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Trajectories of Adaptive Functioning Among Youth with Spina Bifida: The Influence of Neurocognitive Functioning and Parental Scaffolding

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LOYOLA UNIVERSITY CHICAGO

TRAJECTORIES OF ADAPTIVE FUNCTIONING AMONG YOUTH WITH SPINA BIFIDA:
THE INFLUENCE OF NEUROCOGNITIVE FUNCTIONING
AND PARENTAL SCAFFOLDING

A THESIS SUBMITTED TO
THE FACULTY OF THE GRADUATE SCHOOL
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MASTER OF ARTS

PROGRAM IN CLINICAL PSYCHOLOGY

BY
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ABSTRACT

Youth with spina bifida (SB), a congenital birth defect affecting the central nervous system, are at risk of experiencing an array of psychosocial and functional deficits (Copp et al., 2015; Holmbeck et al., 2003). Indeed, previous research has documented difficulties across the three adaptive functioning domains outlined by the American Association on Intellectual and Developmental Disabilities (AAIDD): conceptual (e.g., communication, self-direction, functional academics), social (e.g., interpersonal skills), and practical (e.g., self-care, navigating health-care; Copp et al., 2015). Despite this evidence, whether or not children with SB typically acquire skills across development is largely unknown. Additionally, little is known about risk and protective factors that may influence long-term adaptive functioning outcomes in this population. Therefore, the current study examined (1) trajectories of adaptive functioning in youth with SB as they transitioned from childhood into adolescence, (2) neuropsychological functioning as a potential risk factor for long-term difficulties, and (3) parental scaffolding as a protective factor that may buffer the negative impact of cognitive dysfunction on adaptive functioning.

Participants \((n = 131, M_{\text{age } T1} = 11.26)\) were recruited as part of a larger ongoing longitudinal study (Devine, Holmbeck, Gayes, & Purnell, 2011). The current study included parent report of six adaptive functioning skills across the three AAIDD domains: communication, self-direction, functional academics, social, self-care, and home living skills.
Additionally, youth’s attention and executive functioning (i.e., working memory, planning/organizational skills, cognitive flexibility, inhibition) were assessed via parent- and teacher-report, as well as performance-based assessments. Finally, parental scaffolding was assessed via observational data.

Youth’s communication, self-direction, functional academics, self-care, and home living skills increased over time across age, whereas youth’s social skills did not. Rather than predicting growth in adaptive functioning, better attention and executive functioning predicted a higher intercept for most adaptive functioning abilities at 11.5 years old. Two significant moderation effects emerged, such that maternal scaffolding moderated the association between (1) youth’s planning/organizational abilities and home living skills and (2) youth’s inhibition abilities and functional academics skills.

Results indicate that youth with SB acquire skills across development to better meet the demands of daily life. However, youth with poorer neurocognitive functioning may demonstrate adaptive functioning deficits in early childhood and benefit from timely intervention. Parental scaffolding may be one mechanism for intervention, yet additional research examining the impact of parenting on adaptive functioning is needed in this population.
Spina bifida (SB), a congenital birth defect affecting the central nervous system, occurs in approximately 3 of every 10,000 live births in the United States (Boulet et al., 2008). While advancements in medical care have improved newborn survival rates (McLaughlin et al., 1985), SB continues to have a widespread impact on the well-being of youth. In particular, research has documented notable physical disabilities, neurocognitive deficits, and problems with psychosocial adjustment (Copp et al., 2015; Holmbeck et al., 2003). Mounting evidence also suggests that functional abilities are often compromised in youth with SB, as they display deficits in school performance, social functioning, and managing the demands of daily life compared to their typically developing peers (Copp et al., 2015; Holmbeck et al., 2003). This is concerning as adaptive functioning is linked to overall quality of life (Bier, Prince, Tremont, & Msall, 2005). Despite this evidence, significant gaps remain in the existing literature as it has yet to isolate developmental trajectories of adaptive functioning in youth with SB. Characterizing changes in adaptive functioning over time (i.e., overall increases or decreases), as well as isolating risk and protective factors of such trajectories, is crucial in facilitating the development of targeted interventions in this population.

The American Association on Intellectual and Developmental Disabilities (AAIDD) characterizes adaptive functioning as abilities across three distinct domains: conceptual, practical, and social (Shalock et al., 2010). The conceptual domain includes skills such as
literacy, language, and self-direction, whereas the practical domain includes skills of daily living (e.g., self-care, navigating transportation and health-care; Shalock et al., 2010). Further, the social domain includes skills related to interacting with others, such as social problem solving (Shalock et al., 2010). Previous research in youth with SB has documented deficits in global adaptive functioning (Danzer et al., 2016), as well as difficulties across all three AAIDD domains. For example, multiple studies have found that youth with SB demonstrate difficulties with conceptual skills, such as language comprehension and flexibility, self-direction, and academics, as well as social skills (Coster & Haltiwanger, 2004; Dennis et al., 2006; Holbein et al., 2014; Holmbeck et al., 2003; Taylor, Landry, English, & Barnes, 2010). Research examining practical skills in SB is more limited, but also documents deficits in self-care and home living skills among youth (Andren & Grimby, 2000; Bellin, Sawin, Roux, Buran, & Brei, 2007; Buran, Sawin, Brei, & Fastenau, 2004). A few studies have separately examined changes in the social and conceptual domains of adaptive functioning over time, finding that social and academic deficits in SB are maintained from childhood into adolescence (Dennis et al., 2006; Holmbeck & Devine, 2010; Holmbeck et al., 2010). Apart from these few longitudinal studies, previous research is largely cross-sectional and has yet to characterize changes in all skills areas within the conceptual and practical domains of adaptive functioning over time. Additional longitudinal research is needed to examine adaptive functioning over time across all three AAIDD domains.

Such deficits in adaptive functioning may be partially due to underlying neurocognitive impairments. Though youth with SB demonstrate a complex neuropsychological profile (Brown et al., 2008; Dennis et al., 2006; Rose & Holmbeck, 2007; Wasserman & Holmbeck, 2016), previous research indicates that youth with SB are especially vulnerable to difficulties with
executive functioning and attention, including cognitive rigidity and deficits in working memory, planning, organizing, self-monitoring, and abstract reasoning and sequencing (Brown et al., 2008; Burmeister et al., 2005; Fletcher et al., 1996; Hampton et al., 2011; Rose & Holmbeck, 2007; Tuminello, Holmbeck, & Olson, 2012; Zabel et al., 2011). Given that many adaptive functioning skills depend on higher order cognitive processes, executive functioning and attention deficits may preclude youth with SB from being able to effectively complete certain adaptive functioning tasks. For instance, self-care tasks and participating in social activities both involve planning and organizational skills (Tarazi, Mahone, & Zabel, 2007). Delineating the interplay between cognitive and adaptive functioning across key developmental periods is imperative to identify optimal time points for intervention.

Considering the pervasive impact of SB on youth and their families, it is also crucial to begin isolating modifiable factors that mitigate adaptive functioning deficits in youth with SB. According to social-ecological and systems perspectives, as well as the Ecological Model of Adaptation for Adolescents with SB, parent and family processes may be one promising mechanism for intervention (Heffelfinger et al., 2008; Kazak, Rourke, & Crump, 2003). Previous research in SB supports this notion, documenting a link between effective parenting behaviors (e.g., higher warmth and behavioral control, lower psychological control) and healthy adjustment among youth with SB (Holmbeck, Shapera, & Hommeyer, 2002; O’Hara & Holmbeck, 2013). Given the executive function deficits characteristic of SB, parenting that provides structure and guidance for youth may be a particularly important compensatory process. Indeed, research in the field of developmental psychology indicates that scaffolding, a process through which adults support youth’s learning and ultimately enhance task performance, is linked to better executive functioning, problem-solving, and academic outcomes among typically developing youth.
Despite this evidence, the ability of parental scaffolding to buffer (i.e., moderate) the negative impact of cognitive dysfunction on adaptive functioning has not been examined in the context of SB, necessitating extension of the current literature.

Collectively, the existing literature reveals a need to more comprehensively characterize adaptive functioning among youth with SB, and delineate the influence of risk and protective factors. Thus, the goal of the current study was to isolate developmental trajectories of adaptive functioning (i.e., overall increases or decreases) across all AAIDD domains in youth with SB as they transition into adolescence. Examining the transition from childhood to adolescence is especially important as this is a time when maladaptive pathways may emerge or be altered by protective processes (Cicchetti & Rogosch, 2002). Guided by previous research, neurocognitive functioning and parental scaffolding were also examined as risk and protective factors, respectively. This study addressed limitations of past research by utilizing a longitudinal study design, questionnaire data from multiple informants (mother, father, teacher), performance-based neuropsychological measures, and video-taped family interaction data. The following sections provide an overview of current research on adaptive and neurocognitive functioning in youth with SB, as well as an overview of the current research on parenting in SB and parental scaffolding in typically/atypically developing child populations. Finally, a detailed description of the current study is provided, along with the aims and specific hypotheses.
Time 1
Parental Scaffolding
- Family Interaction Macro-Coding System: Parental Scaffolding (M, F observational data)

Time 1
Youth Neurocognitive Functioning
- Attention
  - SNAP-IV (M, F, T)
  - CBCL/TRF Attention Problems (M, F, T)
  - CAS Number Detection (N)
- Executive Functioning: Working Memory
  - BRIEF Working Memory (M, F, T)
  - WISC Digit Span (N)
- Executive Functioning: Planning and Organizing
  - BRIEF Plan/Organize (M, F, T)
  - BRIEF Organization of Materials (M, F, T)
  - CAS Planned Connections (N)
- Executive Functioning: Cognitive Flexibility
  - BRIEF Shift (M, F, T)
- Executive Functioning: Inhibition
  - BRIEF Inhibit (M, F, T)

Change from Time 1-3
Youth Adaptive Functioning
  - Conceptual Domain: Communication, Self-Direction, Functional Academics skills
  - Social Domain: Social skills
  - Practical Domain: Self-Care and Home Living skills

Note. Informants for each data field denoted by the following letters: M=Mother, F=Father, T=Teacher, N= Neuropsychological Assessment.
CHAPTER TWO

REVIEW OF THE RELEVANT LITERATURE

Adaptive Functioning in Youth with Spina Bifida

Spina bifida (SB) is one of the most complex chronic medical conditions in children, occurring in approximately 3 of every 10,000 births in the United States (Boulet et al., 2008). Resulting from the failed closure of the embryonic neural tube during the first month of pregnancy, SB has significant consequences for the central nervous system (Copp et al., 2015). Fortunately, medical advancements have improved newborn survival rates (McLaughlin et al., 1985), yet SB continues to have a pervasive impact on children and their families. Mounting evidence suggests that SB is associated with significant physical and cognitive impairments (e.g., bladder and bowel incontinence, motor and sensory neurological deficits, hydrocephalus, paralyzed lower extremities; Copp et al., 2015), the severity of which varies based on spinal cord lesion level and neurological complications (e.g., Chiari II malformations resulting in shunt revisions and infections; Copp et al., 2015; Fletcher et al., 2005). Specifically, higher spinal lesion levels and the presence of a shunt are associated with more abnormal brain development, as well as greater cognitive and motor functioning impairment (Fletcher et al., 1996; Fletcher et al., 2005).

This constellation of primary impairments can then have downstream effects on children’s academic, psychosocial, and functional outcomes (Holmbeck & Devine, 2010; Holmbeck & Faier-Routman, 1995; Holmbeck et al., 2003). Notably, the American Association
on Intellectual and Developmental Disabilities (AAIDD) defines adaptive functioning as an assortment of conceptual (e.g., literacy, language, and self-direction), social (e.g., interpersonal skills, social problem solving), and practical abilities (e.g., self-care, navigating transportation and health-care; Shalock et al., 2010), and existing literature in SB highlights difficulties across all three domains of functioning. Preliminary evidence suggests that adaptive functioning deficits are present as early as six months of age (e.g., poorer cognitive, language, and motor skills; Lomax-Bream, Barnes, Copeland, Taylor, & Landry, 2007) and endure into adulthood, resulting in a failure to reach developmental milestones (e.g., poor educational and employment outcomes, low rates of independent living and community participation) and overall poorer quality of life among adults with SB (Bier et al., 2005; Mahmood, Dicianno, & Bellin, 2011; Mukherjee, 2007; Oakeshott & Hunt, 2003). However, previous work is largely cross-sectional and developmental trajectories of adaptive functioning have yet to be comprehensively examined across all three AAIDD domains.

**Conceptual Domain**

Youth with SB experience difficulties in the conceptual domain of adaptive functioning, specifically across communication, self-direction, and functional academic skill areas. The ability to communicate information, thoughts, ideas, and needs is considered an essential skill to navigate daily life (Owens, 2001). Effective communication not only involves the ability to speak and hear, but also adeptly use language skills and interpret nonverbals (e.g., facial expressions). Previous research suggests that youth with SB have a complex language profile, excelling in vocabulary but struggling with comprehension, language flexibility, and verbosity (Holbein et al., 2014; Taylor et al., 2010). Youth also display difficulties recognizing and
interpreting nonverbal cues, and this may be particularly challenging for those with myelomeningocele and shunted hydrocephalus (Brookshire et al., 1995; Yeates, Loss, Colvin, & Enrile, 2003). Though developmental research indicates that communication proficiency increases as a function of age (Krauss & Glucksberg, 1969), research characterizing communication in SB across development is largely cross-sectional (Brookshire et al., 1995; Dennis, Hendrick, Hoffman, & Humphreys, 1987; Fletcher, Barnes, & Dennis, 2002).

In addition to communication, self-direction may also be challenging for youth with SB. Self-direction reflects skills related to self-control, making decisions, completing tasks, and following directions, and these skills are naturally acquired during typical development (Harrison & Oakland, 2003). Despite research documenting self-direction deficits in children with disabilities (e.g., autism, learning disabilities, emotional disturbance; Ditterline, Banner, Oakland, & Becton, 2008; Harrison & Oakland, 2003), research examining self-direction in the context of SB is scarce. Preliminary work suggests that youth with SB perform below the grade-expected level on tasks that involve self-direction (Coster & Haltiwanger, 2004) and generally struggle to initiate routines (Warchausky, Kaufman, Schutt, Evitts, & Hurvitz, 2017). However, existing literature in this area has not explicitly examined self-direction (i.e., lumps “self-direction” in with other constructs, like “initiative”; Coster & Haltiwanger, 2004) and typically includes samples in which individuals with SB are combined with other disabilities (e.g., cerebral palsy, orthopedic impairment; Coster & Haltiwanger, 2004; Warchausky et al., 2017), limiting the generalizability of these findings. Given evidence suggesting that deficits in self-direction skills during childhood can negatively affect future self-determination and well-being (Martin, Marshall, & Maxson, 1993; Ryan & Deci, 2000; Wehmeyer & Palmer, 2000), it is
imperative to fill these gaps in the existing literature and better understand the development of self-direction skills in children with SB.

The final skill area within the conceptual domain is functional academics, which encompasses basic reading, writing, and arithmetic abilities. These basic academic skills are important as they enable individuals to perform everyday tasks (e.g., reading signs, completing job applications) and have been associated with overall quality of life among young adults with SB (Hetherington, Dennis, Barnes, Drake, & Gentili, 2006). In general, youth with SB display a distinct cognitive phenotype (Dennis et al., 2006), which is characterized by relative strengths and weakness in the information processing systems underlying content domains. Specifically, Dennis and colleagues (2006) note that youth with SB exhibit a relative strength in associative processing and relative weakness in assembled processing. Associative processing is considered to be data driven (e.g., word recognition), whereas assembled processing requires the integration of various cognitive domains (e.g., performing mental rotations, applying real world knowledge to reading comprehension; Dennis et al., 2006).

Consistent with this discrepancy in associative and assembled processing abilities, youth with SB exhibit difficulties with reading comprehension (Barnes & Dennis, 1992), numerical estimation (e.g., estimating size or length; Barnes et al., 2002), and complex arithmetic (Ayr, Yeates, & Enrile, 2005), all of which involve integrating multiple sources of information. Youth also generally tend to perform better in reading than mathematics (Barnes & Dennis, 1992; Barnes et al., 2002; Barnes et al., 2006). In fact, one study found that of children with SB who do not have an intellectual disability, approximately half have a math disability (Fletcher et al., 2005). In contrast, skills that involve associative processing, such as vocabulary, word
recognition and decoding, and performing simple mathematical calculations, appear to remain intact in youth with SB (Dennis et al., 2006).

Given these findings, there is a need to create effective and targeted interventions for youth with SB to ameliorate academic problems. Indeed, previous work has isolated risk factors for poorer academic outcomes among youth with SB, including higher lesion levels, shunt placements and revisions, and cognitive functioning deficits (Hetherington et al., 2006; Swartwout, Garnaat, Myszka, Fletcher, & Dennis, 2010; Wasserman & Holmbeck, 2016). Though some preliminary evidence suggests that sleep, neurocognitive functioning, and parent factors may be potential mechanisms for intervention (Barnes et al., 2014; Holmbeck et al., 2003; Murray, 2017), there remains a need to expand upon this work and better understand modifiable individual or environmental factors that may benefit youth with SB.

**Social Domain**

With regard to social abilities, previous research has documented noteworthy deficits among children with SB compared to their typically developing peers. Children with SB experience overall poorer social competence than their able-bodied peers, and are likely to be socially immature, dependent on their parents, and experience social isolation (Blum, Resnick, Nelson, & St. Germaine, 1991; Holmbeck et al., 2003; Kazak & Clark, 1986). One study found that although children with SB value social engagement, their peer relationships typically do not extend outside of school and they have limited involvement in extracurricular activities (Blum et al., 1991). Behaviorally, children with SB demonstrate passivity, as well as a lack of assertiveness and confidence in their interactions with others (Holmbeck et al., 2003). Compared to their peers, youth with SB also report less security and closeness in their friendships (Devine
et al., 2012). These findings have been reported across multiple settings (e.g., home, school) using diverse methods of data collection (Blum et al., 1991; Holmbeck et al., 2003). In addition to difficulties with friendships, dating activity is rare among adolescents with SB, with one study finding that only about 14.7% of teenagers have ever been on a date (Blum et al., 1991). This is notable given that many adolescents with SB reportedly hope to marry in adulthood (Blum et al., 1991).

Though most research is cross-sectional, the few existing longitudinal studies suggest that social functioning deficits in SB are maintained from childhood into adolescence (Holmbeck & Devine, 2010; Holmbeck et al., 2010). For example, one study found that group differences in social functioning between children with SB and their typically developing peers endured from ages 8 to 15 (e.g., fewer friendships), with girls at risk for increasing social difficulties over time (Holmbeck et al., 2010). This highlights the lasting nature of social difficulties, which can then result in social isolation during adulthood (Castree & Walker, 1981). Notably, previous research has identified risk factors for social maladjustment (e.g., poorer neuropsychological functioning, higher body mass index; Holbein, Peugh, & Holmbeck, 2017), but protective factors remain understudied. Isolating modifiable, protective factors that promote healthy social adjustment is crucial to identify potential mechanisms for intervention.

**Practical Domain**

According to the AAIDD, the practical domain is the third and final adaptive functioning domain and involves skills related to daily living (e.g., self-care, navigating transportation and health-care; Shalock et al., 2010). Compared to the conceptual and social domains of adaptive functioning, literature in the practical domain remains sparse. However, preliminary evidence
suggests that children and adolescents with SB do experience difficulties in this domain, especially with tasks such as home living or self-care (Andren & Grimby, 2000). Given the plethora of medical complications that accompany SB, including orthopedic, bladder and bowel, and neurological difficulties, children with this condition must manage a complex and demanding medical regimen (Copp et al., 2015). Not only does their medical regimen complicate their daily routine, but children with SB may struggle to master self-care activities (e.g., eating, dressing, grooming) and home living (e.g., cleaning, food preparation) on a fundamental level as these skills are often dependent upon motor and cognitive abilities (Hetherington et al., 2006).

With regard to self-care, previous cross-sectional work has found that most youth with SB are independent in eating, dressing, bathing, and hygiene (Buran et al., 2004; Börjeson & Lagergren, 1990). Notably, one study found that youth struggled most with bladder and bowel management, toilet transfer, and stair mobility (Buran et al., 2004). Another study with adults found that those who did not have hydrocephalus were generally independent, whereas most (54%) with hydrocephalus and a spinal lesion level above L2 required assistance with self-care (Verhoef et al., 2006). Research examining home living in SB has almost exclusively focused on adults, finding that most adults continue to live at home and require assistance with the tasks of daily living (e.g., cooking, cleaning; Andren & Grimby, 2000; Bellin et al., 2007; Castree & Walker, 1981; Oakeshott & Hunt, 2003). In fact, studies have found that adults with SB are often able to cook or prepare simple meals (e.g., sandwich, hot drink), but require at least minimal assistance with most other home living tasks, such as cleaning and shopping (Andren & Grimby, 2000; Andren & Grimby, 2004). Moreover, the few existing longitudinal studies indicate that though youth with SB demonstrate a delay in autonomy skill development (e.g., hygiene, making
shopping choices, cleans room; Davis, Shurtleff, Walker, Seidel, & Duguay, 2006), they do appear to acquire skills over time (Jacobson et al., 2013).

During adolescence, health care responsibilities are typically transferred from parents to youth with SB (Stepansky, Roache, Holmbeck & Schultz, 2010), which is crucial to enable youth to function independently at home and within the community (Beacham & Deatrick, 2013; Dicianno et al., 2008). This is consistent with recommendations from healthcare providers, noting that mildly to moderately impaired individuals should be able to independently manage self-care tasks prior to adulthood (e.g., self-catheterization, skin checks, bowel program management; Greenley, 2010). However, youth may encounter difficulties managing self-care and home living responsibilities due to their passivity and tendency to rely on adults for direction and guidance (Holmbeck et al., 2003). Despite this push to improve self-management among youth with SB, risk and protective factors that influence changes in self-care and home living abilities across development remains unknown.

Neuropsychological Profile of Youth with Spina Bifida

In addition to comprehensively examining trajectories of adaptive functioning, there remains a need to isolate risk factors for long-term maladjustment among youth with SB. This is important given the heterogeneity in adaptive functioning outcomes among youth with SB and would allow for the development and implementation of targeted interventions. Executive functioning and attention are two possible risk factors as these are cognitive domains in which youth with SB tend to have significant deficits. In general, youth with SB have a complex neuropsychological profile, with deficits across multiple cognitive domains (e.g., intelligence, attention, memory, processing speed; Brown et al., 2008; Dennis et al., 2006; Rose & Holmbeck,
and significant variability in cognitive functioning exists within the population. This variability may be due to multiple neurological factors, including spinal cord lesion level, hydrocephalus, and shunt infections and revisions (Erikson, Baron, & Fantie, 2001; Fletcher et al., 2005; Rose & Holmbeck, 2007). Given that many of the skills involved in adaptive functioning likely rely on the higher order cognitive processes characteristic of executive functioning and attention, the sections below focus explicitly on these domains.

**Executive Functioning Deficits**

Mounting evidence suggests that youth with SB display deficits in executive functioning, a heterogeneous set of cognitive processes that include planning, organization, self-regulation, inhibition, and working memory (Eslinger, 1996). Multiple studies have found that youth with SB demonstrate poorer executive functioning than their typically developing peers (Brown et al., 2008; Rose & Holmbeck, 2007), with one study finding that adolescents with SB fall about one standard deviation below the normative mean (i.e., low average range; Heffelfinger et al., 2008). These deficits appear to be present even after controlling for intellectual ability or motor impairment (Dennis & Barnes, 2010; Rose & Holmbeck, 2007) and degree of executive functioning impairment has been linked to the neurological severity of youth’s SB (e.g., lesion level, shunt status; Brown et al., 2008; Heffelfinger et al., 2008; Rose & Holmbeck, 2007). In particular, given that the Chiari-II malformation and hydrocephalus commonly accompany SB, deficits in executive functioning may result from disruption in the circuits communicating between the prefrontal cortex and other brain regions (Erikson et al., 2001; Fletcher et al., 1996).

Notably, executive functioning abilities can be divided into two categories: behavioral regulation and metacognition. Behavioral regulation includes skills related to impulse and
emotional control, as well as cognitive flexibility. Conversely, metacognition involves skills such as problem-solving, initiation, working memory, planning, organization, and self-monitoring. Some evidence suggests that youth with SB only demonstrate difficulties with metacognition (Brown et al., 2008), whereas other studies indicate that youth display deficits in both executive functioning domains (Tazari, Zabel, & Mahone, 2008).

Previous work indicates that youth with SB experience notable deficits in metacognition, including difficulties in initiation, working memory, planning/organization, goal-directed behavior, and self-monitoring (Burmeister et al., 2005; Tazari et al., 2008; Tuminello et al., 2012). With regards to behavioral regulation, youth with SB tend to display impairments in cognitive flexibility and shifting (Tazari et al., 2008; Tuminello et al., 2012), as well as emotional control (Iddon, Morgan, Loveday, Sahakian, & Pickard, 2004). Not only have deficits been detected in both of these executive functioning domains using performance-based neuropsychological assessments, but also using parent- and teacher-report (Tuminello et al., 2012; Zukerman, Devine, & Holmbeck, 2011). Thus, it is important to utilize both subjective and objective assessments in this population to obtain a comprehensive picture of executive functioning (Driscoll et al., 2018; Brown et al., 2008).

Attention Deficits

Not only do youth with SB demonstrate difficulties with executive functioning, but impairments in attention have also been documented. Broadly, youth are prone to difficulties with the posterior attention system (versus the anterior system), which is known as “bottom-up” processing. Specifically, youth have difficulties effectively shifting their attention from one point of focus to another (Ramsundhar & Donald, 2014; Vinck, Mullart, Rotteveel, & Maaseen, 2009).
Compared to siblings and typically developing peers, youth with SB also exhibit clinically significant deficits in focused attention (i.e., ability to select specific stimuli from a broad array) and perform slower on simple tests of attention, with these impairments persisting after controlling for IQ (Fletcher et al., 1996; Loss, Yeates, & Enrile, 1998; Rose & Holmbeck, 2007). Though youth may have difficulties with sustained attention, evidence is mixed (Caspersen & Habekost, 2013; Erickson et al., 2001; Rose & Holmbeck, 2007).

Additionally, research indicates that youth with SB have a higher incidence of clinical ADHD symptoms than the general population. In contrast to the population prevalence rate of ADHD, which is 8%, studies suggest that almost one-third of youth (28%) with SB present with ADHD-Inattentive Type symptoms (Ammerman et al., 1998; Burmeister et al., 2005; Spellicy et al., 2012). However, given that youth with SB are mostly diagnosed with the inattentive subtype of ADHD, their issues are likely mostly related to distractibility and focusing issues, as opposed to hyperactivity (Ammerman et al., 1998; Burmeister et al., 2005). Consistent with findings in EF, attention deficits among individuals with SB may result from the Chiari-II malformation and hydrocephalus, as well as high lesion levels, which can lead to structural and functional anomalies in the midbrain and hindbrain (i.e., a “posterior presentation” of attention problems; Dennis & Barnes, 2010; Fletcher et al., 2005; Rose & Holmbeck, 2007; Swartwout et al., 2008).

**Link between Underlying Cognitive Deficits and Adaptive Functioning**

Overall, there is significant variability in adaptive functioning among youth with SB, which may be partially due to differences in underlying cognitive abilities. Indeed, the Ecological Model of Adaptation for Adolescents with SB identifies neuropsychological functioning as a risk factor for poor functional independence (Heffelfinger et al., 2008) and data
from previous work provides support for this model. On a global level, better executive functioning and attention are predictive of greater autonomy development (Tuminello et al., 2012), more adaptive skills (Heffelfinger et al., 2008; Loss et al., 1998; Kelly et al., 2012; Rose & Holmbeck, 2007), and the achievement of developmental milestones among youth with SB (Zukerman et al., 2011). Research examining associations between cognitive functioning and specific adaptive functioning skills is more limited, and generally focuses on one specific AAIDD skill domain rather than comprehensively examining associations across all skill domains.

Within the conceptual domain of adaptive functioning (i.e., communication, self-direction, and functional academics skill areas), existing work suggests that executive dysfunction and attention deficits may lead to poorer communication and academic outcomes (Fletcher et al., 1996; Loss, Yeates, & Enrile, 1998). Similar findings have been documented in the social skill domain, such that better executive functioning and attentional abilities are associated with better social skills and competence (Rose & Holmbeck, 2007). Previous work has yet to examine the impact of cognitive functioning on self-direction (conceptual domain), as well as self-care and home living skills (practical domain), in youth with SB. Additionally, though one study has found significant associations between executive functioning and adaptive functioning across all three AAIDD domains (i.e., conceptual, social, practical), this study was cross-sectional, focused exclusively on composite scores, and did not examine the influence of attention (Warschausky, Kaufman, Evitts, Schutt, & Hurvitz, 2017). Thus, additional research delineating the impact of cognitive dysfunction on specific adaptive functioning skills is needed to better understand: 1) specific cognitive processes that are implicated with distinct adaptive
functioning skills and 2) which individuals with SB may be most at-risk for long-term difficulties in adaptive functioning.

**Influence of Parenting on Youth with Spina Bifida**

Given the pervasive impact of SB youth, it is also crucial to begin isolating modifiable factors that mitigate adaptive functioning deficits. Social-ecological and systems perspectives suggest that support resources within the family unit may be particularly important protective factors to consider (Kazak et al., 2003), as does the Ecological Model of Adaptation for Adolescents with SB proposed by Sawin and colleagues (2003a, 2003b; Heffelfinger et al., 2008). These theoretical models are supported by research within the context of SB documenting a link between family and child outcomes (Heffelfinger et al, 2008; Holmbeck & Devine, 2010; Holmbeck et al., 2002a, Holmbeck et al., 2002b). For example, the family environment has been linked to conceptual skill development (e.g., language, academic outcomes), independence, and use of problem-focused coping strategies among youth with SB (McKernon et al., 2001; Loomis, Javornisky, Monahan, Burke, & Lindsay, 1997; Vachha & Adams, 2009). In addition to broad family factors, specific parenting behaviors (e.g., maternal warmth and acceptance, enforcement of age-appropriate rules) have been linked to psychosocial adjustment and autonomy development in youth (Holmbeck & Devine, 2010; Holmbeck et al., 2002a; Holmbeck et al., 2002d; McAndrew, 1979; O’Hara & Holmbeck, 2013; Vermaes, Gerris, & Janssens, 2007).

Research in other neurological populations suggests that adaptive parent adjustment and behaviors may buffer the negative downstream effects of neurocognitive impairment on child adaptive functioning (Micklewright, King, O’Toole, Henrich, & Floyd, 2012; Wade, Zhang, Yeates, Stancin, & Taylor, 2016; Yeates, Taylor, Walz, Stancin, & Wade, 2010). For instance,
Wade and colleagues (2016) found that authoritarian (i.e., parent-centered, demanding, unresponsive, punishment focused) and permissive (i.e., low behavioral expectations given child’s age, lack of structure or instruction) parenting styles moderated the impact of a traumatic brain injury (TBI) on functional outcomes among children. Specifically, functional impairments were more pronounced in children with a severe TBI when parents displayed higher levels of permissive or authoritarian parenting. Another study documented similar results, finding that warm responsiveness and structure from parents buffered the negative impact of a severe TBI on child adjustment (e.g., behavior problems; Treble-Barna et al., 2016). Collectively, these findings suggest that parent-child interactions may influence the acquisition of higher order cognitive processes and skill development in neurologically vulnerable youth (Eisenberg et al., 2005; Landry, Miller-Loncar, Smith, & Swank, 2002; Schroeder & Kelley, 2009), and may help these youth to develop compensatory strategies to better meet the demands of daily life.

Despite this evidence in other populations that parenting may serve a crucial, protective role for individuals with cognitive impairment, to date, only one study has examined this phenomenon in the context of SB. Heffelfinger and colleagues (2008) found that although executive functioning was predictive of functional independence in adolescents with SB, family resourcefulness did not moderate this relationship. This suggests that other family or parenting factors, apart from resourcefulness, may be important specifically for youth with neurocognitive impairment. Parental scaffolding is one promising factor and is discussed in greater detail in the section below.
Influence of Parental Scaffolding on Child Development

Scaffolding, a process through which adults support children’s learning and ultimately enhance task performance, is a theoretical concept that originated from the tutoring literature and is closely linked to Vygotsky’s Zone of Proximal Development (Vygotsky, 1978; Wood et al., 1976). Though the term originally referred to structure provided exclusively during tutorial interactions (Wood et al., 1976), this concept has since been broadened to include diverse settings and populations (Vygotsky, 1978; Wood et al., 1976; Wood & Wood, 1996). Today, scaffolding can broadly be defined as processes whereby adults, “facilitate or otherwise shape children's learning by transforming tasks that are beyond the child's current abilities into activities that the child can understand and master” (p. 369; Hammond & Carpendale, 2015).

During the scaffolding process, parents support children’s mastery of regulatory strategies and the overall task by engaging and maintaining the child’s interest, managing their frustration, and structuring the task to meet the child’s ability/developmental level (Bibok et al., 2009; Wood et al., 1976; Wood & Wood, 1996). Notably, research in the field of developmental psychology has linked greater parental scaffolding to better executive functioning and attention, problem-solving, behavioral functioning, and academic outcomes among typically developing children (Bibok et al., 2009; Bloomquist et al., 1996; Hammond et al., 2012; Mattanah et al., 2005; Neitzel & Stright, 2003). For example, one study found that more parental scaffolding of children’s problem-solving (i.e., structured assistance during a puzzle) at age 3 was predictive of better executive functioning at age 4 (Hammond et al., 2012). Similarly, another study found that more verbal scaffolding from parents (i.e., verbally linking objects with specific actions) during early childhood was predictive of children’s future verbal ability (Landry et al., 2002).
Collectively, these findings suggest that scaffolding not only improves task performance by helping children organize and plan goal-directed behavior, but also by enabling children to eventually master these functions themselves (e.g., develop the skills implicated in executive functioning; Landry et al., 2002).

Though most existing work in this area focuses on typically developing children, researchers have recently begun extending the scaffolding literature to include children with disabilities (e.g., intellectual, language), as well as a traumatic brain injury (TBI; Gerrard-Morris et al., 2010; Treble-Barna et al., 2016; Wade et al., 2008). Preliminary work indicates that scaffolding provided from adults may promote the development of social skills, cognition, and emotion regulation in children with disabilities or cognitive impairment (Baker, Fenning, Crnic, Baker, & Blacher, 2007; Norona & Baker, 2014; Gerrard-Morris et al., 2010). Indeed, Baker and colleagues (2007) found that maternal scaffolding at age 4 predicted social skills at age 6 for children both with and without developmental disabilities. Moreover, Abbeduto and colleagues (1999) found that parents of children with intellectual disabilities are able to scaffold their children’s learning just as effectively as parents of typically developing children. Despite this collective evidence suggesting that parental scaffolding may help children compensate for cognitive challenges, and therefore, may be especially important for neurologically vulnerable populations, it has yet to be explored in SB. Children with SB experience a constellation of neuropsychological deficits and it is crucial to explore parental scaffolding as a potential mechanism for future clinical interventions.
Measurement of Parental Scaffolding

Since its creation, the concept of scaffolding has been operationalized in many ways. When Wood and colleagues (1976) first coined the term in the context of tutoring, they theorized that scaffolding consists of six specific processes, including 1) recruitment (e.g., engaging child’s interest in the task), 2) direction maintenance (e.g., ensuring that child’s actions are geared toward task objectives), 3) frustration control (e.g., regulating child’s negative emotions), 4) reduction in degrees of freedom (e.g., simplifying task), 5) marking critical features (e.g., highlighting key aspects of the task that are critical for its completion), and 6) demonstration (e.g., modeling how to complete the task). As a result, a number of studies have employed methodologies that encompass some or all of these basic tenets when applying the concept of scaffolding specifically to parent-child interactions. Yet, there is notable variability in the types of scaffolding assessed (e.g., verbal versus verbal and nonverbal scaffolding), the tasks developed to elicit scaffolding behaviors from parents, and the coding systems utilized to quantify these behaviors.

Studies examining the effects of parental scaffolding on child development have generally defined scaffolding in one of two ways. Some studies have strictly focused on scaffolding as a verbal process (e.g., parents verbally linking objects with actions, timing of elaborative parental utterances, frequency of verbal support; Bibok et al., 2009; Gerris-Morris et al., 2010; Landry et al., 2002; Treble-Barna et al., 2016), whereas others have attempted to integrate verbal and nonverbal processes into their conceptualization of scaffolding (e.g., parents providing verbal suggestions and physically rearranging puzzle pieces for a child; Bernier, Carlson, & Whipple, 2010; Hammond et al., 2012); with the latter approach more closely
aligning with the framework provided by Wood and colleagues (1976). Such disparities highlight the challenges of studying scaffolding due to its relational and somewhat subjective nature, such that parents must recruit their child’s interest and provide structure, but not be domineering.

Notably, across studies employing both this more restricted and broader view of scaffolding, there are vast differences in the methodologies used to assess scaffolding. Past research has videotaped parent-child dyads completing a variety of tasks, including solving puzzles (Bibok et al., 2009), cleaning up after a tea party (Hammond & Carpendale, 2015), completing typical daily activities and toy play (Gerrard-Morris et al., 2010; Landry et al., 2002), problem-solving paper-and-pencil tasks (e.g., maze; Baker et al., 2007), and conversing about event-type memories (e.g., an important and sad memory; McLean & Mansfield, 2012). When it comes to coding these observational data, studies focusing on verbal scaffolding have often coded the content of adults’ verbalizations, such that hints, prompting, elaborations, and conceptual linkages that facilitated problem-solving were coded as scaffolding (Bibok et al., 2009; Landry et al., 2002). In contrast, studies focusing on both verbal and nonverbal scaffolding have used principles from Wood et al. (1976) to create coding guides (e.g., parents rated on 5-point scale based on how often they meet scaffolding criteria; Hammond & Carpendale, 2015; Hammond et al., 2012), as well as used codes from existing rating systems as a proxy for scaffolding (e.g., autonomy-support; Bernier et al., 2010).

While the majority of the aforementioned studies examined parental scaffolding in the context of younger, typically developing children (Bernier et al., 2010; Bibok et al., 2009; Hammond et al., 2012; Landry et al., 2002), scaffolding research with older children and adolescents (Abbeduto et al., 1999; Mattanah et al., 2005; McLean & Mansfield, 2012) and those
with disabilities/health conditions does exist (Baker et al., 2007; Gerrard-Morris et al., 2010; Guralnick, Neville, Hammond, & Conner, 2008; Treble-Barna et al., 2016). Research with these populations has generally utilized similar methods to those described above. However, given differences in cognitive functioning across these groups, some studies have tailored tasks to meet the developmental level of these participants. Specifically, tasks have been simplified for those with poorer cognitive abilities (Baker et al., 2007), as well as made more complex and pertinent for those in middle childhood or adolescence (e.g., long-division homework, conversations about memories; Mattanah et al., 2005; McLean & Mansfield, 2012; Pratt, Green, MavVicar, & Bountrogianni, 1992).

Given this variability in the scaffolding literature and that this concept has yet to be explored in the context of SB, the current study examined parental scaffolding as a potential protective factor in youth with SB by utilizing a novel methodological approach. First, similar to past research, scaffolding was conceptualized as a verbal and nonverbal process in accordance with the framework provided by Wood and colleagues (1976). Second, observational tasks that were 1) developmentally appropriate and 2) specific to the experiences of those with SB were utilized to elicit parent-child interactions that likely naturally exist within the home. These tasks included age-appropriate vignettes, a transferring of condition-related responsibilities task (e.g., independent catheterization), and a conflict task (e.g., conflictive issues, such as how child with SB does his/her skin checks). Notably, these tasks combine elements of those used in past research, such that they require both parent-child conversations and problem-solving. Third, to richly and comprehensively assess each component of the scaffolding process, this study used a widely validated observational coding system that has been used with a variety of chronic health
conditions to quantify parents’ scaffolding behaviors (i.e., Family Interaction Macro-coding System [FIMS]; Holmbeck, Zebracki, Johnson, Belvedere, & Hommeyer, 2007). In particular, six codes that aligned with the framework by Wood and colleagues (1976) and were thought to capture key elements of the scaffolding process were used to create an innovative scaffolding composite.

Two codes from the FIMS, requests input from child (e.g., requesting direct opinions and asking questions, gesturing towards child) and promotes dialogue and collaboration (e.g., asking child questions, “let’s each take a turn trying to come up with a solution…”), were used to capture the concept of recruitment during the scaffolding process. Additionally, structuring of the task and requests input from child were the two FIMS codes used to capture reduction in degrees of freedom and direction maintenance, respectively. While requests input from child mapped onto two theoretical domains of the scaffolding process (i.e., recruitment and direction maintenance), the actual code was only included once when creating the scaffolding composite. The structuring of the task code assesses whether parents efficiently structure the problem-solving process (e.g., identifying and describing the problem). Finally, attempted resolution of issues (e.g., parent demonstrating flexibility and showing a willingness/interest in working through disagreements), supportiveness (e.g., encouragement, acknowledgement, acceptance via positive listening and speaking skills, physically touching family member supportively such as hand holding), and humor and laughter (e.g., using humor or jokes to improve mood) were the three codes used to capture frustration control in the scaffolding composite. Additional detail regarding the tasks and coding system used in the current study is provided in later sections (see “Parental Scaffolding” section in the methods).
Gaps in the Current Literature

Collectively, the current literature highlights the adaptive functioning difficulties that youth with SB may experience across all three skill domains outlined by the American Association on Intellectual and Developmental Disabilities (AAIDD; i.e., conceptual, social, and practical domains; Shalock et al., 2010). Within these three skill domains, existing research suggests that youth demonstrate difficulties with communication, self-direction, functional academics, and self-care and home living, as well as social performance (Andren & Grimby, 2000; Bellin et al., 2007; Buran et al., 2004; Dennis et al., 2006; Coster & Haltiwanger, 2004; Holbein et al., 2014; Holmbeck et al., 2003; Taylor et al., 2010). Despite this evidence, significant gaps remain in the existing literature as most present research is cross-sectional and developmental trajectories of adaptive functioning from childhood into adolescence are not well-understood. A few studies have examined changes in social and academic functioning over time (Dennis et al., 2006; Holmbeck & Devine, 2010; Holmbeck et al., 2010), but these studies exclusively focus on one or two skill areas and have not comprehensively examined adaptive functioning across all three AAIDD domains. Examining the transition from childhood to adolescence is especially important as this is a time when maladaptive pathways may emerge or be altered by protective processes (Cicchetti & Rogosch, 2002). Therefore, delineating changes in adaptive functioning across key developmental periods can help clinicians to identify optimal time points for intervention.

In addition, it is imperative to illuminate mechanisms underlying developmental changes in adaptive functioning to facilitate the creation and implementation of targeted interventions. Previous research indicates that cognitive factors may be one important risk factor to consider,
particularly executive functioning and attention as these higher order processes are likely implicated in adaptive functioning and are domains in which youth with SB tend to struggle most (Rose & Holmbeck, 2007). Although a few studies have documented associations between executive functioning and/or attention and adaptive functioning (Heffelfinger et al., 2008; Warschauisky et al., 2017), previous work has focused almost exclusively on the effect of cognitive process on academic or social outcomes and largely ignored other skill areas within the conceptual and practical domains of adaptive functioning. Additionally, studies that do include all three AAIDD domains only examine composite scores (i.e., conceptual, social, practical) rather than individual skill areas. Therefore, there remains a need to systematically examine the influence of executive functioning and attention on specific skills within the conceptual, social, and practical domains of adaptive functioning.

Finally, a significant gap remains in the existing literature with regard to protective factors that can ameliorate adaptive functioning deficits in youth with SB. This is an important line of research given the substantial lifetime costs associated with SB and its sequelae (i.e., approximately $600,000 per child; Copp et al., 2015; Yi, Lindemann, Colligs, & Snowball, 2011). Research with SB and the broader literature indicates that parenting may be a key protective factor, yet this has not been systematically examined (Heffelfinger et al., 2008; Holmbeck & Devine, 2010; Holmbeck et al., 2002b; Micklewright et al., 2012; Yeates et al., 2010). Parental scaffolding, in particular, may help children with SB successfully complete everyday tasks by providing structure and promoting goal-directed behavior, as well as by improving children’s ability to engage in these functions themselves (e.g., higher order cognitive skills; Landry et al., 2002). Thus, it is crucial to fill this gap in the current literature to better
understand if parental scaffolding can moderate (i.e., buffer) the negative impact of cognitive dysfunction on adaptive functioning outcomes among youth with SB and serve as a mechanism for future intervention.

**The Current Study**

The present study aimed to extend the existing literature by characterizing developmental trajectories of adaptive functioning in children with SB as they transition into adolescence. Moreover, this study examined neurocognitive functioning (i.e., executive functioning and attention) and parental scaffolding as risk and protective factors, respectively (see Figure 1). Delineating risk and protective factors may help to explain the substantial variability found in this complex condition, and is crucial to facilitate the development of timely and targeted interventions for the vulnerable period of adolescence (Cicchetti & Rogosch, 2002).

By utilizing a multi-method (i.e., performance-based assessments, surveys, and observational data), multi-informant, and longitudinal study design that spans three time points, this study addresses many of the methodological shortcomings of the existing literature. Notably, this longitudinal study is grounded within a developmental framework, which is important for research involving chronic health conditions (Holmbeck et al., 2002c), and allows for the use of more advanced statistical analyses to improve understanding of adaptive functioning trajectories in this population. Another novel aspect of this study is the use of a parental scaffolding measure. Apart from a few studies in the context of pediatric TBI (Treble-Barna et al., 2016; Wade et al., 2008), research has yet to extend findings regarding the benefits of parental scaffolding from the developmental literature to pediatric chronic health populations, which could have important implications for future work in the field of pediatric psychology.
**Study Hypotheses**

The current study had three objectives. The *first objective* of this study was to characterize developmental trajectories of adaptive functioning in youth with SB (see Figure 2). Within the conceptual domain, it was hypothesized that skills related to communication, self-direction, and functional academics would improve over time (*Hypothesis 1a*). Conversely, it was hypothesized that social abilities would remain stable over time in children with SB due to the increasing complexity of social interactions during adolescence (*Hypothesis 1b*; Brown, 1990). Finally, it was hypothesized that skills in the practical domain, including self-care and home living, would increase over time (*Hypothesis 1c*).

The *second objective* of this study was to examine the impact of executive functioning and attention on developmental trajectories of adaptive functioning in youth with SB (see Figure 3). It was hypothesized that poorer executive functioning and attention would be predictive of poorer adaptive functioning over time across all skill domains (*Hypothesis 2*).

Finally, the *third objective* of this study was to examine the moderating role of parental scaffolding on associations between cognitive impairment (i.e., poor executive functioning and attention) and trajectories of adaptive functioning in youth with SB (see Figure 4). It was hypothesized that higher levels of parental scaffolding would buffer the negative impact of cognitive impairment on adaptive functioning trajectories (*Hypothesis 3*).
Figure 2. Objective 1 Conceptual Model: Changes Over Time in Youth Adaptive Functioning.

Time 1
Youth Adaptive Functioning
- Conceptual Domain: Communication, Self-Direction, and Functional Academics skills
- Social Domain: Social skills
- Practical Domain: Home Living and Self-Care skills

Time 2
Youth Adaptive Functioning
- Conceptual Domain: Communication, Self-Direction, and Functional Academics skills
- Social Domain: Social skills
- Practical Domain: Home Living and Self-Care skills

Time 3
Youth Adaptive Functioning
- Conceptual Domain: Communication, Self-Direction, and Functional Academics skills
- Social Domain: Social skills
- Practical Domain: Home Living and Self-Care skills
Figure 3. Objective 2 Conceptual Model: Executive Functioning and Attention as Predictors of Change Over Time in Youth Adaptive Functioning.

Time 1
Youth Neurocognitive Functioning
- Executive Functioning: Working Memory, Planning & Organization, Cognitive Flexibility, and Inhibition
- Attention

Change Time 1 – 3
Youth Adaptive Functioning
- Conceptual Domain: Communication, Self-Direction, and Functional Academics skills
- Social Domain: Social skills
- Practical Domain: Home Living and Self-Care skills
Figure 4. Objective 3 Conceptual Model: Parental Scaffolding Moderating the Relationship between Neurocognitive and Adaptive Functioning.

**Time 1**

**Parental Scaffolding**
- Maternal Scaffolding
- Paternal Scaffolding

**Time 1**

**Youth Neurocognitive Functioning**
- Executive Functioning: Working Memory, Planning & Organization, Cognitive Flexibility, and Inhibition
- Attention

**Change Time 1 – 3**

**Youth Adaptive Functioning**
- Conceptual Domain: Communication, Self-Direction, and Functional Academics skills
- Social Domain: Social skills
- Practical Domain: Home Living and Self-Care skills
CHAPTER THREE

METHODS

Participants

Participants were recruited as part of a larger, ongoing longitudinal study examining neuropsychological functioning and family adjustment among youth with spina bifida (SB; e.g., Devine et al., 2012). Families of youth with SB were initially recruited from four hospitals and a statewide SB association in the Midwest. Families were approached during regularly scheduled clinic visits and sent recruitment letters. Interested families were screened in person or via phone by a trained member of the research team, and eligible children were: (a) diagnosed with SB (types included myelomeningocele, lipomeningocele, and myelocystocele); (b) ages 8-15; (c) proficient in English or Spanish; (d) had the involvement of at least one primary caregiver; and (e) were living within 300 miles of the laboratory (to allow for data collection at participants’ homes).

Of the 246 families approached for recruitment, 163 initially agreed to participate in the study. However, ultimately 21 families were excluded as they were unable to be contacted or later declined participation, and two did not meet inclusion criteria. Thus, the final sample of participants included 140 families of children with SB (53.6% female, 53.5% Caucasian, $M_{age} = 11.40$ at Time 1). Children who declined participation did not significantly differ from those who agreed to participate based on SB type (myelomeningocele versus other), $\chi^2 (1) = 0.0002, p > .05$, shunt status, $\chi^2 (1) = 0.003, p > .05$, or occurrence of shunt infections $\chi^2 (1) = 1.08, p > .05$.  

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Following the baseline assessment, families were contacted again for follow-up time points every two years.

The current project included a subset of 131 families who had at least one parent complete a measure of the child’s adaptive functioning during the first three time points (Time 1 \( T1 \) = baseline; Time 2 \( T2 \) = two year follow-up; Time 3 \( T3 \) = four year follow-up). There were no significant differences in youth IQ, gender, race, lesion level, or family socioeconomic status between the larger sample and this subsample. However, youth included in the current analyses were significantly younger than those who were not, \( t (9.61) = -3.72, p < .01 \). Notably, there was a decrease in sample size over time, which was predominantly due to approximately 25% of youth becoming over 18 years of age and completing the “young adult” assessment protocol (i.e., this protocol does not include adaptive functioning data; T1 = 123 families, T2 = 104 families, T3 = 75 families). Over half of families had complete data at all three time points \( (N = 66, 50.4\%) \); however, the remaining families had incomplete data at one or two time points \( (N_{Time 1 only} = 20, 15.3\%; N_{Time 1 & Time 2} = 31, 23.7\%; N_{Time 1 & Time 3} = 6, 4.6\%; N_{Time 2 &/or Time 3} = 8, 6.1\%) \). Incomplete data were retained for the current analyses to increase sample size. Attrition analyses indicated that families who did not have data at T2 and T3 did not significantly differ from those who did with respect to gender, IQ, age, lesion level, or adaptive functioning at T1. At T1, youth were on average 11.26 years old \( (SD = 2.40) \), most had a diagnosis of myelomeningocele, and a little over half were female (53.3%) and Caucasian (53.4%). Additional information regarding child demographic characteristics is displayed below in Table 1.
Table 1. Child Demographic and Condition-Related Characteristics at Time 1.

<table>
<thead>
<tr>
<th>Description</th>
<th>n (%) or M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender: female</td>
<td>69 (52.7)</td>
</tr>
<tr>
<td>Age</td>
<td>11.26 (2.40)</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>70 (53.4)</td>
</tr>
<tr>
<td>African-American/Black</td>
<td>17 (13.0)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>36 (27.5)</td>
</tr>
<tr>
<td>Other</td>
<td>8 (6.1)</td>
</tr>
<tr>
<td>Family SES</td>
<td>39.48 (15.91)</td>
</tr>
<tr>
<td>IQ</td>
<td>86.38 (19.64)</td>
</tr>
<tr>
<td>Spina bifida type</td>
<td></td>
</tr>
<tr>
<td>Myelomeningocele</td>
<td>108 (82.4)</td>
</tr>
<tr>
<td>Lipomeningocele</td>
<td>13 (9.9)</td>
</tr>
<tr>
<td>Myelocystocele</td>
<td>2 (1.5)</td>
</tr>
<tr>
<td>Unknown/Not reported</td>
<td>8 (6.1)</td>
</tr>
<tr>
<td>Lesion level</td>
<td></td>
</tr>
<tr>
<td>Thoracic</td>
<td>21 (16.0)</td>
</tr>
<tr>
<td>Lumbar</td>
<td>63 (48.1)</td>
</tr>
<tr>
<td>Sacral</td>
<td>39 (29.8)</td>
</tr>
<tr>
<td>Unknown/Not reported</td>
<td>8 (6.1)</td>
</tr>
<tr>
<td>Shunt present</td>
<td>99 (75.6)</td>
</tr>
</tbody>
</table>

Note. Demographic information is based on a sample of 131 youth with spina bifida (SB) who participated in family interaction tasks at T1 with at least one parent. SES = socioeconomic status; IQ = intelligence quotient.
Procedure

The current study was approved by the Institutional Review Board at Loyola University Chicago, as well as Lurie Children’s Hospital. Prior to data collection, parents provided informed consent and children provided informed consent (over 18 years of age) or assent (under 18). Parents also completed releases of information allowing the research team to obtain data from medical charts, health professionals, and teachers. Next, trained research assistants (i.e., undergraduate and graduate students) collected data in families’ homes during visits that lasted approximately three hours. Specifically, data collection consisted of two separate three-hour home visits at T1, as well as one three-hour home visit at T2 and T3. At least one research assistant was bilingual for home visits in which families primarily spoke Spanish and families were compensated with $150, a t-shirt, and a pen at each time point.

During the home visit, family members independently completed questionnaires and participated in video-taped interaction tasks. Though most questionnaires were offered in English and Spanish, those that were only available in English were translated into Spanish by research assistants who were native Spanish speakers. Research assistants read questionnaires aloud to participants as needed (e.g., requested by participant, reading difficulties). In addition to questionnaires and interaction tasks, trained research assistants also administered a battery of neuropsychological assessments to youth with SB. The current study used parent- and teacher-reported questionnaire data, as well as performance-based neuropsychological data and observational data from videotaped parent-child interactions.
Measures

Demographics and Youth Illness Characteristics

Parents reported on family and youth demographic information at T1, including age, gender, race/ethnicity, income, education level, and employment status. Family socioeconomic status (SES) was measured using the Hollingshead Index of Socioeconomic Status, in which higher scores indicate higher SES (Hollingshead, 1975). Detailed information about youth’s SB was collected via parent-report on the Medical History Questionnaire (MHQ; Holmbeck et al., 2003) and hospital medical chart abstractions at T1. Collected data included type of SB (i.e., myelomeningocele, meningocele, or lipomeningocele), shunt status, and lesion level (i.e., sacral, lumbar, or thoracic), as well as ambulation method (i.e., ankle-foot orthoses [AFOs], knee-ankle-foot orthoses [KAFOs] or hip-knee-ankle-foot orthoses [HKAGOs] wheelchair, or no assistance).

Youth IQ

Youth were administered the Vocabulary and Matrix Reasoning subtests of the Wechsler Abbreviated Scale of Intelligence (WASI) at T1, which were then used to compute an estimated Full Scale IQ (FSIQ) that served as a proxy for general intellectual functioning in the current study (Wechsler, 1999). Notably, the WASI is a well-validated measure of intellectual functioning in children, with a normative mean of 100 and standard deviation of 15. The Vocabulary subtest (42 items) assesses expressive vocabulary and verbal knowledge, whereas the Matrix Reasoning subtest (35 items) assesses nonverbal fluid reasoning and general intellectual ability. Both scales have established reliability for individuals aged 6 to 16 years (Vocabulary $\alpha = .89$, Matrix Reasoning $\alpha = .92$; Wechsler, 1999).
Neurocognitive functioning in youth with SB was assessed using questionnaires (i.e., mother-, father-, and teacher-report) and performance-based neuropsychological assessments that were administered by trained research assistants at T1. Guided by previous literature highlighting common neurocognitive deficits in youth with SB (Brown et al., 2008; Dennis et al., 2006; Rose & Holmbeck, 2007), this study evaluated attention and the following domains of executive functioning that may impact adaptive functioning: 1) working memory, 2) planning and organizational skills, 3) cognitive flexibility, and 4) inhibition (See “Youth Neurocognitive Functioning” in Figure 1). In order to isolate specific cognitive processes that are implicated with distinct adaptive functioning skills, these three executive functioning domains were evaluated separately and not as a global executive functioning construct. Apart from cognitive flexibility and inhibition, each domain (i.e., attention, working memory, planning and organizational skills) was comprised of multiple measures and subscales. Though a rational approach was employed to determine which measures would theoretically be included within the five neurocognitive domains, statistical and data reduction techniques were also used when creating composite scores (See “Preliminary Analyses” section for more information). Parent- and teacher-report questionnaires are described in greater detail below, whereas performance-based assessments are described in the subsequent section.

Executive Function. Mothers, fathers, and teachers reported on youth’s executive functioning using the Behavior Rating Inventory of Executive Functioning (BRIEF; Gioia, Isquith, Guy, & Kenworthy, 2000). On this measure, parents (85 items) and teachers (86 items) were instructed to circle whether their child has never, sometimes, or often demonstrated a
particular behavior during the past six months, with higher scores indicating higher levels of executive dysfunction. The BRIEF yields eight subdomains of executive function, including Inhibit, Shift, Emotional Control, Initiate, Working Memory, Plan/Organize, Organization of Materials, and Monitor. These eight subdomains can also be classified within two broad indices, the Behavioral Regulation Index (i.e., inhibit, shift, emotion control) and the Metacognition Index (i.e., initiate, working memory, plan/organize, organization of materials, monitor), which together create an overall Global Executive Composite Score. In the current study, Working Memory, Plan/Organize, Organization of Materials, Shift, and Inhibit were used to assess executive functioning. The BRIEF has demonstrated high internal consistency for parent and teacher reports ($\alpha = .80-.98$ across subdomains) and internal consistency was adequate in the current sample ($\alpha = .74-.95$ across subdomains and reporters).

Attention. Mothers, fathers, and teachers completed the Swanson, Nolan, and Pelham Teacher and Parent Rating Scale version IV (SNAP-IV; Swanson, 1992), which was used to assess youth inattention, impulsivity, and hyperactivity. The 18 items on this measure correspond with the DSM-IV (American Psychiatric Association, 1994) criteria for Attention-Deficit/Hyperactivity Disorder (ADHD) and are rated from 0 (Not at All) to 3 (Very Much), with higher scores indicating greater symptom severity. Though this measure yields both an inattention and hyperactivity/impulsivity subscale, only the inattention subscale was included in the current study. The SNAP-IV demonstrated good levels of internal consistency across reporters in this study ($\alpha = .92-.94$ across reporters).

Additionally, parents and teachers completed the Child Behavior Checklist (CBCL) and Teacher Report Form (TRF), respectively (Achenbach & Rescorla, 2001). Items on these
measures assess behavioral and emotional problems in youth and are rated from 0 (Not True) to 2 (Very True). Both inventories have established reliability and validity, and are widely used for children aged 6-18 years (Achenbach & Rescorla, 2001). In the current study, only the Attention Problems subscale was used, which assesses inattention, hyperactivity, and impulsivity. Internal reliability was adequate in this sample ($\alpha = .81-.85$).

**Youth Neurocognitive Functioning: Performance-Based Measures**

*Executive Function.* First, the Planned Connections subtest from the Cognitive Assessment System (CAS; Naglieri & Das, 1997) was used to measure executive function. The CAS battery is designed to measure non-verbal cognitive processing in children ages 5 through 17 years old. The Planned Connections subtest in particular consists of eight items, in which examinees must connect numbers in sequential order (items 1-6 on subtest) and then connect both numbers and letters (i.e., alternating) in sequential order (items 7-8 on subtest). Completion time is recorded in seconds, with lower scores (i.e., less seconds) indicating greater efficiency. Notably, the Planned Connections subtest of the CAS has high internal consistency ($\alpha = .77$) and test-retest reliability ($r = .73$; Naglieri & Das, 1997).

In addition to the CAS, the Digit Span subtest from the Wechsler Intelligence Scale for Children – Fourth Edition (WISC-IV; Wechsler, 2003) was used as a performance-based assessment of executive function in youth. The WISC-IV is an assessment battery designed to measure cognitive ability in children ages 6 through 16 years old and its subtests yield the following index scores: verbal comprehension, visual spatial processing, fluid reasoning, working memory, and processing speed. The Digit Span subtest that was used in the current study is part of the Working Memory index and is comprised of two tasks: Digit Span Forward
and Digit Span Backward. During Digit Span Forward, the examinee is verbally presented with a list of numbers by the interviewer and is then asked to repeat the sequence aloud. During Digit Span Backward, the examinee is also verbally presented with a list of numbers by the interviewer, but then is asked to repeat the sequence aloud in the reverse order. Raw scores for the Digit Span subtest were converted into age scaled scores, with higher scores indicating better working memory function. The Digit Span subtest has good internal consistency ($r = .87$) and test-retest reliability ($r = .83$; Williams, Weiss, & Rolfhus, 2003).

**Attention.** The Number Detection subtest from the CAS assesses selectivity, ability to shift attention, and resistance to distraction, and was used as one measure of attentional ability. During this task, examinees must locate and underline specific numbers on a page that contains distractors (i.e., the same numbers presented in a different font). Raw scores representing task efficiency were calculated based on accuracy and completion time. These raw scores were then converted into age scaled scores, in which higher scores represent greater attentional ability. The Number Detection subtest of the CAS has high internal consistency ($\alpha = .77$) and test-retest reliability ($r = .77$; Naglieri & Das, 1997). See “Executive Function” section above for additional information about the CAS.

**Youth Adaptive Functioning**

Mothers and fathers completed the Adaptive Behavior Assessment-Second Edition (ABAS-II; Harrison & Oakland, 2003) at T1, T2, and T3 to rate their child’s ability to perform a variety of daily tasks. The ABAS-II assesses nine skill areas, which can be combined into three composites that mirror the AAIDD domains: Conceptual, Social, and Practical. The Conceptual composite includes Communication, Self-Direction, and Functional Academics skill areas (e.g.,
verbal and nonverbal communication skills, basic reading, writing, and arithmetic skills, following directions), whereas the Social composite includes Leisure and Social skill areas (e.g., playing or getting along with others). Moreover, the Practical composite includes Self-Care, Home Living, Health/Safety, and Community Use skill areas (e.g., cleaning the house, following safety rules, grooming). Only six of the nine skill areas were assessed at T1, T2, and T3 in the larger study, including Communication, Self-Direction, Functional Academics, Social, Self-Care, and Home Living. Therefore, analyses in the current study focused on change over time at the skill-level rather than the domain-level (i.e., Conceptual, Social, and Practical). Notably, the ABAS-II provides norm-referenced scores for each of the skill areas (i.e., scaled scores), and has demonstrated high internal consistency (rs range from .85–.99) and high test–retest reliability (rs range from .80–.90). Internal consistency was adequate in this sample across reporters and time (α = .89-.96).

**Parental Scaffolding**

*Observational Assessment of Parent-Child Interactions.* Following a warm-up game, parents and youth with SB completed four interaction tasks that were counterbalanced at T1. Tasks included: (a) two age-appropriate vignettes, (b) transferring of condition-related responsibilities task, and (c) conflict task. During the two vignettes, families were presented with two age-appropriate situations that youth may encounter, one of which was specific to individuals with SB, and asked to discuss potential resolutions. During the transferring of responsibilities task, families identified and discussed one or two SB-related responsibilities that could eventually be transferred from the parent(s) to the child (e.g., independent catheterization).
Prior to conducting the conflict task, families completed the Parent-Adolescent Conflict Scale (PAC; Prinz, Foster, Kent, & O’Leary, 1979) where they indicated the presence, frequency, and intensity of potentially conflictive issues. In addition to the standard 15-items included in the scale (e.g., “Whether he/she does chores around the house”), 10 items were added for the current study to assess conflict specific to SB (e.g., “How he/she does his/her skin checks”). Next, families were presented with the five issues that they rated as the most common and intense, and asked to discuss and problem-solve potential resolutions to at least three of the issues. Families were given 10 minutes to complete each of the four interaction tasks.

Coding of Observational Data. Family interactions were coded using the Family Interaction Macro-coding System (FIMS), which is a global-coding method that has been used with families of youth with a variety of chronic health conditions (Holmbeck et al., 2007; Kaugars et al., 2010). After viewing an entire family interaction task, trained undergraduate and graduate students rated the family on codes assessing interaction style, conflict, affect, control, problem-solving, and family systems using 5-point Likert type ratings. Coders completed comprehensive training and were required to achieve 90% reliability prior to coding the videotapes. Behavioral descriptions for each code are outlined in the manual (Holmbeck et al., 1995; Holmbeck et al., 2007). In the current study, a rational approach to measure development was employed (rather than purely statistical) to determine six codes from the FIMS that were used to capture and create composite measures of maternal and paternal scaffolding (see Table 2 for specific codes). These six codes map onto four theoretical domains that are thought to be implicated in the scaffolding process: recruitment, reduction in degrees of freedom, direction
maintenance, and frustration control (Wood et al., 1976). Reliability for the scaffolding composite is adequate in this sample (see “Preliminary Analyses” section in the results).

Table 2. FIMS Items Included in the Scaffolding Composite.

<table>
<thead>
<tr>
<th>Theoretical Domain</th>
<th>FIMS Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recruitment</td>
<td>Requests input from child*</td>
</tr>
<tr>
<td></td>
<td>Promotes dialogue and collaboration</td>
</tr>
<tr>
<td>Reduction in degrees of freedom</td>
<td>Structuring of task</td>
</tr>
<tr>
<td>Direction maintenance</td>
<td>Requests input from child*</td>
</tr>
<tr>
<td>Frustration control</td>
<td>Attempted resolution of issues</td>
</tr>
<tr>
<td></td>
<td>Supportiveness</td>
</tr>
<tr>
<td></td>
<td>Humor and laughter</td>
</tr>
</tbody>
</table>

*Note. FIMS = Family Interaction Macro-coding System. *FIMS item fulfills two theoretical domains, but was only included once in the scaffolding composite.

**Planned Analyses**

**Preliminary Analyses**

Prior to hypothesis testing, the psychometric properties of all included measures were evaluated, and descriptive statistics were calculated to assess for skewness and outliers. To minimize the number of analyses and probability of Type 1 error, data reduction techniques were employed when appropriate. Specifically, Pearson correlations were used to examine associations between measures with two informants (e.g., mother and father report) or methodologies (e.g., BRIEF and performance-based assessments). Measures were collapsed
across informants for significant correlations in which \( r \geq .40 \) (Holmbeck, Shurman, Friedman, & Coakley, 2002). Similarly, for constructs with three or more informants or methodologies (e.g., mother, father, and teacher report), alpha coefficients were calculated, where total scale scores from different respondents/methodologies were treated as if they were an item in the scale. If \( \alpha \geq .60 \), the respondent-specific measures were aggregated into a composite score.

Analyses were conducted separately for measures that are not significantly correlated.

**Primary Analyses**

Given that families who participated at T1 were invited to complete all subsequent time points, there are slight inconsistencies in the sample from T1 to T3 (e.g., some families participated at T1 and T2, whereas others participated at T1 and T3). In order to obtain the largest possible sample, participants with incomplete data were retained in the current study. Given concerns related to statistical overcorrection, as well as research indicating that controlling for IQ is not methodologically sound when examining neuropsychological deficits in the context of neurodevelopmental disorders, IQ was not included as a covariate in the models (Dennis et al., 2009). Guided by literature about power estimation in growth analyses (Zhang & Wang, 2009), this sample of 131 participants provided ample statistical power (.80) to detect large effects for the following analyses (\( \mu_s = .30 \)).

**Analytic Plan for Objective 1.** Growth curves using a mixed linear effects analysis (PROC MIXED in SAS; SAS Institute, Cary, NC) were used to examine changes in adaptive functioning over time. To define time, participant’s age was used as the predictor variable as this provided greater insight into how adaptive functioning changes across development, as opposed to the arbitrary time points of the study assessment schedule. The mixed-models used were
individual change models that allowed for straight-line change and for fixed and random effects for the individual intercepts and slopes across age. In cases where the variance for the slope random effects was estimated to be zero, the model was re-fit to exclude the slope random effect. To account for data missing at random across time, a maximum likelihood estimation (MLE) procedure was used (Rubin, 1976; Schafer & Graham, 2002). Separate mixed-models were run for each adaptive functioning skill area (i.e., Communication, Self-Direction, Functional Academics, Social, Self-Care, and Home Living) to determine change for the total sample across age.

**Analytic Plan for Objective 2.** After identifying average change in the six adaptive functioning skills across age, predictors were entered into the mixed-models. Specifically, attention and executive functioning variables were examined as predictors of change across age (i.e., intercept and slope growth parameters).

**Analytic Plan for Objective 3.** Finally, two-way interactions were entered into the mixed-models. Specifically, interactions between neurocognitive functioning (i.e., attention and executive functioning) and parental scaffolding were examined as predictors of change across age (i.e., intercept and slope growth parameters).
CHAPTER FOUR

RESULTS

Preliminary Analysis

To reduce the number of analyses, associations between multiple reporters (e.g., mother and father report) and measures (e.g., neuropsychological and questionnaire data) were examined for adaptive and neurocognitive functioning to determine whether composite scores could be created. Specifically, constructs with three or more reporters or methodologies were aggregated if they demonstrated adequate internal consistency ($\alpha > .60$). Of note, total scale scores were treated as items on a scale when computing Cronbach’s alphas. Additionally, constructs with two reporters or methodologies were aggregated if bivariate Pearson coefficients were $\geq .40$.

Notably, questionnaire measures of neurocognitive functioning were reverse-scored so that higher scores represent better cognitive functioning across all cognitive constructs. Composite scores were able to be created for youth adaptive functioning at T1, T2, and T3 (mother and father report on ABAS-II), as well as for youth working memory (mother, father, and teacher report on BRIEF and youth performance on Digit Span on the WISC), planning and organization (mother, father, and teacher report on BRIEF and youth performance on Planned Connections on the CAS), cognitive flexibility (mother, father, and teacher report on BRIEF), inhibition (mother, father, and teacher report on BRIEF), and attention (mother, father, and teacher report on CBCL/TRF and SNAP-IV, as well as youth performance on Number Detection on the CAS) at
T1. While one executive functioning construct did not quite meet the aggregation criteria (i.e.,
cognitive flexibility), a composite score was still created as the internal consistency was close to
the designated cutoff ($\alpha = .57$). Results from preliminary analyses regarding adaptive and
neurocognitive functioning are presented in Table 3 and Table 4, respectively.

With regard to parental scaffolding, intrarater reliability and internal consistency were
examined separately for maternal and paternal scaffolding composites. First, the six items
included in the scaffolding composites were averaged across the four observational tasks (i.e.,
two vignettes, transferring of condition-related responsibilities task, and conflict task) for each
coder. Intraclass correlations (ICCs) were then used to evaluate intrarater reliabilities, with both
composites demonstrating adequate reliability (Mother Scaffolding ICC = .71, Father
Scaffolding ICC = .77). Next, the six items included in the scaffolding composite were averaged
across coders and the four observational tasks. Cronbach’s $\alpha$ reliability coefficients were then
computed using the mean score for each item. Both composites demonstrated adequate internal
consistency, such that alpha coefficients were .84 and .87 for mothers and fathers, respectively.
Results from preliminary analyses regarding parental scaffolding are presented in Table 5.

After creating composite scores, all variables were examined for outliers and then
skewness. Any value that was greater than three standard deviations from the mean and was not
part of the normal distribution was considered an outlier (Cohen, Cohen, West, & Aiken, 2003).
Thirty outliers were identified across 17 variables and were subsequently corrected by changing
the score to one unit greater than the next highest value, as recommended by Cohen and
colleagues (2003). The following variables contained outliers: communication skills at T1 ($n = 3$
outliers), self-care skills at T1 ($n = 1$), social skills at T1 ($n = 2$), communication skills at T2 ($n =
3), functional academics skills at T2 \((n = 2)\), self-care skills at T2 \((n = 3)\), self-direction skills at T2 \((n = 1)\), social skills at T2 \((n = 3)\), communication skills at T3 \((n = 2)\), functional academics skills at T3 \((n = 1)\), self-care skills at T3 \((n = 2)\), self-direction skills at T3 \((n = 1)\), social skills at T3 \((n = 1)\), cognitive flexibility at T1 \((n = 1)\), inhibition at T1 \((n = 2)\), maternal scaffolding at T1 \((n = 1)\), and paternal scaffolding at T1 \((n = 1)\). Next, consistent with guidelines outlined by West and colleagues (1995), variables were considered skewed if their skewness value was greater than 2.0. However, none of the variables were skewed based on this criteria.

Scaled scores for the six adaptive functioning skill areas are also presented in Table 3. Per manual guidelines, the following classifications were used to interpret adaptive skill performance: scaled scores \(\geq 15\) indicated superior performance, 13-14 indicated above average performance, 8-12 indicated average performance, 6-7 indicated below average performance, 4-5 indicated borderline performance, and \(\leq 3\) indicated extremely low performance (Harrison & Oakland, 2003). Results were consistent across all three time points (i.e., T1, T2, T3), such that parents rated youth’s communication, functional academics, and social skills were largely in the average range compared to same aged peers. Home living and self-care skills were in the borderline range, and self-direction skills were in the below average range.

Prior to hypothesis testing, Pearson correlations were conducted to examine associations between youth’s adaptive and neurocognitive functioning, as well as parental scaffolding, both cross-sectionally and longitudinally. Results revealed a number of significant correlations between adaptive functioning, cognition, and parental scaffolding. In general, youth’s adaptive functioning was strongly associated with their executive functioning and attention at all three time points. Results revealed limited significant associations between parental scaffolding and
youth’s adaptive and neurocognitive functioning. Correlation coefficients for associations between neuropsychological functioning/parental scaffolding at T1 and adaptive functioning at T1, T2, and T3 are presented in Table 6, Table 7, and Table 8, respectively.
Table 3. Description of Composite Scores Created for Youth Adaptive Functioning at Time 1, Time 2, and Time 3.

<table>
<thead>
<tr>
<th>Composite Scores</th>
<th>Reporters &amp; Measures</th>
<th>T1 (baseline)</th>
<th>T2 (2 year follow-up)</th>
<th>T3 (4 year follow-up)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td><em>r</em></td>
<td><em>M (SD)</em></td>
<td><em>r</em></td>
</tr>
<tr>
<td>Conceptual Domain</td>
<td></td>
<td>.68</td>
<td>9.79 (3.21)</td>
<td>.61</td>
</tr>
<tr>
<td>Communication skills</td>
<td>ABAS-II: Communication subscale (M, F)</td>
<td>.61</td>
<td>6.93 (3.73)</td>
<td>.54</td>
</tr>
<tr>
<td>Self-Direction skills</td>
<td>ABAS-II: Self-Direction subscale (M, F)</td>
<td>.82</td>
<td>8.12 (4.02)</td>
<td>.62</td>
</tr>
<tr>
<td>Functional Academics skills</td>
<td>ABAS-II: Functional Academics subscale (M, F)</td>
<td>.44</td>
<td>8.21 (3.30)</td>
<td>.45</td>
</tr>
<tr>
<td>Social Domain</td>
<td></td>
<td>.85</td>
<td>5.45 (3.72)</td>
<td>.74</td>
</tr>
<tr>
<td>Social skills</td>
<td>ABAS-II: Social subscale (M, F)</td>
<td>.67</td>
<td>4.40 (3.75)</td>
<td>.74</td>
</tr>
<tr>
<td>Practical Domain</td>
<td></td>
<td>.85</td>
<td>5.45 (3.72)</td>
<td>.74</td>
</tr>
<tr>
<td>Self-Care skills</td>
<td>ABAS-II: Self-Care subscale (M, F)</td>
<td>.67</td>
<td>4.40 (3.75)</td>
<td>.74</td>
</tr>
<tr>
<td>Home Living skills</td>
<td>ABAS-II: Home Living subscale (M, F)</td>
<td>.44</td>
<td>8.21 (3.30)</td>
<td>.45</td>
</tr>
</tbody>
</table>

*Note.* M = Mother Report, F = Father Report. ABAS-II = Adaptive Behavior Assessment System – 2nd Edition. Means and standard deviations are based on scaled scores from the ABAS-II that have a normative mean of 10 and a standard deviation of 3 (lower scores denote poorer functioning). All *ps* < .05.
Table 4. Description of Composite Scores Created for Youth Neurocognitive Functioning at Time 1.

<table>
<thead>
<tr>
<th>Composite Scores</th>
<th>Reporters &amp; Measures</th>
<th>Cronbach’s Alpha (α)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Working Memory</td>
<td>1. BRIEF: Working Memory subscale (M, F, T)</td>
<td>.69</td>
</tr>
<tr>
<td></td>
<td>2. WISC-IV: Digit Span subtest</td>
<td></td>
</tr>
<tr>
<td>Planning &amp; Organization</td>
<td>1. BRIEF: Plan/Organize &amp; Organization of Materials subscales (M, F, T)</td>
<td>.73</td>
</tr>
<tr>
<td></td>
<td>2. CAS: Planned Connections subtest</td>
<td></td>
</tr>
<tr>
<td>Cognitive Flexibility</td>
<td>1. BRIEF: Shift subscale (M, F, T)</td>
<td>.57</td>
</tr>
<tr>
<td>Inhibition</td>
<td>1. BRIEF: Inhibit scale (M, F, T)</td>
<td>.62</td>
</tr>
<tr>
<td>Attention</td>
<td>1. CBCL/TRF: Attention Problems subscale (M, F, T)</td>
<td>.85</td>
</tr>
<tr>
<td></td>
<td>2. SNAP-IV: Inattention subscale (M, F, T)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. CAS: Number Detection subtest</td>
<td></td>
</tr>
</tbody>
</table>

Table 5. Description of Composite Scores Created for Parental Scaffolding at Time 1.

<table>
<thead>
<tr>
<th>Composite Scores</th>
<th>Reporters &amp; Measures</th>
<th>Cronbach’s Alpha (α)</th>
<th>ICC</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother Scaffolding</td>
<td>1. Observational data (6 items from FIMS)</td>
<td>.84</td>
<td>.71</td>
<td>3.31 (.36)</td>
</tr>
<tr>
<td>Father Scaffolding</td>
<td>1. Observational data (6 items from FIMS)</td>
<td>.87</td>
<td>.77</td>
<td>2.99 (.48)</td>
</tr>
</tbody>
</table>

Note. Time 1 = baseline assessment. FIMS = Family Interaction Macro-coding System.
Table 6. Correlation Matrix of Independent Variables, Moderators, and Dependent Variables at Time 1.

<table>
<thead>
<tr>
<th>Variable</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adaptive Functioning (T1)</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>1. Communication</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>2. Functional Academics</td>
<td>.77***</td>
<td>-</td>
<td></td>
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<td></td>
<td></td>
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<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>3. Home Living</td>
<td>.47***</td>
<td>.61***</td>
<td>-</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>4. Self-Care</td>
<td>.57***</td>
<td>.72***</td>
<td>.79***</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Self-Direction</td>
<td>.57***</td>
<td>.71***</td>
<td>.72***</td>
<td>.76***</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Social</td>
<td>.62***</td>
<td>.48***</td>
<td>.50***</td>
<td>.50***</td>
<td>.66***</td>
<td>-</td>
<td></td>
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<tr>
<td>Cognitive Functioning (T1)</td>
<td></td>
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*Note. Time 1 (T1) = baseline assessment. *p < .05, ** p < .01, ***p < .001.*
Table 7. Correlation Matrix of Independent Variables (Time 1), Moderators (Time 1), and Dependent Variables (Time 2).

<table>
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<tr>
<th>Variable</th>
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<td>11. Attention</td>
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Note. Time 1 (T1) = baseline assessment, Time 2 (T2) = 2 year follow-up. *p < .05, **p < .01, ***p < .001.
Table 8. Correlation Matrix of Independent Variables (Time 1), Moderators (Time 1), and Dependent Variables (Time 3).

<table>
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<th>Variable</th>
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<td>11. Attention</td>
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<td>.34**</td>
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<td>.34**</td>
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<td>Parental Scaffolding (T1)</td>
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<td>-.09</td>
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</table>

Note. Time 1 (T1) = baseline assessment, Time 3 (T3) = 4 year follow-up. *p < .05, ** p < .01, ***p < .001.
Hypothesis Testing

Growth curves using a mixed linear effects analysis (PROC MIXED in SAS; SAS Institute, Cary, NC) were used to examine changes in adaptive functioning over time in youth with SB (objective 1). Additionally, growth curves were used to examine whether neurocognitive functioning predicted growth in adaptive functioning (objective 2), as well as whether parental scaffolding moderated the relationship between neurocognitive functioning and growth in adaptive functioning skills (objective 3). For all analyses, participant age was entered as the predictor variable to better understand how adaptive functioning changes across development in youth with SB. Notably, participant age was centered at 11.5 years old, such that 11.5 was subtracted from the age variable at T1, T2, and T3. This value was chosen as it is the midpoint of the age range at T1 (i.e., age range at T1 = 8-15 years).

Objective 1

Using data from three time points (T1-T3), separate growth models were conducted to examine change over time in each of the six adaptive functioning domains (i.e., communication, functional academics, home living, self-care, self-direction, social skills). As expected, youth’s adaptive functioning improved over time in five of the six skill areas. Specifically, youth’s communication, functional academics, home living, self-care, and self-direction skills significantly increased with age. However, youth’s social skills did not significantly change over time. Results for the growth models examining outcomes across age are summarized in Table 9.

Objective 2

Next, the five neurocognitive functioning variables (i.e., working memory, planning and organization, cognitive flexibility, inhibition, attention) were entered as predictors into the
models. Separate growth models were used to examine the relationship between each neurocognitive and adaptive functioning variable. When examining cognitive flexibility as a predictor of communication skills, the variance for the slope random effects was estimated to be zero in the original model. Thus, the model was re-fit to exclude the slope random effect.

Contrary to hypotheses, neurocognitive functioning variables did not predict change across age in most adaptive functioning skills. These non-significant findings may have been due to a lack of statistical power as the sample size only allowed for the detection of large effects (Zhang & Wang, 2009). However, planning and organization abilities at T1 predicted change in communication skills, such that better planning and organization predicted less growth in communication skills over time. Notably, better planning and organization abilities also predicted a higher intercept at 11.5 years of age and was consistently associated with better communication skills across age (see Figure 5). Better inhibition abilities similarly predicted less growth in functional academics skills, as well as a higher intercept at 11.5 years old (see Figure 6). At all ages, better inhibition was associated with better functional academics skills.

Interestingly, a number of neurocognitive variables predicted the intercept for adaptive functioning abilities at 11.5 years old. Specifically, better working memory, planning and organization, cognitive flexibility, inhibition, and attention predicted a higher intercept for adaptive functioning across almost all skills. Specific results for the growth models examining neurocognitive predictors of adaptive functioning outcomes across age are summarized in Table 10.
Objective 3

Finally, two-way interactions between neurocognitive functioning and parental scaffolding variables were entered as predictors into the models. Again, separate growth models were used to examine whether maternal and paternal scaffolding moderated the relationship between neurocognitive functioning and growth in adaptive functioning skills across age. When examining paternal scaffolding x inhibition and paternal scaffolding x attention as predictors of social skills, the variance for the slope random effects was estimated to be zero in the original models. Thus, the models were re-fit to exclude the slope random effect.

Contrary to hypotheses, most models were not significant and parental scaffolding did not moderate the association between neurocognitive and adaptive functioning, which again may have been due to a lack of statistical power (Zhang & Wang, 2009). However, two significant maternal scaffolding x neurocognitive functioning effects were detected, such that: (a) poorer planning and organizational abilities predicted more growth in home living skills over time at high levels of maternal scaffolding and (b) poorer inhibition skills predicted less growth in functional academics skills at high levels of scaffolding. To aid with interpretation, Figure 7 displays the significant interactions between maternal scaffolding x planning and organizational abilities when predicting youth’s home living skills, whereas Figure 8 displays the significant interactions between maternal scaffolding x inhibition abilities when predicting youth’s functional academics skills. Additionally, specific results for the growth models examining parental scaffolding x neurocognitive functioning as predictors of adaptive functioning outcomes across age are summarized in Table 11.
Table 9. Change in Adaptive Functioning Outcomes Across Age.

<table>
<thead>
<tr>
<th>Adaptive Functioning Outcome</th>
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<tr>
<td>Self-Direction</td>
<td>1.706***</td>
</tr>
<tr>
<td>Functional Academics</td>
<td>1.449***</td>
</tr>
<tr>
<td>Social</td>
<td>0.306</td>
</tr>
<tr>
<td>Self-Care</td>
<td>1.367***</td>
</tr>
<tr>
<td>Home Living</td>
<td>1.796***</td>
</tr>
</tbody>
</table>

Note. Table presents coefficients from growth models and indicates change in slope for each unit change of 1 year in age. *p < .05; **p ≤ .01; ***p ≤ .001.
Table 10. Neurocognitive Predictors of Change in Adaptive Functioning Across Age.

<table>
<thead>
<tr>
<th>Adaptive Functioning Outcome</th>
<th>Working Memory</th>
<th>Planning &amp; Organization</th>
<th>Cognitive Flexibility</th>
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<th>Attention</th>
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<td>Intercept</td>
<td>Slope</td>
<td>Intercept</td>
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<td>6.211**</td>
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<td>7.510***</td>
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<td>3.617**</td>
</tr>
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<td>2.764*</td>
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<tr>
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<td>2.928***</td>
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<td>Home Living</td>
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<td>6.561**</td>
<td>0.317</td>
<td>2.826*</td>
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</tbody>
</table>

*Note. Intercept and slope columns present coefficients from growth models. Slope column indicates change in slope for each unit change of 1 year in age. Italics denote models in which the variance for the slope random effects was estimated to be zero; in these cases, the model was re-fit to exclude the slope random effect. *p < .05; **p ≤ .01; ***p ≤ .001.*
Figure 5. Planning and Organizational Skills Predicting Change in Communication Skills Across Age.

Note. High and Low Planning & Organizational Skills denote one standard deviation above and below the mean, respectively. Age is represented in years. Highest possible score for the Communication Skills subscale is 72.
Figure 6. Inhibition Skills Predicting Change in Functional Academics Skills Across Age.

Note. High and Low Inhibition Skills denote one standard deviation above and below the mean, respectively. Age is represented in years. Highest possible score for the Functional Academics Skills subscale is 69.
Table 11. Neurocognitive Predictors of Change in Adaptive Functioning Across Age: Maternal and Paternal Scaffolding as Moderators.

<table>
<thead>
<tr>
<th>Adaptive Functioning Outcome</th>
<th>Working Memory</th>
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<th>Cognitive Flexibility</th>
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<td>P. Scaff</td>
<td>M. Scaff</td>
<td>P. Scaff</td>
<td>M. Scaff</td>
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</table>

*Note. M. Scaff = Maternal Scaffolding, P. Scaff = Paternal Scaffolding. Table presents coefficients from growth models and indicates change in slope for each unit change of 1 year in age. Italics denote models in which the variance for the slope random effects was estimated to be zero; in these cases, the model was re-fit to exclude the slope random effect. *p < .05; **p ≤ .01; ***p ≤ .001.
Figure 7. Maternal Scaffolding Moderating the Relationship between Planning and Organizational Skills and Trajectories of Home Living Skills.

Note. High and Low Planning & Organizational Skills denote one standard deviation above and below the mean, respectively. Age is represented in years. Highest possible score for the Home Living Skills subscale is 75.
Figure 8. Maternal Scaffolding Moderating the Relationship between Inhibition Skills and Trajectories of Functional Academics Skills.

*Note.* High and Low Inhibition Skills denote one standard deviation above and below the mean, respectively. Age is represented in years. Highest possible score for the Functional Academics Skills subscale is 69.
CHAPTER FIVE
DISCUSSION

Mounting evidence suggests that youth with SB frequently experience difficulties managing the demands of daily life. Indeed, past research has documented deficits across the conceptual (e.g., communication, self-direction, and functional academics skills), social (e.g., adeptly interacting with peers), and practical (self-care and home living skills) domains of adaptive functioning outlined by the AAIDD (Copp et al., 2015; Holmbeck et al., 2003; Shalock et al., 2010). The magnitude of these deficits may vary based on condition presentation and severity, resulting in significant variability in functioning across individuals with SB (Copp et al., 2015; Fletcher et al., 2005). Neuropsychological functioning in particular is one factor that may affect adaptive functioning, as many of these skills likely involve higher order cognition (e.g., planning and organization implicated in social participation; Tarazi et al., 2007). Moreover, environmental factors, such as parental scaffolding (i.e., providing structure and support to enhance children’s learning and skill mastery), may serve a protective role and ameliorate the impact of cognitive impairment on adaptive functioning in children with SB (Baker et al., 2007; Bibok et al., 2009). However, research on adaptive functioning in the context of SB is extremely limited, with previous work being largely cross-sectional and failing to systematically examine changes across all adaptive functioning skills defined by the AAIDD. Additionally, neuropsychological functioning and parental scaffolding have yet to be thoroughly evaluated as risk and protective factors, respectively.
Utilizing a longitudinal design, this study attempted to address these gaps in the existing literature by examining changes in adaptive functioning as individuals with SB transitioned from childhood into adolescence. It was hypothesized that youth with SB would acquire skills in most domains as they aged, including communication, self-direction, functional academics, self-care, and home living skills. Guided by previous research, social skills were expected to remain stable over time (Holmbeck et al., 2010). To address additional gaps in the literature, this study also sought to delineate the impact of neuropsychological functioning, namely executive functioning and attention, on skill attainment. Considering that higher-order processes are likely implicated in daily functioning, it was hypothesized that poorer neuropsychological functioning would predict poorer adaptive functioning over time. Finally, parental scaffolding was examined as a moderator, such that greater scaffolding from mothers and fathers was expected to buffer the negative impact of cognitive impairment on adaptive functioning trajectories.

**Change Over Time in Adaptive Functioning**

As hypothesized, findings indicate that youth with SB acquire skills in most adaptive functioning domains as they age, including communication, self-direction, functional academics, self-care, and home living skills. These findings are generally consistent with existing literature in healthy populations (Harrison & Oakland, 2003; Krauss & Glucksberg, 1969; Whitehurst, 1976), as well as limited longitudinal research youth with SB suggesting that youth become more autonomous over time (Jacobson et al., 2013). Interestingly, within the conceptual domain, youth’s communication, self-direction, and functional academics skills were in the low average to average range at all time points, indicating that individuals with SB are performing at about the same level as normative samples. Findings regarding functional academics were not
necessarily surprising given that youth with SB typically demonstrate relative strengths in associative processing (i.e., data driven tasks like word recognition; Dennis et al., 2006), which are the focus of many items on the ABAS-II functional academics subtest (e.g., able to measure in length and height, reads and obeys common signs). However, youth’s relatively average performance with regard to communication and self-direction skills was unexpected considering past research highlighting diminished functioning in these areas (Coster & Haltiwanger, 2004; Dennis et al., 2006; Taylor et al., 2010).

One potential explanation could be that the measure used to assess these domains of adaptive functioning (i.e., ABAS-II) was not sensitive to the specific difficulties faced by this population. For example, youth with SB tend to struggle with more subtle aspects of language and communication (e.g., comprehension, flexibility, interpreting nonverbals; Holbein et al., 2014; Taylor et al., 2010; Yeates et al., 2003), rather than exhibiting blatant aphasic disturbances. Although the present study did reveal some difficulties with self-direction, they were fairly minimal as youth’s performance fell in the low average range. Previous research has often lumped “self-direction” in with other constructs such as “initiative,” which may have led to an underestimation of youth’s skills in this area (Coster & Haltiwanger, 2004). Youth with SB tend to be passive and rely on adults for guidance and, in turn, this lack of initiative may instead have been interpreted as a lack of self-direction (Holmbeck et al., 2003). In contrast, findings in the practical domain were consistent with previous work (Hetherington et al., 2006; Verhoef et al., 2006), revealing that youth’s self-care and home living skills fell in the borderline impaired range and were substantial areas of weakness. Deficits in these skill areas may have a pervasive impact on the lives of youth with SB, leading to difficulties with establishing future autonomy.
Youth’s mastery of social skills did not significantly change over time, which was expected in the context of the existing literature. This lack of growth mirrors a study by Holmbeck and colleagues (2010) finding that youth with SB demonstrated deficits in social acceptance compared to peers and these differences were maintained via a lack of change in either slope over time (i.e., trajectories were flat and parallel). Of note, this same study also found that deficits with regard to number of friendships were maintained over time in the SB group despite longitudinal change, indicating that trajectories may differ across social dimensions (Holmbeck et al., 2010). Nevertheless, these findings suggest that youth with SB move along the same developmental progression as their peers from pre- (ages 8-9) to middle/late adolescence (ages 14-18), even if they lag slightly behind throughout this developmental period. In contrast to reports that youth with SB are socially immature, isolated, and have fewer friendships than typically developing youth (Holmbeck & Devine, 2010), youth’s social skills fell in the average range at all time points in the current study, indicating that youth with SB were performing in line with the general population. Given disparate findings regarding social functioning in this population (Stiles-Shields, Driscoll, Rausch, & Holmbeck, 2019), it is possible that youth thrive in some social domains (e.g., friendship quality, basic social skills like saying “thank you” when receiving a gift) and struggle in others (e.g., acceptance from others, number of friendships). Therefore, additional research characterizing developmental changes across multiple dimensions of social functioning is warranted.

**Impact of Neuropsychological Functioning on Adaptive Functioning**

Findings were also partially consistent with hypotheses that neuropsychological functioning is a significant predictor of adaptive functioning in youth with SB. More specifically,
while executive functioning and attention did not predict growth for most adaptive functioning skills, they did predict the intercept or youth’s level of functioning at 11.5 years old. Across almost all adaptive functioning skills, both better executive functioning and attention were predictive of better functional abilities at age 11.5. These results parallel previous work linking executive functioning/attention with broad adaptive skills, academic functioning, and social outcomes in youth with SB (Fletcher et al., 1995; Heffelfinger et al., 2008; Rose & Holmbeck, 2007), suggesting that those with poorer cognition may demonstrate skill deficits across all AAIDD domains of adaptive functioning. However, given that cognitive functioning did not predict growth in most models, neurologically vulnerable youth may also develop and acquire skills at the same rate as those with more intact cognitive abilities. These findings extend the current literature, underscoring the importance of monitoring cognitive functioning in at-risk youth from an early age. If or once difficulties are detected, initiating early intervention services may help promote independence in children who are lagging behind higher functioning peers with SB. Not only could interventions directly aimed at remediating executive dysfunction and attention problems prove beneficial (Stubberud, Langenbahn, Levine, Stanghelle, & Schanke, 2014), but supportive technologies may also help youth compensate for existing cognitive challenges. For example, children with planning and organizational difficulties may benefit from visual schedules or alarms (i.e., on watches or smart phones) to master self-care or home living tasks.

Interestingly, two executive functioning domains significantly predicted growth in youth’s adaptive functioning skills. Better planning and organizational abilities at baseline predicted less growth in communication skills over time, whereas better inhibition skills
predicted less growth in functional academics skills. Though surprising, one possible explanation for these results is that they may be due to ceiling effects. Rather than assessing superior adaptive functioning skills, the ABAS-II is designed to measure skills that individuals can typically competently perform by adulthood (Tasse et al., 2012). Indeed, in the current study, youth with better cognitive functioning tended to have adaptive functioning scores that clustered near the upper limits of each scale, across all time points. As such, future research should examine the impact of underlying cognitive difficulties on higher-order aspects of functioning, particularly skills in which those with SB are known to struggle (e.g., interpreting nonverbal cues, reading comprehension and complex mathematical equations). Another possible explanation for these results is that youth with poorer neurocognitive functioning may actually be “catching up” to their higher functioning peers over time with regard to adaptive functioning skills. Previous work has found that youth with SB demonstrate resilience across multiple domains of functioning (e.g., externalizing and internalizing symptoms, self-worth, expressed affect in families; Holmbeck et al., 2003). Adaptive functioning skills, such as communication and functional academics, may be additional areas of resilience among youth with SB and important areas of strength to capitalize on during treatment.

**Parental Scaffolding as a Moderator**

When examining whether parental scaffolding moderated the association between neuropsychological functioning and trajectories of adaptive functioning, few significant findings emerged. Given the intricacy of SB and its management (Copp et al., 2015), it is possible that other dimensions of the family environment have a more robust influence on youth’s functional outcomes. For example, family access to support and resources, as well as parent beliefs about
SB (e.g., beliefs about whether their child is/will ever be able to independently manage his/her condition) and what it means for their child’s future (e.g., expectations about educational attainment), may serve a protective role and facilitate independence. An alternative explanation may be tied to the age range of children included in the current study (i.e., ages 8-18 years). The broader literature primarily focuses on the effects of parental scaffolding on younger children, documenting positive associations between scaffolding and child outcomes (e.g., problem-solving, academic outcomes; Bibook et al., 2009; Bloomquist et al., 1996; Hammond et al., 2012). While the developmental age of youth with SB may be substantially lower than their chronological age, thus increasing parental involvement and influence throughout the lifespan, it is still possible that youth with SB are more impacted by relationships outside the home than those with their family as they transition into middle/late adolescence (Holmbeck, 2002c). Indeed, a study by Treble-Barna and colleagues (2016) found that the moderating effects of parental scaffolding diminished over time in the context of pediatric TBI. This suggests that parental scaffolding may differentially affect younger and older children, such that the effects of scaffolding diminish as children age. Parent behaviors, including the support and structure involved in the scaffolding process, may even become frustrating for older adolescents with SB who are: 1) higher functioning, and 2) at a developmental stage where they value and desire increased independence.

That being said, two significant moderation effects were detected for maternal scaffolding. First, maternal scaffolding significantly moderated the impact of youth’s planning and organizational abilities on growth in home living skills, such that poorer cognitive abilities coupled with more maternal scaffolding predicted more growth in adaptive skills. In contrast, in
the second significant model, poorer cognitive abilities (i.e., inhibition) coupled with more maternal scaffolding predicted less growth in adaptive skills. These incongruent findings are difficult to interpret and indicate that these significant interactions may be spurious given the number of interactions examined in the current study (i.e., \( n = 60 \)). However, when looking more closely at the second significant model in particular, those with poorer cognitive abilities (i.e., inhibition) appeared to demonstrate more home living skills during pre-adolescence (ages 8-9) at higher levels of maternal scaffolding. This corresponds with the notion that the effects of parental scaffolding are more salient when children are younger in age. Given the low probability of detecting interactions in nonexperimental research studies (McClelland & Judd, 1993), it is possible that scaffolding plays a role in the development of adaptive functioning skills. Examining parental scaffolding as a predictor of outcomes, as well as additional parenting factors as moderators (e.g., acceptance, psychological/behavioral control), may be an important next step for future research. Moreover, if cognitive-environmental interactions are found in youth with SB, adapting and evaluating parenting interventions from other neurologically vulnerable populations may be beneficial (Wade, Oberjohn, Burkhardt, & Greenberg, 2009).

**Strengths, Limitations, and Future Research**

The current study had a number of strengths. First, it filled crucial gaps in the literature and expanded knowledge about developmental changes in adaptive functioning in youth with SB; novel risk and protective factors were also identified. Second, data from multiple reporters (e.g., parents and teachers) was used to capture youth’s functioning across both home and school environments. Relatedly, performance-based neuropsychological assessments were employed to evaluate youth’s cognitive abilities, which is recommended to capture functioning in structured
and unstructured settings (Toplak, West, & Stanovich, 2013). Third, the study’s longitudinal design allowed for the examination of developmental changes in adaptive functioning from ages 8 to 18 years old, as well as temporal relationships between risk/protective variables and adaptive functioning outcomes.

Although the advanced statistical techniques used in the current study allowed participants with incomplete data to be included in analyses and, in turn, maximized sample size, analyses were generally underpowered and were unable to detect small and medium effects. Therefore, it is difficult to discern whether effects do not exist between some variables of interest or if they were just unable to be detected due to sample size. This is particularly true for the moderation analyses that were likely the most underpowered. Moreover, this study did not examine other potential condition-related moderators, such as spinal lesion level, that are known to influence functioning (Fletcher et al., 2005). Additional, multi-site research is needed to increase sample size and better understand the interplay between condition-related and environmental factors that can influence adaptive functioning in youth with SB.

As previously mentioned, the adaptive functioning measure used for this study inherently introduces possible ceiling effects. More specifically, the ABAS-II assesses individuals’ competence in skills that the general population is thought to master by adulthood. For example, items on the ABAS-II ask about writing first/last name and using a fork to eat solid food for the functional academics and self-care domains, respectively. Given the unique profile of youth with SB (i.e., individuals are often able to perform basic skills and struggle when task complexity increases), as well as the ABAS-II’s lack of specific questions regarding SB and its management, this measure may not be sensitive to the more nuanced anomalies in functioning present in this
population. As such, the development of SB-specific measures in the realm of adaptive functioning may be an important direction for future research. It is also important to note that parent report was used for both the ABAS-II and some neurocognitive functioning variables (e.g., BRIEF, SNAP-IV), introducing common method variance. This common method variance may have inflated correlations found between predictors and outcome variables.

Finally, while innovative, the method used to assess parental scaffolding in the current study has not been widely used or validated. The creation of the parental scaffolding composite was grounded in theoretical formulations from the broader literature and the items used are from a widely validated observational coding system (i.e., Family Interaction Macro-coding System; Holmbeck et al., 2007; Kaugars et al., 2010). However, additional research examining the reliability and validity of this scaffolding composite in this population is needed. Furthermore, it is possible that reciprocal relationships exist between parental scaffolding and youth adaptive functioning, such that youth’s functional levels affect parental scaffolding behaviors and vice versa. These bidirectional relationships were not examined in the present study.

**Conclusions and Clinical Implications**

Despite the aforementioned limitations, the current study addressed multiple gaps in the existing SB literature. In accordance with the AAIDD model, youth’s skills were examined across all three adaptive functioning domains, with findings suggesting that youth with SB acquire numerous skills to meet the demands of daily life as they age. Youth are generally able to complete everyday tasks related to communication, self-direction, functional academics, and social interactions with others at the same level as their peers, but struggle with tasks related to self-care and home living (e.g., cleaning, food preparation). Therefore, interventions aimed at
improving autonomy, especially during the transition from adolescence to early adulthood, may be of utmost importance for this population (Stiles-Shields et al., 2018). Adaptive skills are likely amenable to change, yet it is also important to tailor interventions to meet the specific needs of each individual with SB. This involves a consideration of each individual’s ability level in the context of environmental needs. For instance, gaining complete independence with self-care and home living skills may be an appropriate goal for some youth with SB, whereas others may be lower functioning and benefit more from enhanced communication skills to effectively convey their needs to caregivers.

Functional outcomes may also be related to the synergistic effects of condition-related and environmental factors. Impairments in executive functioning and attention can negatively impact functional outcomes and therefore are likely important to monitor via regular screenings. Creating structured checklists to capture each individual’s cognitive risk factors (e.g., lesion level, presence of shunts) and developmental course (e.g., whether or not they are meeting milestones), in turn, may help healthcare providers efficiently connect families with necessary supportive services in a timely manner. For example, children at risk for cognitive difficulties who are falling behind in school could be flagged and referred for a neuropsychological assessment. Moreover, given that only maternal scaffolding (not paternal) was a significant moderator, mothers may be uniquely situated to support learning and task success in youth with SB, and could serve as an important mechanism for future intervention efforts. Additional research examining the influence of other environmental factors, such as the broader family support system, is needed to improve care for these families.
APPENDIX A

MEASURES
Questionnaire Measures (Alphabetized):


Behavior Rating Inventory of Executive Function (BRIEF)

Child Behavior Checklist (CBCL)

Medical History Questionnaire (MHQ)

Swanson, Nolan, and Pelham-Fourth Edition (SNAP-IV)

Teacher Report Form (TRF)

Direct Assessment Measures:

Cognitive Assessment System (CAS)

Wechsler Abbreviated Scale of Intelligence (WASI)

Wechsler Intelligence Scale for Children-Fourth Edition (WISC-IV)

Observational Measures:

Family Interaction Macro-coding System (FIMS)
REFERENCE LIST


VITA

Adrien Winning is a doctoral student at Loyola University Chicago studying clinical psychology with a specialty in child, adolescent, and family issues. She received her B.S. in Neuroscience and Psychology from The Ohio State University in 2015, graduating cum laude. During her time as an undergraduate at The Ohio State University, Winning conducted research at the James Cancer Hospital and Solove Research Institute examining the impact of primary brain tumors on adults’ cognitive abilities and psychosocial functioning. Concurrently, Winning worked under the mentorship of Dr. Cynthia Gerhardt at Nationwide Children’s Hospital studying family adjustment to various pediatric medical conditions (e.g., cancer, neonatal disorders) and the death of a child. After graduation, Winning continued working at Nationwide Children’s Hospital as a full-time research coordinator, where she solidified her interest in the cascading impact of medical illness on psychosocial adjustment in pediatric populations. Since starting graduate school at Loyola, Winning has been a member of Dr. Grayson Holmbeck’s research lab and her interest in pediatric psychology has continued to grow. As part of this lab, Winning has worked on numerous projects examining the interrelationship between neuropsychological, psychosocial, and family functioning in the context of spina bifida. Winning’s master’s thesis examined the impact of neuropsychological functioning and parental scaffolding on adaptive functioning trajectories in youth with spina bifida. Through these aforementioned experiences, Winning has had the immense privilege of sharing her teams’ innovative research via the dissemination of multiple presentations and peer-reviewed articles.