

# The school functioning of children with additional health and developmental care needs in the primary years

A literature review



The Australian Government and State and Territory Governments are working in partnership with The Royal Children's Hospital Centre for Community Child Health in Melbourne, the Murdoch Childrens Research Institute, and the Telethon Institute for Child Health Research, Perth, to deliver the AEDI. The Social Research Centre, Melbourne is managing the AEDI data.



Australian Early Development Index

June 2014.

Produced by The Royal Children's Hospital Centre for Community Child Health, and the Murdoch Childrens Research Institute.

Details in this report are correct at time of printing. This report can also be found at: [www.aedc.gov.au](http://www.aedc.gov.au)

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Suggested citation

Howell-Meurs, S., O'Connor, M., Kvalsvig, A., Goldfeld, S. The school functioning of children with additional health and developmental care needs in the primary years: A literature review. Centre for Community Child Health, 2014.



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# Contents

<b>1 Executive Summary</b>	<b>1</b>
<b>2 Introduction</b>	<b>3</b>
Defining Additional Health and Developmental Needs	3
Prevalence	4
<b>3 Background</b>	<b>5</b>
Developmental context	5
School functioning	5
Methodology	6
<b>4 Results</b>	<b>9</b>
Transition to school	9
Children’s skills at school entry	10
Readiness of the school	11
The role of families in the transition process	12
Barriers and facilitators of school success in the primary school years	13
Type and severity of condition	14
Individual characteristics that relate to school success	14
The role of families in promoting school success	15
Characteristics of successful schools	15
School integration	16
Models of care	18
<b>5 Implications for policy and practice</b>	<b>21</b>
Disability and education policy in Australia	21
The functional needs approach	22
Specific strategies to support children with AHDN in the educational environment	24
Conceptual framework	24
<b>6 Conclusions</b>	<b>29</b>
<b>7 References</b>	<b>31</b>

# 1 Executive Summary

Children with additional health and developmental needs (AHDN) have or are at increased risk for chronic physical, developmental, behavioural, or emotional conditions and require more health and related supports than their peers. Importantly, this includes children with both established needs (those with a recognised diagnosis) and those with emerging needs (those who either have yet to be diagnosed, or have been identified as requiring further assessment by their teachers). The impact of additional needs on children's early school experiences is critical in helping to establish either positive or negative educational trajectories of school engagement and achievement.

This report provides a narrative literature review of the current research into the impact of additional health and developmental needs on children's experiences during the primary school years. It also highlights the processes and factors that help or hinder children's successful progress through primary school.

## **Key findings:**

Many primary school children experience additional health and developmental needs.

It is important to consider both those children with established additional needs and those with emerging additional needs, as the latter group are also at risk and provide an important target for early intervention.

Additional needs can affect the transition to, and journey through, primary school at an academic, emotional, psychological and physical level.

The level of impact of additional needs on a child's school experience is highly variable, and influenced by factors operating at the individual, family and service systems levels.

Considering children's functioning rather than just their diagnosis is critical to addressing their individual needs.



# 2 Introduction

Children with additional health and developmental needs (AHDN) have or are at increased risk for a chronic physical, developmental, behavioural, or emotional condition and require more health and related supports than their peers (Newacheck et al, 1998). The impact of additional needs on children's early school experiences is critical in helping to establish either positive or negative educational trajectories of school engagement and achievement. It is therefore essential to gain an understanding of the varied influences that shape the learning experience of the diverse population of children with AHDN. This includes mapping the nature of their needs, the manner in which those needs impact upon daily and future functioning and well-being, and how we can best support these children to reach their full potential. The ecological model suggests that these influences are likely to include both characteristics of children and their environments (Bronfenbrenner & Morris, 1998).

*“Children with additional health and developmental needs have or are at increased risk for a chronic physical, developmental, behavioural, or emotional condition and require more health and related supports than their peers.”*

Yet while much research has been conducted on additional needs from a medical and health care perspective, research into the impact of AHDN to school outcomes has been neglected (Forrest, Bevans, Riley, Crespo, & Louis, 2011). As education occupies a fundamental role in children's development, influencing well-being both during the school years and in later life, it is critical to gain an understanding of how the presence of AHDN may impact school experience, particularly in the early years of schooling when academic and social trajectories are formed (Hauser-Cram, Durand, & Warfield, 2007).

The review described in this report seeks to provide an overview of the current research around the impact of additional needs on children as they move through the primary school years. First, key concepts are defined and the review methodology described, before exploring emerging themes from the literature. Implications for intervention and policy responses are then discussed, with the literature suggesting many potential targets for intervention to improve the school journeys of children with AHDN. Finally, a conceptual model is proposed to draw together a more holistic picture of the pathways through which school life can be impacted for children with AHDN.

## Defining Additional Health and Developmental Needs

Definitions of additional health and developmental needs (also termed 'special health care needs' in the academic literature) are diverse and have traditionally incorporated measures such as functional status assessments, condition lists, and limitations in socially defined roles (Newacheck et al., 1998). Nevertheless, children with AHDN can generally be defined according to three key criteria (Newacheck et al., 1998):

1. The presence of a condition that is chronic (usually defined as lasting or expected to last for at least six months)
2. Which has an impact on functioning or quality of life, and
3. Necessitates additional medical, educational, or allied health support beyond that required by children generally.

This incorporates a wide variety of conditions, such as diabetes, learning disabilities, obesity and behavioural disorders. This broad, non-categorical approach is often preferable to conceptualising AHDN in terms of specific diagnoses, as many conditions impact children's educational experience in similar ways, such as through the effects of integration difficulties or school absenteeism. This definition also recognises the full spectrum of the disability continuum, including both children with formally diagnosed and more complex conditions, and those experiencing milder or emerging developmental issues (Goldfeld, O'Connor, Sayers, Moore, & Oberklaid, 2012). This latter group has tended to be under-represented in discussions of the needs of children with AHDN, despite the potential benefits of early intervention for children with milder difficulties (Manning, Homel, & Smith, 2010; Warfield, 1994).

Hence, in this review we have employed this non-categorical approach to understanding the school experiences of children with special health care needs, rather than focusing on children with specific diagnoses. The findings therefore apply more broadly both to children with well established AHDN and those with emerging AHDN.

*One-fifth of children in their first year of schooling experience additional health care needs.*

## Prevalence

Wide variation has been evident in the documented prevalence rates for AHDN among school-aged children. In the United States, estimates have ranged from less than 5% to over 30% (Newacheck et al., 1998). This is due to a variety of factors including variation in definitions of AHDN, the nature and severity of the included conditions, the age cohorts considered in the samples, and the methods and measures used for data collection (Bethell, Read, Blumberg, & Newacheck, 2008; Goldfeld et al., 2012; Newacheck et al., 1998). Taking this into consideration, best estimates in the United States for children under 18 years of age range from 13-19% (Bethell et al., 2008; Forrest et al., 2011). Recent estimates from Australian data similarly suggest that approximately one-fifth of children in their first year of schooling experience additional health care needs (Goldfeld et al., 2012). This included just over 4% identified with well-established needs, and a further 18% displaying emerging developmental issues.



# 3 Background

## Developmental context

The period of middle childhood, when children attend primary school, has been recognised as a time of pivotal importance for psychological and emotional development (Colle & Del Giudice, 2011). Knowledge and experience begin to inform understanding of and participation in complex social organisation, and peer relationships begin to play a larger role as children move outside their nuclear families. Children begin to develop more sophisticated cognitive skills including increased executive function and hence capacity for planning, behaviour regulation, focussed attention, and self-control (Collins, 1984). Middle childhood is also recognised as an important period in the development of mental health trajectories, and is associated with the onset of various pathological disorders including anxiety, anti-social behaviour and Attention Deficit Hyperactivity Disorder (ADHD) (Kessler et al., 2005). Middle childhood thus represents a time of significant emotional, behavioural, and cognitive development. Hence, it is important to understand individual differences in the competencies obtained during this period.

“*School experiences occupy a pivotal role in promoting children’s wellbeing.*”

## School functioning

School provides a significant platform for children’s academic, psychological, emotional and physical development (Fiscella & Kitzman, 2009; Hauser-Cram et al., 2007). School experiences, particularly during the early years, thus occupy a pivotal role in promoting children’s well-being. Yet defining what it means for a child to be functioning well at school is complex and multifaceted. Academic failure is a key indicator and carries both short- and long- term implications, ranging from heightened risk for school dropout (Battin-Pearson et al., 2000), to occupational attainment in adulthood (Wiesner, Vondracek, Capaldi, & Porfeli, 2003). It is also increasingly recognised that children’s engagement with the school context is also a critical aspect of positive school functioning. This includes emotional (positive and negative reactions to teachers, peers, school), behavioural (participation in school tasks and activities), and cognitive (investment of time and effort to master schoolwork) dimensions (Fredricks, Blumenfeld, & Paris, 2004). While engaged students actively participate in their school environment and are motivated to learn (Fredricks et al., 2004), disengaged students are more likely to display disruptive classroom behaviors, bullying, truancy, absenteeism, and school dropout (Osterman, 2000; Reyes, Brackett, Rivers, White, & Salovey, 2012). School functioning is a product of the characteristics of both the child and the school, such as the learning environment and the quality of child-teacher interactions (Reyes et al., 2012). The degree to which schools meet children’s needs such as those for relatedness and autonomy is thus highly relevant to school experience and success (Hauser-Cram et al., 2007; Pianta & Walsh, 1996; Reyes et al., 2012).

Despite the multifaceted nature of school experiences, measures of school success have largely focussed upon academic achievement (Forrest et al., 2011; S. Johnson et al., 2009; S. Johnson, Marlow, & Wolke, 2012; Saigal et al., 2003). Measures are increasingly available to investigate additional aspects of the child's experiences of school, such as their level of engagement and social competencies, some specifically in relation to the experiences of children with AHDN (Burger, Nadirova, & Keefer, 2012; Forrest et al., 2011; MacCann, Lipnevich, & Roberts, 2012). Forrest et al (2011), for example, have measured the influences of AHDN on school outcome both academically, emotionally and behaviourally through examination of attendance, student engagement (encompassing motivation and emotional security), behavioural threats to achievement such as disruptive behaviours and bullying, and academic achievement. While the conceptualisation and measurement of school functioning is clearly complex, an area of consensus is the need to extend our focus beyond academic achievement to also include social elements and the child's own subjective perceptions of the school environment.

In this report we draw on this broader definition of school functioning when exploring the school experiences of children with AHDN.

## Methodology

The literature review was conducted to answer the following questions:

What are the educational outcomes for children with AHDN *at school entry* (including early academic skills and school readiness)?

What are the educational outcomes for children with AHDN during *the later primary school years*?

What *individual, family, and school-level variables* affect these educational outcomes for children with AHDN?

Web of Knowledge, PubMed, ERIC, Expanded Academic ASAP (Gale) and Medline were searched. In order to enhance sensitivity, search strategies were modified according to the database. Searches were conducted between 20/9 and 5/12, 2012. Search terms were developed from MeSH headings and relevant article keywords. The search terms used variants of 'special health care need' (the term generally used in the academic literature to describe AHDN) OR 'SHCN' OR 'special need' OR 'disability' OR 'additional need' OR 'children with special health care needs' OR 'CSHCN', AND 'school' OR 'education' OR 'academic' OR 'education special' OR 'school', AND 'outcome' OR 'milestone' OR 'achievement' OR 'development', AND 'long term' OR 'longitudinal' OR 'trajectory' AND 'girl' OR 'boy' OR 'child'. Searches were subsequently conducted by either MeSH terms (major topic), topic or title. Additional references were gathered from relevant citations in retrieved articles.

Exclusion criteria included articles in a language other than English, and those irrelevant to the review questions (including papers relating to education other than at the primary or elementary level, or where the focus was not on education), and papers dating prior to 1980. Grey literature, which typically has limited distribution, was searched for via three key strategies: through relevant citations from key articles, through relevant databases and websites, and through web based searches using Google. The search of grey literature was focussed on the Australian context and included web-based material. Included papers were reviewed in full and the analysis of the included papers was descriptive.

Of the 1,580 papers identified, 1,448 were excluded on the basis of the title or abstract. Final screening of the full papers identified 63 references meeting the inclusion and exclusion criteria. The search of the grey literature yielded 26 reports, in addition to numerous relevant government web-pages. Limitations of the review included time restraints on the duration of the search period, the use of title and abstract to exclude papers, and the exclusion of papers written in languages other than English.



# 4 Results

Due to the breadth of conditions encompassed by AHDN, and complexity of the issues involved, research has tended to consider the impact of specific conditions upon quality of life and school outcomes. For example, studies have considered the impact of ADHD (Bussing et al., 2010; DuPaul & Power, 2008; LeFever, Villers, Morrow, & Vaughn, 2005), learning disabilities (Mattison, Hooper, & Glassberg, 2002; McKinney & Speece, 1986; Morris, Schraufnagel, Chudnow, & Weinberg, 2009; Scarborough & Parker, 2003), prematurity (S. Johnson et al., 2009; Ortiz-Mantilia, Choudhury, Leever, & Benasich, 2008), and chronic diseases such as diabetes and cancer (Daly, Kral, & Brown, 2008; B. Moore, 2005; Northam, Rankins, & Cameron, 2006). Significantly less research has considered the children with AHDN as a broader group. Nevertheless, a trend is clearly evident for children with AHDN to experience lower levels of engagement and achievement in the primary years, including both during the transition to school and at the end of the primary school years as children prepare for the transition to high school.

*“A trend is clearly evident for children with AHDN to experience lower levels of engagement and achievement across the primary years.”*

A number of key findings emerged in the literature. We have organised these findings around four major areas that align with child development and school engagement:

- transition to school
- school functioning
- later primary years
- barriers to school success.

## Transition to school

Children with AHDN are potentially highly vulnerable at the time of transition to school due to a range of factors including academic and emotional difficulties.

School transition is often a difficult and disjointed process, partly due to the limited information exchange between service providers, for children with AHDN and their families.

Social and emotional skills preparation prior to school entry improves outcomes for children with AHDN.

Children with AHDN may experience a variety of service based impediments to successful transition, including poor communication between service providers, lack of continuity between the preschool and school environments, and lengthy and repetitive assessment processes.

Families of children with AHDN can experience a range of challenges to successful transition including additional financial demands, identifying and accessing support and identifying the most appropriate school.

Interventions are needed to streamline and coordinate this process and support the child and family during the transition journey.

School transition encompasses the process 'beginning before children start school when families start to make decisions and seek information about school and extending beyond the actual start of school until children and families feel comfortable at school' (Dockett, Perry, & Kearney, 2011). Successful transitions to school are influenced by both the child's characteristics and the broader context in which the transition process occurs (Dockett et al., 2011). At the individual level, children's physical development, social competence, emotional maturity, language and cognitive development, and general knowledge and communication skills are all relevant to their capacity to adjust to the new demands of the school context (Farrar, Goldfeld, & Moore, 2007), and can exert a significant influence over the subsequent ease of transition and school success (S. Fowler & Schwartz, 1991; L. L. McIntyre, Blacher, & Baker, 2006).

While school transition can be a difficult process for children generally, involving various challenges for the child and family including issues around separation, independence and institutional expectations on behaviour, communication and academic competency (Rous, Hallam, McCormick, & Cox, 2010), this process can be significantly more demanding for children with AHDN. A number of studies have considered preschool to school transitions for children with AHDN either generally or - in terms of a specific condition (Fowler & Schwartz, 1991; Janus, 2011; Janus & Duku, 2007; L. McIntyre, Eckert, Fiese, DiGennaro, Reed, & Wildenger, 2010; L. McIntyre & Wildenger, 2011; L. L. McIntyre et al., 2006; Janus, Duku, & Hughes, 2010). A picture emerges of children with AHDN as a potentially highly vulnerable population due to a range of factors including lack of academic and emotional skills prior to school entry and suboptimal health, and for whom school transition is a difficult and disjointed process with limited communication between the educational and supporting institutions.

### **Children's skills at school entry**

School readiness, or the capacity and skills of the child to undertake the transition to school, is a vital element dictating the success of school entry. A number of studies have sought to measure school readiness in primary school-aged children with AHDN and their peers. Whiteford et al (2012) studied the early years social-emotional and learning competence of Australian children with AHDN just prior to school entry (at 4 to 5 years of age) and during schooling (at 6 to 7 years of age). Children with AHDN scored significantly lower on teacher rated social-emotional and learning competencies when compared with their peers. This trend existed prior to school entry but was also maintained during the early years of schooling. Indeed, AHDN status among preschool children was identified as a risk factor for poorer future social-emotional and learning outcomes.

Population-level data from the Early Development Index (EDI; Janus et al 2011) and Australian Early Development Index (adapted from the EDI; Goldfeld et al 2011) has demonstrated similar results. The EDI is a teacher-reported measure of children's health and development at the time of school entry across five important domains: physical health and wellbeing, social competence, emotional maturity, language and cognitive development, and communication skills and general knowledge. Looking across EDI data from Australia, Canada and Mexico, Janus et al (2011) found that overall, children with AHDN demonstrated a high level of vulnerability across the developmental domains assessed, compared with their peers. Unsurprisingly, the nature of children's impairments influenced the level of impact. For example, behaviour and learning disability problems were found to exert a moderate to large impact across all domains, whereas children with a visual impairment showed results comparable to those of their peers lacking AHDN across all domains (Janus, 2011).

*Children with AHDN demonstrated a high level of vulnerability across developmental domains.*

Goldfeld et al (2012) looked specifically at data from the AEDI and found that children with both well established (4% of the population) and emerging (18% of the population) health and developmental problems were rated lower by their teachers across the five domains of early childhood assessed. Findings further suggested that complexity of needs (or severity of condition) was also an important consideration, with children with well-established conditions experiencing the poorest outcomes. Critically, while just over half (56.2%) of the children with established needs had participated in an early intervention program, less than a fifth (15.63%) of children with emerging needs had participated in such programs (Goldfeld et al., 2012). Thus, while the benefit of early intervention is well-established, it is clear that many of the children who could gain significant benefits are not accessing such resources.

Observations such as these have prompted the development of future environment surveys (Fowler et al 1991), in which assessments such as teacher interview and checklists or direct observation, inform decision making around goals for skill acquisition for the child. Various intervention programs have also highlighted that children with AHDN taught a range of 'survival skills' for mainstream schooling, including classroom participation and attention to independent tasks, were more likely to be placed and subsequently engage in the mainstream school environment (Fowler et al 1991).

## **Readiness of the school**

Although successful transitions to school are as much a product of the school as of the child, research into school practices that facilitate primary-level transition has been relatively limited. Fowler et al (1991) in their review of the transition process for children with AHDN noted its dependence on three main factors: care provision of the providers and families, the match between the preschool and school environment, and the strategies used to bridge the old and new environment. Impediments to transition include poor information exchange on the nature and degree of the impairment and outcomes at preschool level, lengthy assessment procedures prior to the development of individual education plans, fragmented service provision, the lack of overarching generalised policies, and a lack of functional needs provision prior to school entry. Studies on parental feedback indicate that dissatisfaction with the level of service provision is common (Janus, Lefort, Cameron, & Kopechanski, 2007; Valeo, 2003).

Difficulties surrounding service provision also provide a major impediment to successful transitions for children with AHDN. A recent study found the full complement of required services for school transition to be lacking for over half of the children with AHDN (Janus, Kopechanski, Cameron, & Hughes, 2008). A delay in the implementation, rather than the availability, of the appropriate support resources was evident, despite the maintenance of communication channels by the involved parties both prior to and following transition. Parent's satisfaction with both the educational and health care service provision was low, although, significantly, the post-transition parents reported a decline in the burden of impact of the disability on the family. Unsurprisingly, the types and extent of difficulties again varied across disorders. Parents of children with Autism Spectrum Disorders (ASD) have reported higher rates of difficulties in accessing educational services and qualified professionals, compared with parents of children with other AHDN (Montes, Halterman, & Magyar, 2009). Various barriers to transition planning by service agencies have been identified, including lack of role designation, planning time and inter-agency communication, with various models subsequently developed to facilitate the transition process (S. Fowler & Schwartz, 1991; Hanline, 1988; Iantosca, 2012; Wolery, 1989).

### **The role of families in the transition process**

Families play a significant role during the transition process for children with ADHD (Dockett et al., 2011; S. Fowler & Schwartz, 1991; Hains, Rosenkoetter, & Fowler, 1991; Janus et al., 2008; T. Johnson, 1986; L McIntyre et al., 2010). Successful school transitions can be impacted upon by a number of significant family factors, many of which impact upon children generally, but may be compounded by the presence of AHDN. Inadequate personal and financial support for both the child and family including in the provision of additional services and supports, lack of resource and support continuity between kindergarten and primary school, emotionally and logistically arduous assessment processes, variable family involvement in transition planning, inflexible transition policies, and poor communication and information exchange, can all act as impediments to the transition process. Parent frustration may also arise from excessive expectations placed on parents to act as advocates for their child, poor support, and lack of recognition of parent expertise on their child's condition. Conversely, satisfaction has been shown to rise with increasing information exchange and support from the involved programs.

Dockett et al's qualitative inquiry into school transition for families of children with AHDN in NSW identified additional barriers. These included:

- the difficulties of identifying the most appropriate school for the child
- logistical, policy or administrative barriers to enrolment
- the complexity, difficulties and lack of continuity associated with assessment and assessment outcomes including the withdrawal of previous support
- difficulties surrounding accessing and consistency of support
- the role of parents in terms of advocacy and disempowerment
- financial and other family constraints and pressures
- detrimental impacts on other school-age siblings.



Positives included the provision of informal support, usually from parents in a similar position, family advocacy and resilience, and perceptions of the essential role of education in improving the long-term outcome for their child. In response to these recognised difficulties, various models have been developed to assist the family in the transition process involving overall planning and skill development, information exchange, and assistance with school selection (Diamond, Spiegel-McGill, & Hanrahan, 1988; S. Fowler, Chandler, Johnson, & Stella, 1988).

## Barriers and facilitators of school success in the primary school years

AHDN vary considerably in their nature and severity and therefore their impact on the child.

Children with functional and associated behavioural limitations tend to experience greater challenges in terms of school engagement, but milder or purely physical conditions can also impact on the educational experiences of the child.

A child's personality can impact on school success with a positive relationship between traits such as conscientiousness and emotional competency and higher levels of school engagement.

Early positive attitudes towards schooling are also predictive of improved social and academic outcomes.

A strong partnership between the family and service providers is critical for optimisation of care and planning, but is often lacking for those families with the highest needs.

Coordinated and comprehensive care is critical for supporting school engagement and success, but is often hampered by limited information exchange between health and education service providers.

*Overall, studies have reported poorer outcomes for primary-level children with AHDN, when compared to their peers.*

Relatively few studies have presented data on the primary school outcomes of children with AHDN as a collective group, with analyses and discussions of school outcomes tending to focus on specific conditions (Bender & Wall, 1994; Compton, Fuchs, Fuchs, Lambert, & Hamlett, 2012; McCormack, Harrison, McLeod, & McAllister, 2011). Overall, studies have reported poorer outcomes for primary-level children with AHDN, when compared to their peers. These include decreased school engagement, increased bullying, compromised social relations due to disruptive behaviours, and lower academic achievement overall amongst later primary school age children (Forrest et al., 2011). A number of factors has nevertheless been identified that act to impede or promote progress of children with AHDN through primary-level schooling, and these are described below (Bethell et al., 2012; Forrest et al., 2011; Hauser-Cram et al., 2007; Jimerson, Egeland, & Teo, 1999).

## **Type and severity of condition**

Children with AHDN are a diverse population, whose difficulties can range across physical, behavioural, or social-emotional dimensions. Given this heterogeneity within the AHDN population, the degree to which additional health care needs impact upon educational engagement is highly variable. The diversity of the AHDN population has been recognised by Janus (2011) as a barrier to analysis and policy surrounding the education of children with AHDN.

Due to the variety of disorders encapsulated by the term AHDN, a concomitant variation is evident in the degree to which different conditions impact school outcomes, which may range from extensive to minor. Thus, while ADHD may impact significantly on school functioning (Kawabata, Tseng, & Gau, 2012; Loe & Feldman, 2007), the effects of chronic obesity may be less obvious (Huang, Goran, & Spruijt-Metz, 2006). This variation may also occur within different conditions. While some studies have suggested that academic performance is not compromised by the presence of asthma or obesity, other studies have found an association between the presence of these conditions and factors such as school attendance rates and academic success (Moonie, Sterling, Figgs, & Castro, 2008; Naude & Pretorius, 2003; Taras & Potts-Datema, 2005), with potentially significant implications for levels of school engagement and functioning.

In Forrest's (2011) study, children who qualified as having AHDN solely because of prescription medication use, obesity or asthma had similar outcomes to children without AHDN, whereas those with functional or behavioural limitations experienced the greatest impacts upon their school experience. Those children with diagnosed functional and behavioural limitations tended to experience greater difficulty in paying attention, increased boredom and increased experience of bullying, with lower academic achievement. By contrast, those with only functional impairments were less likely to look forward to school or be motivated to achieve good results, and were more prone to bully others. While being bullied is significantly more common amongst children with AHDN, regardless of condition type, bullying others tends to be associated with behavioural, emotional and developmental conditions (Van Cleave & Davis, 2006).

## **Individual characteristics that relate to school success**

Characteristics of children themselves, like their temperament, personality, and feelings about school, also impact on their educational experiences. Early feelings about the school experience have been shown to impact significantly on later outcomes (Hauser-Cram et al., 2007). Qualitative and quantitative testing of children with AHDN prior to and at the time of school entry and in later elementary school indicated that while later mathematical achievement for example was influenced by feelings of competency in maths and literacy, later literacy outcomes were predicted by general attitudes toward school. The authors speculated that early positive attitudes to schooling enhanced receptivity to instruction, and thus provided scope for additional teacher attention and intervention to improve outcomes. Levels of both behavioural and emotional adjustment and social competence among later primary-aged children with AHDN have been shown to increase with enhanced social bonds to peers or teachers (Murray & Greenberg, 2006). Conversely relationship alienation was associated with increasing self-reported behavioural problems and mental health issues including anxiety and depression.

The interplay between temperament and personality characteristics and behaviours can also influence adjustment to the school setting (Reed-Victor, 2004). Personality dimensions, such as manageability, conscientiousness and extroversion can positively influence the success with which the child adapts to the school environment. For example, lack of manageability as rated by parents was subsequently manifested as disruptive behaviours in the primary school context, with enhancement of the teacher-child relationship being a possible focus for intervention. The child's perception of the school experience is also important. A sense of school engagement and security has been linked to school success (Bethell et al., 2012). These have been found to be lacking in over half of children with AHDN, and was compounded by the presence of emotional, behavioural and developmental problems.

*“The need for a comprehensive and coordinated system of educational care is critical.”*

### **The role of families in promoting school success**

The importance of the family in shared decision making has also been highlighted as critical for children with AHDN (Kogan, Strickland, & Newacheck, 2009), and has been linked to increased parental satisfaction regarding their child's care, improved child outcomes, and reduced levels of unmet needs, school absenteeism, total health care expenditure and utilisation (Denboba, McPherson, Kenney, Strickland, & Newacheck, 2006; Fiks, Mayne, Localio, Alessandrini, & Guevara, 2012; Jimerson et al., 1999; Knapp, Madden, & Marcu, 2010; McPherson et al., 2004). Shared decision making also aligns with the pervasive ideology in Australian and United States welfare policy of the family as the ideal providers of care, and assumptions surrounding the presence of the emotional and economic infrastructure to support this (Breen, 2009; Dunst, 1985), although acknowledging the role of a multidisciplinary approach (Smith et al., 2009). Unfortunately research indicates that those families with children with highest need including lower SES, minority children and those with higher functional needs, are less likely to experience a sense of partnership with the health care provider (Denboba et al., 2006; Knapp et al., 2010; Mayer, Skinner, & Slifkin, 2004). Lack of a sense of partnership has been linked to higher levels of dissatisfaction, unmet child and family needs, and lack of access to specialty services.

### **Characteristics of effective schools**

Schools obviously have a major role to play in promoting positive educational pathways for children with AHDN. Yet many barriers to effective support have been identified. For example, Mukherjee et al.'s (2000) study on the support needs of AHDN school children from the students', teachers' and parents' perspectives in the UK, highlighted barriers to information sharing within and between schools, disparities in the awareness and understanding of school staff, and a lack of coordination and time allocation in the provision of pastoral and medical care to AHDN students. The need for a comprehensive and coordinated system of educational care is critical.

The research also revealed important differences between the perceptions of students and their teachers in terms of the emotional support required, with the former preferring to liaise with 'approachable' teachers rather than a specified individual. Furthermore, the reaction of those without AHDN in terms of their level and capacity for understanding and support or, alternatively, potential to alienate the child must be considered (Forrest et al., 2011). Mukherjee et al (2000) found that amongst children with chronic health conditions, teacher support was important for navigating peer relationships, participating in school activities, explaining the AHDN to the child's peers, and in discussing health-related needs. Further barriers may arise in regards to participation in school and recreational activities, access to support services, professional development of teaching staff and paraprofessionals, the impact of medical treatment plans and treatment side-effects, lack of understanding by teachers and peers, lack of emotional or social support, lack of teacher support including the provision of information about a child's AHDN and its appropriate management, information sharing within and between schools, and the provision of medical and coordinated care in schools (DEEWR, 2012; Dunst, 2000; Lynch, Lewis, & Murphy, 1993; Mukherjee et al., 2000; Whiteford, Walker, & Berthelsen, 2012).

Critically, information provision to teaching staff on the nature of the child's condition can be limited, with the main source of information often being the parents, or child themselves. Furthermore, family report on the experiences of children with AHDN in the school system highlight that their children can be subjected to 'limited opportunities, low expectations, exclusion, bullying, discrimination, assault and violation of human rights' (DEEWR, 2012). Perceived barriers to participation have been shown to be relatively greater for schooling compared to other domains such as service usage, policy or social support amongst children with AHDN compared with their peers (Dunst, 2000). The severity of barriers was shown to increase with age, greater levels of impairment in physical functioning, and increased behavioural difficulties, and appeared to be mediated by the relative supportiveness and attitudes of the school. Recognised differences in the levels of parental satisfaction with service provision for children with AHDN is however also likely to be influenced by the types and severity of the conditions involved (Lynch et al., 1993).

The perceived main barriers to the provision of educational services to children with AHDN may vary depending upon whose perspective is considered. In one qualitative analysis of the provision of educational service to children with chronic illness in the United States, while government and service providers prioritised lack of funding, staff awareness, staff and resource limitations; parents considered a lack of teacher understanding of the child's needs and lack of information to be the primary impediments to service delivery, with emotional and social issues considered by parents to be the primary barriers to participation (Lynch et al., 1993). Similarly, Ingerski et al (2010) have illustrated significant variation between the child and parent reported perceptions of the impact of various chronic conditions on the health-related quality of life, including the school domain. A dichotomy often exists regarding the impact of AHDN between the educational focus of schools, and the parent and child's primary focus on overall well being.

## School integration

Both mainstream and special education offer advantages and disadvantages for children with AHDN.

The choice of mainstream or special education for a given child can be complex.

Integration policies for children with AHDN into mainstream schooling have been introduced in many countries including Australia and Canada, and have resulted in decreased enrolment rates in dedicated special education.

Successful integration policies require support and advocacy for children in mainstream settings.

There has been ongoing discussion in the literature about the advantages and disadvantages of mainstream versus dedicated special education for children with AHDN (Hibel, Farkas, & Morgan, 2010; L McIntyre et al., 2010; Mukherjee et al., 2000; Raviv, 2010; Scruggs & Mastropieri, 1993; Thompson, Ferdig, & Black, 2012). On one hand placement of children with AHDN in mainstream schooling can result in difficulties from both the child and teacher's perspective, such as poorer academic outcomes and school attachment. Children with AHDN with intellectual disabilities in mainstream schooling have demonstrated increased rates of problem behaviours and poorer relationships with both their teachers and peers (McIntyre et al., 2010), and describe increased perceptions of school danger compared with their peers (Murray & Greenberg, 2001). Separate special education classes within mainstream settings has also been criticised for the duplicated system, which diminishes the role of the regular teacher, the fragmentation of services that results from categorical programs, stigmatisation of the participating children, and for being a source of conflict between parents and educators on service provision (Carnine & Kameenui, 1990).

Conversely, dedicated special education contexts may not always provide the most desirable option for children with AHDN. Thompson et al.'s (2012) evaluation of online education for children in the US found that those with AHDN demonstrated poorer outcomes compared with their peers enrolled in mainstream schooling. The poorer outcomes of children with AHDN in special education may be reflective of the greater impairments of children in the program, the lack of efficacy of the programs, or other factors that differentiate children in this group (Jimerson et al., 1999). Of relevance is the finding that, in a US context at least, placement of a student in special education tends to be associated with continued or increasing underperformance of the child, potential stigmatisation and long-term negative outcomes (Hibel et al., 2010; Lynch et al., 1993).

Following on from federal anti-discrimination policies in Australia, the United States and Canada, there has been a move towards greater integration of children with AHDN into mainstream education systems. Despite this, there has been a reluctance to abolish the special school system entirely (Dempsey, Foreman, & Jenkinson, 2002). National quality standards on access and participation in education have been a relatively recent phenomenon in Australia through the Disability Standard for Education 2005, which undergoes a five yearly review process to ensure ongoing efficacy and quality. Overall, the success of integration has been variable. In Australia, access is currently not universal. Policies surrounding school integration have provided scope for refusal of admission to mainstream schooling by principals on the basis of factors such as lack of appropriate facilities or resources. Teacher unions have also resisted integration due to its scope to undermine the careers of special needs educators and increase demands on the working conditions of mainstream teachers. Despite this, data from NSW reveal a general decline in enrolment in special schools across all categories excepting behavioural and emotional disturbance, with corresponding increases in enrolments in support classes in mainstream schools.

Furthermore, for school attendance overall, the proportion of students with a disability has increased significantly over the last two decades (Manning et al., 2010). Although this is partly attributable to an increase in prevalence of children with severe or profound limitations, it also reflects national policies of inclusive education. The involvement of state legislation on the implementation of the national guidelines also fundamentally impacts on the policies and services available in each state. Recent national policy in Australia has recommended increased community-wide advocacy for greater tolerance and explanations of the rationale behind inclusion (DEEWR, 2012). Despite the promotion and benefits of inclusion policies, parents and advocacy groups have indicated that the option of special schooling remains important, due to the complex healthcare needs of some children with AHDN. Special education does indeed carry various benefits including ongoing evaluation and parent teacher partnerships (Lynch et al., 1993), and the majority of children in Australia with multiple AHDN, or severe or profound core activity limitations, continue to attend special schools or classes (Eiser & Town, 1987). The choice of an appropriate setting for children with AHDN can therefore be a highly complex process.

*“The choice of an appropriate setting for children with AHDN can therefore be a highly complex process.”*

## Models of care

Trans-disciplinary models such as the systems model of care in the United States and DisabilityCare in Australia, emphasise care coordinated between the families and service providers, and have been linked to improved health and educational outcomes.

Trans-disciplinary approaches that include the many different types of practitioners that a child with AHDN may interact with, have been linked to improved outcomes.

Variability in the success of different models of care appears to be influenced by levels of implementation and access to facilities and services.

The ‘medical home’ model of care in the United States, designed by the Maternal and Child Health Bureau, is one promising way of addressing the needs of children in AHDN, and outlines six core objectives for children with AHDN that emphasise preventative, accessible, continuous, and well-documented care, coordinated with sub-specialities, schools and community agencies (Kogan et al., 2009). The efficacy of this model is partly dependent on its pervasiveness, with an essential component being awareness of the model extending beyond health practitioners to agencies, parents and schools (Fredricks et al., 2004).

This model has, from an educational perspective, demonstrated improvements in school planning, information comprehension and exchange, and decreased rates of hospitalisation and school absenteeism (Denboba et al., 2006; Murphy, Carbone, & Council Children, 2011; Palfrey et al., 2004). Those children most affected by their condition were the least likely to have access to this system of care (Strickland et al., 2009).

Recent initiatives in Australia through the early intervention programs of the Australian Disability Insurance Scheme ([www.ndis.gov.au](http://www.ndis.gov.au)) similarly emphasise the importance of families and fostering the carer-provider relationship. Liaison between the family and a trans-disciplinary team is therefore encouraged via a key worker who provides a single point of contact for the family, thus promoting trust and rapport. The success of its implementation and outcomes is yet to be assessed as the scheme commenced with a nationwide rollout in July 2013.

Case management in an educational setting is a further strategy for monitoring progress and outcomes in children with AHDN, and can be efficacious in improving outcomes. It includes 'elements to ensure that school health officials, parents, and primary care physicians are part of a team which prepares students to be ready to learn and achieve in the school setting' (Bethell et al., 2012). Bethell et al detected a positive association between the presence of case management and school outcomes in the form of decreased grade repetition across the United States. Similarly, among children in the United States with chronic illness, case management by a school nurse resulted in an increased quality of life, and greater participation in educational and recreational activities (Engelke, Guttu, Warren, & Swanson, 2008). The wide variation in the nature and implementation of resources in case management argues for further research into its impacts on the educational outcomes of children with AHDN. Furthermore, the individualised personality profiles among children with AHDN and their influence on levels of school engagement (Reed-Victor, 2004) argues for the value of including these differences in intervention planning for at-risk children.

The potential success of trans-disciplinary approaches such as the medical home model nevertheless argues for the importance of ongoing efforts to improve outcomes through a multi-disciplinary coordinated approach. Co-ordinated care, for example, has been shown to increase parent satisfaction and decrease absenteeism rates, and time and financial burdens for families (Turchi et al., 2009). It is noteworthy that while collaborative care may occur between doctors, the family, allied health and community services, this may not extend to the school environment. Paediatric residents in the United States report high levels of comfort with involving families in shared decision making, but only low comfort levels were apparent in terms of collaborating with schools (Nazarian, Glader, Choueiri, Shipman, & Sadof, 2010).



Reload Images



# 5 Implications for policy and practice

## Disability and education policy in Australia

National guidelines such as the Disability Standards attempt to provide a framework to guide access to and participation in educational opportunities for people with AHDN.

However, a nationally applied policy of educational services for children with AHDN is inconsistent, with states and territories varying considerably in the types and amount of support.

The National Disability Insurance Agency (NDIA) is a new independent commonwealth statutory agency intended to use best practice frameworks to promote goals that meet support needs, develop individualised plans, early intervention strategies, and provide linkages to government and private service providers implementing the National Disability Insurance Scheme (NDIS).

The role of educational supports explicitly, and the needs of children with emerging AHDN, are unclear under this new framework.

Despite the existence of policies for the inclusion of children with AHDN in mainstream education in countries such as Australia and Canada, nationally applied policies on educational services for children with AHDN are typically lacking, with the result that significant disparities may exist between states, territories or regions in the degree of available guidance and support (Janus, 2011). Within Australia, state-administered policies aim to operationalise the guidelines dictated federally by the Commonwealth Disability Discrimination Act 1992, and the associated subordinate Disability Standards for Education legislation (2005), in conjunction with state-based laws. Victoria, for example, provides support in the form of programs such as the Students Support Group, Language Support Program and Enhanced Transition from Kindergarten to School, which aids students with severe disabilities (DEECD, N.D.).

The Disability Standards were intended to clarify the rights of students with disabilities to access and participate fully in education, and to guide providers on their obligations in this process. A recent review of the Disability Standards (DEEWR, 2012), which incorporated submissions and stakeholder consultation, vindicated the value of the framework for promoting access and participation in comparable educational opportunities between children with AHDN and their peers. Deficits were recognised however in the interpretation and application of the standards, the adherence to requirements and lack of terminological clarity. Various federal and state-based recommendations were proposed to address these issues.

A further recent initiative in Australia is the NDIS, which is being introduced from July 2013 across various launch-sites. The purpose of the scheme is to support people with permanent and significant disability, their families and carers, and to provide funding for long-term individualised support with an emphasis on early intervention to maximise long-term outcomes. The program operates to identify goals and support needs, develop individual plans, highlight required supports, and provide linkages to government and private service providers, all informed by best practice frameworks. Eligibility requirements include the presence of a permanent disability or developmental delay, including intellectual, cognitive, neurological, sensory, physical or psychiatric conditions, that impact upon daily functioning or require additional supports, and that these supports are by necessity lifelong.

Further requirements for eligibility for early intervention include evidence that an early intervention will either assist family or carers in providing current support or improve future outcomes. The scheme emphasises inclusion in mainstream and community services, safeguards, continuity of support, guidance agreements with service providers, listings of registered service providers, and the provision of quality and best practice frameworks, although it lacks detail on the provision of education support specifically. Supports surrounding assistance with integration into school or other educational programs under the NDIS are therefore currently addressed via extant services provided through state-based programs such as the Victorian Disability Services program. Similarly, the listings of registered service providers, while offering many of the physical and emotional supports that may be required by children with AHDN, do not explicitly address educational support.

Early childhood interventions form an important focus of the scheme and are addressed specifically through the implementation of the key worker/primary service provider model (T. Moore, 2013). Based on a trans-disciplinary model, the key worker model provides a key contact from the multidisciplinary team who works directly with the family or carers, including the use of role transfer or role release, to maximise capacity and foster strong carer-provider relationships, with the goal of fulfilling the potential of the child across their environments and experiences rather than within a single context.

The early stages of the scheme currently preclude assessment of its efficacy. The emphases on family support and focus, trans-disciplinary care, and early intervention however provide promising goals for optimising outcomes for children with AHDN. However, it is likely that many children with emerging AHDN, particularly those without a formal diagnosis, would not meet the eligibility requirements for these supports.

## The functional needs approach

The functional needs approach focusses on addressing overarching needs from functional limitations across, rather than according to, specific diagnoses.

It aims to optimise children's capacity to meet the demands of their daily environments and address the limitations that cause the greatest impairment to the child.

A functional needs approach suggests the benefits of a trans-disciplinary management and intervention, which optimises the educational environment of the child with AHDN.

The diversity of needs within diagnostic categories and the wide range of risk and protective factors operating on these means that children with AHDN require tailored responses that reflect their highly individualised needs (Janus, 2011). Currently, provision of additional services at school in countries such as Australia, the US and Canada is generally based on fulfilling requirements for a particular diagnosis. Janus (Janus, 2011) has highlighted that the heterogeneity of conditions and thus problems encapsulated by AHDN provides a barrier to effective programming, as the nuances of need associated with different conditions and varying levels of severity preclude tailored responses. Significant variability subsequently exists in the types and nature of service provision to these children (DEEWR, 2012; Lynch et al., 1993). Janus argues instead for a move away from particular diagnoses in terms of planning, to a broader classificatory framework such as a functional approach.

Functional difficulties include physical, emotional and psychological symptoms such as breathing problems, pain, socialisation and self-care that may impair daily functioning. The concept of functional limitations offers a number of benefits over classification based solely on condition type. Many functional limitations are shared across diverse conditions and are often apparent prior to a clinical diagnosis, thus facilitating planning. The functional approach has been recognised as a fruitful means of classifying and managing children with AHDN (Lollar, Hartzell, & Evans, 2012). This allows targeting of condition-specific problems while still permitting a broader approach to more global needs when required.

A functional, trans-disciplinary approach to management and intervention that optimises the educational environment of the child with AHDN would be directed at overarching categories of need, allowing a cohesive and integrated approach through information sharing within and between schools, staff and peer understanding, and coordinated and informed pastoral and medical care. Indeed, lack of coordination and communication between service providers and involved parties are a common cause of ineffective practice (Janus et al., 2008). The functional approach also minimises the linkage of specific management planning to a particular diagnosis, and thus may avoid the replication of management strategies across conditions. The use of functional limitations also allows for the consideration of needs that may augment the management traditionally provided for a specific diagnosis. Improvement in function is also a more amenable target for interventions than diagnostic categories. Finally, while functional difficulties and condition type are aligned, they do not correlate entirely, and those functional difficulties that cause the greatest impairment to the child may not form a focus of attention in the medical care provided for the condition in question.

From the perspective of intervention funding and planning, a focus on functional limitations rather than specific diagnoses provides scope for the development of interventions that are relevant to the widest number of children, including those with less common diagnoses who may suffer from a lack of specified funding. Data suggest that over 50% of children with a AHDN are identified by their parents as having at least some functional limitation, with a quarter of those describing severe limitations (Nageswaran, Silver, & Stein, 2008).

Furthermore, those with the severest levels of functional limitation tend to be more disadvantaged, such as in their perceived level of partnership with their health care provider (Denboba et al., 2006). Importantly, the role of parents within the development of policies for individual children cannot be overemphasised, due to their intimate knowledge of the child's needs in addition to their advocacy role. This aligns with initiatives in policy development such as the backward mapping approach used for identifying barriers to participation for people with AHDN (Dunst, 1985, 2000; Friedman, 2003). In contrast to traditional top-down policy development in which government level initiatives are implemented at a local level, backward mapping allows for the use of local experience and knowledge to inform policy and enhance local capacity, but also carries potential for wider applicability.

## Specific strategies to support children with AHDN in the educational environment

Various strategies have been proposed to support children with AHDN at school.

Timely and coordinated care directed at optimising children's functioning in their daily environments provides an important goal for family, and health and educational providers.

Many of the identified barriers to school functioning are amenable to change with appropriate supports and interventions. In terms of enhancing information provision to teachers, Lynch et al (1993) suggest simple strategies such as the provision of brief information packs on the more common conditions, augmented by additional teacher training. Barriers to participation can be minimised through strategies directed at physical and structural barriers. Environmental programs and supports, for example, have been shown to significantly enhance participation in schools, with the enhanced effects for children including higher levels of autonomy, child-peer and child-teacher interaction, and an internal locus of control (Lynch et al., 1993). Many parents furthermore identify simple measures of pastoral care for their child and themselves as being important for their child's wellbeing in school. Thus understanding, information exchange, and sense of optimism and hopefulness, and strategies to enhance the child's self-esteem and confidence, have been cited by parents as important contributors to a positive school experience (Lynch et al., 1993).

In the UK at least, methods for addressing AHDN in the school environment have traditionally been driven by resource availability rather than the child's functional status. Decision making is often guided by school-based assessments once the child has entered school rather than being implemented in preparation for school entry. Ideally, however, policy and practice surrounding the educational needs of children with AHDN would involve timely collaboration between teachers, students, parents, health and educational professionals within the context of an overarching policy framework to allow for understanding of need and the generation of informed plans directed at optimising functional capacity.

## Conceptual framework

The literature was used to construct a framework for interpretation of the influences and impacts of AHDN on the functional status of the child in the school context.

This was informed by the International Classification of Functioning, Disability and Health (ICF) guidelines for measuring health and disability.

Functional status was used as the basis for the model to allow for maximum applicability to children with both established and emerging needs.

The educational experience of the child was considered in terms of body functions and structures, activities of daily living, social participation, and educational participation.

The literature was used to highlight the influence of factors operating at the individual, family and service systems levels.

Both risk and protective factors were integrated into the model to allow for a balanced approach to the child's capacity.

The model permits clarity regarding the complex range of factors operating on the functional capacity of a given child with AHDN and children with AHDN more broadly, to facilitate the identification of targets for intervention.

The literature suggests that children with AHDN show reduced school functioning over the elementary school years according to both social and academic dimensions. Despite the evidence that children with AHDN are at risk for poorer school functioning as they enter and move through the early school years, school failure is by no means inevitable and the literature highlights numerous risk and protective factors that serve to amplify or buffer this risk, suggesting potential targets for intervention. Furthermore, the current literature review indicated that the impacts of AHDN are multifactorial, with influences operating at the individual, family and service systems (environment) levels. Clearly the manner in which experiences of AHDN impact on children's school functioning is highly complex and each child's experience is likely to differ, although with many overarching themes. This complexity is reflected in somewhat fragmented research and intervention planning.

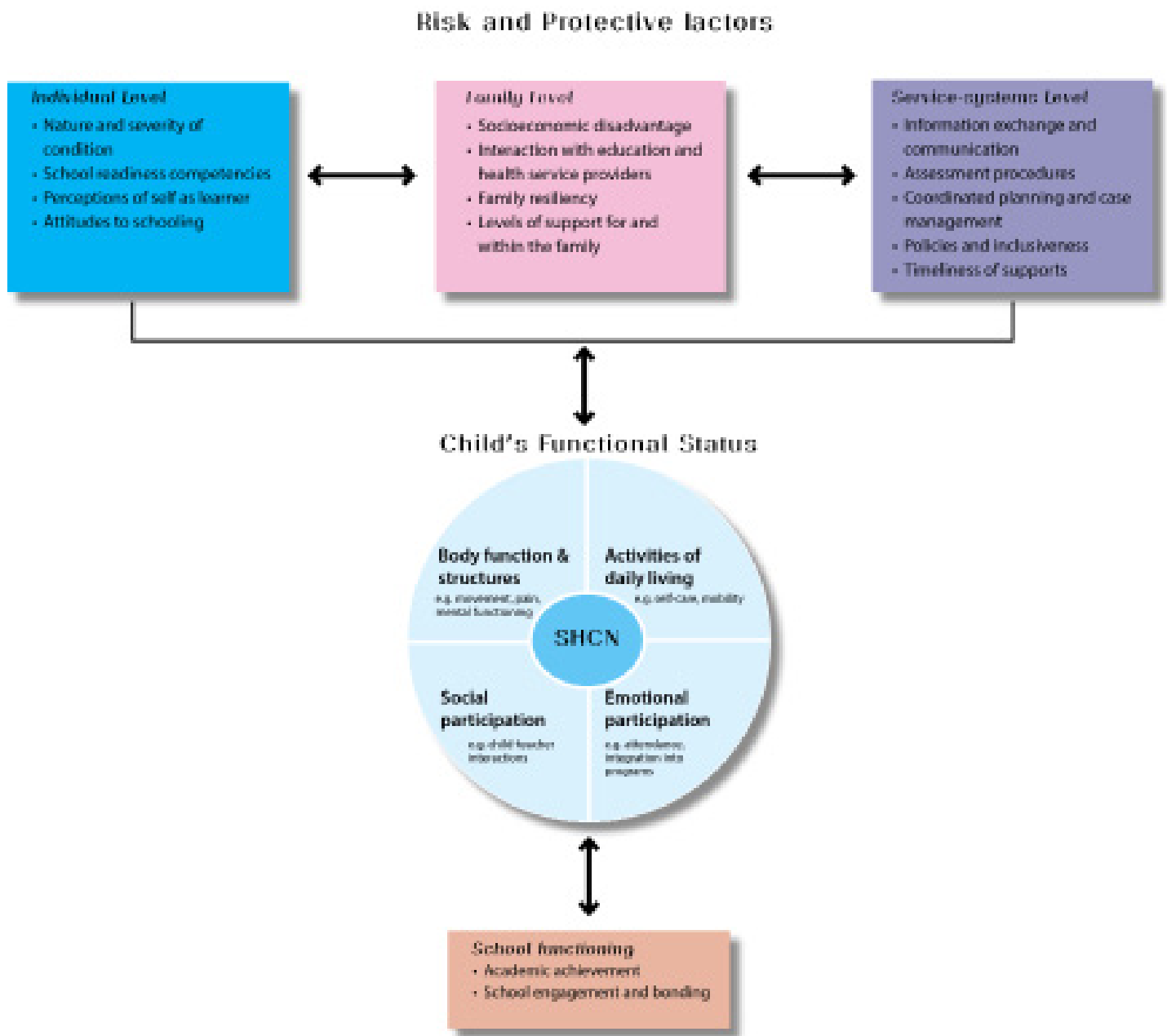
The prevalence of children with AHDN, the level of need and the potential benefits of early and effective interventions, nevertheless makes a clear and accessible framework for exploring this issue of identifying and supporting the needs of these children critical. This process can be facilitated through the use of a conceptual framework that attempts to map the dynamic processes through which AHDNs can impact on school functioning and is centred on children's functional status (see Figure 1). Using functional status as a cornerstone of the framework, findings from the literature were categorised to tease out the range of variables impacting on these children's school experiences. The focus on functional impacts allows for a broadly applicable framework that is of relevance to the diversity of conditions represented under the umbrella of AHDN, and to those children with both established and emerging needs.

Our framework is aligned with the International Classification of Functioning, Disability and Health (ICF) guidelines for measuring health and disability (Üstün, S., Bickenbach, Kostanjsek, & Schneider, 2003). Aspects of the model are adapted from Loe and Feldman's (2007) application of the ICF guidelines to ADHD. The value of the current model lies in the presentation of a comprehensive picture of the child's functioning and the contributing risk and protective factors indicated by the empirical literature, in the context of the broader ICF guidelines.

AHDN are proposed to impact on four interrelated domains of a child's functional status: body functions and structures, activities of daily living, social participation, and educational participation. For example, factors that arise in relation to bodily function, such as neurological changes impacting cognitive functioning, will be closely related to a child's educational participation, such as their capacity to access the curriculum. In addition to the potential impacts of AHDN on a child's functional status, our review of the literature clearly demonstrates that multiple individual and environmental (family and service-system level) processes are also operating to shape children's school outcomes. Although the research has tended to highlight the mechanisms contributing to poor outcomes for children with AHDN, risk and protective factors operate concurrently, and it is essential for the wellbeing of the child to also allow for consideration of positive influences. This includes factors operating at the individual level (for example, self-perception as a learner and level of social competency), the family level (for example socioeconomic status and parental involvement in schooling), and at the service systems level (for example, the level of pastoral, academic and medical support provided in the learning environment).

Our conceptual model (Figure 1) draws together the child's functional status with risk and protective influences and highlights the complexity of the relationship between AHDN and school functioning, suggesting that there are opportunities for positive interventions at a range of levels. The relationship between risk and protective factors and the child's functional status may also be interactive and bidirectional. Together, the child's functional status and surrounding risk and protective factors dynamically combine to shape either positive or negative trajectories of school functioning, which are critical for life course outcomes.

Figure 1. Conceptual model of how AHDN can impact on children’s school functioning.







# 6 Conclusions

It is clear that children with additional health and developmental needs are particularly at risk of being disadvantaged prior to the commencement of primary school. Given a lack of supports, coordination and efforts to promote engagement, this disadvantage may increase during the course of schooling. The impacts of these influences, on not only the child's educational outcomes but also overall wellbeing, can be profound.

Children with additional health and developmental needs would benefit from a coordinated but flexible policy framework that ensures that the potential complexity of their circumstances is satisfactorily addressed.



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