

Kindergarten Readiness Parent Focus Group Summary

Oregon Center for Children & Youth with Special Health Needs

Statewide (Josephine, Lane & Multnomah Counties)

Focus Group Snapshot



8 participants



Have lived in their community from less than 6 months to over 20 years



Have children ages 2 to 9



Live in a mix of rural and urban communities¹, including Eugene (4) and the surrounding area (1), Grants Pass (1), and Portland (2)

“For me, the most important aspect of being ready for kindergarten, and what can potentially be the most challenging for our children, is having that social and emotional readiness.”

What does it mean for you and your child to be ready for school?

Ready Children

Parents emphasized the importance of social-emotional, and executive functioning skills of children, over learning pre-academic skills such as early literacy and numeracy.

Social-emotional skills such as being able to identify and verbalize their feelings, caring for others, and enjoying playing with other children.

Related, that children **feel confident and comfortable communicating** with other children and adults, especially to voice any needs they may have. This was both related to their special health

needs, as well as to find support if they are being targeted for bullying.

“[Being able to] advocate for himself among his peers. He is susceptible to bullying. That is something I’m really focused on, that he is going to be ready to handle being among peers.”

Executive functioning skills such as being able to focus attention, remember instructions, and self-regulate.

“[Child] has hard time with authority figures and following directions.”

Ready Families

Parents focused on being able to find support with professionals and other families with children with special needs, as well as learn parenting strategies for their children.

Parenting education and support was important for families to prevent or respond to challenging behaviors.

“With neurotypical children, it was easy-breezy. With my [child with special health needs], I felt clueless and had a really hard time going anywhere. [Parenting classes] have been awesome.”

Establish relationships with early learning providers and teachers in order to build trust and comfort talking about their child’s special health

¹ Oregon Office of Rural Health designation file, www.ohsu.edu/xd/outreach/oregon-rural-health/data/rural-definitions/index.cfm

and learning needs, as well as seek guidance to support learning at home.

What are trusted sources of information about school readiness?

Parents identified a range of people and resources that serve as trusted sources of information about school readiness.

People in professional roles such as health care providers, Early Intervention specialists, social workers, therapists, early learning providers, and teachers.

Personal connections, including family members, friends, and other parents, especially those who also have children with special health needs.

What kind of early learning supports have you participated in and how do they support school readiness?

Parents have participated in a wide range of early learning programs or services for families with children ages birth to 5.

Parent-child groups include library story times and Mommy & Me.

Parenting education series through Early Childhood (EC) Cares

Home visits through Early Intervention.

Preschool programs through EC Cares and private preschool.

Kindergarten transition programs such as Kids in Transition to School (KITS).

Occupational, speech, and physical therapies through Connect the Dots, Early Intervention.

Additional family support and advocacy groups including The Arc Oregon, EC Cares, and Oregon Family Support Network (OFSN).

How do these early learning programs help you and your child be ready for school?

Ready Children

By far, the primary benefit to children with special health needs for these parents was for their children to **build and strengthen social-emotional skills** through opportunities for children to interact and play with other children in a group setting, and practice listening to an instructor.

Ready Families

Parenting education and support from both early learning providers and other parents was important for families to be able to problem-solve and share strategies for raising their children, both those with special needs and their “typical” children.

“I didn’t really know what I was getting into [with parenting class], I just know I needed help. It is so much more about teaching me different techniques, of course, helping [child] in the long run. I am so much more patient. I didn’t realize we needed to work on our connection so much. He needed to know that I was there for him and I was trying to understand his struggle.”

And by extension, **parenting education normalizes experiences and reduces isolation** by connecting with other parents who have children with special health needs.

“This is my first kid, so I didn’t know [why we were struggling]. I just thought I was a horrible mother. We couldn’t go anywhere, it was so bad. Those classes let me know that I wasn’t alone. I had no friends with special needs kids. This was my first experience with it. They taught me what to include in our home, build routines, do all that stuff that has made our lives better by teaching me.”

Opportunities to build relationships with both early learning providers, teachers, and other parents was important for families to know who to talk with about questions or concerns about their child's learning and behavior.

"I have a good relationship with [child's] preschool teachers. I can always talk to them about his progress. I have to have that. I can talk to her daily if I need to."

Assist with the transition to kindergarten through individual support to identify schools that would best be able to meet the needs of their children with special health needs.

"The EC Cares program is helping us find out which kindergarten will actually fit his particular disabilities best. It is absolutely amazing."

Develop leadership and advocacy skills to be able to navigate early learning, school, and health systems to best meet the needs of their child.

"Collaborative Problem-Solving with Oregon Family Support Network has helped me big time getting [child] ready, or getting us ready for him to be in school. I could advocate for him in IEP [Individualized Education Plan] meetings."

What would help improve early learning programs to support school readiness?

Parents largely had positive experiences with early learning programs, but also had suggestions to improve access and inclusivity.

Improve community awareness and outreach of existing programs. Participants felt like it was by "dumb luck" that they learned about many of the early learning programs their child was engaged in and wished there was a commonly-known place to turn to for information about early learning programs, generally, and those that serve children with special health needs, in particular.

Increase availability and affordability of early learning supports, especially those that can meet the special health needs of children.

"It is really challenging to find [early learning programs] that are one, affordable, and two, willing to work with our children that may have different requirements than typically developing children. But our children need to be in that environment, even starting at an early age."

Provide more training and supports for early learning providers to be able to care for and teach children with special health needs, and to create inclusive settings.

"[Child's teacher] would basically put my kid aside and say, 'You can't follow directions, therefore you can't be part of the group' instead of saying, 'OK, this is how he's behaving. How can we incorporate him into the group?' so he can learn and is not struggling when he goes into preschool."

What kind of health services have you participated in and how do they support school readiness?

Parents described experience with a variety of health services and several expressed the importance of early identification of health needs leading to referral and supports. Half of the parents in this group utilized OHP during the prior year, while the other half utilized private payer insurance.

Participants accessed **in-office** health care services at the following locations:

- Charnelton Community Clinic
- Doernbecher Children's Hospital
- Eugene Speech & Hearing
- Grants Pass Clinic
- Integrative Pediatrics
- Metropolitan Pediatrics
- Oregon Medical Group
- PeaceHealth
- Riverbend Pediatrics
- Shriner's

Home visiting through Early Intervention supports.

School-based integrated health supports and specialists.

How do these health services help you and your child be ready for school?

Parents talked about a largely positive experiences with health care providers that helped support them and their child's school readiness, ranging from monitoring development, hearing families' needs and concerns, and connecting families with additional services.

Having a coordinated health care team to support children and families including primary care providers, specialists, and allied care professionals such as social workers and therapists, who are coordinated and working as a team.

"Putting together a patchwork of different medical specialists, therapists. The therapist at the school, therapists we see at the hospital. The effort of those individual providers [is helpful]. The [health care provider] is thinking about the medical side and also about when [child] gets to school, how to learn to do [her own medical care]. The physical therapist is working on how [child] will transition in and out of a wheelchair and when to use a walker."

Tracking developmental milestones through Ages & Stages Questionnaires (ASQ) was seen as helpful to identify special health needs earlier.

Health care providers who take time to listen and respond to parents were described as making the difference for many parents. When parents felt they had a relationship with their or their child's provider and felt trusted, they were able to raise questions and concerns and get the information they were seeking about child development and ways they can support their child.

"I had to fight with our doctor because she didn't agree with anything that any of the other services recommended. I ended up switching doctors and she is much more open to what were assessing, to

the point of even suggesting getting a dog at home to help with routines and comfort."

Another participant highlighted the time providers take with her child helped her feel more comfortable establishing trust.

"I am used to [health care providers] saying, 'Hey, [your child] needs to sit down and be quiet for the exam.' With [new provider], I started to hush him and she said, 'Oh no, that is how I am going to figure out who and what he's about. Let him do what he is going to do.' That is how she made us aware that she is open to us and his wild ways."

Providers who address insurance and service gaps directly was a tremendous help for parents with children with special health needs.

"[Health care provider] made sure to get on the phone, either her or her assistant, and they called back and forth and back and forth [with insurance and pharmacy] until they figured out what was going on. If [my child] doesn't have that medication, he can't go to school or community events. So [health care providers] are very much on top of making sure that phone calls get made and I'm not so stressed out and the family is good."

Knowing, recommending, and using referral sources, that connected families with supplemental and necessary services. Most participants felt that their child's health care providers were well-aware of referral processes to Early Intervention and used them. One participant also described additional support through her health care provider that helped with referrals:

"One thing we have benefitted from in the clinical environment...clinics include a social worker, so having someone there to say have you tried this, have you tried this and they can name off all the different resources available. That care coordinator, or nurse who specializes in making

referrals to the community. Someone who can orient you and point you in the right direction.”

What would help improve health services to support school readiness?

Parents largely focused on wanting clearer communication and recommendations about referrals and supports in order to help their child with special health needs even earlier.

Provide concrete information and coaching to parents so they know what the developmental milestones and expectations are and clearer recommendations about when additional testing or supports may be needed.

“[Health care providers] have seen 100 kids. I’ve only seen mine. No one wants to hear there is something wrong with your kiddo but it’s frustrating because early intervention is critical.”

Participants generally wanted **more direct feedback and guidance**, and rely on health providers to offer timely information about their children when they are not meeting developmental milestones. Some parents had this experience, while others did not but wished they had.

“My son wasn’t meeting milestones starting at 18 months, so [health care providers] started to raise minor flags. I found in this whole thing everybody is very gentle with you and cheerful about saying the word ‘autism’. I just wanted to shake them and say, ‘What’s going on with my kid?’”

One participant talked about delaying an evaluation by Early Intervention because it also seemed like a “gentle” suggestion from her child’s health care provider, rather than a recommendation based on stronger concern or more direct feedback.

“I got a really gentle referral to [Early Intervention], gentle enough that I ignored it for another 6 months.”

Improve consistency and access to quality care across regions. Although most participants lauded their health care providers and were happy with the quality of care for their children, some noted that this varies substantially across the state. Parents who live in more remote communities had the experience of not being able to find the specialists they felt they needed or had to travel longer distances to receive services.

“It doesn’t feel like there is anything here, even including speech therapy. We are trying right now to branch out and see if we have to travel a bit further to get [child] what he needs to succeed.”

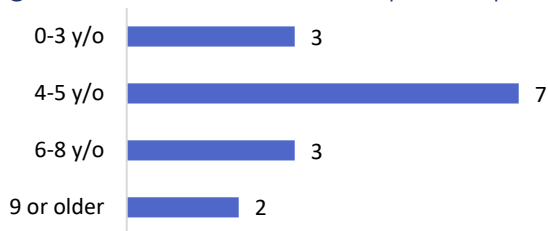
Focus Group & Community Profile

On February 15, 2018 Oregon Center for Children & Youth with Special Health Needs convened a Kindergarten Readiness Parent Focus Group via webconference with 8 parents, including 5 moms and 2 dads, and 1 stepparent. All reported parenting with a partner. Participants were invited by the Family Involvement Network Coordinator of the Oregon Center for Children & Youth with Special Health Needs and were known due to their participation in parent education and support programming.

The **average participant age was 35** and ranged from 27 to 45.

The **average number of children per household was 2** and ranged from 1 to 4.

Ages of Children of Focus Group Participants

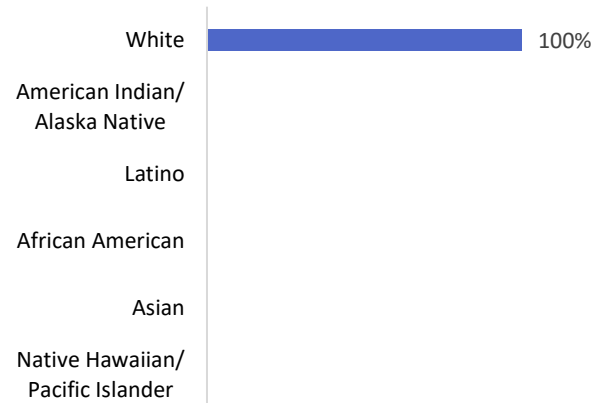


“All the family resources has made it so that we don’t have to live such as isolated life with [children with special needs].”

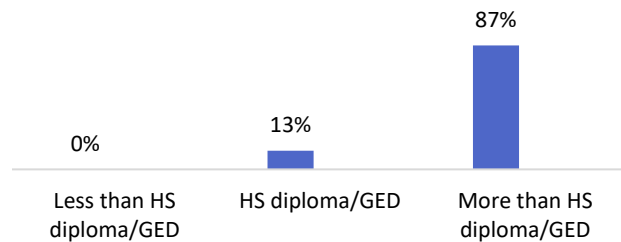
Coming from different communities, participants reported different things they liked about living where they do. Some of the things that were more common across parents’ experiences were appreciating the **family support resources** available, an overall feeling of **inclusivity**, and **quality health care** to meet their child’s needs.

Special health needs of children in participating families included Attention Deficit Hyperactivity Disorder Autism Spectrum Disorder, Cerebral Palsy, diabetes, Down’s Syndrome, Oppositional Defiant Disorder, speech and language challenges, and Spina Bifida.

Race/Ethnicity of Focus Group Participants



Educational Attainment of Focus Group Participants



Services Utilized by Focus Group Participants	% Yes
Public library	75%
SNAP	25%
TANF	0
OHP	50%
WIC	50%
Early Head Start	0
Head Start	0
EI/ECSE	75%