

Family supports for children who have alcohol-related disabilities

Jason D. Brown
University of Manitoba

Since the first publication on fetal alcohol syndrome appeared in the scientific literature over 30 years ago, there has been a great deal of research interest in the topic. This paper reviews findings within the past 10 years related to causes, frequency, and diagnosis of alcohol-related disabilities, before turning to the impact these disabilities have on affected children, their families and communities. The needs of parents who have children with alcohol-related disabilities are described, including a broad support network, helpful professionals, good relationship with the school, income support, and a strengths-based parenting approach. Finally, barriers that families face in service availability, accessibility, appropriateness, adequacy, and acceptability are reviewed.

The scientific study of alcohol-related disabilities is often traced back to 1973, when the American physicians Jones and Smith published their now well-known paper in the British medical journal, *Lancet*, titled "Recognition of the fetal alcohol syndrome in early infancy." Five years earlier, French physicians had documented their findings on common physical and behavioral features of 127 children born to parents where there was a history of alcoholism (Lemoine, Harousseau, Borteryu, & Menuet, 1968). And, in 1957, Rouquette wrote a thesis based on her observations of 100 children of alcoholic parents, focusing on their physical and psychological development (cited in Centre for Substance Abuse Prevention, 2003). However, Burd and colleagues (Burd, Cotsonas-Hassler, Martsof, & Kerbeshian, 2003) point out an earlier published work on the topic by Sullivan (1899), who described a high rate of infant mortality and epilepsy among children born to incarcerated mothers who drank during their pregnancies. It has been argued (Armstrong, 1998) that the medical "discovery" of Fetal Alcohol Syndrome in 1973 occurred within a context of mounting concern about environmental effects on health, advances in fetal medicine, and, in North America, increasing emphasis on creating "the perfect child."

There has been a great deal of subsequent research. A recent search of scholarly literature referenced in health and education databases (MEDLINE, PsycINFO, & ERIC) on the term "fetal alcohol syndrome" resulted in 3430 hits (2612, 613, & 205 hits, respectively). The research foci and utility of the research may be seen through a historical lens as moving through a series of stages, described by Golden (1999) as "Discovering the Offspring of Alcoholic Women" (1973-1977), "The Crusade to Warn" (1977-1986), "The Discourse of Law and Responsibility" (1986-1990), and "From Victims to Victimizers - the Death Row Debates" (1991-1999). Recent literature reflects a dual emphasis on prevention and intervention, with increasing attention to the experiences of youth and adults. This paper focuses on findings within the past 10 years related to causes, frequency, and diagnosis of alcohol-related disabilities, before turning to the impact these disabilities have on affected children, their families and communities. The needs of parents who have children with alcohol-related disabilities are described, before describing some service barriers they may encounter.

Causes

Alcohol is a teratogen. However, the exact mechanisms of its action during pregnancy are still not well understood. There is a great deal of evidence that exposure to various amounts of ethanol during different periods of prenatal development create conditions where the risk for alcohol-related disabilities or fetal death are elevated (Weinberg & Guerri, 1996). However, significant population (Abel, 1998a) and individual differences (Warren & Foudin, 2001) in the frequency of effects of prenatal exposure exist, suggesting that a variety of factors are involved. Maternal risk factors and those associated with the agent have received the most attention by researchers. There has been little emphasis on paternal contributions except to note that the fathers of children with alcohol-related disabilities themselves have problems associated with alcohol use (Cicero, 1994) and epidemiological studies show effects on birth weight, heart defects, and cognition (Abel, 2004).

Factors associated with the agent include studies of the type, timing and dosage. Cigarette smoking, marijuana, cocaine and opiate use may coincide with maternal alcohol use during pregnancy (Hans, 1999). However, the effects of prenatal exposure to marijuana, cocaine and opiates may be relatively short-lived (Lester et al., 2002); there is some

evidence that infants can catch up in their growth and resolve some neurobehavioral abnormalities over time, except among those exposed to alcohol or cigarette smoking during prenatal development (Chiriboga, 2003). However, there is also the potential for interaction effects when two or more substances (e.g. cocaine and alcohol) are used at the same time (British Columbia Reproductive Care Program, 1999).

The timing and amount of exposure can have a differential effect. It appears that binge drinking (i.e., more than five drinks per occasion) is more harmful than non-binge drinking, and that this drinking is most harmful during the first few weeks of gestation (Jacobson & Jacobson, 1999; Polygenis et al., 1998). The first 3-6 weeks of brain development is a critical period for the effects of alcohol (Konovalov, Kovetsky, Bobryshev, & Ashwell, 1997). As well, there is variation in the sensitivity to exposure between different brain regions (Maier & West, 2001). However, it should be noted that the risk of adverse effects is present with any amount of alcohol exposure at any time during pregnancy (March of Dimes, 2005).

There has been a great deal of interest in identifying high-risk populations. Several maternal factors have been studied. In addition to alcohol use, risk for the development of alcohol-related disabilities is elevated by the presence of older maternal age (Bagheri, Burd, Martsof, & Klug, 1998; Jacobson, Jacobson & Sokol, 1996) and low socioeconomic status (Abel, 1995; Abel & Hannigan, 1995). In addition, genetic factors (Rasheed, Hines, & McCarver-May, 1997; Su, Deblak, Tessmer, Cartwright, & Smith, 2001) and maternal alcohol metabolism (Warren, Calhoun et al., 2001) play a protective or risk role.

A variety of personal and social factors are associated with alcohol use among women who are at risk for giving birth to a child with an alcohol-related disability (Walsh-Dotson, Henderson, & Magraw, 2003). Social support, family functioning, general well being, and mental health are interrelated and associated with maternal substance use. A study of birth mothers of children who had been diagnosed with an alcohol-related disability found that abuse and violence were common experiences; mental health concerns and treatment, as well as low levels of social support were prevalent; in addition, 25% of them were missing or deceased and only 10% were parenting their children (Clarren, 2002). Maternal poverty was another common factor. Indeed, "We know from

the etiology of FAS that its roots lie to a large extent in poverty and the economic and social marginalization that poverty produces" (Ternowetsky, 1999, p. 88). Maternal nutrition and prenatal care are inadequate among pregnant women living in poverty (Center for Excellence on Health Disparities, 2005) and, among those who use alcohol, serve to increase the risk for disabilities in their offspring (Abel, 1998b).

Frequency

There are great differences in frequency between and within communities. Definitions used, approaches employed, and recruitment methods vary considerably. May and Gossage (2001) suggest that the most focused approaches, called active case ascertainment models, include outreach to the population of interest and, when conducted within a high-risk group, the frequencies can be very high. Based on their review of a range of different estimates, including those from passive approaches based solely on health system records and yielding much lower estimates, they conclude that the overall frequency, including both new and existing cases, of FAS in the United States is between 0.5 and 2.0 per 1000, and that alcohol-related disabilities are present in about 10 per 1000.

Canadian rates have not been established, but are thought to be in line with the United States and other industrialized countries. A recent publication from the Public Health Agency of Canada (2003) places the national frequency of alcohol-related disabilities at 9 per 1000. Frequency estimates for subpopulations in Canada have also been published. Habbick and colleagues (Habbick, Nanson, Snyder, Casey, & Schulman, 1996) found that the rate of new FAS cases in Saskatchewan between 1973 and 1992 had not changed, and Williams and others (Williams, Odaibo, & McGee, 1999) reported a rate of new FAS cases in a northern Manitoba community that was 7.2 per 1000.

Diagnosis

Alcohol-related disabilities fall along a spectrum. Full-blown Fetal Alcohol Syndrome includes confirmed history of prenatal alcohol exposure, prenatal onset and postnatal continuance of growth deficiency, facial features, and neurocognitive characteristics (College of Physicians

and Surgeons of Manitoba, 2000). The term Fetal Alcohol Effect was introduced to describe disabilities associated with maternal drinking that did not meet the full criteria for FAS (Rosett, 1980), but was found to be ambiguous, with limited use in diagnosis (Aase, Jones, & Clarren, 1995). There are currently two major published sets of diagnostic criteria in use: the International Institute of Medicine (Stratton, Howe, & Battaglia, 1996), and the Washington criteria (Astley & Clarren, 2000). Though both sets have been cited as suffering from a lack of clarity for use in routine medical practice (Hoyme et al., 2005), they do promote consistency and quantify key features of FAS.

The full spectrum of disorders includes five separate diagnostic categories (American Academy of Pediatrics, 2000). Fetal Alcohol Syndrome has two forms, with and without confirmed maternal alcohol exposure. Partial FAS (pFAS) with confirmed exposure, includes facial features, as well as growth deficiency or neurocognitive characteristics. Alcohol-Related Neurodevelopmental Disorder (ARND) is diagnosed when there is a confirmed history of exposure along with neurocognitive features. Alcohol-Related Birth Defects (ARBD) include the presence of cardiac, skeletal, renal, ocular or auditory problems, as a result of confirmed alcohol exposure. ARND and ARBD may be co-morbid. Facial features and growth deficiency are not reliably assessed before age two, and must be based on comparisons using appropriate norms (O'Leary, 2004).

Impact

Children with alcohol-related disabilities may experience medical complications affecting their hearing, speech and vision (Roberts & Nanson, 2000). Cognitive (Sowell et al., 2001), language (Korkman, Autti-Raemoe, Koivulehto, & Granstroem, 1998), visual motor (Kaemingk & Paquette, 1999) and behavioral problems (Roebuck, Mattson, & Riley, 1999) have been documented. Intellectual (Weinberg, 1997) and social skill challenges (Thomas, Kelly, Mattson, & Riley, 1998) are most likely to become apparent during middle childhood, when learning problems (Mattson & Riley, 1999), including attention deficits (Lee, Matson, & Riley, 2004), are also noted. An early diagnosis and a stable home environment reduce the likelihood of secondary disabilities by two to four times for adolescents who are at elevated risk for mental illness,

substance abuse, school leaving, trouble with the law and homelessness (Streissguth et al., 2004).

Despite the best of intentions to raise their children, birth families may have their own challenges in addition to parenting (Jones, 1999); they may struggle with health and addictions issues, compounded by poverty and, in some cases, violence (Murphy & Rosenbaum, 1999). Their children may come into the care of the child protection system, placed in foster care, or adopted (Ernst, Grant, Streissguth, & Sampson, 1999). When in care, children with alcohol-related disabilities often experience multiple placements (Habbick, Nanson, Snyder, Casey, & Schulman, 1996). Although foster parents may not initially be prepared for the special needs of children with alcohol-related disabilities, many do report a sense of satisfaction in their role, appreciate and enjoy the children (Brown & Bednar, 2003).

The impact of primary and secondary disabilities among children and youth resulting from prenatal alcohol exposure is apparent in education, health, social services, and justice systems, and is substantial (Boland, Burrill, Duwyn, & Karp, 1998). Screening for alcohol-related disabilities in elementary schools has shown rates three times higher than the national average (Clarren, Randels, Sanderson, & Fineman, 2001). The hospitalization rate for school-aged children with an alcohol-related disability decreases after early childhood, but remains higher than average through adolescence (Loney, Habbick, & Nanson, 1998). As well, there is evidence that children with alcohol-related disabilities are highly overrepresented in social service caseloads and juvenile justice systems. The proportion of children with alcohol-related disabilities in foster care or awaiting adoption is estimated between 10 to 15 times the national average (Adoptive Families Association of British Columbia, 2002; Astley, Stachowiak, Clarren, & Clausen, 2002), and over 20 times in the juvenile justice system (Fast, Conry, & Loock, 1999).

Supports

While it is reality that the majority of children who have been diagnosed with alcohol-related disabilities do not live with their birth families, in some Canadian jurisdictions there is an increasing emphasis on birth family preservation and, when this is not possible, placing children within the extended family or a home community. It is becoming more

likely that children with alcohol-related disabilities will have greater contact with birth or extended families in their home communities, during or after a period of time in care. While there is a great deal of diversity among families and children with alcohol-related disabilities, recognition of family needs, whether they are birth, extended, foster or adoptive families, is crucial. Major themes running through the available research on issues faced by parents of children with alcohol-related disabilities include a number of needs. Family needs include a broad support network, professionals who will listen and help, good working relationship with the child's school, income support, as well as an individualized and strengths-based approach to parenting.

Broad Network of Support

Families need the support of all members, friends and others in their community. Indeed, several authors have written about the need for a comprehensive network for families caring for an alcohol-affected child, including immediate (i.e., parents and siblings living in the same household), as well as extended families, where grandparents, aunts/uncles, as well as foster/adoptive or birth families, are involved (Connor & Streissguth, 1996; Green, Diaz-Gonzalez, & Vasqualez, 2002; Jones, 1999). The support of friends and neighbors who appreciate that there are challenges inherent in parenting an alcohol-affected child, are compassionate towards the family, can look for the strengths and successes, as well as having a sense of humor about the relatively minor things that go wrong is needed (Guinta & Streissguth, 1988; Hay, 1999).

Knowledgeable and Helpful Professionals

A variety of professionals are likely to be involved with a family of an alcohol-affected child (Hess & Kenner, 1998). Professionals connected to child welfare, health care, education and justice systems, may play a significant role in the lives of children and their families. Willingness among involved professionals to collaborate is necessary (Weinberg, 1997). Parents report that they need professionals who have a good knowledge of alcohol effects (McCarty, Waterman, Burge, & Edelstein, 1999) and local resources (Warren & Foudin, 2001; Weinberg, 1997), respect and compassion for the families, including birth, foster and adoptive parents, as well as others who are involved in the care of the child (Williams, 1999).

Good Working Relationship with the Child's School

Families need a good connection with the child's school, even before the child starts attending. Early diagnosis and intervention are very helpful (Connor & Streissguth, 1996; Hay, 1999) and may include services offered in the community as well as in the home (Weinberg, 1997). For success in the community school, it is very helpful for staff to have current knowledge about alcohol-related disabilities (Lindsay & Preston, 1999; Warner, 1999), as well as strategies that can be used in the classroom to facilitate learning (Short & Hess, 1995). In addition, regular communication between the home and school is crucial in order to maintain consistency, in part because parents and teachers may see the child's learning needs differently (Timler & Olswang, 2001).

Income Support

Families of children with alcohol-related disabilities need income support (Green, Diaz-Gonzalez, & Vasqualez, 2002; Guinta & Streissguth, 1988). This support may include medical costs not covered by health care, such as medication (Oesterheld et al., 1998; Warner, 1999) or support services, such as respite (Hay, 1999). These costs are both necessary and substantial, and easily become a major burden on the family if not covered by an external source.

Individualized, Strengths-Based Approach to Parenting

In addition to understanding a range of alcohol-effects, families need to recognize the particular strengths and difficulties their child(ren) have. Alcohol-affected children are a heterogeneous group (Phelps, 1995). Therefore, no single parenting approach works for each (Streissguth, 1997). Although parents describe some similar needs, including knowledge about child behavior management (Burry, 1999), applied with patience and consistency (Connor & Streissguth, 1996; Warner, 1999) as well as repetition (Zevenbergen & Ferraro, 2001), they report that any realistic expectations must be in line with the child's unique set of abilities (Gardner, 2000; Streissguth & O'Malley, 2000).

Service Barriers

Families with children who have alcohol-related disabilities face a variety of service barriers, including availability, accessibility, appropriateness, adequacy, and acceptability. The availability of services refers to their presence or absence, while accessibility refers to the ability of participants to use them. Appropriateness refers to the suitability of services available to families with alcohol-affected children, and adequacy, to the comprehensiveness of those services. Finally, acceptability refers to the utility of the service according to the families.

Availability

Although many families with children who have alcohol-related disabilities live in urban centers, the highest occurrence may be found in more remote communities, far from the needed intervention and support services. Those communities with the greatest support needs may well be those where the risk factors, such as poor nutrition, poverty and substance use, are most serious. Health service delivery in such communities is, of necessity, inclusive and holistic, with a major purpose of addressing serious socioeconomic challenges, one outcome of which may be alcohol-related disabilities. In cases where specialized resources are needed and not available in the local community, children may be sent to major urban centers, where many will have to move without their families.

The invisibility of most alcohol-related disabilities and the lack of any objective "test" to make a diagnosis, requires some parents to do a great deal of lobbying for confirmation of their suspicions and needed supports, particularly when there is no record of prenatal exposure. Finding a physician who will assess a child for an alcohol-related disability may be challenging, even within a major Canadian centre (Nevin, Parshauram, Nulman, Koren, & Einarson, 2002).

Accessibility

Armed with a diagnosis, parents may still have difficulty accessing services within the regular social or education systems. Sensitivity to the range of behavioral and learning challenges experienced by alcohol-affected children is not prevalent among educators and child protection

staff. Parents often feel blamed for the child's "misbehavior," when it is the failure of the setting and others who do not understand or accommodate to their child's unique way of doing things. As such, learning problems often manifest as behavior problems, and are treated in the same way as a behavior disorder with an intervention approach that was never designed for use with children with organic brain damage.

The potential for isolation is heightened among alcohol-affected children and their families after repeated experience in settings where they are not welcomed as part of the group. Services available to all children in a community, such as an after-school recreation program, may not be welcoming to children with alcohol-related disabilities. A lack of understanding and inclusion continue to be major barriers for families who want to their children to be involved in the community, but find that the cost of that involvement (rejection) is too high.

Appropriateness

An appropriate way to determine what services are needed is to ask the intended clientele what would be helpful. While there have been many studies on the service needs of families with children who have alcohol-related disabilities, relatively few of these studies have been conducted with parents. Parents indicate that, even among the staff with whom they come into contact through health, education, child welfare, and justice systems, who collectively possess a great deal of professional knowledge and expertise, relatively few have developed a specialty for working with alcohol-affected children and families (Brown & Bednar, 2004). It seems that research and practice are slow to capitalize on what parents and alcohol-affected children have learned about what works for them.

In addition, there are significant gaps in research and services related to the transitional needs of children and youth who are alcohol-affected. Very little work has been done to understand the range of issues associated with developmental (e.g., home to school, school to work) and system-related (e.g., foster family to birth family, "aging out" of care) transitions. However, there is research evidence that highlights the importance of stability in living and care arrangements, suggesting that substantial cost savings can be made, *if* transitions are managed well (Streissguth & Kanter, 1997).

Adequacy

Many alcohol-affected children and youth are not in the care of their birth parents. This implies that the quality and range of services available is not meeting the needs of birth families. Child protection and justice systems are highly overrepresented by children with alcohol-related diagnoses. The growing presence of people with alcohol-related disabilities within the juvenile and adult corrections populations suggests that the quality and range of services with, not only birth, but foster and adoptive families, are lacking. Youth with alcohol-related disabilities are also apparent among group home graduates, as well as those who are street-involved and in the shelter systems. The costs of intervention in the justice system are obviously far greater than providing care through families in the community. Community-based care needs to be considered long-term investment.

Acceptability

Services to birth parents tend to be “prevention” services, and follow-up services often target foster and adoptive parents. Birth families typically have access to the fewest resources - both prenatal and postnatal - for their children, yet likely experience the greatest need. To receive specialized services, a mother will likely have to face the stigma associated with an alcohol-related diagnosis, despite the reality that women who drink during pregnancy with the intent of harming their children, if they exist at all, are exceedingly rare. The acceptability of support services to some families, birth families in particular, even if services are present, may be very low.

Conclusion

A range of informal as well as formal, multidisciplinary and local supports for families with children who have alcohol-related disabilities are needed. However, parents report a variety of challenges in obtaining necessary services and supports for their families and children. This lack of community-based support is evident in the significant numbers of children and youth in care of the child protection or justice systems.

There are many groups and community organizations involved in advocacy efforts for families with alcohol-affected children. The grassroots involvement of parents in these initiatives is crucial. The development and maintenance of new services as well as changes needed to bring existing family services and government systems in line with the needs of children with alcohol-related disabilities, require a great deal of public education and political will. The groups already involved in these efforts are well positioned to bring the issues forward to policymakers for action. The costs of inaction are substantial.

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