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Defiant Joy: The Parent-Professional Collaboration Behind the Fostering Joy Movement

By Amy Szarkowski and Candace Lindow-Davies

Fostering Joy is a movement that began in 2017 to support the intentional practice of looking for and encouraging joyful moments between families and/or caregivers and their children who are deaf or hard of hearing. The aim of Fostering Joy is to spark collaboration among families, caregivers, professionals, and adults who are deaf or hard of hearing to encourage a collective shift in focus from mitigating the challenges of raising and supporting deaf and hard of hearing children to celebrating these children, their growth, and the many positive impacts they have on our lives.

Fostering Joy does not deny challenges that can be involved in raising and supporting deaf and hard of hearing children, nor does it ignore the unique needs of these children and their families. Rather, this movement recognizes these challenges and encourages addressing them directly. It promotes the reframing of experiences to intentionally find and foster moments of joy, to celebrate the connections and affections that children who are deaf or hard of hearing bring to those in their lives, and to find opportunities to savor the good moments amidst the challenges.

As the Fostering Joy movement has grown, families from a variety of backgrounds who are raising children with diverse needs—including those with health challenges—have found comfort and fellowship. For example, Joanne Nelson, a Wisconsin mother of two deaf children who have rare, complex medical needs, shared, "I think it's a conscious choice on how you choose to see challenges and life, no matter what happens to you ... to me, love, appreciation, and joy are the only choices that make life worth living."

Photos courtesy of Amy Szarkowski and Candace Lindow-Davies



Left: At the Nevada Hands & Voices "Winter Wonderland" party in Las Vegas in December 2021—the first in-person event in almost two years families had the chance to share what brings them joy while waiting in line to have pictures with Signing Santa. Below: Cora Shahid and family share what brings them joy.

History of the Movement

Following a presentation at a conference that emphasized the need for caregivers to be educators and language role models for their deaf and hard of hearing children, several parent leaders and professionals gathered to discuss the intense pressure placed on families. While acknowledging the vital role that caregivers have in their child's development, the group also shared concern for the development of the family-child bond, the well-being of the child and the family, and the impact that a constant focus within families on "educating and ensuring language input" could have on a child's social-emotional growth. Those parent leaders and professionals shared a desire for families to recognize and celebrate the gifts of their children and to be "present in the moment" to witness the magic that occurs in the everyday interactions between caregivers and their children. That initial set of parent leaders and professionals continued to contemplate how different things might be if families were encouraged to hold on to those precious moments. Those involved in these initial conversations became the "Core Team." Their ideas and desire to shift the focus for families with deaf and hard of hearing children



gave birth to this collaborative project, Fostering Joy.

A Community of Joy Ambassadors

The Fostering Joy founders came from diverse backgrounds, but they were still a small group. As this idea grew into a movement, it became clear that other perspectives not yet at the table were absolutely necessary. The project organically expanded to include even more diverse perspectives from parents in different geographic locations and from fathers, to add more deaf adults with a variety of lived experiences as well as additional professionals in fields such as deaf education and healthcare.

Candace Lindow-

Davies is the mother of an adult son who is deaf with additional health concerns. For 16+ years, she developed and directed parent support services for Minnesota Hands & Voices. In May 2017, she became the director of outreach for Hands & Voices Headquarters (www.handsandvoices.org) and has served on the Core Management Team of the Family Leadership in Language and Learning Center (FL3, www.hands andvoices.org/fl3). She is a Core Team member and lead for the family arm of the Fostering Joy Project.

The authors, on behalf of the Fostering Joy Core Team, welcome questions and comments about this article at *amyszarkowski@ cccbsd.org* and *candace@ handsandvoices.org*, respectively.





Above: The Hands & Voices *Fostering Joy Reflective Journal* is a great way to capture precious moments of raising a deaf or hard of hearing child.

Desiring to extend the impact of focusing on joy beyond the Core Team, Fostering Joy embraced the idea of "Joy Ambassadors." These are family members, caregivers, adults who are deaf or hard of hearing, and professionals who express a desire to center their experiences in raising and supporting deaf and hard of hearing children in joy.

Joy Ambassadors form a community of people finding and celebrating common ground in cherishing children who are deaf or hard of hearing and respecting the many unique and positive ways that they impact their families and the world. Joy Ambassadors, despite the many demands on their time, attention, and resources-and despite the challenges of this unique moment in history-consciously, defiantly choose joy. At conferences and through presentations, the Fostering Joy Core Team has encouraged others to embrace being a Joy Ambassador, whether through making an individual resolution to recognize "joy moments" or by making a commitment to implementing joy in larger ways.

For Joy Ambassadors who wish to invest their time, energy, and ideas into growing this movement, Fostering Joy has working groups to extend the reach of Fostering Joy and provide additional opportunities for individuals interested in this movement to become involved in a meaningful way.

Fostering Joy strives to be inclusive and

"I was invited to a **Fostering Joy** presentation, and it confirmed that our kids may have a diagnosis, they are going to have a lot more struggles, but our kids are beautiful, and they are what makes us our people. This is a different joy, something that once you get it, it doesn't diminish or fade; it manifests, and you start looking at things differently."

> - Aja Gohier-Singnakhone, Hawaii parent of a deaf child

welcoming. Across the Core Team and the working groups, Fostering Joy includes individuals with diverse lived experiences, including those with children who experience "different ways of being deaf" (e.g., Deaf, deaf, hard of hearing) and family members or caregivers of children who are deaf or hard of hearing with health challenges. It also includes individuals who represent different geographic locations and cultural backgrounds. Adults who are deaf or hard of hearing and who also represent "different ways of being deaf" have been invited to join and offer valuable insights from their own lives as well as their work supporting families and caregivers. Professionals from a variety of disciplines (e.g., early intervention, psychology, deaf education, speech-language communication, social work, audiology) have committed to implementing strategies for promoting joy in their work.

As Fostering Joy has grown, there has been an increased awareness of the need for resources and support for the movement. While the collaboration among those supporting children who

Below: Fostering Joy Core Team members ... front row: Cora Shahid, Rashaun Davis, Candace Lindow-Davies, Karen Putz, Stephanie Olson; back row: Jennifer Clark, Nicole Hutchinson, Janet DesGeorges, and Beth Jones. (Missing: Amy Szarkowski).





Above and right: Aja Gohier-Singnakhone, from Hawaii, journals about the joy her daughter Ke'ele brings; the family enjoys spending time together on fun outings, such as the one to Disneyland.

are deaf or hard of hearing remains central to the mission of the group, there are now two "arms" of Fostering Joy to better meet the unique needs of families/caregivers and professionals.

Growing the Movement for Families

Hands & Voices Headquarters now serves as the home for Fostering Joy: Families. Families and caregivers can access a website (*www.handsandvoices.org/resources/fostering-joy.htm*) to download information and resources as well as to reach out to the Fostering Joy Core Team. One resource is a *Fostering Joy Family Tip Sheet*, developed based on ideas offered by families to help other families and caregivers with children who are deaf

or hard of hearing to create joyful moments. To date, these tips are available in 11 languages. There is also a *Fostering Joy* video (*https://vimeo.com/463926086*) composed of submissions from families sharing their joyful reflections about their children. There is *Fostering Joy: A Reflective Journal**

(*www.handsandvoices.org*/ *resources/fostering-joy/journal.html*), available for purchase in English and Spanish, that includes prompts to help families

Right: Amy Szarkowski, Beth Jones, and Jennifer Clark present about Fostering Joy on a National Hearing Assessment and Management webinar in December 2021. and caregivers capture joyful memories. Soon, a *Fostering Joy Journal for Kids* will also be available. An important aspect of building the Fostering Joy community has been the creation of a closed Fostering Joy–Families of Deaf and Hard of Hearing Children Facebook group (*https://m.facebook.com/groups/DHHFosteringJoy/*). For some, this group provides a refuge from the stressors of daily life and a place to celebrate the successes of raising a deaf or hard of hearing child.

Growing the Movement for Professionals

The Institute at The Children's Center for Communication/Beverly School for the Deaf serves as the digital home for Fostering Joy: Professionals (https://cccbsd.org/programs/ institute/fostering-joy-professionals/). The initial focus of the movement was on helping families to foster joy; yet professionals who support children who are deaf or hard of hearing and their families and caregivers can also benefit from mindfully focusing on incorporating joy into their lives and into their work. On the website, professionals can freely access a Joyful Prompts & Activities: Ideas for Working with Families tip sheet and Joy in Work: A Weekly Worksheet for Reflection. The community of professionals interested in centering on joy is growing with the help of the Fostering Joy-Professionals Facebook group (https://m.face book.com/groups/dhhfosteringjoyprof/). As with families

and caregivers, professionals appreciate the shift in focus to center on joy. Professionals have commented, "Recently we have seen an explosion of language growth in some kiddos. That gives me so much joy!" and "A parent that I worked with when her son was 15 months old reached out to check in and let me know he is in his first year of college and loving it!"



Looking Toward the Future

Separately and collectively, groups of families, caregivers, adults who are deaf or hard of hearing, and professionals are drawing from the tenets of Fostering Joy and making them their own, implementing activities within their spheres of influence. These include offering parent workshops, writing joy-focused articles for newsletters, hosting book groups exploring joy as a topic, anointing May as Fostering Joy Month (in one creative state), hosting family retreats that center on growing joy, and providing tools and ideas for families to foster joy at home. Once a mere idea of shifting away from the "problem-focused" approaches that many professionals were using in their work with families and caregivers, Fostering Joy has been adopted as a motto for interacting with families and caregivers and a way of intentionally engaging with children who are deaf or hard of hearing. We look forward to seeing where the movement will take us!

*Authors' note: Fostering Joy: A Reflective Journal is available for \$14.95 each or with a discount for bulk orders (6+ copies); all other Fostering Joy resources are free of charge.



Learn More About Fostering Joy

To learn more about the Fostering Joy movement, including its mission and roots, how to get involved, and its Core Team, visit *www.handsandvoices.org/resources/ fostering-joy.htm.* The *Fostering Joy Family Tip Sheet* is also available on this website for free downloading in ASL, English, French, Hmong, Italian, Japanese, Mandarin, Somali, Spanish, Thai, and Urdu.

