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Callosal Malformations: Developmental Impacts and Parental Adjustment During the COVID-19 Pandemic

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Callosal Malformations: Developmental Impacts and Parental Adjustment During the COVID-19 Pandemic

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Abstract

In March 2020 the 2019 coronavirus disease (COVID-19) was determined to be a global health crisis (Lee et al., 2021). As the virus continued to spread rapidly, individuals had to adjust their daily routines to reduce disease transmission. Agenesis of the Corpus Callosum (AgCC) is a broad term used when there is a presence of congenital brain malformation in the region of the brain responsible for transmitting information to both left and right hemispheres (Paul, 2011). Evaluation of individuals with AgCC have been observed to demonstrate specific deficits including cognitive efficiency, transfer of sensory-motor information, and complex reasoning (Brown & Paul, 2019; Mangum, 2018; Miller et al., 2018) although evolve over time (Badderudin et al. 2007; Paul et al., 2007). Developmental evaluations have demonstrated generalized delays in individuals ranging from age 2-16 years, when compared to those without AgCC (Eddy, 2022). The purpose of this study was to discover whether adaptive development in children aged 6 through 13 years varied based on parent reported Major Life Events (MLE) and COVID-19 pandemic related change. A total of 30 parents of a child with a confirmed anatomic diagnosis of AgCC completed the Vineland Adaptive Behavior Scales, Third Edition in addition to the MLE and/or COVID-19 questionnaire. Results of the retrospective cross-sectional study showed generalized delays across all developmental domains compared to the normative sample. In the communication domain, delays were found to be more apparent when parent-reported stress and impact was also elevated. COVID-19 related change was also identified in the areas of reduced in-person social interaction, delivery of education, and increased parent responsibility. This study broadly identified environmental events as identifiable developmental risk factors.

Keywords: agenesis of the corpus callosum, COVID-19, major life events, adaptive development, parent functioning.

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Chapter 1

Disrupting the Dyad: Parent-Child Interactions

Throughout the early stages of development, children's principal interactions are with their parents and care providers. Children are observed to thrive developmentally in healthy social-emotional, physical, and cognitively stimulating environments, especially when supportive and sensitive parenting practices can be incorporated (Deater-Deckard, 1998; Deater-Deckard & Panneton, 2017). Given the significant overlay of this relationship and child development, it is not surprising that difficulties in family functioning can have short and long-term effects for both parents and children (Deater-Deckard 1998; Azhari et al., 2019; Deater-Deckard & Panneton, 2017; Gülseven et al., 2018; Zonderman, 2012). Stress in the family context can also have negative effects on the well-being of parent-child relationships relationship (Deater-Deckard & Panneton, 2017). Stress to some degree is inevitable, and the impact felt by these experiences arises when individuals feel that they are unable to meet the demands of their environment (Deater-Deckard, 1998; Deater-Deckard & Panneton, 2017). External and internal forms of stress, such as financial adversity or mental health, can also negatively influence psychological tolerance for stress and parenting behavior (Nivear et al., 2014). Depending on the context, stress can be categorized into three domains, "positive" and conducive to healthy development, "tolerable" and easily mediated by supportive relationships or resources, and "toxic" or prolonged chronic stress that can have physical, emotional, and relational impacts (Lazarus & Folkman, 1984; Selye, 1965; Shonokoff, 2010). Therefore, by definition some stressors are directly attributable to the demands of parenthood/caregiving (Deater-Deckard, 1998). For example, parents can experience stress while trying to fulfill the immediate demands of their child's needs (e.g., food, support, attention), balancing personal and family necessities, and perceived social pressure. As such, parental stress must be evaluated within the context of environmental circumstances, responsibilities, and everyday life (Crnic et al., 2002). Thus, parental stress acknowledges that there is a greater context for the stress parents experience (Belsky, 1984).

It is well documented that increased demands can affect overall functioning of the family (Aloia & Solomon, 2015). Abidin (1990) argued that to accurately understand the causes of parental stress and determine child effects, one must acknowledge the interaction between each of the variables to accurately determine the circular effect of parental pressure and child behavior. As indicated above, child development and parent stress are not mutually exclusive, such that increased parental stress can result in more child behavior problems, which in turn can lead to elevated parental stress (Elgar et al., 2004). This in part is due to parent-child relationships not occurring in a social vacuum, as external factors impact the dyadic reciprocal nature of this relationship (Abidin, 1990; Romero et al., 2020). Although research has observed a connection between parent well-being and child functioning (Franck et al., 2010), parents themselves do not always perceive their own experiences of stress as being impactful to their children (Hickey et al., 2019; Rayce et al., 2020). On behalf of the American Psychological Association, (APA, 2010) Harris Interactive conducted a survey about stress in America and found that 86% of children reported that their parents stress bothers them, whereas 69% of parents reported that their stress had slight or no impact to their children (APA, 2010).

A direct connection between child functioning and parental involvement, social relationships, and health has also been observed (Woodman et al., 2015). Parents play a primary role in filtering the stresses to which children are exposed or from which they will be protected (Skinner & Zimmer-Gembeck, 2016). Parents shape a child's understanding of stress, as parental response and interpretation of stress affect the family climate and their ability to engage in stress appraisal, modulate impact, and access resources (Skinner & Zimmer-Gembeck, 2016; Deater-Deckard & Panneton, 2017). As a result, the effects of parental stress and a child's ability to respond effectively are important to consider, as parents are the primary source from whom children learn effective coping strategies (Yamaoka & Bard, 2019; McKenry & Price, 2005).

Others have posited that the way parents respond to stress correlates with a child's level of externalizing behaviors (e.g., aggression, tantrums, hyperactivity, and impulsivity; Ackard et al., 2006; Crnic et al., 2005; Deater-Deckard & Panneton, 2017; Herbert et al., 2015). Ackard et al. (2006) particularly concluded child behavioral and emotional health was related to parent child connectedness. Emerging evidence on parent well-being and child impact, found that parent-child brain synchronicity, caregiver attunement, and co-regulation were reduced when parents reported higher levels of stress (Azhari et.al., 2019). Other studies have concluded that parental personal discomfort is linked with maladaptive outcomes and poor adaptive functioning in children (Crnic et al., 2005; Deater-Deckard & Panneton, 2017; Yates et al., 2010). Specifically, lower levels of adaptive functioning were predictive of higher levels of parental stress (Weiss et al., 2003). The relationship between stress and behavior problems appears to be reciprocal, such that elevated child behavior problems lead to increases in parental stress which further exacerbate the child's behavior problems.

Parenting strain has also been linked to less optimal parenting styles, lower quality of parent child interactions, and lower levels of positive social development in children (Gülseven et al., 2018; Crawford & Manassis, 2001; Crnic et al., 2005). However, positive parenting was observed to provide a buffer to the negative impacts of family stress (Yamaoka & Bard, 2019). Parenting style is a constellation of practices geared towards creating an emotional environment that influences a child (Marchetti et al., 2020). Parenting style is widely cited in the literature as having an impact on children's emotional and behavioral functioning (Rinaldi & Howe, 2012: Braza et al., 2015; Marchetti et al., 2020). Parental verbal hostility (i.e., yelling, criticizing) directly impacts wellbeing, emotional reactivity, and internalizing responses in young children (Smarius et al., 2019; Pozzi et al., 2020) and preadolescents (Möller et al., 2016). Although parenting style is relatively stable over time (Marchetti et al., 2020**),** some parenting behaviors can be triggered by compromised psychological functioning (Tavassolie et al., 2016), or stressful life events (Marchetti et al., 2020).

Although the demands parents/caregivers face are ultimately varied in type and intensity, research suggests that parent's appraisal and perception of the events as being stressful predicts their behavioral, emotional, cognitive, biological, and interpersonal response (Cohen et al., 2016). Additionally, an individual's perception about their ability to appraise and maneuver impactful events also determines how they quantify the impact of the event (January et al., 2019; Deater-Deckard & Panneton, 2017).

Parental Major Life Events, Daily Hassles, and Child Impact

Major life events (MLE; e.g., bereavement, natural disaster, divorce or relationship discord) are some of the many encounters that can occur during the life course (Holmes & Rahe, 1967; Pedersen et al., 2015; Pocnet et al., 2016; DeLongis, 2014). Some life events last years and are highly impactful (e.g., chronic illness or injury, having a child, etc.) whereas others are minor (i.e., losing keys, arguing with a partner or coworker, or running late; Luhmann et al., 2020; Lavee & Ben-Ari, 2008). Some minor events, such as daily hassles, might be more frequent, while other major and impactful events may be sporadic and may require a higher level of adjustment (e.g., loss of job, changing schools; Gülseven et al., 2018). A growing body of literature has identified a connection between MLEs and various health conditions, especially if these events accumulate (Pedersen et al., 2015). Cohen et al. (2016) argue that environmental demands are not always appraised as negative experiences, indicating that not all stressful experiences are perceived as impactful. However, the process of coping itself (even if unsuccessful) may directly result in physiological and behavioral changes (Cohen et al., 2016).

Other studies have also displayed considerable variability in stress response, adaptation, susceptibility, and subjective wellbeing (Lucas, 2007). Kettlewell et al. (2020) found self-reported wellbeing to be profoundly reduced as a result of experiencing monetary loss, death of partner, and childbirth. Conversely, set-point theory posits that individuals who endure MLE are able to adapt back to pre-event baseline wellbeing levels following the event (Lucas, 2007). An alternative interpretation suggests, that while each event by itself could be considered minor, it is the accumulation of events over time along with other sources of life stress, that can result in considerable adjustment for parents (Riley et al., 2014; Morales & Guerra, 2006; Appleyard et al., 2005), suggesting that MLE have long-lasting effects (Anusic et al., 2014)

Literature implies that the role of parenting alone produces elevated levels of stress (Deater-Deckard, 1998; Crnic et al., 2005; Azhari et al., 2019). However, there is less emphasis placed on the extent to which stressful life events endured by parents' impact children (Luhmann et al., 2020) although researcher has identified a relationship between MLEs and child behavior (Skinner & Zimmer-Gembeck, 2016; Ackard et al., 2006). For instance, Crnic et al., (2005) found the accumulation of daily hassles and MLE to be positively correlated with child behavioral and emotional development. Daily hassles may deplete parents' resources and reduce their ability to regulate emotions; thus, parents may become more irritable, impatient, and self-focused rather than child focused (Gülseven et al., 2018). Research suggests children's behavior is influenced by parental responses to adversity and daily hassles (DeLongis, 2014; Holm & Holroyd, 1992). Recent findings identify a direct correlation between parent stress, MLE, and child adaptive behaviors (Hickey et al., 2019; Deater-Deckard & Panneton, 2017; Gülseven et al., 2018). Camacho-Thompson et al. (2016) found stress to limit parents' involvement in their child's lives. Scannell (2021) contends that understanding these contextual factors will aid in meeting the needs of families faced with compounding stressors.

Parents of Children with Health and Developmental Disabilities

The task of parenting is considered to be multifaceted, as it is often performed within the context of additional environmental stressors and demands. Parents of children with behavioral, medical, and/or developmental complexities, are more likely to report experiencing higher levels of stress due to challenges with accessing services or having a child who requires higher level of care (Abidin, 1990; Salomone et al., 2017; Aishworriva & Kang, 2020). Saunders et al. (2015) found families of children with combined diagnoses of autism spectrum disorder and intellectual disability experienced increased financial strain and employment burdens, compared to parents of children without these developmental diagnoses (Salomone et al., 2017). Woodman et al., (2015) found that parents of children with developmental disabilities were also at increased risk of experiencing elevated psychological stress. Another study evaluating mothers and fathers of children undergoing surgery found parents to have moderate to high levels of self-reported stress in response to their child receiving critical care (Franck et al., 2010).

Several studies have documented a connection between parental stress and child functioning (Cousino & Hazen, 2013; Peterson & Hennon, 2005). Parents of children with chronic illness and developmental disorders may spend more time in urgent care facilities than caregivers with neurotypical or healthy children (Sil et al., 2021). Unplanned hospitalizations are disruptive and straining on normal routines and can potentially lead to parents engaging in behaviors that unintentionally impact child functioning (Sil et al., 2021). Further, child-focused interventions may fail to recognize that children function within a larger system and social context, in which the role of family, parents, and parenting behavior are crucial and impact children's experiences and understanding of their medical differences (Sil et al., 2021). Research has also evaluated parental self-efficacy and found it to be linked to overall parental competence (Bates, 2019). Pisula and Kossakowska (2010) found parents of children with developmental disabilities had decreased confidence in their ability to meet their child's need. However, parents report not always feeling supported while managing the health of their child who has physical and developmental complexities (Smith et al., 2013). For example, qualitative studies distinguished that others' misunderstandings about a child's illness and uncertainty about the illness course contributed to parenting stress (Baraket et al., 2007; Helgeson et al., 2012) Additionally, parents of children with comorbid developmental disorders and chronic disease were more likely to experience personal adversity (i.e., impaired mental health, sense of devaluation, self-blame, impaired physical functioning, and exhaustion (Mugno et al., 2007; Sil et al., 2021).

Studies evaluating parents of children receiving critical care found parents who reported elevated stress related to their child's medical treatment had children who also experienced poorer outcomes (Franck et. al., 2010; Barakat et al., 2007; Helgeson et al., 2012). Another study found when caregivers estimated higher levels of pain in accordance with anticipating a procedure for their child, their children also reported experiencing higher rates of pain (Caes et al., 2016). The stronger impact of feelings of distress on personal pain reports might be due to a stronger elicitation of a fearful and/or aversive response when considering the procedure their child is enduring (Caes et al., 2016), suggesting, parents may be reporting their level of distress rather than estimating the level of pain their child will endure.

The stress experienced by parents of young children with chronic illness was related to perceived behavior problems in their children (Hilliard et al., 2010). Parents' experiences with developmentally normative misbehavior that interferes with disease management or adherence to services exacerbates parental distress (Hilliard et al., 2010; Salomone et al., 2017). January et al, (2019) highlighted the importance of fostering positive coping strategies for parents who have a child with medical and developmental complexities. Literature suggests the effect of having a child with complex medical or behavioral needs was not uniformly negative. Many parents report positive aspects such as increased family closeness (Helgeson et al., 2012). These benefits are consistent with literature highlighting the possibility of growth following a stressful or traumatic event (Helgeson et al., 2012).

Global Implications of the COVID-19 Pandemic

March 2020 the 2019 coronavirus disease (COVID-19) was determined to be a global health crisis (Lee et al., 2021). As the virus spread rapidly, individuals had to adjust their daily routines to account for the Centers for Disease Control and Prevention (CDC) standards and recommendations regarding public safety (Lee et al., 2021). To slow the virus from spreading, governments around the world placed social restrictions, shut down schools, and enacted "stay at home" orders (Marchetti et al., 2020). As a result, individuals across the world encountered a convergence of economic stressors, social alienation, personal difficulties, and health problems or concerns related to COVID-19 (Twenge & Joiner, 2020). The World Health Organization

(WHO, 2020) expressed concerns regarding long-term negative consequences particularly surrounding psychological well-being (Morelli et al., 2020), especially, since effects of the global pandemic inordinately impacted communities of color, individuals socioeconomically dispossessed, people with underlying health conditions, and/or health inequalities (Lee et al., 2021). Although the pandemic continued to impact individuals nationwide, previous research following natural disasters, revealed that in adverse situations it is possible to have positive patterns of adjustment and even post-traumatic growth following an impactful event (Romero et al., 2020). The COVID-19 pandemic underwent a second wave spanning from August 2020 to February 2021 and was characterized by a growing incidence of confirmed cases as new variants emerged (Coccia, 2021). COVID-19 continued to undergo changes, and a third wave was observed to transpire during the beginning of June 2021, following the emergence of the Delta variant (CDC, 2023).

Stress and Parenting During COVID-19

Initial studies conducted at the beginning stages of COVID-19 revealed that individuals were experiencing stress at both the individual (e.g., feeling on edge, worried, irritable, and/or overwhelmed) and at the dyadic levels (e.g., increased time together and limited social activities outside the home; Spinelli et al., 2020; Russell et al., 2020). As such, various parenting duties and roles shifted during COVID-19 (Spinelli et al., 2020), due to children and families being deprived of their educational, work, activities, and relational contacts (Morelli et al., 2020). Lee et al. (2021), found parents during the pandemic were more likely to experience employment changes, qualify for free or reduced-cost school meals, have prominent disruptions to their daily life, and report elevated levels of stress or depression.

Throughout the COVID-19 pandemic parental stress increased dramatically (Adams et al., 2020). Russell et al. (2020) found that parental stress varied between male and female caregivers, revealing that fathers were more likely to feel burdened during COVID-19. Another correlation in this study determined that the way caregivers responded to aversive situations related to COVID-19 and concordant stressors impacted both behavior and well-being of their child (Romero et al., 2020). For instance, coercive patterns and harsh parenting styles predicted unfavorable outcomes in children living in stressful situations, as they were more likely to act out behaviorally or require additional support coping with stressors (Romero et al., 2020). Additional studies have posited that parents who experience elevated levels of psychological distress may become less attentive and warm when interacting with their children (Marchetti et al., 2020). Moreover, parents experiencing elevated levels of stress may potentially transfer the burden of their emotional distress to their children due to their coping strategies being ineffective (Marchetti et al., 2020). This implies that children of parents under increased levels of stress will also display physiological symptoms of stress even if not directly affected by the stressors or fully aware of the events (Marchetti et al., 2020; Fontanesi et al., 2020). Dillmann et al., (2022) found that parent stress was rated as higher in those with older children than younger. However, alternative research suggests that not all parents experiencing cumulative stressors from COVID-19 were at risk of higher perceived stress or poor parenting, suggesting that protective factors may mitigate the effects of COVID-19 on parental stress (Brown, Doom, et al., 2020).

Child Impacts During COVID-19

Throughout the pandemic, parent-child relationships have shifted. Romero et al. (2020) revealed some significant differences in children’s outcomes based on age, finding that younger children (i.e., preschool) displayed more behavioral problems (e.g., outburst and hyperactivity), whereas older children were more reflective over social-oriented situations (e.g., missing connecting with others socially in person). Overall, research concluded that child behavior presentations varied based on both parental impact and response to the added stressors induced by the global pandemic (Canady, 2020; Romero et al., 2020; Spinelli et al., 2020; Tambling et al., 2021). Additionally, a study investigating the short-term effects of the pandemic on children with complex needs, found that children had enhanced adaptive functioning in all domains except for social (Siracusano et al., 2021). However, managing stress during the pandemic and particularly during periods of quarantine, was particularly stressful for both parents and children as they had to re-learn how to function in their day to day lives. COVID-19 puts parents at a higher risk of experiencing distress and may have potentially impaired their ability to be supportive caregivers. As a result, parents who were experiencing higher rates of distress were more likely to fail to respond sensitively to their child's needs (Spinelli et al., 2020). Subsequently, children who do not feel supported or attended to, may be more likely to show externalizing behaviors (i.e., emotional outburst, inattention, and poor concentrating; Spinelli et al., 2020).

Academic and Social Impact

As COVID-19 led to extensive school closures and social impacts, parents were tasked with taking on new roles and responsibilities. Widespread school closures during COVID-19 affected over 1.5 billion children worldwide (UNESCO, 2020) which resulted in rapid transition to distance learning (Moscardino et al., 2021). Evidence surrounding remote education suggests families had to adjust to effectively manage their offspring, procure additional technology services, take on multiple roles (i.e., teacher, employee, caregiver), and continue to mediate stressors (Culver et al., 2020; Golberstein et al., 2020; Moscardino et al., 2021). Research reflects children's education during COVID-19 to be strongly indicative of parental stress, however if mediated by family resources and increased parental self-efficacy, stress related to child education was non-significant (Moscardino et al., 2021; Schmidt et al., 2020; Prime et al., 2020). COVID-19 also posed unique challenges for children, as they were deprived of typical socialization practices and play activities (Morelli et al., 2020). A systematic and meta-analysis of the evidence on learning during COVID-19, revealed substantial learning deficits (Betthäuser et al., 2023).

COVID-19 and Children with Congenital and Developmental Differences

Some literature advocates that COVID-19 alone may not be the best predictor of caregiver burden, as the pandemic impacted families disproportionally. For families with children who have special needs, medical conditions, developmental differences, or challenging behaviors, COVID-19 created additional obstacles (Aishworiya & Kang, 2020), especially, since these children have greater healthcare needs, higher rates of dependency on psychosocial or community-based services, and mental health difficulties (Aishworiya & Kang, 2020). In general, these families were more likely to experience barriers in accessing healthcare, due to a limited number of trained specialists, socio-economic status, complex medical comorbidities, and geographical distance from care (Aishworiya & Kang, 2020). Overall, quality of life of parents with children who have disabilities was observed to decrease as the impact of COVID-19 increased (Rakap, et al., 2022).

Corpus Callosum: Overview of Callosal Development and Malformation

Interhemispheric transfer, or the brains' ability to communicate between the left and right hemispheres, is critically involved in the performance of simple and complex behaviors and interactions. Although other pathways exist, the corpus callosum is the largest neuroanatomical connective structure in the brain (Paul et al., 2007; Paul, 2011; Raybaud 2010; Paradiso et al., 2020). Comprised of about 200 million nerve fibers, the corpus callosum is involved in facilitating transfer of sensory, motor, and cognitive information across the hemispheres (Paul et al., 2007). The primary structures of the corpus callosum can be observed prenatally at 20 weeks' gestation, although postnatal pruning and myelination continue to occur into late adolescence (Paul, 2011; Raybaud, 2010; Jeeves, 1994; De León Reyes et al., 2020; Hagelthorn et al., 2000; Giedd et al., 1994; Yakevlev et al., 1967). Agenesis of the corpus callosum (AgCC), is a type of congenital brain malformation, wherein the callosal fibers fail to develop, and can be classified as either complete or partial depending on the degree of callosal fiber absence (Paul et al., 2007; Schell-Apacik et al., 2008; Rauch & Jinkins 1994). Hypoplasia or thinning of the corpus callosum can also be observed, although there is a higher degree of heterogeneity making generalization of outcomes difficult for this population (Schell-Apacik et al., 2008). As these are anatomic diagnoses, only identifiable via in-vivo visualization of brain structure, confirmation via neuroimaging (ultrasound, CT, or MRI) is required to confirm the presence of callosal malformation (Vergani et al., 1994).

Prevalence rates have identified AgCC to be among the more common congenital neurological disorder, as it occurs in at least one in every 4000 live births (Brown & Paul, 2019; Bernardes et al., 2021; Glass et al., 2008). Although the cause of complete and partial AgCC are variable, known factors including exposure to teratogens (i.e., environmental toxins, substances, infection), vascular problems, and genetic malformations have been identified risk factors (Paul et al., 2007; Bedeschi et al., 2006; Schell-Apacik et al., 2008; Pang et al., 2008; Lieb & Ahlhelm, 2018). While the etiology of AgCC remains largely unknown, genetic mutations have been found to be the most common cause of AgCC, with up to 45% of individuals having an identifiable chromosomal abnormality (Brown & Paul, 2019; Spencer-Smith et al., 2020; Paul et al., 2007; Edwards et al., 2014).

Research has identified that a majority of individuals diagnosed with AgCC may develop and retain alternative commissures (e.g., pathway for some degree of information to be transmitted across the cerebral hemispheres) other than the corpus callosum (Paul et al., 2007; Barr & Corballis, 2002; Brown et al., 1999; Brown et al., 2001). These findings substantiate the idea that complete AgCC is not the same as “split brain” (commissurotomy; Sperry, 1974) or callosotomy (surgical severing of callosal fibers in the corpus callosum to treat intractable epilepsy) with accompanying secondary symptoms of disconnection syndrome (i.e., absence of callosal transfer of sensory information and bimanual motor coordination; Lassonde et al., 1991; Sperry, 1974; Jeeves 1994; Sauerwein et al., 1994). Comparatively, individuals AgCC along with those who underwent childhood callosotomy were likely to exhibit less impaired interhemispheric transfer and only mild evidence of disconnection syndrome, when compared to individuals with adult callosotomy (Paul, 2011; Paul et al., 2007). Suggesting that neuroplasticity in children may allow alternative neural pathways to develop, (Paul et al., 2007), although compared to the corpus callosum the speed of interhemispheric transfer remains less efficient (Brown et al., 1999; Brown et al., 2001).

Long-Term Outcomes in AgCC

Despite relatively high prevalence rates compared to other neurological disorders, the impact of AgCC on neurocognitive functioning is highly variable and an individual’s developmental trajectory is difficult to predict based on anatomical brain diagnosis alone (Siffredi et al., 2018; Brown & Paul, 2019). Additionally, classification of callosal malformation as completely absent (complete AgCC) or remnant (partial AgCC), does not reliably determine outcome (Paul et al., 2007). Although, when AgCC is an isolated finding (i.e., no accompanying or only minor brain or body dysmorphology and full-scale intelligence quotient (FSIQ) ≥80) classified as “Primary AgCC”, three consistent core symptoms are observed (Paul et al., 2007); limited interhemispheric transfer of sensory-motor information and learning, reduced cognitive processing speed, along with deficits in complex reasoning and novel problem-solving (Brown & Paul, 2019).

According to Brown and Paul (2019) individuals with AgCC compared to neurotypical persons demonstrate less interhemispheric transfer of information, although greater than those with a commissurotomy (Lassonde et al., 1991; Brown et al., 1999). Therefore, due to poor interhemispheric transfer, mild to moderate deficits are observed in bimanual coordination of motor movements (Muller et al., 2009; Moes et al., 2008; Genç et al., 2015) along with discrimination of sensory information in individuals diagnosed with AgCC (Jeeves & Silver, 1988; Brown et al., 1999). Reduced cognitive processing speed relative to other neurocognitive skills (Erickson et al., 2014) and impaired abstract reasoning, concept formation, and novel-problem solving (Brown & Paul, 2019).

Given the wide array of skills encompassed by the aforementioned deficits, it is likely that deficits in these areas will have cascading secondary neuropsychological and psychosocial impacts (Siffredi et al., 2018; Brown & Paul, 2019). Among the secondary impacts, research has shown that individuals with AgCC also have impairments in executive functioning processes (e.g., deductive reasoning, flexibility, utilization of information, and inhibition; Su et al., 2023; Mangum et al., 2021; Marco et al., 2012), regulating attention (Brown, Panos, et al., 2020), learning and encoding of new information (Erickson et al., 2014; Paul et al., 2016), appreciation of social consequences (Young et al., 2019; Paul et al., 2004; Brown, 2021), recognizing and labeling of emotions (Bridgman et al., 2014; Paul et al., 2021; Anderson et al., 2017), strategy formation (Marco et al., 2012; Mangum et al., 2021), abstract reasoning (Brown & Paul, 2000), higher order non-literal complex language (Brown, Paul, et al., 2005; Brown, Symington, et al., 2005; Paul et al., 2003; Rehmel et al., 2016), and awareness of functional limitations (Miller et al., 2018; Kaplan et al., 2012).

Developmental Trajectories in AgCC

While there is a robust and ever-growing literature regarding long-term neurocognitive outcomes in AgCC, and their associated psychosocial limitations, the functional and developmental trajectories of children with callosal malformations is less understood. In part due to the small number of studies on children with AgCC, researchers often rely on case studies and anecdotal reports from parents of children with AgCC to extrapolate and delineate aspects of "typical/expected" development. As mentioned above it has been hypothesized by Brown and Paul (2019) that individuals with AgCC demonstrate a pattern of syndromes, which is likely give rise to a wide range of associated developmental disruptions. For example, on a variety of daily tasks require efficient cognitive processes, and those with AgCC are typically less accurate and take longer to respond (Brown et al., 1999; Brown et al., 2001; Hines et al., 2002; Marco et al., 2012), which likely contributes to diminished social functioning (Brown & Paul, 2019; Symington et al., 2010; Young et al., 2019). As a result, social functioning is one of the most challenging developmental tasks for those with AgCC (Renteria-Vazquez et al., 2022). Several studies have observed individuals with AgCC demonstrated difficulty comprehending non-literal language (Brown, Paul, et al., 2005; Brown, Symington, et al., 2005; Paul et al., 2003, Rehmel et al., 2016), understanding the social contexts of emotions (Anderson et al., 2017), perspective taking, and successful integration of information to interpret social situations accurately (Symington et al., 2010).

Research found that children with AgCC under the age of 6 were less likely to demonstrate obvious social, emotional, and cognitive deficits, however moderate speech delays were evident (Badaruddin et al., 2007). Mendez-Vigo and Andrews (2011) found that children with AgCC displayed obvious receptive and expressive language deficits along with delayed reading and phonetic discrimination when compared to a neurotypical control group. Badaruddin et al., (2007) found that 61.5% of individuals with AgCC exhibited “emotional non-communicativeness,” 16% presented symptoms of “social indifference”, 86% displayed echolalia, and 100% showed language characterized as “meaningless/out of place” (p. 288). A case study following an individual with AgCC through their first 23 years of life observed delayed developmental acquisition of expressive language evident in preschool (Stickles et al., 2002). Parents of children with AgCC reported that their child often talked in clichés, displayed poor social judgment, failed to recognize subtle facial expression, and accurately interpret/understand sarcasm (Badaruddin et al., 2007).

Several studies have shown that individuals with AgCC have difficulty in recognizing their own emotional state, regulating emotions, verbally expressing emotion, and verbally identifying emotions expressed by others (Anderson, et al., 2017; Bridgman et al., 2014; O’Brien, 1994). Individuals with AgCC were on average less likely to accurately interpret fear and anger in themselves and others (Bridgman et al., 2014). Turk and colleagues (2010) found that individuals with AgCC used fewer emotion words than matched controls, assessed via the Thematic Apperception Test (Turk et al., 2010). The individuals with AgCC typically used fewer words related to negative emotions (Turk et al., 2010).

Activities of daily living (e.g., eating, dressing, bathing, and mobility) were also found to be impaired in individuals with AgCC. Paul and Turnbull (2003) found that children with AgCC may be able to develop habits and routines consistent with common daily activities, however development of these skill sets is generally delayed and require higher levels of repetition before fully mastered. Doherty et al. (2006) found higher rates of elimination problems in individuals with AgCC, which can impact both practical and health related contexts.

Moes et al. (2008) observed 77% of individuals diagnosed with AgCC were also likely to meet criteria for a developmental diagnosis. Lau et al. (2013) found children and adults who carry a diagnosis of AgCC exhibit autism spectrum disorder-like behaviors and also exceed cut-off scores evaluating diagnostic symptomology. Another study found that those with AgCC to be at a higher risk of being diagnosed with autism spectrum disorder, given the similarities in social, verbal, behavioral, and emotional functioning delays (Paul et al., 2014).

Many studies have postulated that due to the significant myelinization and functional development that continues to occur into adolescence (Giedd et al., 1994; Yajovlev et al., 1967), developmental and neurocognitive deficits in individuals with AgCC may not be readily observable in young children due to reduced requirement of callosal connectivity (Brown & Paul, 2019; Paul et al., 2007; Young et al., 2019). As such, older children with AgCC may fall behind their peers due to increases in task complexity (Garrels et al., 2001) and novelty (Young et al., 2013). Therefore, tasks that can be mastered through practice (e.g., math and reading) will likely be more impaired in children with AgCC than adults, whereas social interaction and problem-solving, which are more complex beginning in adolescence, will likely pose ongoing challenge (Kang et al., 2009; Turk et al., 2010; Mangum et al., 2021; Miller et al., 2018). However, a recent study by Eddy (2022) evaluating the developmental trajectory of 63 individuals with AgCC between the ages of 29–195 months, found generalized delays across age groups in their development of various adaptive functioning skills (e.g., daily living skills, socialization, and communication) when compared to their age and sex equivalent peers.

Parents of Children with Callosal Disorders

To date only one study has investigated the quality of life of a parent who has a child with AgCC. Henninger and Heretick (2020) found that parents' experience of perceived stress, access to resources, sense of coherence, and coping strategies were all significant predictors of overall parent quality of life. The results of this study highlight the importance of considering parent quality of life when evaluating families who have children with developmental disabilities (Henninger & Heretick, 2020). Overall, these results are consistent with prior research identifying a relationship between parent quality of life and perceived parental competency among mothers of children with developmental disabilities (Chen et al., 2022).

Rational and Hypotheses

As highlighted above, no study to date has sought to evaluate the relationship between parent/caregiver major life events, COVID-19, and development, in a sample of children and adolescence with AgCC. Previous literature has highlighted a connection between stressful life events and development, although these studies have primarily been conducted on typically developing individuals. During the COVID-19 pandemic, families in children experienced significant disruptions to their day-to-day routines, which is suspected to have impacted developmental progress, especially in the area of socialization. Those who have a diagnosis of AgCC, have been observed to demonstrate delayed developmental progress when compared to individuals who do not have any conditions and are considered typically developing. Therefore, this study seeks to evaluate the relationships between these factors and identify relationships along with potential developmental risk factors for individuals with AgCC.

The current study aims to investigate data from a clinical database collected during May 2021 to September 2021 to evaluate the developmental impacts of parental MLEs and COVID-19 pandemic related changes on individuals with complete and partial AgCC. Through a retrospective cross-sectional design using scores obtained on the Vineland Adaptive Behavior Scales, Third Edition (VABS-3), MLE, and COVID-19 questionnaires collected within aforementioned time period were included in analyses. I hypothesized that information collected from the MLE, and COVID-19 would be uniquely related to scores on the VABS-3 (Adaptive Behavior Composite, Communication, Daily Living Skills, Socialization).

Hypothesis 1: Adaptive Behavior in Children with AgCC

VABS-3 data were a subset of scores extrapolated from a previous dissertation by Eddy (2022). Consistent with the previous research findings (Eddy, 2022) of lower-than-expected adaptative functioning scores in individuals with AgCC between the ages of 72–156 months, VABS-3 summary scores (total adaptive and three domain scores) from our entire sample of participants with AgCC, will be significantly lower the expected mean from the normal distribution.

Hypothesis 2: Association of Major Life Events with Adaptive Behavior

A. Total MLE Occurrence (MLE-O) and Impact (MLE-I) scores will be negatively correlated with age- and sex-corrected standardized VABS-3 summary scores (Adaptive Behavior Composite and three domain scores).

B. There will be main effects for VABS-3 domains (Communication, Daily Living Skills, and Socialization) in the two MLE groups. Such that parents who report experiencing higher MLE-O and MLE-I will also report higher adaptive impairment in their children with AgCC.

C. There will also be a main effect for age, with older children (i.e., ages 10–13 years) being more likely to demonstrate impairments than younger children when MLE-O and MLE-I scores are elevated.

Hypothesis 3: Association of COVID-19 Behavior Changes and Adaptive Behavior

A. Responses to the COVID-19 questionnaire will demonstrate parent endorsed behavior change related to the pandemic (e.g., change from in-person to online education, access to services, social interaction outside of home, and parenting responsibilities).

B. Parent report of changes in responsibilities on the COVID-19 will be negatively related to the VABS-3 domain scores (Communication, Daily Living Skills, Socialization) and Adaptive Behavior Composite.

C. COVID-19 social interaction scores would be negatively related to age- and sex-corrected standardized VABS-3 Socialization domain scores.

Hypothesis 4: VABS-3, MLE, and COVID-19

For the entire sample of participants with AgCC, standardized VABS-3 scores will be negatively related to MLE-I and MLE-O groups and specific COVID-19 questions.

Chapter 2

Methods

Participants

Participants included parents of children with dysgenesis of the corpus callosum who were between the ages of 6–13 years at the time of administration. Participants evaluated during the present study were initially recruited and enrolled to participate in a large international longitudinal study based at The California Institute of Technology (Caltech). Prior to enrollment in the study, children received a formal diagnosis of callosal malformation or corpus callosal dysgenesis confirmed via neuroimaging (i.e., MRI, CT, or ultrasound). All parents included in the study were English speaking and able to complete forms online and via telephone interview. The initial sample included 30 participants who completed telephone interviews between May 2020 and September 2021. Individuals who completed the questionaries prior or after this time period were excluded given the desire to assess the effects of an isolated period of the pandemic. Demographic information and clinical data were extracted from a secure electronic data base and included age, sex assigned at birth, race (i.e., White, Black, Native American, Asian, Pacific Islander, and other), ethnicity (i.e., Hispanic or Latino), date-of-birth, confirmed callosal malformation diagnosis, relationship to child (e.g., father, mother, caregiver), and country of origin. Participants The Institutional Review Board at Caltech and George Fox University approved the study procedures with a waiver of consent.

Participants were included in the study if they had completed the VABS-3. From this sample, $N = 17$ completed the MLE, $N = 14$ completed the COVID-19 Questionnaire and $N = 11$ completed both the MLE and COVID-19 Questionnaire. See Table 1 for demographics for the full sample and each subsample.

Table 1

Demographic Characteristics of Study Sample and Subsamples

Variables	All *N* = 30	MLE *N* = 17	COVID-19 *N* = 14	MLE & COVID-19 *N* = 11
Sex				
Male	18 (60%)	10 (47.6%)	10 (71.4%)	7 (63.6%)
Female	12 (40%)	7 (33.3%)	4 (28.6%)	4 (36.4%)
Age				
M (*SD*)	8.07 (2.32)	7.71 (2.37)	7.21 (2.16)	7.36 (2.38)
Min – Max	6–13 years	6–12 years	6–12 years	6–13 years
Callosal Malformation Diagnosis Category				
CACC	17 (56.7%)	9 (42.9%)	6 (42.9%)	4 (36.4%)
PACC	12 (40%)	8 (47.1%)	7 (50%)	7 (63.6%)
Unknown			1 (7.1%)	
Group				
Isolated	15 (50%)	10 (47.6%)	6 (42.9%)	5 (45.5%)
Plus	11 (36.7%)	7 (33.3%)	7 (50%)	6 (54.5%)
Uncertain	4 (13.3%)		1 (7.1%)	
Pathology type				
Atypical	10 (33.3%)	7 (33.3%)	7 (50%)	6 (54.5%)
Common	7 (23.3%)	5 (23.8%)	4 (28.6%)	3 (27.3%)
None	13 (43.3%)	5 (23.8%)	3 (21.4%)	2 (18.2%)
Race				
White	19 (63.3%)	12 (57.1%)	12 (85.7%)	10 (90.9%)
Other	11 (36.3%)	5 (23.8%)	2 (14.3%)	1 (9.1%)
Country				
United States	19 (63.3%)	8 (47.1%)	8 (57.2%)	5 (45.5%)
Great Britain	5 (16.7%)	4 (23.5%)	3 (21.4%)	3 (27.2%)
Australia	2 (6.7%)	2 (11.8%)	1 (7.1%)	1 (9.1%)
Norway	1 (3.3%)	1 (5.9%)	1 (7.1%)	1 (9.1%)
Sweden	1 (3.3%)	1 (5.9%)	1 (7.1%)	1 (9.1%)
Thailand	1 (3.3%)	1 (5.9%)		
Canada	1 (3.3%)			
Relationship to child				
Father	2 (6.7%)	2 (9.5%)	2 (14.3%)	2 (18.2%)
Mother	27 (90%)	14 (66.7%)	12 (85.7%)	9 (81.8%)
Other	1 (3.3%)	1 (4.8%)		

Note. MLE = Major Life Events; CACC = complete genesis of the corpus callosum; PACC = partial agenesis of the corpus callosum.

Materials

The VABS-3. The VABS-3 (Hill et al., 2017) is a standardized assessment tool that utilizes a semi-structured interview format to measure behaviors consistent with adaptive functioning and is primarily used to aid in the diagnosis of intellectual and developmental disabilities, autism, and developmental delays (Hill et al., 2017; Appendix B). The VABS-3 Comprehensive Interview Form provides an overall summary score (Adaptive Behavior Composite) in addition to three core adaptive behavior domains: Communication (receptive, expressive, and written), Daily Living Skills (personal, community, and domestic), and Socialization (coping skills, play and leisure, interpersonal relationships; Hill et al., 2017). Additional optional or age-specific domains include Motor Skills (gross and fine motor) given only to individuals between birth to 9 years of age, and Maladaptive Behavior Domains (internalizing, externalizing, and critical items) given to people over the age of 3 years.

The VABS-3 was standardized on 2560 individuals from birth through 90 years using a stratified random sampling based on the United States census on sex, race/ethnicity, individual or parental education level, and geographic region. Further data were collected on seven clinical samples that coincide with the Individuals with Disabilities Education Act (i.e., developmental delay, emotional disturbance, autism, intellectual disability, specific learning disability, speech/language impairment; Hill et al., 2017).

Parents/caregivers of children between the ages of 3 years and 18 years in this study were given the Comprehensive Form, which consists of 502 items and takes 60–90 min to administer. Items in each domain were administered in chronological order based on typical developmental progression and were rated on the following scale; (2 = *usually*- if the individual can perform the behavior without help or prompting, 1 = *sometimes*- if they can sometimes perform without help or prompting, 0 = *never*- if the individual has not learned or is physically unable) and a few items are rated 2 for *yes* or 0 for *no*. Each item has an "estimate" option if the rater has not had the opportunity to observe the behavior.

The VABS-3 demonstrates good psychometric properties with interrater and inter-interview reliability coefficients ranging from 0.70 to 0.81 for the Comprehensive Interview Form. Whereas internal consistency ranged from 0.90 to 0.98 for the Comprehensive Interview For individuals ages 13 years and older, test-retest reliabilities for the Comprehensive Interview Form ranged from 0.81 to 0.92 These represent good to excellent levels of reliability by the criteria of Cicchetti and Sparrow (1981).

MLE Questionnaire. The *MLE Questionnaire* is based on research conducted by Glynn and colleagues (2004) where they evaluated negative life events and their impact during various stages of pregnancy. The questionnaire used in this study was adapted from the measures developed by Glynn et al. (2004). The MLE questionnaire, used for the purpose of this study, is akin to other scales developed to assess life events and determine the degree of impact, number of stressors, date of occurrence, and future implications based on the type of event that transpired. The MLE Questionnaire used in the present study consists of 20 items and takes approximately 15 min to complete. Respondents are asked to indicate either "yes" or "no" to whether they experienced each of the 20 specific life events during the past 12 months and report the exact date when the event occurred. Following each question is a clarification scale whereby respondents report how upsetting they found the event to be using a 4-point rating scale (*not at all*, *very little*, *somewhat*, or *extremely*). The measure is scored as follows; *not at all* = 0, *very little* =1, *somewhat* = 2, or *extremely* = 3.Scores from the MLE were totaled to represent the number of events experienced by each family over the course of the past 12 months (MLE-O total, range = 0–20) and the total impact of these events (MLE-I total, range = 0–60).

The questionnaire utilized in this study is similar to other life events measures, which historically were designed to evaluate the link between stress and illness (Rahe et al., 1970). The Social Readjustment Rating Scale was created by examining a large sample of patient medical records (Rahe et al., 1970). From this sample Rahe et al., (1970) developed a questionnaire consisting of 43 MLEs (e.g., divorce, changes in financial status, etc.). Each item was then awarded a “life change unit” depending on how traumatic the event was felt compared to the sample. A total value for the measure was created by adding up the scores for each event experienced over a 12-month period (Rahe et al., 1970). Based on the sample, a score ranging from 150–300 increased a person’s likelihood of developing a stress-induced health condition in the next 2 years by 50% (Rahe et al., 1970).

COVID-19 Questionnaire: Parent Self Report. The COVID-19 Questionnaire was developed by the research team assembled at George Fox University and Caltech to assess the extent to which the pandemic has significantly impacted parents who have children with AgCC (Appendix D). The self-report questionnaire consists of 22 items relating to how COVID-19 has impacted childcare arrangements and their child's social interaction. The online questionnaire takes 30 min to complete. Questions vary in their format and include the following; “yes” or “no”, rating scales, and open-ended responses questions to assess and capture the variability of impact.

The COVID-19 Questionnaire in this study is similar to other measures developed to quantify the impact of the pandemic. The CoRonavIruS health and Impact Survey (CRISIS) was designed to examine the extent/impact of life changes induced by the pandemic on mental health and behavior of individuals and families across the world (Nikolaidis et al., 2020). The CRISIS was found to demonstrate sound psychometric properties (Nikolaidis et al., 2020). Internal and test-retest reliability was obtained (0.79 and 0.87) in addition to construct validity, which was demonstrated by the reproducible associations of the measure (Nikolaidis et al., 2020). Together, these results demonstrate utility of the CRISIS as a measure of COVID-19 impact.

Select questions and demographic information from this questionnaire were included in the analyses. Item 7 “What type of school did your child attend from April 20202 to present time: public school, private school, special education, home school, other, or not in school?” was included as demographic information. Item 8 “In what ways has your child’s school delivered remote learning from April 2020 to present time: online classes via zoom/other or in-person classes?” was transformed into numerical variable (*online* = 1, *in-person* = 0). Item 9 “Please select the description that best describes the amount of interaction your child had with teachers and peers during remote learning from April 2020 to present time?” was converted and totaled as follows: *none at all* = 0, *very limited* = 1 *a moderate amount* = 2, *a great deal* = 3. Item 12 “Please indicate if your child was involved in any of the following therapies during COVID-19: physical therapy, occupational therapy, speech and language, vison therapy, psychological therapy?” was converted and totaled as follows: *no* = 0, *yes in school* = 1, *yes outside of school* = 2. Follow up questions regarding change related to access to services were totaled and converted as follows: *no change* = 0, *sessions were stopped* = 1, *sessions were cancelled* = 2, *sessions were changed to online* = 3. Item 13 “Consider your child’s opportunity for each of the following social interactions over the past 6 months: in-person contact between child and caregiver, in-person contact between child and other adults in home, in-person contact with siblings, in-person contact between child and other adults outside of home, in-person contact between child and other children, in-person events in community" were totaled and converted as follows; *decreased greatly* = 0, *decreased slightly* = 1, *no change* = 2, *increased slightly* = 3, *increased greatly* = 4. follow up questions about concern were also assessed and coded as follows: *not at all* = 0, *very little* = 1, *somewhat* = 2, *extremely* = 3. Item 14 "Consider your child's time spent playing outdoors and using technology over the past 6 months, playing outdoors and time spent using technology" were totaled and converted as follows: *decreased greatly* = 0, *decreased slightly* = 1, *no change* = 2, *increased slightly* = 3, *increased greatly* = 4. Follow up questions regarding concern for time spent playing outdoors and time spent using technology were also assessed and coded as follows: *not at all* = 0, *very little* = 1, *somewhat* = 2, *extremely* =3. Item number 17 "Since April 2020 have you taken on additional parenting responsibilities and/or roles as a result of the pandemic?" "Yes" or "no" responses were transformed into 0 = *no* and 1 = *yes*.

Procedure

Participants are individuals enrolled in an ongoing longitudinal study conducted at Caltech, who completed the COVID-19 Questionnaire (i.e., added on April 20, 2021). Upon initial enrollment, consent to participate was provided using a consent form approved by the Caltech Institutional Review Board. In this longitudinal study, participants received an email invitation with a personal survey link at age-specific time-points (ages 6, 12, 18, 24, and 36 months, then one time per year from age 48 months up to age 18 years). With approval from the George Fox University Human Subjects Research Committee and as an investigator on the Caltech protocol for this study, the VABS-3 interviews were conducted via telephone interview with participants whose children met inclusion criteria, as described above, and responses were recorded into the Caltech Qualtrics account. The MLE and COVID-19 Questionnaire were administered via self-report surveys emailed directly to participants, with responses recorded into a secure Qualtrics database. Following data collection, Caltech provided an encrypted file containing de-identified raw data from the MLE, VABS-3, and COVID-19 Questionnaires, as well as background demographic data. VABS-3 raw scores were converted to age- and gender-corrected standard scores using the published computer scoring system.

Chapter 3

Results

A total of 11 participants completed VABS-3, MLE, and COVID-19 questionnaires (see Table 2 for a summary of score totals for the subsample that completed these measures).

Table 2

VABS-3 Summary Scores and MLE Totals for Hypothesis 4 Subsample

Variables	*M* (*SD*)	Range
Adaptive Behavior Composite	74.64 (14.69)	49–96
Communication	70.82 (19.6)	34-–100
Daily Living Skills	76.27 (12.52)	50–96
Socialization	75.55 (15.51)	50–100
Major Life Events-Occurrence score	6.91 (8.93)	0–20
Major Life Events-Impact score	2.27 (2.93)	0–9

Note. *N* = 11. VABS-3 = Vineland Adaptive Behavior Scales, Third Edition; MLE = Major Life Events.

Hypothesis 1: Total Sample Comparison of VABS-3 Norms to Sample Scores

VABS-3 summary scores (Adaptive Behavior Composite and three domains - Communication, Daily Living Skills, Socialization), for all 30 participants were compared to normative sample standard scores derived from the manual (Hill et al., 2017).

Analysis of bootstrapped samples drawn from the entire AgCC sample revealed significantly low scores on average for the Adaptive Behavior Composite and across all three domains (Communication, Socialization, Daily Living Skills) compared to the normative population. In addition, a significantly greater than expected number of participants scored 1.5 standard deviation below the mean (see Table 3).

Table 3

Descriptive Statistics for VABS-3 Scores from All Participants and Bootstrapped t-test Comparison to Mean of Normal Distribution

Variables	*M* (*SD*)	Range	*t*-value	*p*	*d*	95% CI	<= *1.5sd (n)*
Adaptive Behavior Composite	74.37 (12.57)	49–96	-7.415	< 0.001	12.57	-29.80, - 20.97	57% (17) *
Communication	68.47 (16.03)	32–100	-7.07	< 0.001	16.03	-37.03, -25.43	60% (18) *
Daily Living Skills	75.80 (14.80)	50–106	-6.47	< 0.001	14.80	-29.10, -18.77	63% (19) *
Socialization	77.43 (13.98)	50–102	-5.80	< 0.001	13.98	-27.13, -17.73	50% (15) *

Note. $N = 30$. VABS-3 = Vineland Adaptive Behavior Scales, Third Edition; CI = confidence interval.

*Significant at Bonferroni adjusted alpha of $p < .0125$

Hypothesis 2: VABS-3 and MLE Sample Groups

For Hypothesis 2, analyses included VABS-3 and MLE responses from 17 participants who completed both questionnaires. VABS-3 summary scores in this subsample were consistent with values in the full sample (see Table 4 for VABS-3 group statistics in this subsample and *t*-test comparison with a normal distribution).

Table 4

Descriptive Statistics for Vineland Scores from Hypothesis 2 Subsample and Bootstrapped t-test Comparison to Mean of Normal Distribution

Domain	*M* (*SD*)	Range	*t*-value	*df*	*p*	*d*	95% CI
Adaptive Behavior Composite	76.12 (13.28)	49–96	-23.88	16	< 0.001	13.28	-30.59, -17.35
Communication	71.06 (16.89)	34–100	-28.94	16	< 0.001	16.89	-36.88, -21.12
Daily Living Skills	76.24 (15.15)	50–106	-23.77	16	< 0.001	15.15	-30.70, -16.29
Socialization	78.82 (15.06)	50–102	-21.176	16	< 0.001	15.06	-28.17, -14.35

Note. N = 17. VABS-3 = Vineland Adaptive Behavior Scales, Third Edition; CI = confidence interval.

In this subsample of children with AgCC, MLE-O total scores ranged from 0–20 with mean of 5.71 (7.03) and MLE-I total scores ranged from 0–9 with mean of 2.41 (2.85). A Spearman rho was used because dichotomous values were used for MLE-O and MLE-I scores. As predicted VABS-3 summary scores were negatively correlated with MLE totals. Although there were no significant correlations with MLE-O, MLE-I totals were significantly correlated with Adaptive Behavior Composite and Communication scores (see Table 5).

Table 5

Spearman rho Correlation of VABS-3 Summary Scores and MLE Totals

Variables	MLE-O	MLE-I
Adaptive Behavior Composite	-.351	**-.436***
Communication	-.368	**-.430***
Daily Living Skills	-.196	-.229
Socialization	-.268	-.214

Note. *N* = 17; VABS-3 = Vineland Adaptive Behavior Scales, Third Edition; MLE = Major Life Events MLE-O = Major Life Events-Occurrences; MLE-I= Major Life Events-Impact.

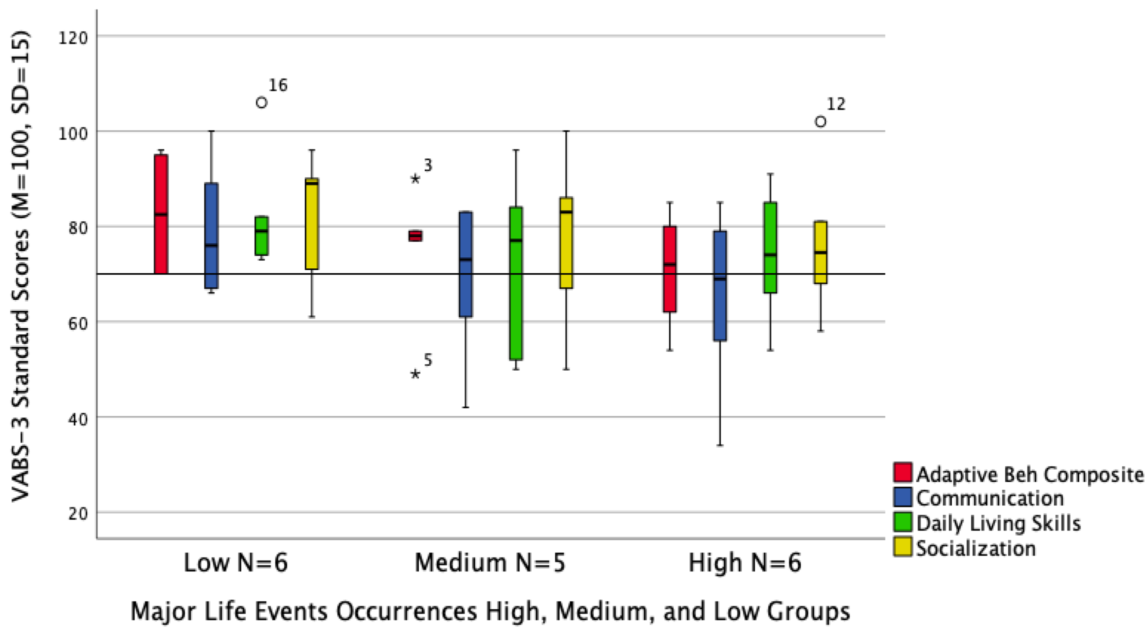
**$p < .01$; * $p < .05$.

Hypothesis 2B: MLE- O and -I Score Comparison to VABS-3

In order to use the MLE-O as an ordinal factor, subsamples were defined based on MLE-O scores: high range = ($N = 6$), medium range = ($N = 5$), and low range ($N = 6$). MLE-O and VABS-3 summary score distributions for each MLE-O subgroup are visually represented (see boxplots in Figure 1).

Figure 1

Boxplot for VABS-3 Summary Scores for High and Low MLE-Occurrences Subgroups



Note. $N = 17$. VABS-3 = Vineland Adaptive Behavior Scales, Third Edition; MLE-O = Major Life Events- Occurrences. Boxplots show the second and third quartiles divided by the sample mean, with whiskers showing the full range (excluding outliers).

VABS-3 and MLE-O scores were normally distributed, as assessed by Shapiro-Wilk's test ($p > .05$; see Table 6).

Table 6

Descriptive Statistics of VABS-3 Summary Scores for High, Medium, and Low MLE-O Subgroups

Variables	Groups	*M*	*SD*
Adaptive Behavior Composite	Low (*N* = 6)	82.67	12.13
	Medium (*N* = 5)	74.60	15.24
	High (*N* = 6)	70.83	12.01
Communication	Low (*N* = 6)	79.00	13.58
	Medium (*N* = 5)	68.40	17.32
	High (*N* = 6)	65.33	19.14
Daily Living Skills	Low (*N* = 6)	82.17	12.30
	Medium (*N* = 5)	71.80	20.18
	High (*N* = 6)	74.00	13.76
Socialization	Low (*N* = 6)	82.67	13.56
	Medium (*N* = 5)	77.20	19.20
	High (*N* = 6)	76.33	14.81

Note. *N* = 17. VABS-3 = Vineland Adaptive Behavior Scales, Third Edition; MLE-O = Major Life Events- Occurrences.

The high, medium, and low MLE-O subgroups did not differ from each other on Adaptive Behavior Composite, or the VABS-3 domain scores $F(12,26) = .837$, $p = .623$; Wilks' $\Lambda = .430$; partial $\eta^2 = .245$, nor on any specific summary score (see Table 7).

Table 7

MANOVA Comparing VABS-3 Domain Scores from High, Medium, and Low MLE-O Subgroups

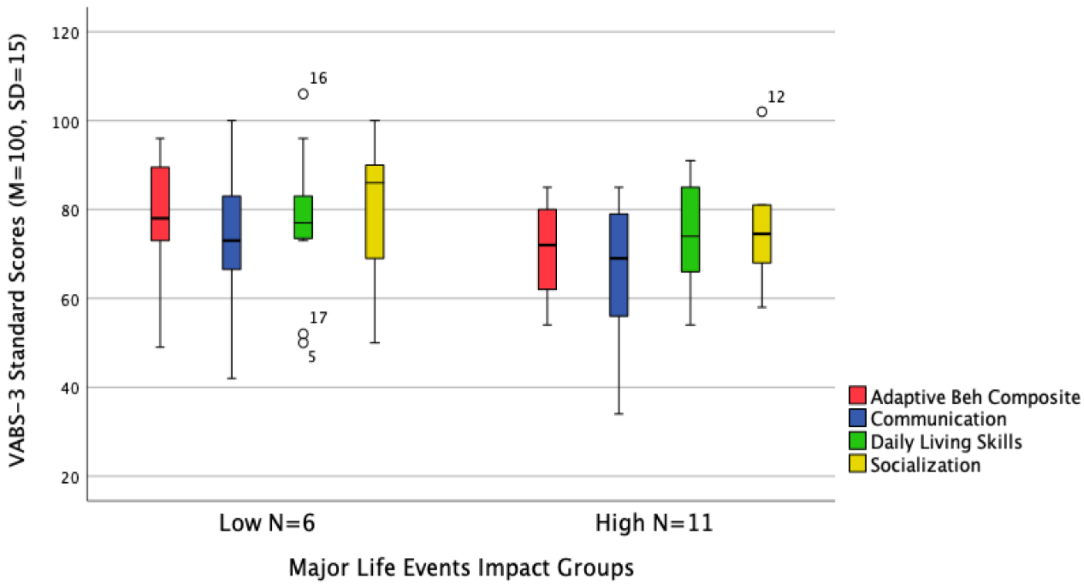
Variables	*df*	*F*	*p*	*ηp2*
Major Life Events- Occurrences				
Communication	2	1.07	.317	.067
Daily Living Skills	2	.192	.668	.013
Socialization	2	.241	.630	.016

Note. *N* = 17. MANOVA = multivariate analysis of variance; VABS-3 = Vineland Adaptive Behavior Scales, Third Edition; MLE-O = Major Life Events- Occurrences.

In order to use MLE-I as a factor, subsamples were defined based on MLE-I scores: high range = 0 to 3 (*N* = 6) and low range = 3 to 9 (*N* = 11). VABS-3 summary score distributions for each MLE-I subgroup are visually represented via boxplots in Figure 2).

Figure 2

Boxplot for VABS-3 Summary Scores for High and Low MLE-Impact Subgroups



Note. *N* = 17. VABS-3 = Vineland Adaptive Behavior Scales, Third Edition; MLE = Major Life Events. Boxplots show the second and third quartiles divided by the sample mean, with whiskers showing the full range (excluding outliers).

VABS-3 scores were normally distributed, as assessed by Shapiro-Wilk's test ($p > .05$; see Table 8)

Table 8

Descriptive Statistics for MLE-I High and Low MANOVA Groups

Variables	Groups	*M*	*SD*
Adaptive Behavior Composite	Low (*N* = 11)	79	13.57
	High (*N* = 6)	70.8	12.01
Communication	Low (*N* = 11)	74.18	15.58
	High (*N* = 6)	65.33	19.14
Daily Living Skills	Low (*N* = 11)	71.06	16.37
	High (*N* = 6)	74	13.76
Socialization	Low (*N* = 11)	80.18	15.73
	High (*N* = 6)	76.33	14.81

Note. *N* = 17. MLE-I = Major Life Events-Impact; MANOVA = multivariate analysis of variance.

The High and Low MLE-I subgroups did not differ on a MANOVA with VABS-3 domain scores, F (4,12) = .672, p =.624; Wilks' Λ =.817; partial η^2 = .183. A moderate effect size was observed in the VABS-3 Communication domain and MLE-I scores (see Table 9). Hypothesis 2B is partially supported.

Table 9

MANOVA Comparing VABS-3 Domain Scores from High and Low MLE-I Subgroups

Variables	*df*	*F*	*p*	*ηp2*
Communication	1	3.45	.049	.443
Daily Living Skills	1	1.89	.183	.302
Socialization	1	1.11	.381	.204

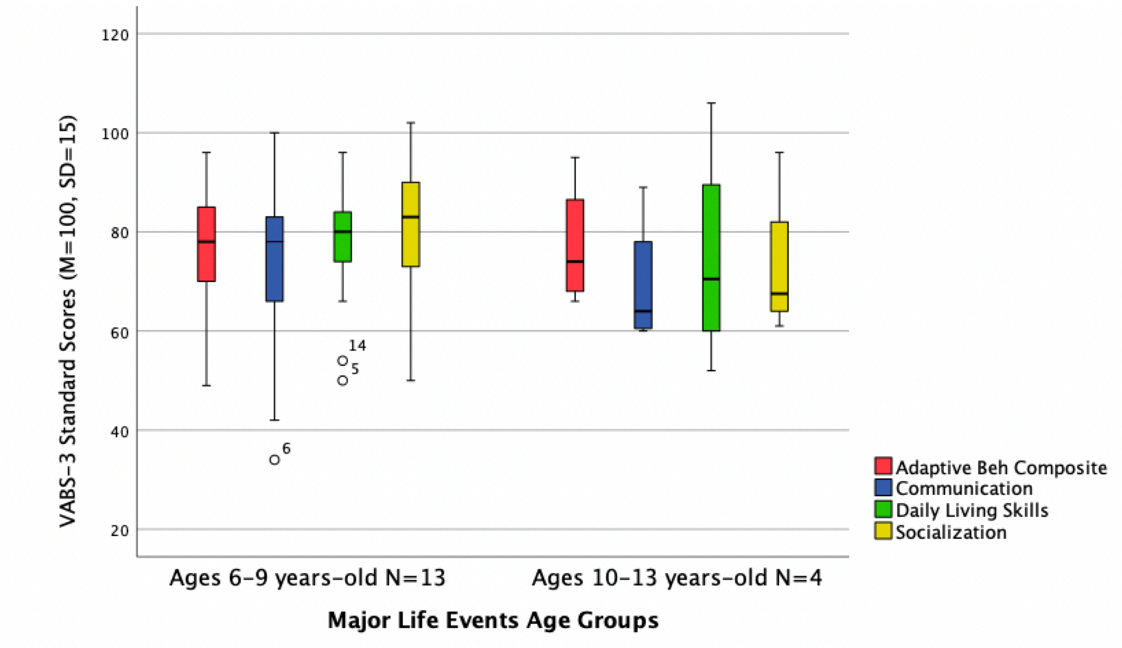
Note. *N* = 17. MANOVA = multivariate analysis of variance, VABS-3 = Vineland Adaptive Behavior Scales, Third Edition; MLE = Major Life Events

Hypothesis 2C: Comparison Between VABS-3 and Age for MLE Sample

For hypothesis 2C, the subsample was further divided into two fixed factor groups comprised of participants ages 6–9-years (*n* = 13, *M* age = 6.53 +/- 0.97) and 10–13 years (*n* = 4, *M* age = 11.5 +/- 1.00; see Table 10).

Figure 3

Boxplot of VABS-3 and Age Groups for MLE Sample



Note. $N = 17$. VABS-3 = Vineland Adaptive Behavior Scales, Third Edition; MLE = Major Life Events. The figure above offers a visual representation of age groups (6–9 years-old and 10–13-years-old respectively) and each groups score disruption across the VABS-3 domains (Communication, Daily Living Skills, Socialization) and Adaptive Behavior Composite. Variability across scores and outliers in groups are visually represented above to demonstrate flow of the variables across group. VABS-3 domain and composite scores were normally distributed, as assessed by Shapiro-Wilk's test ($p > .05$ see Table 10).

Table 10

Descriptive Statistics for Age Group MANOVA

Variables	Age groups by years	*M*	*SD*
Adaptive Behavior Composite	6–9-years-old ($N = 13$)	75.77	13.91
	10–13-years-old ($N = 4$)	77.52	12.84
Communication	6–9-years-old ($N = 13$)	71.62	18.25
	10–13-years-old ($N = 4$)	69.25	13.53
Daily Living Skills	6–9-years-old ($N = 13$)	76.69	13.28
	10–13-years-old ($N = 4$)	74.75	22.68
Socialization	6–9-years-old ($N = 13$)	80.62	15.05
	10–13-years-old ($N = 4$)	73.00	15.64

Note. $N = 17$. MANOVA = multivariate analysis of variance.

The differences between age on the combined dependent variables was not statistically significant, $F(4, 12) = 1.180$, $p = .368$; Wilks' $\Lambda = .718$; partial $\eta 2 = .282$. Hypothesis 2C is not supported (see Table 11).

Table 11

MANOVA of VABS-3 Domain and Total Score for Age Groups

Variables	*df*	*F*	*p*	*ηp2*
Adaptive Behavior Composite	1	.036	.853	.002
Communication	1	.056	.815	.004
Daily Living Skills	1	.047	.831	.003
Socialization	1	.771	.394	.049

Note. *N* = 17; MANOVA = multivariate analysis of variance; VABS-3 = Vineland Adaptive Behavior Scales Third Edition.

Hypothesis 3: Association between Adaptive Behaviors and Restrictions Due to COVID-19

For Hypothesis 3, analyses included VABS-3 and COVID-19 Questionnaire responses from 14 participants who completed both questionnaires. VABS-3 summary scores in this subsample were consistent with values in the full sample (see Table 12 for VABS-3 group statistics in this subsample and *t*-test comparison with a normal distribution).

Table 12

Descriptive Statistics for VABS-3 Scores from Hypothesis 3 Subsample and Bootstrapped t*-test Comparison to Mean of Normal Distribution*

Domain	*M* (*SD*)	*t*-value	*df*	*p*	95% CI	Cohen's *d*
Adaptive Behavior Composite	74.64 (15.59)	-6.09	13	< 0.001	-33.43, -17.500	15.59
Communication	68.00 (20.36)	-5.88	13	< 0.001	-42.28, -21.93	20.36
Daily Living Skills	76.71 (14.92)	-5.84	13	< 0.001	-31.21, -15.86	14.92
Socialization	77.43 (16.35)	-5.17	13	< 0.001	-30.93, -14.30	16.35

Note. *N* = 14. VABS-3 = Vineland Adaptive Behavior Scales, Third Edition; CI = confidence interval.

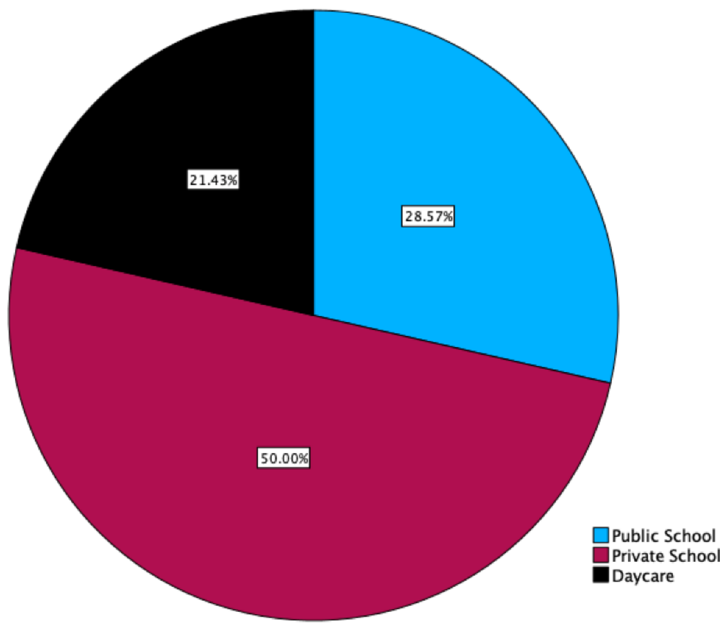
Hypothesis 3A: COVID-19 Questionnaire Response Data

Data derived from the COVID-19 questionnaire were extrapolated and utilized to provide demographic and categorical information, to evaluate aspects of change related to the pandemic. Responses were totaled to reflect the percentage of parents who endorsed change or adjustment as a direct result of the pandemic. Given the number of items on the questionnaire, select questions were chosen to be evaluated and not the entire questionnaire. Following the COVID-19 pandemic being named a health crisis, 71.4% of the sample evaluated reported that their education was received via an online platform (i.e., Zoom, Google Classroom, or other).

Based on the total responses collected from the COVID-19 parents 28.6% of the sample were in first grade at the start of the pandemic. Of the education responses collected, 50% of the sample endorsed that they participated in private education 6 months prior to the pandemic (see Figure 4).

Figure 4

Type of Education 6 Months Prior to COVID-19

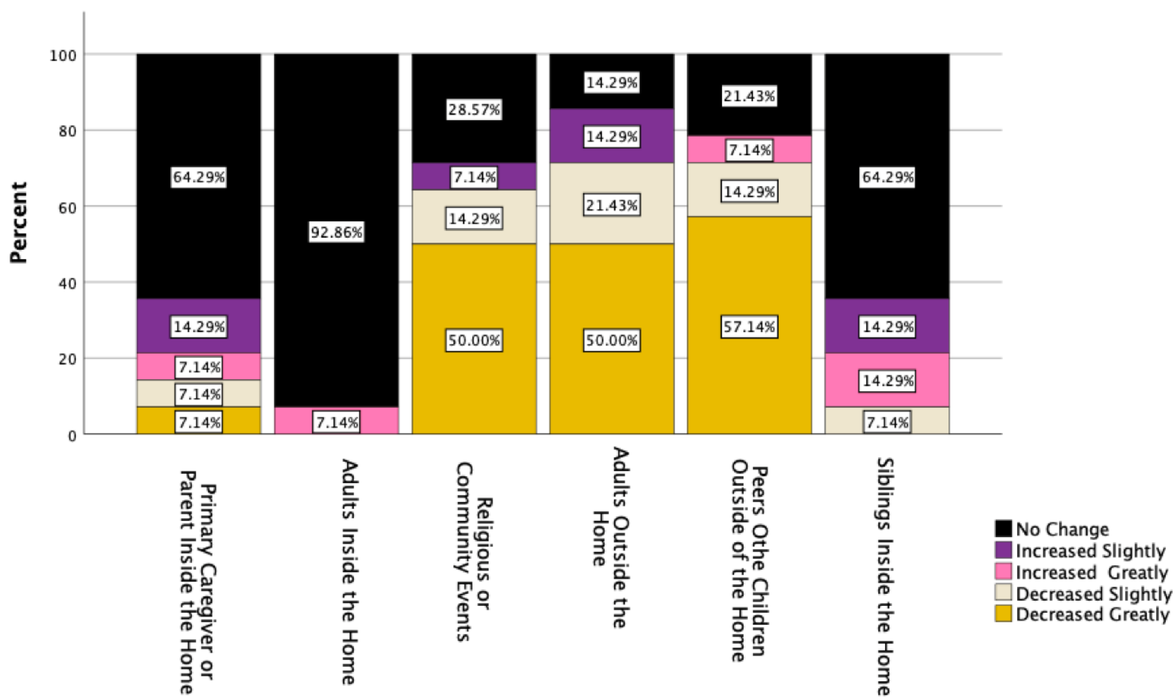


Note. Parents were asked to report on the type of education their child received prior to the pandemic. Of the sample selected 50% reported that their child participated in private school, with 28.57% engaging in public school, and 21.43% engaging in daycare and had not begun to receive formal education.

Parents were asked about changes in their child's opportunity for social interaction both inside and outside of the home, with 50% reporting that their child's ability to interact with other adults outside of the home had "decreased greatly." When asked about changes in their child's ability to interact with other children outside of the home 57.14% reported that interactions had "decreased greatly." Additional questions regarding a decrease in attendance of community events commonly attended prior to COVID-19, with 50% reporting that attendance of these had also "decreased greatly" (see Figure 5).

Figure 5

Bar Graph Representing Parent Responses to Items Assessing Social Interaction Opportunities

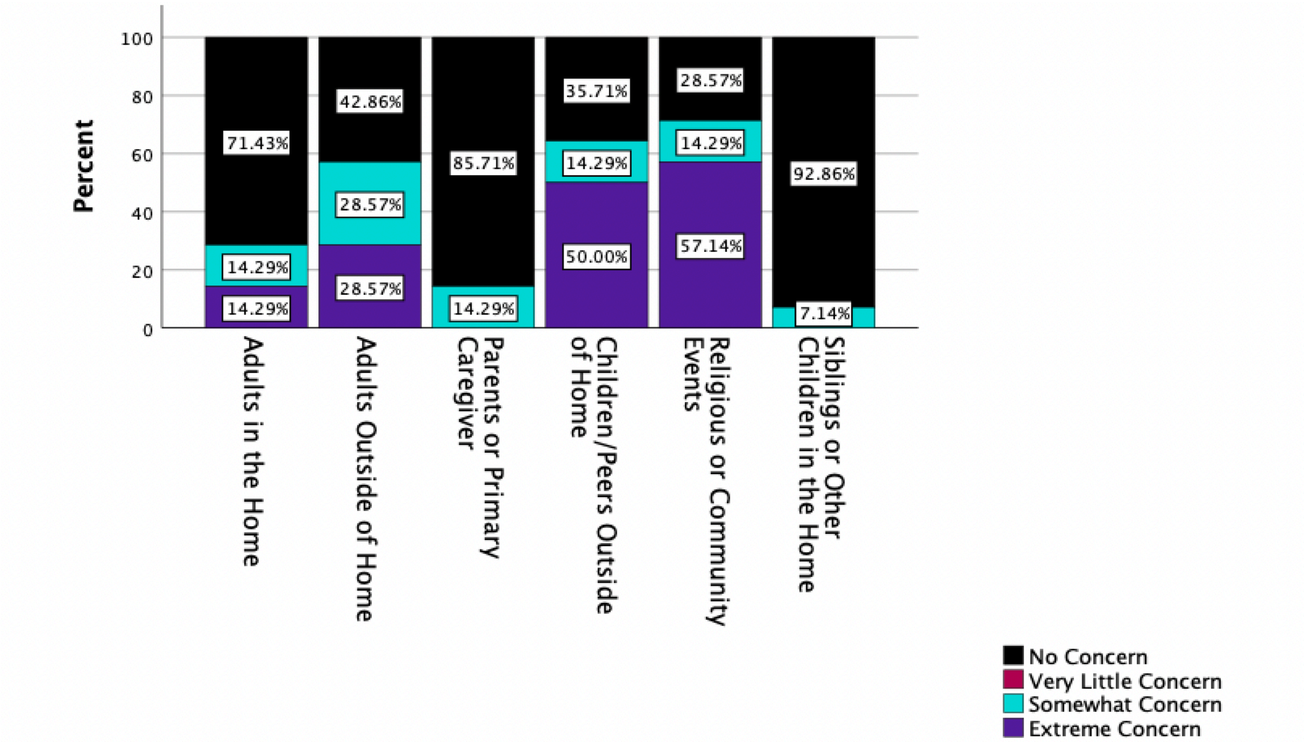


Note. The figure above provides a percentage of responses for each question regarding opportunities for their child to interact with the following groups across six different questions. From left to right parents responded to items regarding opportunities for interaction with primary caregivers or parents inside the home, other adults in the home, engagement in community or religious events, adults outside of the home, children or peers outside of the home, and sibling or other children living in the home.

Follow-up questions regarding the level of concern parents experienced regarding changes in social interaction outside of the home (see Figure 6).

Figure 6

Bar Graph Representing Parent Responses to Items Assessing Concern for Social Interaction



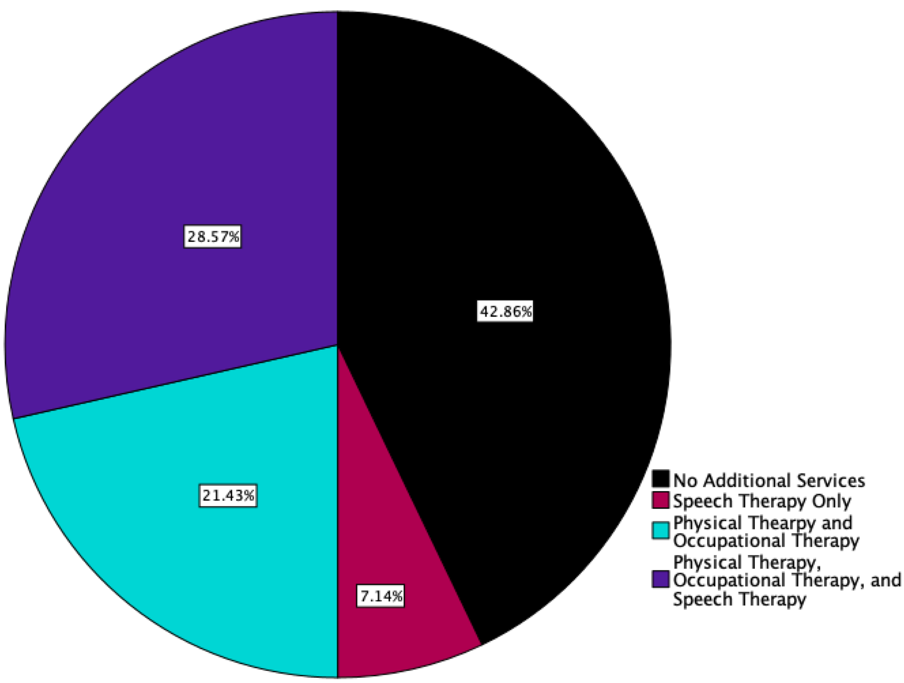
Note. The figure above provides a percentage of responses for each question regarding concern for reduced interaction across six different questions. From left to right parents responded to items regarding concern for reduced interaction with other adults in the home, adults outside of the home, parents/caregivers, children or peers outside of the home, engagement in community or religious events, and sibling or other children living in the home.

Of the sample 42% of parents denied concern for changes in their child's ability to interact with other adults outside of the home. On the question inquiring about changes in their child's interaction with other children outside of the home, 28.5% of parents reported “somewhat” and 35.7% of caregivers endorsing “extreme” concern. When asked about concern for decreased community interaction, 35.7% reported “somewhat” and 21.4% indicated “extreme” concern.

Information was also collected on whether their child participated in specialty care services during COVID-19. Families were asked if their child engaged in either physical therapy, occupational therapy, speech therapy, vison therapy and psychological therapy (see Figure 7).

Figure 7

Percentage of Sample Participating in Specialty Care

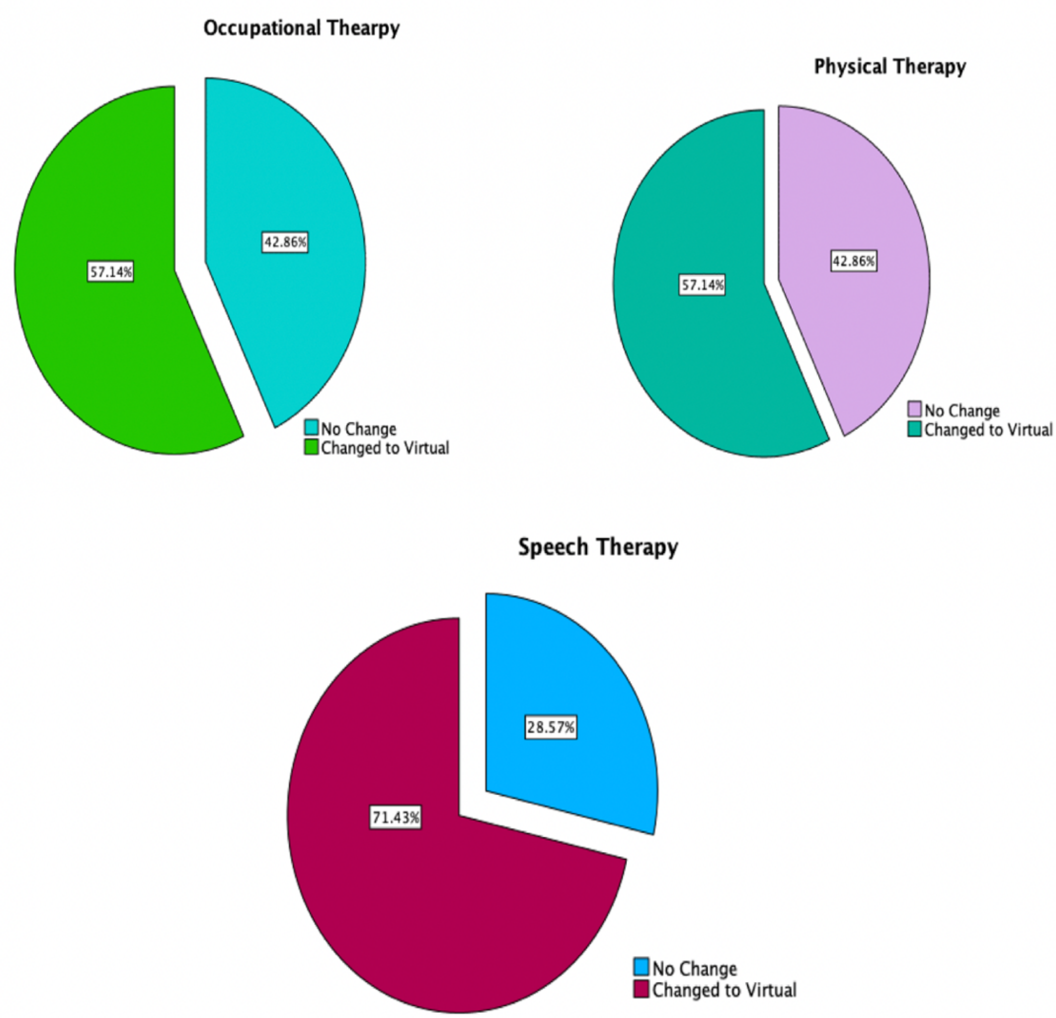


Note. The figure above provides a visual breakdown of specialty care participation across the sample assessed. Notably, no one in this sample endorsed that their child participated in vision therapy or psychological therapy. Additionally, a high proportion of children received a combination of services, which is represented in the chart.

Parents were also asked about changes related to how these services were accessed during the pandemic. Specifically, parents were asked if the format of their child's sessions were changed from in-person to virtual due to concerns surrounding the COVID-19 pandemic. For the total of Parents who reported to be receiving these services, percentages were calculated to demonstrate the proportion of families who experienced change in their access of the aforementioned services (see Figure 8).

Figure 8

Percentage of Change from in-person to Virtual Across Different Specialty Care Supports

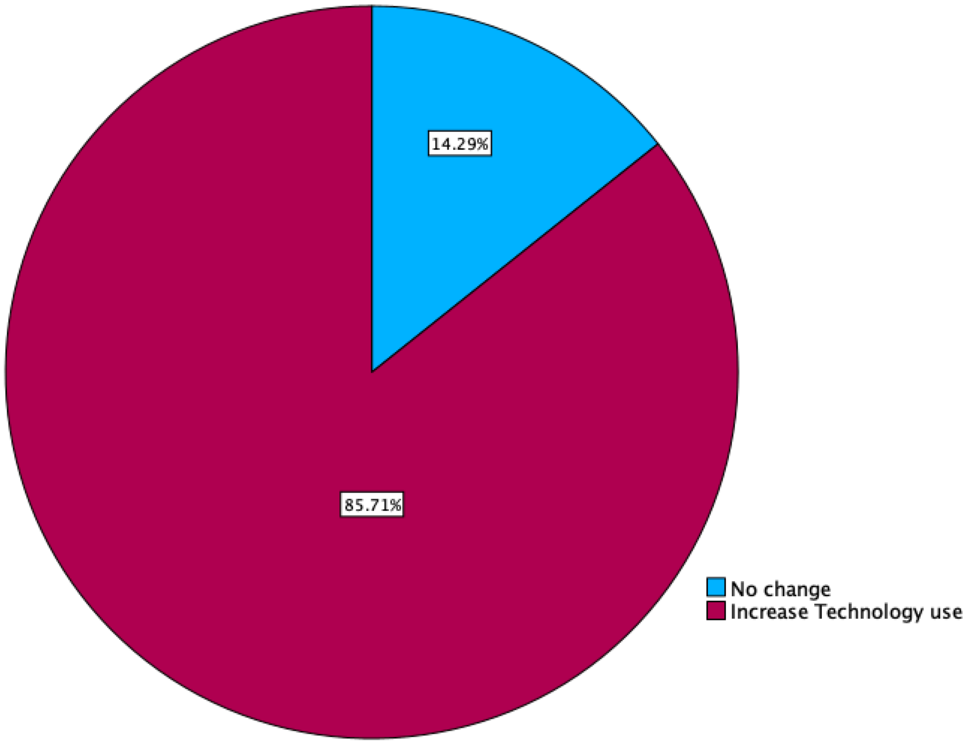


Note. Totals for each therapeutic services are represented above and show the percentage of families who had changes in their access to the following services, physical therapy (57.1%), occupational therapy (57.1%), and speech therapy (71.4%) during COVID-19.

In terms of technology usage, 85.7% of parents indicated that their child's technology use increased during the pandemic (see Figure 9).

Figure 9

Percentage of Technology use During COVID-19



Note. Parents were asked to report on their child's technology use during COVID-19 compared to 6 months prior to the pandemic. The figure above shows the percentage of parents who reported that their child's technology use increased compared to parents who reported no change in the amount of technology use.

Parents were asked if they had taken on any additional parenting responsibilities and/or roles because of the pandemic, with an equal split response of 50% indicating "yes", and the other half reporting "no change" during the pandemic.

Hypothesis 3A was partially supported, with identified changes in education format, in-person interactions outside of the home with adults outside of the home, format/access of specialty care services, and technology use compared to 6 months prior to the pandemic.

Hypothesis 3B: Association Between Adaptive Behavior and Changes in Parent Responsibilities during COVID-19 Pandemic

I hypothesized that parent responses to the COVID-19 questionnaire would demonstrate a significant negative relationship between increased parenting responsibilities (as assessed by parents' agreement by stating "yes" to the following question: "Since April 2020 have you taken on additional parenting responsibilities and/or roles as a result of the pandemic?") and VABS-3 domain scores (Communication, Daily Living Skills, Socialization) and Adaptive Behavior Composite. Results of this Spearman rho revealed a negative correlation between VABS-3 Adaptive Behavior Composite, Daily Living Skills, and Socialization scores (see Table 13). Hypothesis 3B was supported. Parents were also asked to describe how their role as a parent has changed (see Appendix C for a list of responses provided by each parent).

Table 13

Spearman rho Correlation of VABS-3 and COVID-19 Parent Responsibility

Variables	Change in Parent Responsibilities Rho Values
Adaptive Behavior Composite	**-.640***
Communication	-.284
Daily Living Skills	**-.639***
Socialization	**-.588***

Note. $N = 14$; VABS-3 = Vineland Adaptive Behavior Scales, Third Edition.

$^{*}p < .05$, $^{**}p < .01$.

Hypothesis 3C: COVID-19 Questionnaire Response Data

Socialization domain scores were not significantly correlated with COVID-19 variables regarding in-person opportunities and concern for social interaction and involvement outside of the home. However, there was a positive correlation with Socialization and delivery of education. As expected, many of the items from the COVID-19 questionnaire were significantly related indicating a strong relatedness across COVID-19 variables (see Table 14). The hypothesis was not supported as the direction was positive rather than negative.

Table 14

Spearman rho Correlation of VABS-3 Socialization and COVID-19 Variables

Variables	DE	OCOH-A	COH-C	OCE	C-AI	C-CI	C-CE	CAI	CCI	CCE
					RHO Values					
SOC	**.631***	-.051	-.022	-.237	.376	.129	.156	.478	.090	.159
DE		.194	.055	-.050	.456	.347	.163	**.554***	.172	-.128
OCOH-A			**.782****	**.645***	-.374	-.343	-.369	-.110	-.389	-.328
OCOH-C				.440	-.365	-.517	-.382	-.258	-.497	-.140
OCE					.041	.102	.122	.341	.215	.256
C-AI						**.853****	**.862****	**.863****	**.754****	**.600***
C-CI							**.868****	**.800****	**.821****	**.579***
C-CE								**.708****	**.627***	**.761****
CAI									**.797****	**.618****
CCI										**.603****
CCE										

Note. *N* = 14. VABS-3 = Vineland Adaptive Behavior Scales, Third Edition; SOC = Socialization; DE = Delivery of Education; OCOH-A = Opportunity for Contact Outside of Home-Adults; COH-C = Opportunity for Contact Outside of Home- Children; OCE = Opportunity to Attend Community Events; C-AI = Concern-Adult Interaction; C-CI = Concern-Child Interaction; C-CE Concern-Community Events; CAI = Changed Adult Interaction; CCI = Changed Child Interaction; CCE = Changed Community Events.

$*p < .05$, $**p < .01$

Hypothesis 4: VABS-3, MLE, and COVID-19 Sample Comparison

To evaluate parent responses who completed all three forms (VABS-3, MLE, and COVID-19) a total of 11 participants were included in statistical analyses (see Table 5). A total of 11 parents completed all three forms (VABS-3, MLE, COVID-19 questionnaire; see Appendix 1C for comparison of VABS-3 results to the normative sample).

A Spearman rho correlation was completed to evaluate the relationship between MLE-O and MLE-I groups and specific COVID-19 questionnaire responses compared to VABS-3 age- and sex-corrected standard scores (Table 15). The analyses revealed significant correlations between VABS-3 Adaptive Behavior Composite and Communication domain scores and parent reports on the MLE-I. VABS-3 Adaptive Behavior Composite and Socialization domain scores were negatively correlated with COVID-19 Change in Parent Responsibilities questionnaire. Therefore, hypothesis 4 was partially supported.

A significant positive correlation was observed between MLE -I and -MLE-O scores. Significant negative correlations were also observed between the COVID-19 questionnaire and MLE-I or MLE-O variables. Across the COVID-19 questionnaire there were several significant correlations across variables.

Table 15

Spearman rho Correlation of VABS-3, MLE, and COVID-19 Variables

	ABC (1)	COM (2)	DLS (3)	SOC (4)	MLE-O (5)	MLE-I (6)	COH-A (7)	COH-C (8)	OCE (9)	C-AI (10)	C-CI (11)	C-CE (12)	CAI (13)	CCI (14)	CCE (15)	CPR (16)
	RHO Values															
1		**.947****	**.862****	**.939****	-.277	**-.424***	.195	.089	-.249	.121	-.112	.076	.112	.035	-.104	**-.402***
2			**.767****	**.849****	-.266	**-.467***	.185	-.121	-.333	-.324	-.126	.041	.388	-.055	-.149	-.292
3				**.881****	-.001	-.190	.222	.090	.071	-.232	.364	.148	.133	.297	-.046	-.300
4					-.245	-.324	.161	.113	-.029	-.221	.352	.166	.221	.101	-.037	**-.411***
5						**.895****	**-.418***	**-.624***	.039	.306	.295	.171	.222	**-.481***	-.150	.311
6							**-.634***	**-.586***	-.150	.146	.164	.056	-.025	.360	-.117	.397
7								**.671***	**.516***	-.184	-.214	-.229	.231	-.307	-.306	.397
8									.241	-.275	**-.435***	-.342	-.276	-.457	-.172	-.289
9										.225	.287	.370	**.479***	**.495***	**.401***	**-.430***
10											**.866****	**.783****	**.836****	**.818****	**.513***	-.149
11												**.892****	**.792****	**.870****	**.615***	**-.402***
12													**.708***	**.828****	**.851****	-.419
13														**.853****	.580	-.214
14															**.705***	-.155
15																-.281
16																

Note. N = 11; VABS-3 = Vineland Adaptive Behavior Scales Third Edition; MLE = Major Life Events; ABC = Adaptive Behavior Composite; COM = Communication; DLS= Daily Living Skills; SOC = Socialization; MLE-O = Major Life Events- Occurrences; MLE-I= Major Life Events- Impact; COH-A = Opportunity for Contact Outside of Home-Adults; COH-C = Opportunity for Contact Outside of Home- Children; OCE = Opportunity to Attend Community Events; C-AI = Concern-Adult Interaction; C-CI = Concern-Child Interaction; C-CE Concern-Community Events; CAI = Changed Adult Interaction; CCI = Changed Child Interaction; CCE = Changed Community Events; CPR = Change in Parent Responsibilities.

$*p < .05$, $**p < .01$

Chapter 4

Discussion

There is no road map to parenting, let alone a guide for how to navigate unprecedent life events occurring within the context of the COVID-19 pandemic. Children and families that experienced substantial disruption to their usual access to medical or specialty care services, delivery of education, social interaction, community involvement, and changes in parent responsibility related to COVID-19 are likely were purported to experience both immediate and indirect long-term effects of the pandemic (Zhou et al., 2023). Therefore, evaluation of the potential adverse effects on children's and adolescent's development may be underrepresented. When accounting for these considerations in a population of children and adolescents with AgCC, who are more likely to demonstrate developmental delays compared to neurotypical individuals, these disparities and impacts may be more apparent (Eddy, 2022)

Therefore, COVID-19 related impacts, coupled with the effects of family distress related to MLEs, is an important area of consideration when evaluating developmental functioning in children and adolescents with AgCC. The present study contributes to the AgCC literature by providing novel information regarding developmental achievement, parent/caregiver- reported life events and their impacts, and COVID-19 related change during an acute time period of the pandemic. In support of the studies hypotheses, parent reported adaptive development in individuals with AgCC was significantly below the normative population across all domains on the VABS-3 (Communication, Socialization, Daily Living Skills, and Adaptive Behavior Composite). Results revealed that the degree to which parents felt they were impacted by the MLEs they endorsed, also resulted in lower-than-expected delays in the communication development on the VABS-3. Child and family vulnerabilities, as well as lifestyle changes imposed by the COVID-19 pandemic, were also elevated across this sample. Overall, the results of this study further evidence the idea that parent perceived stress of MLEs, COVID-19 related change are intrinsically connected to developmental outcomes and progress in a sample of children and adolescents with AgCC. Furthermore, other factors such as cultural expectations, interpretation of mastery of skills, and education are all confounding variables that may also account for the results of this study revealing delays across all developmental areas assessed.

Developmental Progress in Children and Adolescents with AgCC

In support of the studies hypothesis and consistent with prior literature, children and adolescence with complete and partial AgCC demonstrated a higher proportion of delays across all major developmental domains (Communication, Socialization, Daily Living Skills, Adaptive Behavior Composite) when compared to neurotypical individuals (Eddy, 2022). These findings were observed even when bootstrapping was applied to statistical analyses. Given that developmental trajectories, daily skill acquisition, and long-term outcomes in children and adolescents with congenital brain malformation have not been well understood, this study offers information regard development at a single time-point. These outcomes are also consistent with prior literature postulating that reduced interhemispheric transfer of information, decreased processing speed, along with diminished complex problem solving, may manifest in the form of secondary developmental and functional impairments (Brown & Paul, 2019; Mangum et al., 2021; Miller et al., 2018).

As cognitive skills play a large role in a person’s ability to successful execute daily demands, a deficit in one or more domain (i.e., processing speed, complex problem solving, reduced interhemispheric transmission; Brown & Paul, 2019), likely places an individual at risk for secondary functional impairments, which could account for the results observed in this study.

Further it appears that each of the core developmental domains are intertwined, such that delayed acquisition of communication skills can impact both socialization and daily living skills. Cognitive skills also play a role in a person's ability to successfully execute each of these functional tasks quickly and efficiently. For instance, reduced processing speed, is likely to have global impacts on language acquisition and communication abilities, daily living skill abilities (i.e., taking longer to understand and complete tasks), and socialization skills (e.g., unable to understand quick or subtle changes). For instance, Symington et al. (2010) found that individuals with AgCC displayed substantial deficits in social understanding especially when stimuli involve real-time comprehension/processing of social situations, multisensory discernment, and cognitive integration. Similarly, Paul et al. (2014) identified social communication to be a significant area of challenge for those with AgCC, which may account for the results observed in this study. Purportedly, it is not that those with AgCC are unable to execute these skills, however it is possible that their ability to learn and/or maintain these skills requires a higher level of repetition, support, and hands on demonstration beyond what is typically seen in neurotypical individuals.

Major Life Events

I hypothesized that for the MLE and VABS-3 sample, parent reported MLE-O and –MLE-I scores would demonstrate a reciprocal negative relationship with the developmental domains on the VABS-3. In partial support of this hypothesis, moderately strong negative relationships were seen between parent perceived impact (i.e., degree to which the event was rated as upsetting/distressing) and developmental functioning in Communication and Adaptive Behavior Composite. Additional analyses assessing interactions across MLE variables revealed a moderate interaction between MLE-I and VABS-3 Communication scores. Together, these results evidence that perceived impact of MLEs effects parent rating of developmental functioning. Alternatively, interactions across MLE-O (i.e., the number of MLEs to have occurred over the span of 12 months) scores and VABS-3 developmental domains was not identified. In this study MLE occurrences were assessed categorically with a checklist of pre-determined events. Many researchers have criticized this approach because very different MLEs can fall into the same checklist category and a categorical approach often does not fully account for interindividual differences or perceptions of MLEs (Dohrenwend, 2006; Luhmann et al., 2020; Redfield & Stone, 1979). These findings could explain why MLE-I scores (i.e., perception of events) were related to development instead of MLE-O. Especially given that prior research has observed similar relationship between parent perception of stress and child adaptive development (Fitzgerald et al., 2002; Luhmann et al., 2020; Perrig-Chiello et al., 2016) instead of single occurrence of stressful events (Beck et al., 2004; Lecavalier et al., 2006; Lazarus & Folkman, 1984; Kanner et al., 1981). Together, these results evidence the need for continuing to assess parent perception and felt impact of the MLEs in parents of children with AgCC in order to track and understand the extent to which these variables influence developmental progress.

Changes Imposed by COVID-19

Given that children and adolescents with AgCC are already at risk of demonstrating adaptive delays, any events that impact access to services designed to improve development are likely to also have cascading effects. I hypothesized that responses on the COVID-19 questionnaire would reveal significant changes in the areas of education, access to services, social interaction, technology use, and parent responsibilities/roles compared to the 6 months prior to the pandemic. Education changed were some of the most noteworthy areas wherein children and families were impacted. Compared to the United Sates National Center for Education Statistics 2020, the sample in this study contained a higher portion of children in private education, with 50% of the sample being enrolled in private school (National Center for Education Statistics, 2023). In this study, 71.4% of participants reported that their child's education platform was changed from in-person to distance virtual learning (i.e., Zoom, Google Classroom, or another online platform) at the start of the pandemic in April 2020. These results are consistent with several other studies documenting universal education related changes, from in-person to remote learning (Zhou, et al., 2023; Yildiz, et al., 2023; Naqvi & Sahu, 2020).

Due to education changes, I hypothesized that parents would take on additional responsibilities and roles, which would be negatively correlated with VABS-3 domain scores (Communication, Daily Living, Socialization) and total Adaptive Behavior Composite. On the COVID-19 questionnaire parents were asked whether they had to take on any additional roles as a result of the pandemic. Half of the sample were in agreement that their role had shifted. Parents were asked to elaborate as to why their responsibilities had changed, with most parents identifying distance learning and needing to support their child's education as being a common reason. This hypothesis was partially supported, given that changes in parent responsibilities were negatively correlated with all domains except for Communication. These results indicate a significant relationship exists between development and parent responsibilities. It is suspected that as parents spend more time at home due to due to taking on additional roles (e.g., supporting their child's education and learning directly due to online learning at home) that difficulties in developmental progress became more apparent. One study evaluating parents during COVID-19 observed this phenomenon, with parents indicating that they were more aware of their child's deficits with increased time at home (Shahali et al., 2023). Additional studies specifically with parents of children with a disability during COVID-19, found that theses caregivers were more likely to experience reduced mental and physical health, limited and modified access to certain services, and reduction of social supports for some parents of children with disabilities (Chung et al., 2023: Richard et al., 2023; Dillmann et al., 2022).

Parents also reported change in their access to specialty care services (physical therapy, occupational therapy, and speech therapy). Over half of the sample in this study reported that their child was enrolled in a single service (speech therapy). However, many of the families in this study reported that they either participated in two or three intervention services. Similar to education adjustments, over half of the families who were engaged in one or more of the aforementioned intervention services reported that their services were changed to a virtual telehealth format. Given the importance of children with AgCC engaging in early intervention services, these findings are notable and could have lasting effects long-term effects on development depending on the quality of these remote based services. One study evaluating children and families with disabilities reported that prior to COVID-19 children were receiving a greater number of services (Allison & Levac, 2022; Kaur et al., 2022; Pinkerton et al., 2022). In this study over 40% of parents felt that their child demonstrated developmental declines, with them attributing these declines in motor, behavior, social, and communication acquisition to teletherapy service delivery (Allison & Levac, 2022). Although this study did not directly assess quality of service delivery, given the findings from other studies, coupled with the importance of intervention in this population, long-term effects of COVID-19 related service access should be considered when evaluating delayed developmental progress in this population.

Given the implications of reduced social interaction due to stay-at-home orders encouraged by the Centers for Disease Control (CDC) I hypothesized that parent reported social interaction scores would be negatively correlated with VABS-3 Socialization domain scores. This hypothesis was not supported, given that an inverse relationship was observed with delivery of education being positively related to VABS-3 Socialization. Although the pandemic occurred universally, different countries were impacted at different time points (Coccia, 2021; Webster 2021; Brahma et al., 2020), which could explain why delivery of education was seen as more positive with socialization functioning. Although this hypothesis was not supported, changes in social interaction during COVID-19 were reported. For instance, most of the sample reported that their child has reduced opportunities for participation in community or religious events and also had a reduction in their outside of home interaction with peers and adults. Concern for reduction in these interactions was reported for peer interaction and community involvement. To offset these changes along with education and service delivery being moved to virtual, technology use in this study was also reported to increase. Overall, these results align with other studies identifying loss of peer interaction and participation in events with an uptick in technology use to remain connected, which was also seen in this study (James et al., 2023).

Several studies have documented that children with AgCC begin to show more prominent developmental and social challenges beginning around age 6–11 years old and continuing to be evident as they age (Badaruddin et al., 2007). Given prior literature, I hypothesized that there would be a significant main effect for age, with older children being more likely to demonstrate developmental deficits than younger children. This hypothesis was not supported, likely due to the sample of this study being skewed with having a higher proportion of responses consisting of children ages 6–9 years old.

Altogether, results of this study revealed that individuals with AgCC are more likely to demonstrate developmental delays when compared to normative data and will continue to benefit from continuous intervention to support developmental progress across the lifespan. Further, results involving all three measures observed relationships with parent reported impact MLEs along with several significant areas of change directly tied to the COVID-19 pandemic. Results of this study also demonstrate the need for continued evaluation of environmental factors in order to appropriately identify how children with AgCC and their families were impacted during COVID-19 and whether long-term impacts are present. Further, continuing to explore other significant events that can contribute to reduced access to services is equally important, as these factors seem to be intrinsically connected to development.

Limitations

The present study has several limitations. First, this study is a cohort study with a relatively small sample size largely attributable to the unique population of interest. Additionally, use of a cross-sectional, rather than longitudinal design, also impacts many factors. One major factor is that this design only provides a snapshot of functioning without complete acknowledgement of the many factors that contribute to developmental functioning, which limit determination of causation. Further, due to small sample size, the results of the present study may not be strong enough to be extrapolated to the larger population of individuals with AgCC, although with bootstrapping, we are able to have more confidence in our ability to generalize to the broader population.

As mentioned above the design of this study also limits its generalizability. Given the unprecedented nature of the COVID-19 pandemic and inability to directly compare the results of the present study to pre-pandemic functioning, results of the study may not fully capture or overemphasize the amount of change that occurred secondary to these events. Secondly, the pandemic has also been documented to have impacted various countries at different time periods and levels. This limitation also reduces the generalizability of these results, given that a clear timeline of COVID-19 related impacts was not clearly documented for each participant (e.g., timeframe of different variants, government policies, and access to medical care). Parents also completed the COVID-19 form at different time points between May 2021 to September 2021, which impacts direct comparison given the different time points of when the questionnaire was completed. Although the form asked parents to retrospectively report on their child's school, childcare arrangement, and therapy involvement 3 months prior to COVID-19 outbreak (i.e., December 2019-March 2020) and to also consider possible COVID-19 impacts over the past 6 months prior to completion of this form. Self-reporting bias is a known factor that can arise as a result of several forms of bias including hindsight (e.g., knowledge about an event after it has happened), social desirability (e.g., desire to respond in a way that is positive), and/or selective recall (e.g., distorted or inaccurate recall of past events). Additionally, use of forms with pre-determined multiple-choice items may narrowly or inaccurately capture individual experiences. For example, self-reported answers may be exaggerated or biased by various confounding variables (Treble et al., 2017; Aspland & Gardner, 2003; Hayden et al., 2010; Law & Roy, 2008; Larson et al., 2023).

Further, reliance on parent response versus direct assessment of developmental abilities is also a significant limitation. In part due to the high prevalence of error that is observed anytime parents are asked to rate their children. Although these are standardized measures, parents themselves may have a different understanding of what constitutes developmental success. For instance, parents in this study were asked to consider the extent to which they had observed their child preform various behaviors independently (e.g., read/understand material from a specific grade level or copies appropriate behavior of others when in a new situation). Parents subjective rating may vary based on their own expectations of their child, differing interpretation of mastery, and inability to directly observe certain behaviors to accurately rate performance.

A total of 62 families who qualified for the study were contacted, with only 30 families agreeing to participate in the study. Given that this study required families to devote several hours to completing forms online and answering questions via telephone interview. It is suspected that the families who chose/declined to participate were not able to commit to the time requirements. Alternatively, the families who did not participate may have also been disproportionally impacted by environmental (e.g., COVID-19) and/or personal barriers that made participation in this study difficult for some families. Although this was not directly measured by this study, considering the possible barriers to participation is an important limitation to consider when generalizing the results of this study.

Future Directions

An initial direction would be to conduct a repeat longitudinal study with a larger sample to assess developmental progression of children diagnosed with AgCC at different timeframes across their lifespan. In addition, continuing to evaluate other factors known to impact development, such as access to care/support, environmental changes, family stress, MLEs, and other medical or mental health diagnoses, will also be important to consider when understanding all components that can interfere with development progress overtime. Future studies should also evaluate whether there are long-term impacts of the COVID-19 pandemic.

The VABS-3 developmental domains are highly intertwined, such that if a child is purported to have delays in their acquisition of language, delays in socialization (e.g., using communication to engage with peers) may also be observed. Therefore, in order to distinguish primary from secondary deficits, use of direct assessment of adaptive skill development should be utilized in conjunction with parent report measures to ensure the number of far-reaching interactions present in this population are accurately captured.

As noted in the limitations above, use of multiple-choice questionnaires to assess aspects of stress, development, environmental change, and impact may not fully capture each family's unique experience of having a child/adolescent with a diagnosis of AgCC, how they adjusted to MLEs, or were individually impacted by COVID-19. Therefore, use of open-ended questions designed to allow each family to provide personal responses is recommended to be included in future studies. This design would also allow for other events that were not listed on the questionnaire to be identified. As such, future studies should incorporate a mix of both quantitative and qualitative measures to identify broad themes and individual factors.

Despite AgCC being a relatively common congenital neurological condition, the impact of AgCC classification and future neurocognitive functioning remains highly variable and difficult to predict solely based on neuroimaging. For instance, whether the corpus callosum is classified as completely absent (complete AgCC) or identified as having remnant callosal fibers (partial AgCC) outcomes remain difficult to predict. Although literature has identified isolated AgCC (i.e., without co-occurring medical conditions or accompanying neurological abnormalities) as having more favorable outcomes (Bernardes et al., 2021) another study identified no relationship between additional neurological factors and cognitive abilities (Siffredi et al., 2018). Given this information and small sample size, children with complete and partial AgCC were not separated into separate groups for analyses. However, given the variability in literature, future studies with larger sample sizes should separate complete and partial AgCC groups to assess whether developmental trajectories and behavior phenotype differ depending on callosal malformation.

Conclusion

Results of this present study are consistent with previous literature identifying generalized delays in the development of children and adolescents with AgCC across multiple domains (Communication, Socialization, Daily Living Skills and Adaptive Behavior Composite; Eddy, 2022). Consistent with common cognitive deficits observed in individuals with AgCC (i.e., reduced processing speed, complex reasoning, and problem-solving skills), results of the present study continue to suggest that there is an intrinsic connection between the aforementioned deficits and developmental achievement (Brown & Paul, 2019). This study also evidences the value of addressing MLEs and their felt impact by parents/caregivers, given the relationship observed in this study between level of impact and communication development. Further, attuning to caregiver stress and the areas wherein tension can be moderated for families who have a child with a congenial malformation diagnosis is an additional area specific resources and targeted interventions could be utilized. Secondly, COVID-19 related change was found to span changes in education format, access to intervention services, parent responsibilities, opportunities for social interaction, and concern for reduced interaction in out of home social experiences. Consistent with prior recommendations, the present study continues to evidence the importance of early intervention and access to services to wrap around services designed to ameliorate delayed developmental progress and support long-term impacts of stress and the COVID-19 pandemic. Overall, the current study indicates statistically significant relationships between parent report on the VABS-3, COVID-19 related change, and MLE impact exist. However, future research with greater statistical power is needed to explore the contribution of these factors and the possible long-term outcomes of these events.

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Appendix A

Tables of Different Sample Groups Compared to VABS-3 Standard Scores

An independent-sample *t*-test was run on each group to determine if there were differences in adaptive scores across the four-domains compared to the normative population. Results revealed statistically significant findings, indicating that parents of children with AgCC across the different groups all reported significant adaptive impairment relative to the standard scores on the VABS-3. Therefore, each subgroup was determined to represent similar findings to the entire sample of participants with AgCC. Please refer to the following tables and descriptions to see the results for each group who completed various measures.

A total of 17 participants completed both the VABS-3 and the MLE. The table addresses that the group of participants who completed the VABS and MLE are not different from the entire sample (see Supplemental Table 1).

Supplemental Table 1

T-*test Statistics for VABS-3 and MLE Sample*

Domain	*M* (*SD*)	*t*-value	*df*	*p*	95% CI	Cohen's *d*
Adaptive Behavior Composite***	76.12 (13.28)	-23.88	16	< 0.001	-30.59, -17.35	13.28
Communication***	71.06 (16.89)	-28.94	16	< 0.001	-36.88, -21.12	16.89
Daily Living Skills***	76.24 (15.15)	-23.77	16	< 0.001	-30.70, -16.29	15.15
Socialization***	78.82 (15.06)	-21.176	16	< 0.001	-28.17, -14.35	15.06

Note. VABS-3 = Vineland Adaptive Behavior Scales, Third Edition; MLE =Major Life Events; CI = confidence interval.

***$p < .001$. *Indicates significantly lower than normal population sample.*

A total of 14 participants completed the VABS-3 and COVID-19 measures. Results were aligned with the entire sample revealing overall impairment in adaptive functioning across the entire sample relative to the VABS-3 standard scores (see Supplemental Table 2)

Supplemental Table 2

T-*test Statistics of VABS-3 and COVID-19 Study Sample*

Domain	*M* (*SD*)	*t*-value	*df*	*p*	95% CI	Cohen's *d*
Adaptive Behavior Composite***	74.64 (15.59)	-6.09	13	< 0.001	-33.43, -17.500	15.59
Communication***	68.00 (20.36)	-5.88	13	< 0.001	-42.28, -21.93	20.36
Daily Living Skills***	76.71 (14.92)	-5.84	13	< 0.001	-31.21, -15.86	14.92
Socialization***	77.43 (16.35)	-5.17	13	< 0.001	-30.93, -14.30	16.35

Note. VABS-3 = Vineland Adaptive Behavior Scales, Third Edition; CI = confidence interval.

***$p < .001$. *Indicates significantly lower than normal population sample.*

A total of 11 participants completed the VABS-3, MLE, and COVID-19 measures. Results revealed that this sample also demonstrated significant impairment across VABS-3 domains relative to VABS-3 standard scores (see Supplemental Table 3).

Supplemental Table 3

T-test Statistics for VABS-3, MLE and COVID-19 Sample

Domain	*M* (*SD*)	*t*-value	*df*	*p*	95% CI	Cohen's *d*
Adaptive Behavior Composite***	74.64 (14.69)	-5.73	10	< 0.001	-33.64, -16.82	14.69
Communication***	70.82 (19.61)	-4.94	10	< 0.001	-40.72, -18.18	19.61
Daily Living Skills***	76.27 (12.52)	-6.29	10	< 0.001	-30.73, -16.46	12.52
Socialization***	75.55 (15.51)	-5.23	10	< 0.001	-33.180, -15.64	15.51

Note. VABS-3 = Vineland Adaptive Behavior Scales, Third Edition; MLE = Major Life Events; CI = confidence interval.

****p* < .001. *Indicates significantly lower than normal population sample.*

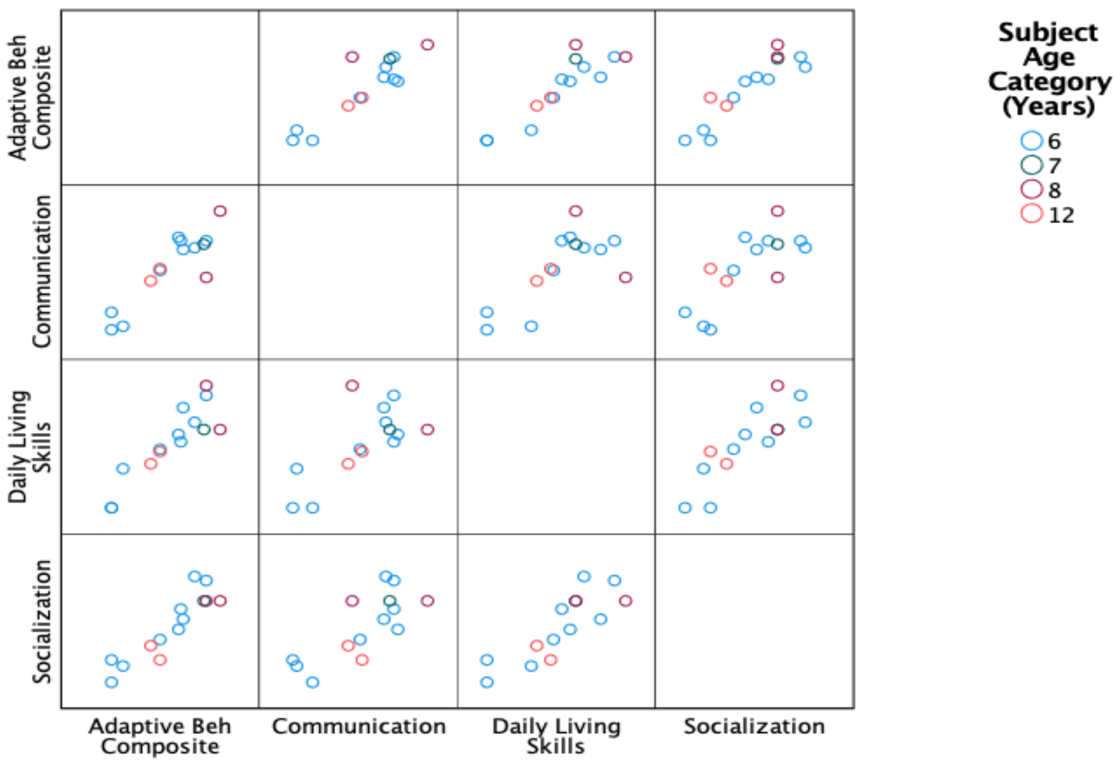
Appendix B

Scatterplot of VABS-3 for Age Groups

The following figure shows the relationship between VABS-3 domains (Communication, Daily Living Skills, and Socialization, and Adaptive Behavior Composite; (See Supplemental Figure 1).

Supplemental Figure 1

Scatterplot of VABS-3 and Age Groups



Note. VABS-3 = Vineland Adaptive Behavior Scales, Third Edition. The figure above provides a visual of age groups and across VABS-3 domains. The visual is intended to demonstrate the cluster of age groups and their scores on the VABS-3

Appendix C

COVID-19 Descriptive Responses About Increased Parent Responsibility

The below figure is a list of descriptive responses from parents who completed the COVID-19 questionnaire and indicated “yes” that their role as a parent had changed due to the pandemic (see Supplemental Table 5).

Supplemental Table 5

Parent Descriptive Responses to COVID-19 Question

1.	Needed to quit work to take care of distance learning for oldest child (non-ACC)
2.	Became her primary educator and therapist, and triaged minor health concerns to avoid hospital.
3.	Home schooling of our oldest child periodically since April 2020.
4.	I had to work so he was with a tutor during the week, and he didn’t get to go out and have play dates so after working all day I would rush home to make dinner pack lunch for the next day. Did not really have any play time with him. I had to review all his online schoolwork. We both struggled.
5.	I started to be also a teacher. I needed to start dealing with much more homework. I teach him to read, write, doing math activities when he has only online teachers. I work at home, study at home. I was also much tired of doing the same activities.
6.	Since he is an only child, my husband and I have been his only playmate. This is hard to do day after day after day.
7.	Providing 1:1 direct academic support while working remotely.

*Note***.** Parent responses to the COVID-19 questionnaire “Please describe how your role as a parent has changed” each person who provided a descriptive response are included in the above table. Each response is taken verbatim from what was written by the parent who completed the COVID-19 questionnaire and elected to provide an elaborative response to the requested question.