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Children with special healthcare needs

Of the Australian children who start their first year of formal full-time school each year, the majority start with their development on track and ready to take advantage of everything that school has to offer. About 4 per cent of children will start school with a significant developmental delay or disability that has been clearly identified; these children are likely to receive some assistance, such as a classroom aide, to help them participate to the fullest at school.

However, Australian Early Development Index (AEDI) data have shown that there is up to 20 per cent of children who start at school with some level of special healthcare need that may not yet have been formally identified, and for which they may not receive any formal special assistance at school.

The 2013 'Acting Early, Changing Lives' report from The Benevolent Society highlighted that many children are at risk of being left behind. The authors noted *"Evidence indicates worsening or unacceptably high levels of problems amongst Australia's children and young people."* (Moore and McDonald, 2013)

By the time children reach school, many are already showing developmental vulnerabilities, often without any formal supports to help them to catch up. Efforts to identify these children and support their healthy development before they start school will make a big difference in the long run.

Defining special healthcare needs

Children with special healthcare needs are those who *"have or are at increased risk for chronic physical, developmental, behavioural, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally."* (Newacheck, Strickland, Shonkoff et al., 1998)

Special healthcare needs can include those that impact primarily on physical health—such as diabetes or epilepsy—and those that impact psychosocial health—such as attention deficit



disorder and autism spectrum disorders. There is a broad range of levels of severity, possible presentations and associated needs (Goldfeld, O'Connor, Sayers, Moore & Oberklaid, 2012).

The Australian Early Development Index (AEDI)

The AEDI is a checklist of a child's development and wellbeing, completed by the child's classroom teacher in their first year of school. The results provide a snapshot of how Australian children are faring during the important transition into formal schooling. The survey was implemented nationally for the first time in 2009, and repeated in 2012; more than 95 per cent of children were covered in each of the surveys.

The AEDI measures children's development across five domains that have been shown to be strong indicators for school success:

- social competence
- language and cognitive skills (school based)
- physical health and wellbeing
- communication skills and general knowledge
- emotional maturity.

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Children with special healthcare needs

In 2009 teachers indicated that there was a significant group of children, up to 20 per cent, who had not been identified as having special healthcare needs, but who were rated by their teachers as requiring further assessment and/or were experiencing some difficulty that was impacting on their learning (Goldfeld, O'Connor, Sayers, Moore, & Oberklaid, 2012). This correlates with US data that has shown similar rates (Bethell, Read, Blumberg, Newacheck, 2008). These special needs ranged from physical disabilities through to emotional and behavioural problems (Goldfeld, O'Connor, Sayers, Moore, & Oberklaid, 2012).

Children with special healthcare needs are often more poorly equipped in terms of their school readiness when they start school (Goldfeld, O'Connor, Sayers, Moore, & Oberklaid, 2012). The initial difficulties that they experience on school entry lead to achievement gaps between them and their peers that only worsen over time if appropriate supports aren't provided (Heckman & Masterov, 2005). The ability of these children to meet the learning demands of the classroom, as well as make friends and fit in with their peer group, can be compromised. Without prompt identification and support, these children can often be left behind.

"Ability gaps between advantaged and other children open up early before schooling begins. Conventional school-based policies start too late to completely remedy early deficits, although they can do some good. Children who start ahead keep accelerating past their peers, widening the gap ... Early advantages accumulate, so do early disadvantages ... The best way to improve the schools is to improve the early environments of the children sent to them."

(Heckman, J. & Masterov, DV, 2005)

The differing levels of advantage referred to by Heckman and Masterov do not just relate to socio-economic status, but to competencies and other measures of school readiness. Understanding the ways in which special healthcare needs can impact on school outcomes, and being aware of the numbers and demographics of affected children, can help education and health service providers to develop and plan services that meet all children's needs. Advocating for the needs of these children is also important, as they are mostly ignored by present funding systems.

Characteristics of children with special healthcare needs

The distribution of children with special healthcare needs varies. The AEDI data found that children with special healthcare needs were represented in all socio-demographic groups. However, proportions were greater among boys, those from lower socio-economic status communities, Indigenous children and children who were older than the average school-start age. Children living in more remote settings were just as likely to be

identified in the AEDI data as 'of concern' as children in urban areas, but were less likely to have established additional healthcare needs (AEDI, 2013).

The AEDI data have also shown that the children with special healthcare needs are usually developmentally vulnerable. Over 80 per cent of children with established additional needs were vulnerable on at least one AEDI domain, as were more than 50 per cent of children 'of concern' or with emerging difficulties. This is compared to fewer than 20 per cent of children without any identified special healthcare needs.

Risk and protective factors

While children with special healthcare needs can be at increased risk for poorer school functioning, there are individual and environmental factors that can protect from this. Awareness of these protective factors (as well the concomitant risk factors) is important in helping to identify when extra early support is needed.

They are:

Child

Protective factors

- Ability to regulate behaviour
- Independence of child
- Skills in classroom participation and attention to independent tasks
- Social skills of child

Risk factors

- Multiple impairments
- Poor social-emotional skills or ability to regulate own behaviour
- Learning difficulties
- Single physical impairment

Environment

Protective factors

- Coordinated multi-disciplinary approach to care
- Planning for the transition to school by providers (e.g. education, health, social services) and families
- Similarities between the preschool and school environment
- The use of strategies to bridge the old and new environment
- Informal support from other parents
- Parents advocacy on behalf of/for the child
- Shared decision making involving the family
- Value placed on education by parents

Risk factors

- Delays in the implementation of support
- Family disadvantage
- Fragmented and complex service provision
- Poor information exchange
- Lack of care provided prior to school entry
- Lack of overarching policies
- Lengthy assessment procedures
- Inadequate personal and financial support for both the child and family
- Lack of family involvement in the transition planning
- Expectations and demands of family
- Inflexible transition policies
- Logistical, policy or administrative barriers to enrolment
- Family stressors including finances, changes to parenting roles for the child (e.g. increased separation of the child and parent with starting school)

(AEDI, 2012)

Making a successful transition to school

A smooth and successful transition is important for all children (CCCH, 2008). When children experience a smooth transition to school, they are more likely to enjoy school, attend regularly, and experience steady growth in their academic and social skills. However negotiating the changes and challenges that come with transition to school can be a time of particular vulnerability for children (CCCH, 2008). For families whose children have special healthcare needs, smooth transition to school can be a significant challenge. Clear communication and information exchange between all of the involved parties and the prompt provision of support are critical factors.

A 2010 US study ascertained the concerns of families whose children had additional needs at the time of their transition into school (McIntyre, Eckert, Fiese, DiGennaro Reed, Wildenger, 2010). The study found that in caregivers of children with special needs:

- Approximately half had concerns about their child's ability to follow directions and make their needs known, compared to 13.9 per cent of caregivers of students without special needs.
- More than 40 per cent were concerned with their child's academic readiness and behaviour problems, compared to less than 20 per cent of caregivers of general education students.

Working with all families in the months leading up to school entry to address their concerns around the transition can help to inform strategies to ensure their children get the smoothest transition experience possible.

The Linking Schools and Early Years project—which operated in Corio-Norlane, Hastings and Footscray (in Victoria) from 2008 until 2012—aimed to improve children's transition to school by enhancing links between schools and early years services. One of the key elements of practice change that came out of the project was enhanced relationships between all of the professionals involved in the early years:

"...schools, early years services, and child, family and community services have developed strong cross-sectoral relationships. These relationships supported their capacity to jointly plan and deliver local transition supports." (CCCH, 2012)

Working in partnership with families and other service providers

Part of the child and family health nurse role is to work with communities to address the underlying determinants of health (Schmied, Homer, Kemp, Thomas, Fowler, Kruske, 2008). As part of that mission, child and family health nurses have been encouraged to participate in family partnership training to enhance their skills in partnership working (Davis, Day, & Bidmead, 2002; Jackiewicz, 2004; Keatinge, Fowler, & Briggs, 2007). Child and family health nurses have also expanded their ability to encourage social networks in their communities by *"bringing families together, supporting the development of playgroups, participating in family fun days and mobile visiting playgroups and strengthening local community connections"* (Kirkpatrick, Barlow, Stewart-Brown, & Davis, 2007; Kruske et al., 2006; Rabab et al., 2006; State Government of Victoria, 2006). These strategies help to integrate child and family health nurses into the broader health system, and also into the broader community of early years services. This can further develop the ability of child and family health nurses to meet the additional needs of children and families, while also maintaining a universal service (Cowley et al., 2007; Department of Health UK, 2004; State Government of Victoria, 2006).

Reflection questions

How can the diverse methods of your practice—drop in visits, telephone calls, home visits—each be best utilised to identify and support families with a child or children with special healthcare needs?

What steps can you take to enhance your partnership working skills for a coordinated, multidisciplinary approach?

What resources and services are you able to direct parents to in order to address particular concerns they might have about their child—for example, problems following directions, making their needs known, academic readiness?

How can your work with families help to mitigate risk factors and enhance protective factors in the family and the environment?

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Atopic dermatitis: an update

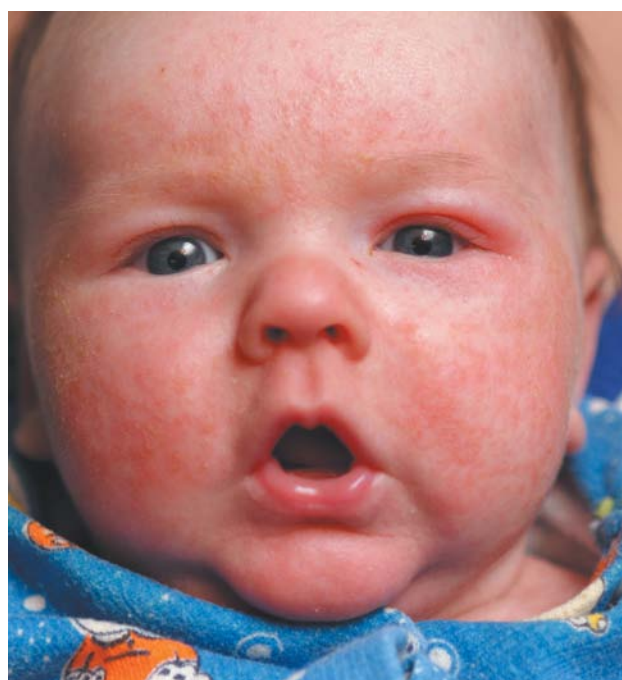
Australian paediatricians report that referrals for atopic dermatitis, or eczema, are number three of the top ten conditions that they see (Hiscock et al, 2011); in fact, Australian children have one of the highest incidences of eczema in the world (Eczema Association, 2012). Childhood eczema affects the quality of life not only of the sufferer, but also their caregiver/s and family, with flare-ups having a profound impact on social, personal and emotional outlooks (Su et al, 1997), and placing a significant strain on family relationships (Eczema Association, 2013).

When it occurs

More than half of all eczema sufferers show signs within their first 12 months of life and 20 per cent of children develop eczema before the age of five (Eczema Association, 2013), leading to regular presentations to the child and family health nursing service. However, for most children eczema does usually resolve. The first presentation is most common in early childhood, around the age of 2-6 months, resolving by around six years of age. While most children will grow out of the condition, a small percentage will continue to experience severe eczema into adulthood (Eczema Association, 2013). It is impossible to predict for an individual whether eczema will improve by itself or not, but certain career paths such as catering, hairdressing or nursing can expose the skin to irritants and allergens that trigger eczema (British Skin Foundation, 2013).

Symptoms

Eczema commonly presents as a dry, red rash and moderate-to-severely itching skin. The skin can become rough, leathery and thick, or cracked, weepy and then scab over (The Royal Children's Hospital, 2013). The lesions can then easily become infected



by bacteria or viruses (Eczema Association, 2013). The rash caused by eczema can affect any skin surface, and in the worst cases it can cover the whole skin surface (The Royal Children's Hospital, 2013).

Babies with eczema will usually have a red, dry rash on their face. The rash also appears on the scalp, behind the ears, on the trunk, and on arms and legs. In toddlers and older children, the rash often appears in the skin creases at the wrists, elbows, ankles and the knees (The Royal Children's Hospital, 2013).

Cause

The cause of eczema is unknown, but triggers and predisposing factors have been identified:

- **Family history:** Eczema is most common in children who have a family history of eczema, asthma or hay fever. If both parents have eczema there is an 80 per cent chance that their children will too (Eczema Association, 2013).
- **Particular food:** In some children eczema can be triggered by dairy and wheat products, citrus fruits, eggs, nuts, seafood, chemical food additives, preservatives and colourings (Eczema Association, 2013). Parents should not change their child's diet to try to remove possible trigger foods without consulting a doctor or dietician (The Royal Children's Hospital, 2013).
- **Irritants:** Common irritants can include tobacco smoke, chemicals, soaps, detergents, fabrics, weather (hot and humid or cold and dry conditions) and air conditioning or overheating (Eczema Association, 2013).
- **Allergens:** Allergens that act as triggers for some sufferers include house dust mites, moulds, grasses, plant pollens, foods, pets and clothing, soaps, shampoos and washing powders, cosmetics and toiletries (Eczema Association, 2013).

Eczema fluctuates in its severity, which is why it is important to manage the eczema and minimise exposure to known triggers. Families need to have a plan in place for managing the eczema as soon as it flares up and maintain a regular care routine for their child's condition (The Royal Children's Hospital, 2013).

Skin care

In your work with parents and caregivers who have concerns about their child's eczema management, the selection of products to use on their child's skin is critical. Parents need to be advised to stick to good quality, soap-free, specially developed hypoallergenic products and avoid anything perfumed. This applies to products including moisturisers, bath oils, body wash and cleansers.

Moisturiser is an essential part of eczema management. Parents should be advised to keep their child's skin well moisturised to prevent flare ups, which may mean moisturising a number of times throughout the day. Thicker creams and ointments are more effective than lotions (The Royal Children's Hospital, 2013), are more likely to prevent skin from cracking, and offer relief and assistance in blocking bacteria, viruses, fungi or microorganisms that cause infections (Eczema Association, 2013).

Common triggers

Heat is the most common trigger of eczema. For bathing, parents and caregivers need to ensure that water is at below 29 degrees, which may require adjusting the thermostat on the home hot water system. Bathing the affected child up to twice a day can help to avoid overheating, another common trigger (The Royal Children's Hospital, 2013). Parents and caregivers should pat children dry, not rub, and use a soft towel to avoid irritating the skin. Moisturiser needs to be applied within three minutes of bathing (Eczema Association, 2013).

Clothing and materials

Making informed choices about clothing and other materials that come into contact with the child's skin, like bedding, can be a big help in the management of eczema. Families should avoid clothing and materials with:

- rough, scratchy fibres (Eczema Association, 2013)
- synthetic fabric (National Eczema Society, 2013)
- wool (including sheepskin) (Campbell, J et al, 2002).

This guide to fabric choice applies to garments, blankets, carpets and rugs. Where there is an option to do so, families may wish to consider entirely removing rugs and carpets from the home, to reduce exposure not only to coarser fibres but also to the dust and mites that floor coverings can harbour. Families should also be advised to avoid stuffed toys as their materials can harbour dust mites, an eczema trigger (Eczema Association, 2013).

Cotton is the best choice of material for bed linen, including blankets or sheets, which need to be changed regularly. Doonas and wool blankets can pose a risk of overheating. Protective bedding covers with an allergen barrier can reduce dust mite allergens in mattresses and bedding (Eczema Association, 2013).

Parents and carers also need to consider the soap powder that they use to wash linens. The Eczema Association recommends non-biological soap powders and detergents instead of regular detergent, soap and fabric softener.

Clothing

- Cotton is the most comfortable fabric for children with eczema; parents and caregivers should aim to dress their child in 1-2 layers of cotton clothing (The Royal Children's Hospital, 2013).
- Parents and caregivers should be advised to avoid tight clothing for their child, remove frills and labels, and cover seams with protective fabric to avoid rubbing on the skin (Campbell, J et al, 2002).
- Clothes need to be kept loose around the neck and joints to reduce friction and allow air circulation.

- Different eczema sufferers will have different reactions to nappy type, meaning that there is no hard and fast rule regarding cloth nappies or disposable nappies. However, parents and caregivers should be advised to choose good quality nappies and to change them regularly (Campbell, J et al, 2002).

Depending on their age, many children with eczema will spend a lot of time in crèche, kindergarten or school. Working in partnership across all the organisations that have regular contact with the affected child is crucial.

Eczema management

Well controlled eczema flare-ups can help children feel more comfortable. Simple treatments include avoiding products containing soap, and keeping the skin moist using large amounts of suitable moisturisers (Eczema Association, 2013).

The Royal Children's Hospital suggests more ways for parents and carers to help prevent their child from scratching and making it worse or causing infection:

- Apply a soft, cool wet towel to the itchy area for immediate relief and leave on for 5-10 minutes. Remove the wet dressing and apply a thick layer of moisturiser.
- Distract the child when he/she is scratching.
- Avoid overheating, particularly in bed, or on long car trips.
- Keep the child's fingernails short and clean.
- Use wet dressings to prevent scratching and encourage the skin to heal. Apply these to the limbs at bedtime, particularly if the eczema is not controlled within 24-48 hours of starting treatment.
- A wet t-shirt or singlet (apply a thin layer of cotton clothing over this) is a good way to reduce the itch and redness.

Eczema can be very stressful for both children and families. The child and family health nurse has an important role to play in not only helping families and caregivers with the practical side of eczema management, but in helping to manage the pressure the condition can put on families and sufferers.

Resources

The Eczema Association (www.eczema.org.au)

The Royal Children's Hospital in Melbourne offers a range of online resources for parents, www.rch.org.au/kidsinfo/ as well as specialist clinics.

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About the Centre for Community Child Health

The Royal Children's Hospital Centre for Community Child Health (CCCH) has been at the forefront of Australian research into early childhood development and behaviour since 1994.

The CCCH conducts research into the many conditions and common problems faced by children that are either preventable or can be improved if recognised and managed early.

Community Paediatric Review

Community Paediatric Review supports child and family health nurses in caring for children and their families through the provision of evidence-based information on current health issues.

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