



Informing Families ...Today and Tomorrow

A project of the Washington State DD Council

Charting a Course

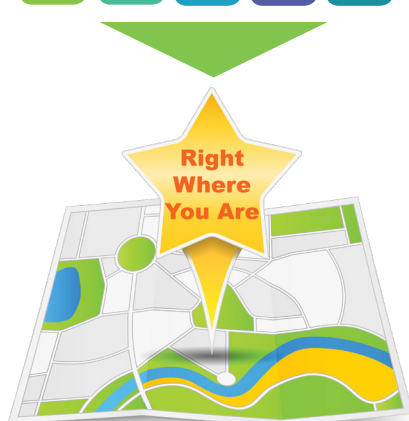
Toward a LIFETIME of LEARNING and GROWING

When we asked parents what they wish they had done when their children were young, they said things like, *have expectations and vision for the future, start planning early, build and maintain social connections.*

In this special edition newsletter, we hope you find information and resources to help you do all this, and more, as your child transitions into early childhood and the school years.



START



Every transition comes with anxiety for all families, no matter the needs of their loved one. As your child transitions from early intervention services to developmental preschool, then on to kindergarten and first grade, know that your feelings are typical of all families.

A good rule of thumb for these early years is to start planning at least six months ahead of each transition.

Before your child leaves early intervention services, find out the name and contact information for each of the school district

professionals involved in your child's education, whether it's an Early Childhood Coordinator, Readiness to Learn Coordinator, or school psychologist. The professionals involved in coordinating special educational services will vary.

The Right to a Free Appropriate Education

Thanks to the Individuals with Disabilities Education Act (IDEA), public schools must provide your child a free appropriate public education (FAPE) from age three to twenty one.

Under IDEA, every child is entitled to have an Individualized Education Program (IEP) that is specifically tailored to meet your child's learning strengths and needs.

An IEP includes education goals and objectives in addition to related services as needed such as speech, physical, or occupational therapies, assistive technology, counseling, or other aides and services that enable your child to receive a free appropriate public education.

Be Your Child's Advocate

It takes a lot of hard work to see that your child gets the services and education he or she needs.

No one knows your child better than you do, so when it comes to making decisions regarding their education, it's important to speak up and ensure that their needs are being met.

Remember, your child has a right to participate and be included like any other student. Would they benefit from an inclusive classroom?

Do they need a full time aide parts of the day or only during certain times of the day?

Organizations such as Parent to Parent (arcwa.org/getsupport) and Partnerships for Action, Voices for Empowerment (wapave.org) will help you learn how to advocate.

In addition, the Office of the Education Ombuds (OEO) resolves complaints, disputes, and problems between families and public schools. 1-866-297-2597; oeo.wa.gov.

If we had the time, I'd tell you all the amazing things about my daughter Paige.

She is 24. She loves music. She enjoys delivering snacks to co-workers three mornings a week. She attends a day program with lots of friends.

She also has significant intellectual and developmental disabilities. It's been quite a journey since the doctors sat us down to have the talk about her rare condition. Tough times were ahead. And, indeed they were. But, there have been a lot of good times, too.

Here are some of the lessons having Paige as our daughter has taught us.

#1 Take care of yourself.

Preserve your physical and mental health to make it possible to care for your loved one. It's OK to ask for help. This is a marathon. Start with a game plan and adjust accordingly. The first few years are so important to every child's health and development, but you have to have the wherewithal to be there 5, 10, 25 years from now.

#2 Get to acceptance.

The grief cycle is real. The faster you get to accepting the hand you have been dealt, the better off everyone will be. Denial can be your friend when you have to block out all the bad stuff, but don't get stuck there.

#3 Stay in the present.

Be aware of what comes next in terms of medical treatments and services,



but don't obsess over what you cannot predict or control. Take it day to day, month to month, year to year. Paige's pediatrician said we had enough real worries that we didn't need to go looking for more.

#4 Don't go it alone. Find a jungle guide.

For us, it was a co-worker who had a daughter with Down Syndrome the same age as our older son. They helped us navigate our rights to services, passed along information and shared a healthy perspective. Get on the internet and connect with other families, organizations and agencies. Many are run by people just like you.

#5 Have fun.

Remember, this is a baby in your arms. Children learn through play. Sing those silly nursery rhymes, blow bubbles, play peek-a-boo. Go outside. Get in your loved one's face and engage with them. Talk to them.

#6 Take charge.

No one cares more about your loved one. It is up to you to pick and choose which tests will be done by whom, when. What works for you and your loved one comes first. We learned to say *Enough, we'll take it from here.*

#7 Support skill development.

You want your loved one to be as independent as possible. Start early with helping them brush their own teeth, bathing, dressing, putting their toys away, etc. As they gain skills, keep moving your expectations higher. You are going to be amazed. We did everything for Paige far too long, and breaking those bad habits is difficult.

#8 Try anything. Try everything. Repeat.

You don't know what will click until you try. And, if it doesn't work out this time, it might in the future.

#9 Stay positive.

We focus on the many similarities we have with "typical" families. We want our loved ones to be happy, healthy and safe. Check. We want them to attend school and reach their full potential. Check. We want them to develop friends and areas of interest. Check.

#10 Expect to be amazed.

Paige continues to gain skills and be more active. Keep resetting your expectations higher.

You have an incredible journey ahead of you. I wish you well.

Community connections and relationships are vital to your child's long-term success.

Being included in all aspects of life is key to your child's social, psychological and cognitive development. The more your child learns to participate in groups and socialize with other children, the better they will make the transition to school.

The Family Community Connections Guidebook, a publication of The Arc of Washington State, offers valuable tips and worksheets for identifying people, places and ideas to help broaden your family member's social circle and community connections.

Visit informingfamilies.org/guide to download a free copy in English or Spanish.



Creating A Foundation for the Future

Everything your loved one does in the coming months and years offers opportunities to build skills that lead to greater independence, social connections and employment.

The following chart, adapted from the Kitsap County

Transition Council's *Nine Critical Areas of Focus for IEPs*, illustrates key skills important for every child to develop.

Make note of where your child is on the chart and consider each of these skill areas when shaping goals for their Individual

Education Program (IEP). And be sure to reinforce development in these areas at home and in the community.

For the complete chart (including adult years) and companion materials, visit: informingfamilies.org/skills.



Skills to Maximize Independence

Adapted from *Nine Critical Areas of Focus for IEPs*, developed by the Kitsap County Transition Council

Developing

+++++
Important

SKILLS	Birth to 3 Years Old	3-6 Years Old	6-16 Years Old
Communication Initiates, understands, can respond, make choices, able to make needs/wants known, generalize across environments/people. Assistive technology if needed.	*****	+++++	+++++
Social Skills Understands and respects personal space, boundaries, and appropriate behaviors.	*****	*****	+++++
Independence w/Personal Hygiene Initiates and performs with/without external cues and assistance, including assistive technology.	*****	***** +	+++++
Team Work Gets along well with others. Relationship development.	*****	*****	+++++
Dependability, Follows Directions, Timeliness Stays on task. Understands the passage of time.	*****	*****	+++++
Work Ethics, Pre-employment Skills, Academics	*****	*****	***** ++
Self Advocacy and Self Awareness Understands and can ask/indicate needs, can ask/indicate/provide accommodations if needed.	*****	*****	***** +++
Community Awareness and Access Safety skills; Ability to call/indicate needs/help; ability to ride public transportation; aware of surroundings.	*****	*****	***** +++
Health & Nutrition/Emotional & Mental Health Understanding healthy eating and food choices. Addressing medical/mental health needs. Friendships and recreation.	*****	*****	***** +++

State of Washington
DEPARTMENT OF SOCIAL AND HEALTH SERVICES
Developmental Disabilities Administration
P.O. Box 45310
Olympia, WA 98504-5310

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Free RESOURCES for FAMILIES

Publications and Planning Tools

Life Course Welcome Packet: Introduction to Planning & Services in Washington State

This free four-page packet includes:

- ⚙ A **Star Form** to identify supports.
- ⚙ How to apply for a determination of DDA eligibility in Washington.
- ⚙ How to organize key documents that will be needed to apply for programs now and into the future.
- ⚙ Washington State's DDA's wavier programs and Community First Choice (CFC).



Visit informingfamilies.org/publications for a free copy in print or download.

My Life Plan

A free online planning tool that guides you through key questions to help plan and prepare every stage of life. Visit mylifeplan.guide to get started.

Information and Support

Child Care Aware Washington

Child Care Aware Washington has seven local programs around the state to help connect families seeking child care with licensed providers. To learn more about Child Care Aware Washington, visit: wa.childcareaware.org.

Parent to Parent

Parents have many questions and concerns in coping with their child's needs and their own feelings. Personal support from another parent, who has a child with a similar needs, can be helpful in coping with these challenging experiences and feelings. Volunteer Helping Parents are available to provide support and information. Learn more at: arcwa.org/getsupport.

WithinReach

Information on health care coverage and other services for families of children with special health care needs. Call the Family Health Hotline toll-free at 1-800-322-2588 or visit withinreachwa.org.