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Parental Allyship for Children With

**Dyslexia: A Conceptual Lens on** 

**Disability Experience** 

#### **Abstract**

Current understandings of disability experience are centered around individuals who hold the disability identity and membership in the marginalized group. This perspective does not include the experiences of disability allies, such as parents, who act alongside their children to support their access and engagement in the education setting. This partial perspective is of concern because it does not reflect the depth and complexity of disability experience for those in allyship roles. This paper builds on current understandings of disability experience by introducing an emerging conceptual lens that defines and describes the nature of disability experience for those acting in allyship roles. Attention is focused on children with dyslexia and their parents to illustrate this conceptual lens. Extending on ecological models of interactions and understandings of subjective experience, the authors highlight how the proximity of the parental experience to the child's dyslexic identity shapes parental allyship and present a lens of disability experience that includes primary, vicarious, and primary adjacent experience. The proposed conceptual lens offers researchers and educators an opportunity to view disability experience and allyship from an alternative perspective, and in doing so, consider a broader understanding of disability experience and allyship that would potentially provide insights into parent—school partnerships.

#### **Keywords**

parenting, learning disabilities, identification, school(s) and home relationships, inclusion

The role that parents adopt on behalf of their children when engaging in parent-school communication can be conceptualized as a form of allyship or advocacy. Allyship and advocacy have been used interchangeably to some extent in literature, both representing actions undertaken in the pursuit of social justice. Recent discussions around the nature of advocacy and allyship have revealed nuances in these terms that guide this paper. Allies are defined as members of the dominant social group, who take on support roles for those in marginalized groups, with the intention of reducing or ending the disadvantage marginalized group experience (Radke et al., 2020). Allies can also be understood to be those whose role extends beyond the expectations of individuals in dominant social groups, in efforts to support those in marginalized groups (Sue & Spanierman, 2020). Advocacy, on the contrary, is understood to be when an individual takes action to benefit the group in which they are a member (Gray & Gayles, 2018). For example, although both advocacy and allyship are seen as social justice actions (Gray & Gayles, 2018), they also refer to the actions of ingroup members or out-group members, respectively (Vosloo, 2020). However, variances in the terms advocacy and allyship exist in relation to the complexity of experience and intersectionality, particularly when an individual is

simultaneously an in- and out-group member (Vosloo, 2020), such as in the example of the parent of a child with dyslexia, who also has dyslexia themselves. One contribution to the field that this paper makes is the distinction between the two terms, advocacy and allyship. This distinction is an important one to make because, as Freire (2008) highlighted, vulnerable groups need to be able to speak for themselves rather than having out-group members speak on their behalf. For the purposes of this paper, the example of dyslexia as a disability will be referred to throughout to offer an example for reflection about the phenomenon in a way that provides a fresh way to view parental allyship.

In the above definition of allyship, the parents of disabled children, such as children with dyslexia, are members of a privileged and dominant group, that of adulthood, and they act to the benefit of their child, who is a member of an oppressed, marginalized, and/or subordinate social group,

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that of *disabled* and *childhood*. This privilege makes them an out-group member, while their child is an in-group member of the dyslexic community. Parents acting as allies to their disabled child can be seen as part of the dominant, ingroup in two distinct ways. First, they are adults and are in positions of privileged power that children are not (Schultz, 2011; Yoon & Templeton, 2019). Second, if the parent is able-bodied or neurotypical, they will have a position in the dominant culture that their disabled child does not (Lowe, 2020). Even if the parent is a member of the disability community, they will still hold power through their status as an adult (Ryan & Runswick-Cole, 2008). This allyship relationship is in many ways unique, as it specifically relates to interactions within a single context, namely, the education setting, and this has been less conspicuous in the literature.

The experiences of parents of dyslexic children are wellknown in the literature. Current and historical literature has revealed a variety of experiences, including the early identification of reading difficulties by parents (Earey, 2013), difficulties in the diagnostic journey (Levi, 2017), engagement with the school to secure adequate support provisions (Delany, 2017; Ross, 2019), and finally increased parental stress (Abd Rauf et al., 2020; Bonifacci et al., 2019; Carotenuto et al., 2017; Valle, 2018). Research has shown that parents of children with dyslexia experience difficulty communicating with their child's school (Leslie, 2020; Levi, 2017) and that relationships can be fraught with perceived conflict "heartbreak, trauma and battles" (Earey, 2013, p. 39). For example, a study by Levi (2017) found parents described their interactions with their child's school as "driving," "pushing," or "fighting" (p. 281). Similarly, in their investigation into the experiences of American mothers of dyslexic children, Valle (2018) discussed how parents, in particular mothers of dyslexic children, face additional pressures such as trying to navigate their parenthood in a society that can outcast parents of neuro-diverse children. The challenging nature of parent-school interactions may be a factor that contributes to parents of dyslexic children being more likely than parents of neurotypical children to experience elevated stress and depression, as well as difficulties with everyday life (Bonifacci et al., 2014; Carotenuto et al., 2017; Craig et al., 2016).

This rich description of the experiences of parents of children with dyslexia tends to be a broad narrative of experiences, rather than an exploration of the nature of the experiences as allyship due to the proximity of the parent to their child's disability. A constant in the way parents "make sense" of the interactions between themselves and their child, as well as between themselves and their child's school suggests that this experience is shared across schools, irrespective of geographic or contextual boundaries (Valle, 2011). Delany (2017) observed how parents build their sense of self as a result of going through a difficult journey of supporting their child with dyslexia,

highlighting how parental allyship is a type of *disability experience* because the experience happens as a result of the child's disability.

In this paper, the authors present an emerging conceptual lens, to draw attention to and support key stakeholders in better appreciating disability experience as it pertains to the roles of allies, most specifically parents, in the education setting. The authors propose that this lens offers a nuanced view of the experiences of parents of dyslexic children as a form of allyship. Drawing on a substantive literature review undertaken by the first author as part of their doctoral studies (Leslie, 2024), this paper will first outline allyship and disability experience as used in the research literature. Next, the nature of parental experiences in the education context as proximal to the disability identity of the child with dyslexia and as an act of parental allyship will be explored. Finally, the paper presents an emerging conceptual lens for regarding disability experience in relation to the proximity of the experience to the person who holds the dyslexic identity.

### Literature Review

### Parental Allyship

There can be a variety of reasons why a parent goes beyond their parental responsibilities to take on the role of ally to their child. In exploring why parents of lesbian, gay, bisexual, transgender, gender diverse, intersex, queer, asexual, and questioning (LGBTQIA+) children took on allyship roles, Vernaglia (1999) found two main pathways to allyship. The first and primary pathway was parental loyalty, and the desire to reduce hardship for their child. These parents had little prior experience of the marginalized identity before their child was impacted by it and little involvement with activism. Social justice advocacy was the second motivation for becoming an ally. Both pathways to allyship lead to a desire to improve experiences for their child, and others, who may be experiencing similar hardships, due to their membership in the marginalized group.

Similar motivations have been identified in more recent, yet separate, literature on allyship and dyslexia. In their work on the motivations for allyship, Radke et al. (2020) concurred that positive motivations for becoming an ally can be categorized as either a desire to improve the status of the marginalized group or because allyship aligns with the moral beliefs of the ally. In their study of parenting a dyslexic child, Delany (2017) found that parents of dyslexic children describe themselves as "fierce but reluctant warriors" (p. 107) due to their feeling that they wouldn't have to be an ally if the school setting provided adequate support. These parents were motivated to secure adequate academic assistance and, more broadly, a knowledge of broader human rights and social inequality issues to enhance their allyship to their children.

In practical terms, Leitão et al. (2017) explain that parental support for dyslexic children can translate into specific actions such as engaging tutors, moving their child to another school, or communicating with their child's school to seek additional support. More recent findings have shown that parental allyship for students with dyslexia helps to foster academic competency, provides moral support and opportunities for students to experience agency, as well as encouraging students to engage in self-advocacy such as requesting supports in the school setting (Zeng et al., 2023). Although there are descriptions of how parents support their children with dyslexia and the impact of this support, this experience has not been explicitly defined as parental allyship.

# The Proximity of Disability Experience to the Disability Identity

Most often, the term disability experience is used about the first-hand experience of individuals who have the disability identity. For example, this term would be used in reference to the interactions and opportunities afforded a child with dyslexia. The lived experience of a disabled individual, or more specifically their disability experience, is dependent on their disability identity, their interactions with the social world, and how their perceptions and meaning making stem from that identity (Toombs, 1995; Wasserman et al., 2011). In essence, disability experience can be understood as the meaning made of interactions and lived experiences that result from a disability diagnosis, or identity.

Disability experience has traditionally focused on the primary and first-hand experiences of disabled individuals (Goodley et al., 2019); yet in other fields of research related to marginalized groups, such as race, the notion of marginalization can extend to others who do not experience an interaction first-hand, otherwise known as vicarious experiences. For example, Yip et al. (2024) explored the impact of racism experienced in a vicarious capacity between children and their parents. They defined vicarious racism as "witnessing or hearing about other individuals of one's ethnic/racial group being the target of racism" (p.1) and found that there were health implications for those who had vicarious racism experiences, including poor mental health and reduced quality of sleep. Similarly, a systematic review of the literature by Heard-Garris et al. (2018) explored the impact of vicarious racism on children and found that exposure to vicarious racism had implications for children's externalized and internalized behaviors. Studies such as these show vicarious experiences for those in marginalized groups can have significant implications.

The existence of vicarious experience in relation to caring professions is also well established in the literature (Branson, 2019; McCann & Pearlman, 1990; Newell & MacNeil, 2010); however, at this point, there is limited

discussion on the vicarious experiences parents face in their role as ally to their child. This gap offers a potential opportunity to look more closely into how allies of marginalized groups, such as the disability community, are affected by vicarious experiences. Without doing so, there is a risk that our knowledge will remain superficial and lead to generalizing across marginalized groups. Given that parental experiences of the allyship they provide to their child lead to unique realities (Connor & Cavendish, 2018), it makes sense that we investigate vicarious disability experience, and correspondingly the experiences of those who act in ally roles to disabled individuals. Expanding the understanding of disability experience to include vicarious disability experience allows for a deeper understanding of the experiences of those who act in allyship roles to disabled individuals, such as parents of children with dyslexia.

## The Adversity Faced by Parents of Children With Dyslexia

Much literature speaks to the experiences of children with dyslexia and the adversity they face at school. In turn, parental experiences are heavily influenced by the adversity their children experience. There is considerable research into how experiences within education settings can negatively influence the self-esteem and self-image of children with dyslexia (Alexander-Passe, 2015; Boyes et al., 2019) and increase anxiety (Nelson & Harwood, 2011; Novita, 2016) and depression (Livingston et al., 2018). For example, in their study of the coping strategies Dutch children with dyslexia utilize, Singer (2008) found that children were likely to employ maladaptive techniques, such as selftalk, that devalued learning and poor performance, or internalizing feelings of shame and guilt. Consistent with this finding, a study by Zuppardo et al. (2021) with Italian dyslexic children and adolescents found that children and adolescents with dyslexia were far more likely than their neurotypical peers to have higher levels of anxiety, lower levels of self-esteem, and increased behavioral problems. These difficulties become comorbid with the pre-existing difficulties in reading. Findings such as these reinforce that the entry into formal schooling can be a catalyst for mental health issues for dyslexic children (Kelly et al., 2019; McDowell, 2018; Serry & Hammond, 2015).

Given the adversity that children with dyslexia may face in the schooling context, it is understandable that parents likewise face complexities in their parent—school partnerships. The literature on parent experiences tends to consider how parents access support (Abd Rauf et al., 2020), the levels of parental stress (Bonifacci et al., 2019), or the journey from identification to diagnosis (Delany, 2017; Earey, 2013; Levi, 2017). The difficult nature of parent—school interactions may be a contributing factor to parents of children with dyslexia being more likely than parents of

neurotypical children experiencing elevated stress and depression, as well as difficulties with everyday life (Bonifacci et al., 2014; Carotenuto et al., 2017; Craig et al., 2016). At this point, little is understood about the allyship of parents of children with dyslexia, or how their subjective experiences are shaped by interactions with their child and their child's education setting. This opens up the potential for a deeper exploration and appreciation of these experiences by educators, researchers, and other key stakeholders. In turn, this could contribute to developing more productive and empathetic partnerships with parents who act as allies to their children.

## Proposed Lens of Proximal Disability Experience

This paper was inspired by emergent research by the first author into ableist microaggressions toward primary schoolage children with dyslexia. Ableist microaggressions are subtle verbal and non-verbal interactions that devalue disability and perpetuate the marginalization of those with a disability (Sue & Spanierman, 2020). An exploration of the literature revealed four main themes. First, teacher attitudes toward dyslexia and children with dyslexia influenced their conscious and unconscious actions in the classroom (Hornstra et al., 2010; Kerr, 2001). Secondly, racist and ableist microaggressions occur in education settings (Banks et al., 2020; Bell, 2013; Kattari et al., 2020), even from well-meaning teachers (Beaulieu, 2016). Thirdly, parents can share in their child's negative experiences vicariously through the transmission of emotion (Wofford et al., 2019). And finally, parents can have their own negative experience when interacting directly with their child's school (Delany, 2017; Earey, 2013; Levi, 2017). It was through this research that the notion of ableist microaggressions toward a person acting as a disability ally emerged and led to reflection about allies vicariously experiencing marginalization.

Marginalization in schools is a construct whereby individuals (e.g., students with a disability) are excluded from access to and participation in school activities, or they experience barriers to learning and equity (Mowat, 2015). It is a concept that seeks to describe how a dominant social group interacts with another social group within contextual environments and systems of power exchange (Messiou, 2012). Messiou (2012) proposed that marginalization is reliant on the subjective interpretation of these social exchanges by the marginalized individuals and those around them. Marginalization then is something that occurs within a bioecological framework, where reciprocal interaction and transaction are necessary to understand how individuals make meaning from their subjective experience, and cannot be fully understood in isolation from the environment where the interaction takes place (Bronfenbrenner & Morris, 2006). School-based marginalization contributes to the student's disability experience.

This emerging lens for understanding the disability experience of dyslexic children and their parents extends the idea of vicarious marginalization, whereby the parents of children with dyslexia may have vicarious disability experiences through interactions with their child's school context. For example, the communication that a parent receives about their child's education may come from either their child directly, or through communications from the child's school. The parent will build their reality through these reciprocal communications with both their child and their child's school. This lens recognizes that the subjective experience of parents in the school setting is related to their child's disability, which in turn influences the parent—school partnership.

### **Conceptual Lens**

The following sections outline how the proposed conceptual lens supports an understanding of how disability experience is influenced by the proximity of the individual to the disability identity. An explanation of each contributory component that frames this lens is outlined, namely, subjective experience as described by kairotic space and time, and the proximity of experience. The proximity of experience is described as either a primary, vicarious, or a primary adjacent experience. We now address each component in turn.

## Subjective Experience as Described by Kairotic Space and Time

Subjective experience and the meaning making that comes from it can only be truly understood when it is viewed through the lens of both the individual and the environment in which the transactions between individuals and environments occur. A central aspect of a lens from which to view the marginalization and allyship experience is the idea of subjective experience and its impact. This paper looks to Dewey (1994) and Bronfenbrenner and Morris (2006) to define what *experience* is, whereby experience is more than just the individual's participation in an event or activity (Roth & Jornet, 2014). Experience is everything that happens within a moment, and the way that moment contributes to how the individual makes meaning from it.

Just as Bronfenbrenner and Morris (2006) speak to the need for an interaction to be experienced with regularity and frequency for it to have impact, Dewey (1994) also speaks to the importance of continuous interactions as influencing the development of the individual (Sikandar, 2015). For Dewey (1994), experience was a biological (sensory), psychological, and societal construct that enabled an individual to create meaning (Ortiz, 2020). Dewey (1994) further explained that all experience was transactional, requiring an understanding of the world/context influencing that moment, yet also acknowledging that the moment was

also influenced by the individual experiencing it (Sikandar, 2015). Both Dewey (1994) and Bronfenbrenner and Morris (2006) agreed that the subjectivity of an individual's transaction with their environment shaped both their adaptation to the environment and the environment itself (Stark, 2020).

The conceptual lens presented in this paper reflects these sentiments, where experience is understood as ecological, embedded in time, place, and context, where past experience influences future experiences (Stark, 2020). From this perspective, individuals make meaning from and with experience, based on their past and current meaning making, which in turn forges a cornerstone in making meaning for future perspectives, experience, and ways of seeing the world. The perceived significance of an experience, such as one that induces a somatic or physiological response, is related to *the impact* that the experience will have on the individual, as well as contributing to the way an individual will interpret and recall experiences during future experiences (Stark, 2020).

Through the proposed lens, the temporal aspect of subjective experience can be explained as a concept of *kairos*, or kairotic space and time. In his writing on time, Aristotle drew a distinction between quantitative time (chronos), which refers to time as a measurement of "how long?," "how fast?," or "how old?" (pg. 47), and qualitative time (kairos), with kairotic time referring to when and how something occurs in a specific moment, or an opportune time (Smith, 2002). Kairotic space and time, put simply, describes the real-time events where impromptu communication is exchanged, through in-person or online modes, where there is a strong social element, and the individual sees the moment as being of high importance (Price, 2011). The concept can also be described as "the expression of the subjective, relative and qualitative experience of time," rather than an absolute, quantifiable, or objective view of time (Andersen et al., 2015, p. 2).

Further to this, kairotic space and time reflect an individual's transactional relationship with a specific context, in a specific moment. This moment will be subjective, based upon the individual's unique prior experiences, and will ultimately influence future moments. It is the individual interpretation of that kairotic moment (space and time) that creates subjective experience (Smith, 2002). Adopting an understanding of kairotic time is a useful starting point for understanding past events that have a significant impact on shaping an individual's meaning making and reality, both in the moment and in the future (Gannon, 2016). In the context of this paper, the way parents have experienced previous transactions may inform their interpretations of subsequent interactions.

This understanding of experience can be applied to the education setting and the students and parents who interact with that setting. The education setting is one in which the child and parent are both routinely and frequently

interacting with real-time moments of high importance. Concepts of kairotic space and time can also encompass the impromptu exchanges and communications that dyslexic children and their parents view as high stakes; moments of interaction between themselves and the school that have particular significance to them and from which they make meaning (Price, 2011). As noted earlier, parents of dyslexic children have reported experiencing fraught relationships with their child's school, with interactions centered around the parent's allyship and support of their child. These interactions serve to shape parent perceptions and identity as an ally, as well as the way they perceive the school's response to their child's needs (Delany, 2017; Levi, 2017). This is an example of the analytical nature of an experience that results in changes to the individual, based on their subjective interpretation (Roth & Jornet, 2014).

## Primary, Vicarious, and Primary Adjacent Experience

This conceptual lens proposes that there are three levels of experience, and each is categorized by its proximity to the marginalized identity. The first level of experience is that of a primary experience. A primary experience is one had by the child as the holder of the marginalized disability identity. They spend more time than the parent in the school setting and are the primary beneficiary of the education delivered there. The second level is that of a vicarious experience, whereby the child shares their experiences from the school setting with the parent. In this situation, the parent experiences their child's primary experience second-hand, while at the same time still being impacted emotionally. Finally, the third level of proximity is that of primary adjacent experience. Here, the parent has a primary experience acting as an ally within the school setting, whether via parent-teacher meeting, email, or informal conversation. This type of communication is a direct result of the child's disability, and as such, sits adjacent to the dyslexic child's marginalized identity. These experiences occur within the child's microsystems, namely, the home and school environments, where the child inhabits and interacts with frequently and intensely (Bronfenbrenner & Morris, 2006). These three levels of experience are now further explicated.

Primary Experience. As defined by Dewey (1994), all experience requires an interaction between the individual and their social context. Furthermore, primary experience is grounded in the context in which it occurs, and is influenced by the environment where it occurs, as the individual cannot be separated from their environment (Hutchinson, 2015). For this reason, it is important to first understand what experiences the education setting presents for students with dyslexia.

Among the many different experiences a child might have within a school, peer interactions, academic pressure, teacher interactions, and academic self-concept, all have the potential to impact negatively on a child with dyslexia (Alexander-Passe, 2016). For example, in a study of firstyear pre-service education students, Gibson and Kendall (2010) asked participants with dyslexia to recall experiences from their school years. They found that teacher perceptions of dyslexics being low achievers resulted in negative experiences for the participants of the study. These low expectations then had a flow-on effect of low academic self-concept for students (Gibson and Kendall, 2010; Kerr, 2001). Similarly, Leitão et al. (2017) found that students' experiences in the classroom were made difficult when teachers had limited knowledge or understanding of dyslexia or were unable to implement effective teaching strategies to support the student in class.

In many cases, these types of experiences in the education setting are first-hand experiences for a child with dyslexia and can be a primary contributor to how they perceive the interaction and make meaning of themselves and the environment (Alexander-Passe, 2016; Boyes et al., 2019; Gibby-Leversuch et al., 2021). The microsystem includes the people that the child will most frequently interact with, and be influenced by, including parents, educators, and peers, as well as the environments of home, school, and social groups. Interactions within the home context in the microsystem that are invariably shaped in some way by the child's diagnosis include parental allyship (Delany, 2017; Earey, 2013; Griffiths et al., 2004). In the education context, interactions such as literacy instruction will be influenced by and will influence the child's diagnosis (McDowell, 2018; Morgan, 2011; Novita, 2016; Serry & Hammond, 2015).

Vicarious Experience. Vicarious experiences occur when an individual who is the primary experiencer shares their emotionally charged experiences with a secondary person, with whom they have a close bond or relationship (McCann & Pearlman, 1990). This can be described as a shared kairotic moment, or a moment that has such significance for the child and how they are making sense of themselves and their world that they share it with their parent. Vicarious experience does not require that the kairotic moment itself is shared, only that the story of the moment is shared, with the sharing impacting the way the second person views the world (Riggs, 2021). In their work on LGBT allyship, Fingerhut (2011) explored how empathy allows the parent to walk in the shoes of the child, and noted that the parent may undertake this allyship despite the potential for no direct benefit for themselves. In some circumstances, allyship actions may invoke negative consequences (p.20), for example, when a child shares a negative experience the parent experiences negative emotions. In this way, the parent

may experience what their child experiences, albeit secondhand, or vicariously.

There are other examples of vicarious experience among other marginalized communities, and these may be applicable to disabled individuals and their allies. For example, vicarious racism (that is, racist events parents experience and then share with their children) can result in negative health outcomes for the children (Yip et al., 2024). Drawing on definitions of vicarious racism, this conceptual lens proposes that vicarious marginalization (specifically vicarious ableism) can be understood as the second-hand exposure (in this case, a parent) to a primary experience had by the individual with the identity of dyslexia (such as their child) (Yip et al., 2024). Therefore, there is no direct parental exposure to ableism from the education context; it is the child's primary experience that is shared. The vicarious experience of the parent in their role as ally is one step removed from the experience of the child.

One example of a potential negative consequence for engaging in parental allyship can be evident when a parent of a child with dyslexia experiences vicarious ableism, such as when a dyslexic child communicates with their parent about a difficulty they may have faced at school. When parents share in their child's affective experiences as members of a marginalized group, it can lead to an emotional contagion, where the parent experiences the child's emotion (Wofford et al., 2019). This could be particularly so in the case of parents of children with dyslexia, given that dependency on the parental relationship may be a coping strategy used by children with dyslexia with high social and separation anxiety (Zuppardo et al., 2021). Repeated exposure to the negative experiences of the disabled child can result in a type of vicarious experience for the parent because of the degree of social connection they have with their child (American Psychiatric Association, 2013; McCann & Pearlman, 1990).

Parental Allyship as a Primary Adjacent Experience. The second means of defining the parental experience in their role as ally is as a primary adjacent experience. Just as the child with dyslexia will create meaning and reality from their primary experiences as a marginalized individual, so too, does the parent create meaning from their primary experiences as an ally and member of the dominant group. Although the space and interactions for parents will differ from those of the dyslexic child, for example, they are unlikely to occur in the classroom where an English task is being undertaken, they are still interactions that take place in the educational context that is directly related to the child's diagnosis of dyslexia. Within the child's mesosystem, where two microsystems interact (Bronfenbrenner & Morris, 2006), parents will have their own first-hand experiences when interacting directly with the educational setting and professionals. Parents interact with their child's school through emails,

informal conversations at the start or end of the school day, and through formal meetings such as parent–teacher interviews and case management meetings. The kairotic space and time where parents are advocating for, or acting as an ally to their child, lend themselves to the tensions inherent in trying to achieve and promote equity (DeTurk, 2011).

In their role as ally and as a member of an advantaged group, parents sit adjacent to the child's experience. Although their experiences are different from their child's, the parent will have their own experiences directly related to their child's disability when they act in the role of ally to their child. Pragmatically, parents will engage and communicate with their child's school in ways that do not directly involve the child. It is a common occurrence that parents are called on to interact and communicate directly with teachers, principals, support staff, and school administrators when supporting their child's educational journey. Yet, it is in these moments that they are acting as ally and having their own primary experience. Their interactions within the educational context are first-hand, yet they sit beside their child's identity and membership in the dyslexic community. These types of experiences by parents can be understood or seen as proximal to their child's disability or as a result of their child's dyslexia, and potentially would not occur if their child did not have dyslexia.

There are a number of ways that parents will interact with the school setting in a primary capacity on behalf of their child. In a study of mothers of children with dyslexia, Griffiths et al. (2004) found that parental concerns about their children were dismissed, minimized, or ignored by teaching staff. In a similar case study of a primary school in England, Ross (2019) found that some parents of children with dyslexia felt they had to *fight* with their child's teacher in order to advocate for educational support (p.14). This has been supported by recent research in Australia that showed parental expertise in dyslexia can be rejected by educational staff, and that parents can be left feeling as though they are labeled as a difficult parent because of their allyship to their dyslexic child (Leslie, 2020). Clearly, there is evidence to show that when parents of children with dyslexia act in an allyship role, they can encounter first-hand experiences that occur only because of their child's diagnosis, meaning the experience has proximity to their child's disability identity. In addition to this, these experiences can be so significant for the parents as to shape how they view their role as parent ally, and their attitudes and beliefs pertaining to the education system.

## Implications for Research

The conceptual lens presented in this paper offers researchers an alternative perspective to view parental allyship, particularly how parents of children with a disability make meaning from their experiences within the education

setting. It provides the opportunity to see parental allyship as a type of disability experience, albeit an experience that is adjacent to the individual who holds the disability experience. The authors suggest that researchers may wish to use this lens when considering how parents of children, who belong to a marginalized group, experience and make sense of their interactions within the school setting. This lens also has the potential to be used in future qualitative research to interpret data from interviews with parents in ways that offer insight into the nature of allyship between parents and school-age children, and how this allyship influences interactions within the school setting. Finally, future researchers would then be able to explore the motivations for parental allyship for their disabled children, as well as the impact from vicarious and primary adjacent experiences.

## **Implications for Practice**

Educators can also benefit from conceptualizing the role of parents as allies to their children. Application of this proposed lens allows for educators to contemplate the complexity of disability experience for students who are members of a marginalized group and for their parents who are perhaps having both vicarious and primary adjacent disability experiences. This insight affords opportunities to enhance the parent-school partnership. There is a strong understanding in both the literature and in practice that the parent-school partnership plays an influential role in the academic success and well-being of students. To this effect, the proposed lens offers a perspective for educators to enhance this partnership by viewing disability experience not just as something that occurs for the child, but for their allies as well. This has the potential to enhance educational policy regarding parent-school partnerships and, ultimately, the outcomes for students.

### **Conclusion**

This paper contributes to the field in the following ways. First, the distinction made between the terms advocate and ally is an important one that recognizes the need to be mindful of membership status as it relates to the disability community. The strongest voices are those with in-group membership; however, as out-group members, allies have a powerful role to play in seeking to improve the experiences of in-group members. This contrast in the terms is informed by literature in the LGBTQI+ field and the actions and motivations of parents of LGBTQI+ children. Extending on the utility of the term allyship, as we have done in this paper, can help to inform understandings of the actions and motivations of parents of children with disabilities.

The second significant contribution made by this paper is to offer a proposed lens in which to view the experiences of parents acting in the role of ally to their child with a

disability, such as with dyslexia, by defining three different types of experience that relate to disability identity. This lens reflects and recognizes that a child with a disability, such as dyslexia, is the member of marginalized groups and that they will have primary or first-hand experiences related to their disability identity. At the same time, while the parent is not a member of the same marginalized groups as the child (they still retain membership in the dominant group of adulthood even if they are disabled themselves) and are not able to have the primary experience of marginalization that their child has. Instead, they will have vicarious experiences where they share in the depth of emotion felt by their child. These vicarious experiences can be significant enough to impact on the parent's worldview, including how they perceive the actions and attitudes of the education setting. Finally, parents can have primary adjacent experiences, where their experiences with the education setting are first-hand; however, they only occur because of the parents' actions in the role of ally to their child. These experiences can also dramatically influence how parents engage in the parent–school partnership processes.

Given the subjective nature of experience, discussed in detail within this paper, it stands to reason that no one single lens for viewing subjective experience will apply to all individuals. However, the authors hope that the lens presented in this paper offers one way to view and potentially describe the subjective experience children with dyslexia and their parents have within the educational setting. This lens offers a unique conceptualization of experience as either a primary (first-hand) in relation to the child, a vicarious experience of the parent, or a primary adjacent experience of the parent. Each type of experience is determined by the proximity of the experience to the identity of dyslexia and the nature of the relationship between child and parent. A heightened understanding of the nature of experience for children with dyslexia and their parents and the proximity of the experience to the disability identity seeks to respect the disability identity of the child with dyslexia and to afford for greater insight into how parental allyship creates a complex and unique experience for parents.

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