

# Through an international lens

**Janet DesGeorges**, Hands & Voices and The Global Coalition of Parents of Children who are Deaf or Hard of Hearing, discusses the essential role of parental engagement

I will always remember the day I stood in front of a room full of early intervention practitioners, where I was sharing the story of my involvement and advocacy strategies as a parent in navigating the medical and educational systems that were serving our family. One of the professionals raised her hand and commented, "I wish we had parents like you in our area." I was flattered, of course. But later, as I reflected on that comment, I thought of the thousands of families across the world I have had the honor to meet through my work as a director for a non-profit organization, Hands & Voices (based in the United States of America (USA)), as well as my involvement with the Global Coalition of Parents of Children who are Deaf or Hard of Hearing (GPODHH) and realized, of course, there were "other parents like me." I knew that I was not born a natural advocate and had learned advocacy and parent engagement skills along the way. For many parents, becoming an effective advocate for their child may not occur naturally but is something that is learned over time and modeled by other parents and the professionals that serve them. Learning advocacy was a first step in achieving leadership skills that empowered me to lead others towards systemic improvements.

The ability to lead in a complex world is at the heart of accomplishing successful outcomes. In other words, those involved in 'systems', ie deaf education, may know what needs to be accomplished, but leadership is the essential element for how to get there. Effective leadership can lead to improved outcomes and should be a shared responsibility among all those who are a part of effective programming (Clegg, 2000). All practitioners and families who seek to improve the educational system, regardless of their position of authority, have an opportunity as well as responsibility to take the mantle of leadership to create success. And yes, that means parents, too, should and can be seen as leaders. Parents across the globe, whether they come from a culture where terms like 'leadership' and 'advocacy' are not typically ascribed to the parent voice, have learned and taken on their role in partnership with professionals to ensure good services for children and young people who are deaf or hard of hearing (d/hh).

In ensuring an appropriate education and/or medical support for their child who is d/hh, families of students may find delivery of services inferior to established standards and are often forced into the role of reactionary advocacy to overcome lack of effective services in the real world. Examples of the challenges that families face include long wait times for audiological support, educators who do not understand the unique needs of children who are d/hh, or ensuring inclusion in

community life. Frustration occurs for both practitioners and parents who know what appropriate practices should be in place, and then find their own experience is far from that in real life. Imagine a world where standards are implemented in programs and society regardless of geography, disability status, socio-economic status, culture, and other barriers. The gap between what should be and can be is often the leadership ability directly related to effective services for our children (Maxwell, 2007).

## Parents as co-leaders

"Simply put, we are in the trenches 24/7 and live the life we advocate for on an individual and organizational level. We live that life; we are not distant from it ... we never stop being parents to a special needs child and we grow as they grow and their needs grow. We are constantly aware, constantly in touch and we never forget where we have come from and that guides where we are going. Yes, we wear the hat of a leader, but we always wear the hat of a parent. ... we are always in touch with what it means to be simply a parent of a special needs child and the journey of balancing those needs and the creativity in leading others, and how those two needs flow one into another and instead of in tension, ultimately encouraging harmony." (Parent from the USA).

Viewing parents as co-leaders as part of the paradigm towards successful outcomes goes beyond simply viewing family roles as partners in the process, or recipients of programming. Co-leading can also occur within the concept of co-production theory. The theory of co-production of services (Batalden, 2015) encouraged collaborative work, initially implemented in healthcare system design. As noted in 'A conceptual model of healthcare service,' co-production of services should not be viewed as a 'product delivered'; it is better conceived as a service. Services are always co-produced by service professionals and service users. Partnership is a relationship where professionals and families share power to plan and deliver support together, [each group] recognizing that [the other has] vital contributions to make to improve quality of life for people and communities (National Co-production Critical Friends, 2015).

Parent involvement is a major predictor of a child's developmental outcomes and educational success and includes being an active participant in the decision-making process. Many studies have been conducted over the past 30 years that identify parent involvement as the one most important factor in student success in school (Henderson and Berla, 1995). Benefits of parent involvement include higher reading scores, higher grades

on homework, improved attitudes towards school, and improved relationships between parents and teachers (Donahoo, 2001). In the past, parents were often invited to share their feelings and experiences about their lives but were not integrally involved in the actual hands-on processes of developing systems. Today, you will find parents at the decision-making tables of systems development, state advisory councils, staff positions in agencies, and directing their own family-based organizations such as Hands & Voices ([www.handsandvoices.org](http://www.handsandvoices.org)) and GPODHH ([www.gpodhh.org](http://www.gpodhh.org)). Engaged families often learn their skills in leadership from one another in these types of organizations.

Hands & Voices is a US-based non-profit organization with chapters in the US and Canada, which has found the key to successful representation and parent-to-parent support through developing leaders in the skills needed for parents to support their own child, other parents, and improvement in systems building. Hands & Voices emphasizes that every child and family is different, and

there is no single "right" way to approach raising a d/hh child. Our slogan, 'What works for your child is what makes the choice right,' reflects our focus on family-driven decision-making. The parent-driven yet professionally collaborative model of Hands & Voices leverages the strengths of both parents and professionals, ensuring that children who are d/hh receive the best possible support and opportunities. This partnership creates a culture of mutual respect, shared learning, and better outcomes for children and their families.

GPODHH is an international alliance of parent-led organizations that advocate for the rights and well-being of children who are d/hh. GPODHH unites parents and caregivers across the globe to share knowledge, collaborate, and advocate for policies and practices that benefit children with hearing differences and their families. The mission of GPODHH is to empower and support parents and caregivers to ensure the full inclusion, participation, and development of children who are d/hh, regardless of their circumstances or communication preferences. GPODHH has strengthened ►

## BATOD membership: developing professional world partners in deaf education

BATOD is a professional body which offers a 'community' of dialogue and information.

If a UK-based BATOD member has an established involvement with a developing world project, they can make a recommendation for the head teacher of the school for the deaf or teacher in a deaf resource base associated with their project to be registered with BATOD as an online 'overseas special member' at no charge to either member.

- BATOD has an expectation for the overseas special member to submit an annual magazine article or information for a blog post. BATOD encourages the overseas special member to be the author/co-author of the article submitted.
- The BATOD overseas special member must have internet access in order to access the online resources which may be of interest.
- Online members can access the five magazine editions/year in the electronic version. The BATOD magazine frequently features articles about deaf education from across the world. Thus, our special overseas members can share with and learn from UK and other worldwide professional peers in deaf and deaf related education.

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## Retiring?

**As another school year draws to an end, you may be thinking of changing your membership arrangements.**

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If we are alerted early, we can take the necessary steps to ensure that payments are amended as required.

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### Please let us know:

- what changes you wish to make
- the date you wish to implement those changes

Please also contact your bank to ensure that direct debits are cancelled and ensure that recurring card payments are stopped if you are cancelling membership.

If you have any queries re your membership options, further information is available here [www.batod.org.uk/memberships](http://www.batod.org.uk/memberships) and please do not hesitate to contact us.

## Regulars

the collective voice of parents worldwide, ensuring that their insights and experiences are central to shaping policies and practices. By working across borders and collaborating with key stakeholders, the coalition has become a powerful advocate for creating a more inclusive and supportive world for children who are d/hh. Through its efforts, GPODHH strives to ensure that no child or

family is left behind, fostering a global network of support and decision-making processes, we pave the way for systemic improvements that benefit all children and families. Together, parents and professionals have the power to bridge gaps, overcome challenges, and build a future where every child, regardless of circumstance, can thrive.



*Janet DesGeorges lives in Boulder, Colorado, USA with her husband Joe and is mom to three daughters, including Sara, who is deaf/hard of hearing. She is a co-founder and the Executive Director of Hands & Voices Headquarters, a parent support and advocacy organization for families who have children who are deaf/hard of hearing. Janet has presented to groups worldwide on a wide variety of topics, including leadership development for parents who participate in systemic improvement, Deaf Education improvement, Children's Safety and Success (preventing child abuse and neglect), Early Hearing Detection and Intervention Systems, and Parent/Professional partnerships. Her starting point is always about the experiences of families as they journey through life with a child with deafness or hearing loss. She is also a founding and current member of GPODHH.*

*Ms DesGeorges has contributed to many publications, including the 'Hands & Voices guidebook'; 'Educational advocacy for students who are deaf or hard of hearing'; the 'Consensus practice parameter': audiological assessment and management of unilateral hearing loss in children, International Journal of Audiology, along with a companion user guide for families; 'Avoiding assumptions: Communication decisions by hearing parents of deaf children, American Medical Association Journal of Ethics; and a self-published book, Not a leader, now a leader. Ms DesGeorges received a program certificate from the MCH Public Health Leadership Institute in 2011 at the University of North Carolina, Chapel Hill.*

*As an advocate, Janet believes in the principles and guiding philosophies of Hands & Voices towards a parent-driven, professionally collaborative approach when supporting families and working towards systemic improvements.*

*To find out more about Hands & Voices and GPODHH, contact the author at [janet@handsandvoices.org](mailto:janet@handsandvoices.org)*

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## We all need personal assistants

Several months ago, I created [hear2learnGPT](#) as an expert artificial intelligence (AI) assistant, designed to support practising Qualified Teachers of Deaf Children and Young People, including those in advisory, peripatetic, leadership, and management roles. Particular attention was given to the Special Educational Needs and Disability (SEND) Code of Practice and best practices in inclusion and deaf education. The GPT (generative pre-trained transformer) offers tailored guidance to help educators navigate complex educational landscapes.

For busy teachers and educational professionals, hear2learnGPT can be a significant time saver. It provides, amongst many functions, quick access to specialised information, assists with improving educational plans, and offers insights into effective inclusive teaching strategies. While hear2learnGPT strives to be a valuable resource, it is a tool meant to complement, not replace, professional expertise and judgement.

If you are not a user of OpenAI, you will need to create a free account to use this tool. I'd love to hear if it helps, and if there is the demand, I'll develop other tools.

Expert assistant: [bit.ly/hear2learnGPT](https://bit.ly/hear2learnGPT)

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# BATOD Magazine

This article was published in the March 2025 issue.

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British Association of Teachers of Deaf Children and Young People

MAGAZINE • March 2025 • ISSN 1336-0799 • [www.batod.org.uk](http://www.batod.org.uk)

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