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# THE CO-DEVELOPMENT OF A FRAMEWORK TO SUPPORT PARENTS OF CHILDREN WITH A HEARING LOSS: USING A CONSENSUS WORKSHOP

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# ABSTRACT

Research highlights the complex needs of parents of children with hearing loss. These complex needs include the need for parents to have access to information, be connected with social support networks, consider communication options and have collaborative partnerships with professionals. A mixed-methods approach with a sequential explanatory design using a two-phased approach was implemented in the study. This article reports on the last phase of the study, the consensus workshop. The consensus workshop approach allowed for greater participation, interaction and discussion in the decision-making process in the co-development of a framework to support parents. This phase consisted of two workshops where experts, stakeholders and parents reached consensus on four topics and fifteen sub-topics. Each topic with its sub-topics offers insights into the kind of professional support parents require. The consensus workshop can be considered a valuable tool for multidisciplinary engagement to support parents of children with hearing loss.

Keywords: framework consensus workshop; parents; children with a hearing loss

# **INTRODUCTION**

It is estimated that 90% of children who are born with hearing loss are born to hearing parents (Chaudhury, 2014; Cole & Flexer, 2015; Lederberg, Schick & Spencer, 2013; Smith, Shearer, Hilderbrand & Van Camp, 2014), who often know nothing or very little

about hearing loss. When a child with a hearing loss is born into a hearing family, it can be inferred that the hearing loss does not only affect the child but the whole family (Henderson & Hendershott, 1991; Humphries, Kushalnagar, Mathur, Napoli, Rathmann & Smith, 2019; Seligman & Darling, 2009). For these parents, information on various forms of support serves as a frame of reference as they begin their parenting journey of searching, inquiring, learning and making informed decisions that are most appropriate and applicable for them as parents, their families and the child. Research shows a need to support, guide and provide parents with information (Szarkowski & Brice, 2019; Zaidman-Zait & Jamieson, 2004) as parents weigh up information about communication options and education choices (DesGeorges, 2016). Information on these topics may assist parents in making well-informed choices and aid them in managing their child's hearing loss.

Over the years, there has been an increased awareness of the importance of professional support in the field of family-centred interventions for parents and children with a hearing loss (Moeller, Carr, Seaver, Stredler-Brown & Holzinger, 2013). Many studies have highlighted parents' multifaceted need for support and unbiased information (Goodall & Vorhaus, 2011; Wang, Norris & Bero, 2018; Zaidman-Zait & Jamieson, 2004). Solutions to address these needs can be developed through participation and collaboration with parents and professionals in the area of hearing loss. In this study, the co-development of a framework by parents, experts and stakeholders is intended as a type of support for parents parenting children with hearing loss. It does not replace any ongoing services provided to parents, but complements and contributes to the existing professional services offered to parents. Therefore, the co-development of a framework helps to identify 1) what has already been done, 2) to build and strengthen partnerships with parents and between parents and professionals, and 3) to provide services that are effective, familycentred and strengths-based (Hamilton, 2017). Moreover, the development of any framework cannot be the sole responsibility of professionals in caregiving settings. Experts and stakeholders, including parent participation, can work towards creating a tailored framework that reflects the processes of engagement contributing to the codevelopment of the framework. In co-developing this framework, a consensus workshop was incorporated into the process. A consensus workshop approach allowed for greater participation, interaction and discussion in the decision-making process through individual, small group and extensive group discussions (Hall et al., 2019).

Several researchers have used consensus workshops in disability studies, for example, to establish research priorities in the field of post-traumatic pain and disability (Walton *et al.*, 2016), promoting physical activity and health among people with disabilities (Cooper *et al.*, 1999) and facilitating disability inclusion in poverty-reduction processes (MacLachlan *et al.*, 2017). Other researchers have provided valuable information on the differences between consensus workshops and Delphi techniques (McMillan, King & Tully, 2016), practical applications and methods of analysis (McMillan *et al.*, 2014; Tully & Cantrill, 1997).

However, only two published studies focusing on parents of children with hearing loss using a consensus framework were found. In 2012 at an international conference, an international panel of experts – parents, professionals who are deaf, researchers and early intervention specialists – came together as a consensus panel to reach consensus on ten guiding principles to implement a family-centred intervention. Following the conference, the consensus panel came together again to refine the principles and co-develop a document that described these guiding principles. Five of the guiding principles (2, 3, 4, 6 and 7) placed an emphasis on neutral and unbiased information. They included objectives that provide practical guidance on improving services to families and parents of children with hearing loss (Moeller *et al.*, 2013). However, the document does not detail the consensus-making process.

Hendersen's (2015) study on parent-to-parent support for parents of children who are deaf or hard of hearing used a modified Delphi research design and consulted with experts in the area of parent-to-parent support. Her study included the use of web-survey software and a panel of international experts who contributed to the framework through two rounds of mixed-method questionnaires. The study provides important information on the processes followed using the Delphi design and the way that the experts engaged in decision-making.

In this article we describe the process of the consensus workshop that led to the collaboration between experts, stakeholders and parents from two workshops with the aim of co-developing a framework to support parents of children with hearing loss.

# BACKGROUND

Before conducting the consensus workshop, a study with a mixed-methods approach with a sequential explanatory design was completed. This mixed-method study endeavoured to identify the problem and explore the needs of parents by adopting a two-stage approach. In stage one 103 respondents participated in a quantitative study, and in stage two 13 participants participated in a qualitative study. The findings of the mixed-method study produced 22 recommendations/topics (Table 1). These recommendations inform the implementation of the consensus workshop.

Table 1: A summary of the findings of the mixed-methods research approach with
a sequential explanatory design

Stage 1	Findings and recommendations to be considered in the co-	
	development of a framework of support strategies for parents	
Stage 1: Quantitative	Topics	
inquiry	Socio-emotional support for parents	
	Parent's understanding of the aetiology of the child's hearing loss	
	Information and resources on hearing loss	
	Parent support and intervention programmes	
	Father support programmes	
	Understanding parenting a child with a hearing loss	
	Communication challengers	

Stage 2: Qualitative inquiry	Topics
	Support groups and guidance
	Support for parents in terms of resources
	Support groups for a child with a hearing loss
	Support for siblings of children with a hearing loss
	Professional, empathetic and unbiased support
	Parents' challenges when parenting a child with a hearing loss
	Need guidance on specific information on hearing loss, and
	support
	Communication challenges and needs, and unbiased support for
	communication choices

#### METHODOLOGY

The aim of the consensus workshop was to co-develop a framework to provide practical support strategies for parents of children with hearing loss. The objective of the study was to engage with experts, stakeholders and parents to reach consensus on the recommendations/topics emanating from the mixed-method study. The research question was "How can a framework for hearing parents parenting a child with a hearing loss be co-developed with parents and experts in the field of deafness, using a consensus workshop?"

The workshop employed a qualitative research approach, which is considered a promising tool for collecting data in qualitative research (Ørngreen & Levinsen, 2017). Recent literature on workshops as a methodological research approach (Ørngreen & Levinsen, 2017) states that a workshop is reliable in producing valid data. It aims to meet participants' expectations to realise a matter associated with their interests. These authors found a variety of basic shared features in a workshop methodology, namely: 1) the workshop was arranged and conducted with participants with a common interest and conducted within a limited timeframe; 2) it was carried out with experienced people familiar with the research topic; 3) active participation among all attendees was encouraged; and 4) participants expected an explicitly formulated outcome at the end of the workshop.

Our study implemented a consensus workshop design to co-develop a framework to support hearing parents who are parenting children with hearing loss. The primary purpose of the consensus workshop was to generate ideas by using methods that promote structured feedback and a combination of individual responses to arrive at a consensus (Cantrill, Sibbald & Buetow, 1996). Unlike a Delphi design, which uses a written survey method via email or anonymous postal questionnaire for decision making among respondents, the consensus workshop is a group technique where the objective of the group is to have face-to-face discussions in a small group, feedback is prompt and consensus is reached (Cantrill, Sibbald & Buetow, 1996). An advantage of the consensus workshop is that it allows for more agreement and greater clarity and understanding of reasons for possible disagreement in face-to-face meetings; it is also associated with practical considerations such as time and geography (McMillan, King & Tully, 2016). For our study, the consensus workshop was appropriate as it sought to engage with

academic experts, stakeholders and parents in order to address the needs of these parents of children with a hearing loss. Likewise, the decision to adopt this method was influenced by the time and geography of the study.

#### **Data collection**

Data were collected from two sets of participants. The first set of data was collected from academics from an academic institution with relevant experience in the field of family and disability. The second data set was collected from stakeholders in the field of hearing loss and parents who participated in the mixed-method study. This ensured that people working in the field of hearing loss, including parents, contributed to the topics in the framework. All participants signed an informed consent form indicating their voluntary participation in the workshop, with the researcher undertaking to protect their identity and the nature of their contribution. The workshops took place during September and October 2019.

All participants worked and stayed within the geographical setting of the current study, that is, within the Cape Metropole, situated in the south-western part of South Africa.

#### Sampling strategy

Pragmatic considerations determined the sampling size of the panels; for example, in round 1 a purposive selection strategy was used to identify ten academic experts. In round 2 stakeholders were selected from non-governmental organisations for the Deaf and hearing parents who participated in the mixed-method study. All of the participants were recruited within the Cape Metropole area.

#### Participants and criteria for inclusion

In round 1 the study facilitator extended invitations via emails to 10 potential academic expert panellists from a University in the Western Cape. The inclusion criteria included: 1) academics who are teaching, researching and publishing on child, family and disability; and 2) who have relevant knowledge and expertise at clinical and policy levels. On the day of the workshop, six of the panel of experts attended the workshop. The selection of ten academic experts allowed for the possible withdrawal of some, as all academic experts have similar professional experiences as mentioned above to maintain the sample size and ensure the integrity of round 1. The workshop was held in a meeting room at the University in the Western Cape, ensuring confidentiality and privacy. The workshop was scheduled to last for two hours.

In round 2 the facilitator invited 19 stakeholder panellists and parents. The inclusion criteria included: 1) stakeholders working in the field of hearing loss; and 2) parents who participated in the mixed-method study (whose children with hearing loss were between the ages of 8 and 14. Invitations were sent via email to stakeholders and parents to participate in this consensus round. Among the stakeholders who attended were: two social workers working at local organisations for the Deaf, one provincial director of an organisation for the Deaf, two audiologists (one from a public hospital and one in private practice), two school social workers, five parents of children with hearing loss, two volunteers from organisations for the Deaf (long service in the Deaf community), and

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three Deaf mentors. All stakeholders and parents participated in the face-to-face consensus workshop at a community centre that was not affiliated with any stakeholder and was scheduled for two hours.

#### **Ethical considerations**

This study received ethical approval from the Research Ethics Committee at the University of the Western Cape (Ethical clearance number HS16/6/12).

# Conducting the consensus workshop

In conducting the consensus workshop, the study researcher served as the facilitator of both workshops. The facilitator's role during the consensus workshops was to: 1) explain the aim, objectives and procedure of the workshop, 2) facilitate sharing of ideas, 3) facilitate group discussion and expression of opinions, and suggestions for change among expert and stakeholder members, 4) combine topics that were similar, and 5) facilitate voting and prioritise ideas before the recommendations were agreed upon (Table 1).

**Round 1:** The goal of round 1 was to share the following with the panel of academic experts: 1) the aim and objectives of the consensus workshop; 2) present the findings of the mixed-method research; and 3) identify topics and sub-topics resonating with the findings of the mixed-method study. The panel of academic experts was asked to respond to a set of propositions corresponding with the findings: 1) indicate which topics resonate with the research study's findings and their usefulness for implementation; 2) comment on the language used, particularly disability-friendly language; and 3) was there any additional information they felt could be addressed by the framework.

**Consensus reached in round 1:** In response to the above set of questions, the following consensus was reached by the panel of experts:

1) As a result of similarities and overlapping of some of the findings, the panel of experts agreed to the merging of several of the findings and proposed clustering them into common topics, which resulted in 3 topics and 12 sub-topics;

2) One additional topic should be included, namely early intervention programmes, which would encompass issues concerning early screening and diagnosis, and counselling for parents; and

3) The inclusion of an additional sub-topic, namely a resource list under the overarching theme of resource support.

There was unanimous agreement by all the experts concerning these topics and subtopics. A final consensus was reached on four topics and fourteen sub-topics (Table 2).

Topics	Sub-topics	Comments made by a
		panel of experts
Early intervention	Early screening and	"This must be included in
programmes	diagnosis and counselling	the framework as it will
	for parents	inform parents that early
		diagnosis is important"
		"This is also an important
		recommendation for the
		drafting and implementing
		a policy."
		"Yes, this recommendation
		we support."
Parent social and emotional	Professional counselling	"Agree"
support	Support groups for a child	
	with hearing loss/ siblings /	"No additions need to be
	others /fathers	made."
	Support groups for parents	
	(to improve parent self-	"Nothing at this point, as it
	efficacy)	is clear."
	Support groups for father	
	Support groups for a	"I see that the
	sibling	recommendations include
	Increase social network	the hearing loss child; I am
	with other parents	glad about this."
	Professional and	
	empathetic, and unbiased	
	support	
	Parenting challenges	
Information and resource	Need guidance,	"Agree"
support	information on hearing	
	loss, information and	"I think we need to add a
	support	resource list for parents as
	Provide knowledge on	they will need to be
	child's hearing loss and	provided with the
	skills to deal with this	information on where to
	Understanding the	get support."
	aetiology of hearing loss	
	(type/degree)	"Yes, agree, the
	Resource list for parents	information in the resource
		list must also be unbiased
		and present parents with
		choices."
		"The resource list can be
		read anytime and shared
		with other family
		members."
		memoers.

# *Table 2:* First round of recommended topics to be in the framework with comments from academic experts

Communication	Communication challenges	"Yes, we agree that
intervention	and needs and unbiased	communication is very
	support for communication	important for parents."
	choices	

**Round 2:** The goal of round 2 was to generate further stakeholder and parent opinions and feedback on the framework resulting from round 1. Additional goals were 1) to share with the panel of stakeholders the aim and objectives of the consensus workshop; and 2) based on the topics and sub-topics formulated in round 1 with the panel of academic experts, to identify other topics and sub-topics that resonate with the findings.

The panel of stakeholders and parents, as in round 1, were also asked to respond to a set of questions corresponding to the recommendations made. These included: 1) topics that resonate with the recommendation made in the research study; 2) the importance of the recommendation made in the context of the research study – priority of topics; 3) comment on the language used, particularly disability-friendly language; and 4) indicate whether there was any additional information they felt could be addressed by the framework.

**Consensus reached in round 2:** The clustered topics and sub-topics made in round 1 by the panel of academic experts were agreed upon, with the suggestion of two additional sub-topics by the panel of stakeholders and parents, namely on "parenting styles" and "Deaf mentors". The panel of stakeholders and parents felt that parenting styles should be addressed. They thought parents should be aware of different parenting styles and how these may contribute to their parenting experiences. Consensus was reached that the sub-topic "parenting styles" be included under Theme 2: "Parent social and emotional support". It was further agreed that this sub-topic would encompass the content on different parenting styles (involved parenting, avoidance parenting and protective parenting) and independent living.

The panel of stakeholders and parents also felt strongly about and supported the inclusion of adult Deaf mentors. They considered Deaf mentors to be an integral part of providing parents and children with a hearing loss with support. After a brief discussion, Deaf mentors were included under Topic 3: "Resource support". The content area of Deaf mentors addresses issues of guidance, information to promote knowledge on hearing loss, and information and support where Deaf role models, who are powerful influences, can provide parents and professionals with an understanding of their day-to-day real-life experiences living in a hearing world (Hamilton & Clark, 2020; Hintermair, 2000; Shuler-Krause, & White, 2019). The panel of stakeholders and parents reached unanimity on four topics and 15 sub-topics, as reflected in Table 3.

Table 3: Second round of recommended topics with stakeholder and parent
comments

Topics	Additional recommendations for sub-topics	Comments made by a panel of stakeholders
Early intervention programmes	Early screening and diagnosis and counselling for parents	"Agree with the theme as well as the recommendation made by the panellist in round 1"
		All in agreement/consensus reached
Parent social and emotional support	<ul> <li>Professional support</li> <li>(counselling)</li> <li>Support groups for a child</li> <li>with hearing loss /siblings</li> <li>/mothers /fathers</li> <li>Support groups for parents</li> <li>Support groups for fathers</li> <li>Support groups for siblings</li> <li>Increase social network</li> <li>with other parents</li> <li>Professional, empathetic</li> <li>and unbiased support</li> <li>Parenting challenges</li> </ul>	<ul> <li>"Agree with this theme; however, we need to look at parenting approaches, especially the different styles by parents."</li> <li>"Yes, what about styles, like involved parenting, overprotective parenting, and so on."</li> <li>Agreed by the rest of the panel/consensus reached</li> </ul>
Resources support	Parenting stylesNeed guidance,information on hearingloss, information andsupportProvide knowledge andskills on child's hearinglossUnderstanding theaetiology of hearing loss –including audiogramList of resources forparentsDeaf mentors	<ul> <li>"Agree to the themes; however, can you add Deaf mentors as they have an important role to play."</li> <li>"Parents and children with a hearing loss can see that there are Deaf youths who have gone through the same challenges and succeeded."</li> <li>"A deaf mentor shows parents that there is hope."</li> <li>"Deaf mentors can teach deaf culture to parents."</li> </ul>
Supporting means of communication intervention	Communication challenges and needs, and unbiased support for communication choices	"I agree that parents must be provided with unbiased information regarding communication choices for their children." "The framework must include how to

communicate with our child as communication includes the visual language."
"Parents need to understand the child's way of life, including [that] communication is influenced by their hearing loss."
"Parents must be provided with unbiased communication choices."

# FINDINGS AND DISCUSSION

The purpose of the consensus workshop was to co-develop a framework to support hearing parents who are parenting children with hearing loss. In meeting the aim of the research study, consensus was reached on the following topics to be included in the framework: 1) early intervention, 2) parental support, 3) resources, and 4) communication options be integrated as recommendations into a framework for parents. The findings of the consensus workshop conform to an international consensus on family-centred early intervention with children who are deaf and hard of hearing and their families (Moeller *et al.*, 2013).

Firstly, although the sample of parents was with parents of children between the ages of 8 and 14 years, both panels reached consensus to include early intervention as a topic. This topic deals with early intervention and screening for children diagnosed with hearing loss. The sub-topic focused on offering the parents support at the onset of hearing their child's diagnosis. As agreed upon by all panellists, the motivation for this inclusion was that parents should be provided with guidance, information and counselling on early identification and screening programmes as early as possible. For example, parents should be referred timeously for confirmation and counselling when the child is diagnosed with hearing loss (Shezi & Lavanithum, 2021). These suggestions put forward by the study panellist corroborate the findings of Yoshinaga-Itano (2014), who posited 12 best practice guidelines for early identification, including timely referrals to early intervention services and infusing parent-professional partnership in the best interests of a child with a hearing loss.

Secondly, consensus was reached on topic two on parent social and emotional support. The sub-topic content focused on professional support (counselling), support groups for children with hearing loss, support groups for parents (mothers as well as fathers), support groups for siblings, the need for increased social networks with other parents, and the need for professional and empathetic support. Panellists concur with Meibos (2018) that healthcare professionals should be more empathetic, compassionate and sensitive and

have a greater understanding of the emotional impact of the diagnosis on the family, taking into account the feelings of the parents and the child with hearing loss. Our findings show that parents want to receive unbiased professional social support, which includes counselling and connecting parents to support groups that can expand the social network of parents, siblings and children with hearing loss, and at the same time reinforce parents' self-confidence. A framework that offers information on support groups serves as a strong healing and educational tool, providing parents with the opportunities to share their feelings and concerns on issues they are experiencing when parenting a child with hearing loss (Hendersen, 2015). The need for such a framework concurs with the studies by Asberg, Vogel and Bowers (2008) and Davids, Roman and Schenck. (2018), which found a strong correlation between levels of social support and parental stress and life satisfaction, with lower levels of stress experienced by parents parenting a child with hearing loss. Further recommendations were made to include professional support targeting and involving hearing siblings and siblings with hearing loss, offering them the opportunity to share their experiences with parents and families. Previous studies have found that parents' behaviour and feelings towards their child with hearing loss influence a hearing sibling's behaviour and feelings towards their sibling with hearing loss (Bat-Chava & Martin, 2002; Eichengreen & Zaidman-Zait, 2020). It is envisioned that the framework will go a long way towards contributing to the psychological development of the siblings of a child with a hearing loss and promote supportive sibling relationships.

Panel two further recognised the need for parents' understanding of their parenting styles when parenting their child with a hearing loss. Several studies have suggested that raising a child with a hearing loss may require parents to adapt their parenting styles and skills in ways that would influence the quality of the parent-child relationship (Davids, Roman & Schenck, 2020; Raya, Ruiz-Olivares, Pino & Herruzo, 2014; Sams, 2012; Woodgate, Edwards, Ripat, Borton & Rempel, 2015). Parents who were part of the second consensus workshop admitted to being overprotective in how they parent because of their uncertainties, as confirmed in studies conducted by Jackson and Turnbull (2004) and Raya *et al.* (2014). Our findings corroborate with those of Calderon, Bargones and Sidman (1998), Calderon and Greenberg (1999), and Davids, Roman and Schenck (2021). They suggest that parents may experience difficulties developing effective child-rearing styles, leading them to become unsure of how they raise their child with a hearing loss. Therefore, the framework has the potential to introduce parents to different parenting styles and assist them in their role of parenting their child with a hearing loss.

Thirdly, panel 1 reached consensus to include a resource list in the framework. The common sentiment among the panellists was that the resource list could be shared with extended family members to address their needs and concerns related to the child's hearing loss, thereby serving as a referral list. After a brief discussion, the panellists saw the value of a resource list and reached consensus on including it in the framework. It was agreed that the list would encompass information that is comprehensive, unbiased, accurate and well-balanced (Hendersen, 2015; Moeller *et al.*, 2016). Such information would include contact details of all organisations, schools, hospitals, professionals in deaf care, etc. It was suggested and agreed that the resource list needs to include information

on the aetiology of child hearing loss (Duckworth, Steen & Seligman, 2005:3), which would consist of a detailed explanation and description of the audiogram. It was also agreed that written, unbiased information with simple diagrams should be included to help parents, siblings and children with hearing loss understand matters of child hearing loss (Mehta, Mahon, Watkin, Marriage & Vickers, 2019). Consensus was reached around identifying Deaf mentors as a resource for hearing parents. There is a dearth of studies on Deaf mentors, with limited research conducted on the invaluable assistance they can provide to parents and families (Hamilton, 2017). Helping parents see the value of Deaf mentors will help parents understand the personal insight and experience of growing up in hearing families and overcoming obstacles (Hamilton & Clark, 2020).

Fourthly, our findings indicate that parents should receive guidance and support for communication intervention. The consensus of the panel of participants highlighted the view that parents should be provided with objective information on a full range of communication options as early as possible. Our findings are broadly consistent with previous literature on communication challenges that arise between parents and children with hearing loss (Ching, Scarinci, Marnane, Sjahalam-King, Button & Whitfield, 2018; Davids *et al.*, 2021). Communication difficulties challenge interaction between parents and their children and can negatively affect parenting roles and responsibilities (DesGeorges, 2016; Tamis-LeMonda, Uzgiris & Bornstein, 2002). The consensus was that information on communication should be comprehensive and unbiased, regardless of the communication modality, i.e. sign language, oral communication or total communication, between parent and child. Early and mutual modes of communication between the parents and the child are encouraged, thus ensuring amiable parent-child communication interchanges and experiences.

Notably, all the panellists recommended consistency in language use. For example, they suggested that the words "deaf" and "hearing loss" not be used interchangeably. One academic expert preferred the word "Deaf" and not "hearing loss" to be used. The word deaf using the capital "D" was suggested as the term deaf with a small "d" is most often described as a pathological condition needing medical intervention (Pendergrass, Newman, Jones, & Jenkins, 2019). Others perceived the words "hearing loss" as all-encompassing, including different types and degrees of hearing loss. Eventually, consensus was reached to use "hearing loss" in the framework (World Health Organisation (WHO), 2021) and in this article.

#### RECOMMENDATIONS

To reiterate, the co-development of the framework is not intended to replace existing professional support offered to parents. Instead, the implications of the co-development of the framework are to suggest implementable, practical content to support parents in assuming the role of an expert in parenting their child. The framework is based on hearing parents' daily experiences of parenting a hearing loss child.

Advancing intervention in the field of disability, this study is especially significant for those working within the field of social work and the emerging field of public health enquiry characterised by respect, open communication, unbiased information sharing,

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and mutual consensus. Reaching consensus on a set of topics in the framework will hopefully stimulate practical social work support and implementation, thus leading to programme and training applications. These applications include the need for counselling for parents, the facilitation of parent-to-parent support groups and specific programmes engaging fathers, connecting parents with Deaf mentors and connecting them to, or developing, programmes within the domain of parenting and parenting styles.

The framework helps to build and strengthen partnerships between parents and professionals (Hamilton, 2017). Such partnerships between parents and practitioner are imperative, as they create a collaborative environment that allows for the best strategies to be implemented. Most importantly, healthcare professionals must be aware of parenting dynamics to offer comprehensive parent support. The understanding of parents' experiences and challenges when parenting a child with a hearing loss can provide essential information necessary for valid assessments and appropriate planning and intervention (Kemp, Marcenko, Hoagwood & Vesneski, 2009; Ross, 2016). Collaborations between parents, academic experts and stakeholders in the field of dealing with hearing loss point to parent leadership, ownership of intervention services and, more importantly, building and strengthening parents' capabilities.

Interdisciplinary collaborations among healthcare practitioners are also meaningful. This approach includes collaboration between social workers, psychologists, audiologists, Deaf mentors and service providers/organisations of the deaf. These professionals have the necessary skills to address the needs/concerns of parents and make referrals in the family's best interest. Professionals should guard against self-interest, which includes providing biased information and opinions, but should engage in self-assessment and self-reflection when rendering services to parents.

# CONCLUSION

The use of a consensus workshop provided rich, multifaceted information to support the co-development of a framework providing support for parents who are parenting a child with a hearing loss. It offers a method that promotes practice-based evidence, whereby parents and practitioners are exposed to the findings of scientific interventions and are encouraged to discuss/critique the findings based on their experience (Sabir *et al.*, 2006). Furthermore, the collaborations/dialogue and consensus reached among the experts, stakeholders and parents will enhance the 'buy-in' of parents – so that they are part of the research and intervention process. A consensus workshop helps balance influences, especially by allowing stakeholders and parents to engage, voice concerns and share in the decision-making process.

The findings and the methodology used in this research can be helpful, especially in community-based research, where community members and researchers form partnerships/alliances to address a particular problem/need. Through such alliances and collaborations, recommendations can be made to policymakers, programme implementors or professionals working in the field of deafness to effect change.

# **DISCLOSURE STATEMENT**

The authors reported no potential conflict of interest.

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## REFERENCES

Asberg, K. K., Vogel, J. J. & Bowers, C. A. 2008. Exploring correlates and predictors of stress in parents of children who are deaf: Implications of perceived social support and mode of communication. *Journal of Child and Family Studies*, 17(4): 486–499.

Bat-Chava, Y. & Martin, D. 2002. Sibling relationships of deaf children: The impact of child and family characteristics. *Rehabilitation Psychology*, 46:4.

Calderon, R., Bargones, J. & Sidman S. 1998. Characteristics of hearing families and their young deaf and hard of hearing children: Early intervention follow-up. *American Annals of the Deaf*, 143: 347-362.

Calderon, R. & Greenberg, M. 1999. Stress and coping in hearing mothers with children with hearing loss. Factors affecting mothers and child adjustment. *American Annals of the Deaf*, 144: 7–18.

Cantrill, J. A., Sibbald, B. & Buetow, S. 1996. The Delphi and nominal group techniques in health services research. *International Journal of Pharmacy Practice*, 4: 67–74.

Chaudhury, S. 2014. Anxiety and depression in mothers of deaf children: Awareness needed. *Medical Journal DY Patil University*, 7(6):720-721.

Ching, T. Y. C., Scarinci, N., Marnane, V., Sjahalam-King, J., Button, L. & Whitfield, J. 2018. Factors influencing parents' decisions about communication choices during early education of their child with hearing loss: A qualitative study. *Deafness Education International*, 20: 154–181.

Cole, E. B. & Flexer, C. 2015. *Children with hearing loss: Developing listening and talking, birth to six.* San Diego, CA: Plural Publishing.

Cooper, R. A., Quatrano, L. A., Axelson, P. W., Harlan, W., Stineman, M., Franklin, B., Krause, J. S, Bach, J., Chambers, H., Chao, E. Y, Alexander, M. & Painter, P. 1999. Research on physical activity and health among people with disabilities: A consensus statement. *Journal of Rehabilitation Res Development*, 36(2): 42-54.

Davids, R. S., Roman, N. V. & Schenck, C. J. 2018. Interventions on parenting styles of hearing parents parenting children with a hearing loss: A scoping review. *Deafness & Education International*, 20(1): 41-58.

Davids, R. S., Roman, N. V. & Schenck, C. J. 2020. Horende moeders en vaders se benadering van ouerskap tot kinders met gehoorverlies. *The Journal of Humanities/Tydskrif vir Geesteswetenskappe*, 60(3): 727-744.

Davids, R. S., Roman, N. V. & Schenck, C. J. 2021. The challenges experienced by parents when parenting a child with hearing loss within a South African context. *Journal of Family and Social Work*, 24(1): 60-78.

DesGeorges, J. 2016. Avoiding assumptions: Communication decisions made by hearing parents of deaf children. *AMA Journal of Ethics*, 18(4): 442-446.

Duckworth. A. L., Steen, T. A. & Seligman, M. E. P. 2005. Positive psychology in clinical practice. *Annual Review of Clinical Psychology*, 1(1): 629–651.

Eichengreen A. & Zaidman-Zait, A. 2020. Relationships among deaf/hard-of-hearing siblings: Developing a sense of self. *Journal of Deaf Studies Deaf Education Journal*, 25(1): 43-54.

Goodall, J. & Vorhaus, J. 2011. *Review of best practice in parental engagement*. London, Department of Education.

Hall, C. L., Brown, S., James, M., Martin, J. L., Brown, N., Selby, K., Clarke. J., Williams, L., Sayal, K., Hollis, C. & Groom, M. J. 2019. Consensus workshops on the development of an ADHD medication management protocol using QbTest: Developing a clinical trial protocol with multidisciplinary stakeholders. *BMC Medical Research Methodology*, 19: 126.

Hamilton, B. 2017. *The deaf mentor program: Benefits to families and professionals*. Doctoral dissertation. Lamar University, Texas, United States.

Hamilton, B. & Clark, M. 2020. The deaf mentor program: Benefits to families. *Psychology*, 11: 713-736.

Hendersen, R. 2015. *Parent-to-parent support for parents of deaf or hard of hearing: a conceptual framework*. Master's thesis. University of Western Ontario, London, Ontario, Canada.

Henderson, D. & Hendershott, A. 1991. ASL and the family system. *American Annals of the Deaf*, 136(4):325-329. https://doi.org/10.1353/aad.2012.0546

Hintermair, M. 2000. Hearing impairment, social networks, and coping: The need for families with hearing-impaired children to relate to other parents and to hearing-impaired adults. *American Annals of the Deaf*, 145: 41–53.

Humphries, T., Kushalnagar, P., Mathur, G., Napoli, D.J., Rathmann, C. & Smith, S. 2019. Support for parents of deaf children: Common questions and informed, evidence-based answers. *International Journal of Paediatric Otorhinolaryngology*, 118:134-142.

Kemp, S. P., Marcenko, M. O., Hoagwood, K., & Vesneski, W. (2009). Engaging parents in child welfare services: Bridging family needs and child welfare mandates. *Child Welfare: Journal of Policy, Practice, and Program, 88*(1), 101–126.

Social Work/Maatskaplike Werk, 2023: 59(1)

Jackson, C. W. & Turnbull, A. P. 2004. Impact of deafness on family life: A review of the literature. *Topics in Early Childhood Special Education*, 24: 15–29.

Lederberg, A. R., Schick, B. & Spencer, P. E. 2013. Language and literacy development of deaf and hard of hearing children: Successes and challenges. *Developmental Psychology*, 49(1):15-30.

MacLachlan, M., Mji, C., Chataika, T., Wazakili, M., Dube, A. K., Mulumba, M., Massah, B., Wakene, D., Kallon, F. & Maughan, M. 2014. Facilitating disability inclusion in poverty reduction processes: Group consensus perspectives from disability stakeholders in Uganda, Malawi, Ethiopia, and Sierra Leone. *Disability and the global South*, 1(1): 107-127.

McMillan, S.S., Kelly, F., Sav, A., Kendall, E., King, M. A., Whitty, J. A. & Wheeler, A. 2014. Using the nominal group technique: How to analyse across multiple groups. *Health Service Outcomes Research Methodology*, 14(3): 92–108.

McMillan, S., King, M. & Tully, M. P. 2016. How to use the nominal group and Delphi techniques. *International Journal of Clinical Pharmacy*, 38(3): 655-662.

Mehta, K., Mahon, M., Watkin, P., Marriage, J. & Vickers, D. 2019. A qualitative review of parents' perspectives on the value of CAEP recording in influencing their acceptance of hearing devices for their child. *International Journal of Audiology*, 58(7): 401-407.

Meibos, A. R. 2018. *Counseling competencies in audiology: Important knowledge, skills, and attitudes*. Master's thesis. Utah State University, United States.

Moeller, M. P., Carr, G., Seaver, L., Stredler-Brown, A. & Holzinger, D. 2013. Best practices in family-centred early intervention for children who are deaf or hard of hearing: An international consensus statement. *Journal of Deaf Studies and Deaf Education*, 18(4): 429–445. doi:10.1093/deafed/ent034.

Pendergrass, K. M., Newman, S. D., Jones, E. & Jenkins, C. H. 2019. Deaf: A concept analysis from a cultural perspective using the Wilson Method of Concept Analysis Development. *Clinical Nursing Research*, 28(1): 79–93.

Ørngreen, R. & Levinsen, K. T. 2017. Workshops as a research methodology. *Electronic Journal of E-Learning*, 15(1): 70–81.

Raya, A. F., Ruiz-Olivares, R., Pino, M. J. & Herruzo, J. 2014. A review about parenting style and parenting practices and their consequences in disabled and nondisabled children. *International Journal of Higher Education*, 2(4): 205–213.

Ross, S. 2016. *Parents' perspectives and experiences of having a child with hereditary hearing loss.* Master's thesis. University of Cape Town, South Africa.

Sabir, M., Breckman, R., Meador, R., Wethington, E., Carrington Reid, M. & Pillemer, K. 2006. The CITRA research-practice consensus-workshop model: Exploring a new method of research translation in aging. *The Gerontologist*, 46(6): 833–839.

Sams, J. M. 2012. *Expanded parenting: Fathers' and mothers' experiences of parenting young children with disabilities*. Doctoral thesis. University of Tennessee, United States.

Seligman, M. & Darling, R. 2009. *Ordinary families, special children*. New York, NY: The Guilford Press.

Shezi, Z. M. & Lavanithum, J. N. 2021. Parental views on informational counselling provided by audiologists for children with permanent childhood hearing loss. *South African Journal of Communication Disorders*, 68(1): 1-8.

Shuler-Krause, E. & White, K. R. 2019. Involvement of adults who are deaf or hard of hearing in EHDI programs. *The Journal of Early Hearing Detection and Intervention*, 4(1): 54-61.

Smith, R. J. H., Eliot Shearer, A., Hildebrand, M. S. & Van Camp, G. 2014. Deafness and hereditary hearing loss overview. *Genes Review*, 512-518.

Szarkowski, A. & Brice, P. 2019. Positive aspects of parenting a deaf child: Categories of potential positive influences. *JADARA*, 37(2): Article 6.

Tamis-LeMonda, C. S., Užgiris, I. Č. & Bornstein, M. H. 2002. Play in parent-child interactions. In: Bornstein, M. H. (ed.). *Handbook of parenting*. 2<sup>nd</sup> ed. Mahwah, NJ: Erlbaum.

Tully, M. P. & Cantrill, J. A. 1997. The use of the nominal group technique in pharmacy practice research: Processes and practicalities. *Journal of Sociology Admin Pharmacy*, 14: 93–104.

Walton, D. M., Elliott, J. M., Lee, J., Loh, E., MacDermid, J. C, Schabrun, S., Siqueira,
W. L., Corneil, B. D., Aal, B., Birmingham, T., Brown, A., Cooper, L. K, Dickey, J. P.,
Dixon, S. J., Fraser, D. D., Gati, J. S, Gloor, G. B., Good, G., Holdsworth, D., McLean,
S. A., Millard, W., Miller. J., Sadi, J., Seminowicz, D. A., Shoemaker, J. K., Siegmund,
G. P., Vertseegh, T., Wideman, T. H. 2016. Research priorities in the field of
posttraumatic pain and disability: Results of a transdisciplinary consensus-generating
workshop. *Pain Research Management*, 14 June 2016: 1859434. Doi:
10.1155/2016/1859434.

Wang, Z., Norris, S. L. & Bero, L. 2018. The advantages and limitations of guideline adaptation frameworks. *Implementation Science News*, 13(1): 72. Doi: 10.1186/s13012-018-0763-4.

Woodgate, R. L., Edwards, M., Ripat, J. D., Borton, B. & Rempel, G. 2015. Intense parenting: A qualitative study detailing the experiences of parenting children with complex care needs. *BMC Paediatrics*, 15:1.

World Health Organization (WHO). 2021. *Factsheet on hearing loss and deafness*. Geneva: WHO Press.

Yoshinaga-Itano, C. 2014. Principles and guidelines for early intervention after confirmation that a child is deaf or hard of hearing. *The Journal of Deaf Studies and Deaf Education*, 19(2): 143–175.

Zaidman-Zait, A. & Jamieson, J. 2004. Searching for cochlear implant information on the internet maze: Implications for parents and professionals. *Journal of Deaf Studies and Deaf Education*, 9(4): 413-426.