



**Wait-Lifting:
Active waiting for speech and language services
by children and families**

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Certificate of Authorship

I hereby declare that this submission is my own work and, to the best of my knowledge and belief, understand that it contains no material previously published or written by another person, nor material which to a substantial extent has been accepted for the award of any other degree or diploma at Charles Sturt University or any other educational institution, except where due acknowledgement is made in the thesis. Any contribution made to the research by colleagues with whom I have worked at Charles Sturt University or elsewhere during my candidature is fully acknowledged. I agree that this thesis be accessible for the purpose of study and research in accordance with normal conditions established by the Executive Director, Division of Library Services or nominee, and Charles Sturt University or nominee for the care, loan and reproduction of theses.



Nicole McGill
February, 2020

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I feel so grateful to have had the opportunity to follow my passion of improving access to support for children with communication needs and their families and addressing an issue I have faced in my clinical practice. A key intention of this doctoral research was to empower families and others while waiting, as well as inspire action to improve waiting lists for speech and language services. What I had not anticipated, was the sense of empowerment that I have experienced throughout this journey, in work and in life. This is largely due to the support, encouragement, knowledge, and leadership that surrounded me, inspiring confidence and belief in myself and enabling me to achieve this milestone.

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Ethical Approval

The research outlined in this thesis received ethical approval from the following human research ethics committees:

1. Charles Sturt University Human Research Ethics Committee - Protocol number: H17181 (Chapters 3, 4, and 6)
2. South Eastern Sydney Local Health District Human Research Ethics Committee - Protocol number: HREC/17/POWH/535 (Chapter 7)
3. Site-specific approval from research site in Victoria, Australia - Protocol number: GVH 50/17 (Chapter 7)

The research reported in Chapter 2 did not require ethical approval as the study involved publicly available data. Chapter 8 also did not require ethical approval as it was a review of previous research.

Publications and Conference Papers Arising from this Doctoral Research

Publications (in the order they appear in this doctoral research)

PAPER 1 (Chapter 2):

McGill, N., Crowe, K., & McLeod, S. (2020). “Many wasted months”: Stakeholders’ perspectives about waiting for speech-language pathology services. *International Journal of Speech-Language Pathology*, 22(3), 313-326. doi: 10.1080/17549507.2020.1747541

PAPER 2 (Chapter 3):

McGill, N., McLeod, S., Crowe, K., Hopf, S. C., & Wang, C. (2019, August). *Waiting lists and prioritization of children for services: Speech-language pathologists' perspectives*. Manuscript in submission.

PAPER 3 (Chapter 4):

McGill, N., McLeod, S., & Hopf, S. C. (2020). *Waiting list management: Professionals' perspectives and innovations*. Manuscript in preparation.

PAPER 4 (Chapter 6):

McGill, N., & McLeod, S. (2019). Aspirations for a website to support families’ active waiting for speech-language pathology. *International Journal of Speech-Language Pathology*, 21(3), 263-274. doi:10.1080/17549507.2019.1604802

PAPER 5 (Chapter 7):

McGill, N., McLeod, S., Ivory, N., Davis, E., & Rohr, K. (2020). Randomised controlled trial evaluating active versus passive waiting for speech-language pathology. *Folia Phoniatrica et Logopaedica*. Advance online publication. doi:10.1159/000508830

PAPER 6 (Chapter 8):

McGill, N., & McLeod, S. (2020). Waiting list management in speech-language pathology: Translating research to practice. *Speech, Language and Hearing*, 23(1), 2-8. doi:10.1080/2050571X.2020.1716471

Conference Papers and Posters (peer reviewed, published abstracts)

McGill, N., McLeod, S., Davis, E., Rohr, K., Miller, K., & Ivory, N. (2019, November). *Randomised controlled trial evaluating provision of a website to*

promote active waiting for speech pathology. Poster presented at Safer Care Victoria Giant Steps Conference, Melbourne, Australia.

McGill, N., McLeod, S., Crowe, K., & Hopf, S. C. (2019, June). *Waiting lists and prioritisation for paediatric speech pathology services: Speech pathologists' perspectives.* Paper presented at Speech Pathology Australia National Conference. Brisbane, Australia.

McGill, N., Crowe, K., & McLeod, S. (2019, June). *"Struggling" and needing help: Experiences of waiting for speech pathology services in Australia.* Paper presented at Speech Pathology Australia National Conference. Brisbane, Australia.

McGill, N., McLeod, S., Davis, E., Rohr, K., & Miller, K. (2019, June). *'Wait' lifting: Randomised controlled trial evaluating active versus passive waiting for speech pathology by children with speech and language difficulties.* Poster presented at Speech Pathology Australia National Conference, Brisbane, Australia.

McGill, N., & McLeod, S. (2018, November). *Designing a website to support children and families who are waiting for speech-language pathology services.* Paper presented at American Speech-Language-Hearing Association (ASHA) Annual Convention. Boston, MA.

McGill, N., & McLeod, S. (2018, May). *Designing a website to support children and families who are waiting for speech pathology.* Paper presented at Speech Pathology Australia National Conference. Adelaide, Australia.

McGill, N., & McLeod, S. (2018, May). *The theory of preparative waiting: A framework for considering parents' experiences of waiting for speech pathology services.* Poster presented at Speech Pathology Australia National Conference, Adelaide, Australia.

Invited Presentations

McGill, N., & McLeod, S. (2020, February). *Managing speech pathology waiting lists.* Invited paper to be presented at Regional Speech Pathology Forum, Albury, Australia.

McGill, N. (2019, November). *The Wait Lifting Study: Understanding and managing speech pathology waiting lists.* Invited paper presented at Speech Pathology Australia Northern Territory Branch Meeting, Darwin, Australia.

Grants

- Davis, E., McLeod, S., Rohr, K., Roberts, A., **McGill, N.**, & Miller, K. (2017-2019).
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- McGill, N.** (2018). Use of a website to facilitate active waiting for speech pathology.
Speech Pathology Australia Nadia Verrall Memorial Research Grant. \$5000.

Abstract

Throughout the world, some children with communication and swallowing needs must wait for support since there are not enough speech and language services to meet demand. While waiting, children miss the benefits of early intervention and their caregivers may feel fearful, stressed, and disempowered. There is limited knowledge about waiting for speech and language services, solutions for managing waiting lists, and provision of support to those who are waiting. Consequently, this doctoral research explored current perspectives, experiences, and solutions regarding waiting for speech and language services across stakeholder groups (e.g., consumers, professionals), client populations, service contexts, and countries.

This doctoral research, known as the Wait-Lifting Study, consisted of a four-phase program of research: (1) thematic analysis of stakeholders' written submissions to a government Senate Inquiry ($n = 133$; Chapter 2); (2) quantitative and qualitative analysis of SLPs' questionnaire responses ($n = 264$; Chapters 3 and 4); (3) a mixed methods study informing the design of an evidence-based active waiting website via an evaluation of existing sites ($n = 25$), and consultation with members of the public via a questionnaire ($n = 119$) and focus groups ($n = 16$; Chapter 6); and (4) a randomised controlled trial evaluating active (provision of the website) versus passive waiting (control group) by children and families ($n = 97$; Chapter 7). Two theoretical frameworks were applied: (1) the International Classification of Functioning, Disability and Health: Children and Youth Version (ICF-CY), and (2) the theory of preparative waiting. This doctoral research was presented as a series of six journal articles and an exegesis.

Understanding the status quo (Chapters 2-4): Waiting lists had significant consequences for many consumers, professionals, and for society, including physical, psychological, financial, and ethical burdens. SLPs indicated that waiting duration for both assessment and intervention ranged from 0-42 months. Overall, children most often waited for assessments (referral → wait → assessment → therapy; $n = 67$, 33.8%) but could follow a multitude of care pathways depending on their needs or the service they were referred to (e.g., referral → triage → assessment → therapy). Although passive strategies were evident, many consumers and professionals engaged in active strategies to address waiting lists and their consequences. Consumer actions included conducting their own research and relocating to a larger city. Professional actions related to service delivery (e.g., parent information, use of technology),

workplace processes and policies (e.g., prioritisation policies), and the workforce (e.g., recruiting more SLPs). Young children and children with feeding and stuttering needs were most often high priority for speech and language services. Severity of communication/swallowing disorder and availability of resources (e.g., funding, staff) were considered the most important factors in prioritisation.

Designing and evaluating solutions (Chapters 6-7): A waiting for speech-language pathology website was proposed and evidence-based resources about strategies to implement with children, readable information, and simple web architecture were recommended. A randomised controlled trial comparing active waiting (provision of the website) and passive waiting (control group) by children and caregivers found no statistically significant changes between active and passive waiting groups, indicating that those on waiting lists may require more support than can be provided by a website.

Conclusions and contributions: Waiting lists can be burdensome for consumers, professionals, and society. Implicit decision-making, variation, and a lack of clear evidence guiding waiting list practices were apparent. Evidence-building in real-world clinical settings may guide professionals regarding effective waiting list management practices, including creation of care pathways. Transparent and collaborative actions at local and systemic levels are needed to reimagine service provision and access, and optimise outcomes for children and their families.

Note on Style

This doctoral thesis is presented in a logical, although not chronological, sequence and was undertaken as a series of publications. Due to articles being submitted to and/or published in journals prior to insertion in the thesis chapters, findings from later chapters are also referenced and described in earlier chapters. For instance, in Chapter 2, findings from Chapters 4 and 6 were referenced. Relevant tables, figures, and appendices are numbered and contained within each chapter. Past tense was used throughout this thesis for consistency.

Note on Terminology

Some intentional inconsistencies in terminology and spelling were used throughout this thesis to accommodate the target journal styles. In Australia, *speech pathology* is the preferred term; whereas *speech-language pathology* is used in the United States and *speech and language therapy* is used in the United Kingdom. *Speech-language pathology/pathologist* were the preferred terms used in this thesis, unless reporting a direct quote (e.g., from a participant) or adhering to journal styles.

Note on Spelling and Language Conventions

The overall doctoral thesis adhered to American Psychological Association (6th edition) style, although Australian/British English spelling was used. Spelling and terminology were modified in each thesis chapter depending on the publishing requirements of the target journals. For example, Chapter 3 was submitted to a North American journal, so American English spelling and language conventions were adopted (e.g., pediatric, prioritization). Chapter 4 was in preparation for a UK journal, so British English spelling conventions were adopted (e.g., paediatric, prioritisation).

Key Terminology within this Doctoral Research

Key term	Definition
Waiting list	A list of people waiting to receive a health care service which “is not immediately available but will be in the future” (Cambridge University Press, 2020, n.p). Waiting for health care has been defined as “an unspecified yet measurable period of time between identification of a healthcare problem and its diagnosis and treatment” (Fogarty & Cronin, 2008, p. 469).
Duration	The length of time a person has waited or is anticipated to wait. Used interchangeably with “waiting time”.
Service delivery	The manner or way in which speech and language services are provided. Variations can be based on type of service, location/context, service providers, amount of time spent with clients, and mode of delivery (e.g., face-to-face) (Blosser & Kratcoski, 1997).
Prioritisation	Judgements and decisions regarding the timing, amount, and type of intervention clients receive services based on fairness, equity, and client need (Pickstone, 2007). An emotive term for prioritisation is “rationing” (Roulstone, 2007, p. 4).
Evidence-based practice	Hoffman, Bennett, and Del Mar (2013, pp. 3-4) proposed that evidence-based practice (EBP) involves the integration of four sources of information and knowledge to inform health professionals’ clinical practice and decision-making regarding client care: (1) “research evidence”; (2) “clinical expertise” of the health professional; (3), client preferences, values, and circumstances; and (4) the “practice context” relating to the setting and client. Alternatively, Dollaghan’s (2007) earlier E ³ BP framework (which is commonly cited and recognised in speech-language pathology) described consideration of three types of evidence: (1) “external evidence from systematic research”, (2) “internal” evidence from clinical practice or expertise, and (3) evidence gained from the preferences of fully informed clients (Dollaghan, 2007, p. 2). Hoffman et al.’s (2013) framework will be referred to throughout this doctoral research as it extends upon Dollaghan’s (2007) framework by emphasising the importance and impact of practice context. For instance, Hoffman et al.’s (2013) framework acknowledges that the demands, constraints, and resource limitations of a workplace can influence decision-making.
Direct	Strategies to target/reduce waiting times (e.g., recruiting additional staff, obtaining increased funding).
Indirect	Strategies designed to compensate for waiting times (rather than directly reduce them), such as by supporting children and families while they wait (e.g., providing information to families).

Active	Involving effort or work (e.g., parents accessing private services while waiting for public services, professionals managing their waiting lists by offering more group therapy).
Passive	Involving little effort, work, or action (e.g., consumer attrition from services or not following up on referrals).
Stakeholders	Individuals/groups of people or entities who can affect/be affected by waiting lists, or those with an interest/concern regarding the issue. These include consumers ¹ , professionals ² , organisations ³ , governments, and policymakers.
Consumers ¹	Individuals who access speech and language services and significant others who support them, including clients (children), caregivers/parents, families, siblings, and carers.
Professionals ²	Includes speech-language pathologists (SLPs), other allied health professionals (e.g., occupational therapists), educators (e.g., teachers), nurses (e.g., child health nurses), medical professionals (e.g., doctors, paediatricians), and academics/researchers.
Organisations ³	Includes services that provide benefits and structured programs that are designed to meet individuals' needs, such as public health service providers (e.g., hospitals), private services (e.g., private practices), not-for-profit/charitable services (e.g., disability services, support groups), agencies, and professional associations (e.g., Speech Pathology Australia) (World Health Organization [WHO], 2007).

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**Statements from Co-Authors Confirming the Authorship Contribution of the
Doctoral Candidate**

Paper 1

As co-authors of the paper entitled “*Many wasted months*”: Stakeholders’ perspectives about waiting for speech-language pathology services, we confirm that Nicole McGill has made the following contributions:

- Conceptualisation of the paper
- Review and interpretation of the literature
- Analysis of data from a publicly available dataset
- Interpretation of findings
- Writing, editing, and revision of the manuscript

Furthermore, we agree to the inclusion of the paper in this doctoral research submitted for examination.



Nicole McGill
December, 2019



Kathryn Crowe
December, 2019



Sharynne McLeod
December, 2019

Paper 2

As co-authors of the paper entitled *Waiting lists and prioritization of children for services: Speech-language pathologists' perspectives*, we confirm that Nicole McGill has made the following contributions:

- Conceptualisation of the paper
- Review and interpretation of the literature
- Design of the research questionnaire
- Collection of data
- Analysis of data
- Interpretation of findings
- Writing, editing, and revision of the manuscript

Furthermore, we agree to the inclusion of the paper in this doctoral research submitted for examination.



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Sharynne McLeod
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Kathryn Crowe
December, 2019



Suzanne C. Hopf
December, 2019



Cen (Audrey) Wang
December, 2019

Paper 3

As co-authors of the paper entitled *Waiting list management: Professionals' perspectives and innovations*, we confirm that Nicole McGill has made the following contributions:

- Conceptualisation of the paper
- Review and interpretation of the literature
- Design of the research questionnaire
- Collection of data
- Analysis of data
- Interpretation of findings
- Writing, editing, and revision of the manuscript

Furthermore, we agree to the inclusion of the paper in this doctoral research submitted for examination.



Nicole McGill
December, 2019



Sharynne McLeod
December, 2019



Suzanne C. Hopf
December, 2019

Paper 4

As co-authors of the paper entitled *Aspirations for a website to support families' active waiting for speech-language pathology*, which was published in International Journal of Speech-Language Pathology, we confirm that Nicole McGill has made the following contributions:

- Conceptualisation of the paper
- Review and interpretation of the literature
- Design of the instruments (questionnaire, focus group schedules)
- Collection of data
- Analysis of data
- Interpretation of findings
- Writing, editing, and revision of the manuscript

Furthermore, we agree to the inclusion of the paper in this doctoral research submitted for examination.



Nicole McGill
December, 2019



Sharynne McLeod
December, 2019

Paper 5

As co-authors of the paper entitled *Randomised controlled trial evaluating active versus passive waiting for speech-language pathology*, we confirm that Nicole McGill has made the following contributions:

- Conceptualisation of the paper
- Review and interpretation of the literature
- Design of research questionnaires
- Collection of data
- Interpretation of findings
- Writing, editing, and revision of the manuscript

Furthermore, we agree to the inclusion of the paper in this doctoral research submitted for examination.



Nicole McGill
February, 2020



Sharynne McLeod
February, 2020



Nicola Ivory
February, 2020



Emily Davis
February, 2020



Katrina Rohr
February, 2020

Paper 6

As co-authors of the paper entitled *Waiting list management in speech-language pathology: Translating research to practice*, which was published in Speech, Language and Hearing, we confirm that Nicole McGill has made the following contributions:

- Conceptualisation of the paper
- Review and interpretation of the literature
- Writing, editing, and revision of the manuscript

Furthermore, we agree to the inclusion of the paper in this doctoral research submitted for examination.



Nicole McGill
December, 2019



Sharynne McLeod
December, 2019

Part One

General Introduction

Chapter 1: Introduction and Orientation to this Doctoral Research

Waiting is the hardest work of hope – Lewis B. Smedes

Background

Many people have speech, language, and communication needs throughout the world and require specialised assessment and intervention from speech-language pathologists (SLPs). Speech, language, and communication disorders can be effectively remediated with speech-language pathology intervention (e.g., Almost & Rosenbaum, 1998; Law, Garrett, & Nye, 2005; McLeod & Baker, 2014). Outcomes are optimal when intervention is received in a timely manner, typically in early childhood (Law et al., 2005). Early childhood is a period of rapid physical and cognitive development when gains from intervention can be most effective. Therefore, it is important that children receive speech-language pathology intervention at a young age to promote optimal outcomes and minimise the likelihood of difficulties persisting throughout their school-age years and into adulthood.

Service Delivery of Speech and Language Services

Children and families access speech and language support through various forms of service delivery. Service delivery may be dependent on many factors, including geographic location, that is, children located in one area may receive intervention delivered in a different way to children based in another area. Children often attend sessions with an SLP in a one-on-one setting with family members present, although they may also participate in group interventions with other children who have similar speech and language needs (McLeod & Baker, 2014). Services may also be delivered using a response to intervention (RTI) model of tiered service provision with a focus on universal prevention and early intervention at tier 1, through to more intensive and individualised support at tier 3 (Fuchs, Mock, Morgan, & Young, 2003; Swanson, Solis, Ciullo, & McKenna, 2012). Children may access services within a community health centre, the school system, or within their home. Sometimes SLPs train non-SLP agents to deliver intervention, including therapy assistants (e.g., teaching assistants, SLP assistants, allied health assistants) or children's caregivers, with reviews, monitoring, and support from the SLPs. Involving caregivers in speech and language intervention aligns with the principles of family-centred practice and is considered best practice when providing speech and language services (Division for Early Childhood, 2014; Sugden, Baker, Munro,

Williams, & Trivette, 2018a). A common way to involve caregivers is through caregiver training and education to facilitate home practice of target skills and strategies with children, to supplement the sessions with the SLP (Bowen, 2010). Training caregivers to undertake home practice with children during games and activities, and everyday conversation and routines can increase the intensity, and potentially the effectiveness, of speech and language intervention (Sugden, Baker, Munro, Williams, & Trivette, 2018a). Since children spend a large proportion of their time with their caregivers in natural environments outside of the speech-language pathology sessions there are many opportunities for caregivers to reinforce and facilitate practise of speech and language skills (Bowen & Cupples, 2004).

In addition to the more traditional services for supporting children with speech and language needs, innovative forms of service delivery also exist. An example from the United States is the use of mobile health (mHealth) programs such as the uTalk (Texts Advancing Language in Kids) program, where families received text messages containing language promotion activities to complete with their children and information about local organisations relevant to child development (Olson et al., 2016). Telehealth intervention is another alternative mode of service delivery, which involves the use of telecommunications technology (e.g., videoconferencing) to provide services to children. A systematic review by Wales, Skinner, and Hayman (2017) found that telehealth delivery of intervention led to similar, significant improvements for school-aged children with speech and language needs as in-person delivery of intervention. These findings are encouraging for telehealth speech and language services, which may be particularly beneficial for children in rural areas or who face other barriers to service access (Wales et al., 2017). However, telehealth or other forms of technology are not yet widely used in service delivery and are typically provided once children have been accepted on SLPs' caseloads, rather than for those on waiting lists. With the demand for speech and language services expected to increase in future years, innovative models of service provision and practice may be necessary (Commonwealth of Australia, 2014).

SLPs are increasingly expected to follow the principles of evidence-based practice (EBP) in their decision-making and work with children and families. A framework known as E³BP is widely recognised within speech-language pathology and underpins recommendations from professional associations such as Speech Pathology Australia (SPA) and American Speech-Language-Hearing Association (ASHA) (ASHA, n.d.; Dollaghan, 2007; SPA, 2010). E³BP involves integration of

three types of evidence: the best available (1) “external evidence” from research literature, (2) “internal evidence” from SLPs’ clinical practice and expertise, and (3) evidence regarding client preferences (Dollaghan, 2007, p. 2). However, in reality SLPs’ decisions regarding service delivery may also be impacted by resource constraints or organisational policies, demands, and expectations, rather than purely reflecting the needs and preferences of children and families, SLPs’ clinical expertise, or the best available research evidence. For instance, many organisations have prioritisation policies which influence the timing, amount, and type of intervention children receive to ration resources (Morgan et al., 2017; Roulstone, 2007; Rvachew & Rafaat, 2014). Whether children receive intervention in a group or one-on-one context, or with a therapy assistant, may relate to the level of priority they have been assigned or a need to increase through-put within the organisation, rather than based on evidence of effectiveness alone. An EBP framework described by Hoffman, Bennett, and Del Mar (2013) extends upon E³BP by acknowledging and emphasising the importance of a fourth source of information and knowledge: the practice context. Practice context relates to both the setting and client and may include consideration of how workplace constraints, such as the availability of resources, can shape professional practice and constrain what services or support the SLP can and cannot provide (Hoffman, Bennett, & Del Mar, 2013). Although historically underemphasised, practice context is therefore an important fourth source of information and knowledge for SLPs to consider in their practice (Hoffman, Bennett, & Del Mar, 2013). Ethical dilemmas for SLPs can result in instances where the realities of clinical practice and the practice context conflicts with the best available evidence (Hoffman, Bennett, & Del Mar, 2013; Kenny & Lincoln, 2012; Kenny, Lincoln, & Balandin, 2010). The lack of emphasis on practice context in some existing EBP frameworks may contribute to SLPs’ frustrations and ethical dilemmas if they are aspiring to provide best-practice interventions that may not be practical or possible in their real-world clinical setting.

Barriers to Accessing Speech and Language Services

Children with speech and language needs and their families are often faced with many barriers or challenges when attempting to access speech and language services (McCartney, 2000; Paradice & Adewusi, 2002). Limited service options or a lack of services in the local area may form a significant barrier for families. Access to services has been described as a “postcode lottery” (I CAN & Royal College of Speech and Language Therapists [RCSLT], 2018, p. 19) and an “accident of

geography” (Foxe, 2019, n.p), whereby services are inequitably distributed based on where children live. It can be particularly difficult for families to access speech and language services if they live in rural or remote areas (Verdon, Wilson, Smith-Tamaray, & McAllister, 2011). Many barriers to service access for families of children with speech and language difficulties stem from systemic issues such as resource limitations and shortages of SLPs (Dew et al., 2013; Glover, McCormack, & Smith-Tamaray, 2015; Kenny & Lincoln, 2012; McAllister, McCormack, McLeod, & Harrison, 2011; Ruggero, McCabe, Ballard, & Munro, 2012; Verdon et al., 2011). For example, in a study by Glover et al. (2015), SLPs and educators felt that the speech and language services available in Australian schools was insufficient to meet the increasing need and there was insufficient funding available. Funding and resource restrictions often result in waiting lists. For children and families attempting to access speech and language services, waiting lists form a significant barrier and may become an even greater issue as demand for these services increases in coming years (Commonwealth of Australia, 2014).

Waiting Lists for Speech and Language Services

Waiting lists refer to “an unspecified yet measurable period of time between identification of a healthcare problem and its diagnosis and treatment” (Fogarty & Cronin, 2008, p. 463) and often exist when there are not enough resources or services available to meet the need or demand and services are subsequently rationed (Martin et al., 2003). Waiting lists occur across many areas of health care, including for speech and language services, most commonly in countries with government funded or subsidised health care (e.g., Australia, Canada, Republic of Ireland, New Zealand, United Kingdom). Waiting lists are often managed by individual organisations or clinicians, rather than having centralised, coordinated waiting list management systems in place across regions or disciplines (Sanmartin et al., 2000). For professionals and organisations, waiting lists can be considered a routine, normal aspect of health care culture (Rittenmeyer, Huffman, & Godfrey, 2012). However, long waiting lists are often associated with consumer dissatisfaction (Rittenmeyer et al., 2012) and have been the focus of consumer complaints (Clinical Excellence Commission, 2016) and media stories (Appendix A). Duration, or waiting times, for speech and language services varies between organisations, ranging from no wait at all to waiting years (O’Callaghan, McAllister, & Wilson, 2005; Ruggero et al., 2012; Rvachew & Rafaat, 2014). Waiting for health care occurs in stages (Giske & Gjengedal, 2007; Lebel et al., 2003; Thorne, Harris, Hislop, & Vestrup, 1999), for

example, waiting for assessment, diagnosis, and intervention (Fogarty & Cronin, 2008). Organisations do not always consider the entire waiting duration, predominantly focusing on the time between referral and initial assessment (Kennedy, 2000; Pope & Sykes, 2003), and there is variability in the measurement and reporting of waiting times (Sanmartin et al., 2000).

Waiting for health care can evoke feelings of stress, anger, fear, uncertainty, and powerlessness for people waiting for surgery (Derrett, Paul, & Morris, 1999), gastrointestinal investigations (Giske & Gjengedal, 2007), breast disease investigation or surgery (Drageset, Lindstrøm, Giske, & Underlid, 2011; Lebel et al., 2003), developmental disability services and paediatric rehabilitation (Connolly & Gersch, 2013; Miller et al., 2008), and speech and language services (Dew et al., 2013). A systematic review of 39 qualitative and mixed methods studies exploring waiting in health care contexts found waiting to be a “fearful” (p. 194), “turbulent” (p. 194), and “sometimes tortuous” (p. 195) experience for consumers, who reported feeling “forgotten about” (p. 213) or “abandoned” (p. 213) (Rittenmeyer et al., 2012). Factors underlying consumers’ negative perceptions include waiting list duration; dishonesty from professionals regarding waiting times; a lack of information, choices, and control; and a lack of contact from the organisation regarding their position on the waiting list (Derrett et al., 1999; Rittenmeyer et al., 2012).

Alternatively, not all consumers or professionals view waiting lists as problematic. Research into the natural history (prognosis without intervention) of speech and language disorders suggests that a degree of spontaneous improvement or resolution may occur for some children over time (Gordis, 1996; Law, Boyle, Harris, Harkness, & Nye, 2000). For instance, children with speech delay rather than disorder may be more likely to resolve their difficulties (Morgan et al., 2017). If children make progress while waiting, they may require less intervention, potentially saving SLT resources and alleviating pressure on services. Additionally, Glogowska and Campbell (2000) found that some parents expressed positive views about their child being monitored for 12 months before receiving speech and language intervention (Therapy Later group) as opposed to receiving immediate intervention (Therapy Now group), since the waiting/monitoring period gave children an opportunity to develop at their own pace, some children demonstrated noticeable improvement, and some children increased their readiness to participate in intervention (Glogowska & Campbell, 2000). However, half of the families ($n = 5$) allocated to receive Therapy Later requested to change to the Therapy Now group and receive intervention during

the 12-month period (Glogowska & Campbell, 2000). Given that the impact of speech and language difficulties and the benefits of early intervention are well documented, and it remains unclear which children's difficulties may resolve and which may persist, waiting for speech and language services can pose a significant risk to children's outcomes. There is also a risk that the critical period of language acquisition in early childhood may pass while children are waiting, when intervention gains may be optimal.

Traditionally, waiting has been perceived as a passive and inactive process (Glogowska & Campbell, 2000). However, researchers have challenged this notion and indicate that waiting can be an active process (Feldman, Champagne, Korner-Bitensky, & Meshefedjian, 2002; Giske & Gjengedal, 2007; Rittenmeyer et al., 2012). In their systematic review, Rittenmeyer et al. (2012) highlighted instances of active waiting by consumers, including attempts to self-manage or control the waiting (e.g., engaging in calming activities while waiting, distracting themselves, communicating with others). Giske and Gjengedal (2007) proposed a theory of preparative waiting to conceptualise the ways individuals hospitalised with gastrointestinal problems experience and handle the wait for a diagnosis. Individuals were found to balance "between hope and despair" while actively engaging in four strategies: "seeking and giving information", "interpreting clues", "struggling with existential threat", and "seeking respite" (Giske & Gjengedal, 2007, p. 90). For example, individuals sought accurate information tailored to their situations and engaged in "continuous work" (p. 90) to interpret clues regarding the level of priority they were given in the health care system, and changes in their symptoms (Giske & Gjengedal, 2007). The theory of preparative waiting has not yet been applied to individuals waiting for speech and language services but has potential for application in this context to validate and refine the model (Fogarty & Cronin, 2008).

Individuals often "long for information, engagement, and support" (p. 218) while waiting; however, they often receive little support from health care organisations (Rittenmeyer et al., 2012). Their need for information reportedly increases as waiting times increase, and provision of information to individuals on waiting lists can lead to greater levels of empowerment (Fordham, Gibson, & Bowes, 2012; Rittenmeyer et al., 2012). Feldman et al. (2002) found that children with physical disabilities on waiting lists for rehabilitation services had shorter waiting times for occupational therapy if their parents were more empowered. That is, if parents scored higher on a measure of empowerment which indicated an

understanding of the system and services their children were receiving, an ability to make decisions about services that were needed, and increased initiative in seeking services for their children. Parents who felt more empowered appeared to take some action while waiting and found “ways to reduce the time that their child will have to wait” (Feldman et al., 2002, p. 357). Few studies have focused on active waiting for speech and language services.

Waiting List Management

SLPs and organisations attempt to manage waiting lists for speech and language services in a variety of ways, including via modifications to service delivery (e.g., group therapy versus one-on-one sessions, conducting screening assessments, providing home programs), policies (e.g., restricting eligibility criteria for services, audits, benchmarking of waiting times, prioritisation), and workforce strategies (e.g., increasing staffing levels, using therapy assistants, lobbying for additional funding) (e.g., McLeod & Baker, 2014; Rvachew & Rafaat, 2014). Appendix A to this thesis (discussed further in Chapter 9) summarises the literature on waiting list management that was reviewed both before and after undertaking this doctoral research. Appendix A was developed using knowledge gained from this doctoral research regarding waiting list management strategies (in particular, findings from Chapters 2 and 4), which enabled discovery of literature from other disciplines, as well as speech-language pathology. This literature will be expanded in the introduction sections of Chapters 3, 4, 6, 7, and 8, and summarised in Chapter 9. The effectiveness of many existing waiting list management strategies is unknown, and evidence-based solutions are lacking. Despite good intentions, some commonly used waiting list management strategies are inadequate in meeting the needs of all children and families. For instance, prioritisation policies aim to equitably divide limited resources across the greatest number of children by selecting for those who have urgent, high-risk needs or may be most likely to benefit from services. However, many children considered lower priority wait a long time and/or never receive services, despite having the need and ability to benefit from support (McCartney, 2000). Some strategies therefore conflict with evidence-based practice, for instance, they are designed for efficiency purposes to address service constraints, rather than to best address the needs of all children and families. Further research is needed, including in real-world clinical settings, regarding waiting list management strategies and ways to support children and families in the interim while waiting to inform SLPs’ practice.

The Australian Context

Waiting lists are common in countries with universal health care, such as Australia. Australia has a population of more than 25 million people spread over 7.6 million square kilometres of land (Australian Bureau of Statistics, 2019; Geoscience Australia, n.d.). Australia is divided into six states (New South Wales, Victoria, Queensland, South Australia, Western Australia, Tasmania) and two territories (Northern Territory, Australian Capital Territory). The most populated states are New South Wales (NSW; >8 million people), followed by Victoria (>6 million people) and Queensland (>5 million people) (Australian Bureau of Statistics, 2019). While most people live in or around large cities, some are spread throughout the country in regional, rural, and remote communities (Australian Bureau of Statistics, 2019).

Australia is multicultural and 22.2% of the population speak languages other than English at home; the most common being Mandarin, Arabic, Cantonese, Vietnamese, and Italian (Australian Bureau of Statistics, 2017). Australia's Indigenous people consists of hundreds of diverse cultural groups, within two overarching groups: Aboriginal and Torres Strait Islander (ATSI) peoples (Australian Institute of Aboriginal and Torres Strait Islander Studies, 2018). There are over 5,000 SLPs working in Australia (Speech Pathology Australia [SPA], 2015). Most SLPs work in NSW, Victoria, and Queensland, predominantly in major cities (SPA, 2015). More than half of Australian SLPs work in the private sector, with some working in the public sector or across both sectors (SPA, 2015). SLPs less commonly work in schools. SLPs can obtain Certified Practising Speech Pathologist status through Speech Pathology Australia, the professional association for Australian SLPs; however, speech-language pathology is not a registered profession in Australia. Sometimes SLPs work with and supervise allied health assistants (AHAs; also referred to as therapy assistants, therapy aides, or support workers) who have varying levels of training and specialisation (SPA, 2019a). Australia does not have many AHAs with specialist qualifications or SLP-specific skillsets. AHAs typically work in hospitals, rehabilitation and aged care facilities, schools, or private practices (SPA, 2019a). With support and guidance from an SLP, AHAs can implement therapy programs and activities, and capacity building tasks to support children's speech and language goals (SPA, 2019a). However, SLPs remain responsible for the identification/selection of clients for services, assessment, diagnosis, therapy planning, and discharge (SPA, 2019a).

Speech and language services in Australia.

Access to speech and language services for children varies in each state of Australia depending on how state and federal legislation relating to children with disabilities is interpreted and applied (Commonwealth of Australia, 2014; McLeod, Press, & Phelan, 2010). Speech and language services are provided via public or private organisations within health, education, and disability sectors (SPA, n.d.).

Speech and language services within the public sector (e.g., community health centres) are typically free (government-subsidised) for families but there may be co-payments in some organisations. Community health services are often situated within or are otherwise linked with public hospitals. Within the public education system, children with speech and language needs may be eligible for individualised government funding if they meet stringent criteria based on severity in Victoria, Queensland, South Australia, and the Australian Capital Territory (Australian Capital Territory Department of Education and Training, 2008; Department of Education and Early Childhood Development [DEECD], 2008; McLeod et al., 2010; Queensland Department of Education, Training and the Arts, 2007; State of South Australia Department of Education and Children's Services, 2008). In Victoria, just 0.1% of students are eligible for individualised funding (DEECD, 2008). However, children with speech and language needs are currently not included in criteria to receive this funding in NSW, Northern Territory, and Tasmania (New South Wales Department of Education and Training, 2008; Northern Territory Government Department of Education and Training, 2008; Tasmanian Department of Education, 2008).

Families sometimes choose to access private speech and language services instead of, or in addition to, public services if they are financially able. Some public services offer a limited number of sessions and require families to take a break between blocks of intervention or re-refer to the service for further sessions, so some families use private services to top up the number of speech and language sessions their children receive. Private practice waiting lists are sometimes shorter since not all families can afford private services and many SLPs work in the private sector (SPA, 2015). Some children with speech and language needs in Australia can receive financial support to access private speech and language services via the Medicare Benefits Schedule (MBS) through the Chronic Disease Management program (CDM; formerly the Enhanced Primary Care program) (SPA, 2019b). Children's eligibility for the CDM program is determined by their doctor (general practitioner, GP), based on children's needs being considered chronic, complex, and requiring

multidisciplinary service input (Skeat, Morgan, & Nickless, 2009; SPA, 2019b). If eligible, children can receive five rebated sessions per year with an SLP who is registered with Medicare to provide services under the CDM program (SPA, 2019b). A further five rebated sessions per year are available to eligible children of Aboriginal or Torres Strait Islander (ATSI) descent. Families with private health insurance can also claim rebates from their private health insurance fund if they access an SLP who is an eligible provider. This rebate is usually available only for a limited number of sessions per year.

The National Disability Insurance Scheme (NDIS) commenced in Australia in 2016 which provided government funding for children with diagnosed disabilities to enable them to access services and equipment, including speech and language services (Buckmaster & Clark, 2018-2019). While some children with speech and language needs have diagnosed disabilities meeting the eligibility criteria for NDIS, many children do not. The amount of funding children receive depends on their level of severity and can vary based on individual circumstances. Funding may be managed by the family (self-managed), by a registered plan manager (plan-managed), or by the National Disability Insurance Agency (NDIA-managed). Families who choose to self-manage their funding can use the funds to see any SLP; whereas, others are restricted to seeing SLPs who are registered as NDIS providers.

While these sources of funding are a welcome contribution to the cost of speech and language services for those accessing private services, they are often inadequate in meeting the needs of children with speech and language difficulties. Australian parents have reported that their children most often attend one-on-one sessions with an SLP and some attend group intervention with other children, with children attending sessions either once a week or 1-2 times per month (Ruggero et al., 2012). While government rebates are offered for five sessions, in reality, researchers have demonstrated that most children with speech and language needs require more than five sessions of intervention per year to make significant change (Glogowska, Roulstone, Enderby, & Peters, 2000; Law & Conti-Ramsden, 2000). Families can claim only one rebate per session, from one funding source, and session fees often exceed the rebated amount. Subsequently, out-of-pocket expenses are usually incurred by families. Not all children are eligible for rebates or funding and not all families can afford private health insurance, so they must pay the full fee for private speech and language services. Regardless of their financial status and payment options, Australian families face significant financial burden when accessing private

speech and language services. Since the public sector currently cannot cope with demand, families either pay for private services for their children with speech and language needs or remain on waiting lists for public services.

Waiting lists for speech and language services in Australia.

One of three key areas of concern highlighted in a 2014 Australian Government Senate Inquiry into speech and language services was “the long waiting lists in the public system” (Commonwealth of Australia, 2014, p. 5). Similarly in NSW, access to services was a major area of complaint, with complaints in this category relating to “the availability of specialist services such as speech pathology, the opening hours of clinics, the postponement of surgery, and waiting ... in a clinic or emergency department” (NSW Department of Health, 2008, p. 29). Variation in waiting times for speech and language services is reported across the Australian literature, with some children waiting years before receiving services (Dew et al., 2012; Glover et al., 2015; McAllister et al., 2011; O’Callaghan et al., 2005; Ruggero et al., 2012). A survey of Australian parents found that children (up to 18 years of age) from the state of Queensland were more likely than those in New South Wales (NSW) or Victoria to wait over 12 months for speech and language services (Ruggero et al., 2012); however, this study only reported on 154 families. Families who waited a long time for an assessment were also more likely to wait a long time for intervention (Ruggero et al., 2012). Long waiting lists deter some families from seeking speech and language services and may prevent children from receiving necessary support (Commonwealth of Australia, 2014).

Gaps in Knowledge

Researchers have explored experiences of individuals on waiting lists for many areas of health care, but few studies have focused specifically on waiting for speech and language services. Speech and language service waiting lists have existed for many years and SLPs may attempt to manage their waiting lists in many ways. Service delivery and waiting list management practices vary and effective solutions to waiting lists are lacking. SLPs may have innovative ideas and solutions that have not yet been implemented or evaluated and more evidence regarding waiting list management is needed. It is unclear if and how children and families are supported while waiting. If families could be provided with information and strategies to facilitate their children’s speech and language development while waiting, that is, to engage in active waiting, this may improve their experiences and children’s

outcomes. The role of technology in supporting active waiting shows promise but is an under-researched area in speech-language pathology. Limited research has explored the impact of active waiting for speech and language services by children and families.

Research Aims

The purpose of this research was to gain a deeper understanding of and explore possible solutions for waiting lists to enhance access to care and optimise outcomes for children with speech and language needs, and their families. This doctoral research addressed five research aims:

1. To understand the experience and impact of waiting for speech and language services from the perspectives of key stakeholders, including consumers (e.g., children and families) and professionals (e.g., SLPs) (Chapters 2, 3, 4, 7)
2. To understand the current state (status quo) of waiting lists for speech and language services (Chapters 2, 3, 4)
3. To understand SLPs' waiting list management practices and perspectives on prioritisation for speech and language services (Chapter 2, 3, 4)
4. To design an evidence-based website to support children, caregivers, and other stakeholders while children are waiting for speech and language services (Chapter 6)
5. To evaluate and compare provision of the evidence-based website (active waiting) with a waiting list control group (passive waiting) and compare children's speech, intelligibility, language, and early literacy, and caregivers' empowerment and satisfaction between groups (Chapter 7).

Outline of this Doctoral Research

This doctoral research consists of nine chapters and four parts. Part One (Chapter 1) titled “General introduction” provides an orientation to the research topic and outlines relevant theoretical frameworks and research methods.

Part Two (Chapters 2 to 4) titled “Desperation and aspirations: Exploring the status quo and imagining solutions to waiting lists” explores perspectives and experiences regarding waiting lists in Australia and other parts of the world. Chapter 2 explores stakeholders' experiences regarding waiting for speech and language services by analysing 133 written submissions to a 2014 Australian Government Senate Inquiry. Chapters 3 and 4 explores questionnaire responses from 264 SLPs' regarding waiting lists and waiting list management strategies.

Part Three (Chapters 5 to 7) titled “Reimagining services: Designing and evaluating waiting list solutions” involves the design and evaluation of one waiting list management strategy from those identified in Part Two. That is, an evidence-based website to encourage active waiting for speech and language services. Chapter 5 provides an orientation and overview of the subsequent chapters. Chapter 6 outlines research informing the design of an evidence-based website for children and families by exploring perspectives from members of the public via a questionnaire ($n = 119$) and focus groups ($n = 16$) and evaluating existing websites and mobile applications (apps) ($n = 25$). Chapter 7 reports on an evaluation of the effectiveness of providing the evidence-based website to families (active waiting) compared with a waiting list control condition (passive waiting) via a randomised controlled trial ($n = 97$) in a real-world clinic.

Part Four (Chapters 8 and 9) titled “Conclusions and contributions” discusses implications of the doctoral research. Chapter 8 presents a speech-language pathology care pathway created based on findings from earlier chapters, and an exemplar informing the planning and evaluation of waiting list management strategies to assist with translation of the findings into practice. A table of possible waiting list management strategies and suggested references was created as a resource for professionals and is included as Appendix A to this thesis. Chapter 9 outlines conclusions and contributions of the research for consumers, professionals and organisations, governments and policymakers, and theory.

Situating the Researcher

As an SLP in a rural Australian setting I am confronted with the issues of waiting lists and prioritisation on a daily basis. These issues are not only relevant to speech and language services, but also to many other areas of health care, including psychology and occupational therapy. In my local area, there is a high demand for services, but limited funding and health professionals are available. Sometimes families have access to funding, but health professionals in the local area have no capacity to see them due to having full caseloads. At my local community health service, the waiting list is 12 months long for speech and language services. I have observed the significant impact that waiting has on children and families such as experiencing stress, concern, worry, and frustration. Waiting lists also place extreme pressure on the SLPs. I frequently receive calls from parents asking how much longer they had to wait, what they could do while they wait to help their child communicate

more effectively, and questions about how delays in treatment affect the prognosis for their child. Families often express concern that their child is becoming increasingly frustrated, is not progressing, or will not be ready to start school. Living in a rural setting, I see these families at the supermarket and the sports oval; their concerns are real. Currently, there is little that SLPs can offer to families while on waiting lists. I am determined and motivated to find a better and evidence-based solution to this issue.

Theoretical Framework for this Doctoral Research

This doctoral research drew upon two guiding theoretical models throughout the planning, data collection, and analysis phases: (1) the International Classification of Functioning, Disability and Health: Children and Youth Version (ICF-CY; World Health Organization [WHO], 2007), and (2) the theory of preparative waiting (Giske & Gjengedal, 2007).

ICF-CY (WHO, 2007)

The ICF-CY is a theoretical framework derived from the International Classification of Functioning, Disability and Health (ICF; WHO, 2001), which reflects the vastly changing nature of health and development in childhood and adolescence. The ICF-CY reflects a biopsychosocial model of health, which shifts the focus from a medical model to considering children's health, wellbeing, and development within their broader "physical, social and attitudinal environment" (WHO, 2007, p. xvi). The ICF-CY enables the classification and description of children's health and wellbeing in a structured and interrelated way (McCormack, McLeod, Harrison, & McAllister, 2010). In doing so, the impact of communication difficulties on children's lives can be explored holistically. The ICF-CY has been applied widely in the speech-language pathology domain, including to children with speech sound disorders (McLeod, 2004; McLeod & Bleile, 2004; McLeod, 2006; McLeod & McCormack, 2007), developmental language disorder (Campbell & Skarakis-Doyle, 2007; Washington, 2007; Westby, 2007; Westby & Washington, 2017), and stuttering (Yaruss, 1998).

The ICF-CY consists of two parts, each with two components (see Figure 1). Part 1 relates to Functioning and Disability, which is broken into the Body Structures and Functions component (comprising eight domains of body structures and systems, such as the structures of the nervous system and mental functions) and the Activities and Participation component (comprising nine domains reflecting the actions and

tasks that children engage in during their daily lives, such as learning and applying knowledge). Part 2 relates to Contextual Factors which is divided into the Environmental Factors component (comprising domains which are external influences on functioning and disability, such as support and relationships) and the Personal Factors component (comprising domains which are internal influences on functioning and disability, such as character and coping style). Contextual Factors can have positive and negative influences on Functioning and Disability.

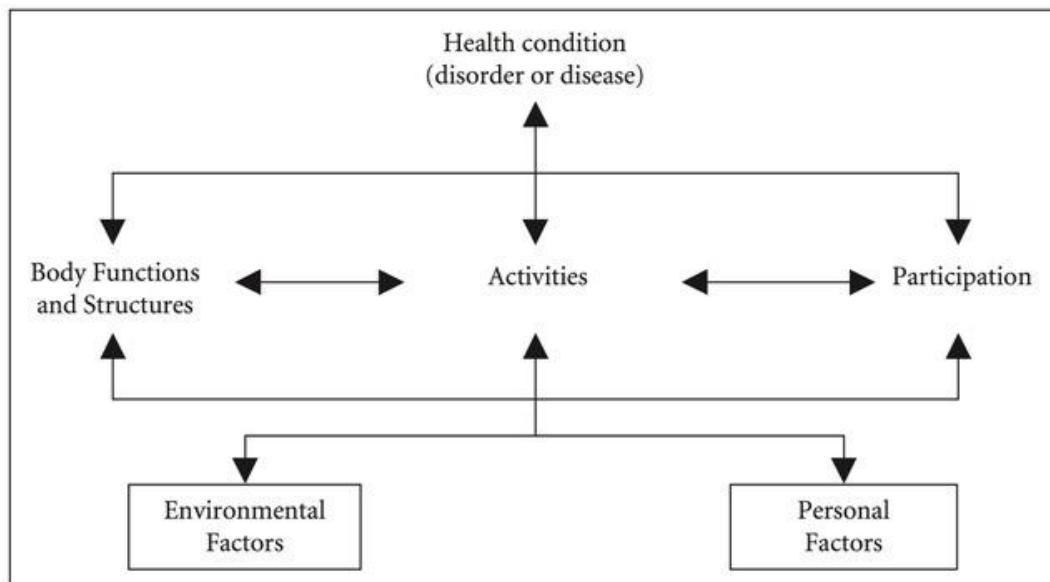


Figure 1. Interactions between the components of the ICF. Reprinted with permission from World Health Organization. (2007). *International classification of functioning, disability and health: Children and youth version*. Geneva, Switzerland: World Health Organization.

The planning of this doctoral research was undertaken using the lens of the ICF-CY, where caregivers and SLPs were considered as providing “support and relationships” for children with speech and language difficulties (Environmental Factors). The ICF-CY also guided the assessment of children for data collection and analysis in Chapter 7. Appendix B summarises the application of the ICF-CY to the research. Chapters 6 and 7 related to all components of the ICF-CY, while Chapters 2 to 4 related mostly to Activities and Participation, Environmental Factors, and Personal Factors components.

Theory of Preparative Waiting (Giske & Gjengedal, 2007)

The theory of preparative waiting was developed by Giske and Gjengedal (2007) from a grounded theory study focused on exploring and understanding how

hospitalised patients with gastrointestinal issues experienced and coped with the diagnostic process (Figure 2).

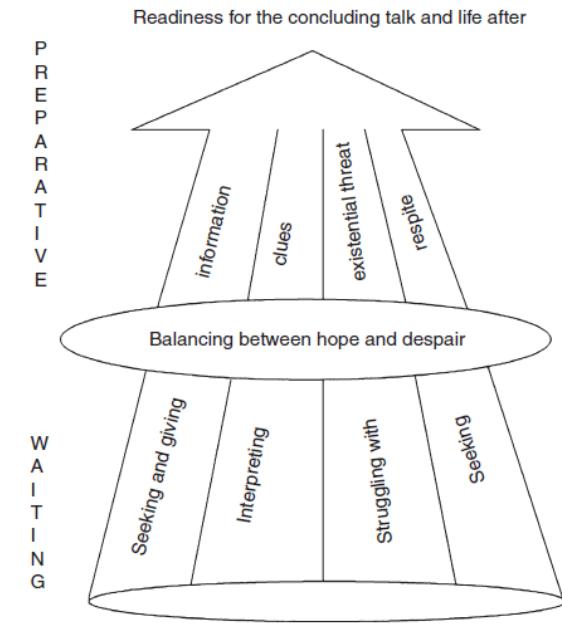


Figure 2. “Model of the substantive theory of preparative waiting” (Giske & Gjengedal, 2007, p. 90). © 2006 The Authors. Journal compilation © 2006 Blackwell Publishing Ltd. Reprinted with permission from Giske, T., & Gjengedal, E. (2007). ‘Preparative waiting’ and coping theory with patients going through gastric diagnosis. *Journal of Advanced Nursing*, 57(1), 87-94. doi:10.1111/j.1365-2648.2006.04082.x

The theory consisted of five strategies undertaken by individuals waiting for health care services (Giske & Gjengedal, 2007):

1. “Seeking and giving information” (p. 90) referred to participants making sense of their situation, reducing uncertainty, and attempting to predict what was going to happen to them by accessing information. They attempted to access accurate and individualised information.
2. “Interpreting clues” (p. 90) involved interpreting changes in symptoms, the examinations/assessments that they underwent, and the level of priority they were assigned in the health care system. They also considered possible outcomes.
3. “Struggling with existential threat” (p. 90) referred to worries about the impact the condition could have on their life, their future, and the lives of significant others.

4. “Seeking respite” (p. 90) involved trying to alleviate the “painful tension of uncertainty” (p. 91) while they engaged in the other strategies (Giske & Gjengedal, 2007).
5. “Balancing between hope and despair” (p. 90) occurred throughout the waiting process and was the filter guiding the other strategies of preparative waiting. This strategy was displayed through four patterns: (a) “rational awaiting-pattern”, characterised by controlled emotions and a focus on facts and specific, accurate information; (b) “denial”, characterised by an emphasis on positive information and experiences and not actively seeking information; (c) “painful control”, involving an openness to the truth about their condition and feelings of significant pain and uncertainty for the future; and (d) “acceptance”, characterised by openly seeking information and believing that they can cope with the outcome of their condition (Giske & Gjengedal, 2007, p. 90).

Whilst the theory of preparative waiting was developed based on hospitalised patients’ experiences, it has potential for application to non-hospitalised individuals waiting for other types of health care to validate and refine the five strategies (Fogarty & Cronin, 2008; Giske & Gjengedal, 2007). The theory of preparative waiting has not previously been explored within speech-language pathology literature; however, there may be similarities with the experiences of waiting in other contexts, such as for speech and language services. Examples of how the theory of preparative waiting may relate to parents of children with speech and language needs are shown in Table 1. This doctoral research drew on the theory of preparative waiting throughout the research design, planning, data analysis, and interpretation of findings to explore its relevance to individuals waiting for speech and language services.

Table 1.

Mapping the Theory of Preparative Waiting (Giske & Gjengedal, 2007) in Relation to Speech and Language Services for Children

Strategy	Examples relevant to speech and language services
1. Seeking and giving information	a. Parents seek information about speech and language difficulties from various sources, including personal sources (e.g., family, friends), professional sources (e.g., teachers, SLPs, doctors), and the media (e.g., Internet, books) (McAllister et al., 2011).

	b. Parents of children with hearing loss search for information online (Porter & Edirippulige, 2007).
2. Interpreting clues	a. Parents may expect others to confirm the concerns or suspicions they have about their child's speech and language development (McAllister et al., 2011). b. Parents may compare their child with siblings or children outside of the family when they notice possible speech and language delay (Glogowska, 2002). c. Parents monitor their child's speech and language to see if it resolves on its own rather than accessing services immediately (Morgan et al., 2017).
3. Struggling with existential threat	a. Parents whose children were waiting to be assessed for autism spectrum disorder by a multidisciplinary team felt they were in "limbo" (p. 300) and changed the way they looked at their child (Connolly & Gersch, 2013). b. Referral to speech-language pathology may mean that "something was wrong" with their child (Glogowska, 2002). c. Parents may worry about whether their child's difficulties are significant and whether they will be able to attend mainstream school, make friends, and live up to expectations they had for their child (McCormack, Baker, & Crowe, 2018).
4. Seeking respite	a. Parents enrol children in singing lessons, or speech and drama classes to develop confidence, voice projection, and intelligibility. b. Parents enrol their children in early childhood education and care or baby-sitting. c. Parents access respite services. d. Parents seek support from a religious advisor, counsellor, or other parents (McAllister et al., 2011).
5. Balancing between hope and despair	a. Parents may deny that their child has difficulties with speech and language (McCormack, McAllister, McLeod, & Harrison, 2012). b. Passive waiting for speech-language pathology services (Glogowska & Campbell, 2000).

Research Methods

The philosophical paradigm underpinning this doctoral research was pragmatism, with its orientation toward social justice (Morgan, 2014). A pragmatic philosophical worldview sees the researchers' experiences and changes anticipated to result from the research being "context bound, embodied and emotional, and thoroughly social in nature" as strengths (Morgan, 2014, p. 1051). Pragmatists view knowledge as being constructed and based on our realities and experiences which can be generated through different sources and research methods (Liampittong, 2010). There is an emphasis on problems or gaps in knowledge within the literature, and pragmatists advocate for use of a range of methods to best address those gaps or research questions (Creswell, 2018; Liampittong, 2010). Pragmatism therefore lends itself to mixed methods research designs.

Mixed Methods Research

This doctoral research used mixed methods to investigate the research aims. Chapters 2, 3, 4, 6, and 7 reported on discrete studies that combined to explore the status quo of speech and language service waiting lists and potential solutions to waiting lists moving forward. A separate method was used in each discrete study, designed to best address the specific research aims for that study, involving both quantitative and qualitative methods. An overview of the range of methods used within each chapter of this doctoral research to address the research aims is provided in Appendix C.

Mixed methods research is recommended for rich, complex, multifaceted research aims and contexts involving large numbers of people or participants (O'Toole & Beckett, 2013). Incorporating a range of quantitative and qualitative methods in the research draws on the strengths of each approach to address the research aims most appropriately (Taket, 2010), whilst offsetting the limitations inherent in each method (Bryman, 2006). Combining methods can enhance the completeness and integrity of the research and findings, enabling a more comprehensive understanding of waiting lists to be obtained (Bryman, 2006). Using a combination of quantitative and qualitative methods enabled both breadth and depth of data collection and analysis, when neither approach alone may have effectively addressed the research questions (Liampittong, 2010). For instance, Chapters 3 and 4 reported on findings from a questionnaire involving both closed (quantitative) and open-ended (qualitative) questions to address aims 2 and 3 of the doctoral research. SLPs' responses to closed questions (quantitative data; Chapter 3) enabled patterns

and relationships between workplace contexts, caseload size, prioritisation policies, and waiting list duration to be identified; while responses to open-ended questions (qualitative data; Chapter 4) enabled exploration of SLPs' perspectives about waiting lists and waiting list management strategies (including prioritisation) in more depth.

Qualitative methods were able to enhance, confirm, illustrate, and explain data obtained via quantitative methods, and vice versa (Bryman, 2006; Hammersley, 1996). For example, an explanatory sequential mixed methods design (Bryman, 2016) was used in Chapter 6 involving a questionnaire and evaluation of the quality of existing websites, followed by focus groups to address aim 4 of the doctoral research. Quantitative findings from the questionnaire regarding the most important content, features, and functions to include on a website for children and families on waiting lists were included in the semi-structured focus group schedules for participants to discuss, question, and explain in more depth.

Qualitative methods.

A range of qualitative methods were incorporated in this doctoral research to allow participants to freely express their thoughts and feelings regarding waiting for speech and language services. An existing dataset of written submissions to a Government Senate Inquiry provided a rich source of stakeholders' (such as families, professionals, clients, and organisations) experiences and perspectives regarding waiting lists (Chapter 2). Open-ended questions were included in questionnaires (Chapters 3 and 4) which enabled detailed responses to be rapidly obtained from large numbers of participants but did not allow for follow-up questions or prompts from the researcher to elicit more information or contextual details (Creswell, 2018). Collecting written responses allowed participants to think more deeply about the questions or topics and provide considered responses. Focus groups (Chapter 6) were undertaken to explore the thoughts and ideas of larger numbers of participants than interviews would allow, with added insights gained when participants interacted with each other during discussions (O'Toole & Beckett, 2013). Semi-structured focus group schedules were used to enhance consistency in data collection while still allowing opportunities for unexpected perspectives to arise and flexibility for the researcher to prompt, probe, and clarify (O'Toole & Beckett, 2013). Qualitative data were analysed thematically to identify key ideas and topics within participants' responses. Thematic analysis was used in Chapter 4 following the six-step procedure outlined in Braun and Clarke (2006) and Chapter 6 following the procedure outlined by Yin (2011). An inductive approach was used in Chapters 2 and 4, where data were

coded without attempting to fit participants' ideas into pre-existing codes (Patton, 1990). A deductive or theoretical approach was used in Chapter 6 whereby coding of data commenced with an initial coding structure in mind, informed by a quantitative analysis of questionnaire responses and the theory of preparative waiting, but new codes were added as novel ideas and themes were identified (Braun & Clarke, 2006; Giske & Gjengedal, 2007).

The rigour of the qualitative studies undertaken in this doctoral research was enhanced in several ways. Thick descriptions and meaning statements were included throughout the results and discussion sections within relevant chapters to allow participants' "voices, feelings, ideas and meanings" to be heard (Denzin, 1989, p. 83). Triangulation of accounts from a variety of sources (e.g., consumers, professionals, and organisations in Chapter 2; members of the public in Chapter 6) enabled consideration of multiple perspectives and experiences as opposed to focusing on the experiences of a single stakeholder group (Denzin & Lincoln, 2005; Shenton, 2004). Triangulation enables consistency of information to be checked and compared across sources (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014). Examination of previous research findings in relation to the findings of this doctoral research was undertaken in each chapter to align findings with existing research and identify new understandings (Morse, 2015; Shenton, 2004). Member checking of focus group transcripts was undertaken where possible (e.g., Chapter 6) to allow participants to check for accuracy or any information to be modified for privacy reasons (Shenton, 2004). Consensus with the doctoral supervisors was obtained during thematic analyses regarding coding structures, as well as defining and naming final themes. This doctoral research therefore demonstrated the doctoral candidate's ability to undertake a range of qualitative research methods in a rigorous manner.

Quantitative methods.

Quantitative methods were also used to address the research aims concerned with numerical data (e.g., duration of waiting lists) and relationships in the data (e.g., between waiting duration and workplace context; Liamputpong, 2010). Data from large numbers of participants was able to be obtained, forming a broad snapshot of the state of waiting lists and perspectives of stakeholders. Closed questions were included in questionnaires (Chapters 3 and 6) to enhance comparability of responses and enable participants to answer multiple questions on several topics of interest quickly and easily (Bryman, 2016). The quality of existing websites about children's speech and language (Chapter 6) was rated numerically using binary and three-way

coding across nine predetermined criteria from an existing measure to evaluate the credibility, currency, and accuracy of online information. An experimental design involving a randomised controlled trial (RCT) was undertaken to compare outcomes for children and their caregivers in treatment (active waiting) and control (passive waiting) conditions (Chapter 7). Quantitative data in this doctoral research were analysed using descriptive statistics to determine frequencies for categorical variables (e.g., n and %) or continuous variables (M and SD), non-parametric analyses such as Chi square analyses, and parametric analyses such as Pearson correlation and ANCOVA (Analysis of Covariance) analyses where data were normally distributed (Pallant, 2016).

Rigour of the quantitative research methods was considered throughout the planning, data collection, and data analysis for each discrete study. Reliability was enhanced through calculating percentage of agreement between coders and scorers in the studies to measure inter- and intra-rater reliability, ensuring satisfactory levels of agreement were obtained (Multon & Coleman, 2018; Shriberg & Lof, 1991).

Questionnaires and website evaluation criteria incorporated existing questions from prior research (e.g., McLeod, Baker, McCormack, Wren, & Roulstone, 2013-2015) or existing tools/measures (e.g., Genetic Alliance, 2013; Koren, DeChillo, & Friesen, 1992; McLeod, Harrison, & McCormack, 2012) to take advantage of their known reliability and validity and enable comparison with other research, enhancing face and construct validity (Bryman, 2016). Valid and reliable instruments with normative and culturally relevant data were used to measure children's and caregivers' outcomes in the RCT (Chapter 7) where possible, or measures which had been used with similar populations or in similar contexts that could be adapted, thus enhancing construct validity (Imms & Greaves, 2010). The design, conduct, and reporting of the RCT (Chapter 7) was informed by the Consolidated Standards of Reporting Trials (CONSORT) guidelines, enhancing transparency, completeness, and accuracy of the research (Montgomery et al., 2018; Schulz, Altman, & Moher, 2010). Random group assignment and examination of group characteristics (e.g., age, sex) prior to intervention increased the likelihood that any differences observed between the two groups at the post-assessment stage could be attributed to the intervention rather than pre-existing differences (Bryman, 2016). In summary, a range of quantitative data collection and analysis methods were rigorously implemented in this doctoral research by the doctoral candidate.

Conclusion

This doctoral research was guided by the ICF-CY (WHO, 2007) and theory of preparative waiting (Giske & Gjengedal, 2007), employing mixed methods to holistically explore perspectives and solutions regarding speech and language service waiting lists across stakeholder groups, client populations, and service contexts. This research increased the evidence about waiting lists to inform professionals, governments, and policymakers regarding improving children's access to services and moving toward a better future for children with speech and language needs and their families.

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Appendix A. Examples of International Media Profiling Waiting for Speech and Language Services

Country	Reference
Australia	<p>Coulter, E. (2019, December 19). Oliver's family had to pay thousands of dollars for him to be diagnosed with autism, or wait two years for public therapy. <i>ABC News</i>. Retrieved from https://www.abc.net.au/news/2019-12-19/olivers-family-paid-thousands-for-autism-diagnosis/11810992</p> <p>Offer, J. (2019, November 21). "The NDIS is just a recipe for carer-burnout, I should know". <i>KidSpot</i>. Retrieved from https://www.kidspot.com.au/parenting/real-life/the-ndis-is-just-a-recipe-for-carerburnout-i-should-know/news-story/86d94d6e21eab7fa501018ed95c892f4</p> <p>Dalzell, S. (2017, August 21). Children with suspected disabilities enduring 12-month wait for diagnosis in parts of Sydney. <i>ABC News</i>. Retrieved from https://mobile.abc.net.au/news/2017-02-05/children-in-diagnosis-limbo-wait-12-months-for-disabilities/8241526?pfmredir=sm</p> <p>Travers, P. (2016, May 19). Canberra speech therapist shortage forcing families to travel to Sydney for child services. <i>ABC Radio Canberra</i>. Retrieved from https://www.abc.net.au/news/2016-05-19/speech-therapist-shortage-in-canberra/7428884</p>
Canada	<p>Lapuz, B. (2018, August 17). Parents file lawsuit against Quebec over delays in getting their child into speech therapy. <i>CBC News</i>. Retrieved from https://www.cbc.ca/news/canada/montreal/parents-sue-quebec-delay-child-speech-therapy-1.4789852</p>
England	<p>Austin, H. (2019, March 9). Speech therapy lottery leaves a million children languishing on waiting lists. <i>Mirror Online</i>. Retrieved from https://www.mirror.co.uk/news/politics/speech-therapy-lottery-leaves-million-</p>

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Richardson, H. (2019, October 23). "Unlawful practices and buck passing" over special needs. *BBC News*. Retrieved from <https://www.bbc.com/news/education-50140141>

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Appendix B: Application of the ICF-CY (WHO, 2007) to the Doctoral Research

ICF-CY components		Example		Thesis chapters
	ICF-CY chapters	codes	Relevant area of doctoral research	
Body Functions	1. Mental functions	b1670-1	Expressive and receptive language assessments Development and evaluation of an evidence-based website to stimulate children's language development	7 6, 7
	2. Sensory functions and pain	b230	Hearing assessments	7
	3. Voice and speech functions	b320	Speech assessments Development and evaluation of an evidence-based website to stimulate children's speech development	7 6, 7
Body Structures	3. Structures involved in voice and speech	s320	Oromotor assessments	7
Activities and Participation	1. Learning and applying knowledge	d133, d140	Development and evaluation of a website containing strategies to assist with speech and language acquisition, and early literacy	6, 7
	3. Communication	d330	Speech intelligibility assessments	7
	7. Interpersonal interactions and relationships	d670 d750	Case history information Caregiver questionnaires	7
	8. Major life areas	d815	Exploring caregivers' and professionals' strategies for supporting children's communication skills while waiting for services	2, 4

	d816, d820	Provision of strategies to facilitate children's communication development at home and in the community via a website	7	
9. Community and civic life	d910	Exploring experiences of waiting for speech and language services across the lifespan	2	
	d940	Developing and evaluating a website to promote early intervention for children with a right to access support	6, 7	
Environmental Factors	1. Products and technology	e130	Evaluation of existing websites about children's speech and language	6
			Designing and evaluating a website for supporting children and families on waiting lists	6, 7
	3. Support and relationships	e310	Assessment of caregivers' satisfaction, and empowerment	7
		e310, e315	Designing and evaluating a website for supporting children and families on waiting lists	6, 7
		e355	The research informs care for children and families on waiting lists	2, 3, 4, 6, 7, 8
	4. Attitudes	e410, e450	Exploring perspectives of key stakeholders in children's environments (e.g., families, SLPs) regarding waiting lists	2, 3, 4, 6, 7
	5. Services, systems and policies	e580	Exploring prioritisation of children for services by SLPs	3, 4
		e580, e585	Exploring the current state of waiting lists for speech and language services throughout the world	2, 3, 4

	e580	Exploring experiences of waiting for speech and language services - a systemic barrier to service access	2, 7
Personal Factors	N/A	Collecting demographic information regarding research participants (e.g., age, gender, language background, and socio-economic status)	2, 3, 4, 6, 7

SLP, speech-language pathologist; N/A, not applicable

Appendix C. Overview of Methods Used in the Doctoral Research

Aim	Chapter	Quantitative methods	Qualitative methods
1. To understand the experience and impact of waiting for speech and language services from the perspectives of key stakeholders, including consumers (e.g., children and families) and professionals (e.g., SLPs)	2	-	Documents analysed using inductive thematic analysis (Braun & Clarke, 2006).
	3	Questionnaire data analysed using descriptive statistics (e.g., frequencies), Chi square, ANOVA, and Pearson's correlation analyses.	-
	4	-	Questionnaire data (open-ended questions) analysed using thematic analysis (Braun & Clarke, 2006).
	7	Child and caregiver assessment outcome data analysed using one-way ANCOVA analyses with intention to treat and per protocol samples.	-
2. To understand the current state (status quo) of waiting lists for speech and language services	2	-	Documents analysed using inductive thematic analysis (Braun & Clarke, 2006).
	3	Questionnaire data analysed using descriptive statistics (e.g., frequencies), Chi	-

			square, ANOVA, and Pearson's correlation analyses.
	4	-	Questionnaire data (open-ended questions) analysed using thematic analysis (Braun & Clarke, 2006).
3. To understand SLPs' waiting list management practices and perspectives on prioritisation for speech and language services	2	-	Documents analysed using inductive thematic analysis (Braun & Clarke, 2006).
	3	Questionnaire data analysed using descriptive statistics (e.g., frequencies), Chi square, ANOVA, and Pearson's correlation analyses.	-
	4	-	Questionnaire data (open-ended questions) analysed using thematic analysis (Braun & Clarke, 2006).
4. To design an evidence-based website to support children, caregivers, and other stakeholders while children are waiting for speech and language services	6	Questionnaire data analysed using descriptive statistics (e.g., mean scores). Scores for website quality analysed using descriptive statistics.	Questionnaire data (open-ended questions) analysed using thematic analysis (Braun & Clarke, 2006). Focus group transcripts analysed using deductive thematic analysis (Yin, 2011).

5. To evaluate and compare provision
of the evidence-based website
(active waiting) with a waiting list
control group (passive waiting) and
compare children's speech,
intelligibility, language, and early
literacy, and caregivers'
empowerment and satisfaction
between groups

7

Child and caregiver assessment outcome data -
analysed using one-way ANCOVA analyses
with intention to treat and per protocol
samples.

Note. SLP, speech-language pathologist; ANOVA, Analysis of Variance; ANCOVA, Analysis of Covariance.

Part Two

**Desperation and Aspirations:
Exploring the Status Quo and Imagining Solutions
to Waiting Lists**

Introduction to Part Two

Waiting: A hope with pain for a beautiful future... – Radha Panjiyar

Part Two of this doctoral research (Chapters 2, 3, and 4) explored the status quo of waiting lists for speech and language services throughout the world; the consequences of waiting lists for stakeholders, including clients, families, professionals (e.g., SLPs), organisations, and society; and current and aspirational strategies for managing waiting lists for speech and language services.

Chapter 2 (McGill, Crowe, & McLeod, 2020) involved a qualitative document analysis drawing on an existing dataset of written submissions to a Government Senate Inquiry regarding the prevalence of speech, language and communication disorders, and speech and language services in Australia (Commonwealth of Australia, 2014). While the terms of reference for the Inquiry included the *demand*, *provision*, *availability*, and *adequacy* of speech and language services, waiting lists were not specifically mentioned (Parliament of Australia, 2014). However, the “long waiting lists in the public system” (p. 5) were identified as one of three key areas of concern in the Senate Inquiry report (Commonwealth of Australia, 2014). Chapter 2 therefore aimed to explore stakeholders’ experiences of waiting for services in greater depth, and broadly explored experiences relating to both paediatric and adult clients. Both children and adults may wait for speech-language pathology services, and Chapter 2 provided insights into the issues and concerns across client populations and stakeholder groups regarding waiting lists.

Chapters 3 and 4 narrowed the focus to waiting lists for paediatric speech and language services and explored SLPs’ perspectives using a questionnaire. Chapter 3 (McGill, McLeod, Crowe, Hopf, & Wang, 2019) reported on quantitative analyses of SLPs’ responses to closed questions regarding waiting list duration, stages of waiting, and prioritisation of children for services, which is a common waiting list management strategy determining the timing, type, and amount of services children receive. Chapter 4 (McGill, McLeod, & Hopf, 2020) reported on qualitative analyses of SLPs’ responses to open-ended questions within the same questionnaire to explore perspectives regarding waiting lists and management strategies.

Part Two of this doctoral research related to both Functioning and Disability (Body Functions, Activities and Participation) and Contextual Factors (Environmental and Personal Factors) within the ICF-CY (WHO, 2007). For instance, consequences of waiting lists for consumers (Chapter 2) related to both

Body Functions (e.g., b167 Mental functions of language; b320 Articulation functions) and Activities and Participation (e.g., d133 Acquiring language; d710 Basic interpersonal interaction) (WHO, 2007). Exploration of stakeholder perspectives on waiting lists and their management (e.g., e310, Immediate family; e355, Health professionals), attitudes regarding waiting lists (e.g., e410 Attitudes of family members), and examining speech and language service delivery and contexts (e.g., e580, Health services, systems and policies) related to Environmental Factors (WHO, 2007). Exploring stakeholders' perspectives regarding waiting lists also related to Personal Factors (e.g., coping styles) (WHO, 2007), as well as the theory of preparative waiting by identifying the types of strategies and "continuous work" many consumers and professionals engaged in (Giske & Gjengedal, 2007, p. 90).

Part Two enabled the level of impact and significant need for research and solutions to address speech and language service waiting lists to be demonstrated. Advocacy for necessary systemic and localised changes within speech and language services and the wider health care, education, and disability sectors relies on research evidence demonstrating the widespread impact of waiting lists. Exploring current and aspirational waiting list management strategies enabled a range of ideas for reimagining speech and language service provision to be gathered, thus setting the context for Part Three of this thesis which investigated one potential waiting list management strategy. Knowledge of the current state of waiting lists and SLPs' practices and perspectives enables more informed steps forward in reimagining service provision, searching for effective waiting list solutions, and moving toward better futures for children with speech and language needs.

Hope is being able to see that there is light despite all of the darkness – Desmond Tutu

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Chapter 2: Stakeholders' Perspectives Regarding Waiting Lists

Paper 1

McGill, N., Crowe, K., & McLeod, S. (2020). "Many wasted months": Stakeholders' perspectives about waiting for speech-language pathology services.

International Journal of Speech-Language Pathology, 22(3), 313-326. doi: 10.1080/17549507.2020.1747541

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Running Head: SLP WAITING LISTS

“Many wasted months”: Stakeholders’ perspectives about waiting for speech-language pathology services

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KEYWORDS: speech-language pathology, waiting list, service delivery, workforce issues, government, retention, consumer, qualitative research

Abstract

Purpose: High demand for speech-language pathology services is reflected in long waiting lists. Waiting can be active or passive and has implications for stakeholders, including consumers, professionals, and organisations. The present study explored experiences and perspectives regarding waiting for speech-language pathology services through analysis of stakeholders' written submissions to an Australian Government Senate Inquiry.

Method: Written submissions ($n = 337$) were screened for terms related to waiting. Included submissions ($n = 133$) were written by organisations (36.8%), speech-language pathologists (29.3%), parents (27.8%), individuals with communication and/or swallowing difficulties (5.3%), and others.

Result: Inductive thematic analysis identified three themes. (1) *Duration*. Consistently described as long. (2) *Consequences*. Consumers' consequences included: burden on physical health, finances, time, emotional wellbeing, and relationships, reduced continuity of care, and increased intervention needs. Professional consequences included: stress and burnout impacting job satisfaction, and reduced effectiveness. Societal consequences included: social and ethical burden, and a drain on health and legal systems. (3) *Actions*. Consumers advocated and sought alternatives (e.g. threats to harm their child, relocation to a capital city), professionals implemented service delivery and policy actions, and organisations lacked effective system-wide strategies.

Conclusion: Existing services did not appear to meet stakeholders' needs. Action is needed to improve speech-language pathology waiting lists and access to services, and minimise possible consequences for stakeholders.

“Many wasted months”: Stakeholders’ perspectives about waiting for speech-language pathology services

Waiting for speech-language pathology services is a common reality, and poses risks for consumers, professionals, and organisations. Waiting lists often occur in health care when demand for services exceeds the supply and the limited resources available must be rationed (Martin et al., 2003). Long waiting lists can prevent access to early intervention and may deter individuals with communication and swallowing difficulties from seeking speech-language pathology support at all, meaning those who need support may miss out (Commonwealth of Australia, 2014). Failure to receive timely speech-language pathology intervention can lead to long-term impacts on academic, occupational, and emotional outcomes (Johnson, Beitchman, & Brownlie, 2010; McLeod, Harrison & Wang, 2019). In under-resourced organisations, speech-language pathology services may be rationed based on priority, with individuals considered higher priority receiving services faster than those considered lower priority (McCartney, 2000). Individuals who are considered low priority for services may be left on waiting lists until their difficulties “become more pressing, or until more resources are available” (McCartney, 2000, p. 166). Although prioritisation policies may vary between services for adults and children, key prioritisation factors include: client safety, prevention of harm, severity of disorder, and the urgency of intervention (Kenny, Lincoln, & Balandin, 2010; McGill, McLeod, Crowe, Hopf, & Wang, 2019; Rice, 1998). For instance, individuals with suspected dysphagia following acute stroke or children with feeding/swallowing difficulties are typically prioritised for urgent speech-language pathology assessment due to potential risks to their physical health (e.g., aspiration pneumonia), whilst individuals with more stable or chronic difficulties (e.g., children or adults with communication difficulties) may be considered lower priority and wait longer for

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services (Eltringham, Smith, Pownall, Sage, & Bray, 2019; Speech Pathology Australia, 2012). Regardless, the impact of any type of communication or swallowing difficulty may be prolonged or exacerbated if individuals do not receive support in a timely manner. Researchers indicate that waiting for health care can impact emotional wellbeing, with individuals experiencing stress, uncertainty, anger, fear, and powerlessness (Dew et al., 2013; Fogarty & Cronin, 2008; Miller et al., 2008; Rittenmeyer, Huffman, & Godfrey, 2012). To date, there has been little research investigating if such feelings are also experienced by individuals waiting for speech-language pathology services. Consumers who endure lengthy waiting times often report lower levels of satisfaction with the organisations, as well as negative perceptions of service providers and the quality of care they receive (Bleustein et al., 2014; Rittenmeyer et al., 2012; Xie & Or, 2017).

Long waiting lists may also have ramifications for professionals. Speech-language pathologists (SLPs) have reported negative feelings about their waiting lists, including frustration, stress, anxiety, concern, and embarrassment (McGill, McLeod, Crowe, & Hopf, 2019). Although not a specific focus, waiting lists may have played a role in the negative impacts reported for SLPs managing large caseloads of clients with few available resources, including increased risk of burnout, and reduced job satisfaction and ability to provide evidence-based client care (Edgar & Rosa-Lugo, 2007; Kenny & Lincoln, 2012). Limited research to date has specifically focused on SLPs' experiences regarding waiting lists.

One of three areas of concern highlighted in the findings of an Australian Government Senate Inquiry was “the long waiting lists in the public system” (Commonwealth of Australia, 2014, p. 5). Long waiting times have similarly been reported in independent work by Australian researchers, with some adults and children waiting over 12 months for services (Dew et al., 2013; Gallego et al., 2017;

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McAllister, McCormack, McLeod, & Harrison, 2011; Ruggero, McCabe, Ballard, & Munro, 2012). The issue of long waiting lists is not unique to Australia. Other research evidence suggests that lengthy waiting times also occur in other countries such as the UK and Canada (Rvachew & Rafaat, 2014). In the UK, the varying levels of support received based on where children live was described as a “postcode lottery” (I CAN & Royal College of Speech and Language Therapists [RCSLT], 2018, p. 19). In addition, more than 1 million children experience inequitable access to services due to funding cuts and have been “left waiting years to be assessed” (Austin, 2019, n.p.). Over one third (34.0%) of children in the UK wait more than 12 months to access speech-language pathology services (I CAN & RCSLT, 2018; Longfield, 2019). Waiting times exceeding 12 months for speech-language pathology services have also been reported in Scotland for adults with learning difficulties and/or autism spectrum disorders (Scottish Executive, 2003). In Ireland, waiting lists have similarly been described as reflecting an “accident of geography” (Foxe, 2019, n.p.), where a child’s address can determine whether they endure lengthy waiting times and likely poorer outcomes, or more timely services (Foxe, 2019). The number of children on speech-language pathology waiting lists in Ireland was reportedly increasing, with recruitment of more professionals needed to respond to the demand (Hutton, 2019). In Canada, concern surrounding lengthy waiting times for health care, including speech-language pathology, prompted a national response involving formation of a “Wait Time Alliance (WTA) for Timely Access to Health Care” among a group of medical societies. One of the Canadian initiatives involved benchmarking of waiting times, including for children with speech sound disorders (Rvachew & Rafaat, 2014).

Waiting tends to be considered a passive process (Glogowska & Campbell, 2000) where individuals “remain in a state of … inaction” (Macquarie Dictionary,

2019, n.p). However, according to the theory of preparative waiting (Giske & Gjengedal, 2007), individuals waiting for health care have been found to undertake “continuous work” (p. 90) and actively engage in “seeking and giving information”, “interpreting clues”, and “seeking respite” while waiting for services (Giske & Gjengedal, 2007, p. 90). The theory of preparative waiting is applicable to the field of speech-language pathology when exploring parents’ experiences of waiting for services (McGill & McLeod, 2019). Individuals who feel more empowered within the health care system may be more active while waiting, for instance, more empowered parents find “ways to reduce the time that their child will have to wait” (Feldman, Champagne, Korner-Bitensky, & Meshefedjian, 2002, p. 357). Few studies have focused on active waiting or exploring the theory of preparative waiting in relation to waiting for speech-language pathology services and little is currently known about individuals’ experiences of waiting for speech-language pathology. The pressing need for this knowledge comes from waiting lists being a widespread, multi-faceted phenomenon affecting a growing number of consumers, professionals, and organisations as demand for speech-language pathology services continues to increase (Commonwealth of Australia, 2014). Subsequently, there was a need to explore experiences of waiting for speech-language pathology services from stakeholders’ perspectives to better understand the issues faced and inform the development of effective strategies for assisting those who are waiting for services.

Aim

The aim of the present study was to explore in more depth “the long waiting lists” (p. 5) for speech-language pathology, one of three areas of concern identified in an Australian Government Senate Inquiry titled the *Prevalence of different types of speech, language and communication disorders, and speech-language pathology services in Australia* (Commonwealth of Australia, 2014). The present study

specifically explored the experiences and perspectives of individuals living with, working with, and supporting those with communication and swallowing difficulties while waiting for speech-language pathology services through analysis of written submissions to the Senate Inquiry (Commonwealth of Australia, 2014).

Method

The present study explored perspectives and experiences of waiting for speech-language pathology services using a qualitative analysis of written documents. Ethical approval was not required for this study as data was obtained from an existing, publicly accessible dataset.

Document selection

In 2014, the Australian Government conducted a Senate Inquiry into the *Prevalence of different types of speech, language and communication disorders, and speech pathology services in Australia* (Commonwealth of Australia, 2014). The terms of reference for the Senate Inquiry focused on prevalence, types, and symptoms of communication and swallowing difficulties in Australia; the availability of speech-language pathology services and how well the demand for services was being met; and the projected demand for speech-language pathology services in Australia. Waiting lists were not directly specified in the Senate Inquiry's terms of reference. Three-hundred and five written submissions were made to the Senate Inquiry (Commonwealth of Australia, 2014) to address the terms of reference, consisting of 337 documents in total¹. Documents were located online and 321 documents (289 submissions) were available for download². Sixteen submissions were not available as participants had requested that their submission be treated confidentially.

¹ Some submissions contained attachments and consisted of multiple documents.

² Downloaded from:

https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Speech_Pathology/Submissions

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Documents were screened for inclusion (see Procedure), yielding 133 relevant documents that described waiting for speech-language pathology services.

Participants

Participants for the present study were the stakeholders who submitted written documents ($n = 337$) to an Australian Government Senate Inquiry (Commonwealth of Australia, 2014). All subsequent analyses in this paper were based on 133 (39.5%) documents that described waiting for speech-language pathology services. All participants who submitted the relevant documents ($n = 133$) were from Australia, as this was a requirement for making a submission to the Senate Inquiry. Documents were predominantly written by organisations ($n = 49$, 36.8%), SLPs ($n = 39$, 29.3%), and parents ($n = 37$, 27.8%). Documents were also written by clients or individuals with communication and/or swallowing difficulties ($n = 7$, 5.3%), researchers ($n = 3$, 2.3%), carers ($n = 3$, 2.3%), paediatricians ($n = 2$, 1.5%), school principals/assistant principals ($n = 2$, 1.5%), and one of each of the following stakeholders: occupational therapist, government minister, audiologist, child health nurse, and learning support coordinator. One (0.8%) involved multiple contributors, including educators and learning support staff. Most documents were in the format of summaries ($n = 64$, 48.1%), personal stories ($n = 43$, 32.3%), or summaries incorporating case examples ($n = 25$, 18.8%).

Documents included content about different geographical locations, service types, and client populations, with participants often describing more than one context or population³. Within the 133 documents, participants described services in all states and territories of Australia, specifically: New South Wales ($n = 38$, 28.6%), Victoria ($n = 23$, 17.3%), Queensland ($n = 20$, 15.0%), Western Australia ($n = 7$,

³ Data regarding service contexts and client populations relate to content within entire documents, not specifically in sections about waiting for speech-language pathology services.

5.3%), Australian Capital Territory ($n = 3$, 2.3%), Tasmania ($n = 2$, 1.5%), Northern Territory ($n = 1$, 0.8%), and South Australia ($n = 1$, 0.8%). Twenty-three (17.3%) documents had a national focus or described services across multiple states of Australia. Documents included content about services in both the public⁴ ($n = 112$, 84.2%) and private sector ($n = 109$, 81.9%). Information was included about the health sector ($n = 77$, 57.9%), education sector ($n = 66$, 49.6%), disability sector ($n = 54$, 40.6%), early intervention ($n = 65$, 48.9%), justice system ($n = 13$, 9.8%), and universities ($n = 10$, 7.5%). Regarding client populations, documents focused on children ($n = 81$, 60.9%), adults ($n = 16$, 12.0%), or both children and adults ($n = 36$, 27.1%). Participants described various types of communication and swallowing difficulties, including speech ($n = 80$, 60.2%), language ($n = 76$, 57.1%), feeding/dysphagia ($n = 30$, 22.6%), literacy ($n = 29$, 21.8%), complex communication needs (e.g. augmentative and alternative communication [AAC] needs, individuals with diagnosed disabilities; $n = 24$, 18.0%), pragmatics/social communication ($n = 14$, 10.5%), acquired communication difficulties (e.g. aphasia; $n = 12$, 9.0%), craniofacial abnormalities (e.g. cleft palate; $n = 7$, 5.3%), stuttering ($n = 6$, 4.5%), voice ($n = 6$, 4.5%), hearing ($n = 3$, 2.3%), and progressive/degenerative neurological conditions (e.g. motor neurone disease; $n = 1$, 0.8%). Some participants also described other domains (e.g. motor skills; $n = 14$, 10.5%) and oral structures (e.g. adenoids, tonsils; $n = 1$, 0.8%) that related to seeking speech-language pathology services.

Procedure

Prior to analysis, documents were screened for applicability for the present study (see Figure 1). The inclusion criteria were: (a) contained the terms *wait* and/or other terms related to waiting, such as *time*, *delay*, and *long*; (b) described the

⁴ Including not-for-profit services and non-government organisations.

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Australian context; and (c) was not a published study. Each document was searched for the term *wait* and related terms including *time*, *delay*, and *long*, using the Adobe PDF search tool (or manually for non-searchable PDFs). Searches yielded 146 relevant documents which were read in full by the first two authors. Data were extracted describing the reporter/source, document format, document focus (e.g. child or adult), location, frequency of key terms, and type of communication/swallowing difficulty, leading to the exclusion of 13 further documents. Subsequently, 133 documents describing waiting for speech-language pathology were included in this study. In the 133 documents, the word *wait* occurred a total of 446 times ($M = 3.4$, range = 0-22 per document). Forty-nine documents (36.8%) contained other terms related to *wait* in the context of service provision and access: *Time* occurred 92 times in total (e.g. timely, timeliness; $M = 1.9$, range = 0-9 per document), *long* occurred 48 times ($M = 1.0$, range = 0-7 per document), and *delay* occurred 21 times (e.g. delayed, delays; $M = 0.4$, range = 0-4 per document).

Insert Figure 1 here

Data analysis.

Inductive thematic analysis was conducted with the 133 documents following the procedure outlined in Braun and Clarke (2006). The first and second authors completed multiple readings of the documents and independently coded 10% ($n = 28$) of the documents to achieve consensus regarding an initial coding structure and themes and promote consistency or dependability of the findings (Baxter & Jack, 2008). The documents were imported into NVivo (QSR International Ltd, 2012) and meaning statements were coded into nodes by the first author. Additional nodes were created when content did not fit under existing nodes. Following coding, all nodes were grouped to form categories, themes, and subthemes by the first and second authors. The first author allowed time to elapse to distance herself from the data, then

reviewed, rearranged, and collapsed themes further to form three overarching categories in consultation with the second and third authors (see Table I). The credibility and dependability of the study were enhanced through inclusion of a positioning statement to situate the researchers, thick description when reporting results, triangulation of data sources (e.g., written documents from a range of stakeholders, including clients, parents, and SLPs), examining the findings in relation to existing literature, and obtaining consensus between authors during coding (McAllister & Lyons, 2019).

Situating the researchers.

The authors are Australian SLPs who focus on working with children, are employed in universities, and have experience conducting qualitative data analysis, specifically using inductive thematic analysis. The second author had previously worked with the same dataset to explore experiences of paediatric communication disorders (McCormack, Baker, & Crowe, 2018). The authors recognise the benefits of early intervention for children with communication difficulties and have an interest in waiting lists. They are motivated to improve access to speech-language pathology services for individuals with communication and swallowing difficulties as they feel the ability to communicate and participate in society is a basic human right (McLeod, 2018). The authors approached the present study with a view of wanting to understand the impact of waiting and issues faced by those seeking services, to advocate for access to speech-language pathology services for all.

Results

Analysis of content about waiting for speech-language pathology services contained in 133 submissions to the Senate Inquiry yielded 183 codes that were grouped into three categories, six themes, 14 subthemes, and 41 major points (Table I). Throughout the results section, original submission numbers have been retained

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and participants have been identified as consumers (C), professionals (P), researchers (R), or organisations (O). Use of capitals, punctuation, and terminology from the original submissions has been retained.

Insert Table I here

Duration

A common theme arising from participants' written accounts related to the duration of waiting for speech-language pathology services. Participants described waiting list magnitude, a mismatch between supply and demand, and an inability to access services.

Magnitude. Participants frequently described waiting list magnitude in terms of size and context, and different stages of waiting within and across speech-language pathology services. Waiting times were described as "huge" (14-C), "DISGUSTING" (28-P), "very long" (67-P), "extensive" (84-P), and "out of control" (145-C).

Participants often reported specific waiting times, including how "the waiting period for a child referred today who is still under 3 years of age is approximately ONE YEAR" (28-P). For individuals with complex communication needs, "waiting list times for specialist AAC services were reported to be up to two years" (128-O). A parent reported being told "it would be a six year wait" for outpatient speech-language pathology services for their child, which "would make him 16!" (145-C), while other school-aged children reportedly waited "up to eight years for a visiting service team" (266-O). Some participants reflected on the length of time they had waited and felt "the long wait was worth it" (45-C). "There was no waiting list" (260-P) for speech-language pathology for some, including a child with Down syndrome; however, this was not common among the documents analysed.

Participants described waiting for public, private, and specialist services, and made comparisons between service types. For instance, "waiting times may be quite

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short for private services, but considerably longer for community health services” (258-P) and participants “were so relieved and … amazed that the public health system was able to accept [name] before the private [service]” (14-C). Multiple stages of waiting were evident within services, including waiting “12 months for an assessment” and then “up to 2 years” to be “followed up” (218-P). Waiting across services was also apparent, where “some children remain on the community health speech pathology wait list until they begin school when they stop being eligible for service”, and then “go on a school waiting list if there is a speech pathology service available” (120-P). Relocating was another reason for waiting as when a child “finally made it to the top of the public waiting list … his family had moved to another area” and “he had to go on a list for another service” (224-P).

Supply and demand. Participants described the increasing demand for speech-language pathology services, and associated funding and workforce issues. Despite “documented evidence that the demand is increasing” (148-P) for speech-language pathology services, “shockingly, there have been no increases in staffing to meet this population explosion over the past forty years!” (59-P). The mismatch between supply and demand was reiterated by an SLP working in a community health centre who reported that “staffing numbers in this area have remained the same for the last TWENTY YEARS”, which was “unbelievable … considering the rapid growth of population in this area” (28-P). “Limited funding” coupled with “a significant increase in referrals in the past two years” led to “a waiting list…of around 5 months” (185-O) in a speech-language pathology clinic specialising in vocal gender affirmation for trans and gender diverse people. Obtaining “increased funding to meet these demands” was “difficult” (148-P) in speech-language pathology services. Participants highlighted SLP recruitment and retention issues, saying there was “too much red tape with the appointment of speech therapists, the ability to fund them and

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the ability to keep them” (106-C). Consequently, “the waiting list continues to build and build” (28-P).

Inability to access services. Participants described inequitable service access due to the location of clients and services, and service affordability. Individuals described travelling “large distances to seek specialist services” (128-O), such as for AAC, or having to “move to access the services … needed” since local services were “overloaded” (282-C). Waiting lists in rural and remote areas were reportedly “considerably greater than those in urban and metropolitan areas” (269-P). Technology such as telehealth was used in some instances to “improve timeliness of access to services” (265-O). A lack of service options was an issue, whereby private services became “the only option” for some due to the “long waiting period … to access public services” (224-O). Costs were “prohibitive” (104-O) and “something that was not affordable” (263-O) for many, which meant they were “worried for … 6 months wishing we could see someone but did not have the \$350 needed to get an assessment at a private speech therapist” (60-C). For one parent of a child with language difficulties “it felt as though salt was being rubbed into our wounds as despite being so desperate for help, it was unavailable either via the public or private systems” due to long waiting lists (14-C).

Consequences

Participants who waited for speech-language pathology services reportedly experienced far-reaching negative consequences. There were consequences for consumers, professionals, and society.

Consumer consequences.

Consequences for consumers included impacts on outcomes and intervention, and practical and psychological consequences. Clients, families, and carers were among the consumers who experienced negative consequences of waiting.

Impact on outcomes. The long-term global impact of waiting for services

was highlighted, including an “adverse impact on the person’s future outcomes”

(213-P). For many, “the waiting period meant that they had missed out on early

intervention services” (141-P). There were significant implications of delaying

intervention, as “every day that essential services are delayed is time that the child

can never recover” (123a-C) and “without early intervention the child’s development

may be compromised for a lifetime” (266-O). Participants also highlighted the

negative impact of waiting lists on academic and behavioural outcomes. Flow on

effects of communication difficulties persisting into school-age were described, as

waiting “up to 18 months for any intervention” through public services means that

children’s “inability to access the curriculum can manifest itself in inappropriate

behaviour as well as poor academic results” (99-P) and those who “missed out” on

services completely “are a nightmare for the school” (158-P). Participants described

long-term trajectories for these children, for instance, “without intervention, [name]

will continue to find himself in trouble at school, and sadly his path may well lead

into the juvenile justice system” (127-P). Waiting lists may impact the realisation of

the fundamental human right to communicate ideas, wants, and needs (McLeod,

2018), such as for adults with cognitive impairment where a “delay in assessment”

can impact “implementation of essential modifications to their support, to give

expression to their needs” (304-P). Extensive consequences of waiting lists were

reported for individuals who required AAC devices to participate in everyday life: “It

is essential that authorities understand that this is about having a voice and having

access to the ability to express wants, needs, thoughts and opinions – about having

access to life” (36-C). The same parent described waiting “over 12 months” for

speech-language pathology services for her nonverbal child, who went on to receive

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little support, which was equivalent to “saying to the child ‘Your voice doesn’t matter. It can wait’” (36-C).

Impact on intervention. Waiting for speech-language pathology services also impacted upon intervention, in terms of continuity of care, the perceived value of intervention, and increased intervention needs. “Extended periods on a waitlist” were reported to be “disruptive to a child’s therapeutic care” and have a negative impact on a “child’s perception of the value of therapeutic care” as well as “the family’s (and possibly teacher’s) commitment to participating in the therapy” (114-O). Participants described how difficulties “had worsened” (191-O) or become “embedded” (257-O) and “more entrenched” (59-P) while waiting, meaning “therapy is more difficult and takes longer using more resources” (158-P), “thus causing a further drain on services” (59-P).

Practical consequences. Practical consequences included the burden on consumers’ finances, physical health, and time. While some participants (e.g. 95-C; 134-O; 211-C; 224-O; 258-P) reported that private services had shorter waiting lists than public services, “the cost of therapy is extensive and can have major implications on an individual’s and a family’s financial situation” (269-O). An individual who experienced a stroke and received timely speech-language pathology services reflected on the stories of others who did have to wait for services, describing how “the economic impacts, both in terms of a significant delay or complete failure to return to work, and continued reliance on the public health purse, must be significant” (2-C). The detrimental effect of waiting on physical health and safety was also highlighted, including “serious health consequences” (176-P) or “major medical implications resulting from long waiting times” (269-O) for individuals with swallowing difficulties. Similarly, children who were “unable to access therapy for their feeding difficulties” were at risk of “poor weight gain,

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delayed feeding development and ... aspiration” (153-P). The burden of waiting lists on consumers’ time was also evident when participants spent “many wasted months chasing people” (179-C) while waiting to access services or, for an adult with a voice disorder, how waiting for funding approval and subsequent access to services was “time consuming and frustrating” (38-C).

Psychological consequences. There were also negative psychological impacts on consumers’ emotional wellbeing and relationships. Waiting for speech-language pathology was described as “stressful” (30-C) and “a time of great despair and frustration” (196-C) for consumers when they “were struggling and needed help” (103-C). Consumers felt “worried” and “concerned” while waiting, due to their child not having “enough time to adequately prepare for school” (87-O) for example. Lengthy waiting lists were reported to have potentially “devastating effects on a child’s speech development ... and their ability to interact and form relationships with peers” (176-P) as well as “increase the pressures on families” and have “significant” impacts on “family structure and cohesiveness” (114-P).

Professional consequences.

Consequences of waiting lists also extended to professionals. Participants described both practical and psychological consequences for professionals.

Practical consequences. Practical consequences for professionals included a reduced ability to deliver effective services. SLPs adopting a consultative role by providing therapy plans for non-SLPs to implement was reportedly “a threat to the effective application of ... speciality skills” which “significantly diminishes” the SLP role (49-O). Consequences extended to professionals from other disciplines, including paediatricians, as “delayed speech assessment and intervention often delays identification of wider difficulties and therefore delays more comprehensive intervention programs” (84-P). Doctors reported that “we can’t help the kids as we

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should” as “we consult, identify potential language problems, but there is little we can do with these” due to “completely inadequate” speech-language pathology services with long waiting lists (118-O). School staff reported “waiting for 12 months to receive some professional learning support” from an SLP “due to the heavy demands of her workload” (257-O).

Psychological consequences. Psychological consequences of waiting lists were also reported for professionals. Children waiting so long for services that they age-out and become ineligible for the service was considered a “shameful situation” and a “sad ‘Catch 22’” (118-O). The “stress it places on the health professionals” (146-P) was also highlighted, in particular on SLPs, with long waiting lists contributing to a “constant and overwhelming feeling of never being able to do quite enough ... that despite working hard, an effective and timely service is not being provided” (144-P). Waiting lists were reported to put “pressure” (49-R) on SLPs, be “detrimental to staff job satisfaction” (144-P), and contribute to “burn out” (28-P).

Societal consequences.

Consequences of waiting lists also existed for broader society. Practical consequences of waiting lists included a financial “drain on services” (59-P) in communities. Timely services on the other hand, reportedly could “reduce improper sentences that clog up our legal system” (26-P), “reduce the financial burden associated with youth justice supervision and incarceration” (26-P), and save “the community from dollars later on” (85-P). The social and ethical burden of waiting lists was also highlighted, with failure to provide timely services in the early years due to waiting lists described as “a tragedy for the child and the community”, where “the children, and ultimately the community, suffer and need not” (158-P). Provision of a limited service to clients as a waiting list management strategy was problematic

as “intensive client-specific interventions leads to better … society outcomes” (152-P).

Actions

Participants described actions taken to avoid or address the negative consequences of waiting for speech-language pathology services. Examples of both consumer actions and professional actions were reported.

Consumer actions.

Consumers were reported to seek alternatives to minimise waiting times or the negative consequences of waiting. Consumers also described instances of inaction, although this was not the experience of the majority of participants.

Seeking alternatives. Some consumers sought alternatives to waiting through accessing multiple services, advocacy, information seeking, and considering relocation. Parents described being on “several” (30-C) or “various” (14-C) waiting lists, at times with services located “all over” (14-C). Participants also utilised “the private system while waiting for service from public providers” (134-O) to “get things underway” (18-P). A parent described “after 9 months of paying privately, we finally were invited to participate in the public speech clinic” (95-C), but accessing private services was “quite expensive and something that was not affordable” (263-C) for some. Accessing a combination of services such as “private services … alongside attending a community communication program” (103-C) or community groups such as “play group” (18-C) were other strategies.

Consumers also described proactive or emotion-based advocacy strategies. Proactive strategies included making a “complaint” and “escalating it … up the chain of command” (14-C), “begging” (252-C), “pushing” (184-C), and “chasing referrals and assistance” (145-C). Emotion-based advocacy was evident when participants described having to emotionally “blow up” (224-P). The story of one parent of an

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infant with feeding difficulties also highlighted an extreme example of emotion-based advocacy: “The only reason we were able to access someone so quickly was because I was so desperate with his condition and not knowing what was wrong with him that I rolled up at Emergency [in the hospital] … and refused to leave until someone saw him” (263-C). The parent then reported “I actually had to say that I would harm him if he was not going to be seen because I was in a very dark and lonely space at that time trying to find out what was wrong with him” (263-C).

Consumers also conducted their own “considerable research” (167-C) to find information, leading some to become “acutely aware” (167-C) of the importance of early intervention. Others described realising that they “could no longer leave [name]’s future in the hands of the public health system” and “started to research for a solution and a strategy” (211-C). Instead of enduring a lengthy wait for services, consumers were “told to investigate other options” (145-C) for services by professionals due to lengthy waiting times at specialised speech-language pathology services; however, the reality was that services with long waiting lists were the “closest and only option” (145-C) for some.

Consumers also described relocating to another area. Waiting lists led some consumers to consider “moving the whole family to a capital city in an attempt to access services quicker” (167-C). A parent of a child with language difficulties who was moving to a different location described making “as many enquiries as I could prior to moving” (150-C) to allow “as much time to get on waiting lists as possible” (150-C) as they were aware of the long waiting times for speech-language pathology.

Other consumers described inaction while waiting, despite feeling that waiting lists were “unacceptable” (85-R). Having to “wait so long” left consumers wondering “what’s the point?” (143a-C). Some parents had “given up” (99-P, 125-P), which sometimes led to attrition from services. Instead of seeking services, consumers may

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“accept or accommodate a treatable developmental delay” (158-P). In situations where “waiting lists are too long” (99-P), some parents “have not followed up with recommendations from health professionals to have their child assessed by a Speech Pathologist” (99-P).

Professional actions

Professionals also reportedly undertook many actions to address the issue of waiting lists. Actions related to service delivery and workplace policies.

Service delivery. Participants described service delivery actions relating to service scope and options, services while waiting, professional efficiency, and conflict between evidence-based practice and reality. Actions relating to service scope and options to “decrease wait times” included utilising “a diverse range of service delivery approaches such as group therapy, paired therapy, whole class therapy and intensive therapy” (269-P). Other actions included “rules only allowing a ‘block’ of treatment at a time” (47-C) or “limiting the number of sessions children can receive” (59-P). Provision of indirect support was another strategy, including “teacher training” (224-O) and “parent education sessions” (134-P). A few participants described provision of services while waiting for speech-language pathology. Some participants reported receiving “advice about different strategies to try” (123a-P) while waiting, and others described a need to “build the capacity of primary care” to “provide early intervention recommendations for children while they wait for professional assessment and intervention” (118-O). Increasing professional efficiency was another response to waiting lists, involving “services trying to do more without any more resources” (148-P).

Conflict between evidence-based practice and reality was a source of tension. “Service pressures” (224-O) sometimes led to “compromised” (224-O) treatment protocols where SLPs responded “to the shortcomings of treatment services in

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unproductive ways ... by taking shortcuts” (188-R). Providing a “limited service” was reported to be “a so-called quick-fix, ‘band-aid for a broken arm’ type approach rather than a comprehensive and quality service” (152-P). Additionally, concerns were raised that “‘innovative’ models of service delivery” used to manage waiting times “may not be based on current evidence” (224-O) and are “not what families indicate they want/need” (148-P).

Policies. Policy responses to waiting lists related to service standards, prioritisation, and funding. There were reportedly “mounting pressures” for SLPs “to increase through-put and decrease waiting times by tightening eligibility criteria” (224-O). SLPs reportedly were “required to limit their service to specific age groups” (64-P) and “parents were angered that their children had become ineligible for public services at a certain age” (85-R), especially if “they had endured a long waiting list only to reach the upper limit of services soon after” (85-R). Discharge processes were implemented where individuals were “discharged despite continuing to have a communication impairment” (144-P) so SLPs could see other clients on the waiting list.

Participants described prioritisation policies based on client and service factors, which were examples of restrictions or limitations on services. With regards to client factors, many participants described prioritisation of services based on age. Prioritisation was favourable for some who felt “very lucky that [SLPs] see infant feeding issues as a priority, so we were seen quickly” (123a-C). SLPs were reported to “have to prioritise younger preschool children for intervention” (168-P) in some settings, whilst “waiting times can be extensive for older children ... who may have presented late or missed intervention when younger” (168-P). Prioritisation also occurred based on type and severity of difficulty, where “often only the most severe of cases receive direct speech pathology services” (176-P) and “children with non-

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complex speech and language difficulties can wait several years to be seen or worse yet are never seen” (49-P). Prioritisation according to risk was also described, where SLPs “had to prioritise cases where immediate action is required … usually, for cases where there is immediate risk to their health” (141-P). Prioritisation was also based on service type or role, for instance “many state government agencies have reduced time allocated” to community-based universal programs “due to the pressures of long therapy waiting lists” (104-O). Others described SLPs’ time being “heavily weighted towards assessment … which is time consuming, and often leaves little time for all important intervention at a one-to-one student level” (127-P).

Participants also described a reliance on government funded programs but acknowledged that they had “strict restrictions” (152-P). Existing funding models were reportedly “limited in … scope for making a difference for children who most often require more services than are allocated” (104-O).

Discussion

The present study explored experiences and perspectives of waiting for speech-language pathology services by analysing submissions to an Australian Government Senate Inquiry (Commonwealth of Australia, 2014). Consumers, professionals, and organisations contributed different perspectives to the discussion of waiting lists; however, overwhelmingly the negative consequences of waiting were far-reaching, leading many consumers and professionals to take action.

Duration

Participants in the present study reported variability in waiting times for services, ranging from no wait to waiting months or years, as well as waiting at multiple time points and across services. Waiting for health care has been previously reported to consist of discrete stages: (a) waiting for assessment, (b) waiting for diagnosis, and (c) waiting for intervention (Fogarty & Cronin, 2008). Although not

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the experience of all participants, waiting for assessment and waiting for intervention were commonly reported by participants in the present study, which is consistent with other Australian and international research (Dew et al., 2013; McGill, McLeod, Crowe, Hopf et al., 2019; O'Callaghan et al., 2005; Ruggero et al., 2012; Rvachew & Rafaat, 2014) and the findings of the Senate Inquiry report (Commonwealth of Australia, 2014). In a study by Ruggero et al. (2012), parents reported most often waiting 2-6 months for an initial assessment and 1 month for intervention for their child. SLPs reported a mean waiting time of 5.20 months (range = 0-20 months, $SD = 3.93$) for an initial assessment and 3.13 months (range = 0-22 months, $SD = 3.74$) for intervention for children in a study by McGill, McLeod, Crowe, Hopf et al. (2019). The long waiting times of up to eight years reported in the present study therefore appear to exceed the times reported in other studies. There are negative implications for extensive delays in receiving speech-language pathology intervention (Rvachew & Rafaat, 2014).

Waiting was raised more frequently as an issue in documents describing children or conditions with onset in childhood than in documents describing the experiences of adults requiring speech-language pathology services for acquired conditions. The discrepancy may reflect the often acute rather than developmental nature of conditions in adulthood, or prioritisation policies based on client safety risk; an important factor to consider in prioritisation due to the “medicolegal implications” (Kenny et al., 2010, p. 127). Such policies may mean individuals with more acute difficulties receive services sooner than individuals with chronic conditions. However, the overall terms of reference and issues explored in the Senate Inquiry may have been more relevant to childhood, not just the issue of waiting lists, or may reflect the level of importance to the respondents.

Difficulties obtaining funding and additional resources to meet the high demand for speech-language pathology services have been previously highlighted (Kenny & Lincoln, 2012), including difficulties recruiting and retaining enough SLPs to meet demand, particularly in rural areas (Dew et al., 2013), inequitable access to services and subsequent need to travel large distances to access services (Dew et al., 2013; I CAN & RCSLT, 2018; Verdon, Wilson, Smith-Tamaray, & McAllister, 2011), and affordability of private services (Dew et al., 2013).

Consequences

Negative consequences for consumers included potential lifelong impacts of missing out on early intervention or timely support, including being at risk of ending up in the justice system, consistent with literature highlighting the likely presence of severe language difficulties among adolescents in the youth justice system (Snow, 2019). Without timely intervention, children's speech and language difficulties may persist into adolescence and adulthood, potentially leading to long term detrimental impacts on the ability to build relationships, cope with stress, manage behaviour, and acquire and keep a job (Johnson et al., 2010; McCormack, McLeod, Harrison, & McAllister, 2010; Ruben, 2000). Cost-benefit analyses of speech-language pathology intervention indicate that the benefits of intervention exceed the costs to society (Burns, Wishart, Kularatna, & Ward, 2020; Law, Zeng, Lindsay, & Beecham, 2012; Marsh, Bertranou, Suominen, & Venkatachalam, 2010). Failure to receive timely treatment, or missing out on necessary services completely, therefore comes at a high cost to society, as recognised by participants in the present study.

Consequences were also reported for professionals and society, with professionals describing working hard and feeling stressed and overwhelmed about waiting lists. Doctors have similarly reported experiencing distress regarding waiting lists (Førde & Aasland, 2008). Community mental health nurses have reported that

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workload- and time-related issues, case overload, and poor resources are among the top five most stressful aspects of their work, and such stress can impact physical and mental health and reduce job satisfaction (Burnard, Edwards, Fothergill, Hannigan, & Coyle, 2000). McGill, McLeod, Crowe, and Hopf (2019) identified that SLPs experienced predominantly negative feelings about their waiting lists, including feeling stressed, frustrated, overwhelmed, and anxious. SLPs in other studies reported feeling stressed, overwhelmed, frustrated, fatigued, and disillusioned when managing significant caseload demands in under-resourced services, feelings which can negatively impact professionals' health, job satisfaction, retention in the workforce, and ability to deliver services effectively and provide best-practice care (Edgar & Rosa-Lugo, 2007; Heritage, Quail, & Cocks, 2019; Harris, Prater, Dyches, & Heath, 2009; McLaughlin, Lincoln, & Adamson, 2008). Whilst waiting lists were not specifically explored in these papers, they may be a contributing factor.

Actions

In line with the theory of preparative waiting (Giske & Gjengedal, 2007), waiting for speech-language pathology services was an active process for many consumers. Consumers reported researching options for services and placing themselves on more than one waiting list. Consumers sought alternatives through advocating and being on more than one waiting list (Dew et al., 2013) and searched for information on the internet (McAllister et al., 2011). Researching service options and early intervention may also be an example of "seeking and giving information", a strategy within the theory of preparative waiting (Giske & Gjengedal, 2007, p. 90). Evidence of passive waiting characterised by inaction was also apparent for some consumers, consistent with the experiences of some participants who had "given up" on services in a study by Dew et al. (2013, p. 1567). The examples of inaction

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identified in the present study may be examples of participants “balancing between hope and despair” (Giske & Gjengedal, 2007, p. 90).

Some professionals were reported to provide strategies and advice to consumers while they were waiting for speech-language pathology services for children. While parent-led interventions can improve children’s communication skills (Roberts & Kaiser, 2011), high dosages and direct parent training is recommended (Tosh, Arnott, & Scarinci, 2017). SLPs may be unable to provide the direct training needed for effective home programs to those on waiting lists, due to time and resource constraints and caseload demands.

Modifications to service delivery and policies in response to waiting lists were common among professionals. There were some areas of consensus among participants who were professionals regarding the actions undertaken to manage waiting lists, including prioritisation based on age, type and severity of difficulty, level of risk, and service type/role. However, many professionals experienced feelings of conflict when the actions were based on efficiency or resource constraints rather than evidence. Many of the approaches described did not appear to be effective long-term solutions for managing waiting lists and the consequences for participants who were consumers. Similarly, SLPs in another Australian study “demonstrated awareness that workplace policies and procedures were inconsistent with evidence-based practice guidelines and their metaphors portrayed frustration with second-best service delivery” (Kenny & Lincoln, 2012, p. 10). The implementation fidelity of intervention, or whether an intervention is delivered as originally intended, can impact intervention outcomes (McCormack et al., 2017). There is a risk of speech-language pathology intervention, and the profession, being considered ineffective if interventions are not delivered in an evidence-based manner.

Limitations

The findings of the present study are based on documents written by stakeholders who reflected on their experiences and perspectives. Relying on memory or knowledge of the outcome of the experience may have impacted the accuracy of participants' reports. However, the ability to provide a considered written response may have led to a richer and more reliable dataset. The participant sample was potentially biased toward more motivated individuals, those with vested interests, or those with negative experiences, who may have been more likely to make a submission. Additionally, the aim and scope of this study focused on experiences of *waiting* for speech-language pathology, as reflected in the document selection process, and the research team were motivated to advocate for improved access to speech-language pathology services. Negative perspectives and instances of long waiting times may therefore have been overrepresented in this study and not reflect the experiences of all participants. However, the findings regarding long waiting lists were consistent with one of three central themes that emerged from the Senate Inquiry report prepared by the Community Affairs References Committee: "the long waiting lists in the public system" (Commonwealth of Australia, 2014, p. 5). Additionally, the committee recommended a cost-benefit analysis of "the current level of funding for public speech pathology positions" which "should include: the impact on individuals of existing waiting lists" (Recommendation 9 of 10; Commonwealth of Australia, 2014, p. xiv). Although the data analysed in the present study was from 2014, waiting lists remain an ongoing issue of relevance in speech-language pathology (McGill, McLeod, Crowe, Hopf et al., 2019). Only sections of documents containing content about waiting for speech-language pathology were analysed thematically, with the aim of ensuring the findings related to the issue of interest (*waiting*) rather than content that was beyond the scope of the research.

However, this may not have captured the broader context of the documents, including issues relating to service provision and access more generally.

Future Directions

The present study highlighted the need for deeper exploration of the issues raised in an Australian Government Senate Inquiry (Commonwealth of Australia, 2014). Future research could focus on obtaining international perspectives and benchmarking about speech-language pathology waiting lists, exploring in more detail the actions SLPs and organisations undertake to manage waiting lists, and testing the effectiveness of these strategies. Ideally, the supply of speech-language pathology services would meet the demand. In the meantime, there is a need to evaluate SLPs' waiting list management strategies and the provision of support to consumers to encourage active waiting, to determine the effectiveness of these strategies and build the evidence-base in this area. Innovative system-level strategies may be needed to address waiting lists and minimise the consequences of waiting lists for consumers and professionals (Rvachew & Rafaat, 2014). Exploring ways of supporting professionals who are managing waiting lists may be beneficial, to enhance workforce retention, promote the provision of effective services, and avoid exacerbating the imbalance between supply and demand for services. Further advocacy by professional associations and consumer groups may be beneficial in lobbying governments to take action regarding speech-language pathology waiting lists to reduce waiting times and minimise the risk of negative consequences for consumers.

Conclusion

Tensions exist between what stakeholders feel is needed, what is available, and what is possible in relation to speech-language pathology services. Many consumers, professionals, and organisations described concerns and experiences

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regarding speech-language pathology waiting lists and services did not always meet stakeholders' needs. Consumers and professionals are at risk of negative consequences of waiting lists extending to many aspects of life. Some consumers reported engaging in (sometimes drastic) actions in response to waiting lists, which appeared ineffective at times. Further research is needed to explore possible ways to facilitate effective action by consumers, such as active waiting through provision of interim support. Professionals often responded to waiting lists with service delivery actions and policies, despite personal sacrifices and organisational demands. Many organisations appeared to lack effective system-wide strategies. Further exploration of speech-language pathology waiting list management strategies, stakeholder perspectives, and instances of timely service provision may identify effective solutions targeting the “tragedy” (158-P) of waiting lists. Until the supply of services meets demand, it is time to take action to reduce the potential physical, social, emotional, financial, and ethical burdens of waiting lists on individuals and society and enhance access to services for all who need them.

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Table I.

Categories, Themes, and Subthemes Identified in the Thematic Analysis

Category	Theme	Subtheme	Points
1. Duration	Waiting lists	Magnitude	Waiting list size Waiting list context Multiple stages of waiting
		Supply and demand	Increasing demand Funding SLP workforce size SLP recruitment and retention
		Inability to access services	Inequitable service provision
2. Consequences	Consumer consequences	Impact on outcomes	Global impact (e.g. on development) Participation in daily life Missing out on early intervention
		Impact on intervention	Continuity of care Perceived value of intervention Increased intervention needs
		Practical consequences	Financial Physical Time spent Commitment to intervention
		Psychological consequences	Relationships Emotional
	Professional consequences	Practical consequences	Ability to deliver effective services
		Psychological consequences	Emotional wellbeing Burn out
	Societal consequences	Practical consequences	Financial
		Social burden	Law and justice/legal system Health system Community capacity/participation
3. Actions	Consumer actions	Seeking alternatives	Accessing multiple services Advocacy Information seeking Relocation Inaction
	Professional actions	Service delivery	Service scope and options Services while waiting Professional efficiency Conflict between EBP and reality
	Policies		Service standards Prioritisation Funding models

SLP: Speech-language pathologist; EBP: Evidence-based practice.

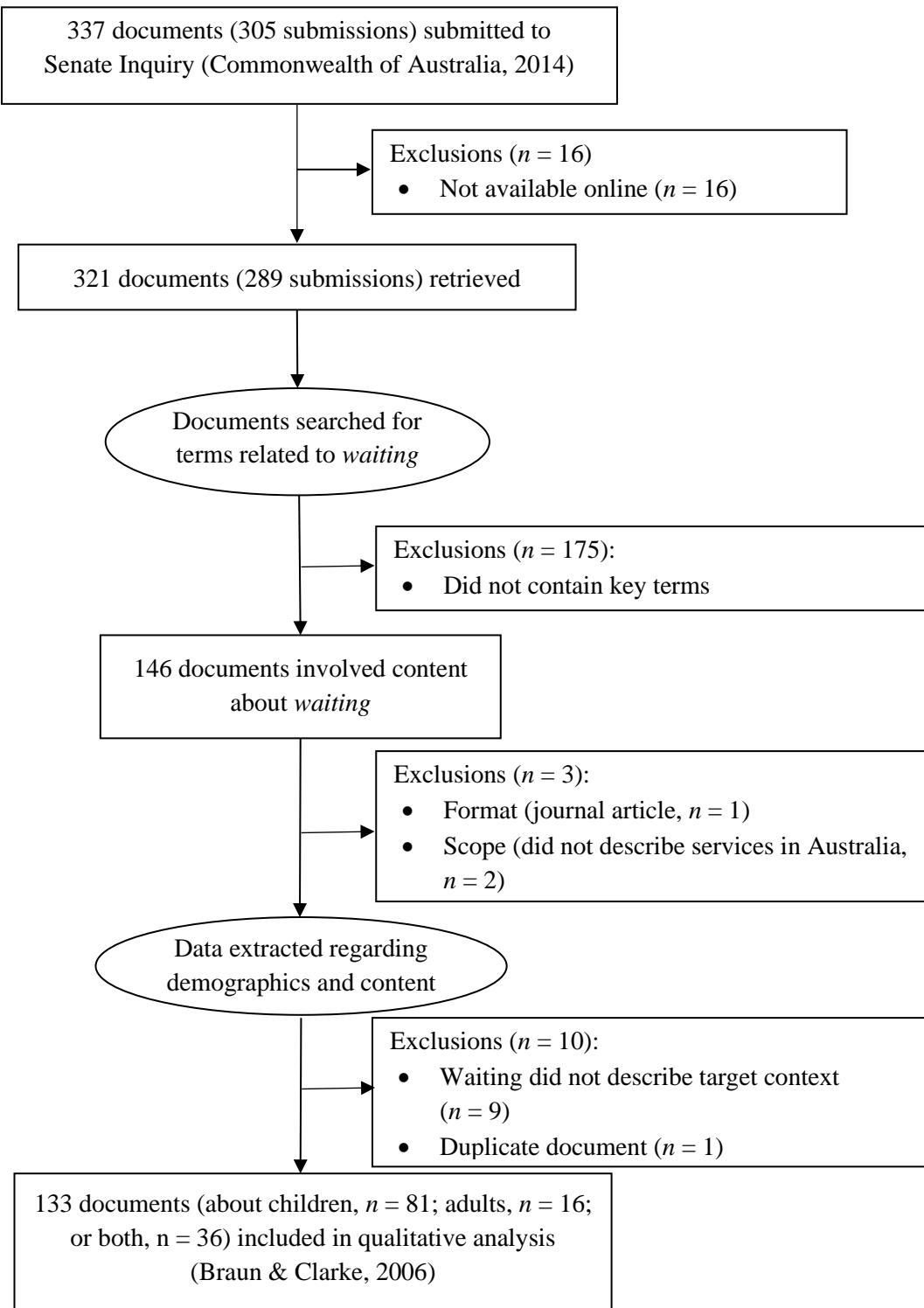


Figure 1. Document Selection Process for Thematic Analysis

Chapter 3: SLPs' Perspectives on Waiting Lists and Prioritization

Paper 2

McGill, N., McLeod, S., Crowe, K., Hopf, S. C., & Wang, C. (2019, August).

Waiting lists and prioritization of children for services: Speech-language pathologists' perspectives. *Manuscript in submission.*

Although Chapter 2 focused on the Australian context, the present chapter explores the issue of waiting lists throughout the world. Since waiting lists occur not only in Australia, it was important to expand the focus to an international context to develop a deeper understanding of the issue. Additionally, since this doctoral research sought to explore waiting list management practices and potential solutions for waiting lists, obtaining perspectives from SLPs internationally may highlight innovative ideas that could otherwise have been missed.

This manuscript was in submission to an international journal and undergoing peer review at the time of submission of the doctoral thesis. The manuscript was prepared using APA 6th edition and American English conventions as per the journal's author guidelines.

Waiting lists and prioritization of children for services: Speech-language pathologists' perspectives.

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Keywords: Waiting, children, service delivery, prioritization, speech-language pathology, caseload management

Running head: SLP waiting lists

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Declaration of Interest

There are no conflicts of interest to report.

Abstract

Background: Waiting lists occur when the availability of speech-language pathology services does not meet the demand. Speech-language pathologists (SLPs) commonly manage waiting lists and their consequences using prioritization.

Aims: The aims of this study were to: (1) describe speech-language pathology waiting lists for children and factors associated with their presence in workplaces throughout the world, and (2) describe factors considered in and influencing SLPs' prioritization of children for services.

Methods: A questionnaire about pediatric waiting lists and prioritization was completed by 267 SLPs from 10 countries working in health, disability, education, and private sectors. Valid responses to closed questions from 264 SLPs were analyzed quantitatively.

Results: Most (73.6%) SLPs reported having a waiting list in their workplace. Waiting lists were most common in community health centres (97.4%). Waiting times ranged from 0-42 months ($M = 8.09$, $SD = 5.84$). Priority was assigned to infants (77.4%), toddlers (65.3%), children with feeding difficulties (88.5%), and children who stutter (47.4%). Prioritization parameters ranked as most important were: severity ($M = 4.34$), availability of resources ($M = 4.11$), diagnosis ($M = 4.04$), and age ($M = 3.91$).

Conclusions: Many workplaces have long waiting lists for speech-language pathology services. Young children, feeding, and stuttering were most often considered high priority; however, prioritization can be complex, implicit, and influenced by external factors. Collaborative development of explicit, transparent waiting list and prioritization guidelines within workplaces, and the development and evaluation of active waiting strategies for children and families are recommended.

1. INTRODUCTION

When families are concerned about children's communication and feeding skills, timely speech-language pathology services should be available. Unfortunately, speech-language pathology services are often in high demand and the need far outweighs the resources that are available so children sometimes wait more than 12 months for support (Ruggero, McCabe, Ballard, & Munro, 2012). Lengthy waiting lists can prevent children from receiving timely specialized support and are challenging for speech-language pathologists (SLPs) to manage in their workplaces.

1.1. Waiting for Health Care

Waiting for health care refers to the time between identification of a health issue and its subsequent diagnosis and intervention (Fogarty & Cronin, 2008). Waiting may involve waiting for an assessment, a diagnosis, and intervention (Fogarty & Cronin, 2008), but audits and health service statistics rarely focus on all of these stages in the care pathway (Pope & Sykes, 2003). Although waiting can be passive, individuals waiting for health care may engage in active strategies such as information-seeking and researching service options while waiting (Giske & Gjengedal, 2007; McGill, Crowe, & McLeod, 2020).

1.1.1. Waiting list contexts

Waiting lists are common in countries where universal health care is provided and a finite amount of resources are distributed across large numbers of individuals in need, such as in the United Kingdom, Canada, and Australia. Shortages of SLPs and funded positions are reported in these and other countries, including the United States, impacting the provision of speech-language pathology services to those who need them (Edgar & Rosa-Lugo, 2007; McLaughlin, Lincoln, & Adamson, 2008; NHS England, 2019; Squires, 2013). Government legislation and funding regarding speech-language pathology services for children with disabilities varies between

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countries and workplace contexts, and there are also differences in the SLP workforce. In Australia, speech-language pathology services are provided within health, disability, and education sectors via public (government funded) and private organizations (SPA, 2015; SPA, n.d). There is a shortage of SLPs in Australia and recruitment and retention of skilled SLPs is an issue (McLaughlin, Lincoln, & Adamson, 2008). Over 10,000 SLPs are members of Speech Pathology Australia (SPA, 2020) with more than half working in private services and fewer SLPs working in schools (SPA, 2015). Despite some children and families having the ability to self-fund or access government funding for private services, where the largest proportion of SLPs are employed, waiting lists and limited SLPs or service options in their local areas can prevent access to services (McGill, Crowe, & McLeod, 2020). Long waiting lists for “free” (government funded) services can also prohibit timely access to support. In the United States, shortages of SLPs are also reported particularly in schools, despite the majority of the SLP workforce being employed in schools (American Speech-Language-Hearing Association [ASHA], 2019; Squires, 2013). SLPs also work in hospitals, private services, universities, and skilled nursing facilities (e.g., nursing homes, aged care services) (ASHA, 2019). Workforce shortages mean SLPs may have unmanageable caseloads, children’s needs may go unmet, or children may receive support from SLP assistants or less specialized staff (Squires, 2013). SLPs in the United States often discuss caseload size and shortages of SLPs rather than using the term “waiting lists”. In the United States, government legislation relating to children with disabilities including the Individuals With Disabilities Education Act [IDEA] (2004) mandates the amount and timing of speech-language pathology service provision. This is not the case in Australia, and children’s access to speech-language pathology support is inconsistent across the states and territories depending on state and federal legislation regarding children

with disabilities (Commonwealth of Australia, 2014; McLeod, Press, & Phelan, 2010). Current and exact figures for waiting list duration and frequency of occurrence are unavailable in either country.

1.1.2. Waiting list duration

Long waiting times and inequitable access to speech-language pathology services have been reported in Australian and international studies, with variation evident across geographical locations and service providers (Commonwealth of Australia, 2014; I CAN & RCSLT, 2010; McAllister, McCormack, McLeod, & Harrison, 2011; Ruggero et al., 2012; Rvachew & Rafaat, 2014). In Australia, children have been reported to commonly wait up to six months for an initial assessment, and then up to one month for intervention (Ruggero et al., 2012); however, some children have been reported to wait up to 8 years for services (McGill, Crowe et al., 2020). Long waiting times for developmental services are reportedly compounded when families have already waited to see a specialist such as a pediatrician (Feldman, Champagne, Korner-Bitensky, & Meshefedjian, 2002). Waiting times can also be cumulative if children wait at multiple stages within the care pathway between referral and receiving intervention (McGill & McLeod, 2020).

1.1.3. Consequences of waiting

Feelings of fear, stress, uncertainty, anger, and powerlessness can be experienced by individuals waiting for health care services (Rittenmeyer, Huffman, & Godfrey, 2012), including for speech-language pathology (Dew et al., 2013; McGill, Crowe et al., 2020), and medical procedures (Fogarty & Cronin, 2008; Giske & Gjengedal, 2007). Waiting lists extend the time children and families spend “getting in” to speech-language pathology services (Glogowska & Campbell, 2000, p. 397), which is problematic as research evidence is in favor of early intervention (Paul & Roth, 2011). For instance, children who do not commence intervention for their

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speech sound disorders until 4 to 5 years of age typically do not achieve normalized speech outcomes before school entry (Rvachew & Rafaat, 2014). Long waiting lists can deter families from seeking speech-language pathology services at all, lead families to seek private services rather than public services if waiting times are shorter, and dissuade professionals from referring children if they think it is unlikely they will receive intervention, highlighting how the perceived demand for services is not necessarily an accurate reflection of need and children may miss out on necessary support (Commonwealth of Australia, 2014; Keating, Syrmis, Hamilton, & McMahon, 1998). In the short term, these children may experience communication or feeding difficulties in childhood. However, it also means that they may carry unresolved difficulties and the consequences of these difficulties into adulthood (Johnson, Beitchman, & Brownlie, 2010). Caregivers' emotional wellbeing, time, and finances may be impacted by waiting lists, with caregivers reporting feelings of stress and despair, and paying high costs for private speech-language pathology services for their children while waiting for public services (McGill, Crowe et al., 2020). Waiting lists can also have negative consequences for professionals, including feelings of shame and worry, reduced job satisfaction, and increased risk of burnout, as well as social, economical, and ethical consequences for society (Kenny & Lincoln, 2012; McGill, Crowe et al., 2020; McGill, McLeod, Crowe, & Hopf, 2019).

1.2. Waiting List Management Strategies

While some health care waiting lists are managed in a centralized manner across regions (Sanmartin et al., 2000), speech-language pathology waiting lists are often managed within individual organizations. Many SLPs actively manage their own waiting lists. Existing strategies used by SLPs and organizations include restricting service provision by introducing session limits for intervention or tightening service eligibility criteria, offering group intervention instead of or to

supplement one-on-one intervention, and providing advice and home activities to families (McGill, Crowe et al., 2020; Pert, 2010). Another common strategy used to address demand is prioritizing children for services (Kenny & Lincoln, 2012; McCartney, 2000).

1.2.1. Prioritization of children for services.

Prioritization involves making judgements and decisions regarding the timing, amount, and type of intervention received in order to “ration” (Roulstone, 2007, p. 4) services in a fair and equitable manner based on client need (Pickstone, 2007). Decisions about prioritization occur across many levels of the health care system, filtering down from a national level to the professionals providing services (Roulstone, 2007). Since SLPs work in a range of workplace contexts operating within multifaceted systems and governance structures throughout the world, variation likely occurs in prioritization policies between countries and workplaces. Some SLPs may lack autonomy in making prioritization decisions, with decisions determined by management, their organizations, or government legislation.

Systematic, evidence-based guidelines exist regarding when to monitor and when to intervene with children with some sub-types of communication difficulty, such as speech sound disorders (Rvachew & Rafaat, 2014). However, for children with other types of communication needs, there are few areas of consensus and SLPs’ decision-making can be difficult, controversial, implicit, and lack transparency (Roulstone, 2007). SLPs may consider a range of parameters when making prioritization decisions, including child, SLP, system, or socio-political factors (Table 1), some of which are consistent with considerations by other allied health professionals (College of Occupational Therapists and the National Association of Paediatric Occupational Therapists, 2003). If viewed through the lens of the International Classification of Functioning, Disability and Health: Children and Youth version (ICF-CY, World

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Health Organization [WHO], 2007), the main focus of prioritization has been on Contextual Factors, such as Environmental Factors and Personal Factors, with some child factors also relating to Body Structures and Functions (WHO, 2007). Despite having the best interests of their clients in mind, the decision-making process can be challenging for professionals if they have incomplete information or there are time constraints, competing pressures within organizations, limited resources, and uncertain client outcomes or prognoses (McCartney, 2000; O'Sullivan, 1999; Pickstone, 2007). For example, it is challenging to predict which children's speech and language difficulties will spontaneously resolve and which children will have difficulties persisting through school and beyond (Law, Boyle, Harris, Harkness, & Nye, 2000; Morgan et al., 2017; Reilly, McKean, Morgan, & Wake, 2015; Roulstone, Miller, Wren, & Peters, 2009; Roulstone, Peters, Glogowska, & Enderby, 2003). Decision-making may also involve consideration of multiple prioritization parameters at a time on a case by case basis, requiring clinical expertise (McCartney, 2000). Therefore, prioritization decisions may be influenced by SLPs' level of experience. SLPs may face ethical dilemmas if decision-making is based on workload management principles rather than client needs or evidence-based practice (Kenny & Lincoln, 2012; Kenny, Lincoln, & Balandin, 2010).

Insert Table 1 here

1.2.1.1. Consequences of prioritization.

Prioritization decisions can negatively impact long-term health outcomes for clients (Kenny & Lincoln, 2012). Children considered to be high priority typically have shorter waiting times for speech-language pathology services, while those considered low priority wait longer until “their problems resolve without therapy”, their needs “become more pressing”, or “until more resources are available” (McCartney, 2000, p. 166). Prioritization of children for speech-language pathology

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services can have a positive impact if it means “the ‘right’ children . . . are selected for service” (McCartney, 2000, p. 169). The intention of this is that those children who *can* benefit from speech-language pathology input do receive services, and children who would *not* benefit do not receive services (McCartney, 2000). However, due to limited available services, the reality is that children who are considered lower priority may never receive speech-language pathology services, even though they may need them (McCartney, 2000).

Waiting lists are common and often seen as a “routine and normalized” part of the culture in contemporary health care services (Rittenmeyer et al., 2012, p. 194). Significant variability in waiting times have been reported across geographic locations and workplaces. To date, little research has been undertaken exploring the current state of speech-language pathology waiting lists and factors associated with their presence in workplaces. Whilst prioritization is a common waiting list management strategy, SLPs’ decision-making can be complex and implicit. The level of consensus among SLPs’ regarding prioritization of children across workplaces and important parameters to consider are currently unclear.

1.3. Research Aims

The focus of the present study was to explore SLPs’ practices and perspectives concerning waiting lists and prioritization of children for speech-language pathology services. Specifically, this study aimed to:

1. Describe speech-language pathology waiting lists (including waiting times and stages of waiting) for children and the factors associated with their presence in workplaces;
2. Describe factors considered in and influencing SLPs’ prioritization of children on speech-language pathology waiting lists.

2. METHODS

The research aims were addressed via quantitative analysis of questionnaire responses, providing an overview of perspectives regarding waiting lists and prioritization from a large sample of participants. Ethical approval for this study was obtained via the Charles Sturt University Human Research Ethics Committee (protocol number: H17181).

2.1. Participants

To qualify for this study, participants needed to be currently working, or have previously worked, with children as an SLP. Two-hundred and seventy-six SLPs responded to the questionnaire and consented to their results being analyzed. A total of 264 participants met the inclusion criterion and their responses were analyzed in the present study.

2.2. Instruments

A questionnaire was developed to obtain SLPs' perspectives regarding speech-language pathology waiting lists and waiting list management strategies including prioritization. Questionnaire items were informed by literature about waiting for health care (e.g., Fogarty & Cronin, 2008; Giske & Gjengedal, 2007, Glogowska & Campbell, 2000), and prioritization. The parameters for prioritizing children for health services that were identified through the literature search and used to create the questionnaire are presented in Table 1, along with the domains and ICF-CY components relevant to each prioritization parameter. Section 1 of the questionnaire focused on demographic information. In section 2, participants were asked to choose a workplace where they had recently worked with children in order to answer questions about waiting lists and prioritization. Closed questions related to demographics (e.g., where SLPs live and work), caseload size, waiting list duration, common care pathways for different client populations, and considerations for

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prioritization, and were the focus of the present paper. Participants were asked to assign levels of priority for client age groups (infants, <1 year; toddlers, 1-2 years; preschool, 3-5 years; primary school, 6-12 years; high school, 13-18 years) and subtypes of communication/swallowing difficulty (speech, language, literacy, stuttering/fluency, feeding/dysphagia, voice, hearing, augmentative and alternative communication [AAC]) relevant to their chosen workplace using a 3-point scale. For example, participants were asked to “Please indicate the priority rating for children in each age group at this workplace: 1 = *high priority*, 2 = *moderate priority*, 3 = *low priority*, N/A = *not applicable*”. Participants were also asked to rank prioritization parameters in order of importance in their workplace using a Likert scale (1 = *not important at all*, to 5 = *very important*). SLPs’ responses to open-ended questions ($n = 187$) within the same questionnaire were analyzed thematically and reported in McGill, McLeod et al. (2019). To collect data in a range of situations, both hard copy and online questionnaire formats were developed. The questionnaire was piloted with an independent paediatric SLP and members of the research team and revised. The online version included two additional closed questions relevant to the present paper and analysed quantitatively, exploring SLPs’ perceptions of the waiting list duration in their workplace (e.g., *much too long* to *about right*), and minor modifications to enhance the user experience (e.g., skip logic). The information sheet on page one of the online questionnaire advised participants not to complete the online version if they had previously completed a hard copy version.

2.3. Procedure

Participants were recruited via opportunity and snowball sampling using a two-stage approach as follows.

2.3.1. Stage 1: Hard copy questionnaire.

Stage 1 involved distribution of hard copy questionnaires at the 2018 Speech Pathology Australia National Conference. Questionnaires were placed on tables (with permission) within a session and attendees were invited to complete the questionnaires and leave them anonymously in a bag beside the door at the end of the session. Questionnaires were also provided to interested conference attendees at a poster presentation by the first author and respondents returned their completed questionnaires to a bag at the poster board. Hard copy questionnaire data were later manually entered into the online questionnaire form by a research assistant who was blinded to the aims of the study. The research assistant recorded ambiguous responses or responses which did not directly correspond with the online response options in a Microsoft Excel spreadsheet. After exporting the questionnaire data to SPSS (IBM, 2017), the first and second authors decided collaboratively how best to code ambiguous responses using a conservative approach, for instance, using a mid-point value if a range was provided.

2.3.2. Stage 2: Online questionnaire.

The online questionnaire was distributed via several methods to recruit participants online, including emails to the research team's professional networks, Speech Pathology Australia's e-News, social media (Twitter and Facebook), and word of mouth. Participants were encouraged to share the questionnaire URL with their own professional networks. Participants' responses were compiled by the online questionnaire software.

2.4. Data Analysis

Descriptive statistics were used to report frequency data on demographics, workplace context and location, caseload characteristics, SLPs' areas of expertise, and other variables to answer the research questions. Where possible, "other"

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responses were recoded into relevant existing categories. Due to the small number of respondents in university, research, and “other” contexts, those categories were removed from the parametric analysis involving workplace contexts. Parametric and non-parametric analyses were also used to address the research aims based on the level of measurement of variables.

To address the first research aim, chi-square tests for independence were conducted to explore the association between the presence of waiting lists and SLP workplace country and workplace context. An adjusted standardized residual value larger than $|2|$ indicates a particular cell contributes to the overall significance of the chi-square value. Analysis of variance (ANOVA) was used to examine differences in waiting times across workplace contexts, countries, and SLPs’ perceptions of waiting list duration.

To address the second research aim, ANOVA was used to examine differences across workplace contexts regarding SLPs’ ranking of prioritization parameters. Pearson’s correlation analyses were used to examine the relationships between SLPs’ ranking of prioritization parameters and their workplace country and years of experience. Comparisons between individual countries were not undertaken using ANOVA or Pearson’s correlation due to small sample sizes for countries other than Australia. Other countries were instead grouped to form a single category, meaning parametric analyses involving workplace country involved a dichotomous categorical variable (“Australia” (1) and “other countries” (0)). In cases where the homogeneity of variance assumption was violated, Welch’s F was used. Tukey’s post hoc was used when homogeneity of variance assumption was met, and Games-Howell post hoc was used when homogeneity of variance assumption was violated. P -values for multiple comparisons were not corrected due to the relatively low sample size in some categories and the increased risk of inflating Type II error.

3. RESULTS

Of the 264 participants who met the inclusion criterion, 78.4% ($n = 207$) completed an online version of the questionnaire, with the remainder completing a hard copy version. As the number of valid responses varied for each question due to missing data, throughout this paper both the number and percentage of respondents have been provided. The majority (97.3%, $n = 257$) of SLPs were females. The SLPs were from ten countries (Figure 1), predominantly Australia (70.8%, $n = 182$), the United States (14.4%, $n = 37$), and United Kingdom (5.8%, $n = 15$). Most SLPs spoke English at home (88.3%, $n = 233$). Other languages spoken were: Arabic, Assyrian, Cantonese, Dutch, French, German, Greek, Gujarati, Hakka, Icelandic, Korean, Malay, Mandarin, Spanish, Tagalog, and Tongan.

Insert Figure 1 here

On average, respondents had been working as SLPs for 11.66 years ($SD = 10.47$, range: 0.17 – 47.42 years) (valid responses $n = 263$). The highest level of education completed by the SLPs was a bachelor's degree (+/- honors; SLPs can practice with a bachelor's degree in some countries) (47.3%, $n = 125$), a master's degree (37.5%, $n = 99$), graduate diploma/certificate (7.2%, $n = 19$), PhD or PhD candidate (7.2%, $n = 19$), and other (0.8%, $n = 2$). Some SLPs reported having qualifications in addition to speech-language pathology (33.7%, $n = 89$), such as in the areas of education, science, and psychology. SLPs reported that they had worked in a range of workplace contexts (Figure 2), most commonly in education settings (61.0%, $n = 161$), community health centres (54.9%, $n = 145$), and private practices (54.5%, $n = 144$). All SLPs reported they had worked with children as SLPs since this was the inclusion criterion. Most SLPs reported they primarily worked with children (77.8%, $n = 203$), some reported working with both children and adults (20.7%, $n = 54$), and a small minority reported primarily working with adults (1.5%,

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$n = 4$). The SLPs reported working with infants (<1 year; 44.7%, $n = 118$), toddlers (1 to 2 years; 71.6%, $n = 189$), preschool-aged children (3 to 5 years; 89.4%, $n = 236$), primary school-aged children (6 to 12 years; 83.3%, $n = 220$), and high school students (13 to 18 years; 43.2%, $n = 114$). SLPs reported having expertise in a range of areas when working with children (Figure 3), most commonly developmental language disorders (73.5%, $n = 194$), speech sound disorders (73.1%, $n = 193$), and autism spectrum disorders (52.7%, $n = 139$). Some SLPs indicated that they had no speciality or primary area of expertise (8.7%, $n = 23$).

Insert Figures 2 and 3 here

SLP participants were asked to choose a current or former workplace in which they had recently worked with children to answer questions about waiting lists and prioritization. Since the number of valid responses varied for each question due to missing data, both the percentage and number of respondents have been provided in the results, enabling calculation of the valid responses for each question. SLPs most commonly based their answers on a workplace located in Australia (62.5%, $n = 125$), or another country (37.5%, $n = 75$), with the United States, United Kingdom, Canada, and New Zealand being the most common. SLPs were asked to identify the primary context/setting of their chosen workplace. The chosen workplaces were: education (schools and early childhood education centres; 19.9%, $n = 51$), community health centres (29.7%, $n = 76$), private practices (21.5%, $n = 55$), hospitals (11.3%, $n = 29$), disability/early intervention services (12.5%, $n = 32$), universities, (1.6%, $n = 4$), research (0.4%, $n = 1$), and other (3.1%, $n = 8$). SLPs were also asked to estimate the number of children on their caseloads. If SLPs provided a range (e.g., 30-40 children), the midpoint was used and, where possible, estimates for individual SLP caseloads only (not departments/services) were included in calculation of caseload

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size. The estimated number of children on the SLPs' caseloads ranged from 2 to 700 ($M = 60.18$, $SD = 73.12$) (valid responses $n = 210$).

3.1. Speech-Language Pathology Waiting Lists for Children

The majority of SLPs (73.6%, $n = 187$) reported having a waiting list in their chosen workplace. A chi-square test for independence result indicated that SLPs in Australian workplaces were more likely to say they had a waiting list (82.1%, $n = 101$), while SLPs in other countries were less likely to have a waiting list (66.7%, $n = 48$) ($\chi^2 (1) = 6.01$, $p = 0.014$). SLPs reported having waiting lists in a range of workplace contexts (Figure 4), most commonly in community health centres (97.4%, $n = 74$) and private practices (56.6%, $n = 30$). Some SLPs (75.0%, $n = 6$) listed "other" workplace contexts which were unable to be recoded into other categories. A chi-square test for independence was conducted to examine the relationship between workplace context and presence of a waiting list. The results from a chi-square test for independence indicated there was a significant association between workplace context and presence of a waiting list ($\chi^2 (4) = 42.71$, $p < 0.001$). Based on adjusted standardized residual values, three categories contributed to the significant association: community health centres, private practices, and education settings. Specifically, SLPs in community health contexts were more likely to say they had a waiting list, while SLPs in private practice and education settings were less likely to have a waiting list.

Insert Figure 4 here

Waiting list duration was also analyzed. When waiting times for *assessment* were combined with waiting times for *intervention* in individual workplaces, the waiting list duration from referral to commencing intervention ranged from 0-42 months ($M = 8.09$, $SD = 5.84$), where "0" reflected waiting times less than 1 month

(valid responses $n = 169$). Results regarding waiting for *assessment* and waiting for *intervention* have been reported separately, as follows.

3.1.1. Waiting lists for assessment.

Assessment waiting times were reported to range from 0-20 months ($M = 5.20$, $SD = 3.93$), where “0” reflected waiting times less than 1 month (valid responses $n = 166$). Mean waiting times for assessment (months) reported for each country are shown in Figure 5. ANOVA analyses were undertaken to examine differences in assessment waiting times across workplace countries, contexts, and SLPs’ perceptions of duration (Table 2). ANOVA results indicated that there was no significant difference in waiting time for assessment between Australia ($M = 5.17$ months) and other countries ($M = 5.69$ months), $F(1, 130) = 0.50, p = 0.48$ (valid responses = 132). ANOVA results also indicated there were no significant differences in waiting times for assessment between workplace contexts: education ($M = 6.25$ months), hospitals ($M = 5.78$ months), community health ($M = 5.61$ months), disability services ($M = 4.82$ months), and private practices ($M = 3.41$ months), $F(4, 151) = 2.11, p = 0.08$ (valid responses = 156). SLPs felt that the amount of time most children waited for an assessment in their workplace was “much too long” (31.6%, $n = 62$), followed by “slightly too long” (29.6%, $n = 58$), “about right” (34.7%, $n = 68$), “other” (2.0%, $n = 4$), or “not applicable” (2.0%, $n = 4$) (valid responses $n = 196$). ANOVA results indicated that there were significant differences in the actual waiting times for assessment across SLPs with different perceptions of waiting times. SLPs who perceived their *assessment* waiting lists to be “much too long” reported the longest waiting times ($M = 8.29$ months), followed by “slightly too long” ($M = 4.08$ months), and then “about right” ($M = 2.02$ months), Welch’s $F(2, 85.25) = 59.89, p < 0.001$.

Insert Figure 5 and Table 2 here

3.1.2. Waiting lists for intervention.

Intervention waiting times were reported to range from 0-22 months ($M = 3.13$, $SD = 3.74$), where “0” reflected waiting times less than 1 month (valid responses $n = 161$). Mean waiting times for intervention (months) reported for each country are shown in Figure 5. ANOVA analyses were undertaken to examine differences in intervention waiting times across workplace countries, contexts, and SLPs’ perceptions of duration (Table 2). ANOVA results indicated that there were no significant differences in waiting times for intervention between Australia ($M = 2.72$ months) and other countries ($M = 3.67$ months), $F (1, 127) = 2.05$, $p = 0.16$ (valid responses = 129). However, there were significant differences in waiting times for intervention between workplace contexts: education ($M = 3.35$ months), hospitals ($M = 4.52$ months), community health ($M = 3.10$ months), disability services ($M = 3.97$ months), and private practices ($M = 1.42$ months), Welch’s $F (4, 43.72) = 2.88$, $p = 0.03$ (valid responses = 150). The Games-Howell post hoc analysis showed that there was a marginally significant difference between private practices and community health centres, $p = 0.057$, with private practices reportedly having slightly shorter waiting times for intervention. SLPs felt that the amount of time most children in their workplace waited for intervention was “much too long” (41.8%, $n = 82$), followed by “slightly too long” (26.0%, $n = 51$), “about right” (26.0%, $n = 51$), “other” (3.1%, $n = 6$), or “not applicable” (3.1%, $n = 6$) (valid responses $n = 196$). ANOVA results indicated that there were significant differences in the actual waiting times for intervention across SLPs with different perceptions of waiting times. SLPs who perceived their *intervention* waiting lists to be “much too long” reported the longest waiting time ($M = 4.63$ months), followed by “slightly too long” ($M = 1.93$ months), and “about right” ($M = 1.09$ months), Welch’s $F (2, 79.95) = 20.40$, $p < 0.001$.

3.2. Speech-Language Pathology Care Pathways

SLPs were provided with five potential pathways that children may follow from *referral to therapy* in speech-language pathology workplaces (Table 3) and were asked to identify the pathway that “best represents the most common process” children follow in their workplace overall, then which pathway was followed by different client populations. The most common pathway overall involved waiting for assessment only, with most children reported to follow the referral → *wait* → assessment → therapy pathway ($n = 67$, 33.8%). Waiting for assessment was the most common stage of waiting overall from the options provided ($n = 94$, 47.5%); referral → *wait* → assessment → therapy, referral → *wait* → assessment → *wait* → therapy). SLPs reported that children with feeding difficulties (61.1%, $n = 44$) and children who stutter (26.7%, $n = 20$) most commonly received speech-language pathology services without waiting (referral → assessment → therapy). Infants and toddlers were the most common age groups to receive services without waiting in speech-language pathology workplaces (referral → assessment → therapy). The pathways followed by children of other ages and sub-types of communication difficulty were more varied across speech-language pathology workplaces. Some SLPs also described alternative pathways for children in their workplaces, for example, pathways involving additional stages (e.g., referral → face-to-face intake/screening → parent strategies → triage → *wait* → assessment → therapy) or not including intervention (e.g., referral → *wait* → assessment/advice → referral/discharge).

Insert Table 3 here

3.3. Prioritization of Children on Speech-Language Pathology Waiting Lists

The majority of SLPs (63.5%, $n = 146$) reported that children were prioritized for speech-language pathology services in their chosen workplace. However, many

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SLPs with valid responses (62.1%, $n = 128$) reported that there were no triaging or priority ranking systems for children in their workplace. For those who had a ranking system, systems often involved point allocations or color coding regarding level of urgency or risk. Many SLPs with valid responses (63.4%, $n = 113$) indicated that prioritization in their chosen workplace was influenced by external factors (e.g., management, limited staffing, organizational policies, funding). SLPs were asked to assign a level of priority (*high, moderate, low*) for different client populations (Table 4). SLPs most commonly rated children with feeding difficulties (88.5%, $n = 85$) and children who stutter (47.4%, $n = 46$) as high priority. Moderate priority was most often assigned to children with speech (52.5%, $n = 52$), language (52.5%, $n = 53$), and literacy (46.5%, $n = 40$) difficulties. SLPs most frequently rated children with voice difficulties as low priority (43.0%, $n = 34$). Regarding age groups, SLPs most often rated infants (77.4%, $n = 48$), toddlers (65.3%, $n = 47$), and preschool-aged children (46.4%, $n = 39$) as high priority. Primary-school aged (43.0%, $n = 34$) and high-school aged populations (55.3%, $n = 26$) were most frequently rated low priority.

Insert Table 4 here

The SLPs were asked to rate 17 parameters according to level of importance when prioritizing children for assessment and/or intervention in their chosen workplace (1 = *not at all important* to 5 = *very important*). Mean scores for each parameter were calculated out of a possible total of 5 and are reported in Table 1. There were between 142 and 178 valid responses for each parameter (not applicable responses were considered missing data for the analyses). SLPs ranked severity ($M = 4.34$ out of 5), availability of resources (e.g., funding, staff; 4.11), diagnosis (4.04), and age (3.91) as the most important parameters in prioritization of children in their workplace.

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The following factors potentially influencing SLPs' ranking of prioritization parameters were examined: years of experience as an SLP, workplace country, and workplace context (Table 5). Results of a correlational analysis indicated that SLPs with more years of experience considered the following parameters to be of higher importance in prioritization than SLPs with fewer years of experience: age ($r = .154$), the communication environment ($r = .169$), readiness for intervention ($r = .169$), efficacy of interventions for communication difficulties ($r = .176$), personal preferences of the SLP ($r = .188$), ethics of the organization ($r = .183$), personal ethical values ($r = .307$), and health care standards ($r = .184$). Correlational analysis of the relationship between level of importance of prioritization parameter and workplace country indicated that SLPs in other countries rated parental pressure as a more important parameter to consider in prioritization than SLPs in Australia ($r = -.250$).

Insert Table 5 here

ANOVA analysis indicated that there were significant differences across workplace contexts regarding the level of importance of the following parameters: personal preferences of the SLP ($p = .039$), triaging systems in the workplace ($p = .021$), and health care standards ($p = .004$) (Table 5). The Tukey post hoc analysis showed that SLPs in private practices rated personal preferences of the SLP as more important in prioritization than SLPs in community health centres. SLPs in community health centres and private practices considered health care standards to be a more important prioritization parameter than SLPs in education settings.

4. DISCUSSION

The present study involved a quantitative analysis of SLPs' questionnaire responses to describe speech-language pathology waiting lists, factors associated with their presence in workplaces, and SLPs' prioritization of children for services.

4.1. Speech-Language Pathology Waiting Lists for Children

SLPs in Australian workplaces were more likely to have waiting lists than SLPs in other countries; however, there were no significant differences in waiting time for assessment or intervention between workplaces in Australia and in other countries. Waiting times for assessment ($M = 5.20$ months, range = 0-20 months) and intervention ($M = 3.13$ months, range = 0-22 months) were reported in speech-language pathology workplaces, which indicated waiting times of less than 1 month in some workplaces. Waiting times were similar to those reported by Ruggero et al. (2012), who identified waiting times ranging from less than one week to longer than 12 months. According to SLPs' perceptions, the mean waiting times in the present study exceeded the acceptable waiting times for assessment (*about right*, $M = 2.02$ months) and intervention (*about right*, $M = 1.09$ months). Similarly, a survey of Australian SLPs found that waiting times of less than 2 months following children's referral to a service were considered acceptable by SLPs, with longer waiting times considered unacceptable (Lyndon, 1997). These perspectives were mirrored by parents in a survey study, most of whom considered 1-2 months' wait for services to be appropriate/acceptable, whereas a 3-6 month wait was "unacceptable" for most parents (Keen, 1999, p. 15). Overall, SLPs in the present study most often perceived the waiting lists for both assessment and intervention to be "much too long" in their workplaces which may reflect the significant and widespread nature of long waiting lists as well as SLPs' professional ethics and duty of care toward their clients. Subsequently, there may be conflict for SLPs between expectations and reality in their workplaces. Similar conflicts exist for parents, for instance, Ruggero et al. (2012) found that long waiting times between assessment and intervention were associated with higher parent dissatisfaction. Long delays in receiving speech-language pathology services can prevent children from accessing early intervention

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and have negative consequences for the wellbeing and outcomes of children, their families, and their SLPs (Johnson et al., 2010; Kenny & Lincoln, 2012; Kenny et al., 2010; McGill, Crowe et al., 2020; Ruggero et al., 2012; Rvachew & Rafaat, 2014).

However, children were reported to receive services in a timely manner in some workplaces, which is encouraging. Waiting times for intervention were marginally longer in community health centres than private practices, with SLPs in community health centres most likely to report having a waiting list. Ruggero et al. (2012) similarly reported that the largest proportion of children who waited over 12 months (or were still waiting) were at community health centres. In countries such as Australia, community health centres often provide “free” (government funded) services, contributing to the high demand, as opposed to fee-for-service organizations such as private practices which are not affordable or accessible for all who require speech-language pathology support (McGill, Crowe et al., 2020).

4.2. Speech-Language Pathology Care Pathways

SLPs in the present study reported that children often waited for a speech-language pathology assessment, and most commonly followed the referral → *wait* → assessment → therapy pathway. Waiting for assessment is problematic as it can impact the accuracy of prioritization and, subsequently, children’s outcomes since some high priority risk factors may not be identified until an assessment has been completed (e.g., family history, comorbid conditions, impact of communication difficulties on children’s activities and participation) (Rvachew & Rafaat, 2014).

Younger children and children with feeding difficulties or stuttering most often followed the streamlined referral → assessment → therapy pathway without waiting, which may reflect prioritization policies within workplaces based on level of urgency or risk (Ward et al., 1990). Feeding and stuttering may be more easily identified from referral documentation, allowing earlier identification of these children to direct them

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to this pathway. Despite areas of consensus, SLPs' responses also indicated that children of all client populations specified may follow any of the five pathways from referral to intervention, or multiple variations of the pathways, depending on the workplace. The variability may reflect the broad range of workplace contexts included in the sample, across which a one-size-fits-all pathway is unlikely to be appropriate or realistic, and the general nature of the question seeking an overall response was unlikely to capture individual client differences within categories. It may also highlight the complexity and multiple layers of decision-making for SLPs, including the potential consideration of other factors not captured in the present study.

4.3. Prioritization of Children on Speech-Language Pathology Waiting Lists

Priority systems and explicit guidelines can enhance consistency and accountability, and reduce subjectivity among SLPs' prioritization decisions (Kot & Hanchet, 1998; Rice, 1998). However, most SLPs (62.1%) reported having no explicit systems in place for triage or prioritization of children in their workplaces (e.g., ranking systems), which may reflect a more implicit process, and many (63.4%) SLPs indicated that their prioritization decisions were influenced by factors external to them (e.g., management, staffing, funding, organizational policies). The need to balance these external influences with evidence-based practice principles in SLPs' decision-making is consistent with the ethical dilemmas and challenges in clinical practice described in other research (McGill, Crowe et al., 2020; McGill, McLeod et al., 2019).

Areas of consensus existed among SLPs regarding prioritization for speech-language pathology services; for instance, young children and children with difficulties considered high safety risk (e.g., feeding) or requiring urgent input for a positive outcome (e.g., stuttering) were most often considered high priority. Children

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possessing these characteristics also most often followed a service pathway involving provision of immediate services without waiting (referral → assessment → therapy).

Considering feeding and stuttering as high priority is consistent with some existing prioritization guidelines where individuals considered high priority for health care can include those who: are a “risk to their own safety or the safety of others” (p. 3) and require an immediate response from a service to fulfil duty of care; have complex care needs requiring coordinated or multidisciplinary management; or are from vulnerable populations (e.g., people who are homeless) (Victorian Government Department of Health, 2009). Client safety is considered an “important determiner of priority” in speech-language pathology due to associated “medicolegal implications” (Kenny et al., 2010, p. 127). Out of 24 criteria identified by SLPs in the United Kingdom, prevention of harm and intervention urgency were two criteria considered “relatively more important” in prioritization (Rice, 1998, p. 92). In contrast, older children and children with speech, language, literacy, and voice difficulties, were considered lower priority for services. Although not necessarily a safety risk, waiting lists can have negative psychological and physical consequences for these children and those who live with and support them (Johnson et al., 2010; McGill, Crowe et al., 2020).

There were also other areas of consensus among SLPs regarding prioritization parameters considered important in speech-language pathology workplaces. Resource availability (e.g., funding, staffing) reportedly influenced SLPs’ prioritization decisions more than many child-related factors including diagnosis, age, prognosis, and readiness for therapy, as well as health care standards and ethical values. Waiting lists exist when there is a discrepancy between supply and demand for resources, often leading to a need to prioritize the available services, so the relative importance of resource availability in this process likely reflects this (McCartney, 2000). SLPs’

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ideas for managing waiting lists commonly related to funding and the SLP workforce, indicating resource availability is a significant issue (McGill, McLeod et al., 2019).

Overall, SLPs considered all 17 of the prioritization parameters included in the questionnaire to be of some importance in their workplaces, highlighting the complex, multifactorial nature of SLPs' decision-making. The prioritization parameters were consistent with many of those used by health professionals identified in previous literature (Table 1), indicating that they remain relevant in current practice. It appears that little has changed over the past three decades regarding prioritization parameters, with the focus predominantly on Contextual Factors (WHO, 2007). Given the potential negative consequences of waiting lists for children and families, adopting more holistic approaches to prioritization and service provision may be beneficial, including greater consideration of children's participation in daily life activities and interactions (Activities and Participation) and the needs of significant others around the child (Environmental Factors) (WHO, 2007). More experienced SLPs considered parameters such as personal ethical values, personal preferences, and organizational ethics to be more important than less experienced SLPs did. Professionals' world views are reported to influence their practice over time as they "establish identities in the workplace" (Kenny et al., 2010, p. 128), possibly contributing to the greater value placed upon personal ethics and preferences in decision-making (Cusick, 2001; Kenny et al., 2010). The complex interaction of parameters in decision-making reportedly demands "clinical skill and experience" (McCartney, 2000, p. 170) and SLPs with fewer years of experience have been reported to focus more on following rules, and minimising conflict and legal ramifications (Kenny et al., 2007). Additionally, SLPs in private practices considered personal preferences to be more important in prioritization, compared with SLPs in community health centres. Private practices can develop specialities and may allow

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for more flexibility or autonomy regarding caseloads, professional development, and workplace processes than publicly-funded organizations delivering universal health care, which may be bound by specific policies, procedures, and funding constraints. However, the need for SLPs to integrate all four sources of information and evidence in their clinical decision-making remains, including consideration of systematic research, the SLPs' clinical expertise, the clients' values and preferences, and the practice context (e.g., workplace context) (Hoffman, Bennett, & Del Mar, 2013), while avoiding overemphasis on their personal preferences.

4.4. Limitations

Despite attempts to recruit a diverse sample, significantly more participants were from Australia than other countries. These other countries were grouped together to form a single category during statistical analyses due to sample sizes. Legislations or standards regarding waiting times and provision of services vary across geographical locations (cf. Rvachew & Rafaat, 2014), so it is possible that some differences between countries were masked. The data did not allow for direct comparison between countries but the knowledge gained from this study may be relevant to speech-language pathology policy and practice in other countries. Some of the groupings of workplace contexts may have masked waiting list differences relating to funding. For instance, education or disability services may have public or private funding streams which impacted the ability to make direct comparisons between contexts. Multiple comparisons were conducted during the analyses which may have increased risk of type I error. However, given the small sample sizes in some categories and the exploratory, innovative nature of this study, correction of *p*-values was not undertaken due to the increased risk of type II error. Future studies are encouraged to validate the findings of the present study.

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SLPs with long waiting lists or higher levels of concern or interest regarding waiting lists may have been more likely to respond to the questionnaire; therefore, the findings of this study may not reflect the views of all SLPs or the situation in all workplaces. Additionally, SLPs were asked to refer to a workplace they had “recently worked in” with children when completing section 2 of the questionnaire. Some SLPs may have answered the questions about a chosen workplace from the past, possibly impacting immediacy of the results. However, the questionnaire enabled a broad range of valuable perspectives from SLPs to be obtained. The online version of the questionnaire contained two additional closed questions compared with the hard copy version, leading to a reduced number of responses for the added questions. However, the additional questions provided insights into SLPs’ perceptions of their waiting list duration which would otherwise have been missed. Since more participants completed the questionnaire online than on a hard copy, perspectives were obtained from the majority of participants. Some questions regarding prioritization included predetermined categories (e.g., age groups) for SLPs to rank in priority order, which aimed to simplify a complex process and provide general insights. The influence of co-morbidities and prioritization parameters on SLPs’ rankings was unable to be determined. Finally, not all prioritization parameters were explored in this study (e.g., predictors relating to children’s speech; Morgan et al., 2017).

4.5. Future Directions

Deciding which children will or will not receive rations of the limited speech-language pathology services available is a complex process and variation between workplaces and professionals is natural. The importance placed on prioritization parameters in the present study likely reflects SLPs’ workplace policies and current practice, influenced by social, economical, and political factors (Rice, 1998). What remains unclear following this study, is how SLPs want or feel they *should* prioritize

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services, how the pathways and prioritization parameters from the present study interrelate, how the parameters are integrated with evidence to make decisions, and which methods of prioritization are most effective. Further research into the complexities of prioritization and decision-making, such as via focus groups, may provide a more detailed understanding of these conflicts and challenges. The present study is unique in its description of waiting lists and prioritization in Australia and other countries. Replication of the present study with larger numbers of SLPs throughout the world may provide a deeper understanding of waiting lists and prioritization, enabling a more nuanced discussion of workplace contexts and the implications for policy and practice within those contexts.

The prioritization parameters identified in Table 1 and SLPs' views regarding their importance may prompt SLPs to reflect on the appropriateness of and evidence for prioritization policies in their workplaces, make implicit processes more explicit, and consider incorporating more holistic prioritization parameters in decision-making. Without imposing a one-size-fits-all approach, explicit and agreed-upon prioritization guidelines and care pathways developed collaboratively in workplaces between SLPs, managers, and other stakeholders may: help support and justify SLPs' difficult clinical decisions; promote proactive rather than reactive decision-making; clarify service expectations for consumers, organizations, and professionals; and reduce the influence of external factors (Kot & Hanchet, 1998; McCartney, 2000; Rice, 1998). Further research exploring the natural history of communication difficulties (cf. Law et al., 2000) may be beneficial to build evidence regarding which children have the ability to benefit most from services, to inform prioritization decisions, service provision, and allocation, and guide referrers regarding appropriate and timely referrals.

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SLPs and organizations may consider the waiting times reported in the present paper in relation to the waiting times in their own services. McGill and McLeod (2020) provide recommendations for mapping care pathways from referral to discharge and documenting waiting times at each stage in order to: highlight inefficiencies and hidden waiting times, enable targeted selection and implementation of waiting list management strategies, and provide benchmarks for measuring change over time. Benchmarking of waiting times across services may also assist with transparency and promote more consistent and timely access to speech-language pathology (Rvachew et al., 2014). If the risks to children of waiting longer than recommended can be made explicit, this may assist SLPs, consumers, and other stakeholders to advocate for more timely speech-language pathology services (Rvachew et al., 2014). Until the availability of speech-language pathology services meets demand, innovative service delivery options may be needed to reimagine service provision (e.g., telehealth; use of non-SLPs to supplement services, such as SLP assistants). Developing and evaluating ways to best support children and families on waiting lists in the interim may be beneficial, such as promoting active waiting through use of technology (McLeod et al., 2020; McGill & McLeod, 2019). Decisions should be guided by the integration of evidence from literature, clinical expertise, and client preferences, not just efficiency or resourcing reasons imposed by constraints within the workplace (Hoffman, Bennett, & Del Mar, 2013; McGill & McLeod, 2020).

5. CONCLUSION

Waiting lists for speech-language pathology varied in duration across workplaces from 0 to 42 months, often exceeding waiting times considered acceptable by SLPs and highlighting a mismatch between supply and demand for services. Waiting occurred at different stages within services, with children reported

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to most often wait for assessment, which has implications for the accuracy and fairness of prioritization since some risk factors are identified following assessment. Areas of consensus existed, with young children, feeding, and stuttering most often considered high priority by SLPs. Severity, resource availability, and diagnosis were considered most important in prioritization, irrespective of SLPs' level of experience or workplace context. However, up to 17 prioritization parameters and external factors (e.g., funding, management) may be considered in decision-making, highlighting the complexity of prioritization and inherent variation between SLPs and workplaces. Given the potential negative consequences of waiting lists for children and families, action is needed to address the issue of waiting lists and reimagine service provision. Increased transparency and collaboration among stakeholders to develop explicit, holistic waiting list and prioritization guidelines is recommended and may promote greater consistency, accountability, fairness, and timeliness of services in speech-language pathology workplaces. Until provision of speech-language pathology services meets demand, the development and evaluation of strategies promoting active waiting for speech-language pathology should be a priority.

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Table 1.

Parameters for Prioritizing Children for Services

Overarching domain	Prioritization parameter	SLP-rated level of importance (M out of 5)	Additional references	Relevant ICF-CY component^a
Child factors	Severity of difficulty	4.34	Lindsay (2007); McCartney (2000); Roulstone (1995)	Body Structures and Functions
	Diagnosis	4.04	Kenny & Lincoln (2012); McCartney (2000); Morgan et al. (2017); Pickstone (2007); RCSLT (1996)	Body Structures and Functions
	Prognosis	3.61		
	Expected permanency or chronicity of difficulties	3.44		
	Age	3.91	Kenny & Lincoln (2012); Lindsay (2007); McCartney (2000); Ward et al. (1990)	Personal Factors
	Efficacy of interventions for particular difficulties	3.51	Lindsay (1997); Ward et al. (1990)	Environmental Factors
	Readiness for intervention/child motivation	3.50	McCartney (2000); Pickstone (1997); Roulstone (1995); Sisson et al. (1994)	Personal Factors
	Communication environment of the child	3.30	McCartney (2000); Roulstone (1995); RCSLT (1996)	Environmental Factors
SLP factors	Risk of difficulties worsening ^b		Ward et al. (1990)	Body Structures and Functions
	Need for SLPs' specific techniques or training	3.39	McCartney (2000); Sisson, Irving, & Walton (1994)	Activities and Participation, Environmental Factors
	Personal ethical values, attitudes, and beliefs	3.38	Lindsay (1997); Petheram & Roulstone (1997)	Personal Factors
	Personal skills of SLPs	3.08	Lindsay (1997)	Personal Factors

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	Personal preferences of SLPs	2.10	Lindsay (1997)	Personal Factors
System factors	Availability of resources	4.11	Lindsay (2007)	Environmental Factors
	Triaging systems	3.48	Pickstone (2007)	Environmental Factors
	Child based work versus systems work (e.g., in-service education programs)	^b	Lindsay (2007)	Environmental Factors
Sociopolitical context	Health care standards	3.79	Lindsay (2007)	Environmental Factors
	Ethics of the organization or service	3.73	Lindsay (2007)	Environmental Factors
	Parental pressure	2.85	Lindsay (2007); Ward et al. (1990)	Environmental Factors, Personal Factors
	Government or media interest in particular cases or communication difficulties	^b	Lindsay (2007)	Environmental Factors
	Organizational interests	^b	Lindsay (2007)	Environmental Factors
	Anticipated level of parental involvement	^b	Ward et al. (1990)	Activities and Participation, Environmental Factors
	Urgency (e.g., if assessment results are needed for diagnostic processes or funding applications)	^b	Ward et al. (1990)	Environmental Factors

Note. Adapted from Lindsay (2007) and McCartney (2000). ICF-CY, International Classification of Functioning, Disability and Health: Children and Youth version; SLP, speech-language pathologist.

^aWorld Health Organization [WHO] (2007).

^bNo mean score calculated as parameter was not included in the questionnaire.

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Table 2.

Differences in Waiting Times across Workplace Countries, Contexts, and SLPs.

	Workplace country			Workplace context			SLPs' perceptions		
	F	p	Valid n	F	p	Valid n	F	p	Valid n
Waiting time for assessment (months)	.50	.48	132	2.11	.08	156	59.89	<.001	196
Waiting time for intervention (months)	2.05	.16	129	2.88	.03	150	20.40	<.001	196

Note. Bold font indicates statistically significant values.

Table 3.

Pathways from Referral to Therapy for Children in Speech-Language Pathology Services.

Pathway	Referral → assessment → therapy		Referral → triage → assessment → therapy		Referral → wait → assessment → therapy		Referral → assessment → wait → therapy		Referral → wait → assessment → wait → therapy		Valid responses N	Not applicable n	Don't know n
	n	%	n	%	n	%	n	%	n	%			
Overall	47	23.7%	38	19.2%	67	33.8%	19	9.6%	27	13.6%	198	0	0
Area of difficulty													
Speech	15	16.3%	18	19.6%	32	34.8%	13	14.1%	14	15.2%	92	4	3
Language	12	12.5%	22	22.9%	32	33.3%	14	14.6%	16	16.7%	96	1	3
Literacy	7	10.1%	18	26.1%	25	36.2%	8	11.6%	11	15.9%	69	12	4
Stuttering	20	26.7%	17	22.7%	21	28.0%	9	12.0%	8	10.7%	75	11	5
Feeding	44	61.1%	18	25.0%	2	2.8%	3	4.2%	5	6.9%	72	10	5
Voice	7	13.0%	16	29.6%	17	31.5%	5	9.3%	9	16.7%	54	18	8
Hearing	3	8.1%	12	32.4%	12	32.4%	5	13.5%	5	13.5%	37	31	6
AAC	9	18.0%	11	22.0%	18	36.0%	5	10.0%	7	14.0%	50	23	4
Age group													
Infants	19	42.2%	15	33.3%	6	13.3%	3	6.7%	2	4.4%	45	10	2
Toddlers	19	32.2%	17	28.8%	12	20.3%	6	10.2%	5	8.5%	59	6	1
Preschool	15	22.1%	18	26.5%	19	27.9%	9	13.2%	7	10.3%	68	1	0
Primary school	6	11.8%	8	15.7%	20	39.2%	8	15.7%	9	17.6%	51	3	0
High school	3	8.1%	7	18.9%	12	32.4%	8	21.6%	7	18.9%	37	17	1

Table 4.
SLPs' Priority Rankings for Children by Age Group and Area of Difficulty.

Priority	High		Moderate		Low		Valid responses <i>N</i>	Not applicable <i>n</i>
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%		
Area of difficulty								
Speech	30	30.3%	52	52.5%	17	17.2%	99	66
Language	36	35.6%	53	52.5%	12	11.9%	101	66
Literacy	12	14.0%	40	46.5%	34	39.5%	86	81
Stuttering	46	47.4%	38	39.2%	13	13.4%	97	69
Feeding	85	88.5%	5	5.2%	6	6.3%	96	77
Voice	13	16.5%	32	40.5%	34	43.0%	79	84
Hearing	21	31.8%	32	48.5%	13	19.7%	66	98
AAC	25	36.8%	33	48.5%	10	14.7%	68	95
Age group								
Infants	48	77.4%	8	12.9%	6	9.7%	62	100
Toddlers	47	65.3%	18	25.0%	7	9.7%	72	95
Preschool	39	46.4%	32	38.1%	13	15.5%	84	81
Primary school	15	19.0%	30	38.0%	34	43.0%	79	89
High school	6	12.8%	15	31.9%	26	55.3%	47	119

Table 5.
Relationships and Differences regarding Importance of Prioritization Parameters for SLPs.

Prioritization parameter	SLPs' years of experience^a			Workplace country^a			Workplace context^b		
	r	p	Valid n	r	p	Valid n	F	p	Valid n
<i>Child factors</i>									
Severity	.100	.186	178	-.060	.495	133	1.13	.346	151
Diagnosis	.110	.143	178	.000	.998	133	.68	.610	167
Prognosis	.089	.248	171	.026	.766	131	.43	.784	160
Expected permanency	.052	.495	174	.031	.722	131	.14	.969	163
Age	.154	.040	177	.142	.105	132	1.47	.213	167
Efficacy of interventions	.176	.025	162	.091	.319	123	1.29	.275	152
Readiness for intervention	.169	.028	170	.002	.983	127	1.74	.143	160
Communication environment	.169	.029	167	-.139	.123	124	.99	.413	156
<i>SLP factors</i>									
Need for specific techniques/approaches to manage/provide intervention for the child	.113	.145	168	.009	.919	126	.31	.872	157
Personal ethical values	.307	<.001	166	-.062	.499	123	1.18	.320	155
Personal skills of the SLP	.148	.058	166	.005	.958	123	1.69	.156	155
Personal preferences of the SLP	.188	.016	164	-.050	.579	124	2.59	.039	154
<i>System factors</i>									
Availability of resources (e.g., funding, staff)	-.094	.205	183	.058	.499	139	1.07	.373	172
Triaging systems in the workplace	.114	.177	142	.081	.407	108	3.01	.021	135
<i>Sociopolitical context</i>									
Health care standards	.184	.021	158	.019	.841	118	4.02	.004	148
Ethics of the organization	.183	.018	167	.008	.931	125	.58	.680	155
Parental pressure	.042	.586	171	-.250	.004	128	1.11	.354	162

Note. SLP, speech-language pathologist. "Valid n" refers to valid responses. Bolded text indicates statistically significant values.

^a Data based on correlational analysis undertaken

^b Data based on ANOVA analysis

SLP WAITING LISTS

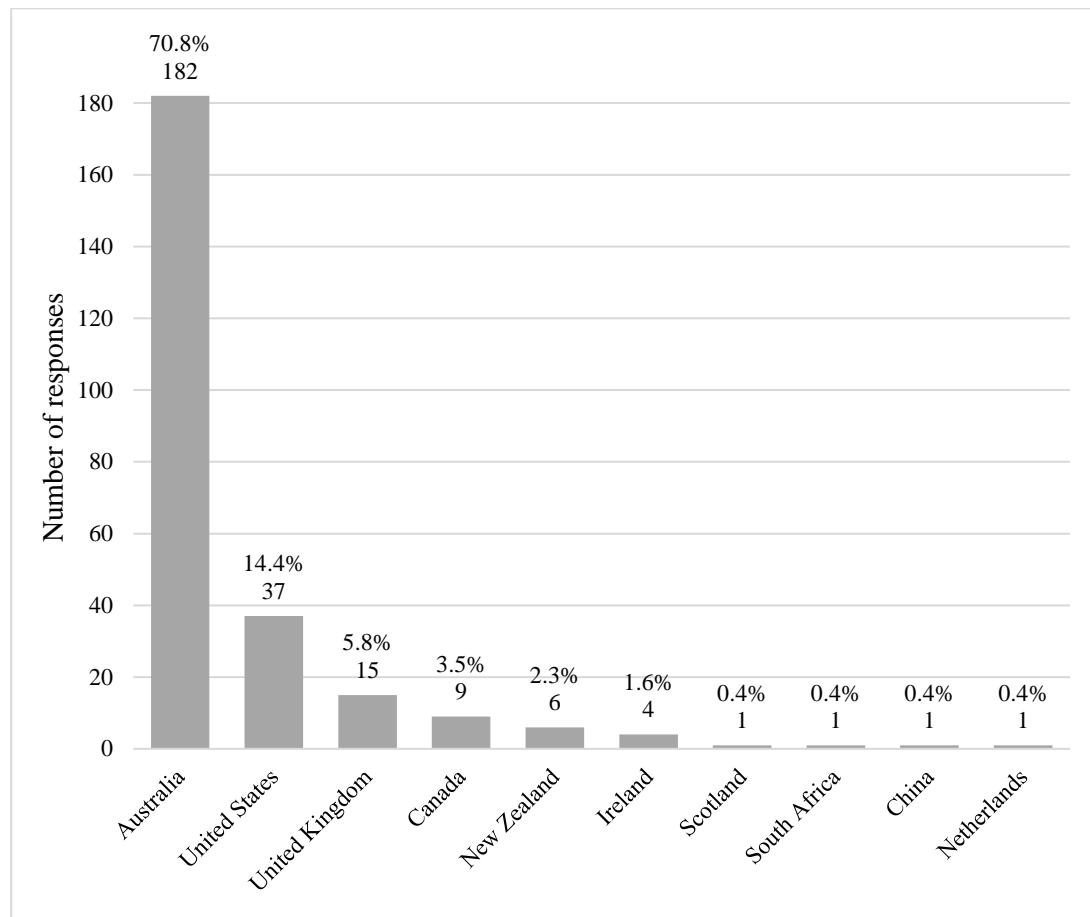


Figure 1. Speech-Language Pathologists' Country of Residence.

Note. Data labels indicate percentage of SLPs followed by number of responses (*n*).

SLP WAITING LISTS

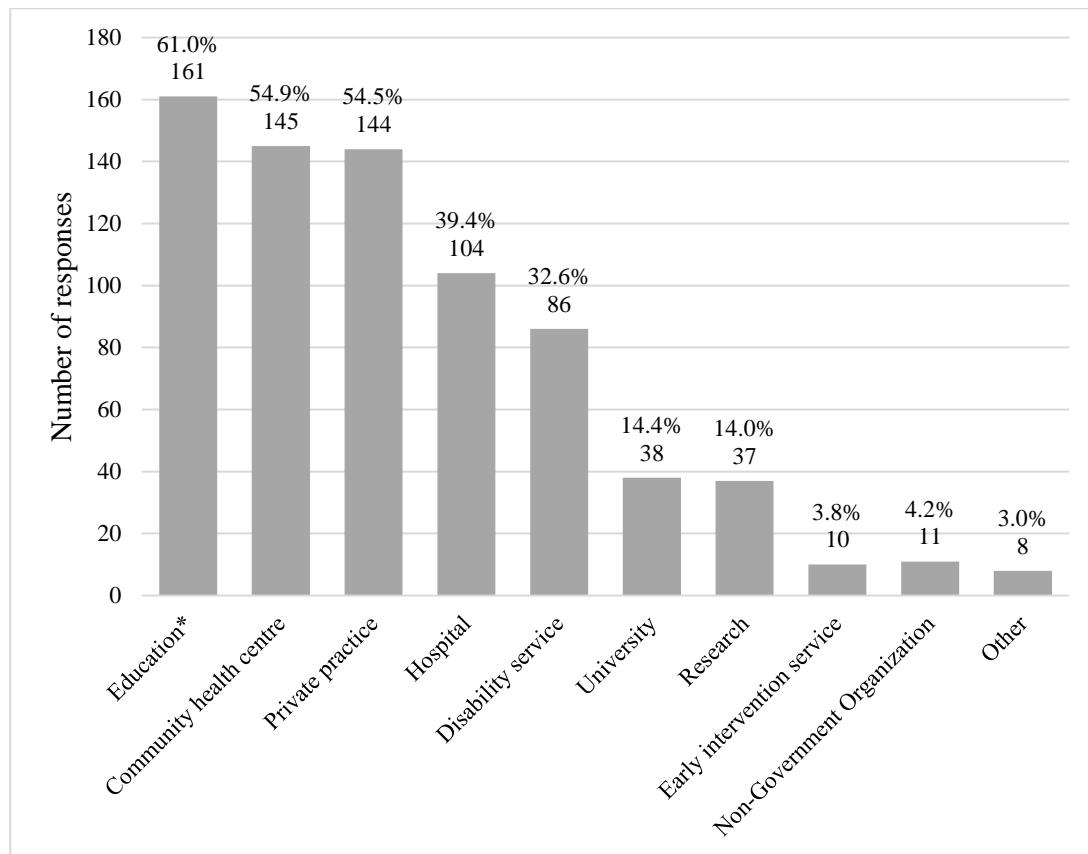


Figure 2. Speech-Language Pathologists' Workplace Contexts

Note. SLPs were able to indicate more than one workplace context that they had worked in.

Data labels indicate percentage of SLPs followed by number of responses (*n*).

*Education category included schools and early childhood education centres.

SLP WAITING LISTS

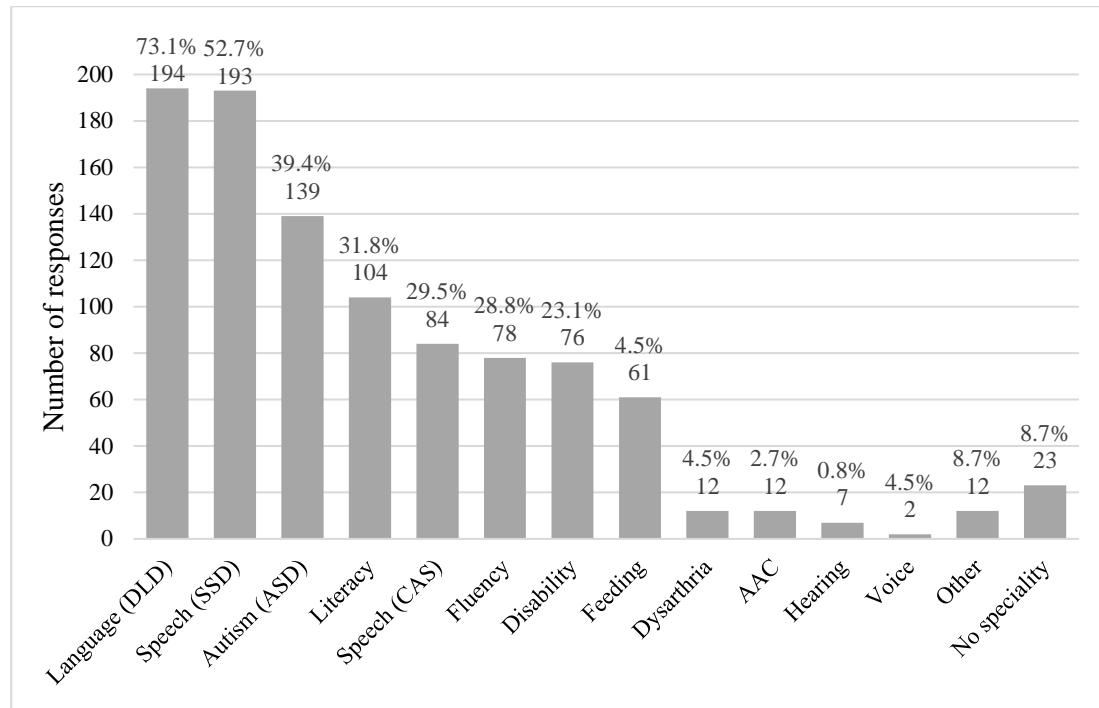


Figure 3. Speech-Language Pathologists' Areas of Professional Expertise when Working with Children.

Note. SLPs were able to indicate more than one area of expertise/specialty. Data labels indicate percentage of SLPs followed by number of responses (*n*). DLD, Developmental language disorders; SSD, Speech sound disorders; ASD, Autism spectrum disorders; CAS, Childhood apraxia of speech; AAC, Augmentative and alternative communication.

SLP WAITING LISTS

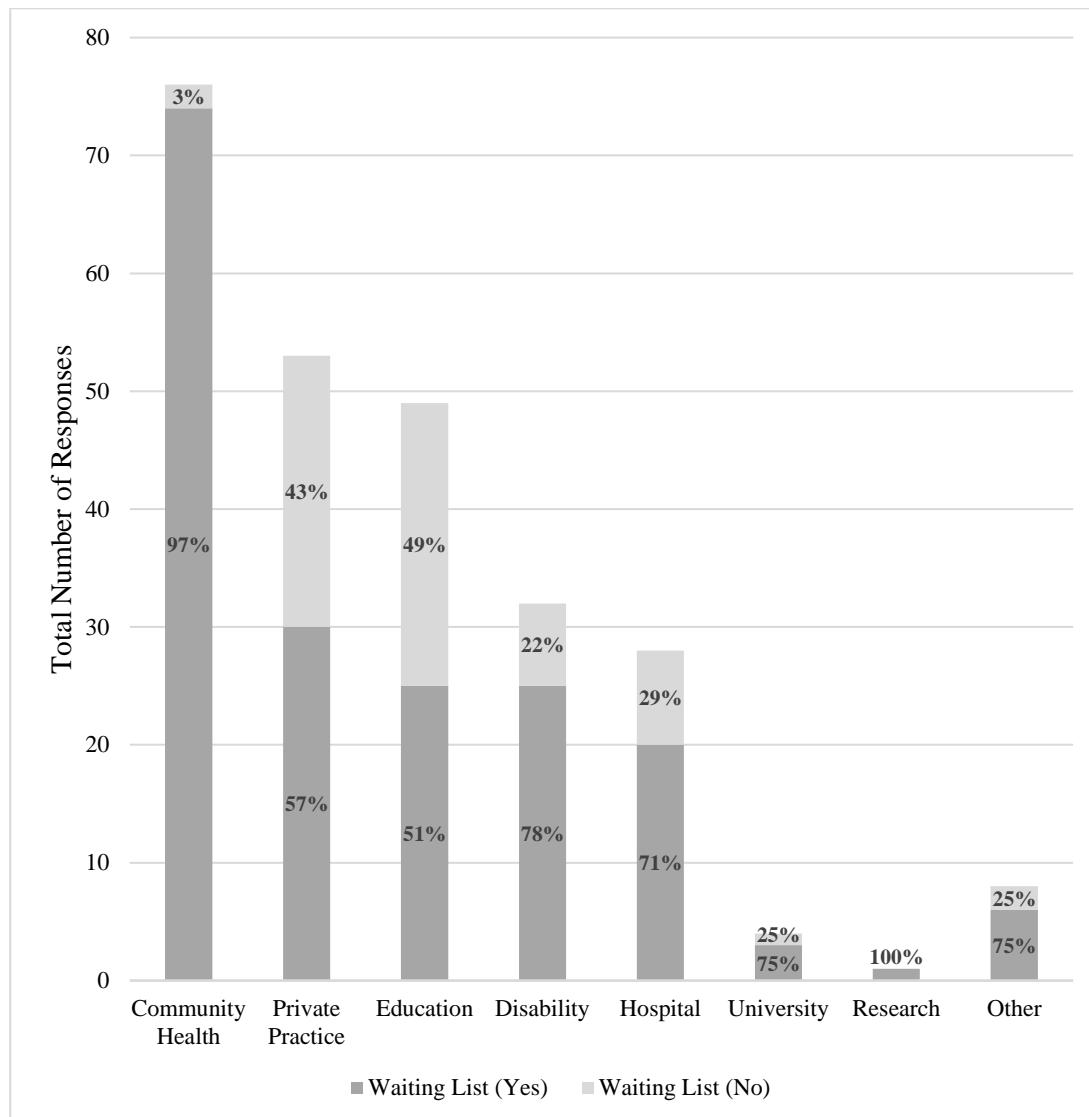


Figure 4. Presence of Waiting Lists in Speech-Language Pathologists' Workplace Contexts.

SLP WAITING LISTS

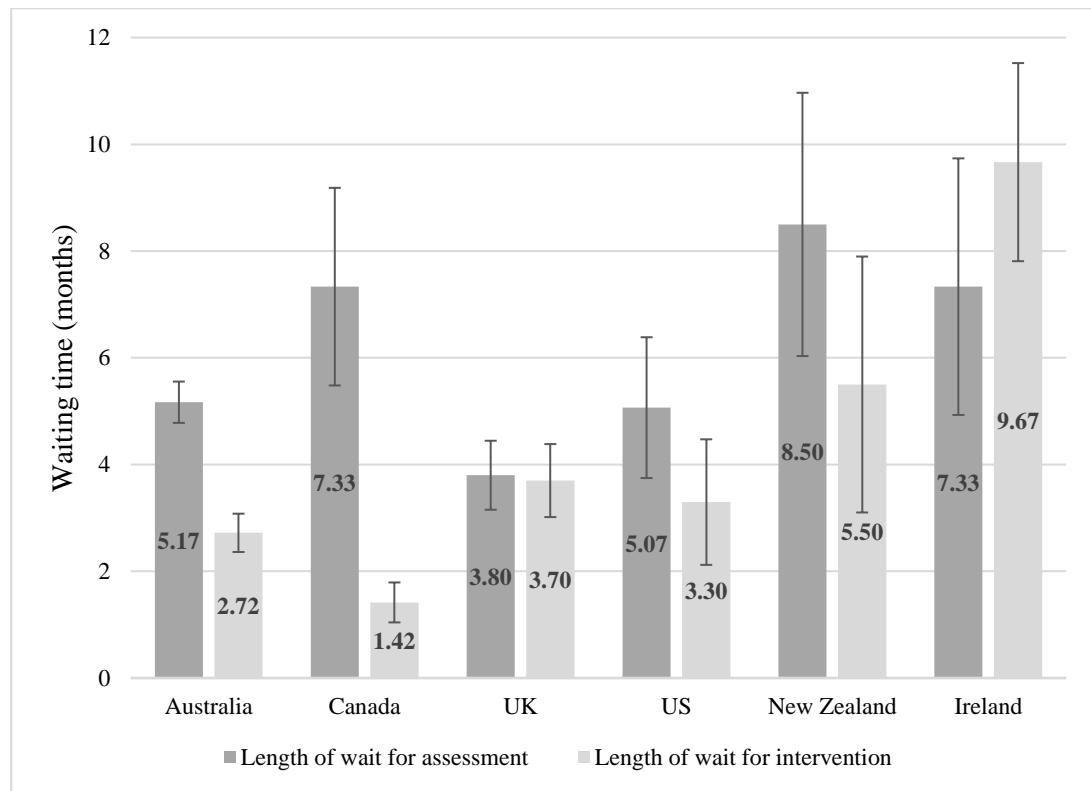


Figure 5. Length of Waiting Time (Months) for Assessment and Intervention by Workplace Country.

Note. Data labels indicate mean waiting times (months) for children, where “0” indicates waiting times less than 1 month. Data for Scotland, South Africa, China, Netherlands and Iceland are not depicted in the figure as only one data-point was available for each country: Scotland (Assessment = 11 months; Therapy = 1.5 months); South Africa (Assessment = 12 months; Therapy = 1 month); China (Assessment = 1 month; Therapy = 6 months); Netherlands (Assessment = 1 month; Therapy = 0 months); Waiting times were not provided for Iceland.

Chapter 4: SLPs' Perspectives and Management of Waiting Lists

Paper 3

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Waiting list management: Professionals' perspectives and innovations

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Running head: SLT waiting lists

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Declaration of interest

There are no conflicts of interest to report.

Abstract

Background: Waiting lists for speech and language therapy exist as current services do not meet the need or demand. Waiting lists pose practical and ethical challenges for speech and language therapists (SLTs) and workplaces to manage, with potential flow on effects for children and families.

Aims: The present study aimed to describe SLTs' perspectives about waiting lists for children with speech, language, and communication needs (SLCN) and explore waiting list management strategies.

Methods & Procedures: The present study reports on 187 SLTs' written responses to open-ended questions in a questionnaire. SLTs were from nine countries, had an average of 12 years' experience in the profession (range 0.2-45 years), and either currently or had previously worked with children. Data were analysed qualitatively using thematic analysis.

Outcomes & Results: SLTs' feelings about their waiting lists were predominantly negative, including feeling "overwhelmed", "stressed", "anxious", and "embarrassed". Waiting list management strategies related to service delivery (e.g., triage, use of technology in service provision), workplace processes and policies (e.g., eligibility criteria, prioritisation), and workforce actions (e.g., recruitment and retention of skilled SLTs). Inaction was also apparent, for example, some SLTs felt waiting lists were "out of my hands".

Conclusions & Implications: Waiting lists can have negative consequences and many SLTs take action to manage waiting lists; however, waiting list management strategies are not necessarily effective which can impact children's outcomes. There is a need to reimagine service delivery and identify effective actions for managing speech and language therapy waiting lists at a local and systemic level in order to optimise outcomes for children and families.

INTRODUCTION

Waiting lists for speech and language therapy are common, particularly in countries with universal or government subsidised health care such as the UK, Canada, and Australia. Access to speech and language therapy has been described as a “postcode lottery” where waiting times for services for children with speech and language needs are based on geographical location (I CAN and Royal College of Speech and Language Therapists [RCSLT], 2018). Children with speech and language needs must sometimes wait more than 12 months for assessment and therapy with a speech and language therapist (SLT) (I CAN and RCSLT, 2018, McGill et al., 2020b, Ruggero et al., 2012). Waiting lists can have negative implications for consumers (e.g., parents, clients) and professionals (e.g., SLTs, doctors, educators), including psychological, physical, financial, and ethical burdens (McGill et al., 2020a). Management of waiting lists and their negative consequences poses a significant challenge for SLTs and workplaces to ensure the quality of care for children and families is not compromised.

SLT workforce

The demand for speech and language therapy services exceeds the capacity of current services which frequently have limited resources and staffing. Recruitment and retention of allied health professionals, including SLTs, is a significant issue (Long et al., 2018). Shortages of SLTs and subsequent gaps in service for children and families can result.

SLTs engage in complex juggling acts of managing caseloads which are increasing in size and complexity, while resources are not necessarily increasing to meet demand (Kenny and Lincoln, 2012). SLTs have reported feeling stressed, overwhelmed, frustrated, fatigued, and disillusioned when managing large client caseloads in under-resourced and under-staffed services, which can impact retention and affect their ability to provide evidence-based care for their clients (Edgar and

Rosa-Lugo, 2007, Harris et al., 2009, Kenny and Lincoln, 2012, McLaughlin et al., 2008).

Poor job satisfaction for SLTs can reflect “a mismatch between personal/professional values and the realities of providing healthcare” (Byng et al., 2002). SLTs are often motivated by helping clients, making a difference, and having quality client relationships, and long waiting lists may conflict with these values, contribute to reduced job satisfaction, and therefore impact workforce retention (Byng et al., 2002, Whitehouse et al., 2007).

Whilst waiting lists may contribute to workload, retention, and job satisfaction issues, limited research has specifically focused on SLTs’ perspectives regarding waiting lists. Allied health professionals have reported feelings of frustration and embarrassment, and the inability to provide evidence-based practice and family-centred care due to waiting lists (Lincoln et al., 2014). Waiting lists have been reported to have negative implications for SLTs’ psychological wellbeing (McGill et al., 2020a); however, few studies have explored how SLTs feel about their waiting lists and whether there are associated implications for workforce planning, recruitment, and retention and any flow on effects to the children for which care is provided.

SLT service delivery

Speech and language therapy service delivery aims to provide person-centred, evidence-based care for all clients. Service delivery may vary according to geographical location, workplace setting/context, waiting list duration, or caseload size (Brandel and Loeb, 2011, Wright and Kersner, 2012). For years, many SLTs have rationed their services to maximise the greater good for the greatest number. For instance, large waiting lists and caseloads can lead SLTs to provide different types or lower doses of therapy than children require, provide group therapy despite one-on-

one therapy being more appropriate, or cancel sessions in an effort to manage their workload, all of which may impact on children's speech and language outcomes (Chiang and Rylance, 2000). For speech and language therapy to be effective, the intensity, or "quality and quantity of ... learning experiences" (Baker, 2012, p. 402), is important. Generally high doses, or high occurrence of learning experiences/practice trials per therapy session, are recommended (Baker, 2012, Glogowska et al., 2000, Law and Conti-Ramsden, 2000; Warren et al., 2007). Therefore, children's therapy outcomes may be compromised by service delivery decisions.

SLTs manage their caseloads and waiting lists using many different strategies and models of service delivery, including triage, screening, prioritisation, providing home programs and information to families, and offering group therapy (McCartney, 2000, Pert, 2010). Constraints within workplaces (e.g., limited funding and resources) may "force" SLTs to adopt service delivery models involving provision of a limited service for financial and efficiency reasons, rather than based on client needs (Wright and Kersner, 2012). For instance, pressure may be placed on SLTs to discharge clients from their caseloads in order to increase throughput and take on new clients from the waiting list, which has been described as "highly unsatisfactory" for SLTs (Hersh, 2010). SLTs may also implement innovative strategies and service delivery models to improve their services and proactively manage their caseloads and waiting lists. Evidence regarding the effectiveness of innovative strategies may be limited or inconclusive, making decisions regarding service delivery and waiting list management strategies difficult (Petticrew, 2003). SLTs' decision-making regarding service delivery is not always made explicit to clients, which may be disempowering for families (Ruggero et al., 2012). Service delivery models do not always fit with families' expectations, wants, and needs (Ruggero et al., 2012). Subsequently, there

are challenges in balancing the need for cost and time efficiency, professional and personal values, evidence-based practice, and the needs of children and families.

Little is known about the types of support, if any, SLTs provide to children and families on waiting lists. Although waiting for speech and language therapy has traditionally been considered a passive stage of families' involvement with speech and language therapy services (Glogowska and Campbell, 2000), provision of information to families may empower them to be active while waiting and find strategies to reduce their waiting times (Feldman et al., 2002, Fordham et al., 2012). SLTs may provide information, strategies, or parent-led therapy programs to families on waiting lists, potentially encouraging active waiting and facilitating improvement in children's speech and language skills. However, the types of support provided to families on waiting lists and the efficacy of these strategies is unclear, particularly since direct parent training and high doses are recommended for parent-led therapy programs (Tosh et al., 2017). SLTs may also have innovative solutions for managing their waiting lists and supporting children and families on waiting lists which have not yet been explored.

Research aims

The aims of the current study were to describe: (1) SLTs' feelings and perspectives about waiting lists, and (2) SLTs' current and aspirational waiting list management strategies.

METHOD

The research aims were addressed using a qualitative approach to explore SLTs' written responses to open-ended questions in a questionnaire. This method enabled broad insights to be obtained from many SLTs across multiple countries without limiting their ideas to pre-determined response options. This study received

ethical approval from the Charles Sturt University Human Research Ethics Committee (Protocol number: H17181).

Participants

Two-hundred and seventy-six SLTs completed questionnaires. Two-hundred and sixty-four SLTs (95.7%) indicated they currently or had previously worked with children, and their responses to closed questions were analysed quantitatively and reported in McGill et al. (2020b). A subset of 187 SLTs (70.8%) responded to at least one of four open-ended questions within the same questionnaire and these SLTs formed the participant sample for the present qualitative study. Of the 187 SLTs, 82.9% ($n = 155$) completed an online version of the questionnaire and the remainder completed a hard copy version. The number of valid responses varied for each question, so the percentage and number of respondents have been provided to enable calculation of the total valid responses. SLTs in the present study were predominantly female ($n = 184$, 98.4%) and most lived in Australia ($n = 131$, 71.2%), while others lived in the United States ($n = 25$, 13.6%), United Kingdom ($n = 11$, 6.0%), Canada ($n = 7$, 3.8%), New Zealand ($n = 4$, 2.2%), Republic of Ireland ($n = 3$, 1.6%), and one each from South Africa, China, and the Netherlands. The SLTs' questionnaire responses related to workplaces based in Australia ($n = 101$, 65.2%) or other countries ($n = 54$, 34.8%) including the United States, United Kingdom, Canada, and New Zealand. Some SLTs ($n = 22$, 11.8%) spoke a language other than English at home, including French, Spanish, Dutch, Arabic, German, and Greek. The SLTs' level of experience ranged from less than one year (0.2 years) to 45 years ($M = 12.0$ years, $SD = 10.6$). The highest levels of education completed by SLTs were a doctoral degree (e.g., PhD; $n = 10$, 5.3%), master's degree ($n = 74$, 39.6%), graduate

diploma/certificate ($n = 13$, 7.0%), and bachelor's degree¹ ($n = 85$, 45.5%). Some SLTs ($n = 66$, 35.3%) had additional qualifications, including in arts, science, and education. SLTs' responses related to the following workplace contexts: community health centres ($n = 72$, 39.1%), private practices ($n = 33$, 17.9%), education settings (e.g., schools, nurseries/early childhood education centres; $n = 33$, 17.9%), hospitals ($n = 21$, 11.4%), disability services ($n = 18$, 9.8%), universities ($n = 2$, 1.1%), research settings ($n = 1$, 0.5%), or other ($n = 4$, 2.2%). SLTs most commonly reported their main areas of expertise (more than one response option was allowed) to be speech sound disorders ($n = 144$, 77.0%), developmental language disorder ($n = 140$, 74.9%), autism spectrum disorder ($n = 94$, 50.3%), literacy ($n = 71$, 38.0%), fluency/stuttering ($n = 61$, 32.6%), and childhood apraxia of speech ($n = 59$, 31.6%).

SLTs reported having client caseloads ranging from 2 to 700 clients ($M = 63.5$, $SD = 66.7$). The mean duration of their waiting lists were 5.3 months between referral and assessment ($SD = 4.0$, range = 0-20 months) and 3.2 months between assessment and therapy ($SD = 3.8$, range = 0-22 months), with a combined duration of 8.4 months ($SD = 5.9$, range = 0-42 months) between referral and therapy for children.

Instrument

A questionnaire was developed to obtain SLTs' perspectives regarding speech and language therapy waiting lists for children. The questionnaire included information and consent forms at the beginning for SLTs to indicate their willingness to participate. Two versions of the questionnaire were developed: (1) a hard copy version to distribute in person, and (2) an online version to distribute internationally. The online version contained four additional questions relevant to the analysis of this paper, and minor changes to the format and structure of the questionnaire to enhance

¹SLTs in Australia, the United Kingdom, and New Zealand can practice with a bachelor's degree qualification.

online usability. Two questions analysed in the present paper were included in both versions of the questionnaire. Piloting of the questionnaire was undertaken with an independent paediatric SLT and members of the research team.

The questions were informed by research on waiting and prioritisation for health care services, including speech and language therapy (Glogowska and Campbell, 2000, Roulstone, 2007). SLTs were asked to answer the questions based on a workplace they currently, or had recently, worked in with children. Closed questions about demographics, caseload size, waiting times, care pathways, and prioritisation parameters have been analysed separately and reported in McGill, McLeod, Crowe et al. (2020b). SLTs were also asked a series of questions regarding their feelings about the waiting list in their workplace, services/service delivery models provided in their workplaces, and their ideas and strategies for waiting list management, which are the focus of the present paper. Firstly, SLTs were asked “How do you feel about the waiting list at this [chosen] workplace?²” and provided with a free-text response box, then they were asked three open-ended questions to explore waiting list management: (1) “What strategies, policies or methods of service delivery do you use to help manage/address your waiting list?³”, (2) “What do you think would help with managing paediatric speech-language pathology waiting lists? Please describe any ideas or solutions you have²”, and (3) “Can you suggest any innovative ways to support children and their families and/or educators while they are waiting for speech-language pathology services²”. SLTs were also provided with a list of service delivery options and a free-text response box to identify the service delivery models used in their workplaces³. Additionally, SLTs were asked to provide their opinion regarding

² Question included in online version of questionnaire only

³ Question included in both hard copy and online versions of questionnaire

how helpful and/or useful a website would be, containing information and ideas for things to do while children are waiting for speech and language services².

Procedure

Participant recruitment involved opportunity and snowball sampling via a two-stage approach. Stage 1 involved distribution of hard copy questionnaires to SLTs at the 2018 Speech Pathology Australia National Conference during a session and poster presentation. Interested SLTs completed the questionnaire anonymously and returned them to a bag by the door/poster board. Stage 2 involved distribution of an online version of the questionnaire via the following methods: emails to the authors' international professional networks, Speech Pathology Australia's e-News, international social media, and word of mouth. Participants were invited to share the online questionnaire link with other interested SLTs. Participants indicated their consent to participate in the study and have their results analysed by completing and returning their hard copy questionnaire to the first and second authors or clicking *continue* on the first page of the online questionnaire. Responses to hard copy questionnaires were manually entered into the online questionnaire form by a research assistant blinded to the aims of the study to enable them to be combined with the online responses. All questionnaire responses were compiled in the online questionnaire software and exported into SPSS (IBM, 2017), then into NVivo (QSR International Pty Ltd, 2019).

Analysis

Qualitative questionnaire data were analysed based on the principles of thematic analysis and six step procedure described by Braun and Clarke (2012). After familiarisation of the data (Step 1), the first and second authors read through the SLTs' responses and discussed initial codes (Step 2). SLTs' responses to three waiting list

management questions were combined and analysed together due to overlapping themes, whereas responses to other questions were analysed separately.

Data within NVivo (QSR International Pty Ltd, 2019) were coded by the first author, informed by the initial coding structure. Codes were added when new content or ideas were identified. Codes were then grouped into themes (Step 3) and confirmed with the second author (Step 4). The author allowed time to elapse to give distance to the data, then collapsed and rearranged codes and modified the themes. Consensus with the second author was obtained regarding defining and naming the final themes (Steps 3 to 5). To enhance transferability of the findings, the authors used thick description through inclusion of verbatim quotes from SLTs when reporting the results (Step 6). The authors replaced other similar terms with “SLT”.

RESULTS AND DISCUSSION

Responses to a question about SLTs’ feelings and perspectives were analysed separately to SLTs’ responses regarding waiting list management and are reported and discussed in two main sections as follows. Original participant identification numbers from the questionnaire have been retained and are reported after SLTs’ quotes.

SLTs’ feelings and perspectives about waiting lists

Three themes were identified in SLTs’ written responses regarding feelings about their waiting lists: negative, neutral, and positive feelings.

Negative feelings.

Most SLTs’ comments described negative feelings about their waiting lists. SLTs described feeling “bad” (28), “frustrated” (4), “anxious” (32), “overwhelmed” (164), “stressed” (250), “concerned” (260), and “embarrassed as a professional” (276) regarding their waiting lists. Most negative responses involved comments about waiting list duration, which SLTs felt was “far too long” (13). SLTs described their waiting lists as “enormous” (119), “horrendous” (16), and “a disgrace, but we can’t

speak about it” (10). Negative comments also related to being “understaffed” (172), “system level road blocks” (4) and “business/money focused” organisations (166), or waiting lists being “poorly managed” (1). SLTs also described experiencing conflict between evidence-based practice and reality as their waiting lists went “against the intention of early intervention” (119) and that “if advocating the benefits of early intervention … [I] should be able to ‘walk the talk’” (276). SLTs described their waiting lists as “unethical” (181), particularly when they had “opened a duty of care to the clients” (220). The negative personal toll of waiting lists on SLTs was highlighted by comments about “feeling stressed…because parents become anxious about waiting” (190), or feeling “a sense of having let others down” (260), meaning waiting lists had the “biggest negative impact upon…job satisfaction” (260).

Similar negative feelings have previously been reported with regards to SLTs’ management of large caseloads in services with resource constraints, which had negative implications for workforce retention and the care provided to clients (Edgar and Rosa-Lugo, 2007, Harris et al., 2009, Kenny and Lincoln, 2012, McLaughlin et al., 2008). Conflict between practice and professional/personal values or ethics has also been found to impact job satisfaction and retention within the workforce (Byng et al., 2002, Lincoln et al., 2014, Whitehouse et al., 2007). Key ethical principles guiding SLTs’ practice include beneficence (doing good for others), nonmaleficence (doing no harm), and justice (fair and equitable access to care) (Fletcher et al., 1997; Rao and Martin, 2004). Waiting lists can delay provision of care for clients who would benefit from support, and factors associated with the practice context (e.g., resource limitations, organisational policies) may contribute to service delivery decisions that conflict with best practice recommendations or clients’ needs, for instance, regarding the timing, type, and intensity of intervention (Hoffman et al., 2013; Rao and Martin, 2004). The findings may illustrate the moral and ethical challenges for SLTs posed by

a “philosophical conflict between desired and allowable practices” (Byng et al., 2002, p. 90). More must be done to address the constraints facing SLTs in their practice contexts, and support and retain SLTs in the workforce to enhance quality and continuity of care for clients.

Positive or neutral feelings.

There were also some neutral and positive responses from SLTs about their waiting lists. Some SLTs indicated they had “mixed feelings about the waiting list” (234) or felt their waiting list was “not too bad” (137), “okay” (169), or “adequate” (238). Others felt that although their waiting list “could be better...prioritising helps get in more urgent patients” (178). Some SLTs displayed a sense of acceptance that “long waiting lists seem to be the nature of community health” (163) with “no available alternative” (246) and “it is unfortunate to have a waitlist; however, it is necessary” (244). These perspectives are consistent with previous research indicating that health professionals view waiting lists as a “normalized” aspect of health care “culture” (Rittenmeyer et al., 2012). Some SLTs reported feeling “generally OK” (26), “fortunate” (184), or “good” (204). Most positive responses involved comparisons with waiting lists in other organisations or reflections on how their waiting list had changed over time. For instance, some SLTs described their waiting list as “a big improvement” (212) or “better than it was” (58), while another felt “a shorter waiting list would be better but compared to other public services it isn’t that bad” (182). These perspectives may indicate that some form of waiting list management strategy had been in place within the workplaces. Some SLTs felt their waiting list was “manageable” (251) and felt “proud that we can respond to requests for service in a timely way” (154). Being proactive by “actively working towards NOT having a waiting list” (176) may have provided a more positive perspective for SLTs regarding

their waiting lists, perhaps due to feeling like they were doing something to address the issue.

SLTs' feelings may have reflected caseload size, which can contribute to perceptions of caseload manageability – a construct interconnected to job satisfaction (Katz et al., 2010). SLTs who expressed neutral or positive views may have had smaller caseloads than those who reported negative feelings. Caseloads exceeding 55 clients have been reported by school-based SLTs to be unmanageable (Katz et al., 2010).

SLTs' waiting list management strategies

SLTs described using service delivery models involving direct support such as screening clinics, complex/multidisciplinary assessment and therapy, one-on-one and group therapy sessions, and intensive clinics/programs. SLTs also provided indirect support via training and upskilling parents and professionals, providing advice, providing home programs for parents and other professionals, and monitoring. SLTs described providing services in clinics, schools, and homes, or via technology (e.g., telehealth). Most SLTs felt that a website containing information and ideas for activities to do while children are waiting for services would be a helpful and useful tool ($n = 129$, 89.6%; valid $n = 144$).

Four overarching themes were identified in SLTs' responses to three questions about waiting list management practices (Supplemental Appendix A): (1) SLT service delivery methods, (2) workplace processes and policies, (3) SLT workforce, and (4) inaction.

SLT service delivery.

Many SLTs described existing or aspirational service delivery strategies in their workplaces to manage waiting lists and support those who are waiting for speech and language therapy. SLTs described assessment practices such as screening,

intake/triage, single session models, and drop in services. An SLT emphasised the importance of families receiving a timely assessment, even if they subsequently waited for therapy: “I believe that assessment is the greatest priority…Assessments take away parental anxiety when no problems are found. Even if therapy cannot be offered for a long time, processes are ‘in motion’ once an assessment is done” (160). In a recent community-based randomised controlled trial (RCT), provision of an assessment following referral to families on a speech and language therapy waiting list led to similar improvements in child outcomes and caregiver satisfaction to those who received both an assessment and access to an evidence-based speech and language website while waiting (McGill et al., 2020c). However, Ruggero et al. (2012) found that parents were dissatisfied with long waits between assessment and commencing therapy.

SLTs described providing group therapy, intensive therapy programs, and therapy blocks, including “shorter block therapy sessions followed by home program and review” (195). Group therapy was described by many SLTs as a way to “decrease waiting times” (193) by seeing multiple clients at once with “similar needs” (60) and offering “places…to children on the wait list” (1), as well as encouraging active waiting by offering “group [therapy] while waiting for individual [therapy]” (255). However, a study by Ruggero et al. (2012) found that most parents preferred one-on-one therapy for their children instead of group therapy and few preferred home programs or parent training. Alternatives to one-on-one therapy were considered acceptable to “fill a gap” (p. 346) rather than replace direct face-to-face support; however, it is possible that greater transparency between SLTs and families regarding service delivery options may alter these perspectives (Ruggero et al., 2012).

SLTs also identified the need for a greater focus on prevention through health promotion or embedding speech and language therapy services within universal

services (e.g., nurseries/early childhood education centres, child health services, playgroups), such as having SLTs as “part of mothers’ groups so early fundamental language teaching can be taught” (33). Historically speech and language services have aligned with a rehabilitative framework and services have typically been provided in one-on-one, clinic-based settings with children diagnosed with speech and language disorders (Law et al., 2013). However, there is an increasing awareness of the social and environmental influences on children’s speech and language development, and a growing focus on and need for prevention, health promotion, and whole population approaches (Law et al., 2013). Such approaches may enable SLTs to expand their reach and provide support earlier to greater numbers of children, both with existing speech and language difficulties and those who are at risk.

SLTs also discussed the use of technology in service delivery, such as “using teletherapy to provide services” (43) or as a way of disseminating information and training to families through “webinars” (1), “moderated online support groups” (1), “SMS messages with tips” (237), a “parent coaching app” (232), “a website to direct them to with appropriate strategies” (273), and “online parental videos for support strategies family can use in interim until they are able to seek help” (64), which have shown promise in other research studies (e.g., Wales et al., 2017). Many technology-based strategies were innovative ideas that SLTs aspired to implement in their workplaces, and fewer SLTs were already using such strategies.

SLTs also described collaboration with parents and professionals as a common strategy. Many SLTs reported providing advice and training to parents, with some providing “phone support” (36), “parent training programs” (207) or “one-off advice sessions to families at time of referral” (196) or soon after intake to “provide parent education to support active waiting while on the wait list for an initial assessment” (215). Some SLTs provided home programs, “general information” (103), and “harm-

free' resources to parents" (104), which have been implemented by SLTs for many years. Others were not currently offering these supports but suggested ways that services could support families on waiting lists, such as providing "parent friendly resources" (167) for "parents to use during wait times or for mild diagnoses" (165), "[an] accessible website for families to use, including some video clips on how to put these [strategies] into practice at home" (206), an "information package for families or...a parent information group to present generic strategies for communication support that could be used while waiting" (182). It was unclear whether the parent education strategies described by SLTs involved direct parent training and high doses, which has been recommended for home therapy programs (Tosh et al., 2017). McLeod et al. (2020) conducted an RCT to evaluate provision of three types of support to children aged 3-6 years on a speech and language therapy waiting list: (1) 12 sessions of immediate face-to-face therapy, (2) a tailored advice session, and (3) provision of a purpose-built website containing information and parent-friendly strategies for stimulating children's speech and language skills. The results indicated that provision of advice sessions or a website to caregivers were not as effective as face-to-face therapy for improving children's speech production or caregivers' satisfaction, but there was little difference in outcomes across groups regarding children's intelligibility, language, and early literacy, and caregivers' feelings of empowerment (McLeod et al., 2020). A concurrent RCT by McGill et al. (2020c) compared two waiting list conditions: (1) provision of the same purpose-built website to caregivers, and (2) a control group involving provision of assessments only. The findings indicated that provision of a website was no more effective at improving children's and caregivers' outcomes than receiving an assessment only while waiting, suggesting families may require more than a generic device alone while waiting (McGill et al., 2020c).

SLTs suggested “strong links and sharing of knowledge” (65) with other health and education professionals would assist with managing speech and language therapy waiting lists and supporting those on waiting lists through “training of health visitors [regarding] appropriate referrals” (146), training “educators and...early childhood providers...in providing language rich environments and in strategies for modelling and eliciting language” (123), and implementing “school/preschool based programs” (21). Interprofessional collaborative practice can enhance access to health care and coordination of services, improve clients’ outcomes, and increase clients’ and caregivers’ satisfaction with care (World Health Organization, 2010). Collaboration between professionals, such as in education settings, can have many benefits for children’s communication development (Hadley et al., 2000). For children with disabilities, interprofessional collaborative practice can enhance progress toward goals and provide “more seamless care” (Sylvester et al., 2017, p. 206). However, collaboration can be time consuming and has been associated with SLTs’ perceiving their caseload to be unmanageable (Katz et al., 2010), potentially impacting their work with children and, subsequently, the outcomes of children and families.

Additionally, relying on non-SLTs in service delivery was suggested, including “recruiting AHAs [allied health assistants] to do the bulk of group work” (166) to “allow the SLTs to see the higher priority clients” (166). Speech and language therapy assistants or allied health assistants work with children and families under the supervision and guidance of SLTs, carrying out therapy plans, completing routine-based tasks, or preparing resources and materials (SPA, 2014). Speech and language therapy assistants may assist with reducing SLTs’ workloads and free up time for other non-delegable complex tasks such as assessment and therapy planning; however, training and supervising assistants also takes time and resources (Goldberg et al., 2002).

Workplace processes and policies.

The second theme related to workplace processes and policies. SLTs' responses related to funding, administrative strategies, referral processes, organisational strategies, and evidence-based practice. With regards to funding, many SLTs indicated that "increased funding" (126) would help with management of waiting lists as "funding is the main issue" (229). However, researchers have recommended that provision of additional resources and funding occurs in combination with other initiatives for effective long-term management of waiting lists (Sanmartin et al., 2000). Many comments about funding were linked with the ability to "increase staffing levels" (165) among the SLT workforce. Others described a need for "bulk funding for health promotion/carer training" (129), "primary health care initiatives" (131), and "communication workshops and training" (129) for early childhood education services. Some SLTs made use of alternative funding models to manage their waiting lists, including encouraging families to access government rebates for private services, or making referrals to disability/medical insurance schemes. However, not all children are eligible for funding and government subsidised sessions, and children who are eligible often require more than their allocated amount of support to make significant improvements in speech and language (Law and Conti-Ramsden, 2000). Private services were not an affordable option for many families (McGill et al., 2020a).

SLTs also reported implementing administrative strategies such as failure to attend policies, cancellation lists, registration forms, limits on advertising, waiting list audits, and templates for documentation to increase efficiency. Some SLTs used scheduling to manage their waiting lists by "reserving assessment appointments to ensure that new referrals are assessed promptly" (212) "regardless of the number of discharges to ensure throughput of clients" (260), and keeping "a full schedule" to

“see as many kids as possible” (241). SLTs also suggested strategic caseload allocation processes could help, including having “allocated teams, within current staffing, to manage each priority level” (237) of clients.

SLTs also described strategies involving referral policies to assist with waiting list management. Some SLTs preferred to “refer excess clients on to others and will not accept clients if they have to wait more than 2-3 weeks” (176) while others referred potentially eligible children to other services to access alternative funding (e.g., disability insurance schemes) as it “is the only way most of these children will access regular and ongoing…intervention” (163). Referrals were a way to “assist in starting processes for further assessment” (113) as well as encourage active waiting through linking families with other “adjunct services…community-based group programs…parent courses and parent support groups” (176) while waiting for speech and language therapy.

Organisational strategies for waiting list management related to both standards and restrictions imposed on services. Some SLTs described having “state mandated timelines” (238) for seeing clients and “strict benchmarks for different ages to be assessed by” (165). Benchmarking is consistent with recommendations from Rvachew and Rafaat (2014). There were many restrictions imposed on the services provided by SLTs, including closing the books, discharge protocols, “strict criteria for acceptance onto waiting lists” (126), and “strict caps on session numbers to help reduce wait times for other clients” (165), which have implications for continuity of care, client satisfaction, and efficacy of interventions (Law and Conti-Ramsden, 2000, Ruggero et al., 2012).

SLTs reported “prioritisation based on outcome evidence” (190) to be an effective waiting list management strategy. Many SLTs used prioritisation to ration the services provided based on factors such as “age, disorder type” (21), “severity, impact

on education...impact on daily functioning" (225), or "vulnerable" (149) and "disadvantaged groups" (167). Some SLTs described formal prioritisation guidelines in their workplaces such as a "clinical prioritisation tool" (167), while others described "a vague prioritisation policy which is not consistently implemented" (206) and thought that "a clear pathway for prioritisation" (206) with greater "consensus" (187) was needed to help manage waiting lists. Prioritisation of children for services based on child and service factors is consistent with previous research (McCartney, 2000, McGill et al., 2020b, Roulstone, 2007). Prioritisation can be problematic as some children who are considered low priority may never receive support, despite the ability to benefit from speech and language therapy (McCartney, 2000).

SLTs' responses also commonly related to evidence-based practice. Some SLTs experienced feelings of conflict regarding their current waiting list management strategies as they felt they were "unable to offer best practice" (250) and were "not providing a good service for children" (126) which was "not good for the reputation of the SLT profession" (126). Speech and language therapy should be evidence-based and person-centred in order to promote optimal outcomes for children, which involves integration of evidence from research literature, clinical experience and expertise, client values and preferences, and the practice context (Hoffman et al., 2013).

Incongruency between strategies implemented in services and evidence-based practice is consistent with prior studies (Hersh, 2010, Ruggero et al., 2012). Although practice context is important to consider in professional practice, the SLTs' responses may highlight a heavily service-centred focus within their workplaces, rather than achieving balance between the constraints of practice contexts and a person-centred focus. SLTs' responses also suggested a lack of control or autonomy over the decision-making processes regarding client care. This could lead to ethical dilemmas

and compromise SLTs' professional and ethical values, ultimately impacting children's care (Keane et al., 2012).

Being able to "empower" families "to do proper research" was another innovative solution identified. SLTs suggested "evidence making" (141) through "more research into group service delivery" (149) and the "most effective time to treat particular disorders" (149) would help with waiting list management. SLTs identified a need for "evaluation of 'while you are waiting' resources" (129) "that are easy to integrate into home routines" (60). Some SLTs acknowledged that although they were "yet to explore" if the resources provided to families to encourage active waiting have "an impact on the referral condition," it "allows parents to have heard the information before when I start to introduce it all during the assessment" (192). Development and evaluation of resources and information for supporting children and families on waiting lists were often identified as aspirational solutions rather than strategies the SLTs were already implementing in practice, and are consistent with recent research (McGill and McLeod, 2019, McLeod et al., 2020). People on waiting lists have been found to "long for information" but seldom receive it from health care services (Rittenmeyer, 2012).

SLT workforce.

The third theme identified in SLTs' responses about waiting list management related to the SLT workforce. SLTs described strategies related to recruitment, stating that more publicly funded SLT positions were "desperately" (119, 164) needed since there are "not enough positions to meet demands" (26). For some workplaces, there had been "no increase in staffing in almost 20 years despite marked growth in population" (164). One SLT described spending "40 years coping with waiting lists" and reported: "There are not enough SLTs in the public health system. Not then; not now...So much angst. So much discussion. So many years. Employ more SLTs - that

is how we can manage paediatric waiting lists” (160). Despite trying “many strategies”, SLTs reported “the only factor that has helped is when we have had periods of increased staffing, but when this ceases, the waiting lists grow again” (167). Recruiting “casual” SLTs to “conduct additional assessments when the waitlist starts to grow too quickly” (224) was effective in some workplaces. SLTs described the need for not only increased numbers of SLTs and positions, but for recruitment and retention of “skilled” (131), “well-trained” (39) SLTs “with experience” (225). Whilst many SLTs suggested recruitment and retention of SLTs were key waiting list management solutions, few identified specific strategies to recruit and retain skilled SLTs in the workforce such as “more training” (127) and “ongoing professional development opportunities” (184). The shortage of SLTs and other health professionals is a well-documented issue impacting children’s access to services (Keane et al., 2012, Lincoln et al., 2014).

Traditionally, speech and language therapy services for children have been provided on weekdays and most often within clinics. However, flexibility of the SLT was another waiting list management strategy identified by SLTs, which included “being flexible with work hours” (102), “scheduling options” (251), and “location options for service delivery” (176). Increased flexibility of service delivery, including location and session times, was one of the most common suggestions from parents for improving speech and language therapy services (Ruggero et al., 2012).

Increasing managerial support for the SLT workforce was identified as an inspirational idea which would help manage waiting lists, as “the worst examples of large waiting lists...are where there is chronic understaffing, appalling management support...and unreasonable workloads” leading to “subsequent staff retention issues” (184). SLTs who felt “overworked, overwhelmed and unsupported” with “little time or energy for inspirational ideas” just kept “continuing on with mostly the same

processes and programs”, rather than feeling supported to implement innovative actions to manage their waiting lists (250). Employees require a positive workplace environment in order to “flourish” and be innovative, which includes managerial support, provision of resources, enhanced autonomy, and reduced workloads (Colligan and Higgins, 2006).

Changes to SLT higher education were also suggested to help manage waiting lists. These included an “increase” in “the number of spaces in graduate programs” (227), and having a “better understanding of workforce need” (40) by teaching “aspects of managing a caseload, prioritisation and how to explain these to others” (270) as well as “service delivery models…taking into consideration telehealth” (270). SLTs also described implementing “university clinics and groups” (260) and having SLT students “carry out assessments” (21) to manage waiting lists. Involving students in the workplace may enable larger numbers of children to be seen or facilitate greater therapy doses for children already on SLT caseloads.

Inaction.

Some SLTs described inaction or passive strategies regarding waiting lists, although this was less common among the respondents. One SLT attributed their inaction to being “just a casual” and “I turn up, see the clients, and leave” (1). Some described facing challenges or barriers in their workplaces preventing them from taking action, including having “not enough staff” (227) and “little time or energy” (250), finding it “too difficult to set aside enough time” (21), or because actions were “not billable services” (42). Another challenge was incomplete or unclear referrals, and since “each child has individual needs and not all strategies are appropriate for every child” (236) it can be “difficult to provide ‘blanket’ strategies for parents” (236). SLTs also described a lack of control leading to their inaction. Some SLTs reported their waiting lists were “out of my hands” (62) and “entirely in the hands of managers”

(181). Other challenges were blocks to collaboration with other organisations at a “systems level” (133) which were “quite depressing” (133) or restrictions on service delivery, including how telehealth was “not yet allowed at our facility” (221). A lack of control and autonomy in the workplace can lead to distress, whilst the ability to influence and contribute meaningfully to decisions in the workplace has been found to reduce work stress, improve performance, and enhance job satisfaction (Colligan and Higgins, 2006, Israel et al., 1989).

Limitations

Despite efforts to report on a range of SLTs’ perspectives, including positive, neutral, and negative feelings about waiting lists, the participant sample may have been biased toward negative perspectives about waiting lists or those who actively manage their waiting lists, as those with strong views may have been more motivated to participate. Additionally, more participants were from Australia than from other countries. The perspectives reported in the present study therefore may not reflect the experiences and thoughts of all SLTs. Secondly, asking SLTs to answer based on a current or previous workplace may have affected the response accuracy if SLTs relied on memory to recall feelings about a previous workplace. Thirdly, since three of the questions that SLTs’ responded to in the present study were included in the online version of the questionnaire only, not all SLTs in the sample had the opportunity to answer all questions; however, the majority of SLTs (82.9%) completed the online version. Fourthly, combining SLTs’ responses to the waiting list management questions may have masked differences between current practice and aspirational solutions/strategies, but did reduce overlap and repetition of themes.

FUTURE DIRECTIONS AND CONCLUSIONS

Service delivery and workplace processes were reimaged by SLTs, including aspirations for the use of technology to provide support, information, and services to

children and families. Whilst many SLTs were actively managing their waiting lists, they acknowledged the lack of external evidence to support some of their waiting list management strategies. There is a need to determine which of the many waiting list management strategies SLTs described (Supplemental Appendix A) are effective or ineffective to ensure SLTs' and organisations' time, effort, and resources are invested in effective actions. Evaluation of waiting list management strategies through real-world research in clinical settings and localised, small-scale testing of solutions is valuable and can move the profession forward regarding waiting list management practices. However, some SLTs were passive and felt constrained by their organisation or the larger system. There is a risk of becoming increasingly service-focused, when the primary responsibility of organisations and SLTs should be the children and families who need services. The needs of children and families must remain at the forefront of decision-making regarding waiting list management. Greater transparency between SLTs' and families regarding service delivery decisions and workplace processes and policies may be beneficial to inform families about the options and alternatives available to them, in line with evidence-based practice (Ruggero et al., 2012).

Many potential solutions to systemic problems were described in individual workplaces; however, localised solutions can only address the issue of waiting lists to a limited extent. Recruitment of more SLTs and retention of skilled SLTs were key waiting list management strategies identified by SLTs and to realise these as possible solutions, governments and policymakers are urged to act to increase funding for speech and language therapy and support growth of the SLT workforce. System-level, top-down change in the supply and provision of services and funding, and collaboration across services and sectors, are needed to support effective bottom-up,

localised strategies in speech and language therapy workplaces and implement lasting solutions to waiting lists.

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Supplemental Appendix A. Actions to Manage Speech and Language Therapy Waiting Lists

Theme	Code	Sub-code	Points
1. SLT service delivery	1.1. Assessment	1.1.1. Triage/intake 1.1.2. Screening 1.1.3. Consultative services 1.1.4. Drop ins 1.1.5. Group assessment 1.1.6. “First stop” service 1.1.7. Monitoring 1.1.8. Single session model	
	1.2. Therapy	1.2.1. Therapy blocks 1.2.2. Group therapy 1.2.3. Intensive programs 1.2.4. One-on-one sessions 1.2.5. Weekend services	
	1.3. Collaboration	1.3.1. Partnerships with parents 1.3.2. Partnerships with professionals	1.3.1.1. Provision of advice/training 1.3.1.2. Home programs/information 1.3.1.3. Phone support 1.3.2.1. Multi-disciplinary involvement 1.3.2.2. Provision of advice/training 1.3.2.3. Use of non-SLTs to deliver services 1.3.2.4. Preschool/school-based programs

	1.4. Prevention-focused services	1.4.1. Embed in universal services 1.4.2. Public health promotion	1.4.1.1. Early detection
	1.5. Technology	1.5.1. Support/education 1.5.2. Method of service delivery	1.5.1.1. Devices (apps, websites, online groups) 1.5.2.1. Telehealth sessions
2. Workplace processes and policies	2.1. Funding	2.1.1. Alternate funding models 2.1.2. Public health funding	
	2.2. Administrative strategies	2.2.1. SLT caseload allocation 2.2.2. Waiting list policies 2.2.3. Scheduling 2.2.4. Administrative policies	2.2.1.1. Autonomy over the waiting list 2.2.1.2. Allocation based on client factors 2.2.2.1. Audits/reviews 2.2.2.2. Separate waiting lists (e.g., for weekend vs weekday appointments) 2.2.3.1. Cancellation lists 2.2.3.2. Flexible appointment times 2.2.4.1. Fail to attend/unable to contact policies 2.2.4.2. Registration forms 2.2.4.3. Limiting advertising 2.2.4.4. Streamlining of documentation
	2.3. Referrals	2.3.1. Referrals to other services 2.3.2. Accessing other services while on waiting lists	
	2.4. Organisational strategies	2.4.1. Standards	2.4.1.1. Benchmarks for waiting times 2.4.1.2. Key Performance Indicators

			2.4.2. Restrictions on services	2.4.1.3. Quality improvement 2.4.1.4. SLT being pressured into actions 2.4.2.1. Prioritisation guidelines 2.4.2.2. Closing the books 2.4.2.3. Costs for services 2.4.2.4. Discharge 2.4.2.5. Eligibility criteria 2.4.2.6. Limited service provision 2.4.2.7. Assessment depends on availability of therapy
	2.5. Evidence-based practice	2.5.1. Conflict/dilemmas		
3. SLT workforce	3.1. Recruitment	3.1.1. More SLT positions		
	3.2. Level of experience	3.2.1. Training/upskilling SLTs		
	3.3. Flexibility of SLT	3.3.1. Work hours		
	3.4. Time constraints			
	3.5. SLT higher education			
	3.6. Students in the workplace			
	3.7. Support from management/organisation			
4. Inaction	4.1. Challenging/difficult to act			
	4.2. Lack of control/“out of my hands”			

Part Three

Reimagining Services: Designing and Evaluating Waiting List Solutions

Chapter 5: Orientation to Part Three

Once you choose hope, anything's possible – Christopher Reeve

Introduction

Part Two of this doctoral research demonstrated the complexities, challenges, and consequences of waiting lists, but also a myriad of possible solutions and strategies. Potential solutions were system-based or localised (see Chapters 2 to 4) and related to service delivery, the workforce, or workplace processes and policies. Solutions may directly target waiting list duration (e.g., introducing screening assessments, employing more SLPs or assistants) or indirectly address waiting lists by compensating for the wait (e.g., by providing information and support to children and families on waiting lists).

One promising waiting list management strategy that has not previously been tested in speech and language services was the development of a website to support children and families while waiting. Parents have indicated that they search for information on the Internet while waiting for speech and language services, and since few existing websites are evidence-based and tailored to families on waiting lists, they are at risk of accessing poor quality, inaccurate information online (McAllister, McCormack, McLeod, & Harrison, 2011). Internet-based health interventions show promise (Bessell et al., 2002; Christensen, Griffiths, & Jorm, 2004), as do caregiver-led speech and language interventions (Roberts & Kaiser, 2011). Technology-based strategies were mentioned by professionals in Chapters 2 and 4, with 89.6% of SLPs ($n = 129$) reporting that a website would be a helpful and useful tool for supporting children and families on waiting lists (Chapter 4). Additionally, collaborations with SLPs in community health centres indicated that a website for families waiting for speech and language services would be a viable strategy that could easily translate into practice. Technology has more commonly been used to deliver services once children are already in the system and receiving services (e.g., via telehealth), rather than for those on waiting lists. If technology has been used, implementation with waiting lists has not been tested rigorously.

Part Three of this doctoral research drew on possible waiting list solutions outlined in Part Two and outlined the selection, design, implementation, and testing of one strategy: an evidence-based website for supporting children and families waiting for speech and language services. Part Three was undertaken in collaboration with practicing SLPs who obtained funding from the NSW Health Translational Research Grant Scheme (NSW Health TRGS). The grant was titled “Waiting for speech

pathology: Device versus advice?” (Davis et al., 2017-2019) and was awarded to four rural SLPs (Davis, Rohr, Roberts, Miller), my PhD supervisor (McLeod), and myself (NM, Nicole McGill). The aim of the NSW Health TRGS grant was:

To evaluate the effectiveness of three types of speech and language support for 3- to 5-year-old children on speech pathology waiting lists:
(1) advice (parent training about book sharing, language and sound stimulation),
(2) device (website containing speech and language information), and
(3) therapy
to determine which condition: improves speech production accuracy, improves expressive and receptive language skills, improves intelligibility, improves participation in daily activities, and decreases parent concern (NSW Health TRGS Grant Scheme full application, p. 6-7).

The NSW Health TRGS grant comprised two phases:

1. Website development: development of an evidence-based website (device) to promote active waiting for speech and language services. The PhD candidate (NM) undertook a 3-stage study to inform the design of the website (Chapter 6). Then the NSW Health TRGS team used this information to develop the website (see below for further details).
2. Implementation and testing of the website: evaluation of three types of support (therapy, advice, device) in two randomised controlled trials (RCTs). The PhD candidate (NM) undertook the Active/Passive Waiting Study in the state of Victoria, comparing the website (device) with a control condition (Chapter 7). Concurrently, the NSW Health TRGS team undertook the Advice/Device Waiting Study in the state of NSW, comparing the website (device), advice, and therapy (McLeod et al., 2020).

Phase 1: Website Development

Chapter 6 of this doctoral thesis informed the design of the evidence-based website (phase 1) through a 3-staged process involving questionnaires ($n = 119$), focus groups ($n = 16$), and an evaluation of existing websites and apps ($n = 25$) to obtain perspectives from members of the public regarding aspirations for a website and guide the website design (McGill & McLeod, 2019). Whilst recommendations from Chapter 6 informed the website design, the development of the website was undertaken in collaboration with the NSW Health TRGS grant team and NSW Health web designers and was *not* part of this PhD thesis. Figure 1 represents the website development process and highlights the contributions of the PhD candidate as part of this doctoral research in light grey (Chapter 6), and the NSW Health TRGS team in dark grey.

Appendix A outlines the chronological order of tasks within Phase 1 of the NSW Health TRGS grant, including tasks the PhD candidate (NM) participated in during the design and development of the website. Tasks which form part of this doctoral research are denoted by superscript ¹ in Appendix A (Chapter 6). Some aspects of website content and format recommended in Chapter 6 were incorporated in the website design; however, it was not possible to incorporate all the recommendations due to cost, time constraints, and style/format limitations of the NSW Health host website.

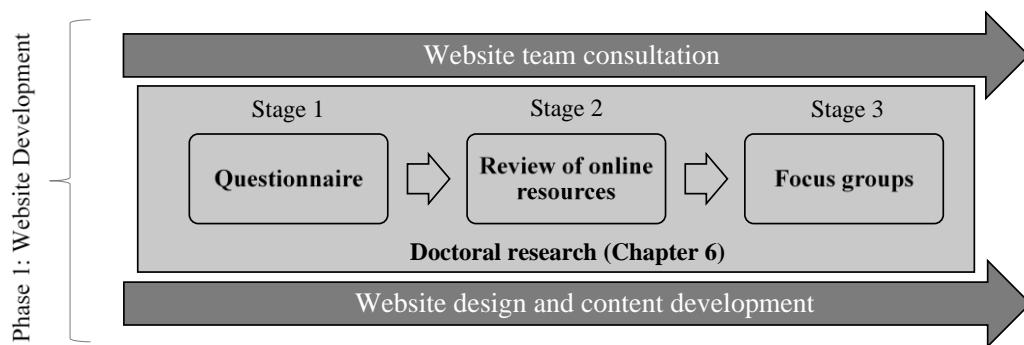


Figure 1. Visual Representation of Website Development (Phase 1). Light grey represents work undertaken for this doctoral research, dark grey represents work undertaken by the NSW TRGS grant team.

The final website titled *Waiting for Speech Pathology* (<https://wnswlhd.health.nsw.gov.au/our-services/speech-pathology>; Waiting for Speech Pathology Team, 2018) contained five online pages: (1) Home Page, (2) Children's Speech, (3) Children's Language, (4) Children's Literacy, and (5) More Information (example shown in Appendix B). Downloadable resources were included on each webpage (examples shown in Appendices C to E) as well as links to external websites, including some of the high-quality websites identified in Chapter 6. Animated videos created by the PhD candidate were included on the speech, language, and literacy pages to summarise written information (screenshots shown in Appendix F). After completion of the website, the PhD candidate evaluated its quality based on the same Trust It or Trash It? (Genetic Alliance, 2013) criteria used in Chapter 6 (Appendix G). The website achieved a score of 9 out of 9, which indicated it was a high-quality website based on those criteria and was comparable with the quality of exemplary websites identified in Chapter 6.

Phase 2: Implementation and Testing of the Website

Phase 2 of the NSW Health TRGS grant involved rigorously evaluating the website in two concurrent RCTs (see Figure 2):

1. Advice/Device Waiting Study (work undertaken by the NSW Health TRGS Grant team (including PhD candidate Nicole McGill; however, the resulting paper was not included in this doctoral research) (dark grey). The Advice/Device Waiting Study (McLeod et al., 2020) was undertaken in two community health centres in regional NSW and compared the provision of device (website), advice (one face-to-face advice session with an SLP), and therapy (12 sessions of face-to-face intervention with an SLP) to children on waiting lists. The abstract for the Advice/Device Waiting Study (McLeod et al., 2020) can be found in Appendix H.
2. Active/Passive Waiting Study (work undertaken as part of this doctoral research and presented in Chapter 7) (light grey). The Active/Passive Waiting Study (Chapter 7) was not funded by the NSW Health TRGS grant and was undertaken in a different Australian state (Victoria) with a different sample of children and caregivers (McGill, McLeod, Ivory, Davis, & Rohr, 2020).

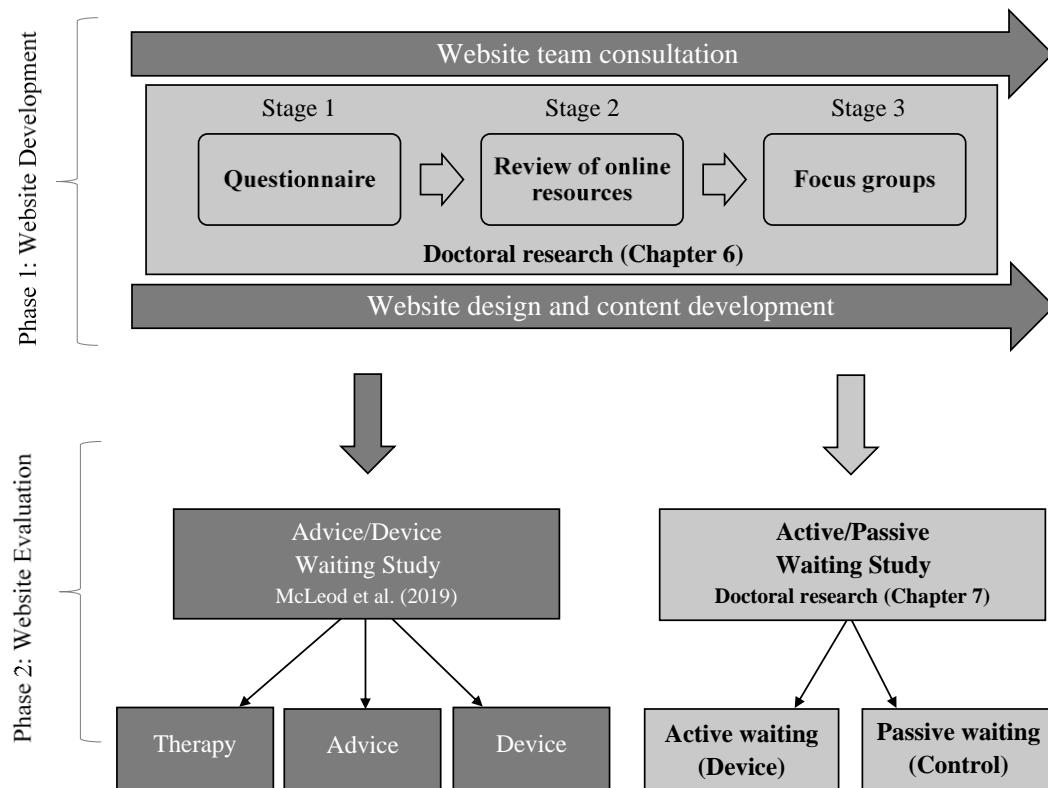


Figure 2. Visual Representation of Website Development (Phase 1) and Evaluation (Phase 2). Light grey represents work undertaken for this doctoral research, dark grey represents work undertaken by the NSW Health TRGS grant team.

The Active/Passive Waiting Study was described in the NSW Health TRGS grant application as follows:

AI McLeod and AI McGill plan to run a concurrent (unfunded) study in Victoria in a centre that does not provide services to children while on the waiting list. The Victoria study will assess children at referral then at 6 months with two conditions (1) wait (true control/usual practice), and (2) device. Data from the Victoria study will be able to be compared with data from the current study to determine the magnitude of change over the 6 months using a true control (NSW Health TRGS Grant Scheme full application, p. 9).

The Active/Passive Waiting Study (Victoria) was undertaken concurrently with the Advice/Device Waiting Study (NSW) to enable comparison with a control group to address the following concerns raised by the NSW Translational Research Grant Independent Selection Panel prior to awarding the grant:

Some issues were raised regarding study design and it is recommended that these are considered for incorporation into the protocol:

- Need to detect difference between advice and device, or advice and advice + device, vs. true control if possible (TRGS Full Application: Review Panel and Independent Selection Panel comments, p. 1).

A waiting list control condition was *not* ethically possible at the NSW sites as children on waiting lists received an advice session as usual practice. At the Victorian site, usual practice involved children waiting without support until they reach the top of the waiting list, so a waiting list control condition *was* ethically possible. The Active/Passive Waiting Study (Chapter 7) subsequently enabled valuable insights into the natural history of communication disorders, an under-researched area within speech-language pathology as natural history research is often not ethically possible (Law et al., 2000).

Part Three of this doctoral research was informed by the ICF-CY (WHO, 2007) and theory of preparative waiting (Giske & Gjengedal, 2007). Members of the public recommended that the website (Environmental Factors; e130 Products and technology for education) include content such as activities and strategies for families to implement with children to stimulate their speech and language development (e.g., Environmental Factors, e310 Support and relationships: immediate family; Body Functions, b167 Mental functions of language, b320 Articulation functions), and information about what to do in the community while waiting (Activities and Participation; d910 community life) (WHO, 2007). Assessments of child and caregiver outcomes and collecting

information regarding children's developmental history in Chapter 7 were also informed by the ICF-CY (e.g., Body Structures, s320 Structure of mouth; Activities and Participation, d140 Learning to read) (WHO, 2007). The design and implementation of a website aimed to provide information to families on waiting lists for speech and language services for their children ("Seeking and giving information," p. 90), including about typical speech and language development so families could identify whether they needed to see an SLP ("Interpreting clues," p. 90), and strategies for families to begin implementing at home while waiting rather than feeling helpless ("Balancing between hope and despair," p. 90) (Giske & Gjengedal, 2007).

Part Three of this doctoral thesis (Chapters 5 to 7) therefore detailed the work of the PhD candidate in the design and testing of a website as a possible waiting list management strategy, which was informed by the ICF-CY (WHO, 2007) and theory of preparative waiting (Giske & Gjengedal, 2007).

Never allow waiting to become a habit – Paulo Coelho

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Appendix A. Collaborative Development of the “Waiting for Speech Pathology” Website

Date	Task	People present	Actions/topics
22/5/17	TRGS team meeting	SM, ED, KM, NM, KR	<ul style="list-style-type: none"> a) Overarching principles for website (easy English, evidence based, appropriate for Australia, purpose and design) b) Initial ideas for content and layout c) Team to identify and list websites of interest
14/6/17	TRGS meeting	ED, SM, NM	<ul style="list-style-type: none"> a) Website hosting and required format/protocols b) Overarching messages/principles for website content: parent friendly, minimalist (clear, brief messages); expected ages for developmental milestones; strategies to implement at home; videos on book sharing, language stimulation, and speech sound stimulation.
23/6/17	TRGS team meeting	ED, KR, AR, SM, KM, ST, NM	<ul style="list-style-type: none"> a) Website content: key messages regarding book sharing, joint attention, prelinguistic skills, language correlating with play. b) Include expected norms for speech and language c) Example website layouts shown d) Website hosting and required format/protocols discussed e) Website architecture/design options (e.g., CSU)
23/6/17	Meeting Re: information organisation	NM, CD	<ul style="list-style-type: none"> a) Use of OneNote for compiling and organising information for evaluation of websites and gathering ideas for website layout
9/8/17	TRGS meeting	ED, SM, NM	<ul style="list-style-type: none"> a) Website intellectual property discussions b) Website sustainability – updates, version control c) Website hosting discussion – state-based versus national hosting d) Website content development: consider replicating advice condition handouts on website, include widget for Western NSW LHD Speech Pathology Facebook page.
16/8/17	TRGS meeting	ED, SM, NM	<ul style="list-style-type: none"> a) Website design and hosting discussions b) Contracts c) Ethics application progress d) Protocol development for randomised controlled trial

22/8/17 ¹	TRGS team meeting	ED, KR, AR, KM, ST, SM, NM	<p>Focus group 1 conducted face-to-face with meeting attendees. Discussed the team's aspirations and ideas for the website. Some topics/important themes were:</p> <ul style="list-style-type: none"> a) Ways to engage parents (text messages/emails, include dosages on the website) b) Widget for Western NSW LHD Speech Pathology Facebook page c) "Package the advice" and put on the website d) "Do no harm' home programs" e) Website responsiveness – "choose your own stories", answer questions then "these are the strategies for you" f) External links g) Helpful strategies to implement at home h) "Make it interactive" i) "Pinterest-y" with quality control" j) "Bridge" to accessing speech pathology k) Most important layout features – white space, plain language, tabs to click on, break up into sections (book sharing, speech, language) l) Developmental Occupational Therapy (DOT) style handouts – scripts for blocks, trains, cars, washing up, going to the shops
1/9/17	Website handout working group meeting	NM, KR, AR	<ul style="list-style-type: none"> a) Website content: <ul style="list-style-type: none"> i. Handout topics: Making longer sentences, using more words, asking questions, using language for different purposes, print knowledge, sound awareness ii. Name the handouts with parent friendly terms rather than speech-language pathology terminology iii. Link to relevant videos iv. Include cartoons to explain key concepts b) Website layout: sections on preparing for speech-language pathology sessions, normative data, prepare parents regarding involvement in sessions and homework tasks c) Rules for handouts: <ul style="list-style-type: none"> i. Heading at the top – consider phrase "Playing with..." rather than "teaching" ii. Limit colour to photos iii. Consider double sided handouts (front – 3 pictures down left hand side; back – 3 pictures down left hand side and 2 sentences of information for each)

6/9/17	TRGS meeting	ED, SM, NM	a) Planned agenda items regarding website design and logistics for upcoming meeting with NSW Health web designers: Can we have a dedicated site? Can we continually upload PDFs to website? Google analytics, source of photos, password protection, badging and Creative Commons, CSU website to keep similar format as other studies. Can we have access to someone on a regular basis towards end of year to organise the website? b) Agreed on proposed Talk Bites handout format
8/9/17	Website handout design meeting	CD, SM, NM	a) Layout of handout template b) Inclusion of Pixabay images
8/9/17 ¹	Questionnaire	NM	a) Commenced drafting questionnaire to obtain perspectives from members of the public regarding website content, format, features, and functions
12/9/17	Website design meeting	KH, ED, SM, NM	a) Requested password protection of website and making it a closed website: this is an IT issue. Can be a published page but not linked to any other menu tabs from the main site b) Google analytics is possible to record number of page hits and users
4/10/17	TRGS meeting	ED, SM, NM, KR, AR	a) Discussion regarding research process for consultation regarding website development (questionnaire, evaluation of online resources, focus groups) b) Powtoon costs for proceeding with developing cartoons c) Referencing and acknowledgement in footer of handouts d) Discussion regarding evidence to support main website content and content of handouts – NM to complete literature review of tier 1 population-based interventions e) Discussion regarding different theoretical paradigms among team – input and provision of opportunity versus output focused f) Aussie Animal Handout drafts presented as an alternative building on the Talk Bites idea. Talk Bites no longer to be double branded as CSU and NSW Health – CSU ownership only
6/10/17	Website handout meeting	ED, NM	a) Concerns raised regarding need for a disclaimer and additional information for parents on the handouts b) Core content needs to include: play with sounds, modelling, imitation, not practising mistakes, and a disclaimer
October – December 2017	Website handout design	ED, KR, CD	a) Multiple meetings regarding handout template design

11/10/17	TRGS meeting	ED, SM, NM	a) KR revising drafts of Aussie Animal handouts – discussion regarding copyright of rhymes/songs and other material. Discussion regarding single sounds on handouts vs groupings of sounds (e.g., front/back sounds)
13/10/17	Website handout meeting	ED, SM, NM, KR, AR	a) Revised draft of speech handouts delivered to team b) Topics for handouts brainstormed c) Bathurst team wanted the handouts on the website to be consistent with the advice condition resources. KR and AR volunteered to develop their ideal handouts for the website d) Cartoon key messages to come from NM's literature review and the main web content
18/10/17 ¹	TRGS meeting	ED, NM, SM	a) Questionnaire on Survey Monkey for feedback b) Aussie Animal handouts to replace Talk Bites on the website
23/10/17	TRGS team meeting	ED, SM, NM, KR, AR, KM, ST	a) Website handouts: need to add easier/harder words section, discussed handouts in the context of cycles approach, Zone of Proximal Development (ZPD) and evidence base b) Revised mock-up of website layout (content and button placement)
30/10/17	Website design meeting	KH, KC, ED, SM, KR, NM	a) Website access (unpublished page) b) Google analytics available c) Dual badging of information developed jointly for the website d) Website layout: launch page and four pages for next layer e) Reviewed visual mock-up of website layout f) External links: no permissions needed g) Graphic designer to develop suite of images and graphics h) Website content to be developed as series of MS Word documents for each webpage i) Timeline for website development agreed upon (website to go live in February 2018)
21/11/17	TRGS meeting	ED, NM, SM	a) Main website content in the process of being developed b) Graphics in the process of being developed
21/11/17 ¹	Questionnaire	NM, SM	a) Questionnaire went live and was distributed widely via professional networks
December 2017 ¹	Website usability	NM, CSU Usability Lab staff	a) Investigation regarding usability technology (e.g., eye gaze software) to incorporate in focus groups
1/12/17	TRGS meeting	ED, NM, SM	a) First draft of main website content completed and distributed to team for feedback b) Graphics distributed to team for feedback c) 98 respondents on questionnaire so far
9/12/17 ¹	Questionnaire	NM	a) Questionnaire closed

19/12/17 ¹	Focus group	NM	a) Focus group 2 was conducted face-to-face. Four participants provided ideas for the website content and layout and commented on the resources that had been developed
22/12/17	Website content	NM	a) Drafts of cartoon scripts sent to TRGS team for feedback
January 2018	Website content	NM	a) Cartoons completed and changes suggested by TRGS team incorporated
17/1/18	Website content	NM, KR	a) Readability scores obtained for main website content
23/1/18 ¹	Focus group	NM	a) Focus group interview schedule sent to ED and KR for comment
24/1/18 ¹	Focus group	NM	a) Face-to-face focus group 3 was conducted involving six participants. Focus group involved usability testing and commenting on the website and resources developed
29/1/18 ¹	Focus group feedback	NM	a) Summary of key themes/comments from focus groups collated and sent to TRGS team for feedback
31/1/18	Website revisions	NM	a) Summary of proposed website changes based on focus group feedback and TRGS team comments sent to TRGS team members for further feedback
5/2/18	Website revisions	NM	a) Requested website changes based on focus group feedback and TRGS team feedback sent to KH

TRGS, Translational Research Grant; **NM (Nicole McGill), PhD candidate**; SM (Sharynne McLeod), PhD supervisor; KH, web designer; CD, initials for university library staff member; CSU, Charles Sturt University; other initials represent community health SLPs.

¹ in “date” column indicates tasks undertaken as part of this doctoral research.

Appendix B. Example of Waiting for Speech Pathology Web Page: Children's Speech

Waiting For Speech Pathology - Children's Speech

WAITING FOR Speech Pathology

Speech refers to the way we make sounds to form syllables and words.

On this page:

- Children's speech - Overview
- What should a child know and when?
- What can I do to help?
- More Information

Children's speech - Overview

We use our lips, teeth, tongue, palate, and voice to make speech sounds so that people can understand what we say.

Some children have difficulty making speech sounds, putting sounds together, hearing/perceiving speech, or thinking about speech. Some children have difficulty with one or two sounds. Other children have difficulty with many consonants and vowels and are hard for others to understand.

Speech pathologists help children with speech difficulties.

For most children, there is no known cause for their speech difficulties. For some children, known reasons include: hearing loss, cleft palate, or a family member has had speech difficulties.

Some terms used to describe different types of speech difficulties in children include:

- speech sound disorders
- phonological disorders
- articulation disorders
- childhood apraxia of speech
- dysarthria

[Click here for a definition of what these terms mean.](#)

The short video below explains:

- What is speech?

Appendix C. Example of Waiting for Speech Pathology Website Handouts: Children's Speech

Speech Pathology



Back sounds



k g ng

 Back sounds are made with your tongue up at the back of your mouth.
Feel your tongue go up at the back for:
k (also spelled 'c') in *car*,
g in *go*, and
ng at the end of *wing*.

 Children sometimes replace back sounds (**k**, **g**, **ng**) in words with sounds made at the front of the mouth (**t**, **d**, **n**) as they are learning.
They might say: *tea* instead of *key*, and
dough instead of *go*.
Children usually learn to say back sounds by 3 years of age.

 Model back sounds when you are talking together.
Child: That's my *tup*.
You: There's your *cup*. Your *cup* is on the table.
Praise your child for trying to say back sounds.
It's OK if your child doesn't say the sounds after you.

 Talk about fixing up back sounds in words, and give your child an example in your own talking.
You: Let's *dough*. Oops! I said *dough* and I meant *go*!
I need to fix it up. Let's try to put our tongues up at the back for *go*.
Don't practice mistakes. It is OK to wait until you see a speech pathologist.

Western NSW LHD Speech Pathology Handouts can be copied using Creative Commons Attribution Non Commercial No Derivs 3.0 Unported License.
Creator: Katrina Rohr, MSLP, Bathurst Community Health Centre.
Photographs are from Pixabay (<https://pixabay.com/en/photos/>) and are freely available via CC0 Creative Commons.
Rohr, K. & Walling for Speech Pathology Team. (2018). *Back sounds*. Bathurst, Australia:
Western NSW Local Health District.
Retrieved from: <https://wnswlhd.health.nsw.gov.au/Pages/Waiting-For-Speech-Pathology.aspx>

Back sounds
Page 1 of 3

Handout reproduced with permission from the creator, K. Rohr.

**k**

Kimmy Koala

The **k** sound (also spelled **c**) is made with your tongue up at the back of your mouth.

It is a short, quiet sound.

Easier words: *cake, cook, king, cow, kick*

Harder words: *cat, kookaburra, kitten, kite, koala*

Sing with sounds: Sing a nursery rhyme

Pat-a-cake, pat-a-cake, Baker's man,

Bake me a *cake* as fast as you *can*.

Pat it, and roll it, and mark it with a 'B'

And put it in the oven for baby and me!

Hey diddle diddle, the *cat* and the fiddle,

The *cow* jumped over the moon,

The little dog laughed to see such fun,

And the dish ran away with the spoon.

Play with sounds: Use **k** words in your play together



Play outside with a ball.
Catch it, bounce it, roll it,
and *kick* it.



Pretend to be a
kookaburra.
Koo koo koo, kar kar!



Cook a *cake*, and *cut* it
into slices. Will you put
candles on top?

Read with sounds: Visit the library and borrow some books

Cows Can't Fly by David Milgram

Kiss the Cow! by Phillis Root

Come Down, Cat! by Sonya Hartnett

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Western NSW Local Health District.
Retrieved from: <https://wnswlhd.health.nsw.gov.au/Pages/Waiting-For-Speech-Pathology.aspx>

Back sounds
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Appendix D. Example of Waiting for Speech Pathology Website Handout: Children's Language



Helping children with language

You can help children learn words and sentences in different ways. You can model words in your own talking, share books and play together, and praise children for trying new words.



Model the way words and sentences are used in your own talking.

You: Let's put apples in the basket.
Child: Apples in.
You: *The apples are in the basket.*

It's OK if your child doesn't say the words after you.



Rephrase what your child says to include all the words in the right order, or to say something in a different way.

Child: Dog gone!
You: *The dog has* gone!
Where has the dog gone?



Turn taking when you are talking and playing together.
Pause and wait for your child to take a turn using words or gestures.

You: That puzzle piece doesn't go there! It won't fit! I'll try it here.
(Pause and look expectantly at the child)
Child: It won't fit!



Reduction

Shorten your sentences so that they are the same length or a bit longer than your child's sentences.

Child: Kick the ball.
You: *Bounce the ball.* (same length as the child's sentence)
I'll bounce the ball very high. (sentence is a bit longer)



Expansion

Add on a word or phrase to what your child has said.

Child: Bird.
You: *A bird in the tree!*
A little bird.

Adding on helps children hear how the sentence can be a bit longer.

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Language handouts
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Helping children with language

The more often children hear different words and sentences in their day, the more likely they will begin to understand them and use them in their own talking.



Use words to describe what you and your child are doing.

Child: (stacking blocks)

You: You're making a tower.

You put a block on the top.

Parallel Talk

Putting words with daily activities helps the words make sense to children.



Give choices when you are offering something to your child.

You: Do you want the red cup, or the green cup?

You want to go on the swing or the slide?

Binary choice

Choices help children get their message across more clearly.



Repeat key words often when you are playing and in daily routines.

You: Put your socks on first. Now one shoe on, and two shoes on!

Hats on, and we're ready to go!

Repeating gives children lots of chances to hear important words.



Praise your child for trying new words and sentences.

You: Great describing words.

I heard all of your words in that sentence, well done!

I like how you said...

Good trying!



Children benefit from opportunities to hear and practice talking as part of their day. Use words and sentences when you are:

Playing together,

Sharing books, and

At home (e.g., meals) and **out and about** (e.g., at the park).

Appendix E. Example of Waiting for Speech Pathology Website Handout: Early Literacy

Speech Pathology



Early literacy skills (sound awareness)

Sound awareness is an understanding of how sounds come together to form words. Sound awareness skills are essential for later reading and writing development.

Early literacy (sound awareness) skills include:

- Identifying sounds at the start and end of words (e.g., *tap* starts with a **t** sound),
- Breaking words into sounds (e.g., *bus* has three sounds, **b...u...s**), and
- The links between speech sounds and letters (i.e. the *sound* each *letter* makes).

Talk about sounds: Share books and talk about sounds



Play with sounds in words

Play 'I spy' using the pictures in books, or when you are outside.

I spy something *starting with a w sound*.

Make silly sentences using words that start with the same sound.

The *pelican* ate a *pear* and some *pancakes* at the *picnic*.



Talk about sounds in words

Talk about the sounds you hear at the start and end of words.

This word starts with the *same sound as your name*.

Dog and *day* both *start with a d sound*.

Bag and *peg* both have a *g sound at the end*.



Talk about sound-letter links

Look at letters in books, magazines, and on signs and labels.

Point to a letter as you talk about the sound it makes.

This letter is **s**. It makes a *ssss* sound.

Your name is *written* here. The *sounds* in your name are...

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Rohr, K. & Waiting for Speech Pathology Team. (2018). *Early literacy skills (sound awareness)*. Bathurst, Australia:
Western NSW Local Health District.
Retrieved from: <https://wnswlhd.health.nsw.gov.au/Pages/Waiting-For-Speech-Pathology.aspx>

Early literacy skills
Page 1 of 1

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**Appendix F. Screenshots of Waiting for Speech Pathology Website Videos:
Children's Speech**



McGill, N., & Waiting for Speech Pathology Team. (2018). *Children's speech: What it is and how to help*. Retrieved from <https://wnswlhd.health.nsw.gov.au/Pages/Waiting-For-Speech-Pathology-Childrens-Speech.aspx>

Appendix G. Evaluation of “Waiting for Speech Pathology” Website Quality

Trust It or Trash It? criteria ¹		Description and scoring	Scores
Who said it?	Who wrote it?	The author’s (or organisation’s) name is easy to find. ^a	1
		The authors have experience with the condition and are respected in the community and by their colleagues. ^b	2
	Who provided the facts?	You can tell where the information comes from - the sources are listed. ^a	1
	Who paid for it?	The sponsor (or organisation) has a lot of experience with the condition. ^a	1
		The information doesn’t try to sell a product or point of view. ^a	1
When did they say it?	When was it written or updated?	The information is current. ^a	1
How did they know?	How do you know this information pertains to you?	The medical information is based on research of many people.	1
	Does the information seem reasonable based on what you’ve read or know?	The information matches what you’ve found in multiple other sources. ^a	1
		If there are no other sources with the same information, it could be new, cutting edge research. ^a	N/A
Total score (out of 9)			9

^a1 = yes, 0 = no, N/A = not applicable; ^b 2 = researcher, academic, leading organisation, 1 = clinical experience, 0 = insufficient experience.

¹Genetic Alliance. (2013). *Trust it or trash it?* Retrieved from <http://www.trustortrash.org/>

Appendix H. Advice/Device Waiting Study Abstract (NSW Health Translational Research Grant)

McLeod, S., Davis, E., Rohr, K., **McGill, N.**, Miller, K., Roberts, A., Thornton, S., Ahio, N., & Ivory, N. (2020). Waiting for speech-language pathology services: A randomised controlled trial comparing device, advice, and therapy. *International Journal of Speech-Language Pathology*, 22(3), 372-386. doi:10.1080/17549507.2020.1731600.

Abstract

Purpose: To compare children's speech, language and early literacy outcomes, and caregiver empowerment and satisfaction following provision of: 12 sessions of direct intervention (**therapy**), or face-to-face **advice**, or a purpose-built website (**device**) while waiting for therapy.

Method: A 4-stage randomised controlled trial was undertaken involving 3- to 6-year-old children referred to speech-language pathology waiting lists at two Australian community health centres over 8 months ($n = 222$). Stage 1 (screening): 149 were eligible to participate. Stage 2 (pre-assessment): 117 were assessed. Stage 3 (intervention): 110 were randomised to advice (33), device (39), or therapy (38). Stage 4 (post-assessment): 101 were re-assessed by a speech-language pathologist blinded to the intervention condition.

Result: After controlling for baseline levels, children's speech (percentage of consonants correct) was significantly higher in the therapy group compared to the advice and device conditions. Caregivers' satisfaction was also significantly higher in the therapy condition compared to the device condition. There were no significant differences between the three conditions for children's intelligibility, language, and early literacy or caregivers' empowerment.

Conclusion: Therapy resulted in significantly higher speech outcomes than the advice and device conditions and was associated with significantly greater caregiver satisfaction. Provision of a website containing evidence-based materials or a single session of advice may be a viable alternative while children wait for therapy targeting intelligibility, language, and early literacy, and to empower caregivers.

Chapter 6: Design of a Waiting List Management Strategy

Paper 4

McGill, N., & McLeod, S. (2019). Aspirations for a website to support families' active waiting for speech-language pathology. *International Journal of Speech-Language Pathology*, 21(3), 263-274.
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Aspirations for a website to support families' active waiting for speech-language pathology

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Key words: Waiting, speech, language, children, parents, website

Running head: Active waiting website

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Abstract

Purpose: Children sometimes wait 12 months or longer to access speech-language pathology services. Information on websites may support families' active waiting for speech-language pathology; however, there are few user-friendly, evidence-based websites specifically designed for children and families for this purpose. The current study aimed to: (1) ascertain appropriate website content, format, features, and functions; (2) evaluate the quality of existing speech and language sites; and (3) obtain feedback on a prototype website.

Method: A 3-stage explanatory sequential mixed methods design was employed. Stage 1 involved 119 participants completing an online questionnaire recommending website content, format, features, and functions. Stage 2 involved evaluating the quality of 25 online sites about children's speech and language. Stage 3 involved focus groups with 16 participants to explore aspirations and feedback on a website to support active waiting.

Results: Participants wanted information about strategies to stimulate children's speech and language development; simple web architecture; and high readability. High scoring sites contained evidence-based information from trustworthy sources. Strategies from the theory of preparative waiting arose in the focus groups.

Conclusion: Participants considered easily identifiable, trustworthy sources of information, and user-friendly strategies and resources to be important on a website to support active waiting for speech-language pathology. The theory of preparative waiting may be a viable framework informing waiting for speech-language pathology for children with speech and language difficulties.

Introduction

When families are concerned about children's speech, language and communication skills, ideally they receive a referral, assessment, and intervention from a speech-language pathologist (SLP) in a timely manner. However, in reality, many children wait to receive an assessment or intervention after referral (Pickstone, 2014; Ruggero et al., 2012) and waiting lists are considered a "norm in contemporary healthcare" (Fogarty & Cronin, 2008, p. 469). In Australia, children most often wait up to six months for an initial assessment, and up to one month for intervention following an assessment; however, some children wait 12 months or longer for an initial assessment and/or intervention (Ruggero et al., 2012). Long waiting times for assessment and intervention are also reported in other Australian and international studies (Commonwealth of Australia, 2014; O'Callaghan, McAllister, & Wilson, 2005; Rvachew & Rafaat, 2014).

Waiting times vary across geographical locations and service providers (Ruggero et al., 2012). Waiting lists can be problematic because while waiting for services, children miss the benefits of early intervention when the foundations for wellbeing and lifelong learning develop. For instance, a delay in commencement of speech-language pathology intervention for children with speech difficulties until 4 to 5 years of age typically does not result in normalised speech outcomes (Rvachew & Rafaat, 2014). Waiting lists can deter families from seeking speech-language pathology services, which may mean children do not receive necessary support (Commonwealth of Australia, 2014).

Experiences of waiting

Waiting for health care can be described in three stages: (1) waiting for an assessment, (2) waiting for a diagnosis, and (3) waiting for intervention (Fogarty & Cronin, 2008). Individuals who wait for health care may experience feelings of stress, uncertainty, and powerlessness (Connolly & Gersch, 2013; Dew et al., 2013). The theory of preparative waiting (Giske & Gjengedal, 2007) was found to be a useful

theory to represent individuals' experiences of waiting for health care from clients' perspectives (Fogarty & Cronin, 2008). The theory of preparative waiting (Giske & Gjengedal, 2007) describes four strategies undertaken by individuals who are waiting for health care and informs the current study: (1) "seeking and giving information" (p. 90) refers to individuals making sense of their situation, reducing uncertainty, and attempting to predict what is going to happen to them by accessing information; (2) "interpreting clues" (p. 90) involves interpreting changes in symptoms, the examinations/assessments that they undergo, prioritisation within the health care system, and possible outcomes; (3) "struggling with existential threat" (p. 90) refers to worries about the impact the condition could have on their life, future, and others; and (4) "seeking respite" (p. 90) involves trying to "get strength to endure uncertainty" (p. 91) while engaging in the other strategies. "Balancing between hope and despair" (p. 90) is the guiding filter throughout the waiting process and individuals can display "rational awaiting", "denial", and "acceptance" patterns (Giske & Gjengedal, 2007, pp. 90-91). The theory has been applied to individuals hospitalised with gastrointestinal issues undergoing diagnostic workups (Giske & Gjengedal, 2007) and women awaiting diagnosis of breast disease (Poole & Lyne, 2000). The theory of preparative waiting (Giske & Gjengedal, 2007) may potentially be extended to include non-hospitalised individuals who are waiting for health care, to further validate or refine the waiting strategies (Fogarty & Cronin, 2008). Therefore, the theory may be appropriate to explore parents' experiences of waiting for speech-language pathology for their children.

Waiting for speech-language pathology has typically been seen as a passive process (Glogowska & Campbell, 2000). However, receipt of general and specialised information has been correlated with greater empowerment among families of children with disabilities (Fordham, Gibson, & Bowes, 2012) and individuals who

felt more empowered within the healthcare system were found to play a more active role during the waiting period (Feldman et al., 2002). Provision of information, including strategies to facilitate children's speech and language development, may empower parents to engage in active waiting, alleviate some stress and uncertainty, and lead to improvement in children's speech and language outcomes. There is evidence that parent-led interventions can support and improve children's communication development (Roberts & Kaiser, 2011); however, there is limited evidence that a small amount of parent training or indirect training is effective. For parent-led home therapy programs, high dosages and direct parent training to build skills is recommended (Tosh, Arnott, & Scarinci, 2017). A rapid review of evidence-based programs in Victoria, Australia, which were aimed at developing babies' and toddlers' communication skills identified ten different programs focusing on increasing parents' capacity (Murdoch Children's Research Institute, 2015). Just two of those ten programs involved provision of educational resources without direct parent training that led to improvements in children's language skills (Albaran & Reich, 2014; Christakis, Zimmerman, & Garrison, 2007). There was a lack of effective home-based interventions for children's speech and language development which did not require direct parent training (Murdoch Children's Research Institute, 2015) as well as a lack of research about families' active waiting for speech-language pathology.

Information seeking and the Internet

Researchers from the nursing and medical fields have shown that individuals actively seek information while waiting for a diagnosis (Giske & Gjengedal, 2007). Engagement in interactive health communication is common, where consumers access or transmit health-related information using an electronic device or communication technology, such as via the Internet (Cline & Haynes, 2001;

Robinson et al., 1998). For instance, 80% of adult Internet users in the US have searched for health information online (Fox, 2011). Individuals who have difficulty accessing necessary health services for various reasons, including being unable to book an appointment soon enough, are reportedly more likely to look for health information online (Amante et al., 2015). The Internet has become an important source of health-related information for both consumers and health professionals (Cline & Haynes, 2001) and may provide timely information and support to enhance care and health outcomes (Bessell et al., 2002). The Internet has been found to be an effective tool in delivering health interventions in the community (Christensen, Griffiths, & Jorm, 2004). Additionally, provision of educational information via a website to individuals waiting for health care has been found to reduce anxiety and lead to perceptions of increased social support (Scherrer-Bannerman et al., 2000).

While waiting for speech-language pathology services, parents search for information from a range of sources including the Internet (McAllister et al., 2011). Parents may have received little to no information about their children's potential communication difficulties from referrers or service providers, particularly if they are waiting for an assessment (stage 1) or diagnosis (stage 2; Fogarty & Cronin, 2008). Parents of children who are waiting for intervention (stage 3; Fogarty & Cronin, 2008) may know more about their child's areas of need, and in some cases have been provided with home programs for parent-led intervention, enabling them to potentially locate more relevant information online. With a plethora of mobile applications (apps) and websites available to families (Furlong et al., 2018), the Internet provides a way for families to access information "quickly, conveniently, and privately" (Porter & Ediripulige, 2007, p. 518). Consumers may use generic search engines to access information, meaning families could access poor quality sites¹

¹ Sites refers to websites and mobile applications (apps)

which lack evidence-based information and are not parent-friendly. There are few evidence-based sites tailored to children and families who are waiting for speech-language pathology, so families may be attempting to interpret or apply information from sites designed for a different purpose and audience and be at risk of receiving inaccurate information. Accurate information can help parents make informed choices and be more active in their child's management (Young, et al., 2005); thus, it is important for families to access quality sites.

Considerations for evaluating the quality of sites and online information

The quality of health information and online sites can be evaluated in a variety of ways. Online information can be evaluated in terms of its credibility, which reflects authoritativeness and trustworthiness (O'Keefe, 2002). Authoritativeness involves a judgement of whether the author or source of information is an expert who knows which information is truthful or evidence-based (O'Keefe, 2002) and includes: easily identifiable authors or sources, references to research or publications, and links to other sites which are monitored (Adelhard & Obst, 1999; Silberg, Lundberg, & Musacchio, 1997). Trustworthiness refers to the integrity and truthfulness of the information source, which includes referencing of sources and avoiding claims which lack evidence (O'Keefe, 2002). Other criteria to consider when evaluating the quality of sites include: currency, accuracy, logical organisation, readability, and intelligibility of the information (Adelhard & Obst, 1999; Silberg et al., 1997).

Important considerations regarding appearance and format when evaluating the quality of sites include evidence of combining text with visuals to suit the users' preferences, minimising clutter, use of easy-to-read text, and simple terminology (Australian Commission on Safety and Quality in Health Care, 2017; Lynch & Horton, 2016; Post, 1996; Rosenfeld, Morville, & Arango, 2015). Other important web design features include simple navigation and architecture to make information

accessible, consistent layouts and graphics, accurate labelling of links, and usability (Cline & Haynes, 2001; Lynch & Horton, 2016).

Usability reflects a website's ease of use and contributes to the quality of the user experience. Website usability consists of five measurable components: (1) "learnability", how quick and easy it is for users to complete basic tasks when using a website for the first time; (2) "efficiency", the speed of task performance; (3) "memorability", how quickly users can regain proficiency of task performance after a break from using a website; (4) "errors" or "error forgiveness", the number, severity, and recovery from errors on the website; and (5) "satisfaction" or "delight", how enjoyable or pleasant the website is to use (Lynch & Horton, 2016; Nielson, 2012b, n.p.). Other aspects of user experience to consider include "ease of orientation", how well users can judge their locations within the website and navigate through the website, and "accessibility", how efficiently users with sensory or physical difficulties can use the website (Lynch & Horton, 2016, n.p.). Usability studies often involve user testing to improve website quality and address design flaws which impact the user experience (Nielson, 2012b; Schade, 2017). Usability studies typically involve three components: (1) identifying representative users of a website (such as parents and SLPs for a website about children's speech and language); (2) asking users to perform "representative tasks" to test aspects of the website and identify limitations; and (3) observing what users do and say when using the website and listening to their feedback (Lynch & Horton, 2016; Nielson, 2012b; Schade, 2017). Usability testing is most useful iteratively, involving small user tests and revisions between each test (Nielson, 2012b).

Whilst consumers, including parents, seek health information on the Internet, many sites and information are of unknown credibility. Apps for treatment of children with speech sound disorders have been evaluated for quality and efficacy

(Furlong et al., 2018), but there remains a need to evaluate the quality of sites about children's speech and language more broadly, which parents may be accessing while their children are waiting for speech-language pathology. Additionally, few sites are dedicated to supporting parents of children with speech and language difficulties who may have little to no information about their children's communication needs while waiting for speech-language pathology services.

Research aims

The current study informs a larger study aiming to design a user-friendly website to support families to play a more active role throughout each stage of waiting for speech-language pathology services for preschool-aged children with speech and language difficulties. The specific aims of the current study were:

1. To ascertain appropriate content, formatting, features, and functions to include on the website
2. To evaluate the quality of existing sites about children's speech and language
3. To obtain feedback on a prototype website developed in response to aims 1 and 2

Method

An explanatory sequential mixed methods study (Creswell & Creswell, 2018) comprising three stages was adopted to design an active waiting for speech-language pathology website: (1) online questionnaire (aim 1), (2) evaluation of online sites (aim 2), and (3) focus groups (aims 1 and 3).

Stage 1: Online questionnaire

Participants

One hundred and nineteen members of the public answered an online questionnaire and consented to their results being analysed. Members of the public were recruited because the website will be made publicly available and may be useful for any individuals who live with, work with, and support children with speech and

language difficulties. Of the valid responses, there were more females ($n = 87$, 93.6%) than males ($n = 6$, 6.45%) and two-thirds of participants were under 40 years of age ($n = 62$, 66.7%), with participants' ages ranging from 20 to 70 years. The majority lived in Australia ($n = 88$, 94.62%), with other participants living in Republic of Ireland, The Netherlands, New Zealand, and UK. Most participants lived in large towns ($n = 31$, 33.7%), smaller towns ($n = 27$, 29.4%), and major cities ($n = 25$, 27.2%). The majority of participants either had a bachelor's degree ($n = 52$, 55.9%) or a postgraduate degree ($n = 32$, 34.4%). Over half of participants were SLPs ($n = 56$, 62.2%) and 19.1% ($n = 17$) of participants were educators who primarily worked with preschool and primary school-aged children. Of the educators, twelve ($n = 12$, 80.0%) had students who had been on a waiting list for speech-language pathology services. Most participants spoke English at home ($n = 86$, 93.5%) with other home languages including Dutch, Serbo-Croatian, Cantonese, and Gujarati. Approximately half of participants indicated they were parents ($n = 51$, 56.0%) and of these, approximately half had a child under the age of 8 years ($n = 26$, 51.0%). A quarter of the parents had a child with speech or language difficulties ($n = 13$, 26.0%) and of those, eight (57.1%) had been on a waiting list for speech-language pathology.

Instruments

An online questionnaire was developed to obtain a broad range of ideas for website content and layout, and suggestions of exemplary sites from interested members of the public or future users of the website. Questions were informed by literature about website design and architecture, and online information quality (Adelhard & Obst, 1999; Australian Commission on Safety and Quality in Health Care, 2017; Cline & Haynes, 2001; Lynch & Horton, 2016; Post, 1996; Rosenfeld et al., 2015; Silberg et al., 1997). Participants were asked to rate the importance or appeal of various website features, such as layout and appearance, and type of content

they would like to see on a website (e.g. videos, printable resources) using a five-point Likert scale (0 = not important at all, to 4 = very important). Free-text questions were included for participants to list their favourite websites, apps, or other online resources (firstly about any topic and then more specifically related to children's speech and language) and other ideas and aspirations for the website, including important topics not already listed in the previous questions.

Procedure

Participants were recruited via purposive and snowball sampling and completed the questionnaire online. The questionnaire was distributed via email to members of the International Expert Panel for Multilingual Children's Speech, the research team's professional and social networks, social media (Twitter and Facebook), and word of mouth. The first page of the questionnaire contained details about the study and ethical approval. Clicking "continue" on page one indicated participants' consent. Response data were compiled by online questionnaire software.

Analysis

Quantitative data were predominantly nominal and ordinal data, analysed using descriptive statistics. A weighted average score (out of a possible total score of 4) was calculated for each aspect of format, feature, or function that participants rated on a five-point scale. Thematic analysis of qualitative data was undertaken using NVivo (QSR International Pty Ltd, 2012) with codes informed by preliminary analysis and the theory of preparative waiting (Giske & Gjengedal, 2007).

Stage 2: Evaluation of online sites

Online sites

Ninety-two sites about children's speech and language were nominated by participants in stage 1. Sites were screened for inclusion in the evaluation using a four-step inclusionary process: (1) sites needed to have been nominated by two or

more participants in stage 1 ($n = 27$, 29.4%); (2) of those sites, they needed to contain content about children's speech and language² ($n = 26$, 96.3%); (3) of those sites, there needed to be sufficient detail provided by participants in their questionnaire responses to locate and evaluate the sites online ($n = 25$, 96.2%); and (4) only subscription-free content on the sites was included in the evaluation. Twenty-five sites were included in the evaluation, comprising 23 websites (92.0%) and two apps (8.0%).

Instruments

Nine criteria were used to evaluate sites which were informed by the Trust It or Trash It? tool (Genetic Alliance, 2013), a tool designed to evaluate the quality of online materials about genetic conditions and guide the development of new materials. The Trust It or Trash It? tool outlines three overarching questions to consider when evaluating the quality of online information: (1) "Who said it?", which evaluates credibility of information and sources; (2) "When did they say it?", which evaluates currency of information; and (3) "How did they know?", which further evaluates credibility as well as accuracy of information (Adelhard & Obst, 1999; Genetic Alliance, 2013; O'Keefe, 2002; Silberg et al., 1997). Each overarching question lists aspects to consider when evaluating online materials. An example of a criterion used in the evaluation is "You can tell where the information comes from - the sources are listed" (1 = Yes, 0 = No), which relates to question (1) "Who said it?" and forms part of the evaluation of authoritativeness (credibility) of information (Adelhard & Obst, 1999; Genetic Alliance, 2013; Silberg et al., 1997). Sites could obtain a maximum score of 9 using the Trust It or Trash It? criteria.

² The primary intent was to identify sites focused on children with speech and language difficulties of unknown causes. However, if sites were designed for children with known causes for their speech and language difficulties or children with complex communication and additional developmental needs, this was not an exclusionary factor.

Procedure

Sites recommended by two or more participants in stage 1 that met the inclusionary criteria were evaluated using Trust It or Trash It? (Genetic Alliance, 2013) criteria. Demographic data were also recorded (e.g. resource type, intended audience). Where broad websites were recommended (e.g. large sites belonging to organisations), search terms such as *speech*, *language*, and *parents* were entered into the website search bar or webpages were scanned for content relating to those terms. Data were coded numerically and entered into a Microsoft Excel spreadsheet, using binary coding (e.g. “The author’s name is easy to find”: 0 = No, 1 = Yes) or three-way coding (e.g. 0 = No relevant information provided about the characteristic being examined; 1 = Provides some information but does not meet the criterion; and 2 = Sufficient detail provided to meet the criterion).

Analysis

Quantitative data were analysed in Microsoft Excel and a range of descriptive statistics were undertaken. Sites which scored highly for quality informed the content development and design of the waiting for speech-language pathology website.

Reliability and validity

Evaluation of the sites was undertaken by the first author. Five (20%) of the sites were randomly selected and independently coded by another experienced SLP. The percentage of agreement between the two reviewers was 89.1% for 55 data points. A percentage agreement above 70% is typically considered to be adequate inter-rater reliability (Multon & Coleman, 2018).

Stage 3: Focus groups

Participants

People with experience or an interest in children’s speech and language were invited to participate in focus groups via purposive and snowball sampling at three

different time points (prior to each focus group). Participants were recruited via emails to the research team's professional and non-professional networks, social media, and word of mouth. Participants were also recruited after indicating interest following the stage 1 questionnaire. Sixteen participants attended three focus groups (Group 1, $n = 6$; Group 2, $n = 4$; Group 3, $n = 6$). All participants were female ($n = 16$, 100.0%) and were located in large towns ($n = 9$, 56.25%) or in rural locations ($n = 5$, 31.3%) in the states of NSW and Victoria, Australia. The majority of participants had a bachelor's degree ($n = 8$, 50.0%) or a postgraduate degree (e.g. Masters/PhD; $n = 7$, 43.8%). Participants included SLPs ($n = 12$, 75.0%), an educator ($n = 1$, 8.0%), and a health nurse ($n = 1$, 8.0%). Of those participants, nine were parents (56.3%), four of whom had children who were aged under eight years (44.4%). Twelve participants indicated they had searched online for information about children's speech and language (75.0%). Two participants (12.5%) attended more than one focus group.

Instruments

A brief questionnaire was developed to obtain demographic data from participants.

Semi-structured focus group schedules were developed to outline participants' rights and the purpose of the research, to guide and promote consistency across the focus groups, and ensure nothing was missed (Wilkinson & Birmingham, 2003). The semi-structured focus group schedules were informed by literature in the areas of waiting for health care (Giske & Gjengedal, 2007), usability testing (Lynch & Horton, 2016; Nielson, 2000, 2012ab; Schade, 2017), web design and architecture (Cline & Haynes, 2001; Lynch & Horton; 2016; Rosenfeld et al., 2015), and preliminary findings from the stage 1 questionnaire responses. Topics included aspirations for the website, website features and content, feedback on resources developed for the website, and

some qualitative usability testing principles to obtain feedback on a website prototype (Schade, 2017).

Procedure

Participants provided consent to participate in the focus groups by signing and returning consent forms to the first author. The focus groups were conducted sequentially over a five-month period whilst the website was being developed. Focus groups were conducted face-to-face by the first author and each focus group took approximately one hour. Semi-structured focus group schedules guided the topics of discussion, beginning with open-ended questions followed by more specific questions using a “funnelling technique” (Wilkinson & Birmingham, 2003, p. 47). Probes and follow-up questions were used to clarify comments and obtain further detail when necessary. The interviewer remained as neutral as possible regarding tone of voice, body language, and mannerisms to encourage the participants to express their own “candid views” (Yin, 2011, p. 137). Focus group 1 predominantly focused on aspirations and generation of initial ideas for the website. Focus group 2 explored preliminary findings from the stage 1 questionnaire about website content, features and functions. Focus group 3 involved seeking feedback on a prototype of the website and undertaking aspects of qualitative usability testing. In focus group 3, participants were emailed the link to the beta version of a website developed in response to the earlier stages of this research. They were asked to access the site on their own device and explore and comment. Aspects of qualitative user testing were incorporated based on the components described by Nielson (2012b), including providing representative hypothetical tasks where participants used the website to locate relevant information. For example, participants were given the following scenario: “You have/are working with a 3-year-old child who is hard to understand. Use the website to find information about whether they are developing appropriately

for their age". Leading terms or words found on the website tabs or interface were removed from the tasks to avoid priming participants with clues for locating the information, thus enabling more accurate testing of the website (Schade, 2017). Participants took turns using the website displayed via a projector screen in front of the group. The group discussed where on the website they would look for relevant information to complete the tasks, the accessibility of website content, the layout of the website, and their successes and difficulties with using the website (Nielsen, 2012b). Focus group 1 was audio recorded and focus groups 2 and 3 were audio and video recorded. All focus groups were transcribed verbatim.

Analysis

Analysis began during the focus groups, as clarifying the meaning of participants' responses enabled some of the responses to begin to fall into themes (O'Toole & Beckett, 2013; Yin, 2011). Where appropriate, focus group transcripts were emailed to participants for member checking (O'Toole & Beckett, 2013). Thematic analysis of qualitative data from focus group transcripts was undertaken (Yin, 2011) using NVivo software (QSR International Pty Ltd, 2012). Nodes were informed by findings from participants' qualitative responses in the stage 1 questionnaire and the theory of preparative waiting (Giske & Gjengedal, 2007). The author coded text throughout the three transcripts, identifying themes or ideas. Any data that did not fit the predetermined nodes were given a new node. The first author completed multiple readings of the transcripts, discussed the coding with the second author, and allowed time to elapse between readings and coding of the data to distance herself from the research and increase reflexivity (Creswell & Creswell, 2018; O'Toole & Beckett, 2013). Again, time elapsed following coding to give distance to the data, then the first author became reimmersed in the data, reviewed the

meaning statements in the various nodes, and linked nodes together (O'Toole & Beckett, 2013).

Results

Stage 1: Online questionnaire

Most participants ($n = 99$, 84.0%) responding to the online questionnaire indicated that they had searched online, viewed websites, or used apps relating to children's speech and language. The most popular speech and language sites identified by participants are outlined in stage 2.

Website content

Reflections about existing sites. When participants were asked to describe what they liked about existing sites addressing children's speech and language, participants most commonly mentioned the content. Participants liked the ability to access information, handouts, and printable resources. These included "fantastic speech and language handouts for parents". Participants also valued evidence-based content and trustworthy sources. For example, when providing a rationale for their choice of recommended sites, one participant wrote "good information that you can trust", and another described how the articles on their recommended sites were "well researched and based on current evidence".

Aspirations for a waiting for speech-language pathology website. Participants were asked to rank a range of topics for website content in order of importance for inclusion on a website about children's speech and language while waiting for speech-language pathology (Table I). Overall, participants indicated that the top 10 most important topics to include were: reading with children ($M = 3.83/4$), children's speech development ($M = 3.76/4$), building vocabulary ($M = 3.69/4$), how to help children learn more words ($M = 3.64/4$), helping children to be understood by others ($M = 3.63/4$), songs and story ideas for children ($M = 3.59/4$), when children should

have a hearing test ($M = 3.53/4$), rhyming and sound awareness ($M = 3.49/4$), how to help children answer questions ($M = 3.48/4$), and getting ready for school ($M = 3.39/4$). There were minor differences when SLP versus non-SLP participants' responses were analysed separately. For instance, non-SLPs ($n = 34$) considered including information about pronouncing speech sounds to be more important ($M = 3.35/4$) than SLPs did ($n = 56; M = 3.23/4$), whilst SLPs thought it was more important to include information about the SLP role ($M = 3.41/4$) than non-SLPs did ($M = 3.35/4$).

When asked to describe what else they wanted to see on a website for children and families waiting for speech-language pathology, participants frequently suggested inclusion of information about home practice and strategies to help support children's communication development in the interim. For example, one participant wanted content describing "simple ways to start to help that can't hurt", while others emphasised the importance of "access to fun and practical activities" which "families can embed into everyday activities". Participants' ideas about what the strategies for families could involve were predominantly input-focused, such as "general speech and language stimulation strategies (e.g. book reading/sharing, modelling correct language or sounds in words for child[ren] to hear)." Many participants also wanted information about referrals and accessing services to be included. For example, one participant wrote that including information about "where to generally find speech pathologists and how to refer" was important. Participants suggested including information about other services in the community for families to access, such as library programs, play groups, mental health services, and social media groups. For instance, one participant described how it was "important that families do the other supportive things they can do whilst waiting - socialise, join groups, go to settings". Participants also wanted content about typical communication development,

including information about “milestones,” “red flags”, and “what to worry about” so that families could identify and act early regarding their concerns “rather than waiting to see if it improves on its own.”

Website format, features, and functions

Reflections about existing sites. Participants described their favourite websites as “enjoyable,” “parent friendly,” and “easy to use and read”. Web architecture and simple navigation were important. One participant liked a site that “directs you to resources/recent information”, while another recommended sites that were “easy to navigate and find information and resources”.

Aspirations for a waiting for speech-language pathology website. Participants were asked to rank various aspects of format, features, and functions in order of importance for inclusion on a website about children’s speech and language while waiting for speech-language pathology (Table I). Participants indicated that the top 10 most important aspects of website format, features, and functions to include were: obvious navigation and icons ($M = 3.82/4$), simple language and terminology ($M = 3.78/4$), practical activities ($M = 3.75/4$), simple text and font ($M = 3.71/4$), printable resources ($M = 3.57/4$), a searching tool ($M = 3.56/4$), videos and animations ($M = 3.32/4$), links to other websites ($M = 3.28/4$), responsiveness ($M = 3.26/4$), and sources of evidence and references ($M = 3.26/4$). There were differences when SLP versus non-SLP participants’ responses were analysed separately. For instance, SLPs ($n = 56$) placed higher importance on the inclusion of sources of evidence and references ($M = 3.4/4$) than non-SLPs did ($n = 34; M = 3.03/4$), whereas non-SLPs valued responsiveness ($M = 3.5/4$) of a website more highly than SLPs did ($M = 3.16/4$).

When asked to describe other features to include on a website for children and families waiting for speech-language pathology, participants commonly mentioned

website usability. Participants wanted simple web architecture and “interactive, clear pathways to desired information”. Readability of the website and use of plain “easy” English was considered “vital”. One participant highlighted the importance of usability and readability when they wrote how “it needs to be a website that is straightforward...without too much technical jargon, not too convoluted, and straight to the point”.

Stage 2: Evaluation of online sites

A total of 92 sites were recommended by participants in stage 1. The websites about children’s speech and language that were most frequently recommended by participants in stage 1 were published by: Dr Caroline Bowen ($n = 36$; www.speech-language-therapy.com/), Speech Pathology Australia ($n = 27$; www.speechpathologyaustralia.org.au), Raising Children Network ($n = 14$; www.raisingchildren.net.au), American Speech-Language-Hearing Association ($n = 12$; www.asha.org), and Mommy Speech Therapy ($n = 12$; www.mommyspeechtherapy.com). Of the 25 sites included in the evaluation, Table II lists those that achieved the highest scores (maximum score of 9) on the Trust It or Trash It? (Genetic Alliance, 2013) criteria. These scores indicated that the sites were evidence-based and higher quality. Many of the sites not included in Table II did not score highly for authoritativeness and trustworthiness or were commercially motivated (Adelhard & Obst, 1999; O’Keefe, 2002; Silberg et al., 1997). Whilst the sites focused on aspects of children’s speech and language, none of the sites were purposely designed for children and families waiting for speech-language pathology or to support families’ active waiting for services.

Stage 3: Focus groups

All three focus group transcripts were analysed together in NVivo (QSR International, 2012). Three overarching themes arose from the focus groups: (1)

website content, (2) website format, features, and functions, and (3) preparative waiting.

Website content

Participants frequently discussed website content during the focus groups.

Most commonly, participants discussed the inclusion of home practice ideas and strategies to help children's communication development. This included a need for advice about what parents or other users of the site could do to develop and support children's communication while waiting for speech-language pathology, including "helpful things that you can do at home whether you've been referred to a speech pathologist or not". One participant commented "if it has links...to activities and ideas for how to help, I think that's really good". Strategies to support children's development in the areas of speech, early language, and book sharing were desired. Strategies to support children's language development commonly arose in the focus groups, with one SLP saying "I would be happy if this website had three language videos that showed recasting, focused stimulation, and...following a child's lead in play...if a parent could do those three language stimulation things then that would be a big change". Participants discussed the inclusion of links to existing resources and the development of new resources for the website, including handouts, information sheets, and assessment or therapy resources. One participant commented "I like the idea of the printable resources, and practical activities. That would take people back there, rather than just using it as a one-off information source".

Content about typical communication development, including "age-appropriate pronunciations", was another common theme. One participant wanted the website to be "somewhere where parents can go and get some information on what would be expected of a child their age, when to be concerned, when to refer".

Another key theme arising from the focus groups was trustworthiness of the website content, including the need for evidence-based content and information from or based on trusted sources. One SLP wanted the website to be “a little bit ‘Pinterest-y’ but with quality control”. Participants wanted information on the website to be regularly “updated”.

Website format, features, and functions

Participants discussed aspects of website format, features, and functions in the focus groups and most frequently spoke about website layout and format. Participants described the need for simple, appealing layouts, and the appearance of the website and resources. Important considerations for layout included “not being busy” and having “lots of white space” and “clear tabs”. Layout and format were commonly discussed during usability testing. For instance, participants preferred text to be “displayed in a really easy table” where possible.

Usability and web architecture also commonly arose in participants’ discussions. “Simple” navigation and architecture were important considerations when designing a website, for instance “the home page might be quite simple and not too overwhelming, but as you start to get into some more of the links in the website then...more information comes out.” One participant’s idea for website architecture was to have a “break out sort of set up where it’s got a main paragraph which then drops down and expands”.

Readability of the website and the use of plain English were also important. This included minimising jargon and ensuring information was worded simply for users. In focus group 3, participants commented that written information on the prototype website could be simplified to “get rid of” any “fluff and extra” words which “just looks like more work for the parent to read”. Including images to “back up the words” was suggested as one way to make the information more readable.

Participants liked the use of animated videos on the prototype website to summarise key written information in a more accessible way. One parent said that “as a layperson...what’s contained in that little video would be of particular interest to me...that would be my port of call”.

Preparative waiting

The third overarching theme from the focus group discussions reflected strategies from the theory of preparative waiting (Giske & Gjengedal, 2007). “Seeking and giving information” (p. 90) and “interpreting clues” (p. 90) were the two strategies which arose most frequently throughout the focus groups. “Seeking and giving information” (Giske & Gjengedal, 2007, p. 90) was reflected in a parent’s comment: “As a parent, I’d like to be able to look at it and go, ‘oh yeah, that’s my child. I’m going to find something useful here’”. This highlighted the need for parents to find information relevant to their own children. Seeking information to learn new strategies was highlighted in a parent’s comment, “I’m going to learn something on here to help them make this sound”. Similarly, another participant asked, “rather than waiting, what else could we do?”, which reinforced the desire to find information to help children while waiting rather than waiting passively. “Interpreting clues” (Giske & Gjengedal, 2007, p. 90) involves using information to confirm or validate concerns. One participant described how some parents “know something’s up, something’s not right...they’re just looking for accurate information telling them that...and validating their concerns”. Another participant described how some parents are “not sure whether they’ve got a problem or not... and they’re wanting that clarified”, thus highlighting the need for the website to include information about typical development. Similarly, a participant commented on the importance of parents interpreting information about typical development to detect difficulties early and “see someone at this stage” to act on them.

The other three preparative waiting strategies of “struggling with existential threat”, “seeking respite”, and “balancing between hope and despair” (Giske & Gjengedal, 2007, p. 90) arose less frequently in the focus groups. The following participant’s statement is an example of “struggling with existential threat”: “The last thing you want to do is get the person or parent all stressed out and despondent...‘this is worse...I can’t help and now I’ve got to wait 12 months’”. This statement highlighted the worry that parents may have about the future and their ability to meet the needs of their children. “Balancing between hope and despair” (Giske & Gjengedal, 2007, p. 90) was also evident, where parents may feel helpless and disempowered to do anything to help their children while waiting. Additionally, the acceptance pattern for “balancing between hope and despair” also arose during the focus group discussions, when one participant described “that acceptance of ‘yes, you do need to act’”. An example of “seeking respite” involved problem solving “what else can I do to get in to see someone” for help with their child’s communication, including exploring funding options to access services.

Discussion

This 3-stage explanatory sequential mixed methods study identified the desired content, features, and functions for websites for children and families who are waiting for speech-language pathology. The quality of existing sites about children’s speech and language was evaluated and feedback on a prototype website was obtained.

Participants in both stages 1 and 3 valued the ability to access information, handouts, and printable resources on websites about children’s speech and language. Most commonly, participants wanted information about strategies and practical ways for families to help facilitate children’s speech, language, and early literacy development while waiting for speech-language pathology services. Preliminary

evidence for parent-led home programs provides some support for such strategies (Tosh et al., 2017). The lack of evidence-based interventions for building parents' capacity to facilitate children's communication development which require no direct parent training, highlights a gap in this area (Murdoch Children's Research Institute, 2015). The participants' need for information was consistent with the "seeking and giving information" strategy within the theory of preparative waiting (Giske & Gjengedal, 2007, p. 90), where individuals seek out information to help them "make sense of their situation" (p. 90) and make predictions about outcomes. Additionally, participants wanted information about typical development or communication milestones, which may demonstrate the strategy of "interpreting clues" (Giske & Gjengedal, 2007, p. 90), and suggests that the theory of preparative waiting may be a viable framework for considering parents' experiences of waiting for speech-language pathology for their children. However, it is important to note that some of the strategies within the theory of preparative waiting which were reflected less frequently in participants' responses (e.g. "struggling with existential threat") may be more relevant to individuals who are hospitalised and waiting for health care (Giske & Gjengedal, 2007). In stage 2, both SLP and non-SLP participants often recommended sites sponsored by leading organisations in the field of speech-language pathology and children's health and development. Similarly, Porter and Edirippulige (2007) indicated that parents of children with hearing loss searched for information about parent support groups, and relevant organisations and societies. Participants' desire for information was consistent with previous research highlighting that parents search online for speech and language information (McAllister et al., 2011).

Participants also valued access to evidence-based content and trustworthy sources, which was highlighted in both their reflections about existing sites and their

aspirations for the waiting for speech-language pathology website. Sites achieving higher scores in the stage 2 evaluations demonstrated authoritativeness and trustworthiness as they typically referenced the sources of the information, contained evidence-based information, and the authors or sponsors of the sites were well renowned in the field of children's speech and language. Similarly, Porter and Edirippulige (2007) indicated the desire for evidence-based information online was mirrored by parents of children with hearing loss. In contrast, according to Fox (2006), three-quarters of Internet users in the US who searched for health information online did not check the source or date of the information. Interestingly, most participants in stage 1 and stage 3 of the current study had a bachelor's or postgraduate degree and more than half of participants were SLPs. It is possible that the education level of the participants in this study may have contributed to their interest in and desire for evidence-based, trustworthy information.

Participants also valued ease of use, basic architecture, readability, and simple formatting of sites. These features and functions are synonymous with components of usability and a positive user experience on websites, including "learnability", "efficiency", and "satisfaction/delight" (Lynch & Horton, 2016; Nielson, 2012b, n.p.). Participants felt it was important to use visuals to support the text, as well as incorporate lots of white space on a site. These layout and design elements are consistent with health literacy recommendations for writing health information (Australian Commission on Safety and Quality in Health Care, 2017) and considerations for quality web design (Lynch & Horton, 2016; Post, 1996). With these considerations in mind, findings from the 3-stage study can inform the development of an evidence-based website to support children and families who are waiting for speech-language pathology services and reflect the aspirations of participants. The effectiveness of providing a purpose-built speech and language

website to families of children on speech-language pathology waiting lists will be evaluated in a future randomised controlled trial.

Limitations

While participants belonged to key intended user groups for the site (SLPs, parents, and educators; Nielson, 2000, 2012a), this study reports on the views of mainly highly educated participants which may not be representative of all future users of the waiting for speech-language pathology website. Despite aiming to recruit diverse members of the public with an interest in children's speech and language, a high proportion of participants in stage 1 and 3 were SLPs with high levels of education, which may have skewed the data. The nature of the topic likely appealed to SLPs, as many SLPs work with children with speech and language difficulties and have knowledge about the conditions. Some members of the public may not have participated if they had limited knowledge about children's speech and language, despite having experience using online sites. Some of the participants were known to the first author and some participants were familiar with other participants (O'Toole & Beckett, 2013). As the focus groups were undertaken in rural locations, this was difficult to avoid. Familiarity can be an advantage, as participants may have been more "at ease" talking with familiar people, which may have led to richer information (O'Toole & Beckett, 2013, p. 130) or it may have led to participants withholding information. The first author remained as neutral as possible to allow participants to share their own "candid views" (Yin, 2011, p. 137) and participants were informed of their rights to confidentiality and the need to respect others' opinions in the group (O'Toole & Beckett, 2013). It is also important to note that the views and experiences of participants in rural areas may be different to those in metropolitan areas with regards to service access, waiting lists for speech-language pathology, and aspirations for the website (Verdon et al., 2011). Additionally, as SLPs work with children with a

diverse range of communication needs, the needs of children and families on speech-language pathology waiting lists may vary and the findings from this study may not be generalisable to all. Similarly, although the website will not be specifically designed for children with complex communication and additional developmental needs (e.g. autism spectrum disorder) or speech and language difficulties with known causes (e.g. cleft palate, hearing loss), the website may have some relevance for parents of these children if they are waiting for speech-language pathology services. The intention of the website is not to replace access to individualised support from SLPs.

In study 2, sites nominated by fewer than two participants were excluded from the evaluation, so some quality sites may not have been included. Neilson (2000, 2012a) recommended undertaking usability testing with three users per target audience. However, since some focus group participants in stage 3 belonged to more than one audience (e.g. SLP and a parent) it is feasible that the user experiences of the site would overlap (Neilson, 2012a). Additionally, the gains from testing with one participant are reportedly “exponentially greater than doing no usability testing at all” (Lynch & Horton, 2016). Usability testing is often completed in a one-on-one context and can incorporate eye tracking and card sorting (Neilson, 2012a; Rosenfeld, 2015). The time and budget constraints of this study meant usability testing principles were incorporated into focus group 3. However, one-on-one user testing may have resulted in more detailed feedback and better replicated the actual environment of a website user (Rosenfeld et al., 2015).

Conclusion

This 3-stage study enabled the researchers to determine aspects of desired content, format, features, and functions for a website to support children and families who are waiting for speech-language pathology services. This study identified what

participants valued about existing sites regarding children's speech and language and their aspirations for a new website. Participants valued the ability to access information, handouts, and printable resources; evidence-based content and trustworthy sources; and ease of use, simple navigation, a high degree of readability, and simple formatting of sites. The highest rating sites for quality in the evaluation were predominantly hosted or developed by respected and trusted organisations or professionals in the speech-language pathology field and included easily identifiable and credible sources. However, none of the existing sites evaluated were designed to support families who are waiting for speech-language pathology services. This study supported the theory of preparative waiting (Giske & Gjengedal, 2007) as applicable to the field of speech-language pathology to understand parents' experiences of waiting for services.

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Table I.

Most important topics, formatting, features, and functions to include on a website about children's speech and language

Topics/information	Weighted average (/4)
1. Reading with children	3.83
2. Children's speech development	3.76
3. Building vocabulary	3.69
4. How to help children learn more words	3.64
5. Helping children to be understood by others	3.63
6. Songs and story ideas for children	3.59
7. When children should have a hearing test	3.53
8. Rhyming and sound awareness	3.49
9. How to help children answer questions	3.48
10. Getting ready for school	3.39
11. What speech-language pathologists do	3.38
12. Pronouncing speech sounds	3.32
13. Using longer sentences	3.23
14. What happens during a speech-language pathology visit?	3.19
15. Using electronic devices and apps with children	3.04
16. Developing appropriate grammar (e.g., mice vs mouses)	3.00
17. Raising children to speak more than one language	2.56
Features and functions	
1. Obvious navigation and icons	3.82
2. Simple language, wording, and terminology	3.78
3. Practical activities	3.75
4. Simple text and font	3.71
5. Printable resources	3.57
6. Searching tool	3.56
7. Videos and animations	3.32
8. Links to other websites	3.28
9. Responsiveness	3.26
10. Sources of evidence and references	3.26
11. A frequently asked questions (FAQ) section	3.20
12. Sound files (e.g., samples of speech)	3.06
13. Photos	2.99
14. Games	2.87
15. Stories from professionals (e.g., speech-language pathologists)	2.85
16. Stories and anecdotes about families' and children's experiences	2.79
17. Alerts and/or reminders via email/phone/social media	2.16

Table II.

Highest scoring sites about children's speech and language using Trust It or Trash It? (Genetic Alliance, 2013) quality criteria

Name of site	URL	Total score (out of 9)
American Speech-Language-Hearing Association	https://www.asha.org	9
Dr Caroline Bowen's www.speech-language-therapy.com	https://www.speech-language-therapy.com/	9
Five from Five	http://www.fivefromfive.org.au/	9
Multilingual Children's Speech	http://www.csu.edu.au/research/multilingual-speech	9
Raising Children Network	http://raisingchildren.net.au/	9
Speech Pathology Australia	https://www.speechpathologyaustralia.org.au	9
Afasic	https://www.afasic.org.uk/	8
Better Health Channel	https://www.betterhealth.vic.gov.au/	8
Black Sheep Press	https://www.blacksheeppress.co.uk/	8
I CAN	https://www.ican.org.uk/	8
The Communication Trust	https://www.thecommunicationtrust.org.uk/	8

URL, Universal Resource Locator

Chapter 7: Evaluation of a Waiting List Management Strategy

Paper 5

McGill, N., McLeod, S., Ivory, N., Davis, E., & Rohr, K. (2020). Randomised controlled trial evaluating active versus passive waiting for speech-language pathology. *Folia Phoniatrica et Logopaedica*. Advance online publication. doi:10.1159/000508830

As outlined in Chapter 5, Chapter 6 informed the design of a website for children and families on speech and language service waiting lists by obtaining members of the public's perspectives and aspirations regarding content, format, and usability. The "Waiting for Speech Pathology" website was subsequently developed based on those recommendations in collaboration with SLPs on the NSW Health TRGS grant team and NSW Health web designers (*not* part of this doctoral research). The strategies included on the website for stimulating children's speech, language, and early literacy skills had been trialled in the SLPs' clinical practice over many years and were supported by research and anecdotal evidence regarding their feasibility for use with families. The present chapter (Chapter 7) reports on one of two concurrent RCTs to evaluate provision of the website to families in comparison to a waiting list control group, known as the Active/Passive Waiting Study.

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The full list of instruments used in the study to measure primary and secondary outcomes of children and caregivers can be found in Appendix A of this Chapter. However, since the primary outcome measures did not reach statistical significance, it was not appropriate to analyse the secondary outcome measures within this study.

Randomised Controlled Trial Evaluating Active versus Passive Waiting for Speech-Language Pathology

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Keywords

Waiting list · Speech-language pathology · Website · Technology · Service delivery · Caseload

Abstract

Introduction: High demand for speech-language pathology means children sometimes wait over 12 months for services, missing out on timely support. Waiting can be a time of stress, concern, and powerlessness for caregivers. Provision of information via a website may support families and encourage active waiting. **Objective:** The aim of this study was to compare children's speech, intelligibility, language, and literacy outcomes, and caregivers' satisfaction and empowerment in active versus passive waiting conditions. **Methods:** Ninety-seven preschool-aged children referred to a community health speech-language pathology service in Australia were screened for eligibility. Eligible children ($n = 42$) with speech/language difficulties were randomly allocated to: (a) active waiting (provision of a purpose-built website; $n = 20$), or (b) passive waiting (control group; $n = 22$). Pre- and post-assessments (after 6 months on a waiting list) were completed with children and caregivers by a speech-language pathologist blinded to group allocations. **Results:** Intention to treat ($n = 36$) and per-protocol analyses ($n = 30$

were conducted to measure group differences in child and caregiver outcomes at post-assessment using one-way ANCOVA, controlling for baseline scores. There were no statistically significant differences between groups for children's speech, intelligibility, language, and literacy, or caregivers' empowerment and satisfaction. Children in both groups made minimal gains over 6 months. **Conclusions:** Provision of an active waiting website did not lead to statistically significant change in child or caregiver outcomes, and children in both groups made little progress over a 6-month period. Early speech-language pathology intervention delivered with appropriate dosage is needed to optimise children's outcomes. Until timely and effective speech-language pathology intervention can be provided for all who need it, provision of early assessments may be beneficial. There remains a need for effective ways to support children and families on waiting lists.

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Introduction

When families are concerned about their children's communication development, ideally they are referred to and seen by a speech-language pathologist (SLP) in a

timely manner. However, many children and families must wait for months or years to receive speech-language pathology services, due to the high (and increasing) demand for services [1–4]. Existing speech-language pathology services are often inadequately resourced to cope with the large numbers of children and families seeking support, and so waiting lists occur due to the limited available services.

The first stage of caregivers' involvement in speech-language pathology involves referral and attendance at an initial assessment appointment and has been referred to as "getting in" [5]. Waiting lists form a barrier to service access and extend the time families spend "getting in" to speech-language pathology services, resulting in some families' decisions not to seek services at all [1]. Speech-language pathology interventions, which usually commence following the initial assessment appointment, can be effective in remediating communication difficulties [6]. However, if access to intervention is delayed due to waiting lists, children may miss out on the benefits of specialised support in early childhood.

Consequences of Waiting

Waiting lists for speech-language pathology can have widespread negative consequences. For instance, without timely intervention, children's speech, language, and subsequent literacy difficulties may extend throughout their school-age years and beyond with implications for social, emotional, academic, and occupational outcomes [7–9]. Early intervention can minimise the risk of persisting difficulties, improve outcomes for children with speech and language difficulties, and be cost-effective for communities [10].

Negative consequences of speech-language pathology waiting lists have been described by caregivers, professionals, and broader society. Consequences of waiting lists described by caregivers have included feelings of worry and concern, financial burden of paying for alternative services, and considering relocation to a capital city to access services more quickly [11]. Professionals can also experience negative consequences of waiting lists, including feelings of shame, reduced job satisfaction, and burnout [11, 12]. There are negative implications for society more broadly, including ethical, social, and financial burdens on communities [11]. For instance, undiagnosed and/or unremediated speech and language difficulties in childhood can increase the likelihood of later interactions with the youth justice system [13].

Passive Waiting

Traditionally, "getting in" to speech-language pathology services was seen as a "passive" phase for families involving waiting for an appointment [5]. To "watch and wait" or "wait and see" presupposes spontaneous improvement whereby some children's communication difficulties may progress or resolve without speech-language pathology intervention [14, 15] forming part of the natural history of speech, language, and communication difficulties. Few studies have focused on the natural history of communication difficulties, since undertaking research with a sample of children who have received no intervention can be challenging ethically and practically. A systematic review of 12 natural history studies was undertaken by Law et al. [14] who identified that communication difficulties persisted in the absence of intervention for a median of 50% (range 22–54%) of children with speech difficulties, 66% (range 0–100%) of children with language difficulties, and 38% (range n/a) with co-occurring speech and language difficulties, indicating significant variability in spontaneous resolution. Gruber [16] similarly proposed two possible pathways for children with speech difficulties, whereby children in Path A were more likely to achieve normalised speech outcomes, and the speech difficulties of children in Path B were characterised by increased clinical distortions and were less likely to resolve. Glogowska et al. [17] conducted a randomised controlled trial (RCT) in the UK comparing a "watchful waiting" (p. 1) group with a group of preschool-aged children who accessed six speech-language pathology intervention sessions. They found that speech or language difficulties persisted for most children over the 12-month study time-frame, regardless of group allocation, indicating there was "little evidence for the effectiveness of speech and language therapy compared with watchful waiting" [17]. However, 6 hours of intervention has been argued to be insufficient to make a difference to children's outcomes [18]. A study of natural history undertaken in the UK with preschool-aged children with speech and/or language difficulties who received no speech-language pathology intervention over a 12-month period found that 58.3% of children with speech difficulties improved and no longer required intervention after 12 months [15]. Fewer children with receptive (19.4%) or expressive (28.6%) language difficulties demonstrated the same improvement, indicating that monitoring (in the absence of immediate intervention) may be appropriate for some children, such as those with speech difficulties only, but that parents' views should also be considered in decision-making [15]. A longitudinal study also conducted in the UK explored

the natural history of 741 children with speech difficulties and found that by the age of 8 years, 132 (18%) children had persisting speech errors, with the proportion of speech errors at age 5 years identified as a predictor of persisting difficulties [19]. However, the history of speech-language pathology intervention for the sample was unknown [19]. An Australian study by Morgan et al. [20] examined speech assessment data for 93 children at ages 4 and 7 years from the Early Language in Victoria Study. They found that 69.6% of children with delayed speech at 4 years of age had resolved by 7 years of age, compared with 40.5% of children with disordered speech at 4 years of age, indicating that error type was a predictor of persisting speech difficulties [20]. However, the outcomes of 30.4% of children with speech delay who did not resolve their errors remained unexplained [20]. Although some children evidently improve without intervention, waiting for speech-language pathology has risks and consequences as it cannot be reliably predicted which children's difficulties will spontaneously resolve as they develop, and which children will have persisting difficulties [20, 21].

Active Waiting

In contrast to passive waiting, waiting for speech-language pathology can also be active. For example, individuals may search for information on service options and engage in proactive or emotion-based advocacy (e.g., making complaints) while waiting [11, 22, 23]. People "long for information... and support" [24] from health care services, and families of children with disabilities who receive general and specialised information have been found to report higher levels of empowerment [25]. More empowered parents have been found to access services for their children faster than less empowered parents [26]. Information and strategies for families to facilitate children's speech and language development while waiting, provided during the "getting in" phase [5], may increase levels of caregiver empowerment and lead to enhanced access to services and improved outcomes for children.

Provision of information and advice to families by SLPs, such as via home therapy programs or caregiver education programs, may supplement face-to-face therapy or support children on waiting lists [27]. Some evidence supports the effectiveness of programs to improve children's communication outcomes by educating caregivers in providing language-rich environments and responding to children's communication attempts and interests [28–30]. Some interventions increase caregivers' capacity to improve children's communication skills without the

need for direct caregiver training [31, 32]. However, dose, intensity, and duration can impact the effectiveness of caregiver-based therapy programs, and high doses and direct caregiver training are typically recommended [33, 34]. Resource constraints in many speech-language pathology services impact the feasibility and practicality of such programs to support families on waiting lists in the interim while waiting for assessment and intervention.

Technology also provides an opportunity to deliver services, support, and health-related information to consumers in a time- and cost-effective manner. The Internet is a key source of health information with the potential to enhance health care and outcomes through timely delivery of information, support, and interventions in the community [35–37]. Provision of health information via a website has been found to increase perceptions of support and reduce anxiety in individuals on waiting lists [38]. Internet-based health interventions and their implementation have been evaluated for use in other disciplines, such as psychology. For Internet-based interventions, such as those for managing depression, regular (e.g., weekly) guided support or ongoing help from a clinician may be included to facilitate program usage or uptake for individuals accessing the intervention [39]. Other Internet-based interventions aiming to promote behaviour change, such as for individuals with mental illness or substance addictions, may comprise: educational modules and intensive step-by-step programs completed over weeks or months, interactive elements (e.g., interactive journaling, personalised feedback mechanisms, goal setting, customised outputs), self-monitoring, video-based modelling, and assignments or tasks to complete whilst offline (e.g., recording and tracking habits) [40]. Despite their effectiveness in research studies, not all Internet-based interventions are made available at the conclusion of the studies and many do not make it to the public domain due to difficulties finding suitable and sustainable hosts, impacting their successful translation into practice [40]. The costs associated with developing such technology can be prohibitive and few comprehensive Internet-based interventions exist within speech-language pathology. Although ideal, the level of guided support and interaction from professionals to complement Internet-based interventions is unlikely to be possible or practical in many real-world health care settings due to funding, staffing, and time constraints, including in speech-language pathology services for families on waiting lists.

Use of technology is appealing for children, families, and professionals alike, with parents reporting seeking

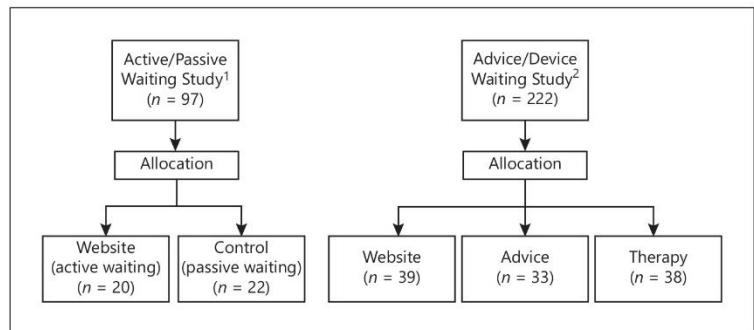


Fig. 1. Concurrent RCTs and participant group allocations. ¹ RCT described in the current paper, undertaken in Victoria, Australia. ² Concurrent RCT undertaken in New South Wales, Australia [45].

information online regarding children's communication and hearing [23, 41]. Websites, mobile applications (apps), and computer software programs about children's speech and language exist and some have been evaluated in research studies [42, 43]. Some apps designed to improve children's speech rely on SLPs or caregivers to provide feedback on children's performance on target items within the app, and caregivers have been found to be lenient when evaluating children's productions [44]. Built-in automatic speech recognition attempts to address this issue and provide timely, specific feedback in newer apps such as Apraxia World, to reduce the burden on caregivers, engage children, supplement within-clinic speech practice, and increase the frequency of home-based speech practice [44]. McLeod et al. [45] compared face-to-face speech-language pathology intervention with advice sessions and provision of a website to families on a waiting list and found a significant difference for the face-to-face intervention condition only, whereby children's speech and caregivers' satisfaction improved. The Sound Start Study, a cluster RCT, evaluated an input-based speech intervention (computer program) delivered by educators in early childhood education centres with 123 children, and found the technology-based intervention made no significant difference to children's speech outcomes [46, 47]. Not all existing websites and apps about children's speech and language have been found to be high quality or effective, and few are purposely designed or applicable for use with children and families on waiting lists for speech-language pathology services [42, 43]. Some apps and programs require children to have undertaken an assessment with an SLP to identify appropriate intervention targets, which is not always possible in services with long waiting lists.

Although showing potential, further research is needed regarding the design and use of technology-based

strategies, including websites, to support children and families on speech-language pathology waiting lists. Limited research to date has explored active and passive waiting by children and families in speech-language pathology or the natural history of communication disorders in children on speech-language pathology waiting lists. The present study, known as the Active/Passive Waiting Study, aims to add to the evidence base by providing insights into the natural history of speech and language difficulties and waiting list management within real-world clinical contexts. Although not intended as a substitute for face-to-face intervention or to directly remove waiting times, provision of information via a website may be a feasible strategy to address the psychological consequences of waiting for caregivers, including feelings of powerlessness and dissatisfaction which can be overlooked in traditional health care settings, and may also enhance children's outcomes [11].

Background Context

The present paper reports on an RCT undertaken in a community health centre in Victoria, Australia, comparing provision of a purpose-built website (active waiting condition [48]), with a control group (passive waiting condition; usual practice at the site). The Active/Passive Waiting Study was undertaken concurrently to another RCT (Advice/Device Waiting Study) conducted in New South Wales, Australia, which compared three intervention conditions: (1) therapy: 12 sessions of face-to-face intervention, (2) advice: a face-to-face advice session, and (3) device: provision of the same purpose-built website used in the present study [45, 48]. Although the study protocols were consistent, participants, SLPs, and researchers did not overlap across sites and each study enabled unique contributions to the literature regarding different intervention conditions (Fig. 1).

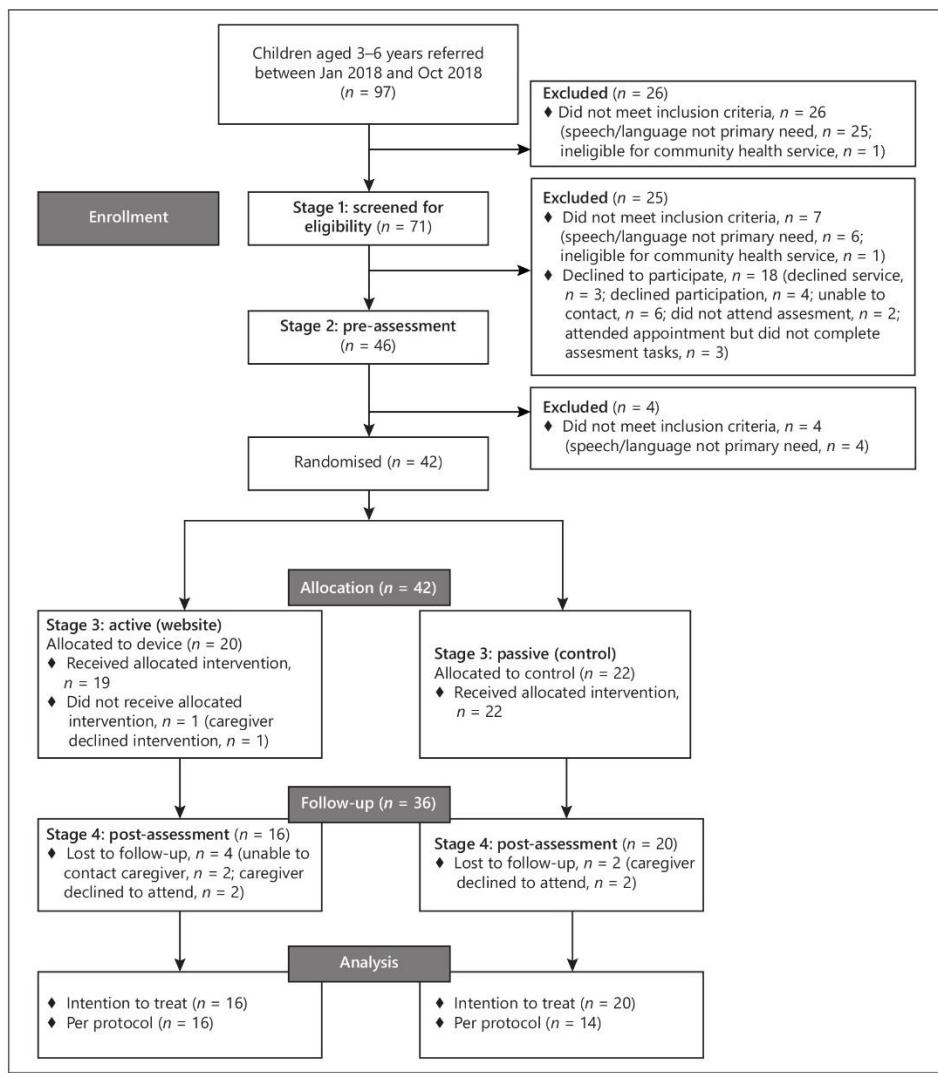


Fig. 2. Participant recruitment and randomisation diagram.

Aim

The aim of the Active/Passive Waiting Study was to determine whether active or passive waiting conditions were associated with differences in the speech, intelligibility, language, and early literacy outcomes of children aged 3–6 years with speech and/or language difficulties on a speech-language pathology waiting list, and levels of satisfaction and empowerment of their caregivers.

Two intervention conditions were compared over a 6-month period: (1) active waiting: provision of a purpose-built website to caregivers containing information and strategies to stimulate children's speech, language, and early literacy skills while on a waiting list, and (2) passive waiting: a control condition involving waiting on a waiting list without support (usual practice at the research site).

Table 1. Characteristics of the groups prior to intervention: intention to treat (complete cases; $n = 36$)

	Valid, <i>n</i>	Passive waiting group (control)	Active waiting group	Significant difference (<i>p</i>)
Age (mean \pm SD), months	36	48.35 (5.45)	48.19 (6.68)	0.936
Sex, <i>n</i> (%)				
Male	22	14 (70.0)	8 (50.0)	0.221
Female	14	6 (30.0)	8 (50.0)	
English main language ^a , <i>n</i> (%)				
Yes	36	20 (100.0)	16 (100.0)	— ^b
No	0	0 (0.0)	0 (0.0)	
Aboriginal/Torres Strait Islander ^c , <i>n</i> (%)				
Yes	3	0 (0.0)	3 (18.8)	0.078 ^d
No	33	20 (100.0)	13 (81.2)	

Independent samples *t* test used to examine differences between groups on continuous variables and Pearson χ^2 test of association or Fisher exact test used to examine differences between groups for categorical variables.

^a Main language spoken at home.

^b No significance test conducted as all participants in both groups spoke English as their main language.

^c Caregiver identified the child as Aboriginal or Torres Strait Islander.

^d Fisher exact test (two expected cell counts less than 5).

Materials and Methods

The Consolidated Standards of Reporting Trials (CONSORT) guidelines [49, 50] informed the design, conduct, and reporting of this study. An RCT with parallel-group design and equal allocation was utilised to investigate the research aim. Ethical approval was obtained from the South Eastern Sydney Local Health District Human Research Ethics Committee (approval No. HREC/17/POWH/535), and site-specific ethical approval was obtained from the community health centre in Victoria, Australia (approval No. GVH 50/17). Participants' caregivers provided written consent to participate in the research.

Participant Recruitment and Eligibility

All children aged 3.0–6.0 years who were referred to a community health speech-language pathology service in Victoria, Australia, over a pre-determined 10-month period ($n = 97$) were screened for inclusion in the study. Eligible children had an identified speech and/or language delay/disorder, English as the main language spoken at home, and caregivers with access to the Internet (online suppl. Appendix A; for all online suppl. material, see www.karger.com/doi/10.1159/000508830). Children were excluded if speech and/or language were not the primary areas of need (e.g., referred for fluency, feeding, or voice), or if they had multiple, complex needs or diagnosed disabilities and were eligible for other speech-language pathology services (e.g., early childhood intervention within another service). Children were also excluded from the study if their caregivers declined to participate.

The research involved four stages (Fig. 2). In stage 1 (screening), 71 children were identified as eligible for the study based on their referral information, after 26 children referred to the service were excluded for not meeting the inclusion criteria. Of the 71 children, 25 were excluded as they failed to meet the inclusion criteria ($n = 7$) or their caregivers declined to participate ($n = 18$). In stage 2 (pre-assessment), 46 participants were assessed, and 4 were ex-

cluded for not meeting the inclusion criteria (speech/language not primary need). In stage 3 (intervention), 42 children were randomly allocated to either active waiting ($n = 20$) or passive waiting (control, $n = 22$). In stage 4 (post-assessment), 36 participants were assessed. Of those, 30 received per protocol intervention.

A G*Power calculation indicated 90 participants were needed for one-way ANCOVA analyses between two groups to be undertaken with an effect size of 0.3 for eta squared (medium effect size), probability of ≤ 0.05 , power level of 0.8, numerator df of 1, and 1 covariate [51]. With an additional 9 participants added to account for attrition, the researchers therefore aimed to recruit a minimum of 99 participants (parent-child dyads) to achieve the desired power and effect size [52].

Participants in the RCT

The participants in this study were 36 children and their caregivers who were allocated to intervention groups (stage 3) and attended post-assessments (stage 4), known as the intention to treat sample (Table 1). Children were aged between 3.0 and 6.0 years (mean 48.2 months, SD 5.9 months) and all spoke English as their main language. There were more males ($n = 22$) than females ($n = 14$) in the sample, which is expected for a clinical sample of children with speech and language difficulties [53]. Three (8.3%) children identified as Aboriginal or Torres Strait Islander. Most mothers had completed higher education (e.g., certificate, bachelor, or postgraduate degree; $n = 21$, 58.3%), or schooling up to year 11 ($n = 9$, 25%) or year 12 ($n = 6$, 16.7%). Participants lived in Inner Regional Australia according to the Australian Statistical Geographic Standard (ASGS) Remoteness Structure index [54]. The community health centre was located in quintile 1 (on a 1–5 scale where 1 was least advantaged) on the index of relative socio-economic advantage and disadvantage (IRSAD), based on 2016 Postal Area (POA) [55]. The primary areas of difficulty identified by the SLP in stage 2 were: speech ($n = 23$, 63.9%), language ($n = 6$, 16.7%), or both speech and language ($n = 7$, 19.4%). Follow-up was

recommended for 21 (58.3%) children based on their oromotor assessment, primarily for review of tonsils and/or adenoids (e.g., with an ear, nose, and throat specialist; total structure score: mean 19.6 out of 21, SD 1.4, $n = 36$; total function score: mean 36.2 out of 42, SD 6.2, $n = 36$). Most children passed a hearing assessment ($n = 30$, 83.3%) undertaken by an audiologist or an SLP who was trained in hearing screenings. Three (8.3%) children did not have their hearing assessed during the research timeframe.

Instruments

Assessments were conducted with children and caregivers at stages 2 (pre-assessment) and 4 (post-assessment). The assessments used to measure outcomes are summarised as follows.

Caregiver Questionnaires

Case history forms (stage 2) based on usual practice and caregiver questionnaires (stages 2 and 4) were provided to caregivers to obtain information about demographics, children's developmental history and involvement with speech-language pathology services, and caregivers' perceptions [56–65].

Instruments Used to Describe the Sample

Oromotor assessments based on Robbins and Klee [66] were conducted with the children to evaluate oral structures and functions and the need for referral to specialists. Hearing assessments were recommended for all children at stage 2 who had not had their hearing tested within a month prior to their referral to speech-language pathology. At stage 4, any children who still had not had their hearing assessed were screened by the assessing SLP (who was trained in hearing screening) using an audiometer (Maico MA 1) and headphones (3M Optime 101 Peltor cups).

Instruments Used for Pre- and Post-Assessments

Child and caregiver outcomes were assessed at stage 2 and 4 using valid and reliable published measures. The instruments used to measure primary outcomes are outlined below, but those used to measure secondary outcomes are not reported here.

Children's Speech. Children's speech was assessed using the Phonology Assessment from the Diagnostic Evaluation of Articulation and Phonology (DEAP) [67]. The DEAP has high validity and reliability, Australian/UK norms, and comprehensively samples the range of sounds and syllable shapes in Australian children's speech [67]. Children's speech was transcribed online using broad transcription using the International Phonetic Alphabet. The percentage of consonants correct (PCC; primary outcome measure) and PCC adjusted (PCC-A) were manually calculated to obtain scores out of 100 [68].

Children's Intelligibility. Children's speech intelligibility was measured using the Intelligibility in Context Scale (ICS) [64, 69], where caregivers provided ratings from 5 (always) to 1 (never) for their children's intelligibility across seven different communicative contexts. Mean scores ranging from 1 to 5 were obtained. The ICS has been found to be a valid measure and has Australian norms [69, 70].

Children's Language. Children's language skills were measured using the core language subtests (sentence structure, word structure, expressive vocabulary) from the Clinical Evaluation of Language Fundamentals Preschool – Second Edition – Australian Standardised Edition (CELF-P2) [71]. Raw scores for each subtest were combined to obtain total raw scores out of 86 for each child.

The CELF-P2 is a valid and reliable measure [71], with normative data for Australian children, and is widely used in clinical practice.

Children's Early Literacy. Children's early literacy was assessed using the Preschool Word and Print Awareness (PWPA) measure [72], to obtain total raw scores out of 17. The measure involved the SLP asking children 12 questions about the text and pictures while looking at the book *Nine Ducks Nine* [73]. The PWPA has adequate validity and reliability [72].

Caregivers' Empowerment. Caregivers' empowerment was measured using 18 questions from the Family Empowerment Scale (FES) [62] within the Systems Advocacy, Knowledge, Competence, and Self-Efficacy subscales, which were identified as most relevant to the current research. Caregivers were asked to respond to statements (e.g., "I am able to get information to help me better understand my child") by rating them from 1 (not true at all) to 5 (very true), obtaining a mean score ranging from 1 to 5. The FES has been found to be a reliable measure [74] and has been previously used to measure empowerment among families of children with disabilities [25].

Caregivers' Satisfaction. Caregivers' satisfaction was measured using 12 questions adapted from the Patient Enablement and Satisfaction Survey (PESS) [57] where caregivers were asked to indicate their level of agreement with statements using a Likert scale from 1 (strongly disagree) to 5 (strongly agree) to obtain mean scores ranging from 1 to 5. The PESS has previously been used in nursing and allied health settings to measure consumers' satisfaction [57].

Instrument for Intervention: Purpose-Built Website

A purpose-built website for caregivers (<https://wnswlhd.health.nsw.gov.au/our-services/speech-pathology>) [48] was created by a team of SLPs/researchers in consultation with web designers. The design of the website was informed by a three-stage mixed methods study involving: (1) exploring preferences for website content, features, and functions from members of the public via an online questionnaire ($n = 119$), (2) an evaluation of the quality of existing sites (websites and apps; $n = 25$) about children's speech and language, and (3) feedback from members of the public (e.g., parents, SLPs; $n = 16$) via focus groups regarding aspirations for the purpose-built website and feedback on the content, features, and functions of a prototype version of the website (e.g., usability of the site, readability of information, appearance/format) [42]. Prior research regarding considerations for website architecture and usability, health literacy, and online health information quality summarised in McGill and McLeod [42] also informed the website design.

The website contained evidence-based information and general strategies for caregivers to implement at home to stimulate children's speech, language, and early literacy skills (e.g., modeling, recasting, expanding). The website consisted of five main webpages (Home, Children's Speech, Children's Language, Children's Literacy, More Information). The Home page provided information about the research project, development of the website, and the role of SLPs. The Children's Speech, Children's Language, and Children's Literacy pages each contained evidence-based written information outlining: an overview of the relevant subtype of communication difficulty, age-appropriate development, strategies to facilitate children's development, and links to further information. Each of those pages included a purpose-designed animated video to summarise the written content. Downloadable hand-

outs (speech, $n = 36$; language, $n = 13$; early literacy, $n = 2$) were developed containing activity ideas for caregivers to practise speech, language, and literacy skills with children (e.g., songs, rhymes, book sharing, play routines, daily routines). The More Information page contained information about what to expect from a speech-language pathology appointment (e.g., observations/assessments, completion of questionnaires, referrals to other professionals/services, home and clinic-based therapy activities), additional information about the SLP role, and a glossary of commonly used speech-language pathology-related words. External websites and apps were selected based on those deemed high quality in the evaluation by McGill and McLeod [42] or identified by the research team, and links to these sources were included on the website. The website was not released to the public until after data collection for the present research project concluded.

Procedure

Stage 1 (Screening for Eligibility)

All children, referred to the community health speech-language pathology service over the pre-determined 10-month period, were initially screened by an SLP who was independent to the study. The SLP entered demographic details and referral reasons for all children within the 3.0–6.0 age range ($n = 97$) into an Excel spreadsheet and forwarded it to the first author/assessing SLP. Based on this referral documentation and phone calls with caregivers, children were screened for eligibility. Potentially eligible children had speech and/or language difficulties as the main referral reason, English as the main language in the home, and caregivers with access to the Internet and adequate literacy skills to read information written in English. Those who met these criteria were provided with information about the study and a case history form via email/post and invited to attend an assessment. Children whose parents signed the consent form were eligible for participation in stage 2.

Stage 2 (Pre-Assessment)

Children and caregivers attended an initial assessment which took approximately 1.5–2 hours. Assessments were typically completed during one session, although for some children who became fatigued or had difficulty concentrating, the tasks were split over two assessment sessions. The assessing SLP confirmed that caregivers had read the information sheet prior to the session. Those who had not were provided with another copy to read in the waiting room before commencing the session. Sessions were video recorded using a Panasonic HC-V700 Full HD video camera with inbuilt microphone and audio recorded using a Zoom H1 Handy Recorder with foam windscreens attachment and Promaster tabletop tripod. Caregivers were provided with a case history form (if they had not completed it at home) and caregiver questionnaire to complete during the session. The assessment battery was completed with each child (in the following order: DEAP, CELF-P2, PWPA, oromotor assessment), using visual schedules and 5- to 10-min activity/play breaks between assessments if needed. At the completion of the assessments, the assessing SLP scored the assessments and provided feedback about areas of strength and difficulties for each child. Caregivers were provided with the opportunity to ask questions about their child's performance. If children had not had their hearing assessed in the month prior to the assessment, a referral to an audiologist was provided for a hearing test. Additional referrals to other services (e.g., occupational therapy)

were completed by either the assessing or independent SLP with caregiver consent as required. At the end of the session, a post-assessment was scheduled for approximately 6 months' time, and caregivers were advised that they would receive a report summarising the assessment results. Summary reports were completed by the assessing SLP and sent to caregivers via email and/or post within approximately 1 month after the assessment.

Randomisation

The independent SLP randomly allocated participants to one of two groups (active waiting or passive waiting) using a spreadsheet created by an independent statistician. The randomisation spreadsheet was created in SPSS version 22 [75] using a random variable following an unrestricted realisation of a uniform distribution to generate random values and sort them into groups of equal size.

Stage 3 (Intervention)

Participants were allocated to either the active waiting group or passive waiting group and were blinded to the alternate condition. Participants in the active waiting group received access to a purpose-built website [48] for caregivers containing evidence-based information and strategies to stimulate children's speech and language development while on a waiting list. The independent SLP contacted participants allocated to the active waiting group by phone and followed a pre-determined script to inform them about the purpose-built website, and invite them to take their time exploring the website, access the website as many times as they liked, and focus on "pages that relate to [their] child's difficulties, based on the results from their assessment." The independent SLP then emailed the website URL to participants, along with a standardised script containing information about the website. Participants were asked not to share the URL or tell anyone about the website. Reminder emails were sent 2 and 4 months after group allocation. Participants in the passive waiting group were not contacted by the independent SLP and went on the waiting list as per usual practice at the service.

Stage 4 (Post-Assessment)

Participants attended a post-assessment appointment approximately 6 months after their pre-assessment (mean 6.18 months, SD 0.61, range 5.50–8.80). Participants were contacted via email or phone approximately 1 week prior to their post-assessment appointment to confirm their attendance. Each post-assessment involved completing the DEAP, CELF-P2, and PWPA with the children and took approximately 1–1.5 hours in total. Visual schedules and 5- to 10-min activity/play breaks were used as needed. Oromotor assessments were completed with 2 (5.6%) children who did not complete the task in the pre-assessment due to non-compliance. Hearing screenings were conducted by the assessing SLP in the session if children had not previously had their hearing assessed within the project timeframe. The SLP scored the assessments and provided feedback about each child's performance, with reference to their pre-assessment results. Caregivers completed the post-assessment caregiver questionnaire during the session. Caregivers were advised that the project had concluded and that their child would continue on the waiting list as per usual practice at the service. Summary reports were completed by the assessing SLP and sent to caregivers via email and/or post within approximately 1 month after the assessment.

Table 2. Outcomes of the intervention and control groups: intention to treat (complete cases; $n = 36$)

	Measure	Valid, <i>n</i>	Post-intervention, <i>F</i> mean (SE)	<i>p</i>	η^2_p
Children's speech Passive waiting (control)	DEAP	20	68.46 (1.47)	0.02	0.902
Active waiting		16	68.70 (1.31)		
Children's intelligibility Passive waiting (control)	ICS	19	3.67 (0.09)	0.01	0.946
Active waiting		15	3.68 (0.10)		
Children's language ^a Passive waiting (control)	CELF-P2	19	44.00 (0.89)	3.08	0.089
Active waiting		16	41.69 (0.97)		
Children's early literacy Passive waiting (control)	PWPA	20	5.78 (0.63)	1.72	0.199
Active waiting		16	7.02 (0.70)		
Caregivers' empowerment Passive waiting (control)	FES	20	4.11 (0.08)	2.12	0.155
Active waiting		16	4.29 (0.09)		
Caregivers' satisfaction Passive waiting (control)	PESS	12	3.40 (0.18)	0.05	0.835
Active waiting		12	3.34 (0.18)		

Speech: DEAP, Diagnostic Evaluation of Articulation and Phonology – phonology subtest, percentage of consonants correct (scores between 0–100) [67]. Intelligibility: ICS, Intelligibility in Context Scale (mean score between 1 and 5) [64]. Language: CELF-P2, Clinical Evaluation of Language Fundamentals Preschool – 2nd ed., Australian Standardised Edition, three core language subtests (raw score between 0 and 86) [71]. Early literacy: PWPA, Preschool Word and Print Awareness measure (raw score between 0 and 17) [72]. Empowerment: FES, Family Empowerment Scale (mean score between 1 and 5) [62]. Satisfaction: PESS, Patient Enablement and Satisfaction Survey (mean score between 1 and 5) [57].

^a Analysis with one outlier removed (analyses were run with/without this outlier and there were no interpretational differences between the two analyses).

Reliability

Both intra- and inter-rater reliability were calculated for the DEAP and CELF-P2 assessments. A random number generator was used to select 6 participants (13% of 46 participants assessed at stage 2) for the purposes of reliability calculations.

Intra-Rater Reliability

The first author/assessing SLP independently reviewed and scored audio and video recordings of the participants' stage 2 DEAP and CELF-P2 assessments, enabling point-to-point intra-rater agreement to be calculated. Intra-rater agreement was 90.2% for the DEAP over 2,648 data points based on broad phonetic transcription and 97.5% over 792 data points for the CELF-P2.

Inter-Rater Reliability

The fifth author and an independent SLP each reviewed audio and video recordings of the same 6 participants' stage 2 DEAP and CELF-P2 assessments and completed scoresheets, which were then compared with the first author/assessing SLP's original scoresheets. Inter-rater reliability based on broad phonetic transcription of the DEAP was 86.2% 3-way agreement across 3,972 data points. Inter-rater reliability for scoring of the CELF-P2 was 95.5% 3-way agreement across 1,188 data points. Both inter- and intra-rater reliabil-

ity scores were above 85% agreement, which was "acceptable" for speech transcription [76] and above 90% for the CELF-P2, which was considered a high level of agreement [77].

Data Analysis

The RCT (stage 3) comprised two randomised groups (active waiting, passive waiting/control) and data collection occurred at two time points (stage 2 and 4). Thus, one-way ANCOVAs were conducted. This approach permitted examination of mean differences in outcome variables for each group at post-assessment (stage 4), after controlling for pre-assessment (stage 2) scores. The six primary outcome variables were: (1) children's speech: DEAP PCC score out of 100 [67]; (2) children's intelligibility: ICS mean score out of 5 [64]; (3) children's language: CELF-P2 Core Language subtests total raw score out of 86 [71]; (4) children's literacy: PWPA total score out of 17 [72]; (5) caregivers' empowerment: FES mean score out of 5 (from a subset of 18 questions) [62], and (6) caregivers' satisfaction: PESS mean score out of 5 (from a subset of 12 questions adapted from the original measure) [57]. An intention to treat analysis followed by a per protocol analysis (sample of participants who received their allocated intervention) was carried out on each primary outcome variable. In all analyses, the assumptions of linearity, normality (Shapiro-Wilk test, $p > 0.05$), homogeneity of regres-

sion slopes, homoscedasticity, and homogeneity of variance (Levene test) were assessed and the effect size was quantified using partial eta squared (η_p^2). Data are the adjusted mean \pm standard error (SE), unless otherwise stated.

Results

The Active/Passive Waiting Study compared two intervention conditions over a 6-month period: (1) active waiting: provision of a purpose-built website to caregivers containing information and strategies to stimulate children's speech, language, and early literacy development while on a waiting list, and (2) passive waiting: a control condition involving waiting on a waiting list without support (usual practice at research site). Participants received pre- and post-assessments to measure outcomes. While randomisation aims to minimise selection bias and the effect of pre-existing differences on outcomes, the two groups were compared on key demographics to reduce the likelihood that any differences in outcomes could be attributed to group assignment. No significant differences were identified between the groups for child age, sex, Aboriginal or Torres Strait Islander status, or English language status (Table 1), therefore these variables were not controlled for in later analyses.

Intention to Treat Analyses

Intention to treat analyses ($n = 36$) were undertaken with the primary outcome variables (Table 2). Overall, there were no statistically significant differences between groups for child or caregiver outcomes. Unless otherwise stated, the intention to treat analyses met statistical assumptions regarding linearity, normality, homogeneity of regression slopes and variance, and homoscedasticity, with no outliers identified in the data.

Children's Speech

Results of a one-way ANCOVA, controlling for baseline speech production, indicated that there was no significant difference in post-intervention speech production between the active and passive waiting (control) groups ($F(1, 33) = 0.015, p = 0.902, \eta_p^2 = 0.000$).

Children's Intelligibility

After adjustment for pre-intervention intelligibility, there was no statistically significant difference in post-intervention intelligibility between the active and passive waiting (control) groups ($F(1, 31) = 0.005, p = 0.946, \eta_p^2 = 0.000$).

Children's Language

After controlling for baseline language skills, there was no significant difference in post-intervention language scores between the active waiting and passive waiting (control) groups ($F(1, 32) = 3.082, p = 0.089, \eta_p^2 = 0.088$). This analysis was based on removal of one outlier from the original data to meet the assumption of normality. In the full data set of intention to treat cases, the assumptions of linearity, homogeneity of regression slopes, homogeneity of variance, and homoscedasticity were met. However, the assumption of normality of the overall model residuals was not met, as assessed by the Shapiro-Wilk test ($p < 0.05$). Visual examination of the QQ (quantile-quantile) plot and boxplot showed a variable that appeared approximately normally distributed (except for one outlying case). This case was excluded from the data and all analyses were re-run. When this case was excluded, the data met the assumption of normality. There were no interpretational differences between the data with or without the outlying case included (in both situations there was no significant mean difference in language between groups). When the outlier was excluded, all statistical assumptions were met.

Children's Early Literacy

Results of a one-way ANCOVA, controlling for baseline early literacy skills, indicated that there was no significant difference in post-intervention early literacy skills between the active waiting and passive waiting (control) groups ($F(1, 33) = 1.721, p = 0.199, \eta_p^2 = 0.050$).

Caregivers' Empowerment

After adjustment for pre-intervention empowerment, there was no statistically significant difference in post-intervention empowerment between the active waiting and passive waiting (control) groups ($F(1, 33) = 2.117, p = 0.155, \eta_p^2 = 0.060$).

Caregivers' Satisfaction

After adjustment for pre-intervention satisfaction, there was no statistically significant difference in post-intervention satisfaction between the active and passive waiting (control) groups ($F(1, 21) = 0.045, p = 0.835, \eta_p^2 = 0.002$).

Adherence to Intervention Protocol (Fidelity)

Fidelity of the intervention was based on determining whether participants received the intervention they were allocated [78]. The per protocol sample included participants who did receive their allocated interven-

Table 3. Outcomes of the intervention and control groups: per protocol (complete cases; $n = 30$)

	Measure	Valid, <i>n</i>	Post-intervention, <i>F</i> mean (SE)	<i>p</i>	η_p^2
Children's speech	DEAP	14	68.03 (1.65)	0.00	0.955
Passive waiting (control)		16	68.16 (1.55)		
Active waiting	ICS	13	3.61 (0.12)	0.17	0.687
Active waiting		15	3.68 (0.11)		
Children's intelligibility	CELF-P2	14	41.61 (1.34)	0.35	0.559
Passive waiting (control)		16	40.53 (1.26)		
Children's language	PWPA	14	5.67 (0.78)	0.98	0.332
Active waiting		16	6.73 (0.73)		
Children's early literacy	FES	14	4.17 (0.10)	0.75	0.395
Passive waiting (control)		16	4.29 (0.10)		
Caregivers' empowerment	PESS	10	3.36 (0.20)	0.00	0.969
Active waiting		12	3.35 (0.18)		

Speech: DEAP, Diagnostic Evaluation of Articulation and Phonology – phonology subtest, percentage of consonants correct (scores between 0 and 100) [67]. Intelligibility: ICS, Intelligibility in Context Scale (mean score between 1 and 5) [64]. Language: CELF-P2, Clinical Evaluation of Language Fundamentals Preschool – 2nd ed., Australian Standardised Edition, three core language subtests (raw score between 0 and 86) [71]. Early literacy: PWPA, Preschool Word and Print Awareness measure (raw score between 0 and 17) [72]. Empowerment: FES, Family Empowerment Scale (mean score between 1 and 5) [62]. Satisfaction: PESS, Patient Enablement and Satisfaction Survey (mean score between 1 and 5) [57].

tions. In the active waiting condition, all participants received the website URL, two email reminders, and reported receiving no 1:1 speech-language pathology intervention during the research timeframe, indicating they all received their allocated intervention (intention to treat, $n = 16$; $n = 16$). Google Analytics data were obtained to measure access to the active waiting website during the intervention period from May 11, 2018 (date of first website allocation) to April 30, 2019. A total of 69 webpage views were recorded (mean 5.75 views/month) with a total of 56 users and 24 new users (which may represent existing users on different devices). Views per page were as follows: Home page ($n = 44$), Children's Speech ($n = 17$), Children's Language ($n = 4$), Children's Literacy ($n = 3$), and More Information ($n = 1$). Participants accessed the website via mobile phones ($n = 39$), desktop computers ($n = 27$), and tablets ($n = 3$).

The passive waiting (control) condition involved receiving no support while waiting, as per usual practice at

the site. In the passive waiting group, 6 participants reported receiving 1:1 speech-language pathology intervention (e.g., at a private service) during the intervention period and so did not receive their allocated intervention (intention to treat, $n = 20$; per protocol, $n = 14$).

Per Protocol Analyses

Per protocol analyses were undertaken with each primary outcome variable to measure group differences (Table 3; Fig. 3). Overall, no statistically significant differences between groups were identified for child or caregiver outcomes. Unadjusted means for the per protocol sample ($n = 30$) are reported in Table 4, indicating a small amount of change in children's language outcomes occurred for both groups which may be of clinical (not statistical) significance, whilst almost no change occurred for the other outcome measures. Unless otherwise stated, the per protocol analyses met statistical assumptions regarding linearity, normality, homogeneity of regression slopes and variance, and homoscedasticity, with no outliers identified in the data.

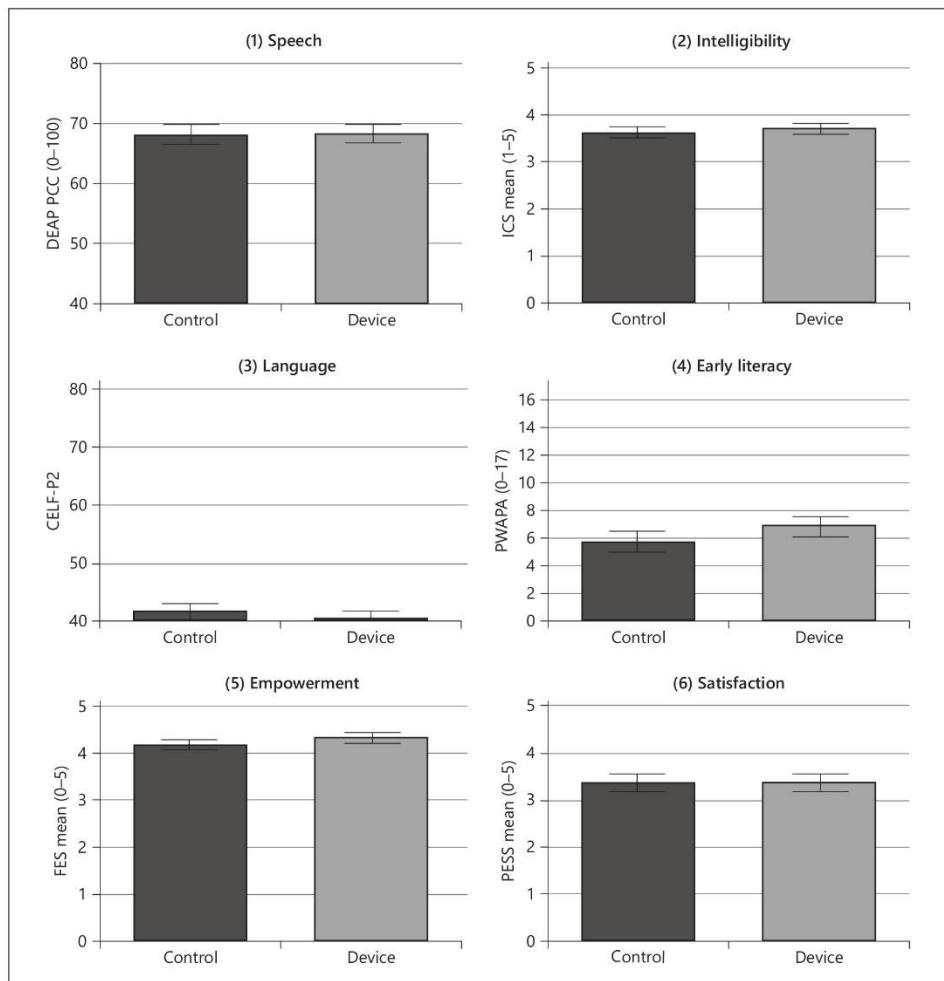


Fig. 3. Primary outcomes of the intervention groups displayed using adjusted means from the ANCOVA analysis in the Active/Pas-sive Waiting Study: per protocol ($n=30$). Speech: DEAP, Diagnostic Evaluation of Articulation and Phonology – phonology subtest, percentage of consonants correct (scores between 0 and 100) [67]. Intelligibility: ICS, Intelligibility in Context Scale (mean score between 1 and 5) [64]. Language: CELF-P2, Clinical Evaluation of

Language Fundamentals Preschool – 2nd ed., Australian Standardised Edition, three core language subtests (raw score between 0 and 86) [71]. Early literacy: PWPA, Preschool Word and Print Awareness measure (raw score between 0 and 17) [72]. Empowerment: FES, Family Empowerment Scale (mean score between 1 and 5) [62]. Satisfaction: PESS, Patient Enablement and Satisfaction Survey (mean score between 1 and 5) [57].

Children's Speech

Results of a one-way ANCOVA, controlling for base-line speech production, indicated that there was no significant difference in post-intervention speech production between the active and passive waiting (control) groups ($F(1, 27) = 0.003, p = 0.955, \eta_p^2 = 0.000$).

Children's Intelligibility

After adjustment for pre-intervention intelligibility, there was no statistically significant difference in post-intervention intelligibility between the active and passive waiting (control) groups ($F(1, 25) = 0.166, p = 0.687, \eta_p^2 = 0.007$).

Table 4. Unadjusted means for all outcome variables at pre- and post-assessment (per protocol; $n = 30$)

	Measure	Pre-assessment (mean \pm SD)	Post-assessment (mean \pm SD)
Children's speech	DEAP		
Passive waiting (control)	DEAP	68.01 \pm 14.56	68.19 \pm 12.02
Active waiting	ICS	67.61 \pm 10.83	68.03 \pm 9.75
Children's intelligibility	ICS		
Passive waiting (control)	CELF-P2	3.30 \pm 0.48	3.49 \pm 0.61
Active waiting	CELF-P2	3.57 \pm 0.43	3.80 \pm 0.46
Children's language	CELF-P2		
Passive waiting (control)	CELF-P2	32.07 \pm 10.57	41.79 \pm 11.89
Active waiting	CELF-P2	31.69 \pm 17.08	40.38 \pm 14.13
Children's early literacy	PWPA		
Passive waiting (Control)	PWPA	4.21 \pm 2.52	5.79 \pm 3.29
Active waiting	PWPA	3.94 \pm 2.62	6.63 \pm 3.74
Caregivers' empowerment	FES		
Passive waiting (control)	FES	4.27 \pm 0.45	4.25 \pm 0.58
Active waiting	FES	4.01 \pm 0.60	4.21 \pm 0.43
Caregivers' satisfaction	PESS		
Passive waiting (control)	PESS	3.52 \pm 0.50	3.42 \pm 0.62
Active waiting	PESS	3.20 \pm 0.71	3.31 \pm 0.67

Speech: DEAP, Diagnostic Evaluation of Articulation and Phonology – phonology subtest, percentage of consonants correct (scores between 0 and 100) [67]. Intelligibility: ICS, Intelligibility in Context Scale (mean score between 1 and 5) [64]. Language: CELF-P2, Clinical Evaluation of Language Fundamentals Preschool – 2nd ed., Australian Standardised Edition, three core language subtests (raw score between 0 and 86) [71]. Early literacy: PWPA, Preschool Word and Print Awareness measure (raw score between 0 and 17) [72]. Empowerment: FES, Family Empowerment Scale (mean score between 1 and 5) [62]. Satisfaction: PESS, Patient Enablement and Satisfaction Survey (mean score between 1 and 5) [57].

Children's Language

After controlling for baseline language skills, there was no significant difference in post-intervention language scores between the active and passive waiting (control) groups ($F(1, 27) = 0.350, p = 0.559, \eta_p^2 = 0.013$). One outlier was identified in the data, as assessed with a standardised residual value greater than -3 standard deviations (value of -3.15). This outlier was removed from the dataset and the analysis was re-run. Removing the outlier did not alter the results, so it was concluded that this outlier did not have an appreciable effect on the analysis, and therefore was retained in the reported results. All other assumptions were met.

Children's Early Literacy

Results of a one-way ANCOVA, controlling for baseline early literacy skills, indicated that there was no significant difference in post-intervention early literacy skills between the active and passive waiting (control) groups ($F(1, 27) = 0.977, p = 0.332, \eta_p^2 = 0.035$).

Caregivers' Empowerment

After adjustment for pre-intervention empowerment scores, there was no statistically significant difference in post-intervention empowerment between the active and passive waiting (control) groups ($F(1, 27) = 0.748, p = 0.395, \eta_p^2 = 0.027$).

Caregivers' Satisfaction

After adjustment for pre-intervention satisfaction scores, there was no statistically significant difference in post-intervention satisfaction between active and passive waiting (control) groups ($F(1, 19) = 0.002, p = 0.969, \eta_p^2 = 0.000$).

Discussion

The findings of the Active/Passive Waiting Study revealed no statistically significant differences between active and passive waiting groups on any of the six primary

outcome measures: children's speech, intelligibility, language, literacy, and caregivers' empowerment and satisfaction. A purpose-built website aimed to provide information and resources to empower caregivers to actively support their children's communication skills while on a waiting list, ease the burden of waiting, and prepare families for commencement of speech-language pathology intervention when they reach the top of the waiting list. No statistically significant changes in children's or caregivers' outcomes were noted (Table 3) which suggests that a website alone may not be enough to facilitate improvement in children's speech, intelligibility, language, and early literacy, or enhance caregivers' empowerment and satisfaction while waiting for speech-language pathology.

A small amount of improvement in children's language was observed for both groups over time when looking at unadjusted means (Table 4) which may be attributed to natural development. Children's exposure to learning opportunities in their daily lives, including through participation in early childhood education or school, may have had an impact, particularly since some children commenced school during the study timeframe. The degree of change in children's language was not considered statistically significant, but may be of clinical significance for some children whose language skills increased to within normal limits at stage 4 for their overall core language standard score ($n = 3$) and/or subtest scaled scores (sentence structure, $n = 7$; word structure, $n = 2$; expressive vocabulary, $n = 2$) [79]. Some children whose scores were within normal limits at stage 2 were no longer considered within normal limits at stage 4 for their overall core language standard score ($n = 1$) and/or subtest scaled scores (sentence structure, $n = 3$; word structure, $n = 1$; expressive vocabulary, $n = 2$); however, each of those children had aged into a different bracket for scaled scoring, indicating the change was likely attributed to this rather than a regression in language abilities. Overall, most children in the present study did not make statistically or clinically significant progress with their language. Children with developmental language disorders tend to display delayed language emergence and acquire language skills over an extended period of time compared with typically developing children, requiring more than just additional time to catch up to typically developing peers [80]. Whilst some spontaneous change in children's language skills may occur while waiting, gains are unlikely to be comparable with those following direct intervention with an SLP.

Over the 6-month period, minimal to no change was recorded for children in either group (active or passive waiting) for speech, intelligibility, or early literacy outcomes when both adjusted (Table 3) and unadjusted (Table 4) mean scores were compared. Previous studies have indicated that some degree of spontaneous improvement may occur over time due to natural development [14, 17, 20], which underpin approaches such as "watch and wait" where children are monitored over time rather than provided with speech-language pathology intervention. Studies of typically developing children's speech acquisition indicate that children's PCC scores gradually increase over time [81]. A cross-linguistic review of 64 studies of typically developing children's consonant acquisition found that 3-year-old children produced 86.39% (SD 9.14) of consonants correctly and 6-year-old children produced 95.12% (SD 3.74) of consonants correctly [81]. However, it is possible that children with speech sound disorders may spontaneously improve at a slower rate than typically developing children. A community-based RCT found that the phonology error rate for children in a "watchful waiting" group reduced by almost 30% over a 12-month period without intervention [17]. A cluster RCT comparing an educator-delivered intervention (input-based computer program) and control group (usual classroom practices) found that 4- to 5-year-old children with speech sound disorders in both groups displayed an average improvement of 6% in their PCC over a 4-month period [46]. Additionally, the children in both groups demonstrated significant improvements in early literacy skills (using the PWPA) over time, while no significant change was observed for intelligibility (using the ICS) [46]. In the concurrent Advice/Device Waiting RCT comparing therapy, advice, and device, unadjusted mean data indicated that children's speech, language, intelligibility, and early literacy increased over time for all groups, although only children who received face-to-face intervention achieved statistically significant change in their speech (PCC) [45]. Dodd et al. [82] found that children with speech sound disorders who received face-to-face phonological intervention with an SLP (30 min per week over a 3-month period) demonstrated increases of over 16% in their PCC. In the present study, the children demonstrated minimal change attributable to natural development in these communication domains over a 6-month period, particularly for children's speech where there was no change. Therefore, children demonstrated far less progress while waiting than may be anticipated if they received speech-language pathology intervention over the same time frame. The findings of this study reinforce the

importance of and need for early speech-language pathology intervention for children with communication difficulties since the children did not spontaneously improve over time without direct intervention from an SLP.

As outlined previously, dosage and intensity are important in caregiver-led interventions [33]. In the present study, caregivers received a low intervention dose as just 69 webpage views in total (mean 3.63 page views/participant) were recorded for the website throughout the intervention timeframe (May 11, 2018 to April 30, 2019), and higher levels of engagement and uptake of the website were likely needed to produce an intervention effect. Whilst the website design, content, and usability were informed by feedback from consumers and professionals [42], the capabilities of the website used in this study may have been inadequate to sufficiently engage caregivers and encourage active waiting. Had the budget and host platform enabled inclusion of interactive elements, guided support from an SLP, and built-in feedback mechanisms regarding children's performance, the effectiveness of the website as an active waiting resource may have been enhanced [40, 44]. These are considerations for future iterations of the website or future studies involving the use of innovative technology in waiting list management. However, the website was designed to be a practical resource for easy translation into real-world speech-language pathology services without the need for additional funding or staffing for implementation, and this study was designed to mirror usual practice as much as possible. Guided support and a high level of interaction between SLPs and families on a waiting list are unlikely to be feasible in real-world settings due to SLPs' existing caseload demands and resource constraints. This study highlights the challenges of working with resource limitations and the need for practicality when optimising care for children and families on waiting lists in real-world settings.

Caregivers' satisfaction scores were high at baseline for both groups, possibly due to receiving an early assessment, which left little room for improvement over time. It could reasonably be anticipated that satisfaction may decrease as waiting time increased, in line with the finding from Ruggiero et al. [3] that caregivers "expressed greater dissatisfaction" (p. 345) when they experienced longer waiting times between initial assessment and intervention. However, caregiver satisfaction remained stable over time in the present study, which may reflect participation in an early assessment, rather than access to the website since levels of satisfaction did not vary between groups. Rittenmeyer et al. [24] suggested that professionals can reduce the impact of waiting through displaying

empathy and warmth, helping families feel understood, and being truthful and realistic about the duration of the wait for intervention. It is possible that the face-to-face interaction with the assessing SLP in the early assessment and again at the follow-up assessment contributed in some way to maintaining caregivers' satisfaction over time, since rapport-building and empathy are inherent in real-world clinical practice. This may highlight the potential value of interaction with an SLP as opposed to a generic device for families on waiting lists. Additionally, the concurrent Advice/Device Waiting Study [45] found that caregivers whose children received face-to-face intervention with an SLP without waiting were significantly more satisfied than those who received the same purpose-built website. Whilst higher caregiver satisfaction in the intervention condition may have been related to the significant improvements seen in children's speech production, the significant finding may also reflect the increased interaction and access to an SLP for those caregivers [45], thus further supporting the provision of early access to speech-language pathology assessment and intervention for children with communication difficulties.

Caregivers also displayed high empowerment scores at baseline and maintained this level of empowerment over time in both groups, indicating no intervention effect. According to Feldman et al. [26], caregivers with higher empowerment scores on the FES [62] were more likely to access services faster for their children with physical disabilities. Every eligible child and caregiver referred during the 10-month recruitment period were invited to participate in the present study. The caregivers who participated may have been more empowered to begin with (corresponding with high baseline scores) which could have contributed to their decision to participate and access earlier speech-language pathology services for their children. Since caregivers completed the questionnaire during the pre-assessment, succeeding in receiving an earlier assessment for their child may have contributed to high baseline scores. Receiving information in the pre-assessment, or anticipating the receipt of information about their child, may also have led to higher baseline empowerment scores since the provision of general and specialised information is associated with increased parental empowerment [25]. Since all families received an assessment on enrolment in this study, it is unclear whether caregivers would perceive themselves as empowered if they received no support or contact with an SLP while waiting for speech-language pathology for their children.

Early triage and assessment also enabled earlier identification of children requiring referrals to alternative or additional services. For instance, for children at stage 2 (pre-assessment; $n = 46$), referrals to early childhood intervention services ($n = 1$), occupational therapy (e.g., fine motor skills; $n = 15$), paediatricians ($n = 8$), dentists ($n = 4$), optometrists ($n = 3$), and dieticians ($n = 1$) were recommended. Although referral to other services was not an outcome measure in this study, it is a clinically important finding. This potentially reduced cumulative waiting times for families as they would not have to experience a second waiting period once referred to a more appropriate service [83]. Referral to additional services (e.g., occupational therapy) enabled children to potentially receive support from another professional while waiting for speech-language pathology, which may also have impacted caregivers' empowerment and satisfaction ratings.

More children were lost to follow-up in the active waiting group ($n = 4$) than in the passive waiting group ($n = 2$) and of all participants who attended post-assessments, a higher proportion of participants received per protocol intervention in the active waiting group ($n = 16/16$) compared with the passive waiting group ($n = 14/20$). The 6 participants who were not included in the per protocol analysis received 1:1 speech-language pathology intervention during the project timeframe (e.g., in private practices). Scherrer-Bannerman et al. [38] indicated that individuals on waiting lists who received educational information via a website perceived having increased social support. It is possible that the provision of a website in the present study may have been perceived as enough support for caregivers in the active waiting group, so alternative services were not sought. Caregivers in the passive waiting group may have felt less supported, so some accessed alternative speech-language pathology services to act on their knowledge obtained from the assessment regarding their child's needs.

Limitations

There were five main limitations of the present study. Firstly, although a two-stage baseline assessment is recommended [84], it was not feasible in the real-world clinical setting in which this research was conducted. Secondly, in the passive waiting condition, caregivers received an assessment and report about their child's performance which may have unintentionally encouraged a more active approach than may have occurred if they had no contact with an SLP. The assessment and report were additional to a true control condition but

were necessary to measure change in child and caregiver outcomes in the present study. This may limit the applicability of the findings to families on waiting lists who receive no contact from an SLP. Thirdly, data regarding website access for the active waiting group were obtained via Google Analytics for total website hits by page, date, and device type. Since the website was hosted on a larger government website, website access and intervention dose could not be tracked for individual participants. Fourthly, while the instruments used to measure child and caregiver outcomes are reliable and valid measures, they may not have been sensitive enough to detect change. For instance, an expressive vocabulary assessment may have been a more sensitive measure of language ability, since the CELF-P2 Core Language subtests measure both expressive and receptive language and change may not be expected across both domains [6]. However, this was a real-world translational research study and the CELF-P2 was part of the SLPs' usual assessment battery at the research site. Since a subset of items from the FES and PESS were used rather than all items, this may have impacted the sensitivity of the measures.

Finally, small group sizes due to attrition, exclusions, and a pre-determined recruitment timeframe may limit the generalisability of the findings. More referrals were received for children with primary needs other than speech or language (e.g., feeding, $n = 37$) than anticipated, highlighting the complexity of the caseload at the community health service. Small group sizes meant that the pre-determined power analysis was not met and, subsequently, the study had low statistical power. Researchers have indicated that studies with low power are more likely to make type 2 errors than high-powered studies [85]. Group sizes were also insufficient to enable children with different areas of communication difficulty to be separated during the analyses. For instance, children with speech or language needs only were grouped with children with both speech and language difficulties, meaning improvements in speech and language outcomes may have been diluted or masked. However, this research provides important insights about a community-based sample, particularly children in a control group on a waiting list. Studies involving participants who do not receive intervention are not always ethically possible in clinically based research projects due to some services providing interim support as usual practice [45].

Future Directions

In the present study, access to a purpose-built website following a speech-language pathology assessment was found to be no more effective at improving children's and caregivers' outcomes than receiving an assessment and waiting without further support on a waiting list. However, the potential impact of accessing a website in combination with other forms of support, such as an advice session, or with the addition of interactive features is currently unknown. Whilst addressing the gap between level of need and availability of speech-language pathology services must remain a priority, research into alternative methods to support children and families on waiting lists, such as via technology, is also a potential way forward. Further analysis of children's assessment results and caregivers' responses may provide additional insights into natural history and factors predicting the amount of spontaneous improvement expected for children on waiting lists, thus informing policy and practice regarding waiting list management and prioritisation of children for services. Follow-up research with caregivers in the present study may also provide more detailed insights into their experiences of being on a waiting list, receiving an early assessment, and what they did while waiting, including details about their website use. These insights may identify further considerations for improvements to the website and the development and evaluation of other active waiting strategies.

Conclusion

This RCT was among the first of its kind to evaluate the provision of a purpose-built website to promote active waiting for speech-language pathology by children and caregivers in a real-world clinical setting. The research site provided an opportunity to include a control group of children to gain insights into passive waiting for speech-language pathology. There were no statistically significant differences between the active (website) and passive (control) waiting groups for the six outcome measures (children's speech, intelligibility, language, and literacy, and caregivers' empowerment and satisfaction), indicating that the purpose-built website was not effective in this study. A small amount of improvement in children's language was observed for both groups which may be of clinical (not statistical) significance and attributed to natural development. No improvement was observed in children's speech over a 6-month period while children waited for face-to-face speech-language pathology interven-

tion, with minimal change occurring for other child and caregiver outcomes. The findings support the importance of and need for early speech-language pathology intervention for children with speech and language difficulties to make progress. The purpose-built website was not an effective solution, but the potential of a website for facilitating active waiting when combined with other forms of support (e.g., SLP monitoring/guided support) or incorporating interactive features is unclear. The practicalities for implementation in real-world settings must be considered. Timely speech-language pathology intervention delivered with appropriate dosage is necessary to optimise children's communication outcomes [86]. Until timely and effective speech-language pathology intervention is accessible for all children who need it, provision of early assessments may be beneficial, and cost-effective, innovative solutions for supporting children and families on waiting lists are needed.

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Statement of Ethics

This research was ethically approved by the South Eastern Sydney Local Health District Human Research Ethics Committee (approval No. HREC/17/POWH/535), with site-specific approval obtained from the Human Research Ethics Committee at the health service in which the research was conducted (GVH 50/17). Participants' caregivers provided written consent to participate in the research.

Conflict of Interest Statement

The authors have no relevant conflicts of interest to declare.

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Author Contributions

N.M. made substantial contributions to the conceptualisation and design of the work, the acquisition and interpretation of data, drafting and revision of the manuscript for important intellectual content, final approval of the version to be published, and agrees to be accountable for all aspects of the work. S.M. made substantial contributions to the conceptualisation and design of the work, interpretation of data, drafting and revision of the manuscript for important intellectual content, final approval of the version to be published, and agrees to be accountable for all aspects of the work. N.I. made substantial contributions to the analysis and interpreta-

tion of data, drafting and revision of the manuscript for important intellectual content, final approval of the version to be published, and agrees to be accountable for all aspects of the work. E.D. made substantial contributions to the conceptualisation and design of the work, revision of the manuscript for important intellectual content, final approval of the version to be published, and agrees to be accountable for all aspects of the work. K.R. made substantial contributions to the conceptualisation and design of the work, revision of the manuscript for important intellectual content, final approval of the version to be published, and agrees to be accountable for all aspects of the work.

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Appendix A. Primary and Secondary Outcome Measures for Children and Caregivers

Outcome	Construct				
Measure	Measured	Instrument	Items	Scoring	Norming, reliability, and validity
Primary Children's speech production: Speech sounds ¹	Children's speech production: Speech sounds ¹	Diagnostic Evaluation of Articulation and Phonology (DEAP; Dodd et al., 2002a – Phonology subtest.)	"What's this?" (child names the picture shown to them). Child's response transcribed using International Phonetic Alphabet (IPA) conventions.	Percentage of consonants correct (PCC) is calculated by counting the number of consonant sounds in words not elicited (a), the number of consonants elicited ($b = 141 - a$), the number of consonants in error (c), total number of correct consonants ($d = b - c$), then PCC is calculated using formula $PCC = d \div b \times 100$ (Dodd et al., 2002b). Higher PCC = greater speech sound clarity.	<i>Test-retest reliability:</i> "test scores for the five measures were all significantly correlated" (Dodd et al., 2002b, p. 39). PCC had a strong positive correlation ($r = 0.94, p = .001$). <i>Inter-rater reliability:</i> Strong positive correlation for PCC measures between raters ($r = 0.89, p = .001$) (Dodd et al., 2002b). <i>Content validity:</i> DEAP "provides a comprehensive diagnostic sample of speech skills" as it tests the full range of sounds and a range of

syllable shapes, length and contexts (Dodd et al., 2002b).

Concurrent validity: A highly significant positive correlation ($r = 0.95, p = <0.001$) was found between PCC scores from the DEAP and the Edinburgh Articulation Test (EAT; Anthony, Bogle, Ingram, & McIsaac, 1971) (Dodd et al., 2002b).

Secondary	Children's speech production: Stimulability of single speech sounds ¹	Informal measure	e.g., "Say 'p'"	Tested in isolation any consonants on the DEAP (Dodd et al., 2002a) form that the child had difficulty with. Total score out of 24 (scores: 1 = "stimulable", 0 = "not stimulable").	-
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	Children's speech structures and functions ¹	Oromotor assessment (based on Robbins & Klee, 1987).	e.g., "Open your mouth", "poke your tongue out".	Total structure score out of 21 (scores: 0 = "abnormal", 1 = "normal"). Total function score out of 42 (scores: 0 = "absent function", 1 = "emerging function", 2 = "adult-like function").	-
N/A	Children's hearing: Hearing screener ¹	Informal measure, based on Sound Start Study protocol (McLeod et al., 2013-2015).	e.g., "Put a stamp on the page when you hear a beep noise".	Scores: 1 = "pass" (<20/30dB at 500, 1000, 2000, and 4000 Hz), 0 = "fail".	-
Primary	Children's language skills ¹	Clinical Evaluation of Language Fundamentals –	"Point to the fish and the ball" (Concepts and Following	Total raw scores out of 86 for Core Language, Receptive Language and Expressive Language subtests.	<i>Test-retest reliability:</i> Subtest scores "possess adequate to excellent stability across time for all ages" ($r = 0.78 - 0.9$), however p

Preschool 2 nd Edition (CELF-P2; Wiig, Secord, & Semel, 2006) – Core Language subtests (3).	Directions subtest). “Here is one book, here are two...(books)” (Word Structure subtest).	Higher raw score = greater language ability.	values were not provided (Wiig et al., 2006, p. 118). <i>Internal reliability:</i> coefficients for subtests to be used in the present study ranged from 0.8 to 0.9 (Wiig et al., 2006, p. 122). <i>Inter-rater reliability:</i> subtest raw scores were correlated to obtain average decision agreement, which ranged between .95 to .97 (Wiig et al., 2006, p. 124). <i>Content validity:</i> “The language skills sampled...are well documented in the literature” (p. 130). An “expert review” was conducted to ensure the content was appropriate for children from
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“diverse linguistic and cultural backgrounds” (Wiig et al., 2006, p. 130).

Primary	Children’s early literacy skills ¹	Preschool Word Awareness	e.g., “Show me the front of the book”, “Show me the first measure (PWPA; letter on this page.” Justice & Ezell, 2001).	Child scores 1 to 2 points for correct responses (according to scoring criteria) or 0 points for incorrect responses. Total raw score out of 17. Higher raw score = greater early literacy skills.	<i>Internal reliability:</i> $\alpha = .74$ (Justice, Bowles, & Skibbe, 2006). <i>Construct validity:</i> “The PCM (partial credit model) fit analyses showed good fit between the overall data and the PCM, indicating that the PWPA provided a valid estimate of the latent PCK (print-concept knowledge) trait” (Justice et al., 2006, p. 224).
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Primary	Children's speech production: Intelligibility of speech ¹	Intelligibility in Context Scale (ICS; McLeod, Harrison, & McCormack, 2012).	e.g., "Do strangers/unfamiliar people understand your child?"	Scores from 1 to 5 (5 = "always", 4 = "usually", 3 = "sometimes", 2 = "rarely", 1 = "never"). Total score (out of 35), mean total score (out of 5). Higher score = greater speech intelligibility.	<i>Internal reliability:</i> $\alpha = .94$ (McLeod, Crowe, & Shahaeian, 2015). <i>Construct validity:</i> range $r = .54$ to $r = .80$, $p < .001$ (McLeod et al., 2015). <i>Criterion validity:</i> Validated with PCC score from DEAP ($r = .24$, $p < .001$) (McLeod et al., 2015).
Secondary	Children's activities and participation outcomes ²	Focus on the Outcomes of Communication Under Six (FOCUS) (Thomas-Stonell et al., 2012).	Part 1: 34 questions (e.g., "My child talks a lot"). Part 2: 17 questions (e.g., "My child can respond to questions").	Part 1 scoring: from 1 = "not at all like my child", to 7 = "exactly like my child". Part 2 scoring: from 1 = "cannot do at all", to 7 = "can always do without help". FOCUS total score (out of possible 350).	<i>Internal consistency:</i> "High internal consistency for both parents (Cronbach $\alpha = 0.96$) and speech-language pathologists (Cronbach $\alpha = 0.94$). A factor analysis demonstrated a structure consistent with a single underlying construct" (Thomas-Stonell et al., 2012, p. 16).

					<i>Test-retest reliability:</i> High for parents ($r > .95$) and “very high” for SLPs (Thomas-Stonell et al., 2012, p. 16).
					<i>Inter-rater reliability:</i> “Good inter-rater reliability” ($r = 0.90, p < 0.001$) (Thomas-Stonell et al., 2012, p. 16).
Primary Caregiver empowerment ²	Family Empowerment Scale (FES; Koren, DeChillo, & Friesen, 1992).	Example item: subscale (2), item 16 “I am able to get information to help me better	Scoring: 1 = “not true at all”, to 5 = “very true”. Mean score out of 5.	Higher score = higher parental empowerment.	<i>Construct validity:</i> “Strong construct validity as a change-detecting instrument” (Thomas-Stonell et al., 2012, p. 18). <i>Internal reliability:</i> $\alpha = .93$ (split-half estimate) (Singh et al., 1995). Subscale reliability: (1) $\alpha = .89$, (2) $\alpha = .89$, (3) $\alpha = .85$, and (4) $\alpha = .78$ (Singh et al., 1995).

18 questions understand my
from subscales: child.”
(1) Systems
advocacy, (2)
knowledge, (3)
competence, (4)
self-efficacy.

Primary	Caregiver satisfaction ²	Adapted from the ‘Patient Enablement and Satisfaction Survey’ (PESS; APHCRI and AMLA, 2012).	Caregivers responded to 12 items based on their level of agreement with the given statements (e.g., “The speech pathologist/s were available when I needed them”).	Scoring: 1 = “strongly disagree”, to 5 = “strongly agree”). Mean score out of 5.	Previously used in nursing (APHCRI and AMLA, 2012) and allied health settings.
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Secondary	Caregiver concern ²	Parent Evaluation of Developmental Status (PEDS; Glascoe, 2000).	8 closed-ended questions (e.g., “Do you have any concerns about how your child talks and makes speech sounds?”).	Scoring: 2 = “Yes”, 1 = “A little”, 0 = “No”. Total raw score out of 12. Higher score = higher caregiver concern.	Moderate sensitivity (74%), low specificity (64%) (Limbos & Joyce, 2011).
Secondary	Children’s communication, activities, and participation outcomes ³	Therapy Outcome Measures (TOMS; Perry & Skeat, 2004) – speech, language, fluency, and dysphonia scales.	Assessing SLP rated children on each TOM domain: Impairment, Activity Limitation, Participation, Restriction, and Distress/Wellbeing.	Scoring: from 0 = “complete difficulty”, to 5 = “no difficulty”. Total score per scale (out of a possible 20). Overall total score (out of 80). Higher score = greater child outcome/participation/wellbeing.	Language scale shows “satisfactory inter-therapist agreement” and “generally satisfactory” test-retest reliability (p. 43). Used as a screening tool in large-scale study Australian preschool children’s speech and language (McLeod, Harrison, McAllister & McCormack, 2013).

¹ Measure administered directly with children; ² Measure involved caregiver report; ³ Measure involved SLP report.

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Part Four

Conclusions and Contributions

Introduction to Part Four

It is...only through mapping what is known and acknowledging uncertainty that scientific knowledge can accumulate – Petticrew (2003, p. 758)

Part Four of this doctoral research outlines the implications, contributions, and conclusions of the research, and consists of two chapters (Chapters 8 and 9). Chapter 8 includes an invited paper about translating this doctoral research into practice (McGill & McLeod, 2020). Research findings from previous papers (Chapters 2, 3, and 4) and existing literature were used to develop a speech-language pathology care pathway to support transparent and holistic thinking about waiting. Recommendations for planning, testing, and implementing waiting list management strategies are outlined, with implications for professionals, governments, and policymakers. Chapter 9 provides a summary of the doctoral research and key findings, outlines the impact of the research, and identifies the contributions of the research with reference to the five aims stated in Chapter 1. This doctoral research concludes with discussion regarding implications for stakeholders and theory, limitations and future directions, and final thoughts and conclusions.

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Chapter 8: Waiting List Management in Practice

Paper 6

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**Waiting list management in speech-language pathology:
Translating research to practice**

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Abstract

Background: Many people with communication disorders wait for speech-language pathology services. Children may miss out on timely intervention and families may feel disempowered. Waiting list management poses a challenge for stakeholders, including children, parents, and speech-language pathologists (SLPs).

Aim: This paper aims to inform SLPs' waiting list management by presenting a care pathway and example framework for planning, evaluating, and implementing waiting list management strategies.

Method: This paper draws on literature and a programme of research involving four studies: (1) submissions to an Australian Government Senate Inquiry ($n = 133$); (2) questionnaire responses about waiting lists from SLPs ($n = 264$); (3) design of an active waiting website based on feedback from members of the public ($n = 119$), focus groups ($n = 16$), and a review of existing sites ($n = 25$); and (4) a randomized controlled trial evaluating active versus passive waiting by children and families ($n = 97$).

Results: Studies 1 and 2 informed the development of a speech-language pathology care pathway, extending on findings from the literature, to promote holistic consideration of the duration and stages of waiting and support advocacy. Studies 3 and 4 were mapped onto Plan-Do-Study-Act cycles to demonstrate a potential framework for planning, evaluating, and implementing waiting list management strategies in clinical settings.

Conclusion: Action is needed to address waiting lists in the absence of timely intervention. When managing waiting lists, professionals, governments, and policymakers are encouraged to consider the impact of waiting throughout the care pathway and adopt a systematic, planned approach when implementing solutions.

Managing speech-language pathology waiting lists:

Translating research to practice

Provision of speech-language pathology services to those who need it, when they need it, is key in achieving optimal outcomes. Unfortunately, receipt of timely services is not the reality for many individuals with communication and swallowing needs (Commonwealth of Australia, 2014; Ruggero et al., 2012; Rvachew & Rafaat, 2014). A mismatch between supply, need, and demand for speech-language pathology services can lead to long waiting lists, as in many countries there are not enough services for all individuals who need them. Waiting lists also exist in other healthcare domains, particularly in countries where government subsidized healthcare services are available (e.g., United Kingdom, Canada, Australia). Waiting lists pose a significant and worsening problem with the demand for speech-language pathology anticipated to increase in coming years (Commonwealth of Australia, 2014). However, few researchers have explored perspectives, experiences, and aspirations specifically regarding waiting for speech-language pathology services, from consumers' and professionals' viewpoints.

To better understand speech-language pathology waiting lists from stakeholders' perspectives (consumers, professionals, and organizations) and explore possible solutions, a 4-stage programme of research was undertaken, known as the Wait-Lifting Study. Study 1 involved thematic analysis of stakeholder submissions about waiting for speech-language pathology ($n = 133$) made to an Australian Government Senate Inquiry (Commonwealth of Australia, 2014; McGill, Crowe, & McLeod, 2019). Study 2 explored speech-language pathologists' (SLPs') perspectives regarding paediatric waiting lists and prioritization via a questionnaire ($n = 264$; McGill, McLeod, Crowe et al., 2019). Study 3 involved the design of an evidence-based website (Waiting for Speech Pathology Team, 2018) for children and families informed by stakeholder consultation via a questionnaire ($n = 119$) and focus

groups ($n = 16$), and evaluation of existing speech and language sites ($n = 25$; McGill & McLeod, 2019). Study 4 involved a randomized controlled trial (RCT; Active/Passive Waiting Study) to compare children's and caregivers' ($n = 97$) outcomes in two waiting list conditions: (1) active waiting, involving provision of the website (Waiting for Speech Pathology Team, 2018), and (2) passive waiting, a control condition involving waiting without support (usual practice at research site; McGill, McLeod, Ivory et al., 2019). Study 4 was undertaken concurrently with an RCT conducted in another Australian state (McLeod et al., 2019). Key findings from the Wait-Lifting Study and international literature informed the development of a care pathway and present a potential framework for the planning and evaluation of waiting list management strategies, as follows.

Impact of waiting lists

Consequences of waiting lists are reported for consumers, professionals, organizations, and society throughout the literature. Consumers (e.g., children, families) can experience the burden of waiting lists on: (1) long term developmental outcomes (e.g., poorer academic and behavioural outcomes), (2) physical health (e.g., swallowing aspiration risk), (3) emotional wellbeing (e.g., feeling stressed, concerned, frustrated), (4) finances (e.g., costs of accessing private services), (5) relationships (e.g., family cohesiveness, peer relationships), and (6) time (e.g., months spent waiting for support) (e.g., McGill, Crowe et al., 2019).

Professionals can experience psychological and practical consequences of waiting lists. SLPs have reported feeling stressed, anxious, frustrated, overwhelmed, and embarrassed about their waiting lists, although a few SLPs also reported neutral or positive feelings (McGill, McLeod, Crowe et al., 2019). The “pressure” (McGill, Crowe et al., 2019, p. 14) of waiting lists and managing large caseloads can contribute to burnout and job dissatisfaction among SLPs, as well as impact SLPs’

ability to provide effective, evidence-based services (Edgar & Rosa-Lugo, 2007; Kenny & Lincoln, 2012; McGill, Crowe, & McLeod, 2019). Other professionals (e.g., doctors, allied health professionals, educators) have similarly reported feeling distressed and unable to provide optimal services due to waiting lists (Førde & Aasland, 2008; Lincoln et al., 2014; McGill, Crowe et al., 2019). Societal consequences of waiting lists include financial, social, and ethical burdens (McGill, Crowe et al., 2019).

Waiting list duration

Speech-language pathology waiting list duration has been reported to range from no waiting to more than one year (Ruggero et al., 2012; Rvachew & Rafaat, 2014), with one person reporting waiting eight years (McGill, Crowe et al., 2019). In an international study, waiting times were reported by SLPs to range from 0-20 months ($M = 5.20$ months) for assessment and 0-22 months ($M = 3.13$ months) for intervention (McGill, McLeod, Crowe et al., 2019). These waiting times exceeded SLPs' expectations of what was "about right" (assessment, $M = 2.02$ months; intervention, $M = 1.09$ months) (McGill, McLeod, Crowe et al., 2019). Some benchmarking has been undertaken to document maximum waiting times, for example, for children with speech sound disorders in Canada (Rvachew & Rafaat, 2014); however, guidelines are lacking for many countries and sub-types of communication disability. Duration may fluctuate in response to staffing and funding availability, service type (e.g., public, private), service delivery methods, or workplace processes and policies (e.g., the level of priority children are assigned).

Stages of waiting

Waiting for healthcare can occur in three main stages: waiting for (1) assessment, (2) diagnosis, and/or (3) intervention (Fogarty & Cronin, 2008). Giske and Gjengedal (2007) referred to stages 1 and 2 as the prediagnostic phase. Waiting

for a diagnosis (stage 2) may consist of two separate stages if multidisciplinary/specialist perspectives or more in-depth assessment are needed prior to diagnosis: (a) the time between initial assessment and a secondary assessment, and (b) the time between a secondary assessment and receiving a diagnosis (Lebel et al., 2003; Thorne et al., 1999). Glogowska and Campbell (2000) proposed three phases for parental involvement in speech-language pathology: (1) “getting in” (p. 397), typically involving the referral process and attending an initial appointment, (2) “getting on” (p. 398), when children are beginning to progress toward goals, often coinciding with commencing intervention, and (3) “getting there” (p. 400), when children can participate and cope in everyday environments, often occurring around discharge or beyond. In McGill, Crowe, and McLeod (2019), stakeholders (e.g., parents) also described waiting for multiple speech-language pathology services at once, cumulative waiting at services (e.g., due to moving to a new city), waiting for funding approvals, and waiting between intervention appointments or blocks of intervention. In a study by McGill, McLeod, Crowe, et al. (2019), SLPs reported that waiting for assessment was most common for children overall. In contrast, young children and children with feeding and stuttering needs most often received immediate assessment and intervention (referral → assessment → intervention). However, variation was evident across workplaces (McGill, McLeod, Crowe et al., 2019).

Speech-language pathology care pathway

The stages of waiting proposed by previous researchers (Fogarty & Cronin, 2008; Giske & Gjengedal, 2007; Glogowska & Campbell, 2000; Lebel et al., 2003; Thorne et al., 1999) along with additional stages identified in more recent research (McGill, Crowe et al., 2019; McGill, McLeod, Crowe et al., 2019) are reflective of a multitude of care pathways that children and families may follow when accessing

speech-language pathology services. The findings regarding duration and stages of waiting were integrated to form a speech-language pathology care pathway (Figure 1) to reflect key stages and highlight individual variations between workplaces. Waiting may occur at any point along the care pathway, with differing and potentially cumulative impacts on individuals who are waiting. Variation in the duration and stages of waiting may occur across countries, workplaces, and client populations. The care pathway may be used as a powerful advocacy tool, to prompt more holistic awareness of waiting among professionals and organizations, and enable more targeted planning, evaluation, and implementation of waiting list management strategies.

[INSERT FIGURE 1 HERE]

Waiting list management

Professionals can, and often do, actively manage waiting lists and their consequences. SLPs have described waiting list management strategies relating to workforce, service delivery, and workplace processes and policies (McGill, McLeod, Crowe et al., 2019). Prioritization for services is a common strategy involving needs-based rationing of resources, which determines who receives services and when (McCartney, 2000; McGill, McLeod, Crowe et al., 2019; Pickstone, 2007; Roulstone, 2007). More recent strategies involve technology, such as telehealth service delivery and mobile health programmes (McGill, McLeod, Crowe et al., 2019; Olson, Wilkinson, Jackson Wilkinson, Harris, & Whittle, 2016; Wales, Skinner, & Hayman, 2017), while other strategies (e.g., indirect intervention, home programs, and group intervention) have been implemented in workplaces for many years (Pert, 2010; Schooling, Venediktov, & Leech, 2010). Waiting list management strategies may be direct, that is, they directly impact waiting list duration/magnitude (e.g., employment of additional SLPs, receiving additional funding, restriction of eligibility criteria), or

indirect, whereby they aim to compensate for the wait or support individuals while waiting (e.g., provision of information to families on waiting lists). A lack of unified, evidence-based strategies for managing waiting lists and supporting those who are waiting leads to variation in practice, uncertainty, and ethical dilemmas.

Some waiting list management strategies reflect the notion that waiting can be an active process (Feldman et al., 2002; Giske & Gjengedal, 2007; McGill, Crowe et al., 2019; McGill, McLeod, Crowe et al., 2019; McLeod et al., 2019). Examples of consumer actions undertaken while waiting for speech-language pathology include searching for information online, researching options for services, and advocating and making complaints (McAllister et al., 2011; McGill, Crowe et al., 2019). Access to information can be empowering for families of children with disabilities, and those who are empowered may be more active while waiting (Feldman et al., 2002; Fordham, Gibson, & Bowes, 2012). An evaluation of three strategies to support families and encourage active waiting for speech-language pathology (face-to-face intervention, advice sessions, and a website) found that face-to-face intervention led to significantly more improvement in children's speech and caregivers' satisfaction outcomes; whilst there were no significant differences between the three strategies for improving children's intelligibility, language, and literacy, or caregivers' empowerment outcomes (McLeod et al., 2019). The Active/Passive Waiting Study (McGill, McLeod, Ivory et al., 2019) evaluated provision of the same website with a waiting list control group and found similar child and caregiver outcomes for both groups.

An alternative perspective is that waiting for speech-language pathology is a passive, inactive process (Glogowska & Campbell, 2000), which may influence SLPs' waiting list management. Some individuals with communication disabilities may experience spontaneous improvement or normalization without speech-language

pathology intervention, reflecting the natural history of communication disorders (Law et al., 2000; Roulstone et al., 2003). Studies exploring natural history or service delivery approaches such as watch and wait or monitoring examine the possibility of spontaneous improvement rather than providing early intervention, reporting mixed outcomes for children's communication and no reliable predictors for determining 'normalization' versus persistence of communication disabilities (Glogowska et al., 2000; Law et al., 2000; McGill, McLeod, Ivory et al., 2019; Morgan et al., 2017; Roulstone et al., 2003, 2009). Implementation of waiting list management strategies such as watch and wait or monitoring without direct intervention, or not acting on waiting lists at all, may also be a consequence of resource constraints and restrictions imposed by organizations.

Implementation of a waiting list management strategy:

Plan-Do-Study-Act

Selection and implementation of waiting list management strategies can be challenging, particularly in the case of resource and time constraints, innovative approaches, or uncertainty regarding evidence (Petticrew, 2003). However, passive inaction is not the solution, and consideration of internal evidence and client preferences alongside external evidence from the literature is recommended (Dollaghan, 2007; Petticrew, 2003). Small-scale testing of waiting list management strategies in real-world clinical settings, with thorough planning and evaluation, can build the evidence base in this under-researched area, inform future policy and practice, and assist with translating existing research evidence into practice.

The Plan-Do-Study-Act (PDSA) cycle (Institute for Healthcare Improvement [IHI], 2017) was adapted (Table 1) to summarize the planning, implementation, and evaluation of a waiting list management strategy to create an active waiting website (McGill & McLeod, 2019; McGill, McLeod, Ivory et al., 2019). PDSA cycles have

been used in clinical improvement projects throughout the world for many years when testing change and form one potential framework which may guide SLPs' planning, evaluation, and implementation of waiting list management strategies. The *Plan* stage involves identifying the issue or question to answer, planning the change/strategy to be tested, and planning data collection (ACT Academy, 2018; IHI, 2017). A detailed guide to planning a practice-based research project can be found in Dobinson and Wren (2019). The *Do* stage involves trialling the strategy and collecting data (IHI, 2017). The *Study* stage involves analysing data, interpreting findings, and reflecting on learnings (IHI, 2017). Finally, the *Act* stage involves forming an action plan based on the findings, such as implementing the strategy in practice or trialling it on a larger scale, modifying the strategy and beginning another PDSA cycle, or trialling a different strategy (IHI, 2017). PDSA cycles can occur sequentially (Table 1) or simultaneously (ACT Academy, 2018). The Wait-Lifting study (Table 1) involved reviewing websites and consulting with stakeholders, creating a purpose-built website for families waiting for speech-language pathology services (McGill & McLeod, 2019), and studying the effectiveness of the website on children's speech, language and literacy, as well as caregivers' empowerment and satisfaction via an RCT (McGill, McLeod, Ivory et al., 2019). Since there was no significant benefit of the website compared with the control condition, the researchers may need to go back to the *plan* stage and select another management strategy or consider implementing changes to service delivery and the care pathway (e.g., offering early assessments) based on learnings from the PDSA cycles.

[INSERT TABLE 1 HERE]

Clinical implications and future directions

There is a desperate need to question the status quo due to the "DISGUSTING" state of waiting lists in many workplaces (McGill, Crowe et al.,

2019, p. 1). Stakeholders are encouraged to consider holistic waiting list management strategies by mapping care pathways within their own services (Figure 1). Greater attention to care pathways within services enables more appropriate selection, planning, evaluation, and implementation of waiting list management strategies targeting certain stages, increasing the visibility of changes and flow on effects to other stages. Exploring consumer experiences and the impact of waiting at each stage in the care pathway may assist in advocating for resources and organizational change.

Effective action is needed to address waiting lists. Collaboration and transparency between consumers and professionals across multiple levels of organizations and at a systemic level is recommended from the outset when planning and testing strategies, and partnerships between researchers and clinicians are encouraged. Until adequate services are available for all consumers when needed, indirect strategies facilitating active waiting may provide interim support. Professionals should consider internal and external evidence and client preferences when making decisions regarding waiting list management (Dollaghan, 2007). To translate research into practice, professionals are encouraged to add to the evidence base through planned implementation and evaluation of waiting list management strategies in their own clinical settings, guided by frameworks such as PDSA. Professionals' own wellbeing must be supported by teams and organizations (e.g., time, resources) to undertake innovative initiatives.

Conclusion

Waiting lists for speech-language pathology can profoundly impact consumers, professionals, organizations, and society. Waiting list management should involve consideration of consumers' needs and experiences, internal and external evidence, and professionals' wellbeing and capacity. Collaboration and transparency between professionals and consumers within and across organizations,

governments, and policymakers is recommended for effective waiting list management at a systemic level. However, with support, professionals on the frontline are encouraged to question the status quo, reimagine service provision, and take action to address waiting lists (e.g., using PDSA) and support individuals who are waiting for speech-language pathology services.

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Table 1.

Research interpretation of sequential Plan-Do-Study-Act cycles within a clinical setting

PDSA stage	Cycle 1: Website development (based on McGill & McLeod, 2019)	Cycle 2: Randomized controlled trial (based on McGill, McLeod, Ivory, et al., 2019)
Plan	<ul style="list-style-type: none"> Reviewed existing websites and apps Consulted with stakeholders via questionnaire and focus groups Designed website content and format as part of larger team 	<ul style="list-style-type: none"> Reviewed existing literature Developed protocol for randomized controlled trial (e.g., planned recruitment, measures, data analysis) Obtained ethical approvals
Do	<ul style="list-style-type: none"> Created website Obtained feedback on website content, format and usability via focus group 	<ul style="list-style-type: none"> Recruited participants Completed pre-assessments Randomly allocated participants to: (1) active waiting (provided website), or (2) passive waiting (control) group Completed post-assessments
Study	<ul style="list-style-type: none"> Transcribed and analysed focus group transcript Discussed findings with team Compiled list of changes to website 	<ul style="list-style-type: none"> Statistically analysed data to measure group outcomes. Discussed findings with team Discussed possible changes to service delivery (e.g., modify care pathway, website provision at triage)
Act	<ul style="list-style-type: none"> Modified website based on feedback (e.g., additional graphics to summarize text) Planned larger scale evaluation of website in clinical setting 	<ul style="list-style-type: none"> Proposed changes at service included offering website to all clients at referral, and/or implementing triage/early assessment Released website to general public Commenced further website revisions (e.g., additional content)

Note. Studies in cycles 1 and 2 were supported by funding from Charles Sturt University and a NSW Health Translational Research Grant.

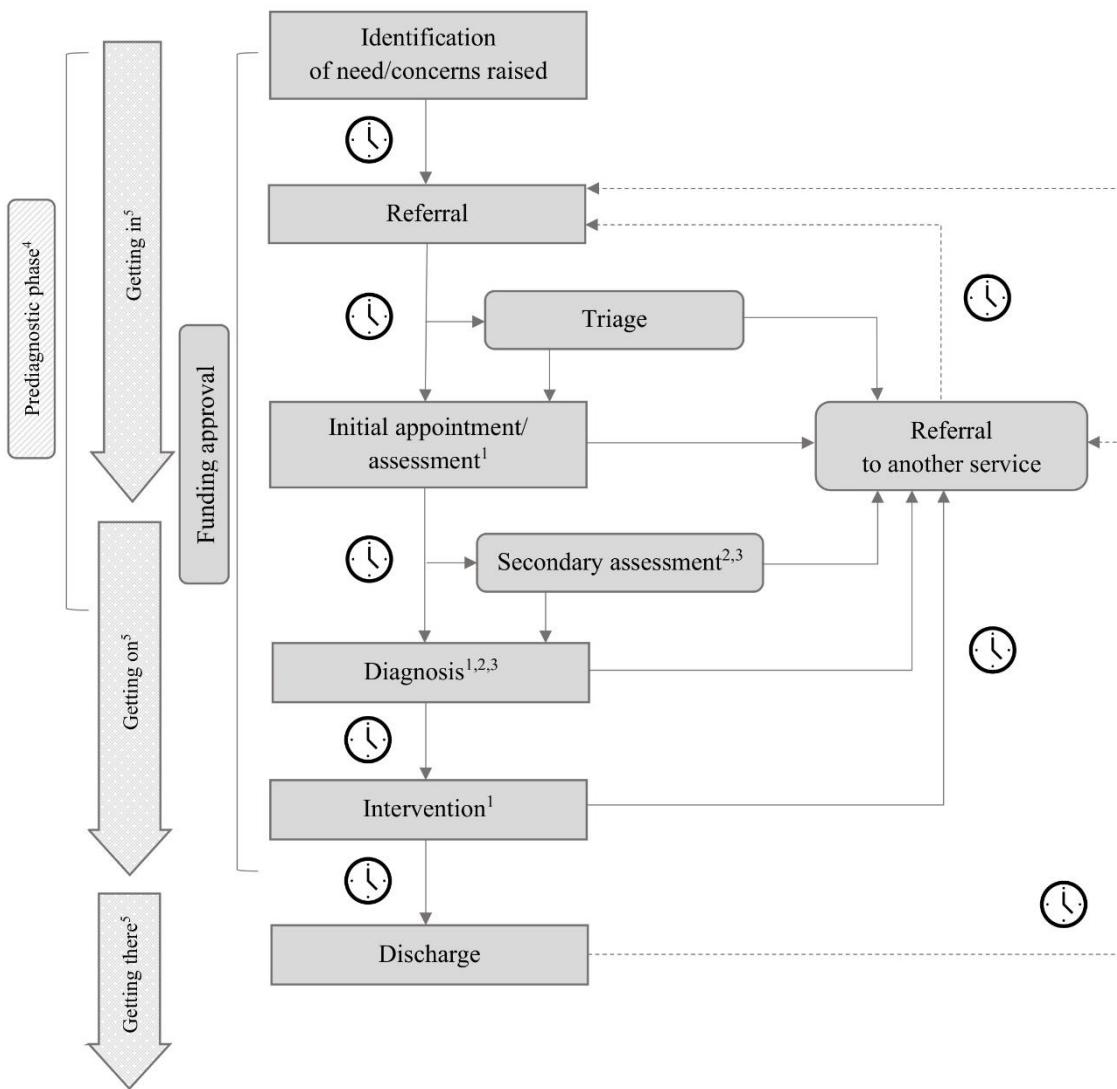


Figure 1. Speech-language pathology care pathway (© McGill, 2019). Figure extends the work of Fogarty and Cronin (2008)¹, Lebel et al. (2003)², Thorne et al. (1999)³, Giske and Gjengedal (2007)⁴, Glogowska and Campbell (2000)⁵, McGill, Crowe, and McLeod (2019), and McGill, McLeod, Crowe, et al. (2019). Final version of Figure 1 reprinted with permission from the creator, Nicole McGill.

Chapter 9: Conclusions and Contributions of this Doctoral Research

Absence of clear evidence...does not mean that inertia is the recommended course of action – Petticrew (2003, p. 758)

The ability to communicate is a basic human right (McLeod, 2018; United Nations, 1948; United Nations Human Rights Office of the High Commissioner, 1989). Many children grow and develop into competent communicators throughout early childhood; however, this is not the reality for all children. Some children have speech and language needs impacting upon their ability to communicate and participate effectively in their social environments. These children require specialised speech and language services in a timely manner to optimise their outcomes for the future and avoid potential immediate and long-term academic, social, emotional, and occupational consequences. If children's access to assessment and intervention is delayed due to waiting lists, their difficulties may remain unresolved, the risk of long-term consequences is increased, including that they may be more likely to end up in youth detention or jail (Johnson et al., 2010; Snow, 2019).

This doctoral research explored the impact of and solutions for managing waiting lists and supporting children and families while waiting for speech and language services. The research provided insights into stakeholders' experiences of waiting, perspectives on managing waiting lists, and potential solutions which inform practice, policy, and interim care for children and families. Most prior research had focused on local contexts or specific client populations (e.g., diagnostic categories, age groups); whereas, this doctoral research adopted a holistic approach and explored perspectives and practices regarding waiting lists across many stakeholder groups, workplace contexts, client diagnostic categories, and age groups. The findings may be used to advocate for more resources and speech and language services, which may facilitate greater access to much-needed support for not only vulnerable children and families, but clients across the lifespan. As discussed in this final chapter, this research has implications for professionals on the frontline of service provision by highlighting the challenges and impact of having waiting lists in workplaces, efforts and actions taken to manage waiting lists, evidence to reimagine service provision, and the need for systemic change and support for the frontline workforce. Improving the situation for professionals can enhance their ability to care for their clients, thus also improving outcomes for children and families.

Unified and effective strategies to manage waiting lists and support children and families on waiting lists are lacking. This doctoral research adds to the evidence base regarding waiting list management by designing and evaluating a potential solution, and informing SLPs' rigorous implementation and evaluation of strategies within their own workplaces to further build evidence in this area. This doctoral research involved evaluating the provision of an evidence-based website to families on a waiting list to encourage active waiting for speech and language services and is one of few studies of its kind conducted in a real-world clinical setting (Chapter 7). Although a website did not appear to be enough for statistically significant change in children's outcomes and caregivers' attitudes, the study highlighted the potential value of modifying care pathways, such as by providing earlier assessments and information to families on waiting lists (Chapter 7). Active waiting may have the potential to empower families and facilitate improvement or resolution of children's speech and language needs as an indirect waiting list management strategy. When children eventually reach the top of the waiting list, children may no longer require speech and language services or may require fewer services, freeing up resources for children who need them most. Additionally, this research gathered data regarding the natural history of children's communication disabilities, or the spontaneous improvement of speech and language difficulties without intervention, which is an under-researched area. Natural history research can provide insights into characteristics and predictors for spontaneous improvement which has the potential to inform the allocation of services and waiting list management, and subsequently impact client care.

The Doctoral Research Revisited

This doctoral research consisted of four parts presented as a series of publications exploring experiences and perspectives regarding waiting lists for speech and language services.

Part One – General Introduction

Part One (Chapter 1) provided a general introduction and orientation to the doctoral research, outlining relevant background literature, gaps in existing literature, research aims, relevant theoretical frameworks, and methodology. With regards to theoretical frameworks, the ICF-CY (WHO, 2007) informed the conceptualisation, planning, and design of the discrete studies within this thesis (Chapter 1, Appendix B), including the design of an evidence-based website for families (Chapter 6) and assessment of children and caregivers on a waiting list (Chapter 7). The theory of

preparative waiting (Giske & Gjengedal, 2007), although based on the experiences of hospitalised patients, was outlined as having potential for application with non-hospitalised individuals waiting for health care (Fogarty & Cronin, 2008) which permitted discussion of the theory in relation to speech and language services. A pragmatic philosophical worldview was adopted for this research and mixed methods were selected to best address each of the research aims (Chapter 1, Appendix C).

Part Two – Desperation and Aspirations: Exploring the Status Quo and Imagining Solutions to Waiting Lists

Part Two (Chapters 2 to 5) explored the current state or status quo of waiting lists and stakeholders' perspectives on current and aspirational waiting list management strategies in three chapters. Chapter 2 presented a qualitative analysis of written submissions ($n = 133$) to a Government Senate Inquiry that described waiting for speech and language services (McGill, Crowe et al., 2020). Consequences of long waiting lists for consumers, professionals, and society included physical, financial, and psychological impacts. Active strategies were common in response to waiting lists (e.g., advocacy, information seeking) but did not reflect the experience of all participants, as some consumers had “given up” (Chapter 2, p. 86) and decided to “accept or accommodate” (Chapter 2, p. 87) speech and language difficulties.

Chapters 3 and 4 reported on SLPs' responses to a questionnaire. Chapter 3 presented a quantitative analysis of SLPs' responses ($n = 264$) to closed questions about waiting list duration, care pathways, and prioritisation policies (McGill, McLeod, Crowe et al., 2019). Variation was evident between workplaces, with duration ranging from 0-42 months ($M = 8.09$, $SD = 5.84$) for assessment and intervention and children potentially following a myriad of care pathways to access support. Areas of consensus existed; for instance, severity ($M = 4.34/5$) and resource availability ($M = 4.11/5$) were considered the most important prioritisation parameters in SLPs' workplaces. Young children and children with stuttering or feeding difficulties were most often considered high priority for services.

Chapter 4 presented a qualitative analysis of SLPs' responses ($n = 187$) to open-ended questions on the same questionnaire (McGill, McLeod et al., 2020). Many SLPs had negative perspectives about their waiting lists (e.g., “embarrassed”, “stressed”), but some described positive (e.g., “proud”) or neutral (e.g., “OK”) feelings. Potential solutions to waiting lists related to service delivery (e.g., group therapy, home programs, online support), workforce (e.g., recruitment and retention of SLPs), and workplace policies and procedures (e.g., session limits, discharge

policies). Findings from Part Two established the problem and impact of waiting lists, which informed Part Three of this doctoral research.

Part Three – Reimagining Services: Designing and Evaluating Waiting List Solutions

Part Three (Chapters 5 to 7) of this doctoral research drew upon findings from Part Two to design and evaluate a waiting list management strategy involving provision of interim support for children and families waiting for services. An overview was provided regarding the PhD candidate's involvement in a NSW Health Translational Research grant as part of a larger team and the components included in this doctoral research, which included consultation with members of the public in the design of an evidence-based website (Chapter 6), and the Active/Passive Waiting randomised controlled trial (RCT) (Chapter 7).

Chapter 6 (McGill & McLeod, 2019) reported on a three-stage study exploring members of the public's aspirations for a website designed to provide interim support while children wait for speech and language services. Findings from a questionnaire ($n = 119$), focus groups ($n = 16$), and a review of existing speech and language websites and apps ($n = 25$) indicated that few (if any) quality websites existed which were purposely designed for families on waiting lists, and members of the public wanted evidence-based information and handouts about strategies for stimulating children's speech and language development, simple web architecture, videos, and easy-to-read information on a new website.

Chapter 7 reported on the Active/Passive Waiting Study (McGill, McLeod, Ivory et al., 2020) which evaluated the provision of a purpose-built website developed based on feedback obtained in Chapter 6. Two waiting list conditions were compared in a real-world clinic setting: (1) active waiting, provision of the website containing speech and language stimulation strategies and information; and (2) passive waiting, a control condition. There were no statistically significant differences between the groups for child outcomes (speech, intelligibility, language, early literacy) or caregiver outcomes (empowerment, satisfaction). Although the sample size and intervention dose may have impacted the findings, the website did not appear to be enough to make a difference to children's and caregivers' outcomes beyond the provision of early assessments only, indicating the need for other solutions and further research in this area.

Part Four – Conclusions and Contributions

Part Four (Chapters 8 and 9) outlined implications, contributions, and conclusions of the research. Chapter 8 integrated the findings from earlier chapters and presented a speech-language pathology care pathway and potential framework (Plan-Do-Study-Act) to guide the planning and rigorous evaluation of waiting list management strategies in workplaces to build the evidence base and improve access to services and care for children and families. Recommendations were outlined for consumers, professionals, governments, and policymakers.

This final chapter (Chapter 9) summarised the findings from previous chapters and outlined the key contributions of this doctoral research with reference to the research questions. This chapter highlighted the impact and challenges of waiting lists, suggested strategies to address waiting lists at a local and/or systemic level, and provided an example of rigorous planning and evaluation of a waiting list management strategy to add to the evidence base and guide others to do the same. This chapter described the contributions of the research and implications for consumers, professionals, governments, policymakers, and theory. Limitations of the research and future directions were also discussed.

Key Contributions of this Doctoral Research

The six publications embedded within the chapters of this doctoral research were designed to address five research questions exploring the status quo of waiting lists, waiting list management practices, and the design and evaluation of one potential solution. The unique contributions of this doctoral research are summarised with reference to the research aims as follows.

- 1. To understand the experience and impact of waiting for speech and language services from the perspectives of key stakeholders, including consumers (e.g., children and families) and professionals (e.g., SLPs).*

One of the unique contributions of this doctoral research was the exploration of perspectives and experiences from a broad range of stakeholders including consumers, professionals, and organisations (Chapters 2 to 4). Consumers included clients, parents/caregivers, grandparents, and carers/spouses. Professional voices included those of SLPs, educators, doctors, paediatricians, child health nurses, and academics. Organisations included public, private, and not-for-profit services from health, education, and disability sectors. Triangulation of perspectives from a range of stakeholders adds weight to the findings. In this doctoral research, children's outcomes (speech, intelligibility, language, early literacy) were directly assessed and

caregivers' outcomes (empowerment, satisfaction) were indirectly assessed to measure the impact and experiences of waiting for 6 months on a waiting list (Chapter 7). Rare insights into the natural history of children's speech and language disorders and experiences of waiting in a control condition were obtained, which is often not ethically possible but was appropriate at the chosen research site.

The profound impact and negative experiences regarding waiting lists were evident in many participants' responses. An almost desperate account of the impact of waiting lists was provided in Chapter 2, including one parent saying that she "would harm [her child] if he was not going to be seen [by an SLP] because I was in a very dark and lonely space" (p. 86). Waiting lists had consequences for many consumers (Chapter 2) and professionals (Chapters 2 and 4), as well as society more broadly (Chapter 2), including physical, psychological, financial, time, and ethical burdens. Many SLPs described negative feelings about their waiting lists (e.g., shame, worry, embarrassment), with some claiming waiting lists had the "biggest negative impact upon...job satisfaction" (Chapter 4, p. 170) which may have flow on effects for children and families. Few previous studies have focused specifically on the experiences and perspectives of stakeholders regarding waiting lists for speech and language services.

The experiences of consumers and professionals included engaging in both active and passive strategies regarding waiting lists, which varied in effectiveness as indicated in Figure 1. Examples of **effective active** strategies included professionals obtaining funding to recruit additional SLPs, and consumers accessing private services while on waiting lists for public services. In contrast, potentially **effective passive** strategies included the spontaneous improvement of children on a waiting list (Chapter 7). **Ineffective active** strategies included consumers waiting on multiple waiting lists and spending months chasing referrals, or professionals working harder and trying to do more. **Ineffective passive** strategies included consumer attrition from waiting lists or not acting on referrals to speech and language services, and professionals not attempting to manage waiting lists due to it being "out of [their] hands" and "entirely in the hands of managers" (Chapter 4, p. 182). The Active/Passive Waiting Matrix contrasts with previous findings that depicted waiting as a predominantly passive process for consumers (Glogowska & Campbell, 2000).

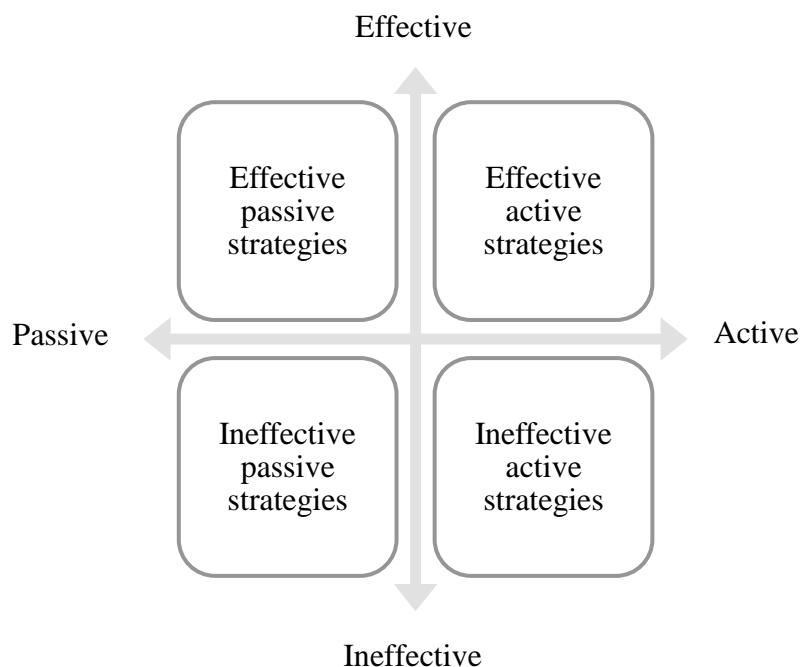


Figure 1. Active/Passive Waiting Matrix © McGill (2020)

2. *To understand the current state (status quo) of waiting lists for speech and language services.*

Waiting list duration, care pathways, and stages of waiting across client groups, workplace contexts, and geographical locations were explored in this doctoral research, which provided an understanding of the current state of waiting lists. Place of work mattered when considering waiting lists, with waiting times and stages varying within care pathways (Chapters 2 to 4). Waiting list duration from referral to receiving intervention was highly variable for children, reportedly ranging from 0-42 months in workplaces. Children followed a myriad of different care pathways depending on age, diagnostic category, or workplace, with the most common care pathway involving waiting for assessment only. A speech-language pathology care pathway was presented (Chapter 8, p. 297, Figure 1) which extended upon previous literature (Fogarty & Cronin, 2008; Giske & Gjengedal, 2007; Glogowska & Campbell, 2000; Lebel et al., 2003; Thorne et al., 1999) and incorporated findings from Chapter 2 (McGill, Crowe et al., 2020) and Chapter 3 (McGill, McLeod, Crowe et al., 2019) to make a unique contribution to the literature. This care pathway enables professionals to explore waiting holistically in workplaces, measure duration across stages, and have transparent discussions with families regarding waiting lists.

3. To understand SLPs' waiting list management practices and perspectives on prioritisation for speech and language services.

Both current and aspirational waiting list management practices were explored in this doctoral research (Chapters 2 to 4). Waiting list management practices varied among professionals, workplaces, and client populations, but some areas of consensus existed. For instance, prioritisation of children for services was common, despite a lack of formal prioritisation policies in some workplaces, and severity, availability of resources, and diagnosis were rated the most important prioritisation parameters overall. Decision-making appeared complex, with 17 different parameters (Chapter 3, Table 1) identified in the literature considered to be of some importance to SLPs in prioritisation, and the level of importance placed on these parameters varied based on level of experience, and workplace context and country.

SLPs' current and aspirational waiting list management strategies from Chapters 2 and 4 were collated and presented with example references from the speech-language pathology field and beyond (e.g., education) in Appendix A of this chapter, which appears to be the most comprehensive list of speech-language pathology waiting list management strategies published to date. Appendix A was used in an invited presentation about management of waiting lists with SLPs from the Northern Territory (NT) in Australia (December, 2019) to assist with translation of the research findings and provide a resource for SLPs to refer to when making waiting list management decisions. It was evident that many SLPs are already working to challenge the status quo and address waiting lists in their workplaces. SLP participants demonstrated an ability to reimagine services by not only describing what they were currently doing, but also engaging in aspirational thinking about what they could do if they had the means or were without limits. However, gaps in knowledge remained regarding which strategies were effective active strategies for managing speech and language service waiting lists.

4. To design an evidence-based website to support children, caregivers, and other stakeholders while children are waiting for speech and language services.

A three-stage explanatory sequential mixed methods study was conducted to inform the design of a website (Chapter 6). The PhD candidate's role as part of a NSW Health Translational Research grant to develop a website was outlined (Chapter 5). This doctoral research explored the content, features, and functions that

members of the public recommended for a website, the usability of a prototype website, and the quality of existing websites and apps (Chapter 6). The findings of Chapter 6 informed the development of an evidence-based Waiting for Speech Pathology website (Waiting for Speech Pathology Team, 2018) which was evaluated in an RCT (Chapter 7) and then released to the public. The website was one of few of its kind in the world designed to support children, families, and others while children wait for speech and language services. The three-stage research and consultation process undertaken in Chapter 6 may inform other professionals when designing websites, apps, or online resources and highlighted the relevance of web architecture and design within the speech-language pathology field.

5. *To evaluate and compare provision of the evidence-based website (active waiting) with a waiting list control group (passive waiting) and compare children's speech, intelligibility, language, and early literacy, and caregivers' empowerment and satisfaction between groups.*

The provision of an evidence-based website to encourage active waiting by families on waiting lists was rigorously evaluated in an RCT (Chapter 7). The website appeared to be no more effective at promoting change in children's and caregivers' outcomes than provision of an early assessment but provided an exemplar for other professionals and organisations regarding the planning and evaluation of a waiting list management strategy in a real-world clinic (Chapter 8). Little prior research has explored or evaluated active waiting for speech and language services, and few other studies have rigorously evaluated the role of a website in facilitating active waiting for speech and language services. Insights into the natural history of speech and language disorders were also obtained (Chapter 7), which is an under-researched area and enables more in-depth analysis to be undertaken in future to further inform practice.

Implications of this Doctoral Research

Lack of clear evidence should not...be a reason for inaction on health inequalities – we should be guided by what we know about the mechanisms by which interventions might plausibly be expected to affect health...Decisions may be guided by the best “available” research evidence – and other guidance on action can also be sought (Petticrew, 2003, p. 758)

This doctoral research has implications for consumers, professionals and organisations, governments and policymakers, and theory, as follows. All stakeholders have a role to play in addressing the issue of waiting lists.

Implications for Consumers

Waiting lists were reported to have widespread negative consequences for many consumers and the findings of this research may support consumers and consumer groups in advocating for change regarding availability of and access to speech and language services. Greater support and effective interim care are needed for children and families while waiting. Whilst some consumers shared examples of passive strategies while waiting, many consumers described active strategies involving advocating for services (desperately in some instances, for example threatening to “harm” their child as in Chapter 2, p. 86), researching alternative options and solutions online, considering relocation to another city, and being on more than one waiting list, which supported the concept of active waiting. These were examples of strengths that SLPs may be able to build upon and encourage through provision of information and active waiting strategies. However, not all consumer actions appeared to be helpful and there is a need to direct consumers’ efforts into effective strategies.

Implications for Professionals and Organisations

It was evident that many SLPs had negative perspectives regarding their waiting lists, describing being confronted with the struggle, ethical conflict, and weight of responsibility for clients that the system was letting down. There is a need to not only support consumers on waiting lists, but also the professionals shouldering the burden of waiting lists and large caseloads on the frontline of service provision. Increased support and resources are recommended to empower professionals to challenge the status quo, implement changes, and work effectively to provide safe, optimal care for children and families.

Some workplaces had no waiting list or short waiting times, some SLPs felt positively about their waiting lists (or lack thereof), and some waiting list management strategies were reportedly effective in providing local solutions to systemic problems (e.g., periods of increased funding to enable recruitment of additional SLPs). These triumphs provide an opportunity to learn from other professionals and services and highlight how local solutions may have the ability to make a difference with systemic issues. However, without professionals publishing or disseminating their successes and challenges, the benefits to other services and clients beyond that service are limited. Professionals’ and clients’ perspectives are valued components of evidence-based practice (EBP; Hoffman, Bennett, & Del Mar, 2013) and generation of practice-based evidence from these views and experiences is

needed. Undertaking rigorous, systematic testing of strategies in real-world contexts (e.g., guided by frameworks such as Plan-Do-Study-Act, as discussed in Chapter 8), even on a small scale, and sharing the findings widely has the capacity to help other clients and professionals exponentially by building the evidence base regarding what may, or may not, be effective solutions in different practice contexts (Hoffman, Bennett, & Del Mar, 2013). Mapping care pathways (e.g., Chapter 8, Figure 1) within workplaces can help increase transparency regarding waiting times and promote more holistic and targeted waiting list management practices. Both direct and indirect waiting list management strategies may be of value, including ways to encourage effective active waiting and provide support to children and families while on waiting lists.

Professionals are encouraged to look beyond their local contexts, range of practice areas, and disciplines, for practice-based evidence and professionals' perspectives to integrate with external evidence from research literature regarding waiting list management. The increasing level of connectedness made possible with technology (e.g., social media, web conferencing, teleconferencing) can, and should, be used to enhance collaboration between professionals and organisations throughout the world regarding waiting list management. For instance, communities of practice, working parties, or research networks regarding this issue may have members spanning across organisations and countries and be powerful in advocating for change.

Implications for Governments and Policymakers

“Long waiting lists” (Commonwealth of Australia, 2014, p. 5) for speech and language services were identified as a key area of concern arising from an Australian Government Senate Inquiry into speech and language disorders and services in 2014. In the UK, the Bercow Report (Bercow, 2008) found children’s access to speech and language services to be variable and inequitable, and this “postcode lottery” was unresolved ten years later (I CAN & RCSLT, 2018, p. 19). Waiting lists remain a significant concern, prohibiting children from reaching their potential in a timely manner and realising their human right to communicate and participate effectively in society. This doctoral research and other literature provide pathways for how to address the issue. Care pathways need to be considered across sectors and service provision and access must be reimagined. However, aspirational thinking is not enough; action is needed based on the knowledge, ideas, and efforts of consumers and professionals in local contexts. Professionals on the frontline need support,

including more funding and workforce recruitment and retention efforts, to reduce the pressures of large caseloads and promote cultures of innovation, creativity, collaboration and transparency, which optimise care for clients. This will enable those with experiences of waiting lists and waiting list management, who know their local contexts best, to challenge the status quo and reimagine solutions from the ground up. Often people working at the frontline or those with lived experiences have the solutions. While local solutions may have the capacity to impact systemic issues to some extent, action is needed at government and policy levels for waiting list solutions to be more than a “quick-fix, ‘band-aid for a broken arm’ type approach” (Chapter 2, p. 88).

Theoretical Implications

The International Classification of Functioning, Disability and Health: Children and Youth Version (ICF-CY; WHO, 2007) and theory of preparative waiting (Giske & Gjengedal, 2007) informed and guided the design and analysis of data throughout this doctoral research. The findings of this doctoral research have implications for theory, outlined as follows.

ICF-CY (WHO, 2007)

In prior studies, researchers holistically explored the impact, assessment, and management of communication and swallowing difficulties with reference to the ICF (WHO, 2001) and ICF-CY (WHO, 2007) (e.g., McLeod & Threats, 2008; McCormack et al., 2010; Threats, 2007; Washington, 2007). The consequences and impact of waiting lists for consumers and professionals outlined in Chapters 2 and 4 can also be considered using the domains of the ICF (WHO, 2001) and ICF-CY (WHO, 2007), which contributes new understandings of these frameworks in relation to waiting lists (Appendix B). The Body Functions, Activities and Participation, Environmental Factors, and Personal Factors domains were relevant to stakeholders' experiences and perspectives regarding waiting and managing waiting lists, while Body Structures appeared to be less relevant for the participants within this doctoral research. Activities and Participation and Environmental Factors domains were most applicable, for instance, waiting lists were described as impacting self-expression and “access to life” (Chapter 2, p. 81) for people with communication difficulties (Activities and Participation, d9 Community, social and civic life), while accessing private services due to long waiting times for public services had implications for consumers' finances (Environmental Factors, e1 Products and technology). For

professionals, waiting lists impacted their ability to do their jobs effectively (Activities and Participation, d8 Major life areas). Some insights into Personal Factors were obtained in Chapters 2 and 4 through consumers' emotional reactions to long waiting times and SLPs' feelings about waiting lists, which may highlight differences in coping styles among participants. It remains unclear how Personal Factors such as individual coping styles, education levels, professional backgrounds, past experiences, and character styles may act as facilitators or protective factors while waiting (McCormack et al., 2009, 2010; WHO, 2001, 2007). Personal factors may be associated with participation in active strategies, such as consumers seeking alternatives to minimise or avoid waiting by researching options for services, thus reducing the negative consequences of waiting.

Parameters considered by SLPs in the prioritisation of children for services also related to the ICF-CY (WHO, 2007), as outlined in Chapter 3. Prioritisation parameters predominantly related to Contextual Factors (Environmental Factors, Personal Factors), for example, the availability of resources and ethics of the health care organisation (e580, Health services, systems and policies). Some child factors also related to Body Structures and Functions, such as the severity and permanency/chronicity of speech (b320, Articulation functions) or language (b167, Mental functions of language) disorders. Since waiting for speech and language services can have consequences across many domains of the ICF and ICF-CY, this doctoral research supported the need for a more holistic approach to service provision (WHO, 2001, 2007). An increased focus on Activities and Participation (e.g., children's ability to interact with peers and participate fully in preschool and community life) and the needs of significant others within children's environments when allocating services, which have limited representation in current prioritisation parameters, may assist with advocating for allocation of more services, sooner, for greater numbers of children (WHO, 2001, 2007).

Theory of preparative waiting (Giske & Gjengedal, 2007)

As previously outlined, the theory of preparative waiting (Giske & Gjengedal, 2007) involves five strategies that individuals may undertake while waiting for health care, which arose from the experiences of hospitalised patients undergoing gastrointestinal diagnoses. The theory was described as potentially applicable to non-hospitalised patients' experiences (Fogarty & Cronin, 2008) and its relevance to speech and language services was explored in Chapter 1 (Table 1) using existing literature. To extend on this earlier table, examples from this doctoral research have

been included in Appendix C, demonstrating the applicability of the preparative waiting strategies to stakeholders' experiences of waiting for speech and language services. For example, consumers researched solutions and strategies to avoid long waiting lists, which was consistent with "seeking and giving information" (Giske & Gjengedal, 2007, p. 90), and an awareness of prioritisation policies within speech and language services in relation to children's needs related to "interpreting clues" (Giske & Gjengedal, 2007, p. 90). Similarities were apparent between examples of "struggling with existential threat" and "balancing between hope and despair" from the theory of preparative waiting (Giske & Gjengedal, 2007, p. 90; Appendix C), such as attrition from speech and language services and consumers'/professionals' negative feelings about waiting lists.

Findings from this doctoral research indicated that consumers (e.g., parents, families) with children on speech and language service waiting lists may undertake "continuous work" (Giske & Gjengedal, 2007, p. 90) and engage in similar strategies to critically ill, hospitalised individuals waiting for health care. This doctoral research therefore extended upon previous studies (Giske & Artinian, 2008; Giske & Gjengedal, 2007) by highlighting the relevance and applicability of the theory of preparative waiting to experiences of waiting for speech and language services. Since individuals may display different patterns for "balancing between hope and despair" (Giske & Gjengedal, p. 90), such as denial or acceptance, further research exploring experiences of waiting for speech and language services may enable provision of information and support to be tailored to their informational and emotional needs (Giske & Artinian, 2008).

Limitations of this Doctoral Research

Several limitations may have impacted the findings of this doctoral research. Specific limitations for each chapter are outlined within the individual chapters, including: potential bias toward a sample of motivated participants such as those with negative experiences regarding waiting lists, or a greater tendency to actively wait or manage waiting lists (Chapters 2, 3, 4, and 6); the accuracy of participants' responses when relying on memory or knowledge of the outcome (Chapters 2 to 4); and small participant sample sizes within certain categories which may have masked some findings (e.g., sample sizes for participants from countries outside of Australia meant participants were grouped together into one category for statistical analysis; Chapter 3). Although international perspectives were obtained (Chapters 3, 4, and 6), most participants involved in this doctoral research were from Australia, limiting the

ability to make direct comparisons between countries. However, the research team viewed the broad scope of this research as a strength and a starting point for other countries to employ similar strategies. The knowledge gained from this doctoral research may be relevant to policy and practice in other countries. Limitations of the RCT (Chapter 7), including sample size, constraints regarding tracking of participants' use of the website, and the need for pre- and post-intervention assessments to be undertaken with the control group, impact the strength of the conclusions drawn and generalisability of the findings. This doctoral research provided valuable insights into stakeholders' perspectives and experiences, the current state of waiting lists, and waiting list management practices, but due to limitations such as those listed above, the findings may not represent the experiences of all stakeholders or the situation in all speech and language services.

Future Directions

Although many consumers and professionals in this doctoral research described active waiting and waiting list management practices, this was not the experience of all participants. Further exploration of caregivers' experiences of waiting through focus groups or interviews may be beneficial in developing a deeper understanding of their journeys while waiting for speech and language services and as they proceed through service care pathways. Follow up with caregivers who participated in the Active/Passive Waiting Study (Chapter 7) to explore their perspectives, experiences, and use of the evidence-based website, may further contextualise the findings reported in Chapter 7 and assist with understanding the improvement observed within the passive waiting group. A deeper understanding of consumers' experiences of waiting may enable the provision of information and support to be tailored to individuals' needs. For instance, with reference to the theory of preparative waiting (Giske & Gjengedal, 2007), individuals who balance between hope and despair using the pattern of acceptance may require more information and be able to process it more effectively than individuals using the pattern of denial, who may be less likely to actively seek information (Giske & Artinian, 2008).

In depth exploration of SLPs' waiting list management practices through focus groups or interviews with SLPs may provide further detail regarding their rationales, planning, and implementation of waiting list management strategies. Further insights into the influences of workplace contexts on decision-making and practices may also be obtained. For instance, in Chapter 3, SLPs were asked to respond to questions based on pre-determined response options and the policies and

practices implemented within a chosen workplace. Focus groups or interviews may enable exploration of the conflicts and ethical dilemmas faced by SLPs when policies and practices do not align with their professional values and the way they feel things *should* be done.

Deeper analysis of data obtained from the Active/Passive Waiting Study (Chapter 7) regarding children's outcomes within the passive waiting (control) group may provide further insights into the natural history of speech and language disabilities and possible predictors for spontaneous improvement, which may inform policy and practice regarding client care, prioritisation, and caseload allocation.

Provision of professional learning and support for professionals and organisations regarding waiting list management strategies is another way forward. For instance, consulting and conducting workshops with professionals and other stakeholders (e.g., consumers, managers) to map care pathways, plan and evaluate strategies in their local contexts (e.g., Chapter 8), and disseminate the findings may assist with translating findings from existing literature and building practice-based evidence in this area. Further SLP training in quality improvement and practice-based research, along with greater opportunities and funding for researcher-clinician partnerships may also help to address waiting lists. Professional development opportunities such as these may also act as incentives for professionals by helping them gain skills important for promotion to senior or leadership positions, which may assist with workforce recruitment and retention.

A useful resource for professionals may be the development of an online innovation hub of waiting list management strategies which builds on the strategies listed in Appendix A, involves a critique of available evidence for and against their implementation, and contains details explaining the strategies and contexts in which they have been implemented. Waiting list taskforces or advocacy groups which share ideas and work toward solutions may be effective, such as the Wait Time Alliance (WTA) for Timely Access to Health Care in Canada that formed from concerns regarding delayed access to health care due to waiting lists. Benchmarking of waiting times, such as the collaborative work undertaken by the Pan Canadian Alliance of Speech-Language Pathology and Audiology Organizations for children with speech sound disorders may also be useful (Rvachew & Rafaat, 2014). Community of practice groups or working parties involving professionals and consumers from different organisations in local contexts may be effective, particularly if groups connect and share ideas with those from broader contexts.

Final Summary and Concluding Remarks

This doctoral research explored the status quo and potential solutions for waiting lists within speech and language services. Waiting lists not only delay access to care but prevent children from effectively exercising their human right to communicate. Waiting lists can have a profound impact on consumers, professionals, and on society. Many consumers played an active role while waiting and most professionals described active waiting list management practices; however, not all appeared to be effective strategies. This doctoral research outlined pathways and an Active/Passive Waiting Matrix for considering the issue of waiting lists and had implications for consumers, professionals, governments, and policymakers regarding waiting list management and interim care for children and families on waiting lists. Rigorous testing of strategies in local contexts is needed to build practise-based evidence, while systemic change is also needed to reimagine service provision. In order to move beyond aspirations and local solutions to systemic issues, effective action at government and policy levels is needed to improve access to speech and language services for children and families.

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Appendix A. Summary of Waiting List Management Strategies © McGill (2020)

Topic	Example references
1. SLP workforce actions	
1.1. Recruitment¹	
<ul style="list-style-type: none"> • Creating more SLP positions • Employing more SLPs 	Arnold et al. (2003) ^b ; Davis, Bauer, & Rohr (2017) ^a ; Harding et al. (2018) ^b ; Hutchins et al. (2010) ^a ; Keating et al. (1998) ^a
1.2. SLP experience¹	
<ul style="list-style-type: none"> • Training and upskilling SLPs • Retaining experienced SLPs 	Gillham & Ristevski (2007) ^b ; Hutchins et al. (2010) ^a ; Keane, Lincoln, & Smith (2012) ^b ; Kenny, Lincoln, & Balandin (2010) ^a
1.3. Flexibility¹	
<ul style="list-style-type: none"> • Adopting flexible work hours 	Davis, Bauer, & Rohr (2017) ^a ; Kossek & Nichol (1992) ^c
1.4. Time constraints¹	
<ul style="list-style-type: none"> • Provision of more time 	Davis, Bauer, & Rohr (2017) ^a
1.5. SLP higher education¹	
<ul style="list-style-type: none"> • Modifying SLP higher education courses 	Lincoln, Adamson, & Cant (2001) ^a ; Wylie et al. (2014) ^a
1.6. Students in the workplace¹	
<ul style="list-style-type: none"> • Using students in the workplace 	Allan et al. (2011) ^{a,b} ; Sales et al. (2015) ^a
1.7. Support from management/organisation¹	
<ul style="list-style-type: none"> • Obtaining increased managerial or organisational support 	Rachlis (2005) ^c
1.8. Professional efficiency² (e.g., working harder/doing more)	Duckett, Breadon, & Farmer (2014) ^c ; Naiker et al. (2018) ^{b,c} ; Nancarrow et al. (2013) ^b ; Rachlis (2005) ^c

2. Organisational process and policy actions

2.1. Funding^{1,2}

- Utilising alternate funding models^{1,2} Kreindler (2010)^c; Skeat et al. (2010)^a; Stute et al. (2018)^b
 - Obtaining increased public health funding¹ Kreindler (2010)^c; Ruggero et al. (2012)^a
 - Lobbying the government² (e.g., for more funding) Allan et al. (2007)^{a,b}; Paige-Smith (2013)^e; Polikowski & Santos-Eggimann (2002)^d
-

2.2. Administrative strategies

- SLP caseload allocation¹ Pickstone (2007)^a
- Professionals having autonomy over their waiting lists Hughes & Griffiths (1997)^c; Lincoln et al. (2014a)^b; Rachlis (2005)^c; Stute et al. (2018)^b
- Allocating caseload based on client factors Davidson & Bressler (2010)^b
- Implementing waiting list policies Little & Grasselli (2013)^a; Shiraev & McGarry (1996)^a
- Conducting audits and reviews¹ Naiker et al. (2018)^{b,c}; Sanmartin et al. (2000)^c; Sell & Ma (1996)^a; Stute et al. (2018)^b
- Having separate waiting lists (e.g., weekend vs weekday appointments)¹ Davis, Bauer, & Rohr (2017)^a
- Not keeping a waiting list² Breton et al. (2018)^c; Kreindler (2010)^c; Naiker et al. (2018)^{b,c}; Rachlis (2005)^c; Sanmartin et al. (2000)^c
- Independent oversight of waiting lists² Flores, Price, & Rayl (2017)^c; Rachlis (2005)^c
- Scheduling Davis, Bauer, & Rohr (2017)^a
- Using cancellation lists¹
- Offering flexible appointment times¹

- Implementing administrative policies
 - Implementing failure to attend/unable to contact policies¹
 - Registration forms¹
 - Limiting advertising¹
 - Streamlining of documentation¹ or processes
- Naiker et al. (2018)^{b,c}; Rachlis (2005)^c
- Kreindler (2010)^c; Lodge & Bamford (2008)^b; Rachlis (2005)^c;
-

2.3. Referrals

- Referring clients on to other services^{1,2}
 - Referring clients to other services with shorter waiting lists
 - Access to other services while waiting^{1,2}
 - Clients waiting on more than one waiting list
 - Clients accessing community groups while waiting
- Wright (1998)^c
- Kennedy & McConnell (1993)^c; Kreindler (2010)^c; Peeters & Bayer (1999)^b; Vallerand & McLennan (2013)^b
- Passalent, Landry, & Cott (2010)^b; Seabrook et al. (2019)^a
- Kreindler (2010)^c
- DePompei et al. (2001)^{a,b}; Langstaff et al. (2014)^a
-

2.4. Organisational strategies

- Standards
 - Developing waiting time benchmarks or maximum waiting times^{1,2}
 - Introducing key performance indicators regarding waiting times¹
- Hurst & Siciliani (2003)^c; Scott et al. (2002)^b
- Dimakou et al. (2009)^c; Kreindler (2010)^c; Naiker et al. (2018)^{b,c}; Payne (2001)^c
- Shiraev & McGarry (1996)^a

- Implementing quality improvement projects¹
 - Forcing SLPs into actions¹
 - Restrictions on services
 - Introducing prioritisation guidelines based on client factors^{1,2}
 - Functional impact^{1,2}
 - Severity^{1,2}
 - Diagnosis/disorder type^{1,2}
 - Level of clinical need¹
 - Age^{1,2}
 - Complex cases¹
 - Intervention history²
 - Error type²
 - Urgency¹
 - Vulnerability of family (cultural identity^{1,2}, socioeconomic status¹),
 - Emotion-based advocacy^{1,2}
 - Prognosis¹, permanency, or chronicity
- Mormer & Stevens (2019)^a; Phelps & Coker (2019)^c; Roberts (2017)^a; Lincoln, Adamson, & Cant (2001)^a; Little & Grasselli (2013)^a; O'Callaghan, McAllister, & Wilson (2005a,b)^a; Prud'homme (2007)^a
- Hughes, Carrick, & Byrne (2013)^b; Kreindler (2010)c; Stute et al. (2018)^b
- Roberts (2017)^a; Rvachew & Rafaat (2014)^a; Seabrook et al. (2019)^a
Lindsay (2007)^e; McCartney, 2000^a; Roulstone (1995)^a
- Morgan et al. (2017)^a
Harding et al (2012)^b
- Kenny & Lincoln (2012)^a; Lindsay (2007)^e; McCartney, 2000^a; Rvachew & Rafaat (2014)^a; Ward, Birkett, & Kellett (1990)^a
- Johnson & Bloomberg (1988)^a
Dodd (2007)^a; Rousseau et al. (2007)^a
- Morgan et al. (2017)^a
Rachlis (2005)^c; Roberts (2017)^a; Sales et al. (2015)^a; Sanmartin et al. (2000)^c; Ward et al. (1990)^a
- Benzies et al. (2011)^a; Flatley, Kenny, & Lincoln (2014)^a; McCormack & Verdon (2015)^a
- Lindsay (2007)^e; Ward et al. (1990)^a
Kenny & Lincoln (2012)^a; McCartney, 2000^a; Pickstone (1997)^a; Royal College of Speech and Language Therapists [RCSLT] (1996)^a

- Expected duration of therapy¹
 - Location of client¹
 - Returning client¹
 - Sibling of known client¹
 - Introducing prioritisation guidelines based on service factors^{1,2}
 - Type of service²
 - Role of service²
 - Diagnostic purposes¹
 - Eligibility for group intervention¹
 - Referral date¹
 - Referral type¹
 - Closing the books/not accepting referrals^{1,2}
 - Introducing costs/fees for service^{1,2}
 - Implementing discharge processes^{1,2}
 - Introducing eligibility criteria^{1,2}
 - Limiting service provision^{1,2}
 - Reducing duration of service provision¹
 - Reducing frequency of sessions¹
 - Capping/limiting sessions²
- Carlom, Carter, & Stephenson (2013)^b
Meikle (1995)^a; Rachlis (2005)^c
Meikle (1995)^a
Byrne & Lyddiard (2013)^a; Ruggero et al. (2012)^a
Kenny & Joffres (2008)^c
- Chan (2009)^b
Lindsay (2007)^e
Ward et al. (1990)^a
Willoughby, Chan, & Marques (2016)^a
McAllister et al. (2011)^a
Chan (2009)^b
Hutton & Caron (2005)^b; Young et al. (2017)^c
- Swigert (2015)^{a,c}; Tsiplova et al. (2019)^b
Corrigan et al. (2011)^c; Hersh (2010)^a; Naiker et al. (2018)^{b,c}; Vasquez, Bingham, & Barnett (2008)^b
Little & Grasselli (2013)^a; Skeat, Morgan, & Nickless (2009)^a; Stute et al. (2018)^b
Cotellesso, Mazer, & Majnemer (2009)^b; Majnemer et al. (2002)^b; Ziviani et al. (2013)^b
Dworkin & Lyddon (1991)^b; Patti et al. (2003)^b
- Baker (2012)^a; McLeod & Baker (2014)^a
Baker (2010)^a; Hersh (2010)^a

- Offering assessments based on availability of therapy¹ Conroy & Noone (2014)^a; Papathanasiou & Heron (1998)^a

2.5. Evidence-based practice^{1,2}

- Balancing conflict/dilemmas regarding waiting list management strategies^{1,2} Flatley, Kenny, & Lincoln (2014)^a

3. SLP service delivery

3.1. Assessment

- Implementing triage/intake models^{1,2} Austin (2010)^a
- Screening^{1,2} Harding et al. (2018, 2019)^b; Harding & Taylor (2013)^{a,b}; Naiker et al. (2018)^{b,c}; Stute et al. (2018)^b
- Providing early/immediate assessment¹ Ball (2007)^a; Mathison et al (2016)^a
- Providing consultative services^{1,2} De Saeger et al. (2014)^b; McGill et al. (2020)^a
- Offering drop in assessments¹ Poulin et al. (2018)^c; Woods et al. (2011)^a
- Providing group assessments¹ Mathison et al. (2016)^a; Naiker et al. (2018)^{b,c}; Price (1994)^b
- Implementing a “first stop” service¹ or primary contact clinic Nancollis, Lawrie, & Dodd (2005)^a; Ward, Sullivan, & Gilmore (2016)^b
- Monitoring^{1,2} Alston et al. (2015)^{b,e}; Naiker et al. (2018)^{b,c}
- Offering a single session model¹ Ball (2007)^a; McGill et al. (2020)^a; Roulstone et al. (2003)^a; Singleton (2018)^a; Ciccone, Hennessy, & Stokes (2012)^a; Eade, Telfer, & Tollit (2018)^{b,c}; Hoyt et al. (2018)^b; Hymmen, Stalker, & Cait (2013)^b; Ryan & O'Connor (2017)^b

3.2. Therapy

- Providing therapy blocks^{1,2} Carter et al. (2011)^a
- Providing group therapy^{1,2} Arnott et al. (2014)^a; Cleave et al. (2006)^a; Ohlsson et al. (2018)^a; Page et al. (1994)^a; Willoughby, Chan, & Marques (2016)^a

- Whole class therapy²
Bratton (2010)^{b,e}; Ebbels et al. (2017)^a; Nelson & Allison (2004)^b; Smith-Lock et al. (2013)^a
 - Paired therapy²
Ebbels et al. (2017)^a; Farahani & Delavar (2018)^b
 - Offering group therapy while waiting²
Ruesch, Helmes, & Bengel (2017)^b
 - Offering intensive therapy programs^{1,2}
Faux et al. (2009)^b; Gallagher & Chiat (2009)^a
 - Providing one-to-one sessions¹
Campbell (1979)^a; Ebbels et al. (2017)^a; McLeod et al. (2020)^a
 - Offering weekend services¹
Davis, Bauer, & Rohr (2017)^a; Macht et al. (2012)^a
-

3.3. Collaboration

- Working in partnership with parents
 - Providing advice/training^{1,2}
Ruggero et al. (2012)^a
 - Providing home programs and information^{1,2}
Cartwright-Hatton et al. (2011)^b; Mathison et al. (2016)^a; Purcal et al. (2018)^b; Vallerand & McLennan (2013)^b
 - Providing phone support¹
Meyer et al. (2018)^{a,b}; Wertz et al. (1986)^a; Zabiela, Williams, & Leitão (2007)^a
 - Offering support groups²
Ehde et al. (2015)^b; Morris et al. (2011)^b; Olson et al. (2016)^a
- Working in partnership with professionals
 - Providing multi-disciplinary services (e.g., key worker model, joint sessions)^{1,2}
Denmon (2019)^a; Morhardt et al (2019)^a
 - Providing advice/training^{1,2}
DePompei et al. (2001)^{a,b}; Roush, Wilson, & Alberg (2008)^a; Ryan & O'Connor (2017)^b; Snyder & Ubben (2003)^a; Stute et al. (2018)^b; Tippin, Maranzan, & Mountain (2016)^b
 - Using non-SLPs (e.g., therapy assistants) to deliver services^{1,2}
Snyder & Ubben (2003)^a; Weiner & Greene (2014)^b
 - O'Brien et al. (2013)^a; Schwarz et al. (2019)^a

	<ul style="list-style-type: none"> ○ Providing preschool/school-based programs (universal access programs)^{1,2} ○ Increasing capacity of primary care services² 	Ciccone, Hennessey, & Stokes (2012) ^a ; Lincoln et al. (2014b) ^a Cup et al. (2011) ^b ; Stute et al. (2018) ^b
3.4. Prevention-focused services		Kreindler (2010)c; Breen, Wildy, & Saggers (2011) ^a ; Horn & Banerjee (2009) ^a ; Woods et al. (2011) ^a Roush, Wilson, & Alberg (2008) ^a Snow (2009) ^a ; Wylie et al. (2014) ^a
3.5. Technology	<ul style="list-style-type: none"> ● Providing support/education using technology¹ <ul style="list-style-type: none"> ○ Using devices (apps, websites, online support groups)¹ ● Using technology as a service delivery method^{1,2} <ul style="list-style-type: none"> ○ Providing telehealth assessment or therapy sessions^{1,2} 	Loomes & Montgomery (2012) ^a ; Erickson et al. (2012) ^a ; Furlong, Erickson, & Morris (2017) ^a Dural & Ünal-Logacev (2018) ^a ; Furlong et al. (2018) ^a ; McGill & McLeod (2019) ^a ; McGill et al. (2020) ^a ; McLeod et al. (2020) ^a Hart (2010) ^a ; Hill & Miller (2012) ^a ; Naiker et al. (2018) ^{b,c} ; Ward & Burns (2012) ^a

Note. SLP, speech-language pathology

Sources: ¹McGill, McLeod, & Hopf (2020); ²McGill, Crowe, & McLeod (2020)

Reference discipline: ^aSpeech-language pathology, ^bAllied health, ^cPrimary care, ^dBusiness/insurance, ^eEducation

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Appendix B. Relevance of the ICF¹ and ICF-CY² to Stakeholders' Perspectives and Experiences Regarding Waiting Lists

Domain	ICF Chapter	Example	Thesis Chapter
Body Functions	b1 Mental functions	“Without early intervention the child’s development may be compromised for a lifetime” (p. 81).	2
	b3 Voice and speech functions	“Your voice doesn’t matter. It can wait” (p. 82).	2
	b5 Functions of the digestive, metabolic and endocrine systems	Children who were “unable to access therapy for their feeding difficulties” were at risk of “poor weight gain, delayed feeding development and … aspiration” (pp. 82-83).	2
		“Major medical implications resulting from long waiting times” (p. 82).	2
Activities and participation	d1 Learning and applying knowledge	“Inability to access the curriculum can manifest itself in inappropriate behaviour as well as poor academic results” (p. 81).	2
	d2 General tasks and demands	SLPs may experience a “constant and overwhelming feeling of never being able to do quite enough … that despite working hard, an effective and timely service is not being provided” (p. 84).	2
	d3 Communication	“This is about having a voice and having access to the ability to express wants, needs, thoughts and opinions” (p. 81).	2
	d5 Self-care	“I actually had to say that I would harm him if he was not going to be seen” (p. 86).	2
	d7 Interpersonal interactions and relationships	Waiting lists can have potentially “devastating effects on a child’s speech development…and their ability to interact and form relationships with peers” (p. 83).	2

	d8 Major life areas	“The economic impacts, both in terms of a significant delay or complete failure to return to work, and continued reliance on the public health purse, must be significant” (p. 82).	2
		Doctors reported “we can’t help the kids as we should” as “we consult, identify potential language problems, but there is little we can do with these” due to “completely inadequate” services with long waiting lists (pp. 83-84).	2
	d9 Community, social and civic life	“It is essential that authorities understand that this is about having a voice and having access to the ability to express wants, needs, thoughts and opinions – about having access to life” (p. 81).	2
		SLPs described linking in families with “adjunct services” such as “community-based group programs...parent courses and parent support groups” while waiting (p. 178).	4
Environmental factors	e1 Products and technology	The need to access the private rather than public sector has “major implications on an individual’s and a family’s financial situation” (p. 82).	2
		“A website to direct them [families] to with appropriate strategies” was a way to support families on waiting lists (p. 174).	4
	e2 Natural environment and human-made changes to environment	Consumers had to “move to access the services ... needed” since local services were “overloaded” (p. 80).	2
	e3 Support and relationships	Waiting for speech-language pathology was “stressful” (30-C) and “a time of great despair and	2

		frustration” (196-C) for consumers when they “were struggling and needed help” (103-C) (p. 83).	
e4 Attitudes		“Extended periods on a waitlist” can negatively impact a “child’s perception of the value of therapeutic care” and “the family’s (and possibly teacher’s) commitment to participating in the therapy” (p. 82).	2
e5 Services, systems and policies		For children on waiting lists, “therapy is more difficult and takes longer using more resources” (158-P), “thus causing a further drain on services” (59-P) (p. 82).	2
		“Waiting times may be quite short for private services, but considerably longer for community health services” (pp. 78-79).	2
		“Strict caps on session numbers to help reduce wait times for other clients” (p. 178).	4
		SLPs felt they were “unable to offer best practice” due to service and resource constraints (p. 179).	4
Personal Factors	N/A	Consumers having to emotionally “blow up” and “beg” for services (p. 85).	2
		Consumers had “given up” on services (p. 86).	2
		SLPs felt “anxious” and “overwhelmed” about their waiting lists (p. 169).	4

Note. Page numbers for quotes refer to page numbers within this doctoral thesis. Corresponding thesis chapters have been provided in the righthand column.

N/A, not applicable

¹World Health Organization [WHO] (2001), ²WHO (2007).

Appendix C. Application of the Theory of Preparative Waiting (Giske & Gjengedal, 2007) to the Doctoral Research

Strategy	Examples from the Doctoral Research	Relevant Chapter
1. Seeking and giving information	<p>a. Consumers reported conducting research “for a solution and a strategy” as an alternative to waiting (p. 86).</p> <p>b. Consumers sought information about strategies to help their child: “rather than waiting, what else could we do?” (p. 238).</p> <p>c. Consumers made enquiries about available services.</p> <p>d. Professionals reported providing information to families while waiting (e.g., home programs).</p>	2 6 2 4
2. Interpreting clues	<p>a. Consumers were aware of prioritisation policies, saying they were “very lucky that [SLPs] see infant feeding issues as a priority, so we were seen quickly” (p. 88).</p> <p>b. Participants wanted information about typical development to be included on an evidence-based website for parents who are “not sure whether they’ve got a problem or not... and they’re wanting that clarified” (p. 238).</p> <p>c. Long waiting times for services were interpreted by a parent as equivalent to “saying to the child ‘Your voice doesn’t matter. It can wait’” (p. 82).</p>	2 6 2
3. Struggling with existential threat	<p>a. A consumer described the impact of failing to receive timely services: “every day that</p>	2

	essential services are delayed is time that the child can never recover” (p. 81).	
b.	Waiting was described as “a time of great despair and frustration” for consumers who were “struggling and needed help” (p. 83).	2
c.	Parents may feel that “I can’t help and now I’ve got to wait 12 months” (p. 239).	6
d.	A consumer realised they could “could no longer leave [name]’s future in the hands of the public health system” (p. 86).	2
4. Seeking respite	a. Accessing a “community communication program” or community groups such as “play group” while waiting for speech-language pathology (p. 85).	2
	b. Professionals suggested having “online support groups” for families on waiting lists (p. 174).	4
5. Balancing between hope and despair	a. Deciding to “accept or accommodate a treatable developmental delay” (p. 87) due to long waiting lists.	2
	b. Parents had reportedly “given up” (p. 86) on services.	2
	c. Professionals reported families “have not followed up with recommendations from health professionals to have their child assessed by a Speech Pathologist” (p. 87) due to long waiting lists.	2

Note. Page numbers for quotes refer to page numbers within this doctoral thesis. Corresponding thesis chapters have been provided in the righthand column.