



Hearing from Parents About Their Child Care Needs

Bridging Communities

In January 2020, a listening session with six parents and caregivers was hosted by Bridging Communities in Medford, Oregon. Bridging Communities is a family support and advocacy network for families with children with disabilities. The listening sessions was part of a series of family listening sessions funded by the Preschool Development Grant as a part of a statewide early learning needs assessment. The listening session was co-designed, organized, and hosted by Bridging Communities in partnership with OSLC Developments, Inc. and Portland State University. The goal of the listening sessions was to hear family voices that have not yet been captured in understanding families' early learning needs and experiences. Four individual listening interviews were also held with parents residing in Southern Oregon who were unable to attend the Bridging Communities listening session. All participating families had a child with special needs, including Down syndrome, cerebral palsy, autism, and fetal alcohol spectrum disorder, and some children had multiple diagnoses.

Current Child Care Experiences and Building School Readiness

Many of these parents indicated that they spent considerable time themselves providing child care, but also frequently described needing multiple, sometimes complex arrangements in order to meet the child and families' needs. These arrangements included part-time child care or preschool, relying on family and friends with no other out-of-home care, and full-time center-based care. In making decisions about child care, parents highlighted the importance of affordability, safety, and quality as most important for them. Most parents overwhelmingly wanted their children to feel comfortable and for providers to be well equipped for handling situations that might arise related to their children's disabilities.

Experiences in Child Care: Adequate Support for Children with Special Needs

Virtually all these parents told us about how challenging it was to find providers who they felt had adequate experience and/or training for working with children with special needs. Related to this, a number of parents told us about having been asked to remove their child



Their Ideal Child Care Situation

As might be expected, different families had different needs. About one third of these parents wanted partial or half-day care a few (2–3 days) a week; another third needed or wanted full-time care, though their desired hours varied; and some preferred to care for their own child at home but expressed a desire for flexible, drop-in, or weekend care, or any amount of care from providers experienced or educated in their children's disabilities.

These parents clearly expressed a desire for child care that would help them as parents, as well as their children, be ready to start kindergarten, noting concerns about their special-needs children being overwhelmed in kindergarten. Specific concerns included coping with stressful sensory situations and concerns about communication for children who are nonverbal. Six parents wanted their children to learn or improve their self-regulatory skills such as sitting in a circle, paying attention, listening, sharing, learning how to work with others, and learning how to take instruction. Further, many parents emphasized the importance of learning the social and other coping skills needed for routines, schedules, and transitions. These parents on the whole were more concerned with social aspects of readiness than with children learning pre-academic skills such as reading or writing.

from child care because the provider felt they “could not meet the child’s needs.” Parents described child care providers who were not trained to work with children experiencing disabilities, and noted specific instances of their children being suspended or expelled.

“They said they could no longer handle his needs and he was being removed from the program, and we were just left with no care and both of us working.”

“The first place flat out said he couldn’t come [anymore]. The second place made it really difficult to get back in after summer break...The third place he’s at currently, they’ve been suspending him pretty frequently. And saying, oh we don’t know if we can handle him so you should come and get him...[For all three providers], it suddenly doesn’t work out...that doesn’t do well for my son or for us with our jobs.”

Many parents had experienced policy limitations with accessing child care services for their children. Some parents wanted more support to help them connect to qualified providers who could allow them to have EI/ECSE services in tandem or within child care, or who could provide care around EI/ECSE service days. Many parents described wanting workable scheduling and availability, help with making decisions about available supports, and having information about or assistance with navigating systemic processes related to disability services.

“...with the early intervention, we only got 75 minutes twice a week, and it was almost more work to load everybody up and take him and drop him off, to have to turn around in 40 minutes or so and drive back.”

Other Challenges Finding Care

In addition to the challenge of finding providers with adequate experience or training in how to support children with disabilities, cost was also noted as a barrier to finding quality care for their children. Many parents highlighted the lack of qualified providers as a need in the community, describing the difficult job of providers and therapists working with children with disabilities.

“...a lot of these programs seem to be really understaffed. That’s really, honestly, when it comes right down to it, that’s really the reason why the availability is so low is because there’s not a lot of people...it’s just such a difficult job.”

Connected to availability, finding care that provided enough flexibility in schedules was also noted as a barrier, specifically with services related to their children's disabilities. Parents talked about limited schedule availability for Early Intervention/Early Childhood Special Education (EI/ECSE) services and needing to be able to juggle those schedules with other scheduling for child care arrangements and/or work.



Finding Appropriate Care

Finding appropriate care for their children experiencing disabilities was clearly challenging for a number of these parents, and one parent told us that she was never able to find appropriate care for her children. Those who had found care described making connections with services and providers through word of mouth with friends, family, or social media, as well as receiving help from various community nonprofits and referral resources. Information and referrals provided by other parents with children with disabilities were seen as one of the most helpful things for finding appropriate care.

“And a lot of it is like, who do you know...find that parent who is just a step ahead of you, and they have that lived experience [that they can share].”

“We also have EI/ECSE, but they only accept him for 2 hours 2 days a week. Now, I can’t go and work if I have to take him to school at 1:45 and pick him up at 3:45. My husband and I have to have full-time jobs to pay our bills. We can’t find another placement for our special-needs child that works with his special education ECSE—so, I guess that’s what we need.”

Compromising for Child Care

These parents described a number of compromises that they were making, or had made in the past, to get child care for their family. Some parents compromised because they could not find a provider they could afford who was qualified or trained to care for children with disabilities. Other parents described feeling uncomfortable asking family members to help care for their child, and placing children in child care instead. A few also described choosing to have friends or family care for their child because other child care options were too expensive. Most parents described some trade offs in which decisions in their households around work were made due to the high cost of child care. Four parents said that they had chosen not to work, and two parents said that they limited their work hours because child care was too expensive.

“I couldn’t leave him with family because nobody understood because of this invisible disability he has. They just think he’s being a bad child and he’s not. I had to go against my better judgement and have someone I didn’t know to watch my children while I was in the hospital.”

“We ended up not being able to afford daycare...So, [with my friend] there was no education, there was no structured this, that, or the other. She made sure the kids were alive at the end of the day, they were fed...That’s what they were doing, whatever worked, whatever she had and I got daycare that was affordable...”

Their Needs as Parents

When asked about what would help them to “be the best parent they could be”, most parents cited more time, money, and support as priorities. Parents also described wanting to have a more stable child care situation and having the same daily schedule, as something that could significantly reduce their day-to-day stress. Some parents also noted that while doctors and other professionals emphasized the importance of ensuring their children got additional support as early as possible, the lack of available appropriate care made them feel they were not meeting their children’s needs and added to parents’ stress:

"...the opposing feeling of doctors and research and the internet, and everybody saying the earliest you can get to everything the better, that message mixed with super-long wait lists, with super-low availability, made me feel like I was doing a horrible job and created this whole panic mode."

"...just somebody to tell people or other parents how to do an IFSP, cause a lot of that is difficult as all get out without any resources."

These parents talked about how important closing the gap between family needs and the disabilities services system would be to helping parents do the best they could as parents of children with special needs.

"Where the system is well intentioned to make everything work and everything function, and then you've got the people over here, the parents, who are basically trying to figure everything out, that are well intentioned, but there's that gap...it's not just passage of information, it's passage of experience. Just that experience back and forth, there's that gap where all the good intentions don't matter if they don't mix."

Creating Change Through Parent Advocacy

Parents talked about the need for parents to advocate for specific services for themselves and their children, and noted success when this happened. In particular, they described situations where the system responded to parents' requested needs for a particular service if many parents are asking for that service:

"[My son's service coordinator and I] were talking about one need he had in particular, and she was like—they all work in cubicles in an office—and they were like, oh, moms are talkin'! Cause they got like 10 moms calling in wanting the same thing for their service all of a sudden, and that's what they call it: moms are talkin'."

"But it's something I find really interesting with the system is that they know that they can provide—the service coordinators know that they can provide this [service]—but they can't tell the parents that they can provide it unless the parents ask for it. But the parents don't ask for it because they don't know it exists and they don't know that they can ask for it. So, as soon as one parent tells another parent, 'Oh, I get this service', it's like, 'Oh, moms are talkin'!'...However, if you don't know to say that and you don't know to ask for that [service], then they won't offer that or ask you."

Key Takeaways

- ▶ Parents need to be able to access information about early intervention, early childhood special education, and other community services for children experiencing disabilities.
- ▶ EI/ECSE service or other therapeutic service options that are provided within child care settings or in tandem with child care providers would allow parents to utilize those services more readily.
- ▶ Working parents need to have access to EI/ECSE services outside of work hours or in ways that accommodate the needs of dual income families
- ▶ More qualified and affordable child care providers are needed to care for children experiencing disabilities.

Acknowledgements

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Responsive Evaluation & Research

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OSLC DEVELOPMENTS, Inc.

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Funding for this work was provided by the Oregon Early Learning Division as part of the Preschool Development Grant. We would like to thank staff from Bridging Communities for agreeing to work with us to create an opportunity to hear from families. We are especially grateful to the families who took the time to share their experiences, needs, and hopes with us.

The project described was supported by Grant Number 90TP0020-01-02 from the Department of Health and Human Services Administration for Children and Families (DHHS). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of DHHS.