



King County

Department of Community and Human Services
Developmental Disabilities Division

BOARD FOR DEVELOPMENTAL DISABILITIES AGENDA

Day/Date: Wednesday, June 1, 2016

Time: 9:30 – 11:30 a.m.

Location: Tukwila Community Center
Community Room B
12424 42nd Avenue South
Tukwila, WA 98168
(Driving direction on the reverse side)

- | | |
|---|--------------------|
| I. Call to Order / Introductions | Leo Finnegan |
| II. Approval of Minutes | Board |
| III. Chair's Remarks | Leo Finnegan |
| IV. Informing Families Website | Ed Holen |
| V. Community of Practice Workshops | Ed Holen |
| VI. "We're Listening" Community Meetings | Stacy Gillett |
| VII. General Public Input | |
| VIII. Positive Happenings | Board |
| IX. Reports | |
| ❖ Discretionary Funding Process | Jim Ott |
| ❖ Regional Administrator / Field Services | Michelle Bauchman |
| ❖ King County Division Director's | Denise Rothleutner |
| X. Adjournment | |



King County

Department of Community and Human Services
 Developmental Disabilities Division
 401 Fifth Avenue, Suite 520
 Seattle, WA 98104

Board for Developmental Disabilities

BOARD MEETING

Date: June 1, 2016

Location: Tukwila Community Center

Time: 9:30 am

PLEASE PRINT

Name	Representing	Email or mailing address Update or add to mailing list only	Would you like to speak?
Shaun Bickley	The Alliance of People with Disabilities	shaun@disabilitypride.org	
Chris Weber	KCPFC Arc of KC	on file	No
Alice Fong	United Way of King County	afong@uwkc.org	No
Eric Matting	The Arc of KC	on file	No
Rob Van Oss	WISE	rob@golise.org	No
Fred Nystrom	LEO	Fred.Nystrom@LifeEmergencyoptions.org	No
Joanne Dikell	Arc of WA	on file	No
Stacy Billitt	Arc of King	on file	YES
Caitlin Withers	Vadis	caitlin@vadis.org	No
Robin Tatsuda	The Arc of KC	rtatsuda@ arcofkingcounty.org	No

[illegible]



King County Board for Developmental Disabilities

M I N U T E S

Day/Date: Wednesday, May 4, 2016
Time: 9:30 – 11:30 a.m.
Location: Tukwila Community Center
12424 42nd Avenue South
Tukwila, WA 98168

Board Members Present: Deborah Anderson, Theresa-Ann Clark,
Leo Finnegan, Marianna Klon, Joseph Phillips,
Hameed Quraishi, Marla Veliz, Nancy Yee

Guest Present: Chris Brandt, AtWork!
Joe Cunningham, The Arc of King County, King
County Parent Coalition
Brian Dahl, Washington State Developmental
Disabilities Council
Cheryl Felak, Parent
Alice Fong, United Way of King County
Stacy Gillet, The Arc of King County
Katie Harris, Parent
Ginger Kwan, Open Doors for Multicultural Families
Jennifer Lengyel, Total Living Concept
Eric Matthes, The Arc of King County
Hodan McHamed, Open Doors for Multicultural
Families
Debbie Meyers, SKCAC
Cathy Murahashi, The Arc of King County, King
County Parent Coalition
Candice Styer, Consultant
Robin Tatsuda, The Arc of King County
Kelli Welter, Direct Interactions
Chris Weber, The Arc of King County, King County
Parent Coalition

*Listed above are individuals who signed the roster

**Department of Social and Health Services (DSHS)
Developmental Disabilities Administration (DDA):**

King County Developmental Disabilities Division (KCDDD):

Lauren Bertagna
Sung Cho
Jim Ott
Michaelle Monday
Susan Stremel
Richard Wilson
Holly Woo

CALL TO ORDER / INTRODUCTIONS

The Board for Developmental Disabilities meeting convened at 9:34 a.m. on Wednesday, May 4, 2016, at the Tukwila Community Center, Community Room B. The Board Chair, Leo Finnegan, called the meeting to order with welcoming remarks and self-introductions.

APPROVAL OF MINUTES

0504201601 Leo Finnegan, Chair called for a motion to approve the March 2, 2016, Minutes. The Minutes were so moved, seconded, and approved as written.

CHAIR'S REMARKS

No remarks

PRESENTATION ON FUNDING RECOMMENDATIONS FOR DISCRETIONARY FUNDING

Jim Ott, KCDDD presented the Board's process in developing funding recommendations for discretionary funding strategies. King County is allocating \$500,000 to enhance the delivery of core services, piloting and implementing new service strategies, and addressing emerging needs, issues, and opportunities. Next steps include:

- Obtain final approval by the Department of Community and Human Services, Director;
- Create a work plan for each funding recommendation; and
- Provide regular progress reports at Board meetings.

Please contact Jim Ott by phone at 206-263-9060 or by email at James.Ott@kingcounty.gov with questions or comments regarding his presentation.

0504201602 Leo Finnegan, Chair called for a motion to approve the 2016 discretionary funding recommendations. Theresa-Ann Clark requested that Strategy #1A be revised to read as follows: Enhance crisis response capacity to serve people with developmental disabilities. The motion was so moved, seconded, and approved as amended.

GENERAL PUBLIC INPUT

Stacey Gillett, The Arc of King County announced Joe Cunningham has accepted a position with King County Councilmember Claudia Balducci's office as a Human Services Policy Analyst. Stacey publicly thanked Joe for his work on behalf of individuals with developmental disabilities.

Susy Stremel, KCDDD introduced a new team member Sung Cho, Employment Program Manager. Sung brings a background in employment services for youth who



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may experience disabilities, homelessness, juvenile justice issues, or have been determined to be at risk.

POSITIVE HAPPENINGS

Deborah Anderson, Board member made the following announcements:

- The Bellevue Aquatic Center's warm water pool is a resource for therapy and rehabilitation.
- Vashon Island families will begin meeting on the fourth Sunday of the month to discuss various disability related topics. On May 22, 2016, families will be discussing Individualized Educational Programs, Title IV, and residential housing.

Marla Veliz, Board member made the following announcements:

- Parent Education Night focuses on preparing students and families for transitioning strategies as they start their life beyond the classroom. The workshop will be held on May 12, 2016, starting at 6 p.m. at the New Horizon School located at 1111 South Carr Road, Renton;
- Seattle Foundation's GiveBIG was extended through May 4, 2016, so donate to your favorite charity.

Kelli Welter, Direct Interactions announced the annual Autism fundraiser at the Museum of Flight on May 22, 2016, from 11:30 a.m. to 4 p.m. located at 9404 E Marginal Way S, Seattle.

Stacy Gillett, The Arc of King County announced their 80th Anniversary Legacy Gala on Saturday, May 14, 2016, from 6 - 10 p.m. at The Westin Bellevue located at 600 Bellevue Way NE, Bellevue.

Leo Finnegan, Chair announced the fourth annual Mother's Brunch on Sunday, May 8, 2016, from 11:00 a.m. - 12:30 p.m. at Swedish Hospital located at 751 N.E. Blakely Drive, Issaquah to celebrate moms who have kids with developmental disabilities. Please download a registration form at <http://lifeenrichmentoptions.org/events/> and email it to Abbey Rodriguez at info@lifeenrichmentoptions.org.

Leo Finnegan also distributed copies of a new resource handout developed by the Washington State Developmental Disabilities Council (DDC) to assist individuals to identify sources of support to reach specific goals and help with planning. He shared information about the Informing Families website, which provides news and information for individuals and families. You can sign up for the newsletter at www.informingfamilies.org/news.



REGIONAL ADMINISTRATOR / FIELD SERVICES REPORT

Lauren Bertagna, DSHS/DDA reported on the following topics:

- Individual and Family Services Waiver;
- School-to-Work Assessments;
- State Only Employment;
- State DSHS/DDA Budget;
- Community First Choice program; and
- Creation of Deputy Regional Administrator positions - Lauren Bertagna was appointed to be the Deputy Regional Administrator for Region 2.

KING COUNTY DIVISION DIRECTOR'S REPORT

Holly Woo, KCDDD reported on the following topics:

- The division is currently working on updating its website to make it more user friendly;
- The division is anticipating that a Request for Qualifications (RFQ) for Employment services and an RFQ for Community Access services will be released in May;
- Publicly thanked Jim Ott for his work with the Board members to develop the funding recommendations;
- The Early Intervention Program's Birth-to-Three Equity Initiative project was featured in the March issue of the Zero to Three Journal. This was a major accomplishment for the program. The project launched in April 2015 as a multiyear systems change process to strengthen equitable access, services, and child and family outcomes in King County's Early Intervention system. The article describes the training of agency leaders and "equity facilitators" that is underway to provide universal access to a foundational level of training for all staff which addresses racism at individual, organizational, and systemic levels.
- The King County Executive recently submitted his proposal for the Youth and Family Homelessness Prevention Initiative to the King County Council. This proposal is the first strategy funded by the Best Starts for Kids levy and focuses on preventing youth and family homelessness.

BOARD RECRUITMENT

The Board for Developmental Disabilities is seeking residents of King County interested in serving on the board. The board is a 15-member citizen's advisory board, which provides oversight of community services for residents of the County who have intellectual/developmental disabilities, cerebral palsy, epilepsy, autism, or other neurological impairments, and their families. The Board develops plans, makes



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recommendations on the use of available funds, and advocates for increases in state funding and improvements in services.

MEETING REMINDER

The next Board for Developmental Disabilities meeting is scheduled for June 1, 2016, from 9:30 – 11:30 a.m. at the Tukwila Community Center, Community Room B located at 12424 42nd Avenue S., Tukwila.

The next King County Interagency Coordinating Council meeting is scheduled for May 9, 2006, from 9:30 a.m. – 12:30 p.m. at Well Spring Family Services, Boeing Community Room located at 1900 Rainier Avenue S., Seattle.

MEETING MATERIALS

All meeting materials presented at the Board meetings will be posted on the KCDDD's website with board meeting minutes at
<http://www.kingcounty.gov/healthservices/DDD/board.aspx>.

ADJOURNMENT

There being no further business to come before the board, the meeting was adjourned at 11:30 a.m.

Prepared by:
Michaelle Monday

Attested by:
Holly Woo





Ready, Set, KNOW...

ANNOUNCING ENROLLMENT OPENINGS

Individual & Family Services

Thanks to additional funding by our state legislature last year, our state has opened its door to enrollment for nearly 4,000 children and adults on DDA's No Paid Services Caseload.

IFS is Open for Enrollment. If your son or daughter is a client of the Developmental Disabilities Administration (DDA) and not receiving a paid service, they may be eligible to receive a broad array of services and supports through the Individual & Family Services (IFS) waiver. IFS has four different funding levels (determined by assessed need): \$1200; \$1800; \$2400; \$3600.

Family Income is Not Considered. After an assessment determines level of need, a financial eligibility determination is made based on the individual's income*, not the family's. In addition to IFS services, clients on the IFS waiver will be eligible for Apple Health/Medicaid health care.

*DDA clients who have resources in their name in excess of \$2,000 may not be eligible for the IFS waiver.

IFS SERVICES INCLUDE:

- ▶ Assistive Technology
- ▶ Behavior Support & Consultation
- ▶ Behavioral Health Stabilization
- ▶ Community Engagement
- ▶ Environmental & Vehicle Modifications
- ▶ Peer Mentoring
- ▶ Person Centered Planning Facilitation
- ▶ PT, OT, Speech, Hearing & Language
- ▶ Sexual Deviancy Evaluation
- ▶ Respite Care
- ▶ Skilled Nursing
- ▶ Specialized Medical Equipment & Supplies
- ▶ Staff/Family Consultation & Training
- ▶ Supportive Parenting Services
- ▶ Therapeutic Equipment & Supplies
- ▶ Transportation (non-Medicaid Broker)



If your son/daughter is on the No Paid Services Caseload and has a need that could be met by the IFS waiver, call DDA and request IFS services.

Service Request and Information Line

Region 1

Spokane: 800-319-7116
Yakima: 866-715-3646

Region 2

Seattle: 800-974-4428
Everett: 800-567-5582

Region 3

Tacoma: 800-735-6740
Olympia: 888-707-1202



CHARTING the life course



Integrated Services and Supports

People need supports to lead good lives. Using support from lots of different sources helps to create a full, inclusive life that's not limited to, or defined by, paid services. Use this form to help identify sources of support and personal strengths to reach a specific goal or larger vision.

My Goal: _____

Technology
(devices, apps,
equipment)

Personal Strengths & Assets

Personal Relationships
(family, friends,
others I know)

**Sources of Support
to Reach My Goal**



For more help with planning,
use our free online planning
tool at www.mylifeplan.guide.

Community Based
(free and low-cost resources in my community)

Eligibility Specific
(paid services and benefits)



Informing Families
Today and Tomorrow

Informing Families is a collaboration between the Washington State Developmental Disabilities Council (DDC), Developmental Disabilities Administration (DDA) and other partners throughout the state. We offer trusted news and information that empowers individuals and families to be active participants in planning and creating opportunities to live a full, inclusive life. Sign up here: www.informingfamilies.org/news.

Applying for Developmental Disability Services



DDA: The Door to DD Services

The main door to services for individuals with intellectual/developmental disabilities in our state is the **Developmental Disabilities Administration (DDA)**. It's where people go to get help for in-home, out-of-home, and community-based services. Learn more about DDA services here: dshs.wa.gov/dda.

Important: Most services are not an entitlement, which means that being eligible for DDA does not automatically result in enrollment for services. There can be a long wait, but it's important to take the first step, which is **applying for a determination of DDA eligibility**.



3 Things to Know About Applying for Determination of DDA Eligibility

#1 To apply for DDA eligibility, you must:

Be a resident of the state.

- DDA cannot even begin to process your application unless you live here.
- If you live in another state, your eligibility for services will not transfer.

and

Have a qualifying condition.

DDA's qualifying conditions for developmental delay and intellectual/developmental disability are used to determine eligibility. You can find them here: www.dshs.wa.gov/dda (click on Eligibility).



#2 How to apply for a determination of DDA eligibility at different ages:

Birth to Three

Apply for Early Support for Infants and Toddlers (ESIT). A Family Resources Coordinator (FRC) will help you obtain screenings, services and supports. Learn more here: www.del.wa.gov/development/esit.

DDA requires a re-determination of eligibility at age 4, so you will need to re-apply for DDA services *before* that happens. DDA will send a notice 6 months prior to your child turning 4.



Age Three and Older

Request a determination of eligibility from your local DDA office (or online). Find the office nearest you: dshs.wa.gov/dda.

You will be asked for documents to verify identity, residency, disability, consent, and (where needed) guardianship or adoption records.

For an application packet, visit: www.dshs.wa.gov/dda (click on Eligibility).

#3 It's up to you to request to be assessed for services.

You must call to request services after you have been determined eligible for DDA. Some services are entitlement, such as personal care through Community First Choice; however, most DDA services are provided through a waiver program, which is not an entitlement. Enrollment in waiver programs are filled based on assessed need when there is available funding.

Once you have been enrolled in services, you will be assigned a case manager and service planning will begin. *It's very important to request the services you need, so that you can be contacted when there's an opening for that program or service.*



Get Organized for Life



No matter your son/daughter's age, chances are, you will need to apply for services, benefits or enrollment in a program throughout many stages of life. Save yourself some time and start giving all your important documents a good home so that you'll be able to find what you need when you need it.

Here are some easy ways to store your files:

- **Low cost file box.** Most stores have lots of fun organizing supplies. Buy an accordion file or portable box with file hangers in a color that stands out from the crowd—something that's easy to spot.
- **Free organizer.** Seattle Children's Hospital also offers an expandable plastic file folder that some families have found really helpful. You can request a file folder here: cshcn.org/planning-record-keeping/care-organizer.
- **Thumb drive.** Many services have online applications to determine eligibility. Scanning and dropping files onto a thumb drive makes it really easy to upload the necessary documents. It is also a great way to back up your paper files and take with you in case of an emergency.

Most Commonly Requested Documents

ID

Birth Certificate, Social Security card, picture ID and proof of Washington State residency (e.g., utility bill, voter registration).

Approvals

Many services use eligibility for another program as criteria for their own, so be sure to keep all approval letters, but especially those from SSI, DDA, Apple Health, and any housing assistance program.

Assessment(s)

Medical, psychological, and educational assessments/evaluations that identify disability and/or a disability-related need for services/treatment.

Diagnosis

Proof of disability is required when applying for disability-related benefits and services in all areas of life: education, medical, housing, employment, home & community supports, special needs trusts, and programs you might not even know exist until your son/daughter needs it.

Education

Psych eval and test results from the school psychologist, notes from school, as well as a log of any school-related incidents or behaviors. Keep copies of all IEPs, and ask your child's school for a copy of the full school file at the end of the year (or anytime, really).

Financial

Most benefits and services have a financial eligibility component to them. If your child is under 18, keep copies of your previous year's tax return, as well as a list of resources and assets. If your child is 18 or older, only his/her income and resources are counted; keep monthly pay stubs for reporting to SSI.

Legal

Guardianship papers, Representative Payee, Power of Attorney for Medical and/or Financial, as well as a Letter of Intent stating what your wishes are for your son/daughter.

Medical

Health insurance; test results; medication; therapies, immunizations; most recent dental/doctor visit; and contact information for all health care professionals.

Plans

Whether it's a person-centered plan for life and/or services, planning documents are an important part of ensuring that everyone is working toward goals driven by the individual and family. In some cases, such as guardianship duties, having a documented plan of care is required.

Trust(s)

Special needs trust account information, records and accounting.

Understanding DDA Services: Waivers and Community First Choice

Nearly all services delivered through DDA are part of a federal Home & Community-Based Services waiver. They're called waivers because they waive the option to receive services in an institutional setting, choosing instead to receive the same or similar services in their own home and community. DDA has five different waivers, each with their own set of services and funding limits:

Individual & Family Services (IFS)

For children and adults living in the family home. Services include: Assistive Technology, Respite, Skilled Nursing, Behavior Support & Consultation, Environmental & Vehicle Modifications, Specialized Medical Equipment, OT/PT, Speech, Hearing & Language Services, Staff/Family Consultation & Training, Transportation, Peer Mentoring, Person-Centered Planning Facilitation, Supported Parenting, and Community Engagement. Annual funding levels are based on assessed need: \$1,200, \$1,800, \$2,400, \$3,600.

IFS
AGES
3 AND UP

Basic Plus

For children and adults living in the family home or other community-based setting (such as Adult Family Homes), and whose ability to continue being supported in that setting is at risk without additional services. Services include: Personal Care, Respite, Skilled Nursing, Behavior Support, Adult Dental Services (Age 21+), Environmental Accessibility Adaptations, Specialized Medical Equipment/Supplies, OT/PT, Specialized Psychiatric Services, Staff/Family Consultation & Training, Transportation, Supported Employment, and Community Access.

BASIC
PLUS
ALL
AGES

CORE

For children and adults at immediate risk of out-of-home placement who have a need that cannot be met by the Basic Plus waiver, and who: may need up to 24-hour residential services that include training and education; or, who may require daily to weekly one-on-one support for physical or health needs. Services include all those available under Basic Plus*, as well as supported living services. (*CORE waiver services provide more funding for services than Basic Plus, based on assessed need.)

CORE
ALL
AGES

Children's Intensive In-Home Behavioral Support (CIIBS)

For children (ages 8-20) living in the family home who are at risk of out-of-home placement due to the intensity of their behavioral challenges. Services include: positive behavior support and team based planning that builds upon strengths and works toward outcomes driven by the family. Each child's team includes family, friends, providers, school staff, and others. The family partners with a behavior specialist to create and follow a positive behavior support plan that fits the whole family. Other services include respite, assistive technology, and therapeutic equipment and supplies.

CIIBS
AGES
8-20

Community Protection

For adults who need 24-hour on-site awake staff supervision and therapies to maintain their own and community safety. The goal of the Community Protection program is to provide a structured, therapeutic environment for persons with community protection issues in order for them to live safely and successfully in the community while minimizing the risk to public safety. Community Protection services include Supported Living (Residential) Services, Supported Employment, Behavior Support and Consultation.

C/P
ADULTS

Increasing Independence: Community First Choice

Community First Choice

(CFC) is a non-waiver program offered by DDA that strives to help children and adults be as independent as possible while living at home.



CFC is an entitlement. This means that if someone meets the financial and functional eligibility for CFC, they can receive it.

CFC Services Include:

Personal Care assistance with everyday tasks, such as bathing, dressing, meal preparation and essential shopping.

Assistive Technology to help individuals be more independent with daily tasks.

Skills Acquisition Training on daily living skills such as cooking, housekeeping tasks or hair care.

Personal Emergency Response Systems (PERS), an electronic device which allows you to call for help in an emergency.

Call DDA's Service Request & Information Line to learn more about waivers and Community First Choice.

Region 1

Spokane: 800-319-7116
Yakima: 866-715-3646

Region 2

Seattle: 800-974-4428
Everett: 800-567-5582

Region 3

Tacoma: 800-735-6740
Olympia: 888-707-1202



“We’re Listening” **Parent Community Listening Sessions Report**

Conducted by:
The Arc of King County,
The King County Parent and Family Coalition
and
King County Division of Developmental Disabilities

Report Issued May, 2016

Summary and Findings

Background

In April and May, 2016, The Arc of King County in collaboration with King County Division of Developmental Disabilities conducted three community listening sessions for families of individuals with intellectual and developmental disabilities (I/DD). The purpose of these sessions was to:

- listen to parents, family members, and caregivers in the region about their access to services and the quality of services
- identify gaps or challenges in getting services and supports
- solicit ideas about changes or improvements to the I/DD system

The sessions were organized through the King County Parent and Family Coalition (KCPFC), a network of over 800 parents and caregivers in King County who support a child or adult with an intellectual or developmental disability.

In order to gather information from a variety of stakeholders, listening sessions were held in three different parts of the Puget Sound region. The sessions were held on April 12, 2016 in Bellevue at the Highland Center; April 18, 2016 in Shoreline at the Public Library; and on May 3, 2016 in Renton at Open Doors for Multicultural Families, all in the evening.

Over 126 people attended the meetings, including families from a variety of ethnic, cultural and language communities: African American, Korean, Cambodian, Spanish, Vietnamese, Somali and Chinese. The largest number of participants were from diverse communities (over 65 individuals) and smaller groups were conducted in the native languages of Spanish, Vietnamese, Somali, Cambodian, and Korean. In the Bellevue session, the larger group was broken into 4 smaller groups with a large group report-out at the end; in Shoreline, there was one big group conversation; and in Renton, smaller groups were conducted in the participant's native language and then a larger group report-out was conducted in English.

Notably, the majority of families who came to the listening sessions were parents or caregivers of adult loved ones. There were no families who identified as having an infant or toddler with I/DD and only a handful of families who presented with school-age child issues. It is recommended that future listening sessions be considered to target a broader audience of young parents and school age parents.

Moreover, these sessions were focused on the needs of families and caregivers, rather than hearing directly from young adults or adults with intellectual and developmental disabilities themselves about what they might experience or want. For individuals with severe behavioral and communication needs, it can be difficult (but not impossible) to solicit these feelings and experiences and an effort should also be made to hear more from self-advocates who are supported to communicate their own needs in future sessions.

Key Themes

Several key themes emerged from the sessions, including:

- 1) **Not enough options** for services and supports overall to provide sufficient respite to families, or create a meaningful day for adults with I/DD in the community.
- 2) **Too few options that would allow adults with I/DD to live independently** from their families with support.
- 3) **Feelings of Isolation** as a caregiver *and* for the people being cared for.
- 4) **Supported employment options for adults with I/DD are too limited, especially for individuals with I/DD who have significant cognitive, behavioral, communication or medical/health needs.**
- 5) **Not enough recreational options** for people with I/DD.
- 6) **Lack of transportation** served as a significant barrier to accessing programs and services which are available. Parents reported few public transportation options, there was a general feeling that Access bus service was an unreliable and unnecessarily inefficient system to use, and working families were stretched to get their loved one anywhere during the work day.
- 7) With too few options for a meaningful day for adults, and no relief from caregiving, many families reported **feelings of being overwhelmed, burned-out and stressed**. Stresses were exacerbated by the financial impact of job loss associated with caring for a family member with I/DD.
- 8) Some families expressed **frustration with policies** that place limitations on the number of individuals with disabilities who can be served in a community setting at a time. These families expressed a concern that with the unavailability of community programs and services, there is more isolation in the community (presumably due to lack of funding for inclusive setting options) and this significantly impacts individuals with the most severe disabilities.¹

For families with **school age children** who attended the listening sessions, the following concerns were shared:

- 1) **Schools are often not culturally or linguistically friendly** for immigrant and refugee families of students with disabilities. Language access is a significant barrier to parent involvement and understanding what is happening at school.

¹ For families who expressed these specific concerns, they often shared the great difficulty or very poor experiences they had finding employment, day, social or living supports. These families felt that group employment or group care would be more cost effective, provide a peer group of disabled peers and would be better than not having adequate and appropriate services. There did not appear to be a belief expressed that segregated services were inherently better, and there was considerable frustration that policies talk about, require, or express desire for employment and inclusion for people with I/DD and then services are inadequately funded or unavailable, putting families in a terrible predicament.

- 2) **Students with behavioral challenges are having a difficult time in school**, some being expelled or suspended for behavior related to their disability, sometimes police are called, and many reported that their teachers did not have the tools to provide positive behavioral support.
- 3) **Transition services provided by schools do not prepare families to fully understand the changes that occur into adulthood.** Many described graduation from the school setting as “dropping off a cliff”. While many reported participating in transition-related discussions with their schools, several described being “shocked” or “panicked” by the lack of services and supports in the community for adults with I/DD.
- 4) **The DDA state system is difficult to navigate.** Especially for immigrant and refugee families for whom English is a second language, the application process, deadlines, and understanding what services are available was reported as being very daunting.
- 5) **Not enough childcare for children with disabilities before/after school and during the summer, especially for children over the age of 12 years old.**
- 6) **There are too few summer programs accessible for children with disabilities, and too few stipends for the summer programs that are available.**

Conclusions

These three listening sessions allowed families to express their concerns, ideas and solutions in order to improve the system of care for individuals with intellectual and developmental disabilities and the support systems for their families and caregivers in the King County region.

The comments and experiences shared by families suggest the following:

- **Collaboration among municipal, county, and state systems is critical because the issues and solutions raised are complex and multifaceted.** In some cases, the issues and solutions raised were not within King County's purview or control. Nonetheless, they are key to understanding the system of care and partnering with families in order to create more effective programs and services.²
- **For many families who care for someone with I/DD, isolation, frustration, anger and hopelessness were expressed toward a system that does not adequately fund the values that it espouses.** Specifically, federal law and state policy mandate that services focus on inclusion and treating people with developmental disabilities and their families as valued citizens of the state of Washington. But families consistently reported that insufficient resources exist in the community to ensure that families are well-supported and there are enough programs that provide for a full and meaningful day, including transportation, and available to all persons with I/DD, regardless of the severity of their disability.

² King County DDD is primarily contracted by the state to provide early intervention and supported employment services. Through local dollars, it also provides information and referral, technical assistance, parent-to-parent and advocacy services. But King County as a whole serves and supports all young children, youth, and families via its strategic plan.

- **King County, which enacts federal and state policy on the local level, plays a pivotal role in expanding the availability of community-based programs to universally meet the needs of its community members, including all children, youth and adults with intellectual and developmental disabilities.** This will assist in the achievement of full inclusion and participation and reduce the isolation and stress associated with over-reliance on families to provide the majority of care throughout the lifetime of someone with I/DD.³
- **The transition to adulthood for families and individuals with intellectual and developmental disabilities is precarious, and sometimes fosters crisis in caregivers and people with I/DD as they cope with this stage of transition.** Due to a lack of programs and services, many parents reported a need to quit their job to stay home and care for their loved one. For the individual with I/DD, this transition often lead to isolation due to a lack of programs and services and loss of a peer group (nondisabled and disabled cohort) developed during many years in school. Upon graduation, many families reported that their loved one no longer had regular contact or relationships with friends or peers, they could not find sufficient day programs where other peer adults were available (with and without disabilities or other similar compatibilities). With only a patchwork of services available, this meant large periods of time caring for or being cared for by a family member. This posed significant strain on both the caregiver and the person with I/DD. For many families who are culturally and linguistically diverse, these challenges were compounded.
- **Family members entering the adulthood stage crave information and supports** so that they don't feel they have "dropped off a cliff". Expansion of parent-to-parent and information/referral resources was an expressed need as well as improvement of transition services from public schools. Parents and caregivers need a place to problem-solve, brainstorm and find solutions to their needs and prefer to get information from each other.
- **Working families have been profoundly and negatively impacted financially from caring for their loved ones with I/DD.** They urgently seek more programs and supports that allow them to continue working while still caring for their adult loved one. Families consistently reported they want programs that allow their adult loved one to have a meaningful, engaged life without one parent quitting work in order to manage the transportation, facilitation of scheduled activities, organization of programs and services, and creation of ongoing relationships with someone other than a family

³ Under Supreme Court decision in Olmstead, all states including Washington must establish a "comprehensive state plan" of services that prevents the isolation, segregation, and unnecessary institutionalization of children and adults with I/DD. The Supreme Court noted that the unjustified institutional isolation of person with disabilities is a form of discrimination and continued institutional placements of people with disabilities who can live in and benefit from community settings perpetuates the unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life. This ruling effects not only all persons in institutions and segregated settings, but also people with disabilities who are at risk of institutionalization, including people with disabilities on waiting lists to receive community based services and supports. And, in a recently released new set of rules from the Center for Medicare and Medicaid Services, home and community-based settings must focus on the nature and quality of individuals' experiences. The requirements are intended to maximize opportunities for individuals to have access to the benefits of community living and the opportunity to receive services in the most integrated setting. The rules specifically provide for systems to support employment and work in competitive integrated settings, and engage in community life.

member. Expansion of before/after school childcare and summer programs with available stipends for working families is also a need.

- For family members who are paid as caregivers for their loved one, a **simplified system of payment and requirements** was requested, and changes to the rules to promote easier access to respite providers and other providers was needed. Families reported a severe shortage of providers available to help them continue caring for their loved one at home. They cited the need to change the training requirements which were reported to be onerous and not relevant to ensuring quality care for people with I/DD who are cared for by a family member.
- **Aging caregivers in their retirement years who have been caring for their loved one in their home for much of their adult life urgently need to plan for the future and want to have sense that their loved one will be safe when they are gone.** That means knowing their loved one will have a place to live and someone who will care for them. But working families also expressed this need and desire to have their loved one well-cared for and engaged in a meaningful day outside their home, and possibly shared living and care outside the home.
- **More options for supported employment and services that constitute a meaningful day for adults with I/DD, especially with the most significant disabilities, are needed.** For many families who reported they received supported employment for their loved one, often the hours were very low per week. The higher the acuity of the individual with a developmental disability – specifically if the individual with I/DD had behavioral, communication, or medical/health or physical care needs – fewer reported hours, if any, were provided. Many families felt that their loved one could not or should not be required to try employment and described years of “waiting” for another service as they unsuccessfully navigated the supported employment world. Many families reported feeling that a combination of supported employment and other day program (social/recreational) options were needed, along with transportation to those activities.
- **Families need more support to navigate the public schools and understand the DDA system of support.** Some families reported learning that at various times they were given incorrect information from their case managers about how they could use their waiver, or what services were available through Medicaid. Other families reported feeling that case managers were not helpful in assisting with “community mapping” or finding services within the person’s local community to build a meaningful day. Families with limited English proficiency also need support to get language access to understand services available to their children, and to be engaged in their child’s school. School age families need help with issues such as disciplinary exclusion and more positive behavioral supports in school.
- **More recreational programs are needed for children and adults with developmental disabilities.** Families reported that few programs were available in general, and camps in particular often ask parents of children with high needs to provide their own additional support. Families are not allowed to use Medicaid funds for respite and personal care at the same time, leaving many to have to pay for these additional services on their own.
- **Overall, programs must be expanded that address the social, behavioral, communication, recreational, supported living and supported employment needs of adults with I/DD in order to include them in the community and support peer relationships.**

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Most importantly, we are extremely grateful to the families who came to each session and shared their stories and ideas with us so we could better understand their needs.

TABLE NOTES

Key Themes from Group Discussion

Overall Shortage of Provider and Program Options in Community

Provider availability

- One of the biggest, most critical problems for in-home care
- For in-home supports, if providers were available, overtime wouldn't happen
- Trouble finding nurse-delegated providers if significant health issues for person with I/DD
- Some contract providers are not skilled or adequately trained in behavior and communication
- Parents are suffering because they can't find suitable care in their communities, then they are judged for choosing institutional care when they are desperate for trained staff and a place for their loved one to be adequately cared for

Provider incentive

- Career path options not available
- Low pay
- High turnover
- Caregivers tired/burnt out

Lack of programs in the community for adults with I/DD

- Working families need help to create a meaningful day for adults with I/DD
- Very hard to find information about programs in the community
- Parents bear the burden of putting together services that are largely unavailable and don't fill a full day with engaging activities, interactions with peers, or employment.
- Some parents have found their adult children jobs on their own

Lack of Respite Services and Providers

Respite availability

- Respite is too difficult to obtain
- Can't find respite providers so can't spend the money the state provides

Respite policies

- Rules are too rigid, training requirements are unrealistic
- New overtime restrictions and assessments reduces parents' ability to use respite

Challenges getting Community access

Transportation

- Metro bus trainers are amazing, but not enough options for public transportation
- A lot of waste in Access bus system – don't come on time, large windows of "waiting", limitations on the footprint for access (availability outside major urban area)
- 90 minutes to get to a location 15 minutes away

Services

- Lack of community-based services overall
- Need Parks Department to expand with more services
- Transportation options need to be expanded
- Lack of after school activities and childcare
- No access outside of school
- Need more day programs for adults
- How can we create a meaningful day after school?
- Barriers to typical activities and programs all kids should have access to
- Even if you find a good program somewhere, kids with behavior issues turned away

Few Social Opportunities or Ways to Develop Relationships

- Individuals with I/DD are isolated with no friends
- No opportunities to meet people and form relationships
- All people need to feel belonging, "find their place in the world"
- Lose all of their school friends, whole community is lost when graduate

Housing and Residential Services

- Extremely hard to find housing – affordable, accessible – even with a Section 8 voucher
- Feelings of a "disaster pending" from senior parents
- "Where will our kids go in 5-10 years"
- Senior parents need supported living, residential provider options desperately
- Feeling that their child will never live outside their family home, even if they just need some supports
- Need to create a single point of entry for services

Parent hardship

Effect on family

- Long-term care is "eroding" parents
- Feelings of hopelessness
- Forced to make some difficult choices if they can't get help supporting family member at home
- Can't work because have to care for children
- Need more family events can attend, circle of friends
- Very hard for single parents
- Need more respite

- Changes in billing system at state level (Individual Provider One) has been very disruptive and hard on families
- State should reconsider using Individual Provider One, go back to a phone system, need better trainings on the changes, many mistakes in system are causing families not to get paid for the services they are providing, many families rely on payments to make ends meet
- The overtime rules are unfair to families who already can't find enough care. If there were enough providers, then there wouldn't be overtime issues

Parents as case managers

- All responsibility has fallen on the parents to find housing, personal care, employment, recreation, day programs, relationships
- Not enough support for parent providers
- Parents need more access to information about where to find services

Cultural and Language Barriers to Services

- Families from different cultural and language backgrounds need language access
- Need interpreters who understand disability, have technical, medical vocabulary, consistent access to quality interpretation, especially in schools
- Many families need translation of written documents
- Many families don't understand how to get services
- Applications are very hard when don't speak English as primary language
- Deadlines for paperwork missed because don't have information in native language
- Parents need help in behavioral supports and understanding their child's disability
- Sometimes families are hurt by what people say to them, they feel discriminated against and that leads to isolation and pain
- Undocumented parents are afraid to ask for help
- Families need support within their own cultural and language communities

Employment

- Very difficult to find employment for people with I/DD with high acuity, behavior, or personal care needs
 - There is a generation of adults who did not receive any school-to-work transition and it is hard to secure them Supported Employment – they have no waiver, no connection to vendors so if they did not transition through school, they fell in a gap
 - Low job retention
 - Need more job coaches
 - Need support to find a job and keep a job
 - Need to be able to combine supported employment with other services to have a full day
 - Need transportation to job

- Adults with very significant cognitive, physical and behavioral needs don't have many options for employment, low hours, many stay at home and not working or getting other services

Education & behavioral support

- Lack of trained educators in Positive Behavioral Support
- School resource officers too often called to deal with behavioral issues at school or just school calls police
- Need more access to tutoring, mentoring
- Kids with behavioral issues often kicked out of school for behavior related to their disability. Not enough behavioral support for children or their families.
- Lack of information given to parents before graduation – what will happen? How connect with adult services?
- Behavioral issues often escalate at school, at home the child does better
- Schools don't work together with the parents
- Isolated in school program, no inclusion

Resources

- Not enough places to go to for information and help
- No coordinated systems
- Not many resources for low incidence disabilities
- Many families cannot afford fees for camps, recreation, private services
- fragmented

Policies & Requirements

Training Required for Providers

- Difficult 72 hours training requirement
- Training and certification not relevant to people with I/DD
- Not enough of the training focused on the individual needs of people with I/DD
- Who's regulating these?
- High fail rate, expensive
- Language barrier

Individual Provider One

- Issues with implementation
- This change is having a negative impact on families
- Confusing system
- Payment issues
- Confusing hour guidelines

General policy issues

- SEIU's influence and decisions by DSHS – who do they help?
- Overtime issues and missing/unclear guidelines (for in-home care providers)

- Focus on rule compliance trumps actual care and jeopardizes quality of care and availability of support
- Some families cannot qualify for DDA services and are struggling

Settings

- Some families have found what they need at an RHC, feel it is unfair that system doesn't recognize the need for some families to have more care, ok with group employment and group living, feel less isolated this way
- Tried many community settings and services and didn't work for loved one with very significant needs, finally got an RHC placement
- Feel policies have swung too far, not allowing group care or employment
- Inadequate choices in the community, and doesn't seem fair that system doesn't allow group employment or build facilities for people with I/DD to go to during the day

Quotes from Participants

School Support

"I'm tired of fighting the school system"

"We can't get an interpreter"

"They call the police and bring him home in a police car"

"My child isn't safe at school"

"Throughout my son's early intervention program, elementary, middle school, and high school years, I always had a network of other parents and educators who helped me navigate services, resources, and the special education system. These networks were a life-line for me. The support really began to drop off at the Adult Transition Program level."

Policies

"We're being suffocated and the government is not listening" and "We are tired of fighting – all of our lives are spent fighting for our kids, in school, when they are adults."

Parent Networks

"Everything I learned was from other parents"

"Parent networks are invaluable resources, but they drop off around the adult transition phase – just as a whole new host of issues are becoming relevant."

"Parents need a network for parents of adults with disabilities. There is a serious lack of support for us. KCPFC meetings provide support but there is not enough opportunity for networking during meetings – parents come early and stay late and have those important conversations while standing in the parking lot. This is not the fault of KCPFC, but it demonstrates more need (opportunity) to connect parents and people with disabilities to discuss the Adult Service System."

Care Providing

"There is a care provider crisis. (Our) son has had 25 different care providers in four years because they (providers) are forced to quit or take second jobs due to low wages. Given the odd hours and stressful/demanding situations, it is extremely difficult to find qualified people who are willing to work for the wages offered."

Housing

"Housing is difficult to find and maintain, even with a Section 8 voucher, primarily because wages and benefits do not cover rising rents. King County DDD needs to put a greater focus on housing options and residential as living in the family home is not a viable long-term solution for most families."

Residential Services

"I know it is difficult to find enough good care providers for adult family homes, shared living homes, respite, supported living, and in-home care, in general. I honestly believe there is a care provider crisis. I REALLY believe this about supported living. In the four years my son has been in supported living, he has had 25 care providers. They often quit or take on a second job, which conflicts with his hours, because they can't make an adequate living otherwise."

Solutions and Ideas Offered by Participants

Community network and support

- Parents need more information at every stage
- More Networking between families – setting up a system to help each other
- Create MORE regularly scheduled groups with speakers on specific topics where parents can get information AND network together to share ideas and information, brainstorm
- Need an online match system for provider partnerships – referral registry so families can share providers, find providers geographically and find providers who are trained, experienced with similar disabilities
- Let parents share care and connect to each other to share care
- Let individuals have employment and community access services under the waiver
- Parent panels needed to improve government systems
- Individuals with I/DD need more funded social opportunities (with peers, with and without disabilities), more opportunities to be together, make friends, engage with each other

Policies

- Counties need to work together more – King and Pierce should share resources in South End
- Counties should share best practices more
- DD needs to be pulled out from Aging and Adult Services because they do not have the same needs
- DDA needs to see parent providers as different from all other providers of care
- Research how other states run programs – look at their models
- Change the definition of long term care providers in WACs
- Create a waiver for training (SEIU)
- Parent provider classification needs its own rules because training needs to be relevant to the person
- Streamline forms

- Create more Simple fact sheets
- Create a better training for parents/caregivers to learn I/DD
- Applies to all categories: More cultural access – language, life experiences – difficulty navigating – more interpreters
- Get rid of Individual Provider One (state)

School

- Need advocates/case managers to go with families to IEP meetings
- More support for parents to navigate educational issues and challenges
- Training for school administration/teachers/counselors to know I/DD systems for transitions
- 1:1 support at school
- More positive behavioral support
- Police should not be called for behavior related to disability, need police to better understand how to respond in these situations when called to school

Community access

- Create more volunteer opportunities
- Create more services for 12-16 year olds as well as transition age individuals
- Need more camps available for low-income families
- Need more services over the summer for school-age children and youth
- Provide scholarships for camps and summer programs
- Offer more childcare stipends
- Develop more childcare options for kids with disabilities over the age of 12

Employment

- More access to Internships, Apprenticeships through county for Youth
- Need behavioral and communication supports

Housing

- Create a single point of entry for services
- Need more affordable housing
- Need more options for supported living models
- Stay focused on community integration
- Focus on models that reduce isolation and connect to public transportation
- Identify more public/private housing options
-

Innovation Needed

- Use existing community centers and expand programs
- Create a single point of entry for services
- Focus on engagement, stimulation (not just respite)
- Provide individuals with a sense of purpose
- Support behavior and communication
- Offer parenting classes
- Offer more information about alternatives to guardianship
- Reach out more to language and cultural communities



The Arc of King County
ACTION PLAN
In response to
Parent Community Listening Sessions
May, 2016

As a result of three listening sessions held in collaboration with King County Division of Developmental Disabilities in April and May, 2016, The Arc of King County identified several major issues that serve as barriers to the health and well-being of families who support children and adults with intellectual and developmental disabilities (I/DD).

Over 126 participants shared their experiences getting access to services for their loved one, including gaps, challenges, and ideas for how to change or improve the systems they use.

In collaboration with the King County Division of Developmental Disabilities, The Arc of King County works to provide effective prevention and intervention strategies for those most at-risk, expand and strengthen the network between family members in King County, and assist with access to services through outreach, advocacy and support.

The Arc of King County would like to lead an organized advocacy campaign and promote community solidarity so families can thrive in their

role supporting someone with I/DD to live actively as valued members of our community.

In an effort to address the concerns raised in the listening sessions, The Arc of King County outlines below several immediate strategies for supporting families in their quest to address some of these problems.

Each of the issues would benefit most from a multifaceted approach that includes families and the King County Board and Division of Developmental Disabilities also playing their own unique role in the solutions. The issues speak to a complex system of services in our state and at the county level – a system often difficult to navigate, especially for culturally and linguistically diverse families.

- 1) There are not enough options to provide sufficient respite to families or create a meaningful day for adults with I/DD in the community.

Action: This summer and fall, The Arc of King County will join with the Washington State Arc and the State Developmental Disabilities Council in their current efforts to negotiate with the NW Training Partnership, seeking ways to increase the number of available providers, reduce barriers to provider training, including changing the number of hours required and ensuring that training is relevant to I/DD populations and family needs.

It may be necessary to revisit the current state law which identifies training requirements. In addition, we will talk with the NW Training Partnership and DDA about developing systems that allow families to better identify providers in their geographic area and potentially share contacts with other families to avoid overtime limitations that are currently impacting (reducing) the ability of families to utilize a shallow pool of trained and eligible providers.

Families may want to be sure and ask for formal person-centered planning as part of their annual DDA assessment or as part of the School-to-Work program supports they receive.

The Arc of King County is also applying for additional funds to expand community mapping and person-centered planning for individuals and cohorts of families who support a young adult or adult loved one. These services are effective at helping families put together a meaningful day with

services THAT EXIST and assist in identifying options that meet individual needs of the family and person with I/DD.

Capacity-building is also needed and families may want to talk with their legislators (off session this summer) about their limited options and the difficult predicament this creates for working families, elder caregivers, and individuals with I/DD who are hard-pressed to find enough options to prevent isolation and institutionalization.

- 2) There are few options that would allow adults with I/DD to live independently from their families with support.

Action: Families may want to take advantage of the summer (without a legislative session in progress) to share this concern with their legislators and share their story.

King County Division of Developmental Disabilities and the Board may want to approach the county executive about this issue and add it to its annual legislative forum agenda.

The Arc of King County will share this issue with the State DDA administrator, the DSHS secretary, and legislators in meetings scheduled for this summer.

The Arc of King County will continue working with the Seattle Mayor's office, state legislators, county officials, and other supported living providers to address the minimum wage requirements, low benchmark rate for providers, and shortage of affordable housing which leads to difficulties finding homes for adults eligible for support to live in the community.

The Arc of King County is also attending Housing Trust Fund Advisory Committee and developing relationships with housing trust fund partners to expand the availability of homes and talking with the state DDA and DSHS about options for living in the community with support.

- 3) Many families reported feeling a sense of isolation, being overwhelmed, burned-out and stressed. Some reported that they had to quit their job to provide caregiving. The transition to adulthood from school was clearly a difficulty for the majority of families.

Action: The Arc of King County will continue to host an Into Adulthood “blog”, upgrading its reach and platform, and request additional funding from the state Arc to have Parent-to-Parent host meetings targeted to families in transition at least twice a year.

The Washington State Arc is also hosting a Fall Family Gathering where families across the state will be talking about their needs. The Arc of King County will reach out to families who would like to attend this meeting in order to invite their participation.

- 4) The supported employment options and hours provided for adults with I/DD are too limited, especially for individuals with significant cognitive, behavioral or medical/health needs.

Action: The King County Division of Developmental Disabilities may want to expand its High Acuity project in order to identify how to find additional employment options and identify ways to provide behavioral and communication support for in order to increase hours for adults with high needs.

The Arc of King County will work with the state Arc to amend the current state law that limits a choice be made between employment or community access so that a person can receive both services.

King County Division of Developmental Disabilities and the Board may want to approach the county executive about this issue and add it to its annual legislative forum agenda.

- 5) There are not enough recreational options for individuals with I/DD.

Action: The Arc of King County will work in partnership with community-based organizations such as Special Olympics, Outdoors for All, Boys/Girls Club, and other organizations to identify capacity-building initiatives.

The Arc of King County will identify who in city government is responsible for developing recreation options within identified cities and develop relationships – in order that families can share their needs and influence the capacity within the community for these programs.

Families may want to meet with city officials identified and express their needs.

King County Division of Developmental Disabilities may want to expand its funding in partnership with municipalities to expand the options for day recreational programs and stipends.

- 6) Many families shared that the challenges of obtaining transportation to the programs they *could* locate. They reported few public transportation options.

Action: The Arc of King County will identify who in city government(s) is responsible for transportation and identify opportunities for families and individuals to share their story and explain their needs.

The Arc will also clarify with state DDA what transportation is allowed under the Medicaid waivers.

Families may want to meet with city officials identified and express their needs.

- 7) Some families of adults with I/DD expressed frustration with policies that place limitations on the number of individuals with disabilities who can be served in a community setting at a time.

Action: The Arc of King County will identify who at the federal Medicaid office families may want to contact to share their concerns.

The Arc of King County will work on capacity-building so that more options are available to families and individuals with I/DD.

For families with **school age children** who attended the meetings the following concerns were shared:

- 1) Schools are often not culturally or linguistically friendly for immigrant and refugee families of students with disabilities. Language access is a significant barrier to parent involvement and understanding what is happening at school.

Action: The Office of the Education Ombuds is working in partnership with legislators of color and The Education Opportunity Gap Oversight and Accountability Committee (EOGOAC) to develop statewide language access policies and increase parent engagement supports to parents who are culturally and linguistically diverse in public schools. (See OEO report at their website: oeo.wa.gov).

Families may want to contact their legislators to support the development of language access policies across the state in every school district and identify this as a McCleary issue since it is a civil rights issue to obtain language access for limited English speaking families in the public schools.

The Arc of King County will meet with interpreter organizations to discuss what additional training could occur that will assist families to get interpreters who have school-related vocabulary and better access to interpreters in school settings.

King County DDD may want to consider a public awareness campaign that informs families of their right to language access in public services, including DDA and public schools and encourage the availability and use of interpreter services (through family education).

- 2) Students with behavioral challenges are having a difficult time in school, some being expelled or suspended for behavior related to their disability, sometimes police are called, and many reported that their teachers did not have the tools to provide positive behavioral support.

Action: The Arc of King County has applied for federal and local grant dollars to expand advocacy services to families of school age children so that a parent can have support at IEP meetings and better understand newly adopted state prohibitions on restraint, isolation, and discriminatory discipline policies.

The Arc will join families in advocating for funding in order to train teachers in positive behavioral supports as part of McCleary.

King County DDD may want to consider making connections with First Responders to have conversations and explore alternatives and options for a first-response when called to school for behavior related to a disability.

- 3) General feeling that the transition services provided by schools do not prepare families to fully understand the changes that occur into adulthood. Many described graduation from the school setting as "dropping off a cliff". While many reported participating in transition-related discussions with their schools, several described being "shocked" or "panicked" by the lack of services and supports in the community for adults with I/DD.

Action: See recommendations in #3 above. In addition, the county may want to consider sharing the results of the listening sessions with the Transition Group at the Puget Sound ESD.

- 4) It is difficult to navigate the DDA state system. Especially for immigrant and refugee families for whom English is a second language, the application process, deadlines, and understanding what services are available was reported as being very daunting.

Action: The Arc of King County will apply for additional funds to expand its outreach into ethnically, culturally and diverse communities in order to provide navigation support to families seeking DDA services.

The Arc of King County will continue to provide language and cultural access to anyone who contacts the organization and asks for assistance, with a particular focus on expanding outreach to the Native American community and local tribal organizations.

The Arc of King County has recently experienced an uptick in contacts by families who are homeless or living in shelters and either have a child with I/DD or are an individual with I/DD who need services from DDA. We are partnering with local shelters and focusing on seeking funding to provide consistent resources to such at-risk families or families in crisis.

- 5) There is not enough childcare for children with disabilities before/after school and during the summer, especially for children over the age of 12 years old.

Action: The Arc of King County will continue its work with the Department of Early Learning and municipalities to build capacity for trained childcare providers and available childcare options for children with I/DD with a special focus on this population.

Families may want to carefully watch for Best Starts for Kids conversations as additional supports are developed in the community for youth – including youth with I/DD. The Arc of King County will also be participating in meetings to be sure that I/DD populations are included in ALL community capacity-building conversations.

- 6) There are too few summer programs accessible for children with disabilities, and too few stipends for the summer programs that are available.

Action: The Arc of King County will continue its work with the Department of Early Learning and local municipalities to build capacity for trained childcare providers and available childcare options for children with I/DD with a special focus on this population.

Families may want to carefully watch for Best Starts for Kids conversations as additional supports are developed in the community for youth – including youth with I/DD. The Arc of King County will also be participating in meetings to be sure that I/DD populations are included in ALL community capacity-building conversations.

Overall Recommendations:

- 1) Additional listening sessions may be developed and should include representation from the state regional Developmental Disability Administration.

Action: The Arc of King County will ask the region to send a representative(s) and take these overall recommendations to meetings with DDA this summer.

- 2) Similar meetings with self-advocates should be organized to hear their concerns.

Action: The Arc of King County will work through its Community Change Champions program to reach out to People First, SAW and other self-advocate organizations to raise this issue at the upcoming People First Conference and other local meetings to enlist their resources to organize additional listening sessions.



The Arc of King County's Critical Pathways to Success

A Picture of Success for Charting the Beginning of the Next 80 Years of Service

The Arc
King County

The Arc of King County is at the heart of our community's civil rights movement for all persons with intellectual and developmental disabilities to thrive as equal, valued and active members of the community.

Goal #1: LEAD ORGANIZED ADVOCACY Organize the Community's Largest Coordinated Advocacy Campaign on Behalf of People with Intellectual and Developmental Disabilities to Fully Live in Community with all People	Goal #2: PROMOTE COMMUNITY SOLIDARITY Mobilize The Community's Largest Organized Group of Advocates and Their Supporters	Goal #3: OFFER RESOURCE & REFERRAL Offer The Most Comprehensive Community-Based Resource Center for Technical Assistance To Serve Individuals, Families and Organizations on the Front Lines of Supporting People with Intellectual and Developmental Disabilities	Goal #4: PROVIDE DIRECT CARE and SERVICE TRAINING Provide Exemplary Care Services as the Community's Example of Quality Service Delivery
Measurements	Measurements	Measurements	Measurements
<ul style="list-style-type: none"> Organize an annual advocacy campaign to elevate the status of civil liberties, protection and involvement of persons with intellectual and developmental disability Publish an annual policy & legislative platform Train 25 activist advocates & other volunteers to effectively advocate 	<ul style="list-style-type: none"> Launch a Membership Program to attract 300 individual and corporate members Increase Charitable Giving by 15% through increased member, volunteer and community engagement approach Analyze and increase In-Kind Contributions and Volunteer Engagement 	<ul style="list-style-type: none"> Provide over 13,000 hours of Peer-Based & Professional Information and Referral Services Recruit, train and involve at least 30 new volunteers in providing peer-based services Act as a resource center to other providers of care in the community 	<ul style="list-style-type: none"> Increase Supported Living Program Participants by 10% Increase Parent-To-Parent programming and support by 20% Double Representative Payee Community Participants Enhance at least 8 Key Partnerships in the community that Increase Service Availability and Quality
Critical Pathways & Outcome	Critical Pathways & Outcome	Critical Pathways & Outcome	Critical Pathways & Outcome
<p>Priority Strategies for 2016-2017: Create and Support a Board-Level Advocacy Team</p> <p>Launch A Community-Wide Awareness Campaign</p> <p>Offer Quarterly Advocacy Training Sessions</p> <p>Priority Partnerships for 2016-2017: Special Olympics, Headstart and ECEAP, Youth-Serving Organizations 19 School Districts in King County Department of Early Learning UW School of Social Work Low Income and Other Housing Providers Local Tribal Organizations</p> <p><i>The Arc of King County unites voices to advance a common agenda.</i></p>	<p>Priority Strategies for 2016-2017: Conduct Quarterly Community Forums</p> <p>Expand Community Participation in culturally and linguistically diverse communities, including the Native American community</p> <p>Establish a Young Professionals Advisory Council</p> <p>Organize a Seattle Town Hall</p> <p>Create and Support a Board-Level Membership Team</p> <p><i>The Arc of King County convenes people to advance the largest community aimed at the civil rights of people with intellectual and development disabilities.</i></p>	<p>Priority Strategies for 2016-2017: Focus on father support and strengthen father's peer network</p> <p>Facilitate Self-Advocate Peer Counseling and Networking</p> <p>Create Volunteer Program Management</p> <p>Become a Provider for Waiver Services such as Person-Centered Planning</p> <p><i>The Arc of King County is the "Go To" organization in King County for information, direction, and linkages to all things related to the intellectual and developmental disabilities community.</i></p>	<p>Priority Strategies for 2016-2017: Offer Partnering and Training to other like-mission agencies in the Community</p> <p>Build relationships with targeted Priority Partnership Organizations</p> <p>Focus on organizational infrastructure and build capacity</p> <p><i>The Arc of King County is the Community's Leader in Supporting Self-Advocates Towards Self-Sufficiency and Full Community Participation.</i></p>

There are over 21,000 King County residents who live with an intellectual or developmental disability whose rights to live, learn, work and play in their communities must be advanced.