes are held on most third Thursdays of the month at Seattle Children's Hospital from 7 to 8:30 p.m. in Wright Auditorium.

Lectures are also recorded and can be viewed on the website following the lecture. For a list of teleconferencing sites or to view past lectures, please visit: <http://www.seattlechildrens.org/classes-community/current-class-offerings/autism-200-series/>

Autism 201: The State of Autism in 2017 January 19, 2017

Instructors: Raphael Bernier, Ph.D. & Jim Mancini MS, CCC-SLP

Considerable advances have occurred in both science and on the community, state and national levels in 2016. Seattle Children's Autism Center's Dr. Raphael Bernier, clinical director and Jim Mancini, coordinator of training, education and outreach, will review the most newsworthy and influential scientific and community advances in the world of autism spectrum disorder from the past year. We will also discuss what we can expect in the changing educational and political landscape of 2017.

Upcoming Dates:

- February 16, Autism 202: Autism Genetics: What Parents Should Know
- March 16, Autism 203: Making Friends on the Playground: Social Skills Support in School
- April 20, Autism 204: Parent Training to Address Problem Behaviors of Youth with Autism
- May 18, Autism 205: Autism and Police: Staying Safe Together
- July 20, Autism 206: Transition to Adulthood: Finding a Job
- August 17, Autism 207: Transition to Adulthood: Keeping a Job
- September 21, Autism 208: Screening for ASD: A Preventative Intervention Approach
- October 19, Autism 209: Early Intervention in Autism: An Overview of the Seattle Children's Autism Center Model
- November 16, Autism 210: Autism from a Sibling's Perspective: A Panel Discussion

Please note: These classes are no longer available at WWU but can be viewed online: <http://www.seattlechildrens.org/classes-community/current-class-offerings/autism-200-series/>

SAVE THE DATE

Whatcom County Transition Fair

9am-12:30pm, Thursday, March 30
St. Luke's Health Education Center
3333 Squalicum Parkway, Bellingham



The Transition Fair is for students with developmental and other disabilities, families, educators, and interested community members. Both middle and high school age students and their families are encouraged to attend. All are welcome who are interested in thinking about the future! Come and learn about: Housing options, recreation, advocacy, employment and vocational supports, guardianship, community/tech colleges, Social Security, Division of Vocational Rehabilitation (DVR), Developmental Disabilities Administration (DDA), and more.

For more information, call the Whatcom County DD Program at (360) 778-6047 or email jlee@co.whatcom.wa.us.



Climb on Board for Advocacy Day!

Wednesday, March 29

All Day

Round-trip bus to Olympia

The Arc of Whatcom County will be chartering a bus from Bellingham to Olympia to participate in the Legislative Advocacy Day "Self-Advocacy and Disability Pride" on **Wednesday, March 29th**. Parents, self-advocates, and care providers are welcome to come at no cost to you. We will provide information and materials to help you understand the issues and share your story.

If you are interested in joining us, please email Monica at monicab@arcwhatcom.org or call (360) 715-0170, ext. 303, to reserve your seat!

YOUNG ADULT SELF-ADVOCACY

Be Strong. Be Proud. Be Heard.

Young Adult Self-Advocacy (YASA), a program of The Arc of Whatcom County, focuses on various aspects of self-advocacy. Through group meetings, individual skill building, involvement in legislative advocacy, and providing outreach and awareness in our community, self-advocates are able to practice their skills and abilities to speak up for themselves and others who may need support.

Jessika Houston, YASA Coordinator, is excited about being able to bring YASA to high school and transition programs. She has taught workshops at Lummi Nation School and Bellingham High School and is looking forward to continuing those partnerships in 2017.

Jessika and The Arc's Inclusion Advocate and mentor for the YASA program Terri Hansen will be going to Bellingham High School's Community Transition (CT) program for a self-advocacy workshop this January. They will discuss self-advocacy: Who do we advocate for? When do we advocate, and how? And perhaps the most important question: Why? It is so important for all of us to know we are valued and important members of our community – to know why it is critical that we all must be able to advocate for ourselves. Other topics for the upcoming workshop will discuss goal setting and person-centered planning. During a workshop with Bellingham High School's CT program in 2016, one student responded, "The Arc is like the Grandmother of our community."

Workshop and meeting topics can also include (but are not limited to) healthy relationships and boundaries, safety, language, and identity. Self-advocates also have the option to connect with Jessika about participating in creative projects as a group and individually, if desired.

Jessika is available for workshops with schools and agencies that serve individuals with disabilities age 16-30. Meeting topics can be tailored to fit the group's needs, curriculum, or other objectives. Contact Jessika for additional information on how to bring YASA to your program!



"It was a good day. I did a good job." -Matthew Best



*"I felt really proud to talk about my needs, and needing more hours at work. It's really important."
-Jaime Kloss*



*"With much appreciation, meeting and talking with our state legislators provided the opportunity for my son to participate in advocating for his needs and goals as a member of our community. For that, we are grateful. Living in this community, we are thankful for our local non-profit agencies that hear our concerns, and provide resources for families to learn where to find answers."
-Maureen Monroe, mom to Jim Monroe*

Legislative Advocacy

Another area of involvement for YASA members is legislative topics and concerns. This allows for self-advocates to build relationships, practice skills in communication and advocacy, and increase awareness, respect and rights of individuals with disabilities. Participants do this in a number of ways. Through gaining skills in the meetings to be strong advocates, several YASA members identified their concerns and presented at The Arc's Legislative Coffee in December. Members are also preparing for Advocacy Days, where they will have another chance to speak with our local representatives. (See page 5 for more info.)

Terri Hansen spoke at the Legislative Coffee about concerns for herself and our community. Every year, Terri has a powerful message to legislators, and this year, she discussed money allotment. Terri said, "How the state does not allow for individuals with disabilities to save money is unfair... Being on Social Security limits my and others' ability to save large amounts of money without losing the services we rely on. Because of this, I've had to put aside money in my family's name so that I am able to purchase an accessible van that meets my needs. I am also unable to earn extra money for a new van because of the income cap." This is a topic that not only concerns Terri, but thousands of people.

Self-advocates often discuss topics around areas that would improve quality

of life as well as areas they have experienced challenges and concerns. Jaime Kloss and Matthew Best are advocates for more hours and opportunities for employment. Jim Monroe is an advocate who would like to see more adult recreation services in Whatcom County as the needs in our community grow.

Laura Rawlins advocates for strengthening school inclusion. Her number one concern is discrimination against all minorities. She would like to see education about inclusion in schools and communities (from early intervention all the way into adulthood) and more open discussions about discrimination and bullying.

Laura says, "We have responsibilities to other people and for ourselves and the people who teach us – those who help to raise the children in our community. The children are the hope of our future. When we teach our children love, compassion, and to include our community, we are one – and as adults we learn that we are a part of each other. We can be stronger because of our differences."

When and where are the meetings?

YASA meets 10 months out of the year, typically on the first Thursday of the month from 4:30-6:30pm. The next YASA meetings are: February 2 and March 2 from 4:30-6:30pm. (No meeting in January.) To see the current schedule, visit www.arcwhatcom.org or contact Jessika (see below). The meetings are held at The Arc's Dan Godwin Community Center at 2602 McLeod Road, Bellingham.

How do I join YASA?

If you are between the ages of 16 and 30 and an eligible client of the Developmental Disabilities Administration (DDA), you are welcome (and encouraged!) to come to a meeting and join.

For more information, contact The Arc's YASA Coordinator, Jessika Houston: jessikah@arcwhatcom.org or (360) 715-0170, ext. 304. We look forward to meeting you!



Down syndrome Outreach Directory

Many people in our Down syndrome community have asked for contact information of others, eager to connect with one another. DsO has listened and is planning to implement a DsO Directory in 2017.

This is an Opt-In Only directory. You must provide the information you wish to share with others (who have also

opted in to the directory) via email (jessikah@arcwhatcom.org) or by filling out and sending in your information. An email has already been sent to the current DsO email list. If you did not receive an email, please contact Jessika as she may not have your current email address.

If your Opt-In Information is not provided by February 1st, you can expect a hard copy of the Opt-In Form in the mail shortly after.

All information received by March 1st will be used for the first draft of the DsO Directory. We will update quarterly, as needed. There will also be opportunities to fill out the necessary information at Spring Fling, Buddy Walk, and other DsO Events.

Information for this Opt-In directory will include: name of parent(s), name of child or adult self-advocate (first and last), self-advocate birth year, siblings, name of city, school district, email, phone number, and any other information you would like to share.

This information is not to be shared outside your family and is to be used to support your family and individuals with Down syndrome. We know it can seem like our experience in our family is not the same as others. The end goal of this project is to connect you, so you can utilize one another as a resource and support one another on your time and your terms.

For now, please continue to reach out to Jessika if you would like a specific connection to be made: jessikah@arcwhatcom.org or (360) 715-0170, ext. 304.



*For people with intellectual
and developmental disabilities*

The Parent Coalition

The Arc of Whatcom County provides leadership support for individuals with developmental disabilities and their parents/guardians. The goal of the Parent Coalition is to enable persons with developmental disabilities and their parents/guardians to become effective and involved in accessing services.

*The Parent Coalition newsletter
is published monthly by:*

The Arc of Whatcom County

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www.arcwhatcom.org
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Susan Larson; Michelle Karaffa

Stay Connected

Online Community Calendar:

Visit The Arc's website at www.arcwhatcom.org and click on Events.

Facebook: Visit our FB page: www.facebook.com/ArcWhatcom for the latest information and events.

E-alerts: The Parent Coalition emails updates on legislation, workshops and upcoming activities. To sign up, visit www.arcwhatcom.org or email monicab@arcwhatcom.org.



PARTNER AGENCY

*The Parent Coalition is funded by grants from the
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DID YOU KNOW?



Washington Health Benefit Exchange is building a collection of stories about people who have recently gained insurance or taken advantage of new benefits to help people understand what health reform means for them. Have you benefited from some of the changes under the Affordable Care Act? If you're interested in sharing your story, please fill out the form here: <https://www.wahbexchange.org/contact-us/share-your-story/>

If your story is used, you may be eligible for a \$50 gift card!



The Arc of Whatcom County
Dan Godwin Community Center
2602 McLeod Road
Bellingham, WA 98225

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Event Calendar

January 2017

14 Saturday, 10:30am
My Way Matinee: Sing
Barkley Village Stadium 16 IMAX & RPX
3005 Cinema Place
Contact: (360) 527-1320

16 Monday, 6-8pm
Spin Dance
Senior Center, 315 Halleck Street
Contact Amanda: 778-7000

17 Tuesday, 6-8pm
PC Workshop: The Art of Aging Well
The Arc's Dan Godwin Community Center
2602 McLeod Road
Contact Monica: 715-0170, ext 303

19 Thursday, 7-8:30pm
Autism 200 Series
See page 5 for details.

21 Saturday, 6-7pm
People First Meeting
For meeting location and details,
contact Susan Larson: 738-2060

25 Wednesday, 5:30-6:30pm
The Arc's Board of Directors Meeting
The Arc's Dan Godwin Community Center
2602 McLeod Road
Contact Beverly: 715-0170, ext 306

February 2017

2 Thursday, 4:30-6:30pm
Young Adult Self-Advocacy Meeting
See page 7 for details.

11 Saturday, 10am
Hearty Party 5K
See page 4 for details.

13 Monday, 7-8:30pm
Parent to Parent Support Meeting
The Arc's Dan Godwin Community Center
2602 McLeod Road
Contact Karlene: 715-0170, ext 302

NOTE: All events listed are in Bellingham unless otherwise noted. Find more events at www.arcwhatcom.org/wp/events/.

Special thanks to this month's sponsor:



2017 Smiles of Life Calendars Are Available Now!



These special calendars make great gifts for family, friends, neighbors, and just about anyone! Featuring beautiful photos, inspiring profiles and motivating quotes, the 2017 Smiles of Life Calendar is dedicated to people with developmental disabilities and their friends and family. It is our true honor to celebrate the accomplishments and joys brought to us by our models. Despite any medical, developmental or behavioral challenges, they live with joy, courage, and determination. Your generous support (suggested donation is \$15 per calendar) will help fund valuable programs for individuals with developmental disabilities. Calendars are now available to order online at www.arcwhatcom.org.