



Informing Families and Community of Practice
July 1, 2017 through June 30 2018
Submitted by Ed Holen

Final Report: July 30, 2018

2018 was a very successful year for Informing Families and the Community of Practice!

The overall focus of Informing Families and the Community of Practice is providing information and building sustainable practices to support people with intellectual/developmental disabilities living meaningful lives over their life course.

Informing Families and the Community of Practice is a collaboration between the Developmental Disabilities Council and the Developmental Disabilities Administration. There are also many partners involved especially the members of the Informing Families Advisory Board.

We continue to build on success as we strive to present information in multiple formats.

Website

Total views: 76,475
Average monthly views: 7,647

Previous 10-month period
Total views: 71,409
Average monthly views: 7,140

Comments:

Monthly views have increased an average of 500 per month over the last July-April period. The following shows the top page views for the last 365 days, with DDA services the most frequently visited internal page.

Top Posts for 365 days ending 2018-04-27 (Summarized)

[7 Days](#) | [30 Days](#) | [Quarter](#) | **Year** | [All time](#)

2017-04-27 to Today

Title	Views
Frontpage	10,303
DDA Services	3,768
+ Home page / Archives	2,801
Guardianship	2,740
News	2,281
Assistive Technology for Social Skills	1,625
Guardianship Duties: Keeping Good Records	1,411
Applying for DD Services	1,386
Ages 14-21: Overview	1,280
DDA Home & Community Based Services Waivers	1,063
Resources	986

[Note: We are unable to filter for the July-April months, so the numbers reflect an entire year.]

Quarterly Print Newsletters

Four newsletters are mailed to 12,500 clients of DDA on the No Paid Services Caseload, including one Early Childhood Transition Special Edition that has been well received.

Bi-Monthly E-Newsletters

Listerserve: 2,400
Previous year: 2,249

Comments:

We have had not seen a big increase in sign-ups, which may be due to the addition of Captcha to filter out spam during initial sign-ups. Captcha may be irritating enough to be a deterrent, but prior to installing it, we were being spammed so often that Constant Contact put a hold on our sign-ups.

Videos Produced

- Understanding the CARE Assessment
- Everyone Wins When Everyone's Included!
- Smart Living
- Community Crisis Stabilization Services
- Person Centered Planning Three Part Series: Tools, My Life Plan, Star Form
- Conversations on Employment

Video views

YouTube total views this 10-month period: 10,313
YouTube total views last year: 8,797

Comments:

Most of our video view stats are on Facebook (below), however YouTube viewing has continued to hold and even increased over the year prior. The most popular video has been Understanding the CARE Assessment (1,086 views)

Facebook video views this year: 20,100
Facebook video views last year: 48,900

Comments:

We had a big bump last year with our “Just Like You” video, which had more than 40,000 views. This year, our most watched video was “Everyone Wins When Everyone’s Included” (6,100 views).

Facebook

Total page likes (i.e., subscribers) 1,080
Previous year page likes: 862

Comments:

Reach refers to the number of News Feeds a post will show up. During this reporting period, the highest reach for a single post was 14,427 for our National DD Awareness month video, “Everyone Wins When Everyone’s Included.” The next highest ranking posts was a video of Emily Rogers talking about the “Service Animal Legislation” (5,525), followed by a link to our bulletin on Medicaid Service Coverage (3,434) and a change to DDA Respite Training Hours (3,225).

We tested the effect of paid promotions, with very small samples of 2 dollars per day for a handful of posts (under \$100 total over 3 months). The results were positive, but modest. The best results came from page promotional ads, which increased the number of page likes. It’s worth targeting more of this in the future, with perhaps higher payments.

Bulletins

We produced 14 bulletins related services and resources, transitioning to the use of “Ready, Set, Know” along with the Informing Families logo, to brand the bulletins.

Resource folders and Life Course tools distributed

Folders: 24,351

Life Course Tools distributed:

Early Welcome Tool: 2,830

Transition from School to Adulthood: 6,425

Living the Middle Years: 3,118

New to Informing Families:

- Informing Families bag for distribution (another way to make people more aware of the website)
- New White board video presentation style used for the DDA Assessment overview

Local Coordinators meetings/gatherings

Michelle/Ellensburg

23 events at which Informing Families material was provided.

Front Door activities were provided at each of the four Transition Fairs in the County: Easton, Kittitas, Cle Elum /Roslyn and Ellensburg School Districts

DVR, DDA, Employment Vendors, Work Source, OIC, IFBT etc. hosted tables at the transition fairs.

“I had the fun task of taking to parents/students at the DDA table, personally introducing each one to our local Case Managers, and get them started on the process of applying for DDA. For those whose path isn’t DDA, the introductions were made.”

Krista/Wenatchee

18 events attended at which Informing Families materials was provided

Debbie Chapman/Eastern, Eastern Washington

I have been a part of 56 opportunities to share Informing Families. I have 10 opportunities throughout the rest of

my contract. It has been a very busy year. It looks nothing like my work plan.

Two events could qualify as front door events, I was unable to attend 4 other events because of scheduling problems. I am now part of the front door committee though Community of Practice Conference.

Darci/Spokane

Informing Families information is shared every month in our Advocacy and Family Support Newsletter (3,264) and weekly in our emailed Parent Connection. The Arc uses the Informing Families in our Employment Department and CI Department, Training Department and in all of the workshops and trainings we do.

Informing Families materials are used in our Transition Workshop series and our Guardianship packets as well as Guardianship workshops.

One front door event but not that successful

Jamie/Snohomish County

See Appendix One for Snohomish Co Report

Children's Village/Yakima County

See Appendix Two for Children's Village report

Front Door

In addition to the Front Door events mentioned above, Jamie, Betsy, Debbie, Darci, Michelle and Linda attended March 20 National Community of Practice meeting on behalf of the Front Door Project.

Community Guides and Community Engagement

Created a CG/CE locator map

Held 7 trainings for potential CG/CE providers

214 people attended the training sessions

133 contracted providers

Engaging Individuals and Families in diverse Cultural Communities

In 2018 we added three local coordinators who focus on diverse cultural communities. One contractor is Children’s Village in Yakima to focus on speaking families in the Yakima Valley. Please note information contained in the Children’s Village report in Appendix Two

We also worked with the Vietnamese community and the Somali Community in the greater Seattle/King County region.

Activities with the Vietnamese families:

Informing Families			
Date	Descriptions	Location	Activities
1/19/2018	Informing Families with VFAAB	SEATTLE’S UNION GOSPEL MISSION, 3800 South Othello Street, Seattle 98118, Phone: 206-723-0767	First meeting with Vietnamese families. There were 25 parents and 12 professionals.
2/10/2018	Tet in Seattle	305 Harrison St - Seattle, WA 98109	Hand out 50 Inform Family Bags. Meet families who had kids or family member with DD. Sign up sheet to follow up.
3/16/2018	Informing Families with VFAAB	SEATTLE’S UNION GOSPEL MISSION, 3800 South Othello Street, Seattle 98118, Phone: 206-723-0767	16 parents came with 8 professionals.
4/27/2018	Informing Families with VFAAB	SEATTLE’S UNION GOSPEL MISSION, 3800 South Othello Street, Seattle 98118, Phone: 206-723-0767	14 parents, 2 Professionals from Health Board, 4 Professional from Vietnamese Community of Seattle. Outreach and Support Group for Vietnamese speaking parents, caregivers, and professionals.
5/18/2018	Informing Families with VFAAB	SEATTLE’S UNION GOSPEL MISSION, 3800 South Othello Street, Seattle 98118, Phone: 206-723-0767	27 parents & 13 professionals. 6 of them from MEDRIX came to share experience they have when they were in Vietnam with mission to TRAIN the TRAINER about Autism.
6/8/2018	Informing Families with VFAAB	Rainier Church - 5900 Rainier Avenue S. Seattle, WA 98118	ABA Workshop by NW ABA. 10 parents and 15 professionals. Hope Central Pediatrics and behavioral health for Seattle’s Rainier Valley
6/23/2018	Zoo Days	Woodland Park Zoo - 5500 Phinney Ave N, Seattle, WA 98103	Zoo Day - Fun Event for families with DD.
Annual Summer Festival at Vietnamese Catholic Church			
8/11/2018	Informing Families with VFAAB	6841 S. 180th Street - Tukwilla, WA 98188 - 206-325-562	Outreach to Vietnamese Community and inform families on 2 days event

The Vietnamese Community has utilized its events for future collaborations. Below are some images of those collaborations.



The Somali Health Board staff reported that they held an Autism-focused community learning and listening session. During our planning phase, we met with families with children with Autism, providers and agencies that specialize in work with children with special needs (particularly those with Autism). The planning phase gave opportunity for families, community members and providers to give input into the purpose, goals, and style of the Autism event. For parents, it was important for them to have a moment celebration, breaking through stigma and advocating for their children. For community members, it was an opportunity to learn more and be part of the solution, rather than the problem. For providers and agencies, it was important to learn about community needs and barriers. The result was a listening session with parents of children with Autism in the center of the dialogue and solution-based dynamic round table discussions with family, providers and community members at the table.

One of the purposes of the event was to utilize the event for advocacy and future collaborative work. In collaboration with Open Doors, we presented the outcomes at the Somali Health Board May quarterly meeting, which is attended both in person and online. In July we - again, in collaboration with Open Doors - presented outcomes at AS3D PAC July conference call meeting.

Also, in collaboration with Louis Mendoza from Father's Network, we have initiated a father's network chapter specific to Somali community. One of the findings was that the fathers were not very active in the support group for Somali parent (which is attended almost exclusively by mothers).

Intellectual/Developmental Disabilities and Dementia Forum

The I/DD Dementia forum was held on June 28, 2018. About 100 participants attended the forum. The highlight of the forum was a presentation by Drs. Seth Keller and Matthew Janicki on how dementia affects individuals with intellectual and developmental disabilities, particularly individuals with Down Syndrome.

Additionally, Lynne Korte gave an overview of the Dementia Action Collaborative. The forum concluded with a conversation amongst the

participants on the next steps to better support individuals with I/DD in Washington State who develop dementia.

Quotes from people about Informing Families:

“I am a Special Education teacher and stumbled across your website when searching for information about CCSS. I wish I had known about this website prior to this week!! I will be sharing this with colleagues of mine as well as families that I work with. (March 2018)
Thank you!”
Kristal

“I have a specialty clinic that cares for Adults with Developmental Disabilities, I have approximately 250 on my panel. I am located in Developmental Pediatrics. Daily I bring up your website and show it to my patients, parents, staff in Developmental Pediatrics and General Pediatrics. I think if I could give them a folder, it would be great. (March 2018)
Thanks Much”
Lorraine Carney ARNP

“We wanted to thank you for producing such fantastic resources to individuals and families. Navigating the legal system in order to obtain appropriate supports can be a real barrier for individuals with disabilities. It's comforting knowing that there are organizations like Informing Families who are producing materials to help families better understand how to obtain the services that they need.” (April 2018)
—Vanessa Zhou
Graduate Research Fellow 2017-2018
Clinical Psychology Doctoral Student
Seattle Pacific University

So does this make a difference?

Based on the 2016 data from the National Core Indicators:

Parents responding for adults with DD living outside the family home say that 82% always or usually get enough information to help them plan for the future and 84% say the information is easy to understand.

Parents responding for adults with DD living in the family home say that 80% get enough information to help them plan for the future and 70% say the information is easy to understand.

Based on the 2014 data from the National Core Indicators:

Parents responding for adults with DD living outside the family/parent home, 85 % say they always or usually get enough information to help them plan and 90% said the information was easy to understand.

Parents responding for adults with DD living at home, 68% say they receive enough information to help them plan for services and 68% say that the information they receive is always or usually easy to understand.

Appendix One: Snohomish County Events

2017 Speaker Events

Date	Description of Training or Presentation	Unmet Need	Group Provided To:	# Attended
7/10	Social Security Benefits	Future Planning	CF	8
7/21	Telling your story with a purpose	Leadership	Padres Unidos	11
8/14	Easing the Back to School Transition	Education	CF	5
8/18	Accessible voting	systems	Padres Unidos	23
9/12	Special Education Roundtable	Systems	CF	12
9/15,22	Helping Parent Training (Spanish)	Peer support	Padres Unidos	22
9/20	Guardianship & Alternatives	Systems	ACG	7
9/25	Social skills through play		SASSIE	7
9/28	Front Door Presentation	Systems navigation	Denny JJC Staff presentation	15
10/9	Able Act Information	Systems Navigation	CF	14
10/18	Social Security Benefits Planning	Systems Navigation	ACG	7
10/20	Spanish – HP	Peer support	Padres Unidos	24
10/24	Emotional Regulation	Behavior	SASSIE	14
11/13	Guardianship & Alternatives	Systems Navigation	CF	10
11/15	Special Needs Trusts	Financial Planning	ACG	14
11/17	Spanish – IEPPP training	Building Leaders	Padres Unidos	24
11/27	SCERTS Model	Communication	SASSIE	13
12/11	Self-Care for the caregiver	Self-care	CF	4

2018 Speaker Events

Organization/ Agency/Arc Group	Description of Training/Topic (Unmet Need)	# Attendees
1/22 FICC	Arc staff presented on Transition from B-3 to preschool. Shared in English & Spanish	30
1/8, 1/22 CF - Helping Parent Training	Helping Parent training (1 parent from Tulalip tribe)	15
1/17 ACG	Guardianship Reporting & Record Keeping- Sage Graves	14
1/19 Padres Unidos	Overview of ECEAP (presented in Spanish) – Alejandra Wood	4
1/29 IEPPP	Special Education Peer Support	12
2/9 Parent Provider Training	CFC	12
2/12 CF	Social Skills for Young Adults	26
2/21, ACG	Person Centered Planning	11
3/12/18 CF	Navigating Special Education PAVE	8
3/12/18	Panelist for Advocacy Panel Breakout Session- Verdant Healthier Communities Conference	
3/14/18	Make-up Helping Parent Session	2
3/16/18 Padres Unidos	National Immigration Project -Spanish	11
3/21/18 ACG	DD Ombuds Program	2
03/23/18-Coffee hour/Hand in Hand	Sharing resources and advocating for our Spanish speaking families with kids with disabilities to be welcome and included in the community.	9
3/26/18 SASSIE	Navigating your child's Autism Diagnosis	5
03/28/18- Madres de Casino Road	Sharing resources, advocating for our Spanish speaking families with kids with disabilities to be welcomed and included in the community; empowering Spanish-speaking women to be involve in their child education and to take leadership roles in the community.	50+
4/11/18	Birds & Bees and Developmental Disabilities (2-11)	7
4/18/18 ACG	Guardianship	8
4/18/18	Birds & Bees and Developmental Disabilities (12-20)	9
4/20/18	Birds & Bees and Developmental Disabilities (Spanish)	18

4/28/18	Behavior Workshop	75
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Monthly Ongoing Support Groups

- Mothers Network
- Fathers Network
- Padres Unidos
- Adult Caregiver

Monthly Transition Clubs in Schools

Youth Self-Advocacy Club/Group (Averages 155 students a month total)

Group
Transition Club Lake Stevens/Granite Falls
Transition Club Lake Stevens High Grp 1
Transition Club Lake Stevens High Grp 2
Transition Club Edmonds Grp 1
Transition Club Edmonds Grp 2
Transition Club Mukilteo
Transition Club Snohomish
Transition Club Monroe
Transition Club Everett –Jackson HS
Transition Club Everett –Everett HS
Star Club Marysville Totem Middle School

2017 Front Door & School District Presentations

Date	Description of Training or Presentation	Unmet Need	School District Provided to:	# Attended
11/21	Front Door		Edmonds, Lynnwood, Mt Lk Terrace	10

9/28	Front door presentation	Transition	Lake Stevens	13
11/14	Front Door		Monroe	13

2018 Front Door & School District Presentations

School District	Group	Description of Training/Topic (Unmet Need)	# Attendees
Everett, Mill Creek	Parents & Staff	Front Door Resource Fair/ all ages	50-60
	Everett PTSA	Overview of Arc Services, IEPPP, & CTIC	8
Lakewood	Lakewood SD Elem Parents & Staff	3/28 Presented Arc Resources and Special Education overview, Parent/ school collaboration & resources	29
Edmonds, Lynnwood, Mt LK Ter.	Natural Leaders Parent Group	College Place El. Shared info. About Arc programs, Special Education (IEP/504) and CtLC	10
	Parents & Staff	Resource table at Saturday morning resource and rec. fair/ all ages	
	Parents & Staff	3/29 Arc presentation at SpEd Listening Session	20-25
	Natural Leaders	March-College Place Elem. – Sharing Resources, CtLC – Some Spanish	9
Marysville	Parents & Staff	Held housing presentation for a group in Marysville	12
Monroe	Monroe Special Education mtg	Provided Arc information and will be attending again to do a Spanish presentation	9
	Parents	March Frank Wagner Elem. Shared info. about resources, IEP, inclusion & community – Some Spanish	14
Mukilteo	Spanish speaking Parents	Horizon Elem. Sharing Resources, IEP, Inclusion & Community – Spanish	13

*These include: CTLC Presentations, Front Door Information Nights etc.

2017 Conferences/ Resource Tables

7/23	Attended Snohomish Counties 1 st SnoHomo Pride event. Shared Arc/ IF programs and gathered resources from other agencies.
8/3	Had a resource table at Everett Housing Authority Resource Fair
Ongoing	FICC
Ongoing	Transition planning committee

2018 Conferences/ Resource Tables

Ongoing FICC (Family Interagency Coordinating Council)
 Ongoing CSHCN (Children with Special Healthcare Needs) Meetings
 Everett Housing Authority Resource Fair
 Snohomish County Transition Fair
 Snohomish County Childrens Mental Health Fair
 Pediatric Northsound Regional Care Summit
 Snohomish County CAM (Community Asset Mapping)
 Snohomish County Transition Back to School Kick off

Appendix Two

Report from Children's Village – Yakima County

Information shared via email distribution to over 1,200 families (with children who have disabilities) and community providers (forwarded by DDC/Ed Holen):

- Informing Families Website
- Community Guide Training
- RAISE Family Caregiver's Act
- DDC Council Recruitment
- DD Awareness Month Video
- DD Community Summit
- I/DD Dementia Forum
- CARE Assessment tutorial

Children's Village Blog posts:

March is Developmental Disability Awareness Month!

Posted on March 13, 2018 by Children's Village

“What does inclusion mean to you? That's the question posed to people with and without disabilities in this video celebration of National Developmental Disabilities Month.”

Resources for children with disabilities and their families.

Posted on January 30, 2018 by Children's Village

Please visit this **excellent website** for up-to-date information about services and resources for children with disabilities and their families.

Scroll through the website by child's age, or scroll to the bottom, and visit the 'bulletins' under News. Many informative Bulletins about a variety of topics.

Informing Families information (bulletins, folders) shared at Parent to Parent groups and events:

English language groups:

Group	Date	Attendance
Valley Parents Sunnyside	1/4/18	8
Autism Support	1/18/18	10
YV Homies with Extra Chromies	1/25/18	5
Sunnyside Valley Parents	2/1/18	3
Autism Support Group	2/15/18	13
YV Homies with Extra Chromies	2/22/18	6
Sunnyside Valley Parents	3/1/18	6
Autism Support Group	3/15/18	4
Holland Evening group	3/28/18	3

Spanish Language Groups:

Group	Date	Attendance
Holland Reunion	1/10/2018	6
Holland Luncheon	1/22/2018	15
Caring for Yourself	1/30/2018	16
Holland Reunion	2/14/2018	9
Yakima Support group	2/21/2018	2
Sunnyside support group	2/28/2018	5
Holland group	3/1/2018	2
Holland group	3/8/2018	3
Holland Reunion	3/14/2018	13
Holland group	3/15/2018	3
Yakima Support group	3/21/2018	6
Holland group	3/22/2018	3
Sunnyside support group	3/27/2018	3

Families United Conference (see attached flyer) - 3/10/18 - 171 in attendance. Informing Families bulletins (English/Spanish), folders (English/Spanish) and bags handed out to families.

The Families United Conference is a bilingual conference for parents, caregivers and providers who come together to learn about various resources for individuals with disabilities and their families. Since 2007, this annual conference has been held in Sunnyside and ranged in

attendance from 50-200 participants. STARS credit is available for childcare providers.

The conference is co-sponsored by local and statewide organizations including: Inspire Development Center, Yakima Valley Farm Workers Clinic, Developmental Disabilities Association, PAVE, and Yakima County Parent to Parent, Astria Health (formerly Sunnyside Community Hospital), Sunnyside School District, and the Division of Vocational Rehabilitation.

This conference was originally planned/developed by DDA, Yakima County Parent to Parent and PAVE.