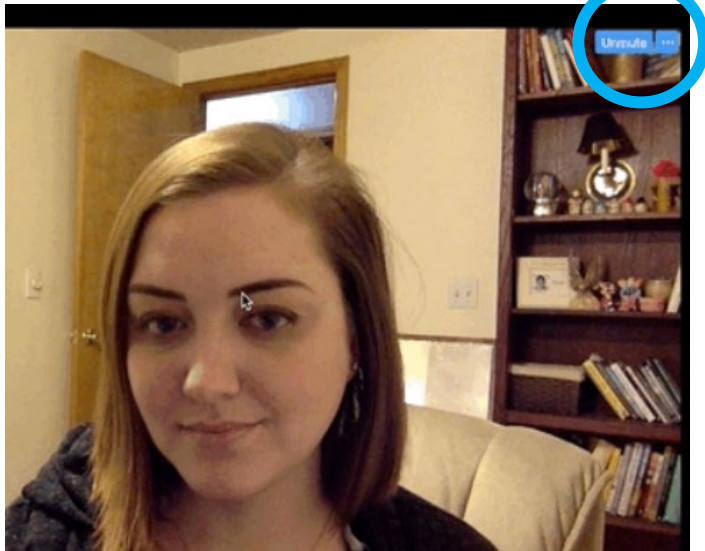


# Welcome!

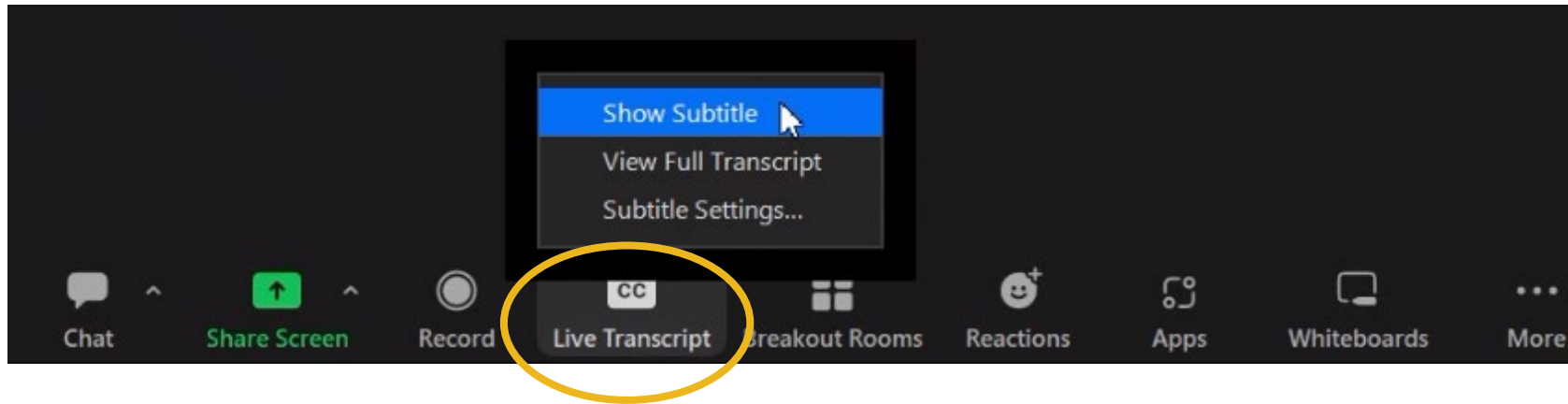
- To the COMM NET Meeting
- We are glad you are here!
- Once you get settled...



- ✓ Click the 3 dots in the top right of your image
- ✓ Select RENAME
- ✓ Enter...
  - ✓ First name,
  - ✓ Pronouns,
  - ✓ Your organization/agency name
- ✓ If you don't see your image, check your view settings at the top of the bar and set to see all webcams or Side-by-Side Gallery View
- ✓ Please make sure you are **muted**, and your **camera is turned off** if not speaking.

# Transcriptions

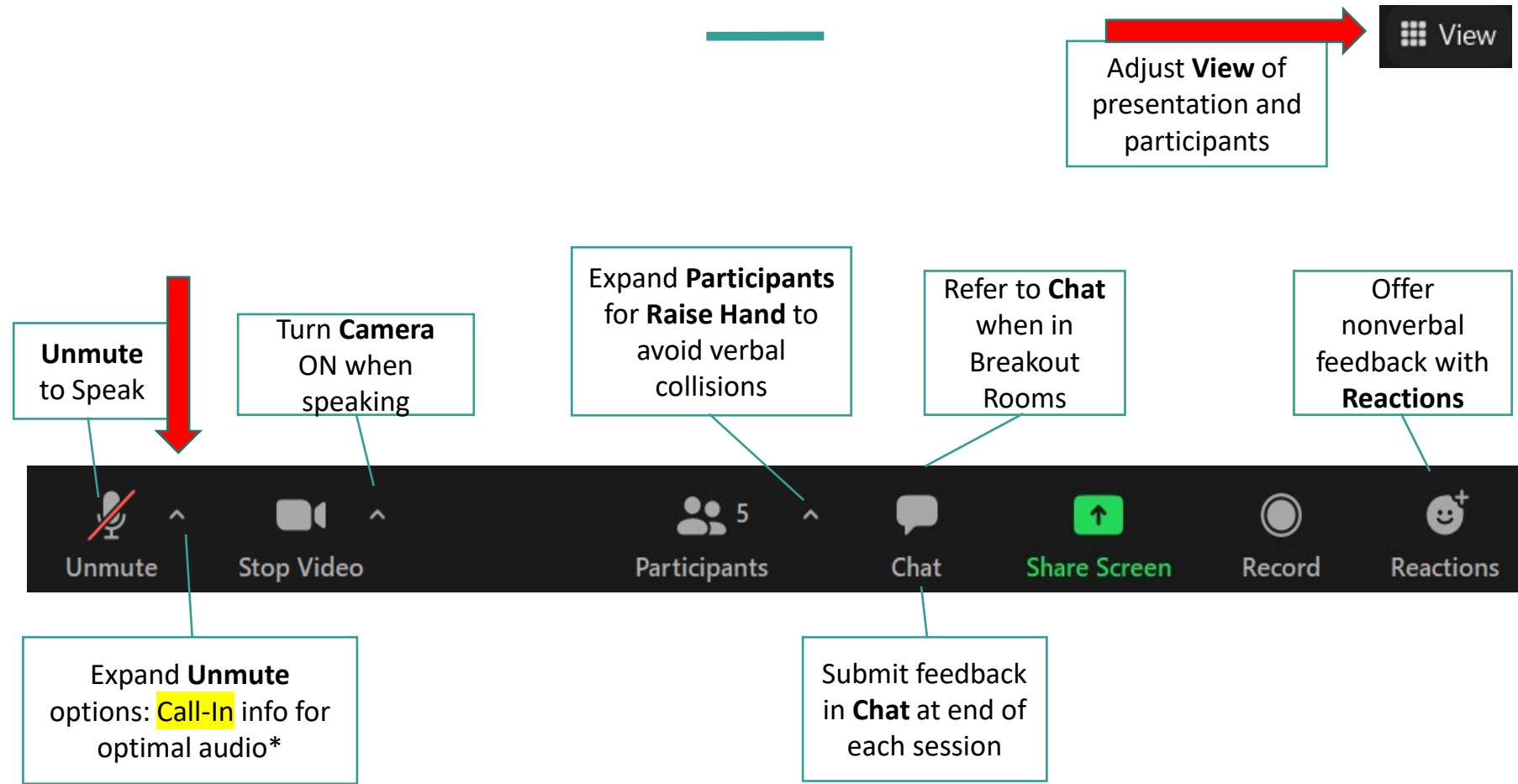
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If you would like to access Transcription resources during the meeting, please select [Live Transcript](#) and click [Show Subtitle](#)



# Zoom Toolbar



\*Call-in feature works best with cell phones (not compatible with soft phones)



COMMUNICATION NETWORK MEETING - 1/12/23  
Children & Youth with Special Health Care Needs

# Housekeeping Items

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- Please list your name, pronouns and affiliation in the chat
- Share one goal you have for the new year (personally or professionally) in the chat
- If you are new, please add your email address in the chat so we can make sure you are added to our list
- This meeting will be recorded
- ASL interpreters will be pinned
- Please keep cameras off unless speaking to help with bandwidth issues



# We honor native land, people, and experience

- The Washington state Department of Health Children and Youth with Special Health Care Needs (CYSHCN) program recognizes and honors the original occupants and stewards of the land where we all individually and collectively gather. Many of us are occupying space from lands that are of the traditional home of the Coast Salish people, the traditional home of all tribes and bands within the Duwamish, Suquamish, Tulalip, and Muckleshoot nations.
- The CYSHCN program honors the survival, the adaptations, the forced assimilation, and the resilience and creativity of Native peoples—past, present, and future. We encourage CYSHCN partners to consider their responsibilities to the people and land, both here and elsewhere, and to stand in solidarity with Native, Indigenous, and First Nations People, and their sovereignty, cultural heritage, and lives.
- We also pause to recognize and acknowledge the labor upon which our country, state, and institutions are built.
- We remember that our country is built on the labor of enslaved people who were kidnapped and brought to the U.S. from the African continent and recognize the continued contribution of their survivors. We also acknowledge all immigrant labor, including voluntary, involuntary, trafficked, forced, and undocumented peoples who contributed to the building of the country and continue to serve within our labor force. We acknowledge all unpaid care-giving labor.
- To the people who contributed this immeasurable work and their descendants, we acknowledge our/their indelible mark on the space in which we gather today. It is our collective responsibility to critically interrogate these histories, to repair harm, and to honor, protect, and sustain this land.
- *\*This land acknowledgement is adapted from Seattle Colleges*
- Please share the people you honor of the land you are occupying in the chatbox [Native-Land.ca](https://www.native-land.ca) | [Our home on native land \(native-land.ca\)](https://www.native-land.ca)



<b>Time</b>	<b>Topic</b>	<b>Presenter</b>
<b>9:00-9:10</b>	Welcome, Agenda, Program Updates	Nikki Dyer
<b>9:10-9:30</b>	Blueprint for Change for CYSHCN	Monica Burke, DOH
<b>9:30-10:30</b>	Supplemental Security Income (SSI)	Todd Wollen, DCYF
<b>10:30-10:45</b>	<b>Break</b>	
<b>10:45-11:15</b>	Informing Families Building Trust	Tracie Hoppis & Darla Helt, Informing Families
<b>11:15-11:50</b>	DDA Eligibility	William Nichol, DSHS/DDA
<b>11:50-12:00</b>	Final Questions & Closing Activities	Nikki Dyer
<b>12:00– 12:10</b>	Break	
<b>12:10-1:00</b>	Networking	ALL

# CYSHCN Team

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**Monica  
Burke, PhD**

*CYSHCN  
Program  
Director*



**Linda  
Ramirez**

*CYSHCN Early  
Childhood &  
Communications  
Consultant*



**Nikki Dyer,  
MA Ed**

*CYSHCN  
Family  
Engagement  
Coordinator*



**Khimberly  
Schoenacker,  
RDN, CSP, CD**

*CYSHCN  
Nutrition  
Consultant*



**Renee Tinder,  
MPH**

*CYSHCN  
Behavioral &  
Adolescent  
Health  
Consultant*



# Updates

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## **General Updates**

Sarah Burdette and Bonnie Burlingham have left DOH – please email CHIF Inbox with CHIF related questions and Linda Ramirez with any other inquiries and she will direct you to the correct person.

CYSHCN Coordinator Orientation: February 13<sup>th</sup> from 9am-12pm.

Please add links in the chat for updates or items of interest to share with the group.

## **CHIF**

CHIF dashboard to be published by the end of this month with 2011-2021 data included for all counties, LHJs, ACHs, and all state roll-up.

CHIF data for Q4 for all partners due 1/15. If anyone needs an extension or help, please contact the CHIF Inbox.

CHIF data will continue to be collected quarterly by spreadsheet as we've done since July 2022.

Please direct any questions about CHIF to the CHIF Inbox.

## **Early Childhood**

Working with Child Health and Essentials for Childhood team on communication plan.

Purpose/Goal: Raise awareness and commitment to preventing child maltreatment and promoting safe, stable relationships and environments so that all children thrive.

# Updates

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## **Family Engagement**

Listening Session set for February 15<sup>th</sup> to hear from families of children and youth living with Type 1 Diabetes, planned in collaboration with Khim Schoenacker. ASL interpretation will be provided.

Exploring possibilities for a Parent Advisory Council to guide care coordination work done in partnership with HCA and PAVE.

## **Behavioral and Adolescent Health**

Year 2 of Pediatric Mental Health Care Access grant has begun. Funding two new projects with PMHCA one year expansion funds, one at Seattle Children's Emergency Department and one with the UW Medical Homes Project.

Working with Khim on mental health and Type 1 Diabetes. Looking at how other states are addressing this issue.

## **Nutrition**

Training Module called "new Educator Course to best Support Development of Cooking Skills for Adolescent with Disabilities" is in development

The Type 1 Diabetes workgroup continues to hold monthly meetings with recent added members post survey that indicated need for more support with mental health in this population.

Work on P2P training specific to T1D with a statewide coordinator role underway.

WIC Office hours continue to be available for CYSHCN Nutrition support.

# New Federal Blueprint for Change

## Guiding Principles for a System of Services for Children and Youth with Special Health Care Needs (CYSHCN) and their Families:

- Health Equity
- Family/Child Well-being and Quality of Life
- Access to Services and Supports
- Financing of Services

This special supplement in *Pediatrics* is freely available



Critical Areas for a Well-Functioning System

## ***Blueprint for Change's Overall Vision***

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Children and youth with special health care needs enjoy a full life, from childhood through adulthood, and thrive in a system that supports their social, health, and emotional needs, ensuring dignity, autonomy, independence, and active participation in their communities.

**Currently only 14% of CYSHCN receive care in a well-functioning system**  
**([National Survey of Children's Health](#))**

[Sarah E. McLellan, Marie Y. Mann, Joan A. Scott, Treeby W. Brown; \*A Blueprint for Change: Guiding Principles for a System of Services for Children and Youth With Special Health Care Needs and Their Families. Pediatrics\* June 2022; 149 \(Supplement 7\): e2021056150C. 10.1542/peds.2021-056150C](#)



## Underlying Assumptions

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- **Disability is a natural part of the human experience** and in no way diminishes the right of individuals to participate in or contribute to society.
- **Racism is a social risk factor** that has a profound impact on the health status of children, adolescents, young adults, and their families.
- CYSHCN require **more and different types of services** than those for typically developing children and youth, yet the **current system is not ensuring access** to these services, particularly for CYSHCN impacted by poverty and discrimination.
- CYSHCN are more severely impacted by the adverse effects of **social determinants of health** and **inequities**.

# Critical Area 1: Health Equity

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- **Vision:**

All CYSHCN have a fair and just **opportunity to be as healthy as possible** and **thrive** throughout their lives (e.g., from school to the workforce), without discrimination, and regardless of the circumstances in which they were born or live.

- **Principle 1:**

Structural and systemic causal **barriers to health equity are eliminated**, including discrimination, poverty, and other social risk factors.

- **Principle 2:**

Sectors, systems, and programs that fund, deliver, and monitor services and supports for CYSHCN are designed and implemented to **reduce health disparities** and **improve health outcomes** for all CYSHCN.

# Critical Area 2: Family and Child Well-Being and Quality of Life

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- **Vision:**

The service system prioritizes **quality of life, well-being**, and supports **flourishing** for CYSHCN and their families.

- **Principle 1:**

Families, **regardless of circumstance**, can access **high-quality, affordable, community-based services** that support the medical, behavioral, social, and emotional **well-being** of the child or youth and whole family.

- **Principle 2:**

Health systems place value on the **measurement** and use of both child and **family well-being** and **quality-of-life outcomes** and health outcomes.

## Critical Area 3: Access to Services

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### ○ Vision:

CYSHCN and their families have **timely access** to the **integrated, easy-to-navigate, high-quality** health care and supports they need, including but not limited to physical, oral, and behavioral health providers; home and community-based supports; and care coordination throughout the life course.

### ○ Principle 1:

All services and supports at the individual, family, community, and provider levels are **easy** for families and professionals **to navigate** when, where, and how they need them.

### ○ Principle 2:

The **workforce is trained to meet the needs** of CYSHCN and their families, **reflects** the families and communities they serve, and is **culturally responsive**.

### ○ Principle 3:

Service sectors increase the ability of CYSHCN and their families to access services by **addressing** administrative and other **processes that hinder access**.



## Critical Area 4: Financing of Services

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### ○ Vision:

Health care and other related services are **accessible, affordable, comprehensive, and continuous**; they **prioritize** the **well-being** of CYSHCN and families.

### ○ Principle 1:

Health care and other related services for CYSHCN and families are **financed** and paid for in ways that support and **maximize** an individual's **values and choice** in meeting needs.

### ○ Principle 2:

Health and social service sector **investments address social determinants** of health to **increase family well-being** and **flourishing**.

### ○ Principle 3:

Payers and service sectors adopt **value-based payment strategies** that support families, advance equity, and incorporate **continuous quality improvement** by enhancing **team-based integrated care**.

# CYSHCN Strategic Planning Goals

## System of Care

Family-centered  
Integrated  
Collaborative  
Coordinated  
Equitable

### Funding

Improve Access  
Flexibility  
Families & Providers  
Best Practices

### Equitable Access

High Quality Care  
Underserved Populations  
Systemic Racism

### Concrete Supports for Well Being

Social/Emotional Support  
Belonging & Inclusion  
Mental Health & Behavior

### Family Navigation & Care Coordination

For Complex Health,  
Socioeconomic, &  
Psychosocial Needs of  
CYSHCN & Families

# Supplemental Security Income (SSI)

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Basics of a SSI Application for children



# What is SSI vs SSA Benefits

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- SSI is a federal program that provides benefits to low income children and families. Children must meet medical eligibility criteria. The Social Security Administration looks at income, resources and assets, living arrangements and medical impairments.
- SSA is a federal program where a child may be eligible for Title II benefits if client is the biological child, adopted child, or dependent stepchild of a parent who is disabled, retired or deceased and insured because they worked enough credit hours to qualify for these benefits. Benefits stop when the child reaches age 18 unless child is a student or disabled.



# Who determines SSI eligibility?

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- The Social Security Administration receives the application and determines if the claimant is financially eligible for SSI. SSA looks at all income, resources, assets, living situation of the claimant. Once determined financially eligible the medical case is sent to the state agency for medical determination.
- The Disability Determinations Services determines the medical decision on the case and reviews all available medical, mental health, school and other lay information in determining eligibility.

# What may qualify a child for SSI

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- Mental Health Diagnosis- Post Traumatic Stress Disorder, Attention Deficit Disorders, Mood Disorders, Personality Disorders
- Developmental Delays, Learning Disability, Borderline Intellectual Functioning, Down's Syndrome
- Emotionally/Behaviorally Disturbed- Sexually Aggressive Youth, Oppositional Defiant Disorder, Conduct Disorder
- Delays in functional domains: acquiring and using information, attending and completing tasks, interacting and relating with others, moving about and manipulating objects, caring for yourself (self-care), and health and well-being.



# What may qualify a child for SSI

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- Medical Conditions- Diabetes, Epilepsy, Fetal Alcohol Syndrome, Crohn's Disease, Congenital Heart Anomaly
- Physical Health Diagnosis-Low birth weight, Cerebral Palsy, Neurological disorders, Visual or Hearing Impaired

# Gather Information for Application

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- Review medical records or reports including well-child visits, evaluations, discharge summaries, intakes.
- Review mental health evaluations, clinical visits or quarterly reports.
- Review school records including IEPs (with evaluation), 504 plans, detentions suspensions.
- Complete functional report for age appropriate child.



# Complete SSI On-line Disability Report

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- Go to SSA website and complete child disability report.
- Make sure you have all provider information with dates seen, addresses, phone numbers to include in the on-line application.
- You will also need to include all medications with provider information and dosage.
- Complete the on-line report.
- [Supplemental Security Income | SSA](#)
- SSA will contact claimant once they receive the on-line disability report with any additional information they need.

# Once SSI application is completed Social Security will likely need more information

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- It's important to read all correspondence from SSA and DDS and respond accordingly.
- DDS will likely need updated functional information from care-giver.
- A Consultative Exam (CE) may be needed if there is a lack of current medical evidence.
- It's very important to confirm CE appointment and take claimant to CE exam.
- The initial application can take several months before a decision is made. Many decisions get denied when there is lack of cooperation from claimant or family.



# The SSI Decision

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- Once medical decision made the claim will either be allowed or denied and sent back to Social Security.
- If the claim is allowed, SSA will complete a PERC with the care-giver and SSI will go into pay.
- If the claim is denied, SSA will close out the file and send a Notice of Denial to family.
- Claimant has 60 days to appeal the denial decision and request a reconsideration.

# SSI Process

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- It's very important to be in good communication with SSA or the DDS adjudicator during the SSI application process.
- Notify DDS of any changes to medical treatments or school supports.
- Attend any appointments that SSA/DDS requests for claimant.
- The SSI application process can take several months up to a year for a decision.

# Final Thoughts & Questions

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- Must be income eligible.
- Have a physical or mental Diagnosis expected to last 12 months or result in death.
- Make sure you complete the disability report with all dates, addresses and diagnoses to the best of your ability.
- Questions?



Thank You

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**10 MINUTE BREAK**

Return by 10:45

# INFORMING FAMILIES

Supporting Washington families today and tomorrow



# INTRODUCTIONS

Tracie Hoppis

Manager of Family Support Services / Children's Village  
WA State P2P Manager/ The Arc of Washington State

Darla Helt

Executive Director PEACE NW

Sarah Forster

Media and Communication Specialist at The Arc of Washington and  
Informing Families



# WHO WE ARE



Started in 2007, Informing Families is a resource provided by the Washington State Developmental Disabilities Council, in partnership with the Developmental Disabilities Administration.

# OUR GOAL

Our goal is to offer trusted news and information to individuals and families that empowers them to be active participants in planning and building a network of support and opportunities.



# OUR TEAM

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Our advisory committee is composed of family members and representatives of DDA and other agencies. They ensure that the issues we follow are relevant to the needs and interests of individuals and families—not just today, but into tomorrow, by offering tools and tips on planning for the future. Along with the committee, Informing Families is supported by 12 coordinators who support and assist families throughout the state.



# THE COORDINATORS

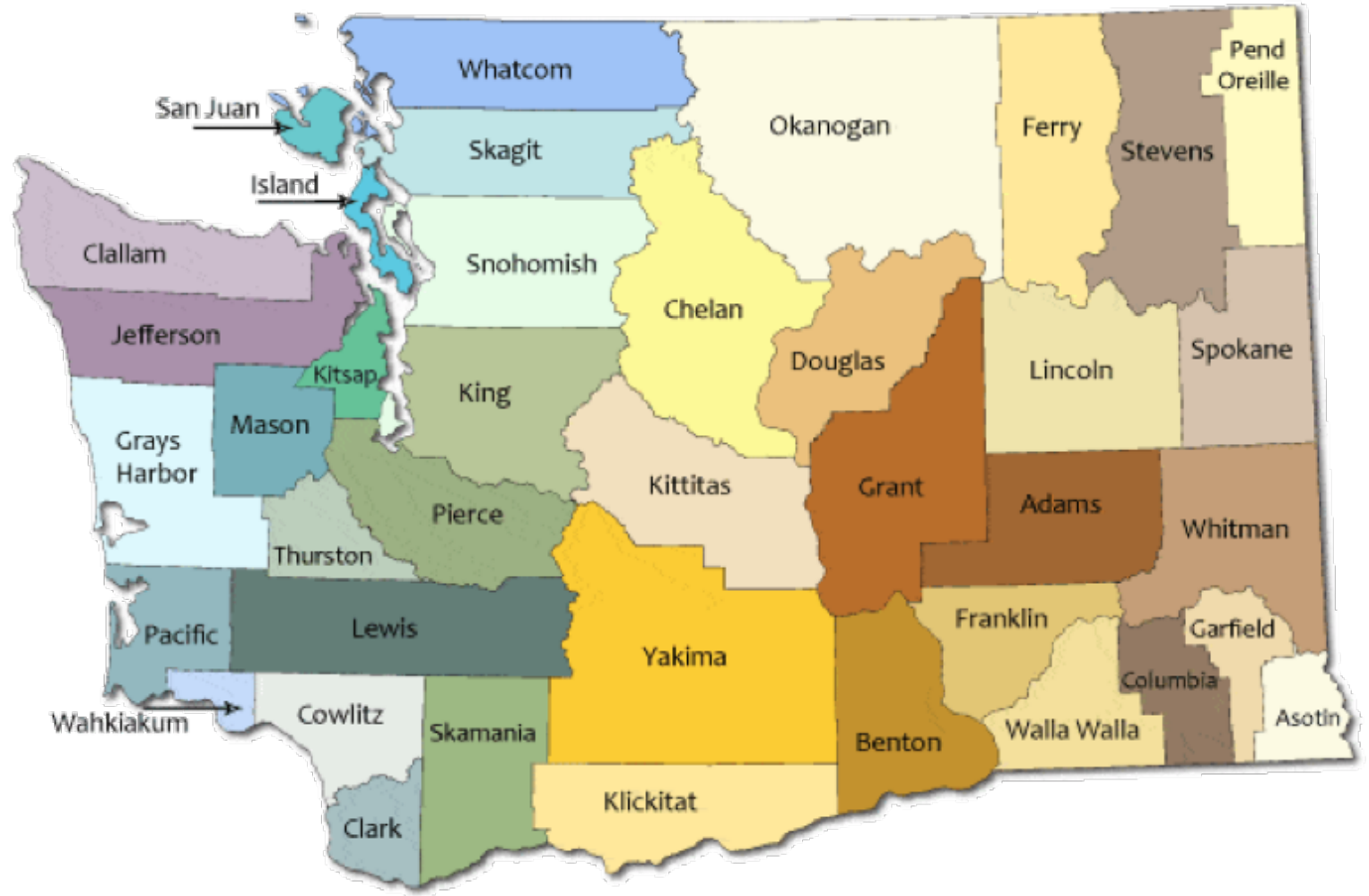
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Informing Families is supported by a team of coordinators throughout the state that provide information, tools, and resources to local communities and families in their area. The coordinators meet with families, listen to their stories, and support them with information and tools. The coordinators also assist in providing insight to what information is needed for the Informing Families website content to keep information up to date and relevant to the day to day lives of the families we aim to support.

## THE COORDINATORS

Informing Families Coordinators are located in the following counties:

- Kittitas
- Grant
- Adams
- Lincoln
- Ferry
- Spokane
- Yakima
- Thurston
- Mason
- Pierce
- Snohomish
- Clark
- Cowlitz
- Skamania
- King
- Kitsap



Along with coordinators throughout the counties we have partnered with other organizations to reach out and support the Somali community (Greater Seattle Area), Vietnamese community (Greater Seattle Area), and the Spanish community (Yakima).

# OUR WORK

We believe information is power. When individuals with disabilities and their family members have accurate information about resources, they can advocate for the most appropriate services.

Informing Families reaches individuals and families through social media, e-news, bulletins, newsletters, and a large library of original content.



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# THE CONTENT

## Bulletins

We provide one page bulletins that cover a variety of topics. Bulletins are vetted by DDA and other organizations. These bulletins provide accurate information on programs, services, and resources in a simple and condensed information. Bulletins are often translated into more than one language including Spanish, Somali, Vietnamese to reach as many communities as possible.

## Newsletters

Informing Families provides a quarterly newsletter that is mailed out to the DDA No Paid Service Caseload and uploaded online. This newsletter includes upcoming changes in services, community events, available programs, and more.

## Content Library

The Informing Families website provides information on over 20+ topics from Legal Advocacy and Services to Assistive Technology. These topics are updated as information and programs change throughout the state. Information is vetted and confirmed by DDA and is intended for parents, self-advocates, and professionals.

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# THE CONTENT

## Facebook

In partnership with our website, Informing Families runs a Facebook page that is consistent with updates and releases on the website. The Facebook page shares events, trainings, and information going on throughout different communities in the state.

## E-News

Between quarterly newsletters, Informing Families sends out an e-newsletter monthly to subscribers. This newsletter includes updates on the site, new bulletins, and upcoming events.



# THE WEBSITE

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Families, professionals, and self-advocates can access a large library of content at anytime for free at the Informing Families website. This website has information to support individuals with disabilities and their families in all stages of life. All content is reliable and vetted by government agencies. Content is created to support and teach the community about supports available to them.

[www.informingfamilies.org](http://www.informingfamilies.org)

The screenshot shows the Informing Families website homepage. The top navigation bar is dark blue with the logo and tagline 'Informing Families Today and Tomorrow' on the left and a 'MENU' button on the right. Below the navigation bar is a search bar with a 'Go' button and a 'TRANSLATE' section with a 'Select Language' dropdown menu. The main content area features a large banner with the text 'SUPPORTING REAL LIVES ACROSS THE LIFE COURSE' in a light blue font. Below the banner is a circular image of a baby's face with the text 'AGES 0-3' overlaid in large red letters. To the right of the baby image is a text box that reads: 'Find opportunities for your child to grow and develop. Learn about early intervention services and connect with other families.' Below this text is a graphic titled 'Navigating Your Way BIRTH to 3' which includes a play button icon and various icons representing different services and resources. At the bottom of the page, there are four small circular icons: a rocket, a bar chart, a road sign, and a scale of justice.



# THANK YOU

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For more information on Informing Families or questions please contact  
[sarah@arcwa.org](mailto:sarah@arcwa.org).





## DDA ELIGIBILITY



# Closing and Next Steps

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- Meeting Minutes and Recording will be available in the coming weeks
  - Please send any program updates you would like included in the minutes to Linda or Nikki
  - [Nikki.Dyer@doh.wa.gov](mailto:Nikki.Dyer@doh.wa.gov)
  - [Linda.Ramirez@doh.wa.gov](mailto:Linda.Ramirez@doh.wa.gov)
- 10-minute break
- Networking Meeting (Optional)





10 MINUTE BREAK

Return by 12:10